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## The Report of the Parliamentary Ad Hoc Committee on AIDS



**Hon. David MacDonald, P.C., M.P.**
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TABLE OF CONTENTS

# AIDS REPORT

## INTRODUCTION

AIDS is a major health challenge in Canada and around the world. It has become a global epidemic. In Canada we are struggling to develop a National AIDS Strategy that will coordinate federal and provincial, public and private actions in a sustained program to fight this disease.

The first case of AIDS was reported in Canada in February, 1982. In the eight years since, at least 3,818 Canadians have been diagnosed with AIDS and almost 2,300 of those have died. These grim facts are, however, only the tip of a huge iceberg of suffering and death. The ominous shape of things to come is reflected in the estimates that between 25,000 and 50,000 Canadians may already be infected with HIV. It is now the general consensus of medical experts that virtually all of those infected will develop AIDS at some point, perhaps five to ten years hence. The long incubation period means that the number of diagnosed cases of AIDS will always lag several years behind the spread of HIV infection. The more than 3,800 cases of AIDS which have developed to date represent the past history of HIV transmission, in many cases five years or more in the past.

This past history of HIV transmission will show in a growing number of actual AIDS cases in the future, a "bulge" of cases that will severely tax Canada's medical and social resources. We must prepare now for these increased demands. The magnitude of the epidemic beyond the next decade, however, will depend upon the efforts we make now in research, education and prevention. We must act <u>now</u> to halt, or at least slow, the transmission of HIV, before this transmission is reflected in more thousands of AIDS cases in the future.

We entered upon this investigation with a sense of urgency, and this sense was quickened by the evidence and opinions which we heard. Witness after witness spoke of the necessity of making maximum efforts now, and of acting before the full evidence of the extent to which the disease has spread in Canada becomes clear. Dr. Normand Lapointe, Chairman of the National Advisory Committee on AIDS (NAC-AIDS), referred to the priority currently being given by the Advisory Committee to prevention measures aimed specifically at youth. Dr. Lapointe noted that the incidence of AIDS among adolescents is still quite low, but - "We are beginning to show ... that the infection has a high chance of being transmitted during adolescence and that the risk is that AIDS will manifest itself among young adults eight or ten years down the road."

Dr. Ian Gemmill, Chairperson of the Canadian Public Health Association's AIDS Education and Awareness Program, described AIDS and HIV infection as "the greatest communicable disease challenge to face public health in the second half of the 20th century." The challenge is to prevent AIDS from establishing itself for the future, particularly as a cause of death of our younger people. Although other major diseases will continue to kill more Canadians, it is the need and opportunity to invest in the future by engaging in AIDS prevention efforts now that commands our attention. These efforts will require significant expenditures by government, and public support for them will be essential. The National Strategy must ensure that support.

A National Strategy will bring all Canadian governments together in a coordinated response to AIDS. More than that, by emphasizing the human dimension of AIDS, the Strategy will join all the partners in the fight - governments, community groups, persons with AIDS/HIV, health and social welfare professionals, foreign aid workers, and many others - in a collaborative effort. In Canada, as in many other countries, the gay and lesbian community was the first to respond effectively to the AIDS crisis. It has been active from the beginning in providing support to persons with AIDS/HIV, and in mounting a network of education and awareness programs that have been very successful. That community has now been joined by groups and individuals across the country. AIDS/HIV threatens all

Canadians, and the National Strategy should be a collective expression of all that Canada and Canadians can do domestically and internationally to combat the disease.

As a Committee of Parliamentarians, we must also focus on the federal component of that strategy, what might be called the federal strategy; one that will comprise those actions that the federal government can take within its own areas of jurisdiction, including the federal spending power. The development of the National Strategy must take into account the differing stages of current provincial responses to the epidemic. Municipal governments should also be meaningful partners in the implementation of a National Strategy. In the meantime, the federal government must have a clear-cut, pro-active policy of its own. To spearhead a National Strategy, the federal government first must have its own house in order. All of the other partners will be looking to that government for bold leadership, and they must not be disappointed.

## THE PARLIAMENTARY AD HOC COMMITTEE ON AIDS

In June 1989, at the Fifth International AIDS Conference in Montreal, the Minister of National Health and Welfare, Perrin Beatty, committed himself and the federal government to the achievement of a National Strategy on AIDS for Canada. The Canadian AIDS Society, responding to that commitment, recognized the contribution made by the Minister: "That we are finally on this road [toward the development of a National AIDS Strategy] is due to the initiative of the federal government and, more particularly, the current Minister of Health and Welfare."

Mr. Beatty's commitment to the fight against AIDS was clear almost as soon as he was sworn in as Minister of Health and Welfare in February of 1989. This commitment led, among other things, to the creation of this Ad Hoc Committee. In the spring of 1989, the Minister approached the Honourable David MacDonald, P.C., M.P., and suggested that he assemble a group of concerned Parliamentarians to discuss the issues that would form part of a National AIDS Strategy.

The group of Members and Honourable Senators soon evolved into an informal committee with some 20 members from both Houses of Parliament and the three major parties, with Mr. MacDonald as Chairperson. The first meetings were informal discussions, followed by meetings with government officials. There were also two meetings with the Minister himself. By early 1990, the Committee members had agreed to hold public meetings with expert witnesses, preparatory to making recommendations to the Minister concerning the development of a National Strategy. From the outset, this Committee has approached the AIDS issue in a non-partisan manner. The fight against this disease transcends political affiliations.

In March and April 1990, the Ad Hoc Committee, as it is now known, held seven public hearings. The Committee met with the consultants to the Department; the Canadian AIDS Society and two of its member groups, AIDS Action Now and Le Comité des Personnes Atteintes du VIH; the Canadian Public Health Association; the Canadian Nurses Association; the Royal Society of Canada; the National Advisory Committee on AIDS; a member of the Federal/Provincial/Territorial Advisory Committee; the Commissioner of the Correctional Service of Canada; and senior officials from the Department of Health and Welfare.

The Committee wishes to thank all of the witnesses who helped us in our study: their valuable testimony has contributed to the Committee's understanding of this complex issue. The final development of a truly comprehensive National Strategy may take some time yet. There will still be issues to resolve, and the evidence which the Committee has received will form a good foundation for further studies of these issues.

## THE NEED FOR A SPECIAL JOINT COMMITTEE OF PARLIAMENT

Quite early in the deliberations of this Committee, the members came to the realization that a joint committee of Parliament should be created to contribute to the development of a National AIDS Strategy, and to monitor its implementation from a federal perspective. The Committee has made a start through the current Ad Hoc structure, but we are convinced that a formal committee must be established to continue the

process. To be fully effective, the input from Parliament into the development and implementation of a National AIDS Strategy requires the mandate, visibility and resources of a Special Joint Committee.

A Joint Committee will also be an essential focal point for the development and organization of Parliamentary support for the initiatives of the federal government in this area. The Committee will also serve as a forum for accountability to the public. The evaluation of programs will require as much input as possible, to help ensure that money is used in the most effective way.

Such a committee will also play an invaluable role as a forum for the development of an informed public opinion on AIDS and HIV infection. As noted earlier, the support of the Canadian public as a whole will be critical to the success of the National Strategy. The Special Joint Committee will contribute to the public's understanding of this complex issue and thus help to engender public support. Public awareness and support must be maintained at a high level, particularly over the next several years while the National Strategy is being implemented.

The concept of a Special Joint Committee has received the complete support of the Canadian AIDS Society - the national organization for Persons Living With AIDS and community-based groups. The National Advisory Committee on AIDS (NAC-AIDS) has also expressed support. Citing the independent role played by such a Committee in the formation of a national strategy in Australia, the Chairman of NAC-AIDS expressed the Advisory Committee's view that a joint committee would be "in keeping with the parliamentary system as we know it in Canada. There is indeed an important role to play for such a committee."

The Ad Hoc Committee has given a voice in Parliament to groups and individuals directly involved in the AIDS struggle, and to other informed Canadians concerned about the crisis. Many issues still need to be looked at, and many of those issues which we did examine require additional study because of their complexity and importance. The nature of the crisis, and its implications for the future, require the creation of a formal committee with a Parliamentary mandate.

**RECOMMENDATION 1:**

**The Committee recommends that a Special Joint Committee of Parliament be established as soon as possible to study and make recommendations on all aspects of the AIDS epidemic in Canada.**

## MANAGEMENT OF A NATIONAL STRATEGY

The makeup, structure and mandate of whatever body is set up to manage the National Strategy will obviously be critical to the success of that Strategy. Several of the witnesses who appeared before the Committee were critical of the proposed Canadian Council on AIDS (CCA) outlined in the document issued by the consultants to the Department, entitled "A Working Document For The Development Of A National Strategy On HIV Infection And AIDS." Even the consultants, Messrs. Sadinsky and Berger, appeared to have abandoned the concept, at least in the form presented in the Working Document, when they appeared before the Committee. The members of the Ad Hoc Committee entirely agree with the view that the proposed CCA is unacceptable as a management body.

The criticisms of the proposed Council revolved around its size and unwieldy structure. The Council was to be composed of the federal/provincial/territorial Deputy Ministers of Health and representatives from a long list of organizations, associations and business sectors. Even the Board of Directors was to have approximately 25 to 30 members, with five sub-committees to do the detailed work in each area. The members of the Board of Directors were to be invited to "represent the perspectives of their jurisdictions on the Board," work with other Board members to review and make decisions about the implementation of the Strategy, and then work to facilitate that implementation within their own jurisdictions.

The sheer number of people involved, and the diversity of the organizations that they would represent, did not suggest to the members of the Committee, or to several witnesses, an executive body that could make decisions and devise appropriate strategies for these decisions to be carried out. The "representative" nature of the makeup of the Council

suggested the possibility of some conflicts of interest. It appeared that these delegates from organizations with very different interests and points of view were to be asked to advocate the positions of those they represented, then stand back and make objective judgments about the overall implementation of the Strategy, and then return to their organizations to lobby for the decisions made. This is perhaps asking too much of those who would be asked to perform these roles.

The development of an appropriate model for a body which would be able to perform an effective management role is certainly a very difficult task. It would have to be a watchdog over, and play an advocacy role on behalf of, the Strategy; but it would also have to be aware of the perspectives and interests of all the partners. Such a body would need an overarching mandate and perspective, but it could not be divorced entirely from some of the major partners. The federal, provincial, and territorial governments in particular would presumably have to be represented in some way, as they would be responsible for the implementation of much of the Strategy.

The Canadian AIDS Society (CAS) has recommended that all levels of government acknowledge a principal role in leading the fight against AIDS, but acknowledge as well that they must do so in partnership with the community-based organizations and organizations representing those living with AIDS. The Society has noted that "there has to be a way of bringing together what the field is feeling, what the field is going through, with policy-makers and make them somehow sit together."

The Committee is of the view that a formal consultative process is necessary to ensure that this "partnership" role is an integral part of the implementation of the National Strategy. The membership of the proposed Council includes all of the partners identified by the Canadian AIDS Society, and several others that the Committee believes should also be involved in a consultative role, although perhaps not all of these interested parties should or need to be involved on the same level. An appropriate structure for this consultative process could be developed which would reflect the nature of the different interests involved. It need not involve the creation of a new bureaucracy. The secretariat

services needed to plan and set up meetings at regular intervals could be provided by the Federal Centre for AIDS.

The actual management body might better be composed of people who have the necessary expertise and involvement with the response to the disease, but who could also maintain an arms length relationship with those who will actually be implementing the Strategy. They should have a sufficient connection to the governments and non-governmental organizations involved, that they will enjoy the confidence of the major partners and be in a position to influence them; but they must also be able to maintain a sufficiently objective detachment so as to be able to play a watchdog role. This would be a difficult prescription to fill, and the responsibility falls ultimately to the Department, in full consultation with its partners in the fight against AIDS, to propose an appropriate management body.

**RECOMMENDATION 2:**

> The Committee recommends that a consultative process be set up to advise on the implementation of a National Strategy, involving representatives from the range of organizations identified in the proposal concerning a Canadian Council on AIDS, as set out in "A Working Document for the Development of a National Strategy on HIV Infection and AIDS."

One essential element in the management of the National Strategy is the involvement of Persons Living With AIDS groups, and such community-based support groups as the Canadian AIDS Society. In addition to their role in delivering programs and services to their communities, these organizations have the knowledge and expertise to make a vital contribution to the design and carrying out of all AIDS/HIV programs.

**RECOMMENDATION 3:**

> The Committee recommends that the management of the National Strategy recognize the necessity of involving Persons Living With AIDS and community-based support groups in the development and implementation of AIDS/HIV programs.

The Committee was both concerned and perplexed when it was revealed that the Federal/Provincial/Territorial Advisory Committee on AIDS

(FPT Committee) has not met in well over a year. The Committee is composed of senior health department officials involved in AIDS programs in the 13 governments, and was set up to work toward a harmonization of policies. The Ad Hoc Committee assumed that a body such as the FPT Committee would be a significant, if not an essential, mechanism in the development of a National Strategy, and would have been regularly involved in the development process. It also feared that if such a body had been abandoned, or fallen into disuse, because it was not working, there would be reason for concern about the prospects for the sort of inter-governmental cooperation that will be necessary to develop, and to implement, a truly National Strategy.

The Committee heard a number of suggestions as to why the Advisory Committee has become dormant, none of them satisfying entirely the Committee's concern and sense of perplexity. It was suggested by NAC-AIDS, which had a representative that attended meetings of the FPT Committee, that while some provinces sent decision-makers, other provinces sent representatives who were primarily observers, and that this disparity of representation made the Committee ineffective. Dr. Evelyne Wallace, an AIDS coordinator for the province of Ontario and a member of the FPT Committee, felt that the primary problem was that the federal government controlled the agenda and the calling of meetings, and that some sharing of control and a better consensus approach would make the Committee more workable.

The views of the officials from the Department of Health and Welfare were particularly interesting, as they presumably reflected the reasons why the federal government has not convened a meeting of the FPT Committee for so long. We were advised that the Committee was "overtaken by the consultations taking place in the context of the development of a national strategy" and that "a number of people felt that it was better to handle these consultations on a bilateral basis." It was suggested that the FPT Committee functioned quite well when it was dealing with technical issues, but that when the larger issues of a National Strategy were raised, "the composition of those who were attending the meetings" and the committee approach in general did not make for sufficient progress.

While it may be that the negotiation of a National Strategy requires bilateral discussions at the highest levels, we do not see why the FPT Committee should not also have been, and could not still be, a useful vehicle for some of the interchange, discussion and negotiation, at least on certain issues, that will be necessary to arrive at a truly comprehensive National Strategy. It should also have a role to play after the Strategy is fully developed. NAC-AIDS has suggested that the management body for the Strategy should report annually to a meeting of the ministers of health and social services, chaired by the Minister of National Health and Welfare. That would certainly give the implementation of the Strategy good public visibility and is an excellent suggestion, but it may be observed that much of the real implementation of the Strategy will take place at a lower level in the federal and provincial departments of health.

The membership of the FPT Committee would appear to include those federal and provincial senior health officials who will be a critical part of the effective implementation of a National Strategy. If decision-makers rather than observers from some provinces are needed, then this should be arranged; but so long as the federal government and the provinces with the majority of HIV and AIDS cases are so represented, the Committee should be able to do useful work. These senior officials will be key participants in the Strategy. Perhaps more importantly, they will have to be able to work together, sometimes in a committee forum.

**RECOMMENDATION 4:**

The Committee, having noted with concern that the Federal/Provincial/Territorial Advisory Committee has not met in over a year, recommends that this body be convened as soon as possible as an additional mechanism to facilitate the development and implementation of a National Strategy.

## THE COORDINATION OF THE FEDERAL RESPONSE TO AIDS

The principal agency in the fight against AIDS in Canada, and the primary source of funding for that fight, is the federal Department of Health and Welfare (DHW). The Committee heard testimony from a number

of witnesses on the role of the Department, and its effectiveness in the fight against AIDS. Some of the testimony suggests that there are deficiencies in the Department's response to AIDS, both organizationally and in terms of the amount of funding available for that response. The following is a quote from the Canadian AIDS Society (CAS):

> For the most part, the federal government response to AIDS has been scattered throughout Health and Welfare Canada. There is a need for some centralized planning and coordination. In whatever reorganization is undertaken, the unit given the responsibility for managing the AIDS programs should report to the Deputy Minister of National Health and Welfare.

The CAS also went on to state that "most of the leadership demonstrated in the fight against AIDS in Canada has come from the community organizations. Now it is time for governments to demonstrate their commitment, to show leadership and to act."

The Committee acknowledges that there is concern that the federal government has not shown a clearly coordinated response to the AIDS epidemic. For example, eight years after the first AIDS case was diagnosed in Canada, there is neither a federal nor a national strategy for AIDS that outlines in detail how the federal government plans to deal with the epidemic.

The Committee also acknowledges that community organizations have been on the front line in the fight against AIDS, dealing with many of the personal and social aspects of the disease - from education, to counselling, to home care support. These community organizations perform an invaluable and irreplaceable service, and the Committee accords them the highest praise and respect.

That having been said, it is important to keep matters in perspective. It is not correct to say that the federal government has shown no commitment to the fight against AIDS and HIV infection, although the Canadian AIDS Society and other groups have expressed dissatisfaction. For example, the Department of Health and Welfare provides core funding to many of the community AIDS organizations, including the Canadian AIDS Society. The Department is also actively involved in a variety of programs and services through the Federal Centre for AIDS.

However, there appears to be a credibility gap, or at the very least a serious communications problem with Health and Welfare Canada's handling of the AIDS crisis, and this is causing difficulties for both the Department and its clients. It is not the Committee's role, or intention, to act as a spokesperson for Health and Welfare Canada, but we have an obvious concern that adequate and correct information be made available to the public on this important issue, and we make the following recommendation.

RECOMMENDATION 5:

The Committee recommends that the Department of National Health and Welfare undertake efforts to communicate more effectively its role and activities to its partners in the battle against AIDS and HIV infection, and also to the general public.

Although there is unanimous agreement among Committee members that it is important to develop a National Strategy on HIV infection and AIDS as soon as possible, we believe that this will be a protracted process, given the difficulties of harmonizing the views of thirteen governments. Further, the concentration of the epidemic thus far in urban centres means that municipal governments should be consulted and play an active role in the Strategy. In the meantime, the fight against this disease must continue. While it would be desirable to have all the governments involved working together toward uniform objectives, it is important that the federal government state clearly what its own strategy will be for the future.

RECOMMENDATION 6:

The Committee recommends, in particular, that the Department of National Health and Welfare develop and publish a document setting out in detail the federal strategy for dealing with AIDS and HIV infection.

The Federal Centre for AIDS (FCA) was created in July 1987 as a Directorate within the Health Protection Branch (HPB) of Health and Welfare Canada. The responsibility for AIDS lay initially with the HPB's Laboratory Centre for Disease Control (LCDC); in 1986, a National AIDS Centre was created within LCDC as a focus for federal activity in this

area. Thus, the FCA is not an independent entity within the Department: organizationally, it is a Directorate with a formal reporting relationship to the Assistant Deputy Minister for HPB.

The Committee is of the opinion that the status of the FCA within the Health Protection Branch is not widely understood among the general public and not always, we feel, among some of the other partners in the fight against AIDS. This misunderstanding leads to frustration among some of the Centre's clients who expect more from the Centre than it is able to deliver. The responsibility for this misunderstanding must fall to the Department, and to the FCA in particular. It has been almost three years since the FCA was created and, clearly, there can be no excuse for any continuing misunderstanding of the Centre's role, responsibilities, and status within the Department.

**RECOMMENDATION 7:**

> The Committee recommends that the Department of National Health and Welfare undertake a re-statement of the role and functions of the Federal Centre for AIDS. The statement should clearly define what the Centre does, and also what it does not do, and should be directed to the Department's partners in the fight against AIDS and HIV infection.

While implementation of this recommendation will clarify the role of the Federal Centre, it will not change the nature of that role, nor the line relationships within the Department's Health Protection Branch. At this stage of the Committee's study of the federal government's response to AIDS/HIV, we do not feel we have enough information to recommend specific changes in the Department's organization. From the material provided to the Committee by the Department, and from information obtained during meetings with Departmental officials, we believe that the federal effort may be better coordinated than sometimes appears to be the case.

We cannot, however, ignore the concern of the Canadian AIDS Society, and others, who have expressed to the Committee the opinion that the federal program is inadequately coordinated. This may be to some degree a communication problem, but structural changes in the Department's response mechanisms may eventually also be necessary.

The Committee has considered the suggestion of the CAS that the Federal Centre should report directly to the Deputy Minister of Health and Welfare Canada. In the current Departmental structure, individual Branches of the Department report to the Deputy Minister, and Directorates, such as the Federal Centre for AIDS, report to the Assistant Deputy Minister of the appropriate Branch. The Directorate status of the Federal Centre for AIDS is both unique and unprecedented.

The Committee is not convinced that the Federal Centre should be accorded Branch status within the Department: at this stage, we have not received enough evidence to indicate that this is justified. We do believe, however, that a higher Departmental profile is desirable for a successful fight against AIDS and HIV infection.

In his appearance before the Committee, the recently-appointed Senior Assistant Deputy Minister of Health and Welfare, Richard Dicerni, made reference to the Departmental Working Group which he chairs, and which was set up for the purpose of developing the National Strategy. The Committee believes it would be both appropriate and useful for this Working Group to be responsible for ensuring that the Department's AIDS activities are effectively coordinated.

The Working Group would not have a line-management function, but would provide a high-profile focus for the Department's AIDS activities, and would be responsible for ensuring that the components of the AIDS Program respond effectively to public concerns. It is the Committee's intent that the Working Group play an active and responsive role in the coordination of the AIDS activities of the Department and that it make any structural changes that may be necessary. The Working Group should also develop a permanent coordination mechanism to replace itself.

**RECOMMENDATION 8:**

The Committee recommends that the Departmental Working Group chaired by the Senior Assistant Deputy Minister of National Health and Welfare, and set up for the purpose of developing the National Strategy, be made responsible for ensuring the effective coordination of all the Department's activities in regard to AIDS and HIV infection.

The Committee earlier called for a recognition that PLWA and community-based groups have an essential role to play in the management of the National Strategy. We wish here to emphasize that there must be more consultation between Health and Welfare Canada and these groups in regard to all federal programs.

RECOMMENDATION 9:

> The Committee recommends that the Department of National Health and Welfare consult to a greater degree with Persons Living With AIDS groups, and support groups such as the Canadian AIDS Society, to ensure greater involvement of these groups in AIDS/HIV program design and implementation.

The National Advisory Committee on AIDS, commonly known as NAC-AIDS, is an important advisory body in the fight against AIDS and HIV infection. NAC-AIDS was created in August 1983 to advise the Minister of Health and Welfare on appropriate action and initiatives to combat the disease: at the time, 31 cases of AIDS had been diagnosed in Canada. The Advisory Committee initially was composed of physicians and scientists, and a representative of the Canadian Red Cross Blood Transfusion Service was also invited to participate.

Like the FCA, the role of NAC-AIDS has evolved in recent years to meet the expanding scope and challenge of the epidemic. The Advisory Committee now formulates advice on the behavioural sciences as well as the legal, economic and ethical aspects of policies and programs under the jurisdiction of the Minister of National Health and Welfare. Secretariat services for NAC-AIDS are provided by the Federal Centre for AIDS.

The Advisory Committee includes 15 members from across Canada, and the Minister has stated that the membership of the Committee will be broadened. Recently, NAC-AIDS has developed a priority list for AIDS research in Canada, has evaluated alternative and traditional treatment approaches to AIDS, has developed a position statement on AIDS and the workplace, and has addressed the question of AIDS and immigration. In December 1989, NAC-AIDS approved the statement of its Working Group on programs regarding HIV transmission in prisons.

NAC-AIDS has a unique position in dealing with the Canadian AIDS epidemic. Its expert membership is drawn from outside government and it has a direct access to the Minister of National Health and Welfare, to whom it makes recommendations. What NAC-AIDS seems to lack at this juncture is a public profile. The access that NAC-AIDS has to the Minister is vitally important, and that should remain intact.

Given the special nature of AIDS and its high visibility, it would be appropriate for NAC-AIDS to act as an expert advisory committee to the Minister and at the same time to assume a more public, and even an advocacy role. NAC-AIDS itself has recommended that it adopt such a dual role. Dr. Lapointe, Chairman of NAC-AIDS, made the following statement to the Committee on 10 April 1990:

> We have recommended ... that ... the Committee (have) an advisory role with respect to the Minister and the Department. That should be the Committee's principal role but we have also recommended that the Committee be granted another role, that of an advocate ... authorized to inform the public (and) have a higher profile ... to set matters straight on a certain number of issues.

The adoption of such a role by NAC-AIDS could also meet a perceived need by community organizations for an advocate, a role that some have suggested be played by the FCA, but which the Federal Centre is not in a position to assume. One way for NAC-AIDS to formally discharge a more public function could be through regular appearances before a Special Joint Committee of Parliament on AIDS, the creation of which comprises our first recommendation.

There are precedents for a ministerial advisory group having a strong public role. An example is the Canadian Advisory Council on the Status of Women (CACSW). Established in 1973 as a consequence of the Report of the Royal Commission on the Status of Women, CACSW has a two-fold mandate:

(a) to bring before the government and the public matters of interest and concern to women; and

(b) to advise the Minister [responsible for the Status of Women] on such matters relating to the status of women

as the Minister may refer to the Council for its consideration or as the Council may deem appropriate.

It is possible, then, for NAC-AIDS to evolve into a body with both a ministerial advisory function and a public advocacy role.

RECOMMENDATION 10:

The Committee recommends that the National Advisory Committee on AIDS (NAC-AIDS) be given an expanded mandate which would include a public advocacy role in regard to all aspects of the battle against AIDS and HIV infection.

## RESEARCH

It is axiomatic that research is essential in all areas associated with AIDS and HIV infection to develop the knowledge and technologies that will prevent, effectively treat, and, hopefully, conquer this disease. During the course of public hearings the Committee received a number of suggestions for research on various aspects of the AIDS epidemic. Our examination of this area was limited by the time and resources at our disposal, but we have gathered enough information to make several recommendations.

The magnitude of the AIDS/HIV epidemic in Canada is not known with precision. The surveillance program of the Federal Centre for AIDS is tracking the course of the epidemic, and we know that more than 3,800 AIDS cases have been reported in Canada to date, and almost 2,300 have died. At least two studies have suggested that AIDS is under-reported in Canada, as it is in other countries. The rate of under-reporting for AIDS is apparently not as high as for other communicable diseases, but it was shown to be 12% in one study and 18% in another.

We also do not know exactly how many people have HIV, although estimates of 25,000-50,000 were cited to the Committee by various witnesses. Since most, and possibly all, of these people will develop AIDS at some time in the future, the implications for Canada's health-care system are very serious. It is therefore important to develop accurate estimates of the number of persons infected with the virus so that appropriate strategies for prevention and treatment may be devised.

It was recently reported that there are currently six studies underway in Canada to screen unlinked blood samples (that is, anonymous random samples) from men, women and children to determine the prevalence of the virus in the Canadian population. The Committee commends the Department of Health and Welfare for this initiative, and urges that the evaluation of these studies be given a top priority. If necessary, additional unlinked, anonymous studies should be commissioned.

**RECOMMENDATION 11:**

> The Committee recommends that the Department of National Health and Welfare give top priority to the evaluation of the unlinked sample surveys already underway, and to the setting up of any additional anonymous surveys that may be necessary, in order to determine the extent of HIV infection in Canada.

The determination of the levels of HIV infection in certain sub-populations in Canada is an important objective: with such information in hand it is then possible to design appropriate education and prevention programs to limit the spread of the virus. Examples of sub-populations known to be at high risk for infection include men who have sex with men, sex-trade workers, injection drug users, street youth, and prison populations. The Committee is aware of the difficulties associated with the design and implementation of such studies, but we want to underline their importance notwithstanding.

**RECOMMENDATION 12:**

> The Committee further recommends that, where appropriate, and with adequate ethical safeguards, the unlinked, anonymous sample surveys include the collection of demographic data which can be used to

determine the extent of HIV infection among important sub-populations in Canada.

Because AIDS is primarily a sexually-transmitted disease, knowledge of sexual practices and attitudes is necessary to devise effective strategies for education and prevention of HIV transmission. In its 1988 report on AIDS, the Royal Society included a major recommendation for a "large multiwave survey" of the Canadian population to provide information on "sexual practices, ideas and feelings about AIDS (and) patterns of social ties and behaviour relevant to the spread of sexual diseases." The Society reaffirmed the need for this type of information, in order to effect behaviourial change, in its appearance before the Committee. We both acknowledge and agree with their recommendation.

RECOMMENDATION 13:

> The Committee recommends that the Department of National Health and Welfare commission a comprehensive social and behaviourial research study on sexual practices and attitudes in Canada, and other issues relevant to the effectiveness of AIDS education and awareness programs. An appropriate body to initiate such a study might be the Social Sciences and Humanities Research Council.

The Working Document on the National Strategy states that biomedical research funding for AIDS/HIV research in Canada "vis-a-vis that in the United States appears to be considerably lacking." The problem may not be related only to the availability of funds, but also to the fact that only a relatively small number of biomedical scientists in Canada are working on AIDS and HIV infection. If there is a shortage of biomedical research funds for AIDS/HIV in Canada, this should be remedied. If there is a shortage of qualified researchers in this area, the solution will lie in increasing the number of students in the biomedical sciences in Canadian universities, and ensuring that sufficient funding and resources are available at this level.

The Committee did not receive a large amount of evidence in this area. We acknowledge, however, a statement and suggestion on biomedical research and the Medical Research Council (MRC) made by a member of NAC-AIDS during their appearance before us. The MRC is the

principal federal agency for biomedical research funding in Canada. We quote the NAC-AIDS statement below:

> MRC has not been involved (in the AIDS research field) because they did not want to dedicate funds specifically for research on AIDS ... We do make a recommendation now that MRC should ... consider getting into the game with AIDS-dedicated money for the basic research field.

The Committee believes that the Minister should take this suggestion under consideration, and also consider increasing the amount of biomedical research funding available for AIDS/HIV.

**RECOMMENDATION 14:**

The Committee recommends that the federal government provide more funding for biomedical research, and that, in particular, the Medical Research Council consider the dedication of funds for basic research on AIDS and HIV infection.

## EDUCATION AND PREVENTION

The Minister of National Health and Welfare has stated that AIDS is an "eminently preventable" disease. The routes of transmission of the virus are well known: blood and semen are the principal body fluids involved in transmission. This being the case, sensible prophylaxis in various activities, particularly sexual activities, will slow down, and even halt, the spread of the epidemic. A vitally important component in the fight against AIDS and HIV infection is education: appropriate public programs should engender the knowledge necessary to effectively combat this disease.

A variety of educational programs have been developed at the federal, provincial, and community levels to prevent HIV transmission. While it is not the Committee's intention to comment on any individual educational program, or to offer suggestions for new programs, we have received evidence from expert witnesses on the importance of continuing, and even expanding, current AIDS education and awareness programs.

One problem that has been brought to the Committee's attention is the suggestion that a false air of security may be developing in some communities that the battle against HIV transmission is being won and, therefore, that a high level of protection against HIV transmission is no longer necessary. This attitude, if in fact it does exist, can lead to a wider spread of the disease. The long incubation period of the virus and the fact that an infected person can be asymptomatic, but is nonetheless capable of transmitting the infectious agent, creates a very dangerous situation for society and could result in an increased rate of infection.

In light of this concern, we make the following recommendation.

**RECOMMENDATION 15:**

> The Committee recommends that the federal government re-affirm the critical importance of AIDS education and awareness programs in the prevention of HIV transmission, to develop and maintain an appropriate level of public concern for the control of this epidemic.

The Committee received evidence that the AIDS epidemic is changing in nature. In Canada, as in the western industrialized nations in general, AIDS was initially a disease that affected the gay community, with young homosexual and bisexual men comprising more than 90% of persons with AIDS. As the epidemic progressed, however, the disease began to spread into other segments of Canadian society. In the United States, in some major cities, the injection drug user sub-population has become widely infected with the virus. Other high risk groups include street youth, sex-trade workers, and prison populations.

**RECOMMENDATION 16:**

> The Committee recommends that targeted programs directed to men who have sex with men and to injection drug users be given top priority, and adequate funding, and that programs directed to street youth, sex-trade workers, and prison inmates be given greater priority and more funding.

The Committee is aware that in some African countries, where the disease is thought to have originated, AIDS is a problem in the population generally, affecting both men and women in equal degree. It is

well known that the virus does not discriminate between the sexes. It was suggested to the Committee by Dr. Evelyne Wallace, a Senior Medical Consultant with the Ontario Ministry of Health, that there is now a special need to educate Canadian women to the danger that AIDS poses to their health and to the health of their babies. Dr. Wallace suggested that there is a need for a targeted educational program to alert women to this danger.

The Committee agrees with this suggestion.

RECOMMENDATION 17:

> The Committee recommends that the Department of National Health and Welfare coordinate the development of education and awareness programs specifically directed toward the threat posed by AIDS to women. These programs must be designed to make both women and men more aware of the need and means for protecting women and their babies from HIV infection.

The Committee is also concerned that effective programs be developed and implemented to deal with the threat that AIDS/HIV poses for Canadian youth. In 1988, Queen's University at Kingston, Ontario published the "Canada Youth and AIDS Study" which presented an in-depth examination of this important issue. The study found that about one-half of young Canadians 16 years of age are sexually active and that three-quarters of older adolescents have had sexual intercourse.

While young Canadians apparently know how HIV is transmitted, they are not as well-informed on how to prevent transmission of the virus. Moreover, the majority of sexually-active young people engage in unprotected sexual intercourse. The study also found that "young people believe there is a low probability of them being infected by HIV regardless of their personal behaviours."

Faced with this serious situation, the Queen's University study team recommended that the federal government provide young people with "clear, frank and complete information about the AIDS epidemic in Canada." The Committee wholeheartedly endorses this recommendation and supports the development and implementation of comprehensive education and awareness programs directed to Canadian youth. Such programs must be carefully designed and targeted so as to influence the behaviour of all

youth, including gay youth. Because the programs would have to be implemented at least partly in the school system, they should be developed and implemented in cooperation with the provinces.

**RECOMMENDATION 18:**

> The Committee recommends that the Department of National Health and Welfare work in cooperation with the provincial governments on the development and implementation of AIDS/HIV education and awareness programs directed to Canadian youth.

During its hearings the Committee was reminded that Canada is a complex, plural society and that many Canadians, particularly new Canadians in large metropolitan centres, speak languages other than English or French. The Working Document on the National Strategy also took note of the fact that AIDS is a threat to all ethnic communities and that there is a need "to develop appropriate communications mechanisms and programs to reach these populations." The Committee agrees that there is a clear need for educational materials and programs in languages other than French or English for distribution to Canada's ethnocultural communities.

**RECOMMENDATION 19:**

> The Committee recommends that the Department of National Health and Welfare, the Department of the Secretary of State, and the Department of Multiculturalism and Citizenship (once it is fully established) jointly coordinate the development of AIDS education and awareness materials in languages other than English and French for distribution to ethnocultural communities.

The Committee has noted, in Recommendation Number 3, that the Federal/Provincial/Territorial Advisory Committee (FPT Committee) on AIDS has not met for more than a year. The FPT Committee, as a mechanism for consultation between the two levels of government on the AIDS issue, could have a role to play in the area of education and prevention. In the 1988 Report of the Federal Centre for AIDS, it was stated that the FPT Committee had "initiated discussion on program direction and priorities to be undertaken at the federal and provincial levels in the context of the National AIDS Education Strategy." At the meeting of 10 April 1990, Dr. Evelyne Wallace, a member of the FPT Committee, stated that she did not

believe that the sub-committee formed to develop a National AIDS Education Strategy had ever met.

The Committee notes this information with some concern, and we reiterate our earlier comment that the FPT Committee has a potentially important role to play in the fight against AIDS. A well-coordinated federal-provincial AIDS education strategy must be, we believe, an integral component of the National Strategy.

**RECOMMENDATION 20:**

> The Committee recommends that the National Strategy include a comprehensive, coordinated federal-provincial AIDS education strategy. The Committee further recommends that the reconvened Federal/Provincial/Territorial Advisory Committee be asked to revive the subcommittee that was to have begun work on a National AIDS Education Strategy, as an additional mechanism to implement a coordinated approach to this critical element of a National Strategy.

A recurrent theme in the Committee's public hearings was that professional and community organizations are in the best position to deliver effective educational material to targeted populations. While national media campaigns have an important role to play in education and prevention, we agree with the statement in the Working Document to the effect that "experience indicates that targeted messages reflecting community language, values and practices, and delivered by peers or those close to the target audiences, are the most likely to be convincing and to encourage the desired behaviour changes."

**RECOMMENDATION 21:**

> The Committee recommends that, in regard to AIDS education and awareness, the federal government give priority to acting as a source of funding and support for groups such as the Canadian Public Health Association, and community-based groups which can mount targeted campaigns at their peers, over other elements of AIDS education such as national media campaigns.

The Committee has concluded that more funding must be provided to these groups, especially to community-based organizations, to

support those education programs and other prevention activities shown to be effective.

**RECOMMENDATION 22:**

The Committee further recommends that the Department of National Health and Welfare ensure that adequate and, where appropriate, increased funding commitments are made to the Canadian Public Health Association and community-based organizations for the purpose of AIDS/HIV education and awareness programs, giving consideration to where the additional funding and other resources can most effectively be channeled.

## TREATMENT, CARE AND SUPPORT

The treatment, care and support of persons with AIDS are issues of major importance. There is as yet no effective vaccine to protect people from the AIDS virus although some are currently being tested. Several drugs have become available to treat HIV infection, notably AZT (zidovudine) and ddI, both of which interfere with the reproduction of the virus. A number of drugs are available also to treat the secondary diseases to which those with AIDS are susceptible. Many of these therapies are experimental, or otherwise not part of the standard medical arsenal. Many of the newer drugs are available only through Health and Welfare Canada's Emergency Drug Release Program (EDRP).

The Canadian Aids Society (CAS), in its appearance before the Committee on 24 April 1990, cited a number of examples where people with AIDS were not receiving available treatments because of a lack of information on the part of their physicians. The Society believes that the sheer volume of information on treatments for AIDS and HIV infection, and the rapid changes in the information, combined with the lack of a suitable vehicle to provide physicians with access to the information, are making it difficult, if not impossible, for many persons with AIDS to receive the best available medical care.

Complicating the situation is the fact that physicians treating people with AIDS face a serious workload problem, partly because

persons with AIDS require more care than the average patient and partly because of the time-consuming process of obtaining experimental drugs through EDRP. The Canadian AIDS Society emphasizes, however, that physicians are not to be blamed for these problems: the problems are inherent in dealing with a new disease which causes, and contributes to, a variety of life-threatening conditions. In the final analysis, however, the welfare of the person with AIDS must be paramount. In the present situation, the person with AIDS cannot be certain that he or she will be able to obtain the best form of treatment.

One approach to this complex problem, an approach put forward by the CAS and supported by this Committee, is to develop a Treatment Registry for persons with AIDS. The Registry essentially would be an information delivery system, comparable to that used in other areas of medicine, especially in the field of cancer. The CAS acknowledges that its proposal is still in the concept stage, and its development will require the involvement of many other partners in the fight against AIDS and HIV infection, including physicians, researchers, universities, governments, and persons with AIDS themselves.

The Treatment Registry concept was first proposed by the Toronto organization, AIDS Action Now. Briefly summarized, the Registry would consist of two units. The Central Unit would collect, evaluate and disseminate information on new experimental treatments, and compile treatment-information regimens which would be made available to physicians, persons with AIDS/HIV, community-based AIDS organizations, and other health-care agencies and workers dealing with AIDS and HIV infection.

The second component of the system is a Monitoring Unit which would evaluate the efficacy of actual treatments being administered to patients, by collecting information on the effectiveness of treatments through analysis of confidential patient profiles. This unit would then feed the results back to the Central Unit and those results would be used to elaborate or fine-tune the information being disseminated.

The CAS has made a proposal for the staffing and operation of the Central Unit of the Treatment Registry and has suggested that it would need an annual operating budget of some $2 million to $3 million. A

cost estimate is not available for the Monitoring Unit at this time. The Society suggested that the Central Unit be affiliated with a university. Also, the Treatment Registry itself could be connected in some fashion with the federal government's Clinical Trials Network for AIDS drugs which was announced in October 1989, and which is being developed by the University of British Columbia at St. Paul's Hospital in Vancouver.

On the same day that the CAS made its proposal for a Treatment Registry to the Committee (24 April 1990), the Minister of Health and Welfare, Mr. Beatty, met in Toronto with a number of people with AIDS. On that occasion, the Minister stated that he favoured a National Treatment Registry and committed his Department to putting one in place. The Minister requested that the University of Toronto prepare a study for his Department, on an urgent basis, on how to implement the Registry. Dr. Kathryn Taylor, Director of the Behaviour Research Unit at the University of Toronto, is responsible for the study, and she is working with the federal government's Expert Advisory Committee on HIV Therapies during this process. The Canadian AIDS Society has also appointed a member to the study group.

The Committee supports fully the proposal of the CAS for the development of a Treatment Registry. We heartily endorse the Minister's adoption of the Registry concept.

**RECOMMENDATION 23:**

The Committee recommends that a National Treatment Registry of therapies for AIDS and HIV infection be established to collect and disseminate information to health-care professionals, persons with AIDS, and community-based support groups. The Committee urges that the Registry be established as soon as possible on a priority basis.

The timely provision of drug therapies to persons with AIDS/HIV is essential. These drugs, particularly the newer experimental chemicals which are designed to attack the virus itself, are often extremely expensive. Most persons with AIDS are young persons who have not accumulated large savings and who are often unable to work once HIV

infection develops into symptomatic AIDS. In many cases, perhaps most, the economic impact of AIDS is crushing to the individual.

For at least some experimental drugs, there is no charge to those receiving them because the manufacturer assumes the cost as part of the drug-development process. The situation is potentially more complicated, however, when the experimental drug is released under an "open treatment" protocol to a clinical trial, where the drug is made available outside the rigorously controlled parts of the trial.

Because treatment delivery is a provincial responsibility in Canada, the decision to pay for drug-treatment costs for persons with AIDS falls to the provincial Ministers of Health. The Minister of National Health and Welfare does have a role to play, however; one that can be discharged through meetings with his provincial counterparts.

RECOMMENDATION 24:

> The Committee recommends that the Minister of Health and Welfare confer with the provincial Ministers of Health on a common policy that would ensure the provision of all AIDS/HIV drugs free of charge, and which would apply whether the drugs were experimental or approved for general distribution.

Once a person develops AIDS, he or she is in need of extensive and continuous care. The Committee has been informed that much of this care is provided by volunteers in a wide variety of community organizations. Indeed, if there can be a bright side in an epidemic as brutally devastating as AIDS, it is the widespread and truly heroic displays of humanity and compassion on the part of the persons who make up community-based AIDS organizations.

The federal government is providing project and core funding to community organizations through ACAP, the AIDS Community Action Program. The federal government has provided funding to community-based AIDS groups since July 1985: until the ACAP was created in May 1989, that funding was provided primarily through the Health Protection Directorate of the Health Services and Promotion Branch. The strategies of ACAP, in fact, recognize AIDS as fundamentally a community issue, a view shared by the Canadian AIDS Society and other witnesses who appeared before us.

A major thrust of ACAP is to enable community organizations to develop educational programs on all aspects of AIDS, including prevention of transmission of the virus, and generally educating the community about the nature of the disease and the needs of persons with AIDS. ACAP also provides funding to community-based groups for the care of persons with AIDS: it is this latter function that concerns us here.

People with AIDS have a great need for care and support, and community-based organizations are in a position to provide, or augment, those services. This can be done, in part, through the training and education of volunteers working with community organizations, whether in hospices, palliative care facilities, or in home care situations. The federal government has an opportunity to make a greater contribution in this area through ACAP funding of community organizations. In making the following recommendation, the Committee acknowledges the Department's past and current support of community organizations, and urges that even more funding be provided now and in the immediate future.

**RECOMMENDATION 25:**

> The Committee recommends that more funding be provided to community-based groups to support the tremendous amount of effective volunteer work that these groups do in providing care and support to persons with AIDS. The Committee recommends, in particular, that the federal government contribute to the financial resources available for hospices, palliative care facilities, and home care support of persons with AIDS, through increased funding of community-based support groups.

A number of witnesses, and in particular the Canadian AIDS Society, made the point that the treatment of AIDS and HIV infection is a rapidly evolving one, with new knowledge being developed almost daily. As a new and extremely serious and demanding disease, AIDS has placed an enormous burden on the health-care community. Physicians and nursing staff are, in many instances, stretched to the limit. Also, the Committee received testimony to the effect that many front-line workers are suffering from a form of "burn-out," caused by the demanding nature of their duties.

It is apparent to the Committee that there is a need, in light of the unusual nature of this disease, and the fact that many physicians and nurses entered professional practice before the AIDS epidemic started, for continuing-education programs on AIDS treatment, care and support, in addition to the need for a National Treatment Registry which is discussed above. The Committee believes that the federal government has an opportunity to contribute materially in this area through funding of national organizations of health care professionals, and we make the following recommendation.

RECOMMENDATION 26:

The Committee recommends that the federal government consider the provision of funding to national organizations of health care professionals for continuing-education programs on AIDS treatment, care and support.

## ACCESS TO NEW DRUGS

Although we are not yet close to a vaccine or a cure for AIDS, scientific and medical knowledge about the disease has progressed quite rapidly. This has produced a number of promising drug therapies. Because in Canada, as in most other western countries, new drugs must be approved before they can be commercially distributed, general access to experimental drugs has not been immediately available. This has been challenged by persons with AIDS, who face probable death and have no other effective therapies available, and their organizations and the groups which support them have lobbied for wider and earlier access to experimental drugs. As a result the traditional drug approval process has already changed.

The process has changed in two different ways. In November of 1988 the Drugs Directorate of the Department of Health and Welfare enacted a pro-active policy to expedite the approval process in the case of AIDS drugs, through improved consultation with the drug manufacturers. Administrative processes have been streamlined while, at the same time, safety standards have been maintained. Dr. Michele Brill-Edwards, the

Assistant Director (Medical) of the Bureau of Human Prescription Drugs, advised us that the approval time had thereby been shortened. The Committee commends the Department for this initiative and hopes that it will be extended to drugs intended for other life-threatening illnesses.

The more controversial question involves access to experimental drugs while they are moving through the approval process. There are two basic routes through which early access is available. The first is the Emergency Drug Release Program (EDRP). This is a program which has been in existence since 1966, although it has generally been used in more isolated situations than are presented by the AIDS epidemic. It involves a case-by-case exception to the approval process where the person's life is in danger and the Directorate does not believe that the experimental drug will make matters worse, although the efficacy of the drug might not have been proven. Access to this program has been made much wider for persons with AIDS, and it would appear that the EDRP is working reasonably well at this time as a means of making experimental AIDS drugs available.

The second approach involves what are called "open arms" or "open treatment" protocols to clinical trials of new drugs. These are additional elements to those parts of the trial which look purely to the evaluation of the new drug, under controlled conditions. This is a relatively new development, and is in large part a reaction to the calls for wider access that have come from persons with AIDS. It involves the release, under certain conditions, of the drug to persons who are not in the controlled part of the drug trial. Although these open treatment programs permit the gathering of information which is also useful for evaluation purposes, the main purpose is to allow access to the experimental drug to persons in desperate need of such treatment. There is a controversy over the conditions that govern eligibility for involvement in these programs.

Witnesses from the Canadian AIDS Society and two of its member groups agreed that there have been significant improvements in access to experimental drugs, both through the drug approval process and through the EDRP. They note, however, that they are well short of having "full access" to experimental drugs. Most of the problems these groups

cite are outside the control of the Drugs Directorate: for example, a lack of information, and of an adequate system for delivering the information that is available. The establishment of a National Treatment Registry, as recommended earlier, should help to alleviate this problem. The groups also cite a reluctance on the part of pharmaceutical companies to make drugs available outside the clinical trials process, severe restrictions imposed by the companies on access, and the high cost of some experimental treatments.

Cost as a factor in access to drugs is dealt with above. The problems that revolve around the role of the pharmaceutical companies is addressed below. The remaining concerns of the Society and its member groups are directed at the legitimacy and integrity of the drug approval process itself.

The Department advised the Committee that the only reason for refusing access under the EDRP would be "a very blatant safety question." The Department also indicated that some of the reluctance of drug companies to make experimental drugs available, and some of the conditions imposed by the companies on access to open treatment protocols, reflect a responsible approach to the safety of these new and relatively untested drugs. The witnesses representing persons with AIDS reply that the Department and the companies are often in their view too cautious about safety questions, and that, in any case, this should be up to the person in jeopardy to decide.

The overriding principle that the Society and its member groups wish to see recognized is the concept of "catastrophic rights." This concept is stated simply as the right of "individuals with a life-threatening illness ... to whatever treatments they or their doctors believe might be beneficial to their health." This is a powerful concept and arguments in its favour can be very persuasive. It seems unacceptably paternalistic to deny to someone who appears to have nothing to lose the opportunity to decide to take a risk with an experimental drug that might work. There are immense implications to this approach, however, and the matter overall is much more complicated than a simple statement of the concept acknowledges.

The Committee endorses the call made by the witnesses to the federal government to "take the first step in establishing dialogue on these issues with the provinces, the pharmaceutical industry and community AIDS organizations." The witnesses also called, however, for a recognition of catastrophic rights to be the "first step," and we are not prepared to endorse the adoption of such a principle before these discussions have been held, and all parties have a clear understanding of what the ramifications might be. We feel that the full implications of the concept, and a clear understanding of how it might operate in practice, must be studied before even a limited endorsement is made. In the final result, a limited recognition of this concept may be appropriate, and beneficial to both the drug approval process and those seeking access to treatments.

The wider access that has been given to persons with AIDS/HIV through the EDRP and "open treatment" protocols already implicitly recognizes that critically-ill persons should be allowed to take much greater risks than would otherwise be acceptable. Indeed, the concept of risk fades for those for whom death seems inevitable. Greater risk and greater choice must be allowed in these cases. The Drugs Directorate appears to have accepted that only overriding considerations of safety should apply in such cases, and it should now spell out the ramifications of this recognition.

Although a limited recognition of catastrophic rights may already be implicit in the present process, a decision to give serious consideration to the full recognition of such rights would be an act of leadership by the federal government. The result would be that all who are involved in the drug approval process, and all those who are affected by it, would become more aware of the concept and its implications.

At the same time it must also be recognized that a similar approach should be taken to drugs designed to treat other life-threatening illnesses. The Department could follow up on the suggestion of AIDS Action Now that the new biomedical ethics centre at the University of Toronto be asked to study the issue. The McGill Centre for Medicine, Ethics and Law should also be involved in a coordinated study.

**RECOMMENDATION 27:**

> The Committee recommends that the Department of National Health and Welfare study the concept of "catastrophic rights," which would recognize a right to choose treatments in life-threatening situations. The Committee further recommends that the Department publish a policy position on this concept as soon as possible, and in any event by 1 January 1991. The Committee acknowledges and supports the limited recognition of such rights that is implicit in recent developments in access to unapproved drugs, and recommends that such access be as wide as possible, consistent with the integrity of the approval process.

Once the concept of catastrophic rights has been studied and an explicit position taken, the Department of Health and Welfare should consider adopting a different approach to the release of experimental drugs in life-threatening situations. This approach would operate as a stage in the drug approval process, rather than as an exception to it, which is still largely the case. It would involve the development of a process of conditional approvals which would allow for general distribution, and for prescribing by physicians in the accepted manner, albeit with additional conditions attached.

The only basis for refusal of release now, in the case of the EDRP, is a "blatant question of safety." The Canadian AIDS Society pointed out, however, that many doctors are unaware of how to access the EDRP, and that the program in any case is not designed to deal with access on a large scale. If a large volume of requests were made, and if the drug companies were willing to make the drugs available, the program could be overwhelmed.

On the other hand, the open treatment protocols which have been grafted on to the drug approval process appear to operate now as a form of conditional approval. The result is that at a point where it is known that a new drug is likely to be beneficial, and does not present any undue safety concerns, it is made available under an appropriate set of conditions to those sufficiently ill to make the risk acceptable. The only purpose for retaining the link to the approval process would appear to be that it ensures that data for evaluation purposes will be collected.

It should be possible to design a system of conditional approvals that feeds back information for evaluation purposes without the

release being tied to a particular clinical trial. The approval would have to be accompanied by information packages that would tell prescribing physicians how to screen their patients for application of the drug, how to use the drug, and what conditions have to be applied because the drug is still undergoing evaluation. We were advised by Dr. Brill-Edwards that such packages are being developed in any case for the open treatment protocols, and that this more "formalized system" of clinical trial protocols is preferable to the ad hoc EDRP approach when drugs are to be used for treatment at an early stage in the approval process.

A system of conditional approvals would take this a step further and would provide a more complete administrative process for making doctors aware of beneficial new drugs and how to access them outside of the clinical trial process, but under controlled conditions. The system could also provide for different kinds of conditional approvals in different cases. If further evaluation showed that an approval should be withdrawn, or further conditions imposed, the approval could be changed; but the risk run in the meantime would be a controlled and reasonable one.

RECOMMENDATION 28:

> The Committee further recommends that, in line with the limited recognition of catastrophic rights that is now implicit in the drug approval process, the Department of National Health and Welfare give consideration to the formal adoption of a system of conditional approvals for drugs designed to treat life-threatening illnesses, after basic safety and efficacy have been established, which would generally permit the prescribing of such drugs by physicians while further evaluations are being conducted.

One concern that has been raised in regard to wider access to experimental drugs is that people who might otherwise have been willing to volunteer for clinical trials of new drugs might opt instead to seek access purely for treatment purposes. If too many potential volunteers were to drop out, it could become difficult to set up adequate trials, and the integrity of the drug approval process could be compromised. We have received evidence that the American "parallel track" experience (their name for open treatment protocols) seemed to indicate that volunteers were

lacking when access was wide, but that this reflected a situation where more people went into open treatment because there were delays in the set-up of the controlled part of the clinical trials. On the other hand, this experience would seem to indicate that there can be problems if the two elements are not handled carefully.

We must be certain that wider access does not undercut the approval process, or both will suffer, and the issue of the availability of volunteers should be carefully researched and guidelines developed. There may be more lessons to be learned from the American experience and that of other countries.

**RECOMMENDATION 29:**

> The Committee recommends that the Department of National Health and Welfare undertake a study of how to ensure the continued availability of volunteers for clinical trials of new drugs in the face of wider access to those drugs. This study should consider, among other things, the American "parallel track" experience.

Many of the concerns raised by the witnesses from the Canadian AIDS Society and its member groups involved the release of experimental drugs by pharmaceutical companies. No company can be required to make experimental drugs available, or even to conduct clinical trials in Canada. The Departmental witnesses made it clear that the companies are often acting responsibly when they decline to release drugs, for reasons of safety, but that they are also understandably concerned about liability and costs.

The Federal Centre for AIDS has been instrumental in the development of the Clinical Trials Network, and we feel that it can play a valuable role in encouraging drug companies to make experimental drugs available for treatment use. It can work with the companies to ensure that unnecessary safety concerns do not impede access, and can generally help to change the thinking that may make the drug companies overly cautious about treatment release. The Centre can also study the question of incentives that would make the companies more willing to allow earlier and wider access.

**RECOMMENDATION 30:**

The Committee recommends that the Department of National Health and Welfare, through the Federal Centre for AIDS, adopt a pro-active stand on encouraging pharmaceutical companies to make AIDS/HIV experimental drugs available in Canada, and consider the development of incentives to encourage their cooperation.

The Department advised us that in AIDS treatment, primary care physicians are dealing with situations that would normally be dealt with by specialist Specifically, they are not accustomed to dealing with unapproved drugs released under the EDRP, and are probably more concerned about the legal implications than specialists would be.

The Committee did not have an opportunity to hear from the pharmaceutical industry, but they are no doubt also concerned about the legal liability implications of making experimental drugs available, particularly on a large scale. If the companies are to be encouraged to permit wider and earlier access, it may be appropriate to find a way to limit this liability while safeguarding the essential safety interests of drug recipients.

**RECOMMENDATION 31:**

The Committee recommends that the federal government immediately convene and coordinate a study of the liability of pharmaceutical companies and physicians in the matter of access to unapproved drugs, with a view to finding ways to limit this liability so as to encourage them to make such drugs available, while safeguarding the interests of those who receive the drugs.

## LEGAL, ETHICAL AND SOCIAL ISSUES

It is often said that AIDS is not a disease like other diseases. One factor that makes AIDS and HIV infection so injurious to our social fabric, as well as to our health, is discrimination. This is an additional and cruel burden placed on persons with AIDS/HIV when members of the public react out of ignorance, fear, and bigotry. This assault on human rights and dignity must be opposed, and strenuously, on every level

possible. One way of doing this is to reinforce the protection provided by human rights statutes.

One form of discrimination is directed at the person who is infected with HIV, or believed to be infected, and is based largely on fear of contact. Although the AIDS virus is not transmitted by casual contact, and there is therefore no reasonable basis for this fear, many people continue to act in a discriminatory manner out of ignorance or indifference. Education and awareness programs must be developed to work toward the elimination of the ignorance that causes this fear. Clear statutory prohibitions and policies are also essential to protect those who are the victims of the bigotry that results from it.

On the federal level, the Canadian Human Rights Act, and the policy that the Canadian Human Rights Commission has developed, together already provide strong protection for those who are discriminated against purely because they are HIV-infected or have AIDS, or are perceived to have HIV or AIDS. There has been criticism of the Commission's view of some of the occupational situations in which an exception to the policy should be allowed, but the basic guarantee of protection has been tested before a Tribunal and confirmed. It is now facing a review in the courts.

The major gap in the protection afforded by the federal Act continues to be any prohibition of discrimination based on sexual orientation. About 80% of AIDS cases in Canada continue to involve men who have sex with men. This group has always been the victim of discrimination in all of its forms, and the AIDS epidemic has made this more acute and perhaps more damaging to those affected.

Sexual orientation is protected in three provinces - Quebec, Ontario and Manitoba - and in the Yukon Territory. Dr. Evelyne Wallace, a senior public health official involved with AIDS in Ontario, confirmed to the Committee that this protection was considered to be an essential part of Ontario's AIDS program. While we are of the view that the other eight provinces and territories should also be encouraged to add sexual

orientation to their statutes as soon as possible, we are particularly concerned about the failure of the federal government to have acted to fulfill its commitment on this important issue. This failure is important on a practical and a symbolic level.

The Canadian Human Rights Commission has urged, from the moment of its creation, that sexual orientation be added to the federal Act. In its most recent Annual Report, for 1988, it repeated this call, noting that: "There is absolutely no question that such discrimination exists and that it is socially harmful." The Commission has also confirmed that it has received untold numbers of inquiries about discrimination based on sexual orientation that could not be pursued because of this gap in the Act. The Parliamentary Sub-committee on Equality Rights recommended, after the equality provisions of the Charter came into effect in 1985, that sexual orientation be added to the federal statute, and the government agreed to act. It has yet to do so.

The Canadian AIDS Society has confirmed that repeated instances of discrimination based on homophobia have been encountered on the front lines of the AIDS struggle by members of the Persons Living With AIDS organizations and community-based groups that the Society represents. Often the bigotry against homosexuals has been intertwined with bigotry against, and fear of, those infected with HIV. On the present state of the federal law, however, it is at least possible for those employers and landlords subject to its jurisdiction to discriminate for either or both reasons, and escape any redress by ascribing their actions to bigotry against homosexuals.

To the parade of injuries suffered by homosexuals there has now been added the combined sting of homophobia and stigmatization and rejection because of fear of AIDS. Because of the connection forged in the minds of many people between homosexuals and AIDS, these related but separate cruelties feed on each other. The recent string of "gay-bashing" incidents in various parts of Canada may, at least in part, be one result of this exacerbated homophobia. To protect both homosexuals and those living with AIDS, we must make it clear that discrimination on either basis will not be tolerated.

For public health reasons alone, action must be taken to protect sexual orientation from discrimination. The dual discrimination suffered by homosexuals who are or may be infected cannot help but inhibit voluntary testing, contact tracing, and other measures necessary to protect public health. The consultants to the Department, on the basis of their first round of consultations, affirmed in "A Working Document For The Development Of A National Strategy On HIV Infection And AIDS", that: "Solely from the perspective of a National Strategy on AIDS, or indeed of any public health effort pertaining to AIDS, the effects of discrimination on the grounds of sexual orientation upon that effort appear to be substantial."

Although the jurisdiction of the federal Act is more restricted than that of most of the provincial statutes, the absence of protection on the federal level may also have great symbolic effect. Joan Anderson, President of the Canadian AIDS Society, in calling for federal leadership on this issue, stated that:

> ...if the leaders in our country give a clear message that they are not homophobic, that they do not hold prejudice against people because of difference, because of their sexual orientation, then again that sends a very important education message out to the community at large.

The Committee calls on the federal government to fulfill its commitment and show leadership in this important area of human rights.

**RECOMMENDATION 32:**

The Committee recommends, in the strongest possible terms, that the federal government fulfill its commitment to add sexual orientation as a prohibited ground of discrimination under the Canadian Human Rights Act as soon as possible.

The Royal Society recommended that both policy-makers and the general public should be better educated about the human rights legislation that does protect those discriminated against because of sexual orientation, HIV infection or AIDS. We endorse this view. Employers, other employees, landlords, those who provide goods and services, and the general public, must all be made more aware that discrimination in these

cases is prohibited, and that those discriminated against can apply to a human rights commission for redress. All jurisdictions should be encouraged to develop express and comprehensive policies on discrimination related to AIDS, and these human rights protections should then be vigorously enforced.

RECOMMENDATION 33:

> The Committee recommends that the Federal Centre for AIDS consult with the Canadian Human Rights Commission and its provincial counterparts with respect to doing more to publicize the statutory protections and policies regarding discrimination based on AIDS and HIV infection and, where the protection exists, based on sexual orientation.

The Canadian AIDS Society and the Royal Society of Canada have both recommended that all HIV-antibody testing should be voluntary, except in cases involving donation of blood, blood products, organs and tissue. The Working Document generally endorsed voluntary testing, but referred to the need for resolution of the "issues" concerning the testing of immigrants, hospital patients and staff, and of "other groups who may be deemed to place others at risk." None of the witnesses who appeared before us raised the issues to which the consultants referred, except to recommend that mandatory testing be rejected in all cases.

The Working Document also affirmed the critical importance of confidentiality, and recommended that it be reinforced by legislation imposing civil liability for breaches of confidentiality without proof of damage, a recommendation that was also made by the Royal Society. We did not hear enough evidence to make recommendations about specific legislative changes that may be needed to strengthen guarantees of confidentiality, but we endorse the importance of protecting information about HIV test results and HIV status, and agree that legislation should be reviewed, and amended where necessary, to ensure this. We also agree that more attention should be given to the enforcement of existing legislation.

**RECOMMENDATION 34:**

The Committee recommends that all HIV-antibody testing be voluntary, except in cases of donations of blood, blood products, organs and tissue, and be accompanied by appropriate guarantees of confidentiality.

The issue of anonymous testing is a more difficult matter. This approach would allow testing to be done without people having to furnish a name or other identifying information, so that only the person tested would be aware of a positive test. The proponents of anonymous testing maintain that many people who should be tested are afraid of being identified and may thus avoid testing altogether. Medical Officers of Health point out, however, that anonymous testing would not allow public health authorities to ensure that those who test positive are adequately counselled, that their sexual contacts are traced and testing done where appropriate, and that, in particular, their partners be made aware of their own need to be tested.

Those who support anonymous testing state, however, that partner notification and contact tracing should in any case be the responsibility of the HIV-positive person. In the Working Document, the consultants to the Department agreed that this should be the position taken by the National Strategy. The proponents also point out that much of the counselling is done by personal physicians, and by PLWA and community-based groups, and that anonymous testing thus does not mean that those who test positive will not receive adequate counselling.

Moreover, they point out that those who avoid being tested are also beyond the control of public health authorities, and will not be certain of any HIV-positive status. Therefore, they will not be put on notice that they have to change their behaviour and warn their partners and sexual contacts. Public health may therefore be endangered, rather than protected, by laws that do not guarantee anonymity. Proponents also argue that anonymous testing is the only sufficient guarantee of confidentiality.

The Committee has not heard enough evidence to make any firm recommendations, although several of our members do firmly believe that the National Strategy must endorse anonymous testing. It is a supremely

important issue, and is considered to be a matter of top priority by the Canadian AIDS Society and others. It is an issue that has to be resolved and we are determined to hear additional evidence so that we will be in a position to make recommendations in the future.

## INJECTION DRUG USERS AND NEEDLE EXCHANGE PROGRAMS

The Committee has heard testimony from a number of witnesses on injection drug users (IDUs) and the issue of needle exchange programs as a means of preventing the transmission of HIV by this route. The issue also has direct relevance to the matter of AIDS among prison populations, an aspect discussed elsewhere in this report. Needle sharing by IDUs has resulted in dramatic increases in the incidence of HIV infection among users in some communities.

The Working Document acknowledges that IDUs "are a particularly difficult group to reach," and goes on to recommend that the Department of Health and Welfare and the provinces work together to "develop, implement and evaluate pilot intervention programs targeted at injection drug users." This recommendation is appropriate but it does not deal directly with the matter of needle exchange programs, unquestionably the most controversial aspect of any IDU intervention effort.

The City of Vancouver initiated a multifaceted, "ways and means" needle exchange program in March, 1989. The proposal for the program was approved by City Council in February of 1989 and a grant of $100,000 was made to a local agency, the Downtown Eastside Youth Activities Society, to develop and run the program. The program apparently has worked well: by October 1989, more than 2,600 IDUs had registered, the needle exchange rate reached a peak of 98% in November, and there was an increase in the number of users requesting referral to addiction-related services. The success of the program was ascribed to the fact that the approach to the IDUs was non-judgmental and non-intrusive.

In July 1989, the Minister of Health and Welfare announced an initiative to address the problem of HIV-transmission among the IDU population. The program was designed to support pilot projects to assess

the effectiveness of targeted prevention strategies for injection drug users. Under this program, federal-provincial cost-shared projects have been started in Quebec and Ontario and pilot projects are underway in Montreal and Toronto. Although these projects bear the title "pilot," they are, in fact, large-scale programs rather than strictly research studies of limited scope.

The Committee accepts that needle exchange programs for injection drug users are controversial, and seen by some as a tacit approval of injection drug use, although that clearly is not the intent of the program. There is evidence from the Vancouver program, cited above, to indicate that needle exchanges can encourage IDUs to seek counselling and treatment for their addiction. Dr. Catherine Hankins, representing NAC-AIDS, discussed this point in two appearances before the Committee:

> I am very much involved in the Montreal (needle-exchange) project where we see over 800 people a week, very positive responses from the drug users and we are beginning to see an impact on treatment demand which was exactly what we hoped we would be able to see ... They come in, they get the needle, if they do not want to talk to anybody they just fill out two or three questions and they leave ... They are completely taken aback that we actually care enough to do something that might not have public support and it is that realization (that) is leading people after 15 or 20 visits to a needle exchange to start to say I would like to see somebody ... they learn to see the non-judgmental attitudes, then they start to realize that maybe they should take that extra step themselves.

On the basis of this type of evidence, presented to the Committee during public hearings, and from the published account of the Vancouver needle exchange program, we support the implementation of positive programs to deal with the threat of HIV transmission among the IDU community, including the use of needle exchange programs, provided such programs are carefully evaluated. The Committee commends the Minister of National Health and Welfare for the positive approach taken by the Department in this area. We believe that the evaluation of the two-year pilot studies should be given top priority so that permanent programs may be developed.

**RECOMMENDATION 35:**

The Committee endorses the current federal program, announced in August, 1989, for two-year pilot studies on programs for injection drug users, including needle exchange programs, and recommends that evaluation of program results by the Department of National Health and Welfare be accorded top priority so that a decision can be made as soon as possible after the studies conclude on future programs for injection drug users.

One aspect of federal-provincial cost-shared programs that is causing concern in the AIDS community is the reluctance, in several cases refusal, of some provinces to participate in needle exchange programs. The governments of British Columbia and Nova Scotia are cases in point. The problem here is that provincial government refusal to participate in cost-shared programs acts as a barrier to the federal funding initiatives in this area, and can prevent the use of federal dollars for the projected program.

Several witnesses suggested that the Department could devise creative solutions to this problem. The involvement of municipalities may be one approach. It would not be appropriate, in Canada's federal system, for the federal government to bypass the provincial authority and deal directly with a municipal government, but agreements involving all three levels of government would appear to be possible. In the City of Toronto, the city has assumed needle exchange costs and related program elements, while the federal and provincial governments have covered other costs and provided other program elements such as nurses and other outreach workers. The Committee welcomes such municipal initiatives and encourages the federal and provincial governments to respond to them.

The Committee hopes that solutions of this nature will enable the federal government to conclude comprehensive cost-sharing agreements with the provinces that will include needle exchanges as well as other programs for injection drug users. As noted earlier, two such agreements are already in place in Quebec and Ontario, and Dr. Alastair Clayton, Director General of the Federal Centre for AIDS, advised the Committee that negotiations are underway with the government of British Columbia on a cost-sharing agreement which could include a needle exchange element.

**RECOMMENDATION 36:**

The Committee recommends that the Department of National Health and Welfare explore solutions to problems caused by the reluctance, or refusal, of some provincial governments to become involved in needle exchange programs, which frustrates the conclusion of federal-provincial shared-cost agreements in this important area.

PRISONS

The recommendations the Committee makes concerning prisons may also apply to provincial institutions, but our focus as federal Parliamentarians is on the federal prison system. What is done, or not done, in that system will in any case affect other institutions across Canada. One of our witnesses advised us that "provincial institutions certainly are waiting to see what the federal government is going to do. Everybody is looking around for some leadership in this area." So far there has been no leadership on the federal level for them to follow.

In some ways the issue of programs to prevent HIV transmission in prisons is relatively simple. The need for such programs would appear to be clear, and the measures that need to be taken are agreed upon by all the medical authorities. The prison population is literally a captive population, and prison authorities are in a position to institute whatever programs are regarded as essential for the protection of the health of inmates. Yet, on the federal level at least, they refuse; and they refuse for reasons that only another prison administrator can presumably understand, because they are all grounded on "correctional experience." On the basis of all the evidence we have heard, the Committee cannot accept that as an answer.

Although we are convinced that there is a clear need for HIV transmission programs in federal prisons, it is not because of the information the Commissioner of the Correctional Service was able to provide to us. Mr. Ingstrup advised the Committee that since the first AIDS case was identified in the federal prison system, 9 cases of AIDS and 49 HIV-positive inmates have been identified. Although the Commissioner

did acknowledge that these figures had to be taken with reservation, the actual numbers must be so vastly different as to make these statistics a mockery.

We know that there is sexual activity in prison; estimates from the U.S. federal prison system suggest that it is in the order of 18% to 28%. Because of Correctional Service policy, this must all be unprotected sexual activity. We also heard evidence that up to 50% of inmates may be involved in drug use, that needle sharing for injection drug use is common, and that needles and other implements are also used for tatooing purposes. Again, because of prison policy, there is no opportunity to clean and sterilize the needles used. There is thus undoubtedly a high incidence of high risk behaviour. The result would surely be an HIV infection rate much higher than the average in the general population. But the figures available to the Commissioner would indicate an infection rate about the same as the high end of the Canadian average. We do not find this credible, and other figures tell a very different story.

Dr. Catherine Hankins, a member of NAC-AIDS, has done research in two provincial institutions in Montreal, a study in a women's institution, which has yielded results, and one just beginning at Bordeaux Jail, a large provincial men's institution. These would appear to be the only studies which have been done in Canada on AIDS/HIV and prisons. In the women's jail there was a high incidence of drug use, the same 50% figure that has been estimated in some federal prisons, and many of the inmates were prostitutes. Her figures show that 7.2% of the prison population were HIV-infected. Although the conditions in federal prisons are different, it is unlikely that the prevalence of HIV-infected inmates would be much lower, and could be higher. Translated to the federal system, Dr. Hankins' figures would indicate that out of a total prison population of 13,500, almost a thousand federal inmates could be HIV-infected and, therefore, capable of transmitting the virus.

We must determine the prevalence of HIV-infected inmates in the federal prison system and, even further, learn something about the incidence of infection incurred in the prisons themselves. It is clearly

possible to do both, although the second would involve more extensive studies. The Commissioner frankly advised us that he did not have any hard information on the extent of HIV infection in the prisons (a lack of hard information was also the case with other relevant matters, such as the extent of sexual activity and drug use). He also suggested that it would not be possible to gather such information, and that any attempt to do so would raise legal and ethical concerns.

Dr. Hankins' work shows that this is simply not the case. Although not without difficulties in the prison setting, unlinked testing using left-over blood samples, which would bear no information identifying any particular inmate, would give us some reliable knowledge about the prevalence of HIV infection in the penal system. The same sort of testing using blood from incoming inmates, and from those being released, would give us a picture of how much infection was being incurred inside the prisons. This is exactly the technique which is being used to gather data on the extent of HIV infection in Canada generally, and there are no legal or ethical implications so long as the study is carried out by professionals using proper techniques.

The Commissioner made frequent references to a lack of information on which to base a more extensive AIDS/HIV policy. But when members of the Committee urged him to do the sort of study suggested by Dr. Hankins, at least on a pilot basis, the Commissioner replied that he did not think that it was necessary, saying that he would watch developments elsewhere.

More certain knowledge about the extent of HIV infection in our prisons is essential. The measures that must be taken are, however, clear. They are comprehensively set out in the "Statement Concerning Correctional Settings Submitted to NAC-AIDS" which is appended to this Report. This statement has been approved by the Minister of Health and Welfare and is in every sense the "health position" on the issue. Even the Commissioner candidly acknowledges that it represents, at least in regard to its primary recommendations, the position of the Royal Society of Canada, his own Health Care Advisory Committee, and, indeed, a medical position that is "completely valid."

The NAC-AIDS recommendations involve a range of measures, including education programs; changes in environmental conditions and other measures designed to limit rape in prisons; truly confidential HIV testing; psychosocial support services; and the sort of research about HIV infection, and its spread in prison settings, that is described above. Of all the measures recommended perhaps the most important, and the most controversial, are the confidential availability of condoms, and the availability of bleach for needle decontamination purposes, including needles used for tatooing, which would prevent both HIV and Hepatitis B transmission.

We have some concerns about the effectiveness of the information programs on HIV to which inmates and staff are exposed. There was evidence that they are not likely to be effective in changing behaviour, and that they are not mandatory or even pressed upon the inmates, although the prison setting would allow for this. Dr. Hankins suggested that those who attended optional programs might fear that other inmates would assume that they were infected. In any case, in terms of anything but abstention from all high risk behaviours, which is surely unlikely, information probably will not be of much use if inmates do not have the means to act on it. Inmates have told Dr. Hankins that education sessions are simply frustrating. "We get them all keen to protect themselves, and then there are no means by which they can do so."

The Commissioner's reply is that the availability of clean needles would condone drug use. This, he says, would be contrary to the basic principles of the criminal justice system, although he admits that the Department of Health and Welfare is not condoning drug use when it participates in needle exchange programs in the world outside in order to deal with an urgent and overriding health concern. In addition, he was certain that providing clean needles would increase drug use, although he agreed that there was no objective evidence that he could point to to prove that this would be the case. He did not really address the effect of making decontamination materials such as bleach available.

Dr. Hankins, on the other hand, stated that "even on the issue of tattooing alone, bleach should be available." On this issue, the

Commissioner said only that needles used for tatooing would be confiscated if found. In regard to condoms, he noted that sexual activity is considered to be a disciplinary offence in prisons. More importantly, he stated that they could be used for smuggling drugs and contraband. He also expressed a concern that they would be dangerous if swallowed while containing such drugs, although HIV transmission is also dangerous and could be viewed as being a more valid health concern.

Two themes dominated the Commissioner's testimony. The first was "balance." Although he stated emphatically that he regarded the recommendations of NAC-AIDS and other groups as being medically "completely valid," he stated that he had to balance them with correctional concerns. We see no evidence of balance. Except for some information programs about which we remain skeptical, all of the primary medical recommendations have been rejected, or if not rejected, 'lost in the balance.' The Commissioner was not even open to the suggestion that some of these measures be <u>tried</u> on a limited basis, with a careful monitoring of the result. Bleach, for example, is available in the provincial institutions with which Dr. Hankins is familiar, and there have been no problems. Dr. Hankins suggested that "we are not doing anything to even see what would happen in reality." The counterpoint offered to that was the Commissioner's instinct, and we feel that this instinct must at least be tested.

This was the other theme which the Commissioner urged upon us - what he referred to as "correctional experience"; which he suggested we would simply have to accept if we did not understand it. "Correctional experience" is a closed system when the lessons learned from it cannot be explained to the satisfaction of those outside it, and it is unacceptable as a complete answer for that reason alone. It would mean that any decision made by a correctional administrator could never be challenged, and the Committee cannot accept that.

In addition, some of the conclusions drawn from this experience we cannot regard as credible. The Commissioner suggested that the presence of condoms would mean that inmates could no longer avoid sexual activity by using the excuse that they were afraid of AIDS. Quite apart from the difficulty we have in believing that this excuse would work

in the coercive atmosphere of a prison, we have difficulty in imagining that those who are too irresponsible, in the Commissioner's view, to use a condom if one was available, would be likely to engage in or accept this rather fragile subterfuge. We have the same reaction to the suggestion that the ability to decontaminate needles would rob inmates with drug addiction problems of the fear of AIDS as a motivation to kick their habits while in prison.

In any case the Commissioner frankly acknowledged that correctional experts are divided on these questions. England and Australia are apparently considering making condoms available; they are already available in France, the American states of Vermont and Mississippi, and the city jails of several major American cities, including New York City.

We would be more willing to give a measure of deference to correctional experience if it was backed up with a little more in the way of objective knowledge. As noted earlier, the Commissioner acknowledged and lamented the lack of such information, but was not willing to seek it in research studies that would gather information concerning inmate attitudes toward the availability of condoms or clean needles, the effects of any pilot programs that might be attempted, and data on such key matters as drug-taking and sexual behaviour (although he stated that he was open to research in general). Dr. Hankins advised us that this is exactly the sort of information that is being sought in the study begun at Bordeaux Jail, and that there were waiting lists of inmates who wished to participate. The key appears to be the involvement of outside researchers whom the inmates will trust to maintain strict confidentiality.

We would understand the difficulties involved in attempting to implement, in a prison setting, some of the measures recommended. We do not understand the refusal to even try to do so. The Correctional Service has a duty to take reasonable measures to protect the health of inmates who are confined under its supervision. The Service should also be concerned about the health threat to the community outside when inmates are released. Dr. Hankins suggested that "somebody has to show a little bit of courage here," and implement at least a pilot project to see what would happen if, for example, condoms were made available in a prison tuck shop.

The Committee is encouraged that the Minister of Health and Welfare has adopted the NAC-AIDS recommendations as his own. We call upon the Minister to urge these recommendations upon his colleague the Solicitor General, and we call upon the Solicitor General to act as soon as possible.

RECOMMENDATION 37:

The Committee strongly recommends that the Solicitor General begin as soon possible to implement the recommendations of NAC-AIDS, supported by the Minister of Health and Welfare, for the prevention of HIV transmission in prisons.

RECOMMENDATION 38:

The Committee recommends, in particular, that the Solicitor General take immediate steps to have bleach for needle decontamination purposes and condoms made available on a confidential basis to inmates of federal prisons.

RECOMMENDATION 39:

The Committee further recommends, in particular, that the Department of National Health and Welfare, in cooperation with the Correctional Service of Canada, immediately set up a pilot study, using unlinked seroprevalence survey techniques, and with appropriate ethical safeguards, to assess the level of HIV infection in federal prisons.

The Commissioner advised the Committee that "we are encouraging community groups to come in and participate in (education sessions). It is our feeling that the inmates may be more likely to believe warnings that come from groups independent of the Correctional Service of Canada. We therefore count to a large extent on these external groups for help." As education sessions are about the only thing that prison inmates are likely to get for the time being in regard to HIV transmission, we believe that the federal government should do everything in its power to make these programs as effective as possible. We know that some community-based groups have already responded to this challenge, and we call on the Department of Health and Welfare to bolster their efforts with more funding and other resources.

**RECOMMENDATION 40:**

The Committee recommends that the Department of National Health and Welfare provide more funding and encouragement to community groups so that they can take up the invitation of the Commissioner of the Correctional Service to mount AIDS education and awareness programs in federal prisons.

The most likely reason for the low number of inmates identified as HIV-positive in the federal prison system is the complete lack of confidence that most inmates appear to have in the confidentiality of prison health services. Many have undoubtedly waited until they were released to be tested. Concern about advertising their sexual activity to prison administrations may also have kept many inmates in Vermont and Mississippi from "requesting" the condoms which are available in those states, limiting the request rate to 10%.

The Commissioner advised us that health information, including HIV status, is considered confidential, but it must be noted on prison health records. Given that such written records would be very difficult to protect in a prison setting, it is not surprising that Dr. Hankins advised us that "When I talk to prisoners they say that under no circumstances would they be tested in the prison environment under the current set-up. I have talked to prison directors who say that they do not trust their health services. They are like a sieve; the information just gets out."

Dr. Hankins' experience suggests that the only solution for this problem may be the use of outside health services such as community clinics that can protect the health and confidentiality of inmates, as is the case with the provincial women's institution that she has studied. The Commissioner objected that this would involve additional costs and would thus be unacceptable. Dr. Hankins suggested that it is not a question of expense, but rather of loss of control by the Service over inmates' health information. As the costs probably involve more nurses' and nursing assistants' salaries than doctors' fees, contracting-out might be no more expensive than in-house services. The federal government's privatization program is based on the idea that outside services can be competitive. It is an idea that is at least worth serious consideration and investigation.

**RECOMMENDATION 41:**

The Committee recommends that the Department of the Solicitor General immediately undertake a study of the advantages of prison health care services being provided by outside agencies. The Committee endorses the view that the confidentiality of health care information involving inmates could be better protected by using outside agencies to provide such services.

## INTERNATIONAL OBLIGATIONS

Although the Committee has not received extensive evidence on the international aspects of the AIDS epidemic, the international dimensions of the disease are well known. AIDS has made particularly rapid advances in a number of less-developed countries. Some of the Sub-Saharan African nations have been almost devastated by the disease, with appalling loss of life and widespread illness. As one example, a recent news report from Kigali, Rwanda stated that an estimated 25-30% of the sexually-active population of that capital city are infected with the AIDS virus. The epidemic is especially cruel in less-developed countries because health-care and social-service infrastructures and programs either do not exist, or are much less effective than in a country like Canada.

By January 1990, more than 200,000 cases of AIDS had been reported by the World Health Organization (WHO), with more than half occurring in the United States. The actual number of cases, worldwide, may be nearer 500,000, however, with the bulk of the unreported cases occurring in less-developed countries. Further, WHO speculates that as many as 10 million people might now be infected with HIV. By the end of the century, there could be as many as six million cases of AIDS around the world.

Canada has been very active and effective in the international fight against AIDS and HIV infection and our funding contributions to international programs compare well with those of other industrialized countries. Canada's Federal Centre for AIDS is a WHO collaborating centre

for AIDS and the FCA's Bureau of External Cooperation is actively involved in WHO programs.

The federal government's principal players on the international scene are the International Development Research Centre (IDRC) and the Canadian International Development Agency (CIDA).

The IDRC works cooperatively with a number of national and international institutions in AIDS-related research. The IDRC is currently funding AIDS projects costing about $2.1 million. The principal thrust of the Centre's research effort deals with sexual behaviour, the objective being to influence behaviour in the direction of safer practices which lead to prevention of HIV transmission. To date, the IDRC programs have concentrated on East Africa, essentially because the requests for assistance have mainly come from countries in this region.

CIDA's involvement in the international fight against AIDS was defined in October 1987 when guidelines were established by the Agency. The Agency's focus is primarily on preventive activities, public awareness programs and primary health care systems. CIDA's funding commitments to date total $70.4 million. The Agency's Multilateral Technical Cooperation Division supports WHO's Global program on AIDS (WHO/GPA) with total multilateral funding of $19.4 million since 1986-87. Other CIDA funding initiatives are as follows: regional and bilateral programs in Francophone Africa - $22.8 million; bilateral programs in Anglophone Africa - $18.3 million; bilateral programs in the Americas - $6.2 million; and programs with Canadian institutions and non-governmental organizations (NGOs) through the Agency's Special Programs Branch - $3.7 million.

The Committee believes that Canada's international activities on AIDS and HIV infection deserve to be better publicized, in part because such publicity will reinforce public awareness of the critically important international dimensions of the disease.

RECOMMENDATION 42:

The Committee recommends that the federal government, through the Federal Centre for AIDS, make greater efforts to publicize the valuable work funded and supported by the Canadian International Development

Agency and the International Development Research Centre in the international battle against AIDS and HIV infection.

The Committee has received extensive evidence that community-based organizations in Canada play an essential role in this country's response to the AIDS crisis. It is important, therefore, that these organizations be able to share their broad experience and knowledge with Canada's international partners, and also learn from the experiences of others. The Committee notes, with approval, that CIDA is currently providing funding to NGOs through its Special Programs Branch. We would urge that the current level of funding to such organizations be reviewed and, if possible, increased.

**RECOMMENDATION 43:**

The Committee recommends that the federal government provide additional resources to Canadian non-governmental organizations so that they can participate actively in international forums and organizations and establish international AIDS development and exchange projects.

The search for treatments and therapies for persons with AIDS or HIV infection has an obvious international scope. In 1989, the federal government initiated development of a Clinical Trials Network for new drugs in Canada, and very recently the Minister announced plans to develop a National Treatment Registry for AIDS and HIV infection. It is essential that both of these initiatives have effective international linkages so that Canadians will have access to the best available therapeutic information and technologies and, also, so that we will be able to share our expertise and knowledge with our international partners. It is in this spirit that the Committee makes the following recommendation.

**RECOMMENDATION 44:**

The Committee recommends that the federal government participate in and encourage international collaboration on drug trials, drug access and treatment protocols, including the provision of resources to international data banks on treatment, research and educational programs and materials.

The issue of travel restrictions on persons with AIDS or HIV infection has been brought to the Committee's attention. Such restrictions have recently become an important issue in connection with the Sixth International Conference on AIDS scheduled for San Francisco this summer. Because the United States prohibits entry of persons with AIDS or HIV infection, and generally enforces this restriction, a boycott of the San Francisco Conference has been developing.

The issue of travel restriction has not yet become controversial in Canada, in spite of the fact that persons with AIDS or HIV could be denied entry into Canada as visitors. The main reason for the relative lack of visibility of the Canadian restriction lies in the fact that it is not rigorously enforced, whereas in the United States it is.

The Committee has considered this issue, and we feel that there is no significant advantage to Canada in banning entry to visitors with AIDS or HIV infection and, moreover, we disapprove of the philosophy that underlies the restriction. We also believe that the federal government should encourage other governments to take a similar non-restrictive position, particularly the United States.

**RECOMMENDATION 45:**

The Committee recommends that the federal government instruct immigration officers not to prohibit the entry into Canada of visitors who have AIDS or are HIV-positive. The Committee further recommends that the federal government encourage other governments to rescind similar restrictions on international travel.

## FUNDING

Throughout the Committee's hearings the issue of funding arose time and time again. Indeed, it may be said that funding is, overall, the central issue. It is the key to the effectiveness of most of the other elements that will make up the National Strategy. Lofty objectives will be illusory or even misleading if there are no financial

resources available to create substantive programs to carry out these objectives.

It is extremely important that programs be well-defined so that scarce resources are used to best effect. Criteria will have to be developed to ensure that all funds are wisely spent. There must be ongoing accountability, and this will require effective monitoring and evaluation of program spending. This does not, however, obviate the need for much more funding than is currently available.

Federal funding in the amount of $39 million was first announced in 1986, for the five-year period to 1991, and a further $129 million was added in 1988. Altogether the federal government has spent or committed $168 million through to the end of the current Federal AIDS Program in March of 1993. This money has been used to fund a variety of programs, including some which go beyond the normal scope of direct federal spending in matters of health, such as the funding of local community-based groups. This level of funding is, however, dwarfed by the economic implications of the epidemic, and by the estimates of the best experts in the field as to the minimum level of funding that should be the responsibility of the federal government in the overall battle against AIDS and HIV infection.

The unanimous view of all the experts who testified before the Committee that more federal funding is needed has convinced the members of the Committee that the federal government must do much more. We are all aware of the difficulty of making more federal money available in a time of restraint. On economic grounds alone, however, it is vital that the funds be found. The money will have to be spent at some point, if not now on prevention so that fewer people become infected, then later on treatment, care and support of those affected by the disease.

Dr. Rod D. Fraser, an expert in the economics of health care, appeared before the Committee and presented an update on the examination of the economic costs of AIDS and HIV infection that he and his colleagues did in 1987-88 as part of the Royal Society of Canada study. While some cost factors have gone down since the original study, the life expectancy of those diagnosed with AIDS has gone up somewhat. Thus, his

estimate of the direct personal costs of caring for a person with AIDS, including hospital costs, drug costs, physicians' costs, and home-care costs, has risen from at least $82,500 to about $100,000 per person.

The non-personal costs, the expenditures made by governments and agencies across Canada because of the presence of HIV infection and AIDS, are estimated to be in the same order as the direct personal costs, that is, in the range of $100,000 per person. When we take into account the value of the lost productive capacity as lives, in many cases young lives, are lost, the total value of actual expenditures and social costs could be more than $1,000,000 per person with AIDS.

The cost of caring for those who have AIDS or are HIV-infected is unlikely to decrease in the future, and if anything may continue to increase as new (and expensive) drug therapies are developed which prolong the lives of those with AIDS. The present projections of the total number of accumulated cases of AIDS by the end of 1993 range from about 7,600 to about 13,000. Taking the lower estimate, the direct personal costs of caring for those people could total $760,000,000, and the non-personal costs could be an equal amount. Because of the long incubation period of the disease, many of those people will already be infected by this point.

Indeed, as noted earlier, the number of those in Canada already infected is estimated by some to be as high as 50,000. Dr. Fraser suggested that the actual number may be much lower, in the range of 25,000 to 30,000. Even if the number is only 25,000, the direct personal costs alone, as these people develop symptomatic AIDS within the next five to ten years, could be in the order of $2.5 billion. The costs beyond that point will depend on the success of our prevention and research efforts now.

The federal commitment for the next three years averages out to just over $30 million per year. There are calls for the federal government to spend at least four times that amount. If the federal commitment were to be quadrupled to $120 million per year, and if the additional $90 million resulted in the prevention of anything more than 900 persons per year from becoming infected (which is less than 4% of Dr. Fraser's lowest estimate of the number of those already infected), that

additional spending would result in future savings in direct personal costs alone.

This is not to say that the primary reason for committing more funds now is the cost saving that would be reaped down the line. A more important aspect is the human cost, in lives lost and suffering endured. The National AIDS Strategy is about the lives at risk and the lives that will be lost if we do not do enough now to stop the transmission of this disease. Those who have AIDS/HIV deserve the best that we can give them in treatment, care and support. They deserve to be able to live with dignity. The economic argument recognizes, however, that even our commitment to human life and human dignity will always be tempered by financial realities. In this case, those financial realities point to the need to act now. The economic argument in this case only buttresses the moral imperative.

Although it is clear that the federal government must commit more funds to this struggle, it is difficult to determine exactly how much more. The Committee heard varying estimates from different witnesses, although they were all in agreement that federal funding should not merely be increased, but multiplied. The Canadian AIDS Society, for example, representing community-based groups from across the country active in the front lines of the battle, called for the federal government to contribute at least four times its current spending commitment.

Such an increase would bring the federal government's effort into line with that of other countries such as Australia and the United States. The Society's first submission concerning a National Strategy, entitled "Working Together: Towards a National AIDS Strategy in Canada," pointed out that the Canadian federal government's most recent commitment of $129 million over five years represented approximately $1.00 per Canadian per year, whereas the Australian federal government's allocation of $314 million over the same period represented (given that country's smaller population) almost $4.00 per Australian per year.

The Society's figure was not based purely on a comparison with spending in other countries. It represents the Society's estimate of the funds needed for "the staff, the infrastructure we need in terms of

biomedical research, the community initiatives across Canada and the kind of core funding they need, and the issues around a national treatment registry."

The witnesses from the Royal Society of Canada called for even more government spending. Dr. Fraser testified that his Economics and Epidemiology Subcommittee had recommended that an additional $50 million annually, for a minimum total of $80 million per year, be spent on education and prevention alone. He added that an almost equivalent figure now appeared to be required for epidemiological and social research. Those estimates alone would point to spending needs many times higher than the current federal government commitment.

NAC-AIDS has also done an economic analysis, for the information of the Minister of Health and Welfare, which looked at Canada's commitment to AIDS and compared it with the American and Australian efforts. This study looked at the data available on the differences in the extent of HIV infection in the three countries, as well as population sizes and funding efforts. Dr. Normand Lapointe, the Chairman of NAC-AIDS, testified that the study showed that Canada's efforts so far have amounted to about 44% of what the Americans have done and 40% of what Australia has done.

Dr. Catherine Hankins, also from the Advisory Committee, testified that the conclusion from the study was that the amount committed by the federal government in Canada for the period from 1989 to 1993 should be "at least $363 million" for research and prevention alone, if this country is to mount an effort comparable to that in the United States and Australia. This would represent an almost three-fold increase over current funding commitments.

Ideally, the Committee would like to have available internally-generated criteria which would tell us exactly how much money is required to deal with the threat posed by the disease in Canada. We would like to be able to determine what effect a given level of expenditure would have on the general pattern of the spread of the disease, and therefore, in general, how much we could expect the spread of the disease to be lessened if expenditures of the order advocated by the witnesses were made.

Such determinations are currently unavailable and may remain so for the indefinite future. The correlation of expenditures with results is extremely difficult. We are dealing with voluntary human behaviour, including the very complex area of sexual behaviour, and it will always be very difficult to isolate and measure the impact of education and prevention programs.

We know from studies that education and awareness programs do work, however, particularly when they are effectively targeted at those engaging in high risk behaviour, as has been the case with programs mounted by and directed at gay communities in several Canadian and American cities. Canada, like other countries, is still in the early stages of implementing large-scale education and prevention programs; evaluation of their effectiveness is ongoing but clear results will not be available for some time yet. Dr. Evelyne Wallace, with the Ontario Ministry of Health, who has been involved in running AIDS programs in that province since 1983, stated frankly that she would not be able to tell us for several years whether all of the $60 million spent by the province on prevention programs has been well spent.

We cannot, however, wait until more reliable cost-benefit analyses are available. As noted earlier, we still need much more data on the present extent of HIV infection in Canada to have even a starting point for any analysis of changes in the rate of infection. The urgency of the situation is such that we must act now before the effects of the epidemic become visible as confirmed HIV-positive persons or symptomatic cases of AIDS. Prevention efforts must be based on the risk of infection, rather than on evidence of actual infection rates.

The Committee would have preferred to accumulate more evidence on the range and nature of additional programs which could be mounted, and their cost implications, had time and circumstances allowed. This is one area of study which a Special Joint Committee of Parliament should take up on an urgent basis.

Effective program proposals will, however, be generated in response to the financial resources which make them possible. For example, Health and Welfare Canada's NHRDP program received a large number of AIDS

research proposals when the most recent funding announcement was made: none could be considered because the funding had already been allocated. The Committee is confident that those organizations which have dedicated their time and energy to fighting the AIDS epidemic will find ample ways to use new money effectively.

The Committee has heard from those best qualified to make judgements about the overall adequacy of federal government funding on AIDS - the Canadian AIDS Society, with its extensive practical experience, and the Royal Society of Canada and the National Advisory Committee on AIDS, which together comprise the very best expertise on the subject. The advice which we have heard is that of the best experts that the Minister of Health and Welfare could assemble to advise him as to what must be done. The federal government will ignore their advice at Canada's peril.

**RECOMMENDATION 46:**

> The Committee recommends, in the strongest terms possible, that the Minister of National Health and Welfare urgently undertake a review of the overall funding commitment of the federal government to the struggle against AIDS and HIV infection, with a view to increasing it to a level which is adequate to meet the increasing challenge which must be faced. The Committee further recommends that the federal government take immediate steps to increase substantially the funding available for the current Federal AIDS Program.

The current Federal AIDS Program projects funding and program mandates through to the end of the 1993 fiscal year, less than three years from now. The AIDS crisis will not have gone away by 1993. It can only be hoped that by then we will have made significant progress in curbing the spread of the disease, but no one familiar with the present state of the epidemic expects that we can look forward to ceasing or even slackening our efforts in three years time. The "bulge" of AIDS cases, of which we spoke in the introduction to this report, may be starting to appear by that point, and the costs of treatment, care and support may be consuming ever larger resources. Funding and program needs for research, education and prevention will nonetheless remain priorities for some years into the future.

The federal government must begin now to plan for the period after the mandate of the current program expires. Those engaged in research, or involved as volunteers on the street, must be assured of future funding and support. The role of the Federal Centre for AIDS in particular must be guaranteed so that the effectiveness of the work it does now will not be hampered by uncertainty about its future. If a change in priorities or a re-organization of structures anywhere in the federal response to AIDS is contemplated, the work of planning must be done now so that the new programs will be ready when they are needed. Prior planning is also necessary where programs and structures will be ongoing. There must be no break in the continuity of the fight against AIDS. Major program funding approval often takes up to two years to move through the bureaucratic and political processes. That work must begin now.

RECOMMENDATION 47:

> The Committee recommends that the Department of National Health and Welfare begin immediately the development of program and funding proposals for the period after March 31, 1993, when the current Federal AIDS Program, including the Federal Centre for AIDS and other funding commitments, will expire.

The core funding for the Canadian AIDS Society has not been increased for the current fiscal year to take account of inflation. That means that in real dollar terms the Society, which is the national umbrella organization for the community groups at work across the country, will receive less during this year than it did last year. The Society opened its office in Ottawa only recently, in September of 1988, to enable it to perform an advocacy role on national issues on behalf of its members. As a National Strategy is developed and implemented, the need for input at the national level of the expertise and perspectives of the community-based sector will become even more important. The federal government must recognize the thousands of community volunteers across Canada as equal partners in the struggle, and confirm this recognition by providing adequate funding to support their work.

The Committee is also recommending that the core funding of the Canadian AIDS Society be increased, but as an immediate step the

government must move to eliminate the effective decrease that the Society has suffered. The recommendation refers only to the CAS because the Committee did not have enough time to gather detailed evidence about the core funding of local community-based groups under the ACAP program in order to know whether they have suffered the same fate. If that is the case the Committee would make the same recommendation concerning the funding of all community-based groups.

RECOMMENDATION 48:

> The Committee recommends, as a first step, that the core funding for the Canadian AIDS Society be indexed to inflation for the current fiscal year, so that funding for the current fiscal year will be at least equal to that for 1989-1990 in real dollar terms.

The importance of the role of community-based groups in responding to the AIDS crisis cannot be over-emphasized. From the beginning of the crisis they have mobilized to provide education and awareness programs directed to their own members or at the local level. They have also provided much of the care and support, physical and emotional, for those with AIDS/HIV. Their support services include counselling, the provision of home support workers, referrals to professionals, and personal support and friendship.

We have earlier noted in this report that education and awareness programs mounted by community-based groups appear to be the most effective, and should be given more funding. These groups cannot, however, carry out effective prevention programs if their core funding is inadequate or uncertain. The Canadian AIDS Society has pointed to this inadequacy and uncertainty as one of the primary difficulties that these groups face. They do their vital work with the labour of hundreds, perhaps several thousand, volunteers and small numbers of committed staff. They need at least adequate core funding support and some guarantee that it will continue.

The Department of Health and Welfare has done much good work in contributing to the funding of community-based groups and supporting their activities. Some groups may indeed be receiving sufficient support,

but we believe that many groups are in serious financial need. We are also convinced that they will use any additional funding they receive to best effect. The President of CAS, Joan Anderson, spoke of the economical manner in which all of the Society's member groups have always had to operate, and assured us that - "We appreciate limited resources, and when we have our resources we use them well and effectively."

RECOMMENDATION 49:

> The Committee has concluded that more core funding must be provided to community-based organizations. The Committee therefore recommends that the Department of National Health and Welfare ensure that increased funding commitments are made to the Canadian AIDS Society and other community-based AIDS organizations to enable them to carry out their ongoing responsibilities.

One of the particular difficulties that community-based groups have faced on both the national and local levels has been the complexity and delay involved in making applications for funding to the Department of Health and Welfare. Different funding streams have been established in the Department for different purposes, and one group will often have to make applications to several sections of the Department. The Canadian AIDS Society, for example, makes applications to at least two different programs administered by the Health Services and Promotion Branch, and to two different bureaus of the Federal Centre for AIDS.

While the manner in which the Department's AIDS activities are structured may be the most effective from the point of view of administering programs, it should not create undue complexity for community groups active on the front lines. The delays experienced in concluding funding arrangements for the current fiscal year may indicate that the complexity is also creating needless and possibly injurious delay. The Department must find ways to deal with this problem.

One of the answers may be multi-year funding agreements. When the officials from the Department appeared before us, Richard Dicerni, the Senior Assistant Deputy Minister, advised us that the Department was working toward such agreements in order to reduce the amount of paperwork required. In endorsing this approach, we do not intend to suggest that it

is the only solution. The Department must work along whatever lines are necessary to remove any burdens which hamper the work of the community groups.

RECOMMENDATION 50:

> The Committee recommends that the Department of National Health and Welfare expedite the development of multi-year funding agreements with the Canadian AIDS Society and other community-based AIDS organizations.

## CONCLUSION

In its presentation to the Committee, the Canadian AIDS Society stressed the importance of a National AIDS Strategy.

> We need it. We need it because as a nation we need to be working together toward a common set of goals and principles in order to defeat this epidemic. Because Canada needs a master plan. Because we need to secure the commitments of all levels of government. Because this epidemic, with its medical, social, economic and political dimensions, transcends the jurisdictions of the three levels of government, and so requires governments to work together on programs in a collaborative way. Because we will not succeed in the fight against HIV/AIDS unless community groups, persons with HIV/AIDS and other frontline workers are treated as equal partners with government, and have the opportunity to input into decisions regarding national priorities and programs.

We endorse this view of the need to develop a true National Strategy. But the Society now sees the development of such a Strategy as a longer-term process that will deal with the longer-term issues. It urges both federal and provincial governments to proceed now with action on those issues which are within their own jurisdictions, while the limited National Strategy that is within reach now is fleshed out into a comprehensive collaboration on all elements of the struggle. We agree, and call on the federal government in particular to articulate and implement on an urgent basis a federal strategy, as an essential building block of a National Strategy, and as a focus for federal efforts now and in the future.

## LIST OF RECOMMENDATIONS

### THE NEED FOR A SPECIAL JOINT COMMITTEE OF PARLIAMENT

**RECOMMENDATION 1:**

The Committee recommends that a Special Joint Committee of Parliament be established as soon as possible to study and make recommendations on all aspects of the AIDS epidemic in Canada.

### MANAGEMENT OF A NATIONAL STRATEGY

**RECOMMENDATION 2:**

The Committee recommends that a consultative process be set up to advise on the implementation of a National Strategy, involving representatives from the range of organizations identified in the proposal concerning a Canadian Council on AIDS, as set out in "A Working Document for the Development of a National Strategy on HIV Infection and AIDS."

**RECOMMENDATION 3:**

The Committee recommends that the management of the National Strategy recognize the necessity of involving Persons Living With AIDS and community-based support groups in the development and implementation of AIDS/HIV programs.

**RECOMMENDATION 4:**

The Committee, having noted with concern that the Federal/Provincial/Territorial Advisory Committee has not met in over a year, recommends that this body be convened as soon as possible as an additional mechanism to facilitate the development and implementation of a National Strategy.

### THE COORDINATION OF THE FEDERAL RESPONSE TO AIDS

**RECOMMENDATION 5:**

The Committee recommends that the Department of National Health and Welfare undertake efforts to communicate more effectively its role and activities to

its partners in the battle against AIDS and HIV infection, and also to the general public.

**RECOMMENDATION 6:**

The Committee recommends, in particular, that the Department of National Health and Welfare develop and publish a document setting out in detail the federal strategy for dealing with AIDS and HIV infection.

**RECOMMENDATION 7:**

The Committee recommends that the Department of National Health and Welfare undertake a re-statement of the role and functions of the Federal Centre for AIDS. The statement should clearly define what the Centre does, and also what it does not do, and should be directed to the Department's partners in the fight against AIDS and HIV infection.

**RECOMMENDATION 8:**

The Committee recommends that the Departmental Working Group chaired by the Senior Assistant Deputy Minister of National Health and Welfare, and set up for the purpose of developing the National Strategy, be made responsible for ensuring the effective coordination of all the Department's activities in regard to AIDS and HIV infection.

**RECOMMENDATION 9:**

The Committee recommends that the Department of National Health and Welfare consult to a greater degree with Persons Living With AIDS groups, and support groups such as the Canadian AIDS Society, to ensure greater involvement of these groups in AIDS/HIV program design and implementation.

**RECOMMENDATION 10:**

The Committee recommends that the National Advisory Committee on AIDS (NAC-AIDS) be given an expanded mandate which would include a public advocacy role in regard to all aspects of the battle against AIDS and HIV infection.

## RESEARCH

**RECOMMENDATION 11:**

The Committee recommends that the Department of National Health and Welfare give top priority to the evaluation of the unlinked sample surveys already underway, and to the setting up of any additional anonymous surveys that may be necessary, in order to determine the extent of HIV infection in Canada.

**RECOMMENDATION 12:**

The Committee further recommends that, where appropriate, and with adequate ethical safeguards, the unlinked, anonymous sample surveys include the collection of demographic data which can be used to determine the extent of HIV infection among important sub-populations in Canada.

**RECOMMENDATION 13:**

The Committee recommends that the Department of National Health and Welfare commission a comprehensive social and behaviourial research study on sexual practices and attitudes in Canada, and other issues relevant to the effectiveness of AIDS education and awareness programs. An appropriate body to initiate such a study might be the Social Sciences and Humanities Research Council.

**RECOMMENDATION 14:**

The Committee recommends that the federal government provide more funding for biomedical research, and that, in particular, the Medical Research Council consider the dedication of funds for basic research on AIDS and HIV infection.

## EDUCATION AND PREVENTION

**RECOMMENDATION 15:**

The Committee recommends that the federal government reaffirm the critical importance of AIDS education and awareness programs in the prevention of HIV transmission, to develop and maintain an appropriate level of public concern for the control of this epidemic.

**RECOMMENDATION 16:**

The Committee recommends that targeted programs directed to men who have sex with men and to injection

drug users be given top priority, and adequate funding, and that programs directed to street youth, sex-trade workers, and prison inmates be given greater priority and more funding.

**RECOMMENDATION 17:**

The Committee recommends that the Department of National Health and Welfare coordinate the development of education and awareness programs specifically directed toward the threat posed by AIDS to women. These programs must be designed to make both women and men more aware of the need and means for protecting women and their babies from HIV infection.

**RECOMMENDATION 18:**

The Committee recommends that the Department of National Health and Welfare work in cooperation with the provincial governments on the development and implementation of AIDS/HIV education and awareness programs directed to Canadian youth.

**RECOMMENDATION 19:**

The Committee recommends that the Department of National Health and Welfare, the Department of the Secretary of State, and the Department of Multiculturalism and Citizenship (once it is fully established) jointly coordinate the development of AIDS education and awareness materials in languages other than English and French for distribution to ethnocultural communities.

**RECOMMENDATION 20:**

The Committee recommends that the National Strategy include a comprehensive, coordinated federal-provincial AIDS education strategy. The Committee further recommends that the reconvened Federal/Provincial/Territorial Advisory Committee be asked to revive the subcommittee that was to have begun work on a National AIDS Education Strategy, as an additional mechanism to implement a coordinated approach to this critical element of a National Strategy.

**RECOMMENDATION 21:**

The Committee recommends that, in regard to AIDS education and awareness, the federal government give priority to acting as a source of funding and support

for groups such as the Canadian Public Health Association, and community-based groups which can mount targeted campaigns at their peers, over other elements of AIDS education such as national media campaigns.

RECOMMENDATION 22:

The Committee further recommends that the Department of National Health and Welfare ensure that adequate and, where appropriate, increased funding commitments are made to the Canadian Public Health Association and community-based organizations for the purpose of AIDS/HIV education and awareness programs, giving consideration to where the additional funding and other resources can most effectively be channeled.

## TREATMENT, CARE AND SUPPORT

RECOMMENDATION 23:

The Committee recommends that a National Treatment Registry of therapies for AIDS and HIV infection be established to collect and disseminate information to health-care professionals, persons with AIDS, and community-based support groups. The Committee urges that the Registry be established as soon as possible on a priority basis.

RECOMMENDATION 24:

The Committee recommends that the Minister of Health and Welfare confer with the provincial Ministers of Health on a common policy that would ensure the provision of all AIDS/HIV drugs free of charge, and which would apply whether the drugs were experimental or approved for general distribution.

RECOMMENDATION 25:

The Committee recommends that more funding be provided to community-based groups to support the tremendous amount of effective volunteer work that these groups do in providing care and support to persons with AIDS. The Committee recommends, in particular, that the federal government contribute to the financial resources available for hospices, palliative care facilities, and home care support of persons with AIDS, through increased funding of communitybased support groups.

**RECOMMENDATION 26:**

The Committee recommends that the federal government consider the provision of funding to national organizations of health care professionals for continuing-education programs on AIDS treatment, care and support.

## ACCESS TO NEW DRUGS

**RECOMMENDATION 27:**

The Committee recommends that the Department of National Health and Welfare study the concept of "catastrophic rights," which would recognize a right to choose treatments in life-threatening situations. The Committee further recommends that the Department publish a policy position on this concept as soon as possible, and in any event by 1 January 1991. The Committee acknowledges and supports the limited recognition of such rights that is implicit in recent developments in access to unapproved drugs, and recommends that such access be as wide as possible, consistent with the integrity of the approval process.

**RECOMMENDATION 28:**

The Committee further recommends that, in line with the limited recognition of catastrophic rights that is now implicit in the drug approval process, the Department of National Health and Welfare give consideration to the formal adoption of a system of conditional approvals for drugs designed to treat life-threatening illnesses, after basic safety and efficacy have been established, which would generally permit the prescribing of such drugs by physicians while further evaluations are being conducted.

**RECOMMENDATION 29:**

The Committee recommends that the Department of National Health and Welfare undertake a study of how to ensure the continued availability of volunteers for clinical trials of new drugs in the face of wider access to those drugs. This study should consider, among other things, the American "parallel track" experience.

**RECOMMENDATION 30:**

The Committee recommends that the Department of National Health and Welfare, through the Federal Centre

for AIDS, adopt a pro-active stand on encouraging pharmaceutical companies to make AIDS/HIV experimental drugs available in Canada, and consider the development of incentives to encourage their cooperation.

RECOMMENDATION 31:

The Committee recommends that the federal government immediately convene and coordinate a study of the liability of pharmaceutical companies and physicians in the matter of access to unapproved drugs, with a view to finding ways to limit this liability so as to encourage them to make such drugs available, while safeguarding the interests of those who receive the drugs.

## LEGAL, ETHICAL AND SOCIAL ISSUES

RECOMMENDATION 32:

The Committee recommends, in the strongest possible terms, that the federal government fulfill its commitment to add sexual orientation as a prohibited ground of discrimination under the Canadian Human Rights Act as soon as possible.

RECOMMENDATION 33:

The Committee recommends that the Federal Centre for AIDS consult with the Canadian Human Rights Commission and its provincial counterparts with respect to doing more to publicize the statutory protections and policies regarding discrimination based on AIDS and HIV infection and, where the protection exists, based on sexual orientation.

RECOMMENDATION 34:

The Committee recommends that all HIV-antibody testing be voluntary, except in cases of donations of blood, blood products, organs and tissue, and be accompanied by appropriate guarantees of confidentiality.

## INJECTION DRUG USERS AND NEEDLE EXCHANGE PROGRAMS

RECOMMENDATION 35:

The Committee endorses the current federal program, announced in August, 1989, for two-year pilot studies on programs for injection drug users, including needle

exchange programs, and recommends that evaluation of program results by the Department of National Health and Welfare be accorded top priority so that a decision can be made as soon as possible after the studies conclude on future programs for injection drug users.

RECOMMENDATION 36:

The Committee recommends that the Department of National Health and Welfare explore solutions to problems caused by the reluctance, or refusal, of some provincial governments to become involved in needle exchange programs, which frustrates the conclusion of federal-provincial shared-cost agreements in this important area.

## PRISONS

RECOMMENDATION 37:

The Committee strongly recommends that the Solicitor General begin as soon possible to implement the recommendations of NAC-AIDS, supported by the Minister of Health and Welfare, for the prevention of HIV transmission in prisons.

RECOMMENDATION 38:

The Committee recommends, in particular, that the Solicitor General take immediate steps to have bleach for needle decontamination purposes and condoms made available on a confidential basis to inmates of federal prisons.

RECOMMENDATION 39:

The Committee further recommends, in particular, that the Department of National Health and Welfare, in cooperation with the Correctional Service of Canada, immediately set up a pilot study, using unlinked seroprevalence survey techniques, and with appropriate ethical safeguards, to assess the level of HIV infection in federal prisons.

RECOMMENDATION 40:

The Committee recommends that the Department of National Health and Welfare provide more funding and encouragement to community groups so that they can take up the invitation of the Commissioner of the Correctional Service to mount AIDS education and awareness programs in federal prisons.

RECOMMENDATION 41:

The Committee recommends that the Department of the Solicitor General immediately undertake a study of the advantages of prison health care services being provided by outside agencies. The Committee endorses the view that the confidentiality of health care information involving inmates could be better protected by using outside agencies to provide such services.

## INTERNATIONAL OBLIGATIONS

RECOMMENDATION 42:

The Committee recommends that the federal government, through the Federal Centre for AIDS, make greater efforts to publicize the valuable work funded and supported by the Canadian International Development Agency and the International Development Research Centre in the international battle against AIDS and HIV infection.

RECOMMENDATION 43:

The Committee recommends that the federal government provide additional resources to Canadian non-governmental organizations so that they can participate actively in international forums and organizations and establish international AIDS development and exchange projects.

RECOMMENDATION 44:

The Committee recommends that the federal government participate in and encourage international collaboration on drug trials, drug access and treatment protocols, including the provision of resources to international data banks on treatment, research and educational programs and materials.

RECOMMENDATION 45:

The Committee recommends that the federal government instruct immigration officers not to prohibit the entry into Canada of visitors who have AIDS or are HIV-positive. The Committee further recommends that the federal government encourage other governments to rescind similar restrictions on international travel.

## FUNDING

**RECOMMENDATION 46:**

The Committee recommends, in the strongest terms possible, that the Minister of National Health and Welfare urgently undertake a review of the overall funding commitment of the federal government to the struggle against AIDS and HIV infection, with a view to increasing it to a level which is adequate to meet the increasing challenge which must be faced. The Committee further recommends that the federal government take immediate steps to increase substantially the funding available for the current Federal AIDS Program.

**RECOMMENDATION 47:**

The Committee recommends that the Department of National Health and Welfare begin immediately the development of program and funding proposals for the period after March 31, 1993, when the current Federal AIDS Program, including the Federal Centre for AIDS and other funding commitments, will expire.

**RECOMMENDATION 48:**

The Committee recommends, as a first step, that the core funding for the Canadian AIDS Society be indexed to inflation for the current fiscal year, so that funding for the current fiscal year will be at least equal to that for 1989-1990 in real dollar terms.

**RECOMMENDATION 49:**

The Committee has concluded that more core funding must be provided to community-based organizations. The Committee therefore recommends that the Department of National Health and Welfare ensure that increased funding commitments are made to the Canadian AIDS Society and other community-based AIDS organizations to enable them to carry out their ongoing responsibilities.

**RECOMMENDATION 50:**

The Committee recommends that the Department of National Health and Welfare expedite the development of multi-year funding agreements with the Canadian AIDS Society and other community-based AIDS organizations.

# APPENDIX

# STATEMENT CONCERNING CORRECTIONAL SETTINGS SUBMITTED TO NAC-AIDS BY ITS WORKING GROUP ON HIV INFECTION AND INJECTION DRUG USE APPROVED DECEMBER 14, 1989

The Working Group on HIV Infection and Injection Drug Use reaffirms its concern that no action has been taken in correctional institutions concerning the prevention of HIV transmission. The problem remains that:

a) A large proportion of injection drug users will temporarily spend time in prison and this opportunity for prevention is being neglected;

b) Some inmates who have been injection drug users before incarceration continue to share drug equipment;

c) In one medium security correctional institution for women, 50% of inmates were injection drug users and, of this group, 15% are now HIV seropositive;

d) Unprotected sexual activity on a consensual, quasi-consensual and non-consensual basis is occurring in Canadian prisons.

Therefore, we strongly advise the implementation of the following recommendations on urgent basis:

1) Measures must be taken immediately to improve education levels of inmates and correctional officers about HIV and risk reduction. This should include both orientation sessions for new inmates and officers as well as ongoing programs.

2) Inmates must be allowed confidential access to condoms.

3) The feasibility should be explored of increasing the availability of conjugal visits. In addition, environmental conditions in correctional institutions that are conducive to non-consensual sexual activity should be modified.

4) Inmates must have access to decontamination materials such as bleach to prevent transmission of such infections as Hepatitis B and HIV via tattooing equipment and needles/syringes as well as for use in cleaning up blood spills.

5) The feasibility should be explored of a programme, similar to those currently offered in prisons in some countries, of providing inmates with confidential access to clean needles and syringes without punishment for possession.

6) Further resources should be made available to provide adequate detoxification and maintenance programs for inmates addicted to narcotics.

7) Voluntary, confidential HIV testing and counselling should be freely available to all inmates.

8) Medical and psychosocial support services should be freely available to every HIV seropositive inmate. These services need to be in continuity with services on the outside where follow-up can be maintained following release from the correctional setting.

9) Isolation of inmates with HIV infection from the rest of the inmate population is not medically warranted.

10) Research is urgently required in order to assess the extent of both HIV infection and spread in correctional settings using unlinked seroprevalence and seroepidemiologic methodologies which protect prisoners' rights to confidentiality as research subjects. We urge the Federal Centre for AIDS to be pro-active in organizing collaborative efforts among researchers, funding agencies and evaluators on this issue.

We strongly urge the Minister of National Health and Welfare to discuss these principles with the Solicitor General who is responsible for the Correctional Service of Canada and to advocate for their implementation.