3-24 The NHSC should establish scholarships,loans, and workstudy opportunities to recruit, train, place, and retain 100 master's degree level social workers per year to staff facilities in underserved ares, including HIV-endemic areas.

3-25 The NHSC should permit specialist physicians who have not as yet met their NHSC scholarship service obligations to fulfill these obligations in an underserved, HIV-endemic area. Those specialties most appropriate to HIV-related care, such as infectious disease or internal medicine, should receive priority.

3-26 The NHSC should ensure that all its professional staff are provided with education and training in the diagnosis, treatment, and prevention of HIV infection, particularly in HIV-endemic areas.

3-27 The NHSC should provide scholarship funds at the undergraduate level to minority students to allow more minorities to continue their education through the professional degree level, with repayment of these scholarship through service in underserved, HIV-endemic areas.

3-28 The Secretary of HHS should ensure that minorities are represented on federal decision-making bodies in order that cultural characteristics are recognized appropriately. All new federally funded HIV treatment service programs should include local advisory boards with appropriate minority representation.

3-29 The Federal government through a central database/hotline should provide: (a) treatment information for those with HIV and for health care professionals; (b) experimental treatment protocol information to practitioners and the public; (c) linkages with international data bases; and (d) clearinghouse for health services.

3-30 The Liaison Committee on Medical Education of the Association of American Medical Colleges and the American Medical Association, which accredits medical colleges, should immediately determine how medical colleges are modifying curricula to assure adequate education about prevention, diagnosis, and treatment HIV infection.

3-31 The American Association of Medical Colleges should develop and circulate to member institutions a model plan for curriculum structure, which medical schools can adapt to develop individualized programs best meeting local needs and circumstances. The HRSA's Multidisciplinary Curriculum Development Conference on HIV Infection in November 1987, produced consensus recommendations which may be useful for this purpose.

3-32 The Special Initiatives Funding of the AHECs Program should be increased to include funds to establish communication channels and outreach programs to research nurses and other health care providers in all settings within the region to disseminate updated information concerning the care of HIV-infected persons. AHECs should establish appropriate training strategies for care providers within their region to learn about HIV including train the trainer and clinical hands-on experience strategies.

3-33 The state regulatory agencies that issue licenses for health care providers should strongly urge completion of comprehensive continuing education programs about HIV, with particular attention to prevention, diagnosis, treatment, and infection control. Those states that require continuing education of health care providers for licensure should include HIV infection. Professional societies should assume the responsibility for seeing that every health professional is educated concerning HIV infection.

3-34 Health professions schools should provide faculty development programs to assure that faculty are adequately prepared to educate students about aspects of HIV. Faculty development grants should be provided by the Federal government, to be administered by the HRSA's Bureau of Health Professions, with matching state funds.

3-35 The DHHS should require any HIV educational programs which receive federal funds for both professional and non-professional health care providers to include culturally relevant and sensitive curriculum and instruction.

3-36 Health professional organizations and societies should immediately develop plans for assessment of their members' HIV-related educational needs, design on-going educational programs to overcome identified deficiencies, and periodically evaluate effectiveness of these programs. Where possible, educational offerings should be multidisciplinary and incorporate hands-on experience.

3-37 The Federal government should provide incentives and funding for the development of systematic, large scale studies of the occupational risk of HIV and other blood-borne agents in the health care setting and the efficacy of Universal Precautions.

3-38 The NIOSH should facilitate cooperative arrangements among health care employers and federal and state agencies to standardize requirements for research efforts in order to maximize the usefulness of the results. Flexibility should be maintained wherever possible.

3-39 The NIOSH, in cooperation with other concerned bodies, should support and conduct studies that document the level and particular types of exposure risks that are taken by emergency and other non-institutional personnel and how they can be prevented.

3-40 The DOL should move expeditiously to develop a permanent and enforceable standard covering blood-borne diseases, with penalties for noncompliance, to protect health care and other workers whose jobs involve exposure to blood and blood-contaminated body fluids.

3-41 All health care professionals should be required to be certified in infection control knowledge and to participate in an appropriate education program.

3-42 All institutions and agencies employing health care workers should require adherence to Universal Precautions or other infection control procedures in performance standards and in workers' evaluations.

3-43 The DOL, through the OSHA, or the Joint Commission on Accreditation of Hospitals should require that all heath care facilities make infection control devises and supplies available in all patient care areas. Institutions should be required to document that adequate stocks and timely disposal of filled infectious waste containers are accomplished.

3-44 Legislation is needed in some states to permit hospitals to notify health care workers, who in the process of providing health care have had an exposure, as defined by the CDC, to the blood or blood-contaminated body fluids of any patient, of that patient's infection status. Notification should be made in such a way to protect the confidentiality of the patient while ensuring prompt notification to the health care worker. All future laws designed to protect confidentiality should include this exception.

3-45 If, in the process of providing health care, a health care worker is exposed to the blood or body fluids of any patient, the health care worker has the right to know the infection status of that individual. Consent agreements obtained in the traditional health care provider/patient context will normally provide for this. In the unusual case of denial of consent, competent medical authorities should make the determination whether testing should be done and should note the rationale in the medial record. (SEE: 9-102)

3-46 The DHHS should provide increased funding for the timely development of curriculum changes and new training materials tailored to address the needs of management, health care personnel, and others who are involved in providing care to HIV-infected and AIDS patients.

3-47 The NIOSH should provide research funds for developing new techniques to decrease risk to health care workers, particularly through equipment design modification. This research should be integrated and should emphasize utilization with Universal Precautions. It should be coordinated in a way to help the entire range of health care providers, including volunteers. The results of such research should be communicated to practitioners in a coherent and timely fashion.

3-48 All employers of health care workers should have prospective personnel policies for employees who have occupational exposure to blood and bodily fluids in order to ensure equitable treatment, appropriate medical surveillance, care and monitoring should the employee become infected.

3-49 All employers should ensure that employees infected with HIV have access to the same sick, disability and vacation leave as employees with other medical conditions.

3-50 Research institutions should give health care workers who become infected on the job priority in treatment programs as new drugs become available and other medical interventions are developed.

3-51 The CDC should encourage voluntary HIV screening programs to monitor and better understand events that cause infection and to provide maximum support and assistance to workers who become infected.

3-52 The NIMH should offer research grants for the purpose of studying the complex psychosocial issues which preclude assimilation of, and compliance with, infection control guidelines by health care professionals.

3-53 The DOT should expand the section of the National Standard Curriculum for the First Responder Course, the Emergency Medical Technician-Ambulance Course, and the Paramedic Course that pertains to communicable diseases so that appropriate infection control techniques, including those that protect against HIV infection are included. States should adopt at least that portion of the National Standard Curriculum which pertains to communicable diseases.

3-54 The certification process of pre-hospital care providers should confirm a sufficient knowledge base about infection control and HIV. In addition, states should incorporate a section on communicable diseases and infection control into their continuing education requirements for emergency care providers, (i.E. first responders, emergency medical technicians, paramedics, police, and fire-fighters).

3-55 Institutions which benefit from the services of health care volunteers should assume responsibility for assuring that they are educated about HIV, including epidemiology, modes of transmission, and methods of infection control.

Code	Chapter 4: Basic Research, Vaccine, and Drug Development
4-1	Escalate existing efforts of the NIH to establish a repository for reagents to be used in HIV research.
4-2	Investigate a fee-for-use basis for reagent distribution that would assist in supporting this program in private sector collaboration.
4-3	Make the development of appropriate animal models for HIV-related research an immediate and high priority, and make additional funds available to enhance primate center development.
4-4	Establish a federally funded central registry of animal model resources for HIV and other diseases.
4-5	The NIH should develop a computerized network of all HIV-related research activities to promote greater exchange of information and data between researchers.
4-6	Increase funds to the NIH Division of Research Services and Research Resources for additional animal model, reagent, and database program support.
4-7	The NIH intramural construction and reinstrumentation needs should be assessed and the information forwarded to the Office of the Secretary for inclusion as a high priority in future budget requests.
4-8	Construction of the NIH Consolidated Office Building should be made a high priority and GSA's approval be expedited.
4-9	NIH construction authority should be reinstated during the Congressional reauthorization of NIH in 1988 to provide for the expeditious granting of funds to universities or medical centers for construction or renovation of research facilities. Construction funds should be available in FY89.
4-10	Funds for construction and modification of university facilities, as well as upgrading of instrumentation, should be provided through federal matching grants.
4-11	Funds should be made available to the NIH Division of Research Services to upgrade or renovate 20 existing laboratories to P-3 level.
4-12	Funds should be made available for the construction of four regional structural biology centers, equipped for X-ray crystallography.
4-13	The NIH should implement a plan for the development of regional retroviral research centers and provide renovation of construction funds for two such centers.

4-14 To better meet the research mission of NIH through a facilitated management process, the Secretary of HHS and appropriate authority as required by law shall mandate that the Director of NIH report directly to the Secretary for a period of two years. The Director will receive a NIH budget directly from the Secretary, and will have discretionary authority over all subsequent allocations of personnel and resources within the NIH institutes. For the 2-year period, Congress, in conjunction with the Secretary, shall exempt NIH from OMB regulation of personnel and resource allocations within NIH institutes.

During this 2-year period, NIH will continue to operate within all remaining confines of law. Following the 2-year period, Congress shall authorize an independent audit to measure the effectiveness of this change. The Director and the Secretary will report to Congress, and if the change in procedure has resulted in greater flexibility for NIH to achieve its scientific mandate, it shall become permanent. If it has not, Congress should consider giving NIH a more independent funding status, similar to that of the National Science Foundation.

4-15 In order to discourage a "business as usual" response to HIV-related requests from the DHHS, representatives of the OPM, GSA, and OMB should participate as active members of the PHS (PHS) Executive Task Force on AIDS in order to assist in rapid implementation of high priority requests from PHS.

4-16 The OPM and the GSA should respond within 21 days to HIV-related priority requests from the Directors of the National Institute for Allergy and Infectious Diseases, National Cancer Institute, and the CDC, or any additional director designated by the Secretary of HHS. Since the Commission's interim report, no identifiable change has occurred.

4-17 To alleviate personnel delays resulting from current procedures, the Director of the NIH should continue to work with the OPM to develop an improved package of incentives to facilitate recruiting of scientific talent.

4-18 The Director of the NIH should be given greater flexibility in both hiring and personnel (FTE) allocation with NIH. All new HIV-related FTEs must be new and not diverted from other programs.

4-19 The proposed "Senior Biomedical Research Service" should be enacted, with the necessary legislation to provide for the recruitment of scientists at salary and benefit levels competitive with private sector research institutions and medical centers.

4-20 Basic research FTE needs should be given high priority review by the Secretary of HHS and a minimum of 100 new positions should be approved for HIV-related basic research.

4-21 The Secretary of HHS should evaluate current FTE ceilings at the NIH in terms of the Institutes' overall ability to respond to a national medical crisis and should work with the OMB to determine ways to add flexibility as needed.

4-22 The Director of the NIH should immediately assess the incremental loss of personnel from other nIH research areas, who have been reassigned to HIV research. As these individuals are not fully accounted for in personnel allocation figures, a detailed assessment must be made of the actual impact HIV research is having on other research areas. Results of this assessment should be forwarded to the Secretary of HHS for evaluation of future resource allocation.

4-23 Research initiatives at the NIH for NCNR should be expanded. Priority should be given to areas already identified by NCNR and the NIH, and the grant funding process for HIV-related research should be expedited. Nurses should be encouraged to submit proposals for HIV-related research to the appropriate institutes at NIH.

4-24 Fast-track recruitment programs to bring more nurses and patient care support personnel into the Clinical Center should be immediately implemented. Appropriate incentive and retention packages should be designed.

4-25 The NIH Clinical Center should assure that the salaries of registered nurses and support personnel are competitive with local standards.

4-26 The NIH Clinical Center should assure that an adequate ratio of support personnel to each registered nurse should be maintained.

4-27 The NIH Clinical Center should utilize innovative nursing practice strategies to make the work environment more attractive to nurses.

4-28 All funds appropriated for HIV-related basic research must be new "add-on" monies and should not be transferred from existing programs.

4-29 Continue and expand support for basic science research, including virology, molecular biology, genetics, immunology, pharmacology, and pathogenesis.

4-30 To encourage the greatest possible breadth of HIV-related research exploration, place greater emphasis on investigator initiated grants.

4-31 Increase funds for "Director's Awards" at the NIH for rapid start-up of projects to pursue new basic research ideas, and increase the upper funding limit of these awards from $50,000 to $100,000.

4-32 A discretionary fund should be created to make available to the Office of AIDS Research funds for rapid implementation of HIV-related project grants.

4-33 Implement within all of NIH the Accelerated-Solicitation-to-Award Program (ASAP) for HIV-related grant proposals.

4-34 Establish longer-term funding mechanisms for grants, expanding three-year grants to five- and seven-year terms whenever appropriate.

4-35 Maintain the HIV-related research programs in existence at the National Cancer Institute in order to allow the NIH the greatest possible variety and breadth of research efforts, and maximize the use of existing talent.

4-36 Publicize the rules and procedures for negotiation and implementation of cooperative agreements between the NIH and private industry.

4-37 Expand and fund the NIH training programs to levels adequate to enable qualified student researchers to continue advanced study; minimum funding levels should include:

* 350 M.D. or M.D./Ph.D. postdoctoral fellowships;
* 150 special postdoctoral fellowships for M.D.s;
* 350 graduate fellowships for Ph.D. or M.D. students; and
* 400 undergraduate or graduate health science non-Ph.D. fellowships.

4-38 Eliminate the regulation that counts short-term "expert" appointments and students participating in summer training programs against the NIH FTE ceilings.

4-39 Enlarge the scope of training grants to include interdisciplinary programs specially tailored for HIV-related research (e.g., psychobiology and immunology).

4-40 Shift priorities in elementary and secondary education to provide greater education in biology and other sciences to young people earlier.

4-41 Develop a prestigious and highly visible set of awards to recognize both outstanding young talent and excellence in teaching areas relating to human biology. These could include:

* Junior Science Corps Awards for elementary school students that include small monetary awards, but are primarily for recognition;

* National Bioscience Awards for high school students, that include the opportunity to work with leading scientists;

* National Science Teachers Awards to recognize professional excellence and enable teachers to spend time with leading researchers; and

* Programs should also be developed that bring researchers into the classroom, so that they can personally convey the excitement of their work.

4-42 All approaches to vaccine development should continue to be explored and developed until one or more are successful.

4-43 The basic scientific information necessary for this development should continue to be a high federal priority.

4-44 The Commission believes that any obstacle to the acquisition of an effective vaccine should be addressed and, if at all possible, removed. The Commission feels that appropriate protection from excessive legal liability should be made available to vaccine manufacturers to encourage research and development.

4-45 The NIH, in cooperation with the Institute of Medicine, the AMA, the ABA, the National Medical Association, and DOJ, should convene a conference on liability related to vaccine and drug development. THe conference should determine whether there is sufficient private sector interest in continued vaccine development. If not, then recommendations should be made as to how best to implement a full-scale government effort. A similar conference should be convened with appropriate agencies and spokespersons to investigate the ethical questions surrounding vaccine development.

4-46 The federal government should fund these conferences in partnership with the private sector.

4-47 The results of the liability conference should be submitted to Congress for the drafting of liability legislation.

4-48 As a near-term drug discovery measure, the NIH should continue screening off-the-shelf compounds for antiviral and immunomodulating activity.

4-49 Research funding should be increased for the development of rational drug models for both immunomodulators and antivirals, at both the NIAID and the National Cancer Institute, and through their grants to universities and medical centers.

4-50 The FDA, in partnership with the private sector, and appropriate federal agencies, should hold a conference on the subject of collaborative Research and Development in drug and vaccine development, outlining the potential benefits, risks, and legal obstacles. Participation in this conference should be sought throughout the pharmaceutical and biotechnology industries, as well as the university research community, community-based clinical trial organizations, and the NIH.

4-51 Fund new multi-center studies where possible, to encourage collaborative research.

4-52 To encourage and reward cooperative investigation, a Nobel prize for collaborative research, both national and international, should be established.

4-53 The team assigned to review the Investigational New Drug (IND) application should become involved with the product as early as possible and remain with the product through New Drug Application approval. Their work should remain subject to independent FDA review.

4-54 The FDA should work with the NIH and private drug companies to develop a software package which can be used to report and review data from pre-clinical and clinical trials, modified for each specific use, to shorten review time.

4-55 Information about which drugs are available under a treatment IND must be more widely disseminated. An information database must be created which should also offer information about potential toxicity as well as information about results of any clinical trials involving the drug.

4-56 If use of treatment INDs increase, the FDA's Commissioner should be given authority to monitor those drugs in Phase IV, after licensing is complete.

4-57 Treatment INDs should be used primarily by those patients who do not have access to experimental drug trials.

4-58 The FDA should fund an independent scientific organization to conduct an independent review of safety regulations dictated by the 1962 Kefauver Amendments to determine whether they should be relaxed for drugs used under Treatment IND regulations that are intended for terminally ill patients who have give informed consent.

4-59 In order to encourage the administration of drugs under treatment IND regulations, Congress should review current liability laws regarding these drugs and take appropriate action to extend liability protection to cover the manufacture and administration of these drugs.

4-60 FDA should meet with industry representatives and Commission on Rare Diseases to determine package to both encourage additional research and development, and allow companies to provide orphan drugs at reasonable costs to patients.

4-61 Cost-effective methods, such as extension of market exclusively, should be favored over those that require additional investment.

4-62 Professional pharmaceutical associations should survey members to determine what package of incentives would be most attractive to the producers.

4-63 Special track approval for medical foods, such as lipids, and especially those with long use in other diseases, should be considered.

4-64 Congress should immediately authorize and fund an additional 50 FTEs for the FDA's review of new drugs and vaccines.

4-65 The FTE level for reviewers should be tied to increases in the number of new IND applications.

4-66 Office and other support for these individuals should be given commensurate funding.

4-67 The Commissioner of the FDA should develop a plan by which medical and other graduate education loans can be repaid through FDA service. Congress and the Administration should provide funds for this training program in FY 1989.

4-68 We urge the FDA to use deliberate haste in approving or rejecting the diagnostic products before them currently and in the developmental pipeline. Particular attention must be given to HIV antigen tests and any other new technology which tests directly for the virus. Consideration by FDA should be given to whether the review process could be expedited by moving regulatory control of HIV diagnostic tests from the Division of Blood and Blood Products to the Division of Medical Devices. We recommend increasing the pool of qualified individuals to staff the approval process by creating training grants in relevant departments of colleges and universities.

4-69 The Commission recommends the timely completion and release of ongoing FDA studies on the efficacy and safety of condoms and surgical gloves in blocking transmission of HIV and recommends that these results be publicized by FDA. In addition, standards for condom safety should be increased, and studies should be conducted to determine the effects of spermicides, solvents, and other lubricants on latex. Studies to determine the shelf life of latex condoms, with or without lubricants or spermicides, should be performed, and packaging dated accordingly.

4-70 The federal government should provide funds for an additional office and laboratory building for the FDA's drug and vaccine application review personnel.

4-71 To inspire pride in the FDA, an annual Presidential Award for Excellence could be bestowed on dedicated FDA scientists who creatively and expeditiously approve life-saving products and discover ways to protect society from unforeseen health hazards.

4-72 Membership in the NIAID' AIDS Program Advisory Committee should include at least one qualified individual with HIV infection and also include representative minorities, parents of HIV-infected children, women, and hemophiliacs.

4-73 The NIAID should develop means by which clinical trials can be made available to individuals in all geographic areas.

4-74 To better understand the natural history of HIV-infection in women, the NIAID should fund female cohort studies and enroll women in different stages of HIV-related illness.

4-75 Registration of all HIV-related clinical trials information, and information on approved substances and INDs should be made available in one central location. If it is modeled after the Physician's Data Query System in the National Library of Medicine, software must be developed to make the retrieval of hard copy information possible.

4-76 Information regarding the nature and status of clinical trials should be readily accessible to all interested parties in this country and to central health agencies in other countries.

4-77 The NIH Office for AIDS Research should assume responsibility for developing an appropriate, quality-assured database for collection and distribution of this information, and should have it operation no later than December 31, 1988.

4-78 All trials should be registered by the sponsor within seven days of approval by the FDA. The sponsor should furnish complete protocol information including but not limited to the drug(s) being tested, inclusion and exclusion of criteria, pertinent drug-taking restrictions, trial site(s), the names of principal investigators with contact information, and trial commencement and termination dates.

4-79 The clinical trials database must be constantly updated and must include information on trials conducted by the NIH, and by private pharmaceutical companies, and must, as soon as possible, include trials conducted in other countries. Patient enrollment information must also be updated.

4-80 If the Physician Data Query System is selected and used in conjunction with the CDC Clearinghouse, a public information campaign should be authorized. Health and science editors of all major media should be made aware of existence of the system to make it more widely understood by physicians and patients alike. This should be done by cooperative agreement between CDC, the National Cancer Institute, and the NIAID, with additional funds made available.

4-81 Use placebo-controlled studies only for patients without immediately life-threatening disease, and positive control studies in patients with symptomatic HIV infection.

4-82 In the process of giving informed consent for participation in a clinical trial, the participant should fully understand all aspects of the study and commit to faithful adherence to the protocols.

4-83 To more effectively analyze information across multiple trials, standardize staffing criteria and utilize the Walter Reed staging system to establish disease stage and clinical trial endpoints.

4-84 In order to accelerate evaluation of efficacy of a new drug, reevaluate the endpoints of current clinical trials to determine whether markers other than clinical morbidity or mortality (e.g., laboratory markers) can be used.

4-85 Develop means of shortening the time frame of Phase II trials, perhaps by increasing sample size or changing the endpoints.

4-86 Establish as a high priority the development of trails with sufficient numbers of women (including pregnant women), infants and children, hemophiliacs, transfusion-infected individuals, and intravenous drug users to both serve these populations and be statistically evaluable.

4-87 Prior to the initiation of all new HIV-related trials, the NIAID should require a commitment on the part of participating institutions to rapid and active facilitation by their Institutional Review Boards and other internal regulatory mechanisms so that protocols are rapidly implemented.

4-88 The federal government should immediately fund a pilot study for the development of computer software that could be used across all HIV clinical trials to standardize clinical data input and facilitate the rapid evaluation of those trials by the FDA. This pilot study should include experts from the computer support divisions of FDA and the NIH, as well as clinical and review experts.

4-89 The software should be immediately used to begin collecting co-factor information on ongoing clinical trial participants.

4-90 Information on placebo recipients should be used to formulate the equivalent of a "historic control" for HIV so that future studies can be designed with decreased reliance on placebo controls.

4-91 NIAID Clinical Trials Centers for children should be expanded from the presently planned three to six to 20 throughout the U.S.

4-92 All clinical trials developed for adults at the national Institutes of Health should also address the possibility of being utilized in pediatric populations, wherever possible in the form of a "concept proposal."

4-93 Because of the high percentage of HIV-infected children who suffer sever neuropathy, drugs that cross the blood-brain barrier should be given highest priority in the design and implementation of clinical trials for this population. Protocols for every trial should include neurologic and neurodevelopmental tests to determine the neurologic efficacy or toxicity of the drug.

4-94 In order to facilitate patient accrual in pediatric trials and deliver experimental treatment and superior care where it is most needed, clinical facilities in areas with high prevalence of pediatric infection must be upgraded so they can conduct more demanding Phase I and Phase II trials; these facilities must be given the means to recruit the personnel necessary to conduct these trials.

4-95 Wherever legal restrictions bar the entry of "boarder babies" and other foster children into clinical trials, these restrictions must be examined and challenged as appropriate, to make certain that these children are not being denied access to palliative or possibly curative therapies.

4-96 Activities already in progress at the NIAID should be encouraged to incorporate greater participation of industry and community physicians in protocol development and implementation.

4-97 A direct grant program should be funded immediately to assist community-based trial sponsors to develop and implement clinical trial protocols, and to encourage increased access to these protocols by any underserved populations.

4-98 The NIH Office of AIDS Research should develop a training program for community practice physicians whereby physicians can acquire both the latest HIV research information and clinical trial management skills. This program could be patterned after the Community Clinical Oncology Program, should be funded through existing AIDS Clinical Trials Group centers, and should be designed to develop a broader base of clinical expertise for administering HIV-related clinical protocols as them become available. Funds for this program should be made available in FY 1989.

4-99 Community-based organizations and community health centers should be consulted in the design and should be used in the execution of clinical trials.

4-100 Community-based trial investigators should be encouraged to work closely with leading clinical researchers and basic scientists and medical institutions in their community to establish better research relationships and provide the best service to their patients.

4-101 The DHHS, through the ADAMHA, the NIH, and the CDC should continue and expand the funding of research on adults and adolescents that identify: determinants of risk behavior; models of behavior change interventions (in laboratory, field, and community-based settings); social factors and strategies to affect behavior change; and evaluation and other methodologies.

4-102 All HIV-related research funded by the NIAID and the NIMH should be reported to a central information gathering source. In the HIV crisis, data sharing should be the rule.

4-103 Funds should be made available through the NIMH and the CDC to sponsor training programs for graduate and post-graduate HIV researchers in the field of behavioral research.

4-104 Funds should be allocated for training grants for pre- and post-doctoral students in academic settings for research in the disciplines related to HIV research such as psychoimmunology, social psychology, human sexuality (including bi-sexuality), and behavioral sciences.

4-105 Social and behavioral research in HIV must be long-term, collaborative efforts such as that found in the NIMH Centers Program grant mechanism. It is imperative that this mechanism for funding research be maintained and increased in behavioral and social sciences research and that the Centers continue to play a significant role in behavioral and social research.

4-106 DHHS, through NIH, CDC, and ADAMHA should take advantage of work already begun by the National Institute of Child Health and Human Development, in collaboration with CDC, and continue to fund national baseline data collection activities with longitudinal components, that would permit a better understanding of sexual practices (including bi-sexual behavior), attitudes, and risk behaviors of adults and adolescents of differing ages and cultural backgrounds in order to assess risks and guide intervention activities. Survey research should include proportionate sampling of ethnic, racial, and cultural groups and regional variations.

4-107 The DHHS, through the NIH, the CDC, and the ADAMHA should fund small-scale surveys and studies in targeted groups to identify attitudes and behaviors that should be modified or reinforced prior to development of education programs or other interventions that will be effective in those target groups and the cost-effectiveness and efficacy of various channels for reaching such groups.

4-108 The NIMH's review panels ("study sections") which determine which grants are approved and given priority scores for funding should maintain a sufficient balance and expertise in the area of behavior change research.

4-109 The NIMH in collaboration with other PHS agencies should continue to fund research to assess the impact of learning the diagnosis of HIV infection on individual behavior, and whether the impact varies by risk group.

4-110 A working group on HIV infection and adolescents should be established through expansion of the mission of the DHHS' Pediatric AIDS Working Group.

4-111 The NIMH, in collaboration with the NIDA, should conduct studies of the determinants of the point of entry that puts an individual at risk and patters of drug use and sexual practices (particularly, bisexual practices).

4-112 Researchers must be given sufficient time to evaluate the effectiveness of programs, and once found effective, the means for widespread dissemination of those findings.

4-113 The NIH and the ADAMHA, and NIMH should ensure that there is sufficient coordination and collaboration in research in the areas of neurosciences and neurobiology to avoid duplication of research efforts. This recommendation is not intended to reduce funding of confirmatory studies.

4-114 The DHHS, through the National Institute of Child Health and Human Development, the NIMH, and the NIDA, should fund a cohort study to determine the natural history of HIV infection in women and special social factors related to women at risk for HIV infection.

4-115 Funds should be made available through the NIMH and the CDC to sponsor training programs for graduate and post-graduate HIV researchers in the area of co-factors associated with onset and progression of HIV-related diseases.

4-116 The NIMH should continue to support research on the neurobiological and psychobiological processes, and the behavioral, psychosocial, and psychiatric factors thought to be associated with both the transmission of HIV infection and the progression of disease.

4-117 The NIMH should issue a competitive request for proposal to establish a center where researchers from various disciplines could convene to exchange information formally and offer training in their discipline to researchers interested in integrating ideas. As the study of HIV co-factors is multidisciplinary, there should be cooperation between NIMH and appropriate agencies whose work is also devoted to concerns surrounding intravenous and other drug abuse.

4-118 The appropriate PHS agencies should continue to fund neuropsychiatric research on symptomatic and asymptomatic HIV-infected patients. Research is needed to improve current testing instruments and methods of neuropsychiatric diagnostic testing for central nervous system involvement.

4-119 The NIMH should continue to conduct research with the NIDA and the NIAAA to better understand the impact of affective states, social isolation, and disinhibitors, such as alcohol and drugs on risk behaviors.

4-220 Funds should be made available through the NIMH, the National Institute of Child Health and Human Development, and the CDC to sponsor training programs for graduate and post-graduate HIV researchers in the area of HIV transmission and maternal, perintal, and neonatal HIV infection.

4-121 Research should be expanded to include studies to determine the effectiveness of viral transmission through various routes such as intravenous drug abuse, various modes of sexual activity, and perintal transmission.

Code	Chapter 5: The Public Health System
5-1	The DHHS should propose and Congress should support mechanisms to sustain longer term commitments to prevention programming than are now the care. Such mechanisms must include annual accountability for programs and regular evaluation of the effects of prevention services.
5-2	Without reducing funds for other prevention activities under the CDC's jurisdiction, appropriations to CDC should include not only funds for direct activities and pass-through allocations to state and local governments, but also funds for the management and evaluation of HIV-related activities.
5-3	Sexually transmitted diseases (STDs) are believed to be a significant co-factor of HIV infection. Recognizing this relationship, the CDC should significantly increase its FY 1989 funding for STD programs.
5-4	The CDC should design and immediately implement an internal plan for coordinating all of their HIV-related efforts. This task should be completed by September 30, 1988. Such a plan should specifically state the responsibilities of all CDC units that are involved in HIV programs. It should also outline the coordination and communication process between all participating CDC entities.
5-5	CDC should establish by August 1, 1988, a clear and comprehensive mission statement for the Office of the Deputy Director for AIDS to include the specific duties for that office and how the office will relate to divisions of CDC.
5-7	CDC should immediately emphasize its focus on the HIV disease, collecting data beginning at infection.
5-8	CDC should devise its own program goals and objectives, and should not enter into contracts with outside consultants for this purpose.
5-8	The CDC should move the National AIDS Information and Education Program (NAIEP) to the Center for Prevention Services by September 30, 1988. This will avoid any duplication of activities that is presently occurring between NAIEP and the Center for Prevention Services.
5-9	CDC must be adequately staffed at all times in order to successfully meet its public health mission, including HIV programming. The Commission's analysis of current and proposed HIV programs at CDC indicates that a total of 523 FTEs are required to be permanently assigned to HIV activities for FY89. CDC should be allowed to hire new staff in sufficient numbers to replace those personnel who have been diverted from other programs, and staff HIV-related programs with a full compliment of 523 FTEs for FY89.

5-10 Congress, in conjunction with OPM, should analyze the recruitment of personnel to the CDC. Federal salaries and benefits should be assessed. Following such an analysis, Congress should make every effort to enact legislation that will attract first-rate personnel to CDC.

5-11 OMB should follow both the GSA and congressional mandates regarding the construction of facilities at the CDC. OMB should not undermine congressional intent.

5-12 The budgeting process needs to be streamlined to ensure that valuable staff time is used in the actual delivery of prevention programs. Funds should be made available to states for prevention services, such as counseling and testing, partner notification, education, and other services as a block grant administered by the CDC and delivered on a formula basis.

That formula should be based on the following principles:

* 35 percent of the funds should be distributed to the states providing:

  -- a base amount to each state for the establishment of basic programmatic efforts as core support;

  - the balance of the amount to be distributed on a per capita basis and utilized by the state in accordance with a plan which incorporates the funding needs of local health departments, community health centers, community-based organizations, and other appropriate institutions.

* 50 percent of the funds should be distributed among states on the basis of a formula reflecting the reported and the estimated HIV prevalence. Funding for FY91 should be awarded on the basis of reported prevalence only.

* 15 percent of the fund should be retained by the CDC for use in capacity building among states, technical assistance to states, federal demonstration and special projects, and research and training, including support for data collection.

5-13 Rational staffing strategies need to be developed at the state and local levels that identify HIV programs as separate entities or that fully incorporate them into existing structures. The end result, however, must be the full delivery of HIV prevention services and other important public health initiatives.

5-14 If not already in place, state and local departments of health should form an advisory committee that consists of health care professionals, community-based service organizations, community leaders, and others to advise on the most appropriate strategy to control the HIV epidemic, including methods to initiate and/or expand and maintain a counseling, testing, and partner notification program within each state. An official from the state department of health should be designated chair of such a committee and should convene meetings at regular intervals.

5-15 State departments of health should coordinate the prevention and education activities of local health departments and community-based service organizations to ensure that there is neither the needless duplication of services nor an absence of needed services within a state. In so doing, state department of health should assign one individual or office to meet regularly and work directly with local health departments, and professional medical and health care associations on HIV prevention and education activities.

5-16 Public health organizations should conduct studies that will enable public health professionals to determine the most valid ways to evaluate HIV prevention and education programs.

5-17 Experienced and well-credentialed specialists in human sexuality should be incorporated into the full-time staff and consulting staff of state local public health departments and the CDC.

5-18 DOD officials should meet with organizations representing state and local public health authorities to ensure that the policy for referral and follow-up for those found to be HIV-infected is implemented. Implementation should be made a part of the normal Military Entrance Processing Command's mission statement.

5-19 Officials from the Job Corps, the State Department (including the Peace Corps), and any other federal agencies conducting HIV screening should meet with organizations representing state and local public health authorities to ensure that a policy for referral and follow-up for those found to be HIV-infected is implemented. Implementation policies and procedures should be part of agencies's mission statements.

5-20 All state and local health authorities should have systems for channeling HIV-infected applicants into appropriate counseling programs and partner notification and available medical services.

Code	Chapter 6: Prevention
6-1	States should adopt statutes that ensure confidentiality in testing and in reporting to public health authorities.
6-2	People who fall into any of the following categories should seek testing and counseling services from their physician or public health agency, regardless of the presence or absence of symptoms: * recipients of blood, blood products, donated semen, or organs since 1977. * intravenous drug abusers. * men who have engaged in sexual activities with other men. * persons who have engaged in sexual activities with more than one partner since 1977. * any person who believes his or her sexual partner, either current or past, is any of the above.
6-3	Voluntary testing for HIV infection on a nationwide basis should be widely encouraged by government at all levels, and physicians and other health care professionals should promote voluntary testing or their potentially exposed patients. To facilitate the performance of such tests, a variety of facilities such as mobile vans should be made widely available by funding through public health agencies and by the private sector.
6-4	Each state, through the local public health system, should increase the number and availability of anonymous and/or confidential testing and counseling sites.
6-5	State departments of health should make new funds available that will ensure that HIV testing and counseling services are a part of the services offered by sexually transmitted disease clinics, family planning centers, drug treatment clinics, and community health centers.
6-6	Private physicians should regularly offer their patients the opportunity for an HIV antibody test.
6-7	State and local departments of health should aggressively advocate the use of HIV testing and counseling services through public health education campaigns. These should highlight the assurance of confidentiality in order to induce more individuals to use the public health system. Special efforts should be focused on those geographic areas or members of groups in which there is evidence of high seroprevalence.

6-8 An incentive grant program should be created to support voluntary testing in counties or other well-defined geographic areas where the incidence of HIV infection rises above a designated level. These funds should be made available by the CDC on an expedited basis to applicants, who can be public or private non-profit agencies. Applicants must show that their program is consistent with the overall state HIV plan, and those tested will be referred to appropriate community services. Funds may be used for both the testing itself and for aggressive outreach and advertising of the program in the target population.

6-9 Where anonymous testing services are offered, the appropriate state or local health authorities should assure that the services are consistent with those offered at other sites, including full access to partner notification assistance and reporting data generated into seroprevalence monitoring systems.

6-10 States laws should not prohibit private laboratories from performing HIV analysis.

6-11 Any HIV-related confidentiality law should provide for confidentially reporting identity-linked test results to public health authorities.

6-12 Each state public health law should protect the confidentiality of an individual's reported infection status but allow for partner notification without informing the contacted partner of the identity of the infected person.

6-13 All state and local health agencies should initiate and be funded adequately to develop HIV partner notification programs without diverting resources from other sexually transmitted disease partner notification programs. These programs should include counseling, testing, and supportive follow-up for those individuals who are notified of their possible exposure.

6-14 To assure maximum use of resources, partner notification programs should be prioritized. Partner notification should begin with the partners of the following persons:

* hemophiliacs.
* persons who have received contaminated blood or blood products identified through "look-back" notification programs and other means.
* rejected military applicants.
* bisexual males.
* intravenous drug abusers.
* persons with multiple sex partners.
* persons with anonymous sex partners.
* infected prison inmates.

6-15 The public health department has an obligation to ensure than any partners are aware of their exposure to the virus. The public health authority and the primary provider should determine the priority of follow-up, the nature of verification that warning occurred, and the role of the identified individuals in notification by considering such factors as:

* the patient's own statements, including commitment to provide notification directly.

* the patient's relationship with the party.

* the potential additional risk presented by a delayed notification.

* evidence that the third party is aware of the risk.

* the strength of the physician-patient relationship.

* other relevant factors.

6-16 Continuing education programs and the policies and programs of professional organizations should emphasize and reinforce the role of the public health authority and the ethical obligation of each health care provider to participate in the reporting process and partner notification programs, as well as include the scientific and behavioral information about the transmission of the virus.

6-17 States should immediately reform existing public health statutes designed to control the spread of communicable diseases according to the following guidelines:

* Rigid distinctions between venereal and communicable diseases should be removed.

* The public health statute should specify that use of personal control measures must be based upon a finding that the person is in an infectious state and is reasonably likely to transmit the infectious agent, posing a serious risk to the public health.

* The public health statute should allow for a range of control measures, imposing on the infected individuals requirements such as:

  -- to report all changes of address to the pubic health department; to attend sessions at appropriate places and times for the purposes of education, counseling, testing, medical examination or treatment; and,

-- if necessary, to be admitted to a hospital, detoxification center, or a clinic for treatment of drug dependency or sexually transmitted disease on an out-patient or day-patient or in-patient basis. Control measures should have the same procedural safeguards and enforcement should be for a specified period of duration.

* The status must provide procedural safeguards of written notice, counsel, presentation of evidence and cross-examination, a clear and convincing standard of proof, and a verbatim transcript for appeal (the procedural safeguards required in civil commitment of the mentally ill). An impartial decision-maker should hear the case prior to, or in cases of urgent necessity, immediately after the imposition of personal control measures. A process for review of the decision must be authorized. Due process must be accorded.

* State public health statutes should include strong uniform confidentiality protection.

6-18 Quarantine or isolation of HIV-infected individuals based only on HIV status without consideration of an individual's behavior is not appropriate and should not be adopted.

6-19 Less restrictive measures under public health laws should be exhausted before more restrictive measures, such as limited isolation, are taken.

6-20 In exercising powers of isolation under public health laws, there should be a heavy burden on the public health official to determine that these are necessary and appropriate and that a factual basis exists for making a determination to isolate.

6-21 As soon as is practically possible, but no later than July 1, 1989, agencies which license and certify health care facilities should make a condition for licensure, a program to notify all recipients of blood or blood products since 1977 of their possible exposure to HIV.

Such "look-back" notification should include a statement about the benefits of receiving counseling and testing services and provide information about where such services are delivered. This may be done in conjunction with local or regional blood banks or the state or local health department. Notification of partners of these persons is the responsibility of public health agencies. If licensing agencies do not take such immediate steps, Congress then should enact a law that requires it.

6-22 Informed consent for transfusion of blood or its components should include an explanation of the risks involved with the transfusion of blood and its components, including the possibility of HIV infection, and information about appropriate alternatives to homologous blood transfusion therapy. These specifically include pre-deposit autologous blood, intra-operative techniques, and post-operative collection.

6-23 The FDA, in an effort to ensure that the nation's blood supply is never contaminated, should define a mechanism that quickly identifies a new threat to the safety of the blood supply and implements procedures that will abrogate that threat.

6-24 The FDA, in collaboration with the Blood Products Advisory Committee, should identify principles on which to base the introduction of new testing requirements and actively assess additional direct or surrogate tests in order to consider their introduction. Surrogate tests, such as serology for syphilis, should be required.

6-25 The FDA should restructure the membership of its Blood Products Advisory Committee so that it reflects the entire blood products community, the plasma industry, and members of the related academic community, as well as one or more public members. In its capacity as an advisory body to FDA, this Committee should actively monitor advances in research and development and recommend changes in policy and practice that should be implemented by the blood industry which will promote the further safety of the blood supply.

6-26 In health care facilities, all reasonable strategies to avoid homologous transfusion (blood from others) should be implemented including pre-deposit autologous transfusions, hemodilution techniques, intra-operative autologous transfusions, and post-operative collection. Health care facilities should offer aggressive in-service training to their staff, particularly blood banking and transfusion services personnel, to bring them up-to-date on current autologous transfusion therapy techniques.

6-27 The HCFA and the HRSA working with the National Hemophilia Foundation should develop alternative payment mechanisms to make clotting factor treatment affordable for patients.

6-28 The CDC should make grants available to Comprehensive Hemophilia Treatment Centers to be used for the design and implementation of risk-reduction and psychosocial support programs. The objectives of such programs should be to educate HIV-infected hemophiliacs about techniques to avoid the further transmission of the virus either sexually, perinatally, or through the sharing of needles.

6-29 All blood banking facilities should implement screening procedures to identify the presence of HTLV-1 in the homologous blood supply.

6-30 The FDA should fund an independent scientific organization to initiate a six-month study of the extent, purpose, and effectiveness of existing blood donor registries and the effect that expansion and/or requirement of donor registries would have on the safety of the blood supply. The independent organization should report the results of such a study to both FDA and the Congress.

6-31 Health care financing plans should treat autologous transfusion therapy no differently than homologous transfusion therapy. Coverage should apply to both.

6-32 All states should immediately enact legislation requiring the registration of facilities for the collection, storage, and transfusion or administration of blood, organs, other tissues, semen, and breast milk, in order to facilitate enforcement of regulations requiring screening for HIV.

6-33 The HCFA, the CDC, the FDA, the National Governors Association, and the Association of State and Territorial Health Officials should develop a model state laboratory licensing law that addresses: types and levels of tests performed; personnel standards; use of proficiency tests; on-site inspections; and participation in education programs.

6-34 The PHS should provide funds that will enable states to implement the above model law.

6-35 The FDA should impose criteria at least as stringent as the model state law on laboratories involved in interstate commerce.

6-36 The FY 1989 allocation for the HCFA should be increased so that it can expand its laboratory inspection efforts.

6-37 Medical professionals and laboratories should immediately adopt the policy of not reporting positive initial screening test results (such as ELISA) to the tested individual or to public health authorities without first having confirmed such positive results by a Western Blot Assay or other approved test.

6-38 Performance of the Western Blot Assay or other confirmatory tests should be restricted immediately to laboratories which currently meet high quality standards, and priority should be given to assessing labs currently doing such tests for possible certification to continue their practice.

6-39 Consideration should be given to contracting our laboratory assessment activities to professional organizations experienced in evaluating laboratory quality.

6-40 Therapists and counselors should counsel their patients/clients who are participating in behaviors that make them vulnerable to infection with HIV with the purpose of behavior and social responsibility.

6-41 Therapists and counselors treating HIV-infected patients/clients should encourage sexual and social responsibility.

6-42 Therapists and counselors should be encouraged to become well-informed and up-to-date on HIV infection. Professional associations should be encouraged to provide this education.

6-43 Incentive programs and grants should be developed to create and attract more qualified counselors to perform test-linked counseling.

6-44 Therapy and counseling association should cooperated in establishing an interdisciplinary advisory committee to develop guidelines for therapists on advising their patients about protecting themselves, their partners, and their unborn children from infection,

Code	Chapter 7: Education
7-1	All HIV programs should emphasize personal responsibility for one's actions. Actions have consequences.
7-2	State departments of health should assume the lead responsibility for coordinating HIV-related educational initiatives within each state. State departments of health should develop a one-year plan and a five-year plan that clearly define the state's educational response to the HIV epidemic. Such a plan must include the input and identify the roles and responsibilities of local health departments, professional health care associations, community-based AIDS service organizations, state and local education agencies, philanthropic organizations, religious institutions, and other appropriate voluntary initiatives. The one-year plan should be developed by September 1, 1988 and the five-year plan by January 1, 1989.
7-3	The electronic media should schedule a majority of its HIV-related public service announcement at times when they will receive high visibility.
7-4	The CDC should create a weekly newsletter targeted specifically to the media that provides accurate, current information about the HIV epidemic, including data as geographically specific as possible. Such a newsletter should include a telephone number that can be called during regular business hours to receive the most up-to-date information about the HIV epidemic. Such a newsletter should be widely advertised through trade journals, conferences, and other appropriate avenues, and should be offered on a subscription basis at reasonable cost.
7-5	State and local health departments and community-based AIDS service organizations should sponsor seminars for members of the local news and entertainment media. The seminars should help coordinate activities, provide current and accurate information about the HIV epidemic, and explain HIV-related services that are being offered throughout a community or state.
7-6	The entertainment industry should portray irresponsible sexual and drug-related activity in a manner that reflects the potentially detrimental emotional and physical consequences of such behavior and should shift focus to presenting the appeal of healthy behavior.
7-7	The CDC should conduct a 90-day study on the effectiveness of purchasing paid advertising, in addition to requesting advertising at no cost, to present information about the HIV epidemic to the general public. If the study concludes that such a purchase would be effective, CDC should purchase paid advertising.

7-8 The CDC should aggressively market the National AIDS Hotline through its ongoing HIV education and information campaign. The toll-free number, along with a description of services offered, should be widely publicized in informational pamphlets and public service announcements that are sponsored by CDC.

7-9 The National AIDS Hotline should continue to offer 24-hour counseling to respond to the needs of any caller. The CDC should ensure that there are sufficient operators on duty at all times to meet demand.

7-10 The CDC should equip the National AIDS Hotline with communications capability for the hearing impaired by August 1, 1988.

7-11 The National AIDS Hotline should serve as a referral center for the following services: community-based service organizations, advocacy and protection programs and services, availability of drug and vaccine trials, counseling and testing centers, and federal, state, and local agencies that deliver HIV-related services.

7-12 The National AIDS Clearinghouse should continue to make available free of charge those documents pertaining to the HIV epidemic produced by the federal government.

7-13 The CDC should conduct a potential user survey of state and local departments of health, community-based service organizations, and individual practitioners to determine their information requirements. At the conclusion of the survey, CDC should then ensure that the clearinghouse has the necessary funding and direction to meet those requirements.

7-14 The National AIDS Clearinghouse should collect and disseminate educational materials, including curricula and methods of instruction related to both the medical and the societal aspects of the HIV epidemic that are produced by federal, state, or local agencies or community-based service organizations. The Clearinghouse should make a catalog of these materials available free of charge, and provide copies of such material on a fee-for-service basis.

7-15 The National AIDS Clearinghouse should collect and actively disseminate to education associations, chief state school officers, school districts, and others school-based educational materials, including sample curricula nd methods of instruction concerning the HIV epidemic. The Clearinghouse should make a catalog of these materials available free of charge, and provide hard copy of such material on a fee-for-service basis.

7-16 The National AIDS Clearinghouse should make federally produced documents available in braille and on audio cassette.

7-17 The National AIDS Clearinghouse should become connected with the electronic information networks that serve state and local departments of health.

7-18 CDC, in conjunction with the PHS Office of Minority Health, should increase its information and education programs targeted toward minority communities. In so doing, CDC should contract directly with minority advertising agencies and community-based service organizations to develop a media-based information and education campaign including the input from the community-based service organizations targeted toward specific minority populations in 10 metropolitan areas that have significant minority populations. CDC and the Office of Minority Health should choose those 10 cities.

The content of such a campaign should be clear and unequivocable (sic) and culturally relevant to the communities. CDC should be responsible for the content of such a campaign ant the advertising agencies should be responsible for determining the most effective way to package and delver that information.

The major objective of such a media campaign should be to inform people about activities that place them at risk of becoming infected with the virus and to identify HIV-related services that are available within a specific community. The result of this media-based minority information and education initiative should be the creation of model media-based public information programs that can be easily replicated in other parts of the country. Consideration should be given to use of extended presentations, not just spot announcements.

7-19 Once such a media-based campaign has been developed, the CDC should make funds available to state and local departments of health so that targeted paid advertising can be purchased in media outlets specific to minorities and other distinct populations. Such funding should reflect the need to present paid programs, not just spot announcements.

7-20 When federal money is used to finance all or a part of an educational program, CDC should ensure that all program sponsors have a detailed evaluation component included in the program that measures, among others indicators, changes in behavior, knowledge, and attitudes pertaining to the HIV epidemic.

7-21 State and local departments of health should recognize the disproportionate way in which the HIV epidemic has affected minority populations. They should, at a minimum, allocate a percentage of their HIV prevention and education budgets directly proportional to the minority populations within their jurisdiction for the delivery of prevention and education programs to those minority populations. State and local departments of health should ensure that all educational programming produced is linguistically relevant to the targeted audience.

7-22 State and local departments of health should ensure that easily accessible HIV-related services, including public health education programs, peer counseling, and other risk reduction interventions, are being offered within their jurisdictions.

7-23 The CDC, states, and localities should increase funds to state and local health departments to initiate and/or increase HIV prevention and education activities. These activities should include public health education campaigns, peer counseling, outreach education, and other risk reduction interventions.

7-24 The CDC in conjunction with states should increase funds and technical assistance in program development, management, and fundraising(including grant writing) to community-based service organizations so they can develop appropriate prevention programs. These programs should include public health education campaigns, peer counseling, outreach education, and other risk-reduction interventions. Where federal money is involved, CDC should require that all grant applicants include detailed evidence of their ongoing coordination with state and local departments of health.

7-25 Because community-based organizations have successfully used their credibility with hare-to-reach populations to bring their educational messages to a broad audience, state and local health departments should provide support to responsible community-based organizations providing such services.

7-26 All citizens and philanthropic groups should be challenged to target at least a portion of their activities over the next 10 years to programs and services which will further reduce the risk of HIV transmission. Economic and political realities make it impossible for public funds to support all possible activities related to control of HIV infection. Public funds will only sustain basic services and may not be able to provide the specificity needed by some groups. Private support can extend the services and can experiment creatively with new approaches.

7-27 HHS, HUD, and states should increase funds to national and local organizations that provide services to homeless and runaway youth. The funds should be used to initiate and/or expand programs designed to provide appropriate education strategies for runaway and homeless youth. When federal money is involved, HHS and HUD should require that all recipients provide detailed evidence of ongoing coordination with state and local departments of health and other social service agencies. Funding should be based on an established history of positive interventions with homeless and runaway youth and innovative program design.

7-28 The CDC should make funds available to organizations representing persons with disabilities and special education professionals to develop materials and disseminate information about HIV infection. Such materials should be targeted to the unique needs of individuals with mental retardation, mental illness, hearing impairments, visual impairments and other learning and physical impairments.

7-29 CDC should make evaluation grants to state departments of health to conduct special studies to determine what programmatic interventions are most effective in reducing transmission of the virus in various communities. Detailed information about the programs, including program content and implementation strategies, should be provided to other departments of health and to national and community-based AIDS service organizations for possible replication.

7-30 State boards of education should mandate that an HIV education curriculum with appropriate content for age be offered to all students at each schooling level (e.g. elementary, middle, and high school) throughout the state.

7-31 If such a system is not already in place, the state director of health and the chief state school officer in every state should establish a formal mechanism to exchange information about the HIV epidemic, including current technical information and model education programs.

7-32 School staff who deliver HIV education should receive extensive in-service education before they begin instruction. The content of which should be designed in conjunction with state education and health agencies. No member of the school staff should be forced to deliver education about HIV if uncomfortable with the subject.

7-33 Local school boards should establish an advisory committee, consisting of school board members, professionals from the state and/or local public health department, parents, teachers and students, to develop an HIV education curriculum. The committee should meet at frequent intervals until the curriculum is enacted and thereafter at least annually to monitor and evaluate HIV school-based education.

7-34 The DOEd, the CDC, states and localities should increase funds to national education organizations, school districts, and other educational entities to design and implement HIV education curricula.

7-35 The CDC should increase funds to colleges and universities for creation and/or expansion of HIV prevention and education programs on campus. The schools should use these funds to educate their students about the medical aspects, including appropriate risk-reduction techniques, and the societal aspects of the epidemic.

7-36 State and local health departments should conduct conferences to provide current technical information about the HIV epidemic to state and local school boards, principals, and teachers. Such conferences should be held regularly, based on the amount of new information available or requests for updated information.

7-37 State and local health departments, in conjunction with state and local school boards, should conduct conferences to provide current and accurate information about the HIV epidemic and school-based education initiative, including the description of model programs, for parents of school-age children. Such Conferences should be made available free of charge to all parents of school-age children, and should be held regularly, based on the amount to new information available, turnover in the student population, or requests for updated information.

7-38 The President should direct the Secretary of HHS and the Secretary of Education to co-chair a task force on comprehensive school-based health programs. The task force should articulate concepts which will drive development of a truly comprehensive health education program at the local level. Strategies for funding should also be produced. Additionally, the task force should explore the development of incentives for school systems to incorporate these concepts into their programs. The Elementary and Secondary Education Act Amendments of 1988 (the Hawkins-Stafford bill), which provides funds for school systems to develop coordinated health and physical education programs, is an example of such an incentive.

7-39 All schools, both public and private, should have comprehensive health education programs for grades K through 12 fully implemented by the year 2000.

7-40 School boards and parents should develop means to incorporate values emphasizing personal responsibility in the general education curriculum.

Code	Chapter 8: Societal Issues
8-1	In the near term, NIDA, with state agencies, local drug abuse officials, and drug treatment providers, should develop a plan for increasing the capacity of the drug treatment system so the goal of treatment-on-demand can be met. The plan should designate an implementing office with the staff and technical capacity to guide implementation of the plan. The plan should provide for matching funding on a 50 percent federal and 50 percent state-and-local basis. It should have elements for a phased, targeted increase in programs insuring the quality of care, and mechanisms to evaluate progress and make appropriate adjustments.
8-2	The ADAMHA Block Grant program should continue to be the mechanism for disbursing treatment funds. However, provisions must be made for expediting disbursements and targeting the money to those areas with the largest numbers of intravenous drug abusers. If the block grant mechanism causes undue delays, consideration should be given to such methods as state and citywide contracts that could later be folded into the block grants.
8-3	The ADAMHA Block Grant funds should be directed to activities that stimulate and help patients to enter the treatment system. These activities should include, but not be limited to: aggressive outreach services to drug abusers; telephone hotlines that provide treatment information and initial access to treatment programs; centralized assessment, referral, or intake units; linkages between drug abuse programs and community service agencies, criminal justice and correctional systems, employers, schools, churches, clinics for treatment of sexually transmitted diseases, prenatal clinics, mental health professionals, marriage, family, and sexual counselors and therapists, hospice care, HIV crisis networks and coalitions; and mechanisms for identifying, developing, and cataloguing treatment resources within the community.
8-4	Federal constraints on funds for constructing, expanding, and renovating facilities for intravenous drug treatment should be made more flexible in response to increased treatment needs. In addition, a wide range of federal and local financing arrangements for community-based treatment programs should be considered.
8-5	Since an estimates 1.2 million intravenous drug abusers are concentrated in 24 cities in the U.S., treatment should be quickly expanded in those cities by having state, city, local, and community officials identify facilities which could be used for treatment centers. These should include hospitals, clinics, and other health-related sites. Approximately 2,500 new facilities may need to be developed this way.

8-6 As an interim step until new treatment facilities can abe developed, state drug abuse agencies should consider contracting with allied health professionals and social workers or organizations to serve as case managers for drug abuse clients. Case managers, who need not be affiliated with traditional drug abuse facilities, could procure medical, educational, job training and social services, and other necessary services, form existing community resources. They could assess client needs develop individualized treatment plans, procure services, and monitor service deliver. The federal government should provide demonstration funds for projects that use the case management approach to bring external community resources into treatment plans.

8-7 The NIDA should develop model demonstration programs that are community-based. These should focus on ethnic and minority populations that have been disproportionately affected by the HIV epidemic, and on the treatment needs of teenaged intravenous drug abusers. In addition, grants should be made to communities which are designing and implementing treatment programs that integrate community services and have the support of community leaders.

8-8 More emphasis needs to be placed on matching treatment with the specific needs of clients. Drug addiction is a disease of the whole person involving multiple areas of function. To be effective, any treatment approaches must ultimately address many dimensions of the client.

Those who fund and administer treatment programs should become more flexible, focusing not only on drug abuse behaviors, but also on other dimensions of the client's life (e.g., educational and vocational deficiencies and family problems) that may contribute to drug abuse. Services should not be limited to those that can be provided within a program's own facilities or by its own staff. There should be more extensive use of services available in local communities which can help to rehabilitate the drug abuser. This will require a focus on continuity of care, whether services are provided in one facility or in a number of community facilities. Community care facilities which receive public funds should be required to coordinate services with drug treatment programs and should be monitored by appropriate authorities.

8-9 Treatment programs should try different strategies to encourage patients to participate. These should include: extended hours of operation, operation during unusual hours, mobile treatment units, 24-hour satellite clinics in medical facilities, and storefronts in communities. Results of these efforts should be carefully evaluated.

8-10 Effective drug treatment, especially in this HIV epidemic, includes dealing not only with the health care needs of patients but also of their families. Treatment should include on-site primary services or referrals to community health centers, mental health centers, and other accessible community-based resources.

8-11 Comprehensive programs should be made available for women who are intravenous drug abusers and are of child-bearing age, pregnant, or mothers. These programs should provide treatment as well as prenatal and postnatal care, day care facilities, family planning, HIV testing, counseling, and child welfare services. It is essential that these services be provided during extended hours.

8-12 Drug treatment programs must aggressively provide HIV prevention and risk reduction education to clients and their sexual partners. Information must be provided on the dangers of needle and paraphernalia sharing, the immunosuppressive effect of drugs (including non-intravenous drugs and alcohol), sexual transmission, and risks to the unborn. Voluntary HIV testing should be strongly encouraged for clients, their sexual partners, children of intravenous drug-abusing mothers, and children of sexual partners of intravenous drug abusers. Any such testing must be accompanied by a counseling program.

Collaborative efforts should be established to routinely refer released prisoners to drug treatment programs near their homes, for HIV services as well as drug intervention, if such prisoners are known to have a history of drug use.

8-13 Political and community leadership should be exerted to reduce barriers to the establishment of community treatment facilities in appropriate locations. In communities where there are high rates of drug abuse and a proven need for drug abuse rehabilitation programs, but continued resistance to their establishment, health commissioners should review the possibility of invoking emergency health measures to overcome this inertia and resistance.

8-14 Quality assurance in drug abuse treatment programs needs to be reexamined. Quality of care needs to be better defined by the drug abuse treatment field and standards for programs and practitioners need to be established or refined. States should reexamine their licensing procedures for drug abuse treatment programs. The federal government should support studies of treatment outcome and the development of scientifically based quality assurance mechanisms.

8-15 A significant increase in trained personnel will be needed to implement new programs. Approximately 59,000 persons will abe needed to join the ranks of drug abuse workers. New staff training programs should be developed at universities,

community colleges, vocational and technical schools, and through internships in existing drug programs and the training of ex-addicts. Curricula dealing with education, prevention, and treatment of substance abuse and HIV should be developed throughout the educational systems for physicians, nurses, and social service workers. Federal leadership is needed to foster and identify model curricula for training programs as well as establishing the fields of drug abuse prevention, treatment, and research as viable and rewarding professions.

8-16 Staff development and training for drug abuse treatment providers must include education and skill development related to HIV, such as education in the modes of HIV transmission and prevention.

8-17 State judicial and correctional systems should consider assigning individuals to drug treatment programs as a sentence or in connection with sentencing. For persons convicted of drug-related offenses or those convicted on non-drug-related offenses but found to abe drug abusers, the convicted person should be placed in a drug treatment program in those instances where probation authorities recommend alternatives to imprisonment. To assure program compliance, the convicted person should serve a prison sentence for violating the terms of the drug treatment program. Those who are incarcerated should be referred upon release to drug treatment facilities near their homes.

8-18 The NIDA should expand its comprehensive research program. It should particularly emphasize strategies for the treatment of intravenous cocaine use.

8-19 The NIDA should sponsor additional research to determine which clients will most likely succeed in a particular treatment program.

8-20 The NIDA should sponsor additional research in improved pharmacological agents for drug abuse treatment, including narcotic antagonists, mixed agonist-antagonists, not-pharmacological strategies and more effective delivery systems.

8-21 The NIDA should fund research to improve service delivery, treatment methods, and innovative types of treatment. Results should be disseminated to the field.

8-22 Federally sponsored research should be conducted on the effects of drug abuse on the immune system in order to determine the efficiency of HIV transmission to and from drug abusers and to prevent asymptomatic HIV-infected individuals from progressing to symptomatic disease.

8-23 The grant processing cycle must be shortened throughout government to provide quicker review and approval of applications for grants related to HIV research i general, and in particular as it relates to drug abuse research in data collection, demonstration programs, prevention and treatment research.

8-24 Studies funded by the NIDA should be undertaken expeditiously to provide adequate data on the number of drug abusers, the number in treatment, the HIV rates among drug abusers, and baseline research into the sexual patterns of drug abusers. The data can be used to promote detailed planning by the federal government, states, cities, and communities. Also needed is research that examines the characteristics of addicts which lead them to respond to various social and environmental pressures. Since success rates in treatment are related to length of stay in treatment, research should continue on ways to improve retention in treatment.

8-25 The ADAMHA's Office of Substance Abuse Prevention should sponsor more research into the root cause of drug abuse, determination of those at greatest risk, and the most effective means of preventing drug abuse.

8-26 The federal effort should emphasize the development, implementation, and evaluation of model prevention programs with aggressive dissemination of effective models. Current knowledge of effective prevention and intervention strategies, such as those based on the significant influence of family and peers, should be used in developing additional prevention programs.

8-27 To the extent that current research provides the tools necessary to identify young people at risk for drug abuse through their behaviors, OSAP should make this information, as well as proven intervention techniques, widely available thorough publication, conferences, training sessions, and a national clearinghouse.

8-29 State and local drug agencies should support community plans to identify and develop human resources within minority communities for the drug abuse and HIV intervention effort and implement them on an urgent basis.

8-30 The federal government should support regional workshops to provide educators, parent groups, voluntary organizations, and community leaders with skills to conduct effective prevention programs to meet local needs.

8-31 Community and parental involvement should be sought in community-wide drug abuse programs. Developing public commitment to the elimination of drug trafficking should be an integral part of this effort.

8-32 Innovative community-based prevention programs should be implemented, such as culturally significant and current modes of communication, like "Rap" contests on preventing drug abuse and HIV, and peer youth training aimed at preventing initiation into the drug culture.

8-33 Current information and prevention strategies should be used widely within our education systems and communities to create an atmosphere which promotes drug-free lifestyles. Educational materials and prevention strategies must be age-appropriate and culturally relevant.

8-34 The media should be urged to donate air time for appropriate messages on drug abuse and HIV. Additionally, programming should include accurate messages on the consequences of drug abuse.

8-35 The HUD, in conjunction with state drug abuse agencies, should give special attention to public and other low income housing in creating a drug-free environment for youth. Communities in public housing that want to establish drug abuse prevention programs should be offered the organizational support of drug abuse prevention specialists and funding to support drug abuse education and prevention campaigns.

8-36 Schools, churches, and religious institutions should be encouraged to design appropriate value-oriented educational programs to discourage drug abuse and to encourage rehabilitation.

8-37 The NIDA should sponsor additional research to determine which techniques are effective in producing behavior change among intravenous drug abusers. Particularly needed is research examining the most effective ways of educating ethnically and culturally diverse groups. Since time is critical, research must take place in conjunction with the institution of programs.

8-38 While drug-using populations in high HIV-prevalence regions are targeted, those communities in low-incidence areas should recognize the threat of HIV spread and encourage drug users to seek treatment. While treatment has proven effective in reducing the rate of spread of the HIV, the spread will not be stemmed without intervention in both low- and high-incidence communities. Outreach programs to the drug-abusing population should therefore be expanded in both high- and low-incidence areas. In addition, communities with low HIV prevalence rates in their intravenous drug-using population should engage in prevention and education campaigns to keep those rates low.

8-39 State and local drug abuse agencies should expand the treatment system and outreach efforts together. Outreach workers must have treatment programs available to offer drug users who are willing to take action. Education without treatment is empty.

8-40 Programs aimed at prevention, intervention, and rehabilitation among intravenous drug users should include outreach to their sexual partners. All providers of care in substance abuse programs should be enlisted in efforts to prevent sexual transmission of HIV.

8-41 Creative outreach programs should be implemented to reach drug users and adolescent runaways in homeless shelters, shooting galleries, hospitals, and other places where addict congregate. Innovative outreach techniques should be used, including such ideas as the distribution of coupons to be redeemed for drug treatment and the use of mobile vans. One-on-one communication should be supplemented by flyers, posters, and other creative means of presenting information.

8-42 Outreach efforts should have an HIV prevention and risk reduction emphasis, focusing on the risks associated with needle- and paraphernalia-sharing as well as sexual and perinatal transmission.

8-43 Training of street outreach workers and of staff should be continued and expanded. Ex-addict street educators should be integrated with community-based treatment staffs who are familiar with the communities where they work and reflect the ethnic composition of the communities.

8-44 Prevention programs for minorities should be established at the grass roots level and on a one-to-one basis with peer contact, in shooting galleries and in neighborhoods. The information presented must be understandable, culturally sensitive, and direct. Ethnic minorities should be included in tea planning, developing, and implementation of such efforts.

8-45 Outreach efforts should be targeted at female intravenous drug users and females of childbearing age who are sexual partners of intravenous drug users. All providers of women's health care should be enlisted in efforts to prevent sexual transmission of HIV. Most women who visit a women's health care provider, whether it be for family planning or a routine checkup, have no other health contact annually.

8-46 All women's health care providers, in providing pregnancy and maternity services, should make maximum effort to avoid increasing the risk of infection of neonates by infected pregnant women.

8-47 State and local governments should make illicit drug control a high priority and provide adequate funds for drug-related programs. Increased funding should be provided for addition law enforcement personnel, prosecutors, judicial resources, and prisons.

8-48 State and local governments must strengthen their drug abuse laws and regulations and increase their enforcement. In addition to strengthening programs to reduce the supply of illicit drugs, individuals and community organizations should establish strong anti-drug policies aimed at reducing the demand for drugs. For example, schools and colleges and universities must establish and enforce strict anti-drug policies and procedures for students, teachers, administrators, and staff. All private and public employers, including transportation organizations, should have a strong anti-drug work policy applicable to all employees.

8-49 States should enact stronger penalties for those convicted of selling, possessing, and/or using drugs, including, where appropriate, minimum mandatory sentences. Individuals on probation or parole from drug sentences should have probation or parole revoked upon violation of the conditions of their release, especially where those violations are drug-related.

8-50 State and local government should develop programs aimed at parents of minors convicted of drug-related offenses, including elements such as training courses and community service requirements.

8-51 The process for confiscating, liquidating, and distributing the assets of drug sellers and users must be enhanced:

* The FBI and the DEA must hire and train more forfeiture specialists to ensure more expeditious review of seizures.

* All states should enact asset seizure and forfeiture statutes.

* Greater effort must be made to protect seized assets in custody to ensure that assets retain their maximum value.

* Consideration should be given to permitting, under certain circumstance, asset forfeiture funds to be disbursed for capital expenditures related to drug control operations.

* With respect to the sharing of funds generated by forfeited property pursuant to statutory provision, consideration should be given to expanding the scope of such equitable sharing provisions to permit sharing by foreign government law enforcement authorities assisting in U.S. government drug control operations.

8-52 Federal anti-discrimination protection for persons with disabilities, including persons with HIV infection, should be expanded to cover housing that does not receive federal funds. The HUD should clarify that Section 504 of the Rehabilitation Act currently prohibits discrimination against persons with HIV infection if federal funds are involved. HUD should actively enforce Section 504.

8-53 The HUD funding for homeless assistance programs should be increased, and funds should be made more easily available to cities and private sector organizations to build both temporary shelters and permanent residences for homeless persons with HIV infection.

8-54 Operators of all homeless shelters and residences must treat those clients who are HIV-infected in an anti-discriminatory manner, protect them from abuse, and help them seek medical assistance as needed.

8-55 The CDC should fund and coordinate targeted seroprevalence studies (e.g., on adolescents, women, and adult men) to be conducted by city agencies in high prevalence cities to establish the size of the homeless population of persons with symptomatic HIV infection and to help cities determine the need for services. In addition to HIV antibody status, these studies should gather information on concurrent medical problems, such as tuberculosis and drug addiction, to both collect co-factor information, and determine the need for greater medical intervention in municipal shelters. Study results including geographic breakdowns should be made available to national mayors' associations, the Association of State and Territorial Health Officials, and to state and local officials, as appropriate.

8-56 The joint project between the NIMH and HRSA on adolescent homeless youth and HIV infection should be expanded and funding increased. More programs on homeless youth should be funded.

8-57 The HUD should provide renovation grants to public hospitals to convert underutilized acute care beds into long-term care beds for HIV-infected individuals requiring hospice or other long-term care.

8-58 The use of HUD funds to help finance construction and improvement of nursing homes and related facilities should be encouraged to make additional long-term care and hospice care beds available

8-59 The Veterans' Administration should conduct a short-term study to determine the extent of homelessness among veterans, and the HIV infection in this population. The results of this study should be forwarded to the Secretaries of HUD and HHS for future resource allocation.

8-60 State and local social service agencies should establish a special HIV unit charged with development of a comprehensive care program for biological and foster families with children with HIV infection. Children with HIV infection should be assigned to case managers who will be responsible for developing networks to provide supportive services, including visiting nurse and other medical services, counseling and mental health services, nutritional programs, day care, and housing.

8-61 State and local social service agencies should train special caseworkers to be assigned to cases involving HIV infection. Case loads should be small so that the caseworker will be readily available to support the family in time of crisis.

8-62 All social service agencies working with HIV-infected children should encourage kinship foster care, which has been a frequent solution in minority families especially. In particular, the grandmothers of children with HIv infection have come forward to care for them and should receive appropriate support services to enable them to provide homes for these children. Through local community and church groups, agencies should develop outreach programs for the grandmothers and other relatives of children with HIV infection.

8-63 Social service agencies should undertake aggressive recruitment of foster families, including contacting existing networks of foster parents in the community and employing publicity to focus public attention on these children and the need for foster homes. Agencies should consider non-traditional foster parents, including single and handicapped individuals, older parents, and senior citizens for children with HIV infection.

8-64 Agencies funding foster care should give foster parents of children with HIV infection special incentives such as access to day care and respite care and an increased foster care stipend. Day care centers, with specially trained personnel, should be established to make foster care possible for a larger number of parents. Grandmothers and other relatives of children with HIV infection should be made eligible for foster care stipends.

8-65 The HCFA, in conjunction with state Medicaid agencies, should re-evaluate the eligibility of infants with HIV infection for Medicaid through the Supplemental Security Income and Aid to Families with Dependent Children programs. The release of these children from hospitals should not be delayed simply because of the need for confirmatory testing and diagnosis at 15 months to provide Medicaid eligibility.

8-66 The HCFA should encourage and support state social service agencies and Medicaid agencies to collaborate in applying for and using any available waivers to assure coverage for the full range of in-home and community-based services needed by HIV-infected eligible children. The state and local agencies involved should closely monitor the services provided under these waivers and request new waiver provisions from HCFA if necessary.

8-67 The HHS should provide adequate funding for demonstration programs providing residential care for babies who are abandoned in hospitals and temporary non-medical care for children with serious illness. Programs should include both foster family care and innovative community based alternatives to hospitalization along with provision of day care, respite care, and other support services for care givers. Model programs should be developed in conjunction with local public social service and health agencies, religious organization, child welfare agencies, community service, and voluntary organizations. Dissemination and replication of models should be encouraged. Where appropriate, foster and respite care provided through not-for-profit sectarian and non-sectarian organizations should be supported through federal and state funds.

8-68 The HUD should make available to states and localities matching funds for the construction or renovation of small group homes for HIV-infected children. These funds should be available for facilities for day care and respite care for families of HIV-infected children as well as for group homes.

8=69 Funds should be provided by HHS for a national technical assistance program for community-based organizations. Technical assistance should include training in general management practices, fund raising, and program development.

8-70 A clear funding system, with increased fund, which provides money directly to community-based organizations, should be established by HHS. The grants should be used to provide a variety of services including counseling, prevention and education programs, assistance with housing, food, clothing, transportation, and securing needed medical and social services. Grant applicants should provide evidence of the ongoing coordination with state and local departments of health.

8-71 All public and private employers should ensure that their workplace policies provide HIV-infected employees with the same rights and benefits offered other employees with other illnesses and disabilities. Employers are encouraged to use the OPM guidelines as a reference when planning their HIV policies and programs. (these guidelines appear in the Appendix).

8-72 All federal agencies should serve as a role model for the private sector by immediately adopting and implementing the employment policies for HIV-infected workers described in the OPM guidelines. The guideline establish a policy for employers of responding to HIV-infected individuals just as employers should with an individual with any other disease or disability (i.e., in a compassionate, humane, and fair manner).

8-73 The President should consider requiring all federal agencies to comply with the OPM guidelines and report annually to him on compliance.

8-74 All employers are encouraged to take active roles in the community response to the HIV epidemic by supporting research, education, health care coalitions, and local HIV support groups.

8-75 Large corporations are encouraged to work with other area businesses to help employers develop appropriate HIV-related policies and to develop, print, and distribute education materials appropriate to the workplace.

8-76 Low-cost or free information about model HIV policies and programs for the workplace should be made more readily available through the support of the private sector, non-profit organizations, business and health coalitions, local Chambers of Commerce, and local, state, and federal governments.

8-77 The CDC's National Clearinghouse for AIDS and the GSA's Consumer Information Center should disseminate exemplary publications on HIV infection in the workplace produced by both the public and private sectors.

8-78 Employees with any disease or disability, including HIV infection, should be treated with compassion and understanding and allowed to continue working as long as they are able to perform their job. The "otherwise qualified" standards articulated by **Arine** should be applied and reasonable accommodation should be made for the employee.

8-79 Employers should, where indicated to protect the public safety, provide performance testing and evaluation, including neurological assessment, to detect functional impairment. The Commission does not recommend HIV blood screening for this purpose.

8-80 The CDC should classify the transmission modes of organisms which cause secondary infections in HIV-infected individuals. This information should be written in easy-to-understand terms and made available to employers and the general public through brochures or other appropriate means.

8-81 Employers should take a personal and active role in providing both management and employees with information about HIV and its transmission.

8-82 Employers should work with employee representatives as well as area HIV education and health experts to tailor the HIV information program to the needs of the work force.

8-83 The HHS should study reimbursement regulations and practices with regard to those voluntary organizations which serve indigent populations to ensure that regulations are not unnecessarily restrictive.

8-84 Convocations of religious and lay leaders of the country should be convened in conjunction with health care providers to develop policy guidelines regarding provision of care and education about high-risk behavior. Increased coordination of effort along these lines could be extremely helpful in bringing to fruition so many of the care and education objectives we all share.

8-85 Religious institutions should address their congregations concerning compassionate treatment of persons with HIV disease and should continue to educate their congregations about scientifically substantiated modes of transmission of HIV. This education should allay unwarranted fears and attempt to put an end to discriminatory practices in their communities.

8-86 Religious educators themselves should be provided with a thorough education about HIV so that they, in turn, can provide accurate and consistent information to the laity.

8-87 The nation's business leadership should convene a highly visible conference, bringing together national corporate and foundation leaders and leaders of regional and community philanthropic organizations. The conference should include organizations such as the National Leadership Coalition, the National Business Council, and others likely to represent broad coordinated leadership. Key government officials should be invited to provide a briefing on the epidemic and rationale for corporate and foundation involvement in all aspects of the epidemic.

8-88 Philanthropies should more actively participate in local community involvement by meeting with local HIV-related organizations to determine needs and share information and resources.

8-89 Corporations should focus grant award efforts on areas most underserved by federal and state funding (e.g., housing and food for the homeless, foster care for HIV-infected children, and provision of services for the homebound person with HIV-related illnesses).

8-90 Both the federal government and the private sector funding organizations should more frequently employ challenge or matching grant programs to encourage a wider participation in funding for epidemic relief and education by a broader base of business, foundation, and individual donors.

8-91 National trade associations and their networks should encourage medium and small businesses, as well as those outside major cities on the EAst and West Coasts, to become more actively involved in funding programs, and should encourage their membership to support local efforts.

8-92 Recipient agencies should make every effort to become enrolled in employee "matching gift" programs, by which a corporation will contribute to a non-profit organization an amount equal to the employee's contribution.,

8-93 Corporations and foundations should develop ways to provide technical support to newly emerging community-based organizations by loaning middle level managers, accounting services, printing and design services, and other practical contributions that will help the new organizations develop technical expertise and increase funding eligibility.

8-94 Government agencies responsible for designing prevention messages targeted to special populations, such as minorities or adolescents, should utilize the services of well-known personalities in the creative arts, film, and television industries to present those messages through well-known models.

Code	Chapter 9: Legal and Ethical Issues
9-1	The President should issue an executive order banning discrimination on the basis of handicap, with HIV infection included as a handicapping condition. This executive order would reinforce existing Section 504 regulations and clarify that all persons with HIV infection are covered by Section 504. Such an executive order would reaffirm existing federal anti-discrimination law which prohibits discrimination on the basis of handicap and would be a powerful message from the leadership of the nation. One basis for this directive could be the excellent policy guidance on "AIDS in the Workplace," recently issued by OPM.
9-2	A strong anti-discrimination message, clarifying that HIV infection, like other disabilities, cannot be a basis for discrimination, should be a part of all national HIV education and information materials and activities, including the CDC National AIDS INformation and Education Program. In addition to providing the facts about transmission of the virus, national education efforts should emphasize that HIV-related discrimination is both irrational and illegal. The federal government should provide leadership in asserting that HIV-related discrimination will not be tolerated.
9-3	Special incentives or awards for positive, innovative HIV policies and programs in workplaces and schools should be highlighted and promoted by a high-level federal government office, such as the Office of the Surgeon General.
9-4	Comprehensive federal anti-discrimination legislation which prohibits discrimination against persons with disabilities in the public and private sectors, including employment, housing, public accommodations, and participation in government programs, should be enacted. All persons with symptomatic or asymptomatic HIV infection should be clearly included as persons with disabilities who are covered by the anti-discrimination protection of this legislation.
9-5	DOJ, which has been designated to coordinate the enforcement of disability discrimination law for all federal agencies, should issue a follow-up memorandum expressing support for the Arline decision and withdrawing its earlier opinion that fear of contagion is not a basis for Sec. 504 coverage. In addition, the DOJ memorandum should take the lead in endorsing lower court rulings by clarifying that persons who are HIV-infected yet asymptomatic, as well as persons with symptomatic HIV infection, are covered by Sec. 504.
9-6	The Office of Civil Rights within each agency should develop policy guidelines state that all HIV-infected persons, including those who are asymptomatic, are subject to the jurisdiction of the Office. The agencies should publicize

the availability of the services of their Offices of Civil Rights to those who have experienced HIV-related discrimination and should publish their intent to investigate actively all complaints. The agencies should distribute these policy guidelines to all contractors and grantees.

9-7 All agency Offices of Civil Rights should establish a system of aggressive investigation of violations of Sec. 504 in HIV infection-related cases, including expedited procedures for review of complaints and regular monitoring of procedures.

9-8 Supplemental funds should be allocated to all agency Office of Civil Rights to increase staff and resources for the enforcement of Section 504.

9-9 If not now the case, states should amend their disability laws to prohibit discrimination against persons with disabilities, including persons with HIV infection who are asymptomatic or symptomatic, and persons with AIDS, in public and private settings including employment, housing, public accommodations, and governmental services.

9-10 State-sponsored HIV education campaigns should include anti-discrimination components.

9-11 Arbitration, mediation, and accelerated settlement procedures and programs should be developed and utilized to assist in the speedy resolution of HIV-related discrimination complaints. Mediators and arbitrators should be trained to deal with the special circumstances surrounding HIV-related discrimination cases.

9-12 Organizations representing health professionals should adopt a public policy state that their members have an ethical obligation to treat patients with HIV infection in a non-discriminatory fashion. These organizations should develop education programs for their members which include education on non-discrimination.

9-13 Religious leaders should take an active role in the anti-discrimination education effort with members of their parish or congregation. In addition, religious institutions should develop outreach programs for individuals in their community with HIV infection and should involve the congregation or parish members in volunteer activities.

9-14 Employers should develop an HIV education program for all employees. Education programs to combat discrimination should emphasize two goals: information about transmission to prevent the further spread of HIV infection and education about legal issues such as how to ensure confidentiality and prevent discrimination. This approach should be used in all workplace settings.

9-15 Employers should have each department or office review and revise policies and procedures in light of medical and legal information related to HIV infection, and, where applicable, interact with the community to further public education about HIV infection. This last step may be most applicable in the public sector.

9-16 Each school system should establish a board-developed policy, with accompanying guidelines, for dealing with an individual with HIV infection in the school before it is confronted with the first case. The CDC or other public health guidelines should be utilized but the policy should be flexible and allow each case to be dealt with on an individual basis, based on medical facts.

9-17 Educational materials about the transmission of the disease and the anti-discrimination laws should be developed and disseminated and, where necessary, explained fully by legal and medical experts. Age-appropriate materials on these topics should be developed for students.

9-18 School officials should identify a decision-making structure to review all HIV policies and procedures and to deal with each individual case. Legal, medical, and public health consultants from the community should be involved.

9-19 Open public meetings should be scheduled, featuring school officials, medical and legal consultants, and community officials, to discuss the board's policies and the rationale for its decisions. School officials must be prepared to educate the entire community, including parents, public officials, clergy, pediatricians, students, and media representatives, about the reasons for the board's decisions. Support and counseling should be offered to employees, parents, or children who are troubled by the board's decision.

9-20 In any communications about specific HIV-infected individuals, the confidentiality of the schoolchild or staff member should be maintained to minimize the opportunity for discriminatory behavior.

9-21 A team should be formed with responsibility for reviewing all aspects of the case on an ongoing basis and monitoring medical or legal developments that might affect school district decisions.

9-22 School officials should actively participate in community education efforts so that they support acceptance of HIV-infected individuals in the schools in a non-discriminatory manner.

9-23 Educational associations should disseminate information to their members on the policies and procedures used by those communities which have accepted an HIV-infected individual in their schools without fear and discrimination.

9-24 Hospitals and providers of health care to HIV-infected patients should establish a mandatory education program for all hospital employees, including an anti-discrimination component and professional, confidential counseling for all employees. Health care workers need to be reminded about the social context of HIV infection and the need for confidentiality and protection of private medical information.

9-25 Health care providers dealing with patients with HIV should make available a patient care advocate, if one does not yet exist, to regularly contact individuals with HIV, so that patients could confidentially report treatment problems. Health care professionals who have repeated, substantiated complaints made against them, and who resist education, should be formally reprimanded and placed on probation. In general, the Commission feels that remedies such as this should be short-term in nature and could gradually be phased out.

9-26 State and local governments and health care providers should develop long-range plans now to anticipate the need for community-based health care facilities, and should develop a strategy to education community members to accept facilities and prevent discriminatory responses.

9-27 Those working to educate a community in preparation for acceptance of patients with HIV infection should develop a strategy to prevent discrimination. Some important points to include are: allowing time for education; knowing the legal issues involved; mobilizing political, community, and religious leaders for support; bringing in legal and public health experts; meeting with people who have concerns and listening to their concerns.

9-28 Adoption of federal legislation that mandates that identifying information obtained by any provider, laboratory, payor, or agency through HIV testing and counseling cannot be disclosed without the written sent of the individual except under the following circumstances:

* to members of the individual's direct care giving team (i.e., the attending physicians, primary or staff nurse, consulting physicians with a special need to know, or outpatient case manager).

* to health care workers accidentally "exposed to the blood or blood contaminated body fluids" of the individual, as defined by the CDC guidelines, where information on

exposure cannot otherwise be shared without identifying the individual.

* for statistical reports if used in such a way that no person can be identified.

* to the state health agency, if required by state or federal law or regulation for epidemiologic or partner notification purposes.

* to blood, organ, semen, or breast milk banks, that have received or will receive blood, an organ, semen, or breast milk from the individual.

* to a spouse or sexual partner when the individual will not inform such party with respect to the identifying information.

* by a court order issued pursuant to application of a state public health officer. Court proceedings held in connection with disclosure requests by state public health officers should be held in private. Prior to requiring disclosure, the individual should be proved an opportunity to participate in the proceeding to determine whether a disclosure will be ordered. Records of the proceedings should not be open for public inspection and should be sealed at the close of the proceeding. Public health agencies should advocate that court orders for disclosure of name-linked information should not be issued except when compelling reasons for disclosure are demonstrated.

* to the victim of a sexual assault.

The statute should classify violations of confidentiality as misdemeanors, punishable by a fine of up to $10,000. The statute should not preempt state statutes which are consistent. The statute should restrict the re-release of information shared except as provided with the entire body of the statute.

9-29 Federal and state information and education efforts should continue to emphasize the importance of confidentiality to the success of HIV prevention strategies.

9-30 Public health and health care institutions should adopt strict policies regarding administrative or disciplinary action to be taken if a staff member discloses confidential information, and these institutions should regularly provide training on these policies for all employees and volunteers.

Agencies responsible for accrediting or licensing health care institutions should require as part of their accreditation or licensing process that such institutions adopt strict confidentiality policies. Accrediting and

licensing agencies should prepare and publish guidelines for confidentiality policies, and, in their periodic reviews of health care institutions, evaluated institutions' confidentiality policies for consistency with the agency's minimum standards of compliance.

9-31 Educational programs on confidentiality should discuss: the special sensitivity that must be accorded information about HIV-infected individuals; and the adverse consequences that could occur if information is erroneously released.

9-32 Educational programs for all health care workers should emphasize the importance of confidentiality.

9-33 Insurance companies should adopt clear and comprehensive policies regarding the confidentiality of HIV-related information in their possession. Special care must be taken to avoid inadvertent conveyance of HIV-related information to a proposed insured's employer (even in those situations where the employer is the applicant) or agent, or improper access of such information through the Medical Information Bureau.

9-34 Clear and comprehensive policies must be adopted by the federal government with regard to the confidentiality of HIV-related information held by institutions of the federal government, including the military.

9-35 Health care-giving institutions must assure patients that confidentiality will be respected, expect in the most explicit and rigorously defined instances. Patients should be advised of the potential consequences should they voluntarily disclose confidential HIV information.

9-36 Adoption of federal HIV confidentiality legislation that includes a provision permitting, in specific instances, disclosure by health care providers to a patient's spouse or other specific sexual partner at risk of contracting HIV.

9-37 State statutory provisions for health care provider notification of sexual partners concerning risk of HIV infection should be tied to stringent protection of confidentiality.

9-38 Notification provisions must specify those persons who are authorized to do the notification.

9-39 Notification provisions should include sanctions for confidentiality breaches that are inconsistent with the terms of the statute.

9-40 Notification of sexual partners by health care providers should be discretionary and should not be imposed as a legal duty to warn. However, all health care providers should

report HIV cases with identification to state public health authorities. Using the information reported by providers, all public health agencies should be involved in partner notification programs as discussed in Chapter 6. In no case is the identifying information to be released by the agency to the person notified or forwarded to other agencies such as the CDC.

9-41 All health care providers and public health officials should counsel patients about behaviors that may cause harm to others, encourage them to notify sexual partners, and teach strategies for prevention of the spread of the virus.

9-42 The health care provider's decision to warn should be made on a case-by-case basis and should consider such factors as:

* the patient's own statements, including commitment to notify third parties;

* the patient's relationship with the third party;

* the potential additional risk presented by a delay in notification;

* whether the third party is pregnant or considering pregnancy;

* the likelihood that the third party has no reason to believe that he/she is at risk;

* the availability of partner notification program in the local public health department;

* the strength of the physician-patient relationship; and

* other material factors.

9-43 Education programs for health professionals should include basic skills which enable them to become more adept in counseling HIV-infected individuals and their partners, including the ability to explain viral transmission accurately and clearly in nontechnical language. The curriculum should also include principles of psychosocial counseling and techniques for supporting individuals in patient-managed notification. In addition, the curriculum should clarify the procedures for professional-managed notification if the HIV-infected individual does not warn partners within a specific time frame set by the state. To help train these individuals, HIV counseling programs should be incorporated in the following:

* existing professional education process.

* continuing medical or professional education.

* professional societies and associations.

* existing and planned HIV regional education and training centers.

9-44 Counseling of persons notified should include the provision of information on testing, community health care and other support services available to HIV-infected individuals.

9-45 Notified women of childbearing age and their sexual partners should be provided access to counseling about the risks of perinatal transmission.

9-46 Adoption by the states of a criminal statute directed to those HIV-infected individuals who know of their status and engage in behaviors which they know are, according to scientific research, likely to result in transmission of HIV clearly setting forth those specific behaviors subject to criminal sanctions. With regard to sexual transmission, the statute should impose on HIV-infected individuals who know of their status specific affirmative duties to disclose their condition to sexual partners, to obtain their partners' knowing consent, and to use precautions, punishing only for failure to comply with these affirmative duties.

9-47 HIV criminal statutes should include strong, uniform confidentiality protection.

9-48 Prior to instituting a case against an accused individual, prosecuting officials should consult with local public health officials to determine whether to prosecute the individual for an HIV transmission criminal offense or whether public health intervention would be more appropriate. Systems should be set up to facilitate this dialogue.

During the presentation of the state's case, the prosecuting attorney should introduce, consistent with federal and state rules of evidence, any information held by the public health department regarding intervention measures taken with respect to the infected individual.

9-49 HIV criminal statutes should include a provision stating that prior to termination of any period of incarceration or probation under the statute, the offender will be interviewed by state public health officials for the purpose of determining whether further action will be required by the public health authorities upon release of the individual. Such interview proceeding must be subject to procedural due process safeguards, and any action taken by the public health authorities must be pursuant to powers provided by the state's public health laws.

9-50 States should refrain from criminally prosecuting HIV-infected individuals for HIV transmission when the alleged criminal conduct did not involve a scientifically established mode of transmission.

9-51 Prostitution laws should be strictly enforced.

9-52 Public health officials, criminal justice systems, and various organizations that deal with victims and perpetrators of sexual abuse must collect and compile data so that the scope of HIV prevalence and transmission associated with sexual assault can be determined.

9-53 CDC should monitor and publish the number of reported cases where HIV transmission occurs through sexual assault including geographic breakdowns.

9-54 Criminal justice and victim service organizations should collect data on the frequency of sexual assault victims' requests for HIV testing and the frequency of positive results for both victims and perpetrators.

9-55 Support for incidence and prevalence studies of HIV among the sexual assault population, such as those currently funded by the NIMH, should continue with increased funding.

9-56 Programs which provide medical and counseling services to sexual assault victims should make voluntary HIV testing a part of the sexually transmitted disease screening process free of charge and make appropriate counseling about assaults and HIV available by trained staff.

9-57 Training programs for HIV blood test counseling and partner notification techniques should include components focusing on the sexual assault population.

9-58 Federal and state public health authorities should provide service providers and counselors who assist child and adult victims of sexual crime with the most current information and training on HIV, along with information on the location of confidential and anonymous testing sites and funding and training for the performance of tests.

9-59 Model programs for the long-term follow-up care of victims who do and do not test positive initially should be developed and funded. If a victim converts to positive infection status, there should be counseling and health care intervention provided through the various stages of HIV infection. These individuals should receive highest priority for participation in clinical drug trials.

9-60 Social services, law enforcement, mental health, medicine and community-based services should cooperate to provide effective response to child sexual abuse by a well-coordinated, multidisciplinary team which protects and treats victims and their families and deals effectively with perpetrators, incorporating concerns related to HIV exposure.

9-61 Basic curricula/training programs for health, counseling, and criminal justice professionals should include identification of undisclosed sexual trauma, dynamics of victimization, and patterns of trauma and recovery as well as HIV transmission.

9-62 Victim advocacy programs should increase public awareness concerning the potential impact of HIV on victims of crime through education.

9-63 Criminal justice authorities, under the guidance of public health officials, should develop a mechanism to order that a sexual offender submit to an HIV test at the earliest possible juncture in the criminal justice process. The results of such a test should remain confidential and be disclosed only to the victims, if they so desire, and public health officials. Where the victim of the sexual assault is a minor, the test results should be disclosed to the minor's parents and/or caretakers.

9-64 The criminal justice system should periodically conduct follow-up testing of convicted offenders who test HIV negative to monitor for possible development of antibodies or other evidence of infection at a later time, with notification of victims as appropriate.

9-65 In cases where a sexual offender is not apprehended, or where apprehended and there is a possibility of HIV infection even though current test results are negative, victims should be offered testing and counseling on the transmission of the disease and proper precautions.

9-66 Adult victims who choose not to know of the sexual offender's HIV status should be informed of the possibility of infection and offered testing and counseling so that they can take appropriate precautions.

9-67 Courts should utilize restitution orders whenever possible so that sexual offenders are held directly accountable for the financial effects of their crimes.

9-68 State laws and federal laws (in the limited areas where federal laws preside over criminal actions, such as on Indian reservations) should include provisions for enhanced sentencing in cases where sexual offenders commit sexual crimes knowing they are HIV-infected.

9-69 Criminal justice facilities should test all convicted sexual offenders of HIV prior to a parole hearing or release from prison. If a parole is granted, a positive test result should affect the degree of supervision the sexual offender receives following release.

9-70 If a convicted sexual offender is HIV-infected, this information should be included in the sexual offender's criminal record and used in sentencing hearings for subsequent sexual assault convictions as a basis to further enhance sentencing. The criminal justice system should restrict availability of information on HIV status to those individuals within the criminal justice system with a need to know. Under no circumstances should this information be released as general public information.

9-71 The criminal justice system should restrict develop and implement sound treatment programs for sexual offenders which include an HIV prevention component.

9-72 All correctional systems should immediately institute an HIV prevention program for both inmates and staff. These systems should: provide education and training on a regular basis; be based on the most current medical knowledge; include the latest information on risk reduction behavior and technology; and allow for participant involvement such as question and answer sessions, peer education, and counseling. Teams conducting training should include health personnel whenever possible. Training and informational materials should be brief, presented in a clear straight forward manner, and be structured for the educational level and concerns of the particular audience.

9-73 All correctional systems should regularly offer and strongly urge voluntary HIV testing and counseling for HIV infection at intake, at medical check-ups, during incarceration, and before release to all inmates. Counseling and testing should also be regularly offered to staff.

9-74 All correctional systems should adopt HIV testing policies that are consistent with the Federal Bureau of Prisons' policy for testing inmates for HIV. HIV testing programs should also provide for mandatory testing of inmates whose convictions were a result of sex or drug-related crimes or who have a history of intravenous drug abuse. Testing policies should be consistent with applicable law.

9-75 HIV testing programs instituted by correctional systems should include extensive counseling services pre- and post-testing and while test results are being determined. Counseling of those inmates found be HIV-infected must be consistent with that recommended for all infected persons, including full information about methods of preventing further spread of infection.

9-76 Rights regularly accorded to all inmates (e.g., parole and furlough) should not be abridged solely on the basis of HIV infection.

9-77 Disclosure of test results should be strictly limited. The correctional system's disclosure policy should specify clearly who is permitted to receive the information, what information is to be released, and under what circumstances. Test results should be reported to public health authorities so that partner notification can be performed.

9-78 CDC should work with federal, state and local corrections health officials to evaluate the various inmate testing programs and make those results regularly available to appropriate policymakers.

9-79 NIJ should continue to review and evaluate prison housing policies making up-to-date information and guidance available to prison systems regularly.

9-80 Each correctional facility should establish a policy on how to manage the housing of known HIV-infected prisoners based on such factors as: current public health guidelines, physical space limitations, staffing levels, and prevalence of infection in the facility.

9-81 Correctional facilities should provide a means for protecting those HIV-infected inmates whose safety would be at risk if placed in the general prison population.

9-82 The care and treatment available to HIV-infected inmates in correctional facilities should be equal to that available to HIV-infected individuals in the general community.

9-83 Correctional systems should establish drug treatment programs based on the therapeutic community model for those inmates identified as drug abusers and/or incarcerated for drug-related crimes. This model has successfully utilized former addicts as counselors because of their value as role models. The inmate should remain in drug treatment for no less than nine to 12 months unless precluded by the length of the sentence and should be referred upon release to drug treatment facilities near their homes.

9-84 Correctional systems should make counseling services available to all HIV-infected inmates. For successful treatment of inmates who are intravenous drug abusers, counseling is particularly important during those periods immediately prior to and immediately after release. The inmate should receive concentrated counseling on avoiding risk behaviors and drugs during the pre- and post-release periods. This counseling should also include admonishment that failure to do so could result in immediate disciplinary action and affect parole and/or enhance future sentencing.

9-85 Correctional systems should encourage the development of support groups with their institutions.

9-86 Health care providers have an obligation to provide care, within the limits of their competencies, to all persons who need it, regardless of their HIV status. This obligation does not preclude appropriate referrals when the provider lacks the technical or professional skills to provide the indicated services.

9-87 Health professional associations should establish or reaffirm clear guidelines on their members' obligations and responsibilities and disseminate them widely to all members. The development of such guidelines should be done with the input and participation of practicing members.

9-88 Health care providers have the obligation and responsibility to become and remain educated about HIV infection and related subjects so that they can provide competent care to patients and prevent unnecessary risk to themselves.

9-89 Health care providers should employ appropriate infection control procedures at all times. Employers of health care providers have the obligation to assure that necessary equipment and supplies are available and that all workers are adequately trained in their use.

9-90 Health care providers involved in providing direct care to patients have a right to know all known relevant patient information which might assist them in making treatment or care decisions. All health care providers have the responsibility to use this information appropriately and maintain the confidentiality of this information.

9-91 The health professional associations should continue and expand their efforts to educate their members and the public about HIV infection and should include discussions of pertinent ethical concerns.

9-92 The NIH should encourage interdisciplinary research efforts in ethics directed toward a better understanding of the processes, elements and components of the ethics of the decision-making process with particular emphasis directed toward the ethical dilemmas raised by the HIV epidemic.

9-93 Health care professionals have the responsibility to educate adequately all patients about the transmission of HIV, including those patients who need assurance that they cannot become infected by going to the same provider or the same health care setting as infected patients. Professional organizations should stress this educational responsibility in all of their education and training curricula on an accelerated basis.

9-94 Physicians have the responsibility to take all feasible steps to achieve accurate, early diagnosis.

9-95 All care givers should give HIV-infected patients the same respect, dignity, and decision-making autonomy as any other patient.

9-96 All health care providers should make informed consent by the patient an essential first step in any HIV-related treatment or intervention.

9-97 All health care providers should give HIV-infected patients the opportunity to express preferences about care and about life-sustaining therapies as early and as often as possible after diagnosis. Legal, psychological, and moral counsel should be made available to all patients to help them express their wishes.

9-98 The nation's universities and health care professional schools, through research grants and study groups, should fund and conduct the further examination of actual and potential ethical controversies which arise in providing care to HIV-infected patients.

9-99 Scientists and researchers are encouraged to subject all information related to HIV epidemic to adequate peer review and to report it to the media within a context which promotes understanding among all members of the public, and which minimizes sensationalism.

9-100 Persons infected with HIV or at risk of infection with HIV should take appropriate steps to avoid infecting others. This includes: not donating blood, sperm, or organs; not infecting others sexually; not sharing needles or other sharp instruments contaminated with blood.

9-101 Persons infected with HIV or at risk of infection with HIV should inform those persons who might be at risk of acquiring infection from them in the course of specific interactions. Specifically this includes: informing sexual partners and informing health care providers (doctor, dentist, nurse, and others).

9-102 Any provider of counseling and support to HIV-infected individuals should incorporate these principles into the information and support provided.

9-103 If, in the process of providing health care, a health care worker is exposed to the blood or body fluids of any patient, the health care worker has the right to know the infection status of that individual. Consent agreements obtained in the traditional health care provider/patient context will normally provide for this. In the unusual care

of denial of consent, competent medical authorities should make the determination whether testing should be done and, if done, should note the rationale in the medial record. (SEE: 3-45)

9-104 All human beings deserve respect and preservation of their dignity in interactions with other human beings. HIV-infected persons are no exception to this basic ethical rule.

9-105 Violent acts against individuals with HIV infection or those perceived to carry HIV should be prosecuted to the fullest extent of the law.

Code	Chapter 10: Financing Health Care
10-1	HCFA should continue to encourage states to take advantage of options available in Medicaid programs. These options include, amending plans to provide case management services targeted to certain groups such as persons with HIV infection; adopting hospice benefits useful to persons with AIDS; applying for home and community-based services waivers (Section 2176 waivers); applying for "freedom of choice" waivers permitting case management service mechanisms and innovative reimbursement methods to be used for services to persons with HIV infection; and developing special incentive payment rates for services to persons with AIDS and other patients with high-cost care requirements.
10-2	HCFA should change the Medicaid waiver review process, streamline and eliminate aspects of the application process which delay approval, expande the availability and size of the waiver program, and provide more flexibility for testing innovative treatment alternatives. HCFA should convene a meeting of state officials, including state Medicaid directors, to discuss specific changes in the waiver review process as well as a minimum package of benefits that should be reimbursed for acre of symptomatic HIV patients.
10-3	HCFA with HRSA, should encourage additional demonstration projects of reimbursement mechanisms to providers for cost-effective care of patients, including experimentation in capitation, prepaid care, and use of case management. The results of these demonstration programs should be compiled and distributed to federal and state officials for consideration in legislation and program changes.
10-4	Private health insurers should begin reviewing and revising the services eligible for reimbursement and the rates of reimbursement to cover adequately program costs, such as home health care, focusing on appropriate and cost-effective services for HIV-related illnesses.
10-5	In light of some states' experiences with Diagnostic Related Group (DRG) reimbursement for HIV-related illnesses, the HCFA should consider whether to create a system of well-defined Medicare and Medicaid DRGs which takes into account the full costs of caring for an individual with various manifestations of HIV infection, including the costs of implementing CDC's Universal Infection Control Precautions.
10-6	HCFA should establish a demonstration project which increases the federal Medicaid matching rate for states that give providers a higher rate for promoting long-term care, comprehensive home care, outpatient services, and case management of a full range of services, including coordination with other providers, to encourage cost-effective care for HIV-infected patients.

10-7 The HCFA should amend federal Medicaid regulations to allow non-hospital-based drug rehabilitation programs in a residential setting to receive federal reimbursement and to promote expansion of residential programs. This may entail exempting these programs from inclusion in the definition of Institutions for Mental Diseases.

10-8 States should re-evaluate Medicaid and Supplemental Security Income reimbursement levels for supportive housing programs for people with AIDS and review how facilities are licensed in order to provide in a residential setting the level of care needed for homeless persons.

10-9 The HUD should increase funding to encourage state and local governments, in concert with foundations and private enterprises, to establish programs to subsidize supportive housing for persons with HIV infection.

10-10 The HCFA should encourage states to provide exceptions to limits on state Medicaid payments for providing necessary inpatient care for infants in hospitals with disproportionately large Medicaid patient populations. (SEE: 2-9)

10-11 The HCFA and the HRSA should institute a program of special project grants to private and public agencies for the development or expansion of outpatient services and home care. (SEE: 2-11)

10-12 The HCFA, together with the HRSA, should establish a stop-loss provision for Medicaid which would provide block grants to states when the proportion of Medicaid funds spent on AIDS care exceeds a pre-determined level, similar to the provision under Supplemental Unemployment Benefit Program.

10-13 The Secretary of HHS, in conjunction with an independent outside body, should evaluate our current system of health care financing and recommend changes needed to achieve access to and provision of health care for all segments of society.

10-14 In the course of the evaluation described in (10-13), consideration should be given to two major options:

* Extending the COBRA provision beyond the 18-month period for employee-paid, group rate premiums from the employer's health insurance coverage to provide adequate coverage for the former employee until qualifying the Medicare. Consideration should be given to providing federal assistance to help pay the private insurance premium for persons unable to pay the full premium.
* Decreasing the waiting period for qualifying for Medicare from 24 months to 12 months in order to provide health

insurance coverage after the 18-month COBRA provision has expired. Consideration should be given to providing federal assistance to help pay the private insurance premium for persons unable to pay the full premium.

10-15 The federal government should experiment with providing tax incentives for insurers to provide community-rated, open-enrollment policies. The federal government also should make available refundable tax credits to be used for purchasing insurance by people who do not receive any employer health insurance and provide premium subsidies for private health insurance for persons unable to pay the full premium.

10-16 The federal government should encourage all states to enact a qualified state pool for medically uninsurable individuals with the following provisions:

* The federal government should experiment with providing technical assistance to states to ensure adequate coverage, financing from a combination of private and public sector funds, adequate provision of benefits, and mandated case management;

* The federal government should consider amending the Employee Retirement Income Security Act (ERISA) to include self-insured plans in pool funding; and

* The federal government should consider establishing a risk pool fund, administered by a non-profit or limited-profit corporation acting as a reinsurance organization and should be the source of stop-loss subsidies for state risk pools. HCFA should evaluate the various sources of public and private financing that would be available for this fund to cover administrative losses and to subsidize costs to patients.

10-18 The federal government should require that all patients using 50 percent or more federal dollars for their care participate in a case-managed system.

10-19 The HCFA should consider requiring states to move toward a minimum Medicaid eligibility floor at 50 percent of poverty within two years and implement a phased-in plan for moving to 100 percent of poverty, giving states the option of further raising the income threshold for the disabled.

10-20 The HCFA should consider amending regulations to enable individuals to retain eligibility to Medicaid benefits, although entitlement to Supplemental Security Income benefits may be lost when becoming entitled to Social Security Disability Insurance benefits.

10-21 States should consider enacting medically needy provisions under their Medicaid programs, if they have not done so.

10-22 States should consider expanding their medically needy programs by allowing low-income individuals to pay an income-related premium for the purpose of buying into Medicaid.

10-23 The HCFA should re-evaluate the regulations which stipulate eligibility requirements for hospice care under the Medicaid program and consider the impact of waiving the six-month prognosis requirement for persons with AIDS.

10-24 The SSA should consider proposing a statutory change allowing individuals with symptomatic HIV infection, as well as other disabled persons, to work when they are healthy enough to resume working with earnings offsetting a percentage of benefits, but without disqualifying then for eligibility to their Social Security Disability Insurance benefits, much like the provision of the Supplemental Security Income program under Section 1619 of the Social Security Act.

10-25 Those agencies providing assistance to HIV-infected individuals (such as the SSA and the HCFA) should consider streamlining the processes of enrollment in programs and reducing the bureaucratic red tape.

Code	Chapter 11: The International Response
11-1	Recognizing that the U.S. has paid in full its 1987 assessed contribution to the WHO, the U.S. government should continue direct contribution of sufficient resources to the WHO's Global Programme on AIDS (GPA). In addition, the U.S. should make a long-term commitment of support for the GPA to enhance its capacity for long-range planning.
11-2	The U.S. contribution to the WHO should receive special consideration and be exempt from restrictions placed upon contributions to other specialized agencies of the United Nations. WHO has a superior record both in the proper use of its funding and the elimination of political issues from its agenda. In the event there is any change in the manner or direction in which WHO fulfills its responsibilities, appropriate action could then be taken.
11-3	WHO's GPA should continue efforts to develop national HIV plans, working closely with host-country ministries of health to ensure a sense of national ownership, proper budgeting of recurrent costs, and coordination of donor agency contributions. This collaborative process will help ensure that responsibility for these programs rests with national governments. National HIV programs will be most effective if they are integrated into the primary health care network and do not divert scarce resources from the many other health problems facing developing countries.
11-4	WHO's GPA, through their own resources and those of donor nations, should strengthen and expand training and technical assistance to host country nationals to enable them to implement and sustain national health care programs. Assistance programs must address not only HIV, but also the building of the health care infrastructure.
11-5	WHO's GPA should give specific technical assistance to national institutions in those areas in which it has a decided strength, such as epidemiologic surveys, surveillance, health promotion, blood safety, and laboratory diagnosis, to enable them to develop their own capacity to sustain their programs. Additional programs and services should be carried out by bilateral donors and other organizations with skills in such areas as education, patient management, and counseling, utilizing the coordination mechanism of the HIV committees.
11-6	The regional programs of the WHO's GPA should be enhanced by making it possible for a broader range of interested groups and donor organizations to develop a concerted approach to this complex epidemic. WHO GPA should encourage countries to turn to bilateral donors and non-governmental organizations for assistance in developing HIV-related education and counseling programs.

11-7 Financial and technical resources need to be targeted not only to those countries in which current needs are acute, but equally to those countries where low prevalence rates indicate that education programs may be most effective. A small investment in these low prevalence areas now will results in a greater gain in the future through the containment of HIV.

11-8 Programs must respect human rights. All countries share the dual responsibilities of protecting the rights of the healthy as well as those infected with the virus. Responsible behavior can be undermined by a climate of fear and discrimination. When discrimination occurs, the capacity to fight the disease is effectively reduced, threatening public health.

11-9 The Commission supports the proposal of the WHO's GPA to establish coordinated biennial donor evaluations to diminish the burden of constant evaluations on in-country programs administrators and project staff.

11-10 The WHO should continue its efforts to gather, summarize, and publish all data on HIV for member governments. A collaborative electronic media network for information exchange should be established so that feedback can be shared on epidemiological data as well as effective protocols. This should include shared information about drugs under investigation internationally.

11-11 The WHO's GPA should continue to provide the forum for the exchange of current scientific information. It is important that these exchanges bring together national policymakers, representatives of research communities and working level personnel. Provision should also be made for international coordination of research efforts between both the medical and social science research communities.

11-12 To facilitate these critical exchanges of information, universally standardized terminology should be defined and used. In recognition of this need, the WHO's GPA should convene an international consultation to develop this terminology.

11-13 Research into the development of inexpensive, fast-response tests for detecting HIV infection should be continued.

11-14 The WHO's GPA should play a leadership role in developing and implementing protocols for international vaccine field trials.

11-15 International adoption of standardized clinical staging systems is needed so that comparisons can be made in the natural history of infection and in treatment regimens.

11-16 Epidemiological and behavioral research is required to test new technologies and alternative approaches to the containment of HIV as they are identified. Comparative analysis of this research would facilitate identification of optimal methods of intervention.

11-17 Multidisciplinary international HIV research centers are needed in developing countries. Each center should have sufficient resources to support teams of international and national scientists to make comprehensive studies of HIV in regional settings.

11-18 The A.I.D. should develop a five-year strategy which outlines the main goals of the U.S. in the global effort to address the HIV epidemic. The plan should include objectives for support of the GPA and the development and implementation of bilateral assistance programs which contribute to national HIV programs and which complement those of other donors. If more funding and additional technically qualified health related personnel are needed, representatives of A.I.D. should request them. Current limited funding for critical health programs should not be diverted.

11-19 The A.I.D. should concentrate its HIV-related assistance on clearly defined programs in which it has pronounced expertise. Particular emphasis should be given to those programs which can be sustained and copied.

11-20 The A.I.D. should review existing service delivery programs in child survival, maternal and child health, immunization, and family planning to identify areas where HIV-related components could be added to reach target populations.

11-21 Current support for international health projects needs to be expanded to include basic support for health care infrastructure and delivery systems. This would provide a solid basis for al HIV prevention and care programs.

11-22 Bilateral assistance should emphasize the education and training of local health care workers so they can train others in the community as well as provide services.

11-23 The A.I.D. should increase its support for improved epidemiologic data collection and modeling for a better global understanding of the dynamics of the epidemic in all parts of the world. This work should be coordinated with the WHO's GPA, and the database and modeling should be available to the international assistance community.

11-24 U.S. bilateral assistance should include special attention to the Western Hemisphere and the Pacific Rim in light of immigration, tourist, commercial, and strategic considerations.

11-25 Private sector organizations should join the public sector in support of research projects and field programs.

11-26 Qualified private voluntary organizations should be identified and encouraged through the commitment of funds of the A.I.D. to develop programs of health care service delivery, education and research that support and complement local government and national priorities.

11-27 Non-governmental organizations (NGOs) and private voluntary organizations should, when possible, undertake joint projects with host country NGOs, providing technical assistance and training as requested and assisting them to identify local needs, develop effective responses and monitor outcomes.

11-28 The A.I.D. should clarify the sources and availability of additional funds within other A.I.D. accounts for HIV-related programs. Non-governmental organizations, including universities and private voluntary organizations, should be advised of the availability of these funds and the method of access to them.

11-29 The A.I.D. should identify processes to allow for regular review of all bilateral HIV programs to assess progress, recognize innovations, respond to resource and program gaps, and foster economy and efficiency. A.I.D. should establish a forum for facilitating communication among non-governmental organizations and federal agencies.

11-30 The Peace Corps should develop a portfolio of available HIV-related training and assistance programs to be offered to host country governments that have requested assistance. These programs should complement existing ones. The Peace Corps should receive supplemental funding to finance these programs.

11-31 Using the best health education techniques available, volunteers should respond to requests for assistance by working with host country personnel to integrate HIV education into a full range of curricula. In addition to teaching trainers to work with village level organizations, they should develop targeted education programs for specific hard-to-reach populations.

11-32 Volunteers should help strengthen existing health care services through the training of national health care workers in all specialties.

11-33 The Peace Corps, the U.S. PHS, and non-governmental organizations should work collaboratively to avoid competition for resources and duplication of efforts.

11-34 DHHS strategic planning process should develop a five-year plan outlining research priorities and goals of HHS research institutes. This should be done in conjunction with five-year plan of the A.I.D. and the work of the WHO's GPA.

11-35 Research, epidemiological training, and control programs should have three basic components: collaboration, research training, and institutional support. DHHS should establish a program to assist developing countries to improve the quality and capacity of laboratories and increase the number of epidemiologists capable of tracking the epidemic. Collaborative programs that combine research and training are an appropriate and effective means of strengthening capabilities of developing countries to deal with HIV.

11-36 The federal government should establish an international HIV research support unit. Such a unit could coordinate efforts by A.I.D., NIH, CDC, and other public agencies, thereby responding more effectively to requests from other governments for assistance in research.

11-37 FTE positions in NIH and CDC should be expanded to respond to international requests for technical assistance and enhance cooperation with the WHO's GPA.

11-38 Travel restrictions should be reevaluated to permit appropriate participation in international scientific meetings and to provide requested technical assistance.

11-39 Research grants should be awarded for three- to five-year periods at adequate funding levels.

11-40 Postdoctoral training fellowships should be established to enable social scientists and biomedical researchers to learn more about the socio-behavioral aspects of the epidemic.

11-41 The U.S., through HHS and FDA, should develop a mechanism for working with other nations with similar drug development and control programs to accept their data leading to the approval of experimental drugs for HIV disease to be used in clinical trials.

11-42 Research is needed to determine the clinical significance of HIV-2. Studies conducted in West Africa will be most useful in determining the effects of this virus where levels of infection in certain populations are already high. Continued research is needed to determine the natural history of HIV-2 and analyze its relationship to HIV-1.

11-43 Publication of data has lagged behind the HIV testing program. DOD should pursue expeditious peer-reviewed publication of this data so critical to public health and community leadership as they develop appropriately targeted education and prevention programs.

11-44 To maintain a complete research program, the DOD will need sustained HIV-related funding of $20 million annually.

11-45 The U.S., through its relevant federal agencies, should communicate with other governments that may be considering institution of HIV-related travel restrictions in order to prevent the implementation of ineffective and cumbersome regulations.

11-46 The CDC annually produces and distributes a booklet, "Health Information for International Travel," which is sent to local health departments and individual physicians. Information on HIV infection should be expanded to increase understanding of HIV transmission and prevention, and include information on the relative safety of the blood supply in nations other than the U.S. and the avoidance of high-risk behaviors. These educational materials should discuss specific prevention measures in clear, easily understood language and should caution HIV-infected persons against travel to nations where other communicable diseases are endemic.

11-47 The Department of State, the DHHS, and the INS should reevaluate the policy of testing refugees 12 months after the implementation of this policy. This evaluation should include consideration of the change in level of protection offered to the U.S. by this policy, consideration of potential impact on refugee populations and host governments, and consideration of cost and benefits. Recommendations resulting from this reevaluation should be made to the President.

Code

Chapter 12: Guidance for the Future

12-1 In order to assure rapid implementation of the key recommendations of this report, the President should:

* Appoint a continuing external oversight committee, composed of seven members including experts of HIV infection and public members, to provide an ongoing evaluation of the nation's response to the epidemic.

* Clearly establish the chain of command from the Cabinet to all affected units of the federal government, with a single designated official to manage implementation of this report and related activities within the existing structure.

12-2 For the longer term, the President should assure that the following changes in federal health structure are evaluated:

* Establishment of an independent Department of Health because health care is now taking almost 12 percent of our national resources and may not be receiving appropriate attention or visibility within the current structure.

* An expansion of the Public Health Emergencies provision of the PHS Act to enhance the ability of the nation's chief health officials to request the President to declare public health emergencies in the nation when public health information about such an event is made available by relevant federal, state, or local public health agencies, or other appropriate sources.

* Delegation of authority during a declared public health emergency to facilitate procedures which enhance emergency responsiveness including approaches to hiring, acquisition of new space, increases in personnel ceilings, awarding of grants and contracts, regulatory review, and interdepartmental and interagency activities.