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**AIDS Policy in Canada**

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On June 28th, 1990, the Minister of National Health and Welfare announced a long-awaited National AIDS Strategy at a meeting of the Canadian Public Health Association. Since the first cases were diagnosed in 1982, over 2300 Canadians have died of AIDS, and 50,000 more are estimated to be infected with HIV. As in other countries, the story of AIDS policy in the years leading up to June 28th has been a conflictual one, in which fundamentally different models of how to deal with an epidemic have been pitted against one another. In some important respects, the federal government's new strategy signalled a shift of previously very traditional public health policy towards an approach much more compatible with the views expressed for years by AIDS community groups. The cautious compliments which came from groups normally antagonistic to government authorities contributed to a period of surprising calm, although the stillness could well have been akin to that which comes at the eye of a hurricane.

AIDS has been an agent of transformation in Canada. The political ethos and organization of gay communities across Canada, still the home of the vast majority of people with AIDS, have been radically altered and in many ways strengthened by the epidemic. School boards and politicians have been forced to deal with issues of discrimination and sexuality which they have never had to confront before. Public health bureaucracies, the medical research establishment, and the pharmaceutical industry have, for the first time, had to contend with a well-organized constituency learning quickly how to exert political leverage. Changes in the treatment of the disease, combined with well-organized pressure, have transformed the AIDS policy agenda to include legal, ethical, financial, and political issues far beyond the narrow policy agenda which first characterized most levels of government.

In a country as territorially vast and political decentralized as Canada, there have been considerable variations in the governmental response to AIDS and in community organizing. Local governments, and more especially provincial governments, have been extremely important players in AIDS policy development. Three cities have been especially affected by AIDS -- Montreal, Toronto, and Vancouver, and each has demonstrated distinctive characteristics both in patterns of community organizing and in municipal government response. Each of the three provinces most affected -- Quebec, Ontario, and British Columbia -- have health care systems organized in quite different ways from one another, and each is governed by quite different political parties.

Despite important differences between levels of government and across provincial boundaries, AIDS policy can be seen as developing through three distinct phases. The first period begins with the diagnoses of the first cases in the early 1980s. The second begins in mid-1985, when Rock Hudson's illness with AIDS was made public and greatly intensified public interest in the epidemic. The third begins in mid-1988, when the effigy of the then federal Health Minister was burned in a highly public incident. In characterizing each period, the following account looks first at community groups, which bore the first burdens of public education and caring for the sick and worried, and then examines policies and actions at three levels of government.

### **Canada's Health Care System**

The distribution of responsibilities for health-related activities in Canada has not only left the central government with a narrower jurisdictional realm than its counterpart in just about all other industrialized countries, but has infused actors at different levels with distinctive perspectives on health issues. The complexity of a decentralized system has also meant that community groups have had to operate on a number of very different fronts.

Canada has essentially twelve different health systems, one each for the ten provinces and two territories. Health care is primarily a provincial responsibility, with the provincial governments organizing the delivery of services, chartering and negotiating with various professional bodies to determine fee schedules, funding hospitals for capital expenditure and operating expenditures, and establishing regional and local public health networks.

The federal government plays an important role, however, through its spending power. On a number of occasions, and most notably through the 1960s, the federal government agreed to match provincial contributions to hospital and medical insurance providing their health delivery systems met a set of minimum criteria. The medicare system now available to all Canadians arose, in other words from federal inducement. The most recent imposition of federal stipulations on otherwise-provincially-managed systems was in 1984, when the federal government prohibited the provinces from allowing doctors to bill patients in excess of the provincially-established fee schedules.

The influence of federal spending is also evident in research funding. Most medical research in Canada is governmentally-funded, and the vast majority of grants come from the Medical Research Council, the Natural Sciences and Engineering Research Council of Canada, and the National Health Research and Development Programme (NHRDP), the latter administered by the federal ministry of Health and Welfare.

There are several areas of jurisdiction shared by provincial and federal governments. One which pertains to AIDS is the area of epidemiology and lab testing. Local and provincial officials collect data on various diseases and patient conditions, and in offering testing facilities for physicians and hospitals. The most important federal institution is the Laboratory Centre for Disease Control, located within the Health Protection Branch of the ministry of Health and Welfare. The LCDC acts as an "expert of last resort" if provincial laboratories have difficulty identifying diseases or interpreting test results. It also develops and tests new identification procedures and functions as a training site for scientists and technicians learning those new procedures.

Another area of joint jurisdiction concerns drugs. The federal government's Drug Directorate, also located within the Health Protection Branch, is solely responsible for the testing, approving, and regulating of new drugs, and it covers the cost of those drugs while they are in the experimental phase. (Important for the AIDS story is the fact that the federal government also has an Emergency Drug Release Programme intended for the release of medications which do not have enough demand for pharmaceutical companies to seek approval for regular marketing.) Once a drug is approved in Canada, though, the separate provinces are responsible for determining to what extent the cost of the drug will be covered by public funds. Some provinces, for example, require that patients under 65 pay for drugs used outside of hospitals, unless their income falls below a certain level; most provinces differentiate between drugs they will pay for under particular circumstances, and those they won't.

The supply of blood products is also jointly regulated by federal and provincial governments. In 1981, the Canadian Blood Committee was established within the Health Services and Promotion Branch of the federal ministry of Health and Welfare, to coordinate provincial funding of the Canadian Red Cross, which collects virtually all of the country's blood supply from volunteer donors, and which is responsible for screening that blood.

Despite federal influences, there is considerable variation in how provinces organize health care systems, the most dramatic variation occurring in Quebec. Diversity results partly from the fact that federal funding has been geared toward the

delivery of health care services by physicians and hospitals. The advent of alternative approaches to delivery through para-professionals, outpatient and free-standing clinics, hospices, and the like was generally not included. Underwriting the costs of these elaborations generally fell to provincial authorities, with corresponding variegation in extent and style.

In Ontario, the provincial Ministry of Health enters into direct negotiations with hospitals and other health-related institutions to determine their budgetary allocations. The province also funds Health Units across the province, over which District Health Councils have some monitoring role. Such bodies have volunteer boards made up of professionals and representatives of the general public, and although they have no regulatory control over health care institutions in their area, they are intended to assist provincial officials in planning and coordinating policy. Larger municipalities have Boards of Health, reporting to city councils, and they have stronger powers. In all parts of the province, responsibility for monitoring public health is delegated to Medical Officers of Health, who lead local departments of health or health units. They monitor the outbreak of disease, and if "reportable," they collect data from hospitals and physicians and transmit it to the province's Chief Medical Officer of Health.

The British Columbia System is broadly similar, although more centralized in the provincial Health Ministry. There are fewer provisions for even formal citizen representation on health councils or boards, although municipalities do have some leeway in developing health-related programs. Medical Officers of Health, at least in the major cities, are responsible to both their municipal councils and the provincial government, and can be removed by order of the cabinet.

Quebec's system is in some respects much more decentralized. The province is divided into thirty-two Departments of Community Health (Departments de Sante Communautaire -- DSC), each of them attached to a specially-designated hospital. Much of the policy development which in other provincial jurisdictions would take place within health ministries is decentralized to the level of DSCs. So too is the policy and administrative work delegated in other provinces to local governments. As a result, the municipal government in Montreal has virtually no role to play in the AIDS story. The health care system is also more decentralized in its delivery of services than other province's systems. There are 150 local community health centres (Centres Locales de Sante Communautaire -- CLSC) across the province offering a number of the services delivered by hospitals in other parts of Canada. The DSC's have an advisory relationship to the CLSCs, although the lack of formal authority relationship between them adds to the fragmentary character of the overall system.

There is, then, a highly variegated pattern of branches and divisions of various levels of government with a role to play in health policies relating to AIDS, quite apart from the departments and agencies responsible for issues related to discrimination, housing, social services. The positioning of these administrative units has had important consequences for the kinds of policies developed at the federal, provincial, and local levels, and the medical or public health models they have reflected.

### **June 1981 - June 1985: Bureaucratic Routines; Community Mobilizing**

In 1979, the first Canadian known in retrospect to have had AIDS died, his illness neither labelled nor understood. Four more died the following year, their symptoms still not understood. In 1981, the year that the Centres for Disease Control in Atlanta reported on the occurrence of rare forms of cancer in gay men, six more Canadians died of what came to be known as AIDS. By the end of June 1985, 390 cases of AIDS had been diagnosed, and 92% of them resulted in death. Even more ominous

was the fact that the number of cases had started to double every six months, a trend that mirrored the early epidemiology in the U.S..

During the first four years of the epidemic, public awareness of it increased only gradually; even amidst the gay segment of that public awareness of a the disease posing a threat to Canadians became widespread only after the first couple of years. Apart from routine epidemiological work by the LCDC in Ottawa, and isolated though generally routine interventions by local health authorities, government activity in the face of AIDS was modest and extremely low in profile. It was gay-dominated community groups which first confronted the challenge of educating the public and helping the afflicted, often completely unaided by governments. There were certainly officials and politicians who were hearing stories about how serious the epidemic could become, but most of them avoided pressing the boundaries of the standard operating procedure for disease.

## Community Groups

As long as the AIDS epidemic seemed so shrouded in unknowns, and seemed largely concentrated in the U.S., gay and lesbian community response was uncertain and uneven. By 1983, Canadian incidence rates were climbing, and preventive measures were being clarified, and AIDS community groups emerged in the country's three largest cities. By the end of this period, the increased demands on their services were imposing huge burdens which strained the volunteer bases of the organizations. The low key character of governmental response in almost all jurisdictions eventually produced considerable anger within these community groups, and set the germs for a pattern of conflict between community groups and government agencies that was to dominate the next period.

The first American reports of "gay cancer" in July 1981 had little media impact in Canada, even in the lesbian and gay public. The September issue of The Body Politic, Canada's major gay magazine at the time, contained the publications first article on the subject, critical of what was seen as distortions linking the spread of Kaposi's Sarcoma to homosexual activity. In a more substantial article in the next issue, two medically-trained contributors to the magazine acknowledged that gay men seemed especially vulnerable to this disease, but warned that the linkage to multiple sexual partners could be much less rooted in scientific evidence than in conservative morality.

Those fears were not without foundation. In 1977, local police raided gay bathhouses and bars in Ottawa, Montreal, and Toronto. The Toronto police struck again in 1981, arresting and charging over 300 men for bawdy house offenses. The Body Politic itself was in the midst of protracted litigation over obscenity charges levelled by the Ontario Attorney-General's Department. In Canada, as was the case elsewhere, the gay political agenda had sexual liberation at its centre and was being regularly confronted by attacks from state authority. For gay leaders in Canada to perceive political and press interpretations of this new disease as morally driven was not surprising.

By mid-1982, gay community reaction seemed to attach more significance to the threat posed by AIDS. Still, the disease had low enough Canadian incidence that there were few calls for increased government action. That changed somewhat by the end of the summer, at which time five cases had been recorded by Ottawa's LCDC. In early 1983, there were still some gay political voices resisting or downplaying suggestions that AIDS ought to change sexual practices, and, for example, dismissing calls for increased protection of the blood supply. But enough men and women now knew of the seriousness of the epidemic in the U.S. and sensed the danger to

Canadians that community groups began forming around the issue.

The Quebec AIDS Committee (Comite SIDA du Quebec) had in fact formed in the fall of 1982, but it was composed primarily of medical professionals. It was augmented by representatives of the local gay and Haitian community, the latter included because of the high incidence of AIDS among Quebecers of Haitian descent, but the group never had a high profile. In February 1983, AIDS Vancouver became the first community group in Canada to mobilize significant volunteer energies around the crisis, in part because that city had the highest per capita incidence of AIDS. In April of the same year, a meeting in the heart of Toronto's gay "ghetto" led to the establishment of the AIDS Committee of Toronto (ACT), which began using \$62,000 in government job-creation grants to employ half a dozen staff. (ACT soon became the best off of the AIDS community groups, its annual income jumping from just over \$90,000 in the 1983-84 fiscal year to over a quarter million dollars in the next. Part of its growth came from high profile fund raising in the community, but part came from grants coming not only from the federal government, but the provincial government as well.)

By August 1983, the Canadian press were giving the epidemic more substantial coverage, with headlines such as "AIDS: Deadly Mystery Threatens Canada," and researchers were warning of a potential crisis.<sup>1</sup> The first Canadian seriously ill with AIDS had gone public by then, and the mainstream press began to give the epidemic a compassionate face. Peter Evans, of Ottawa, talked about dispelling the myths around AIDS, indicating that with his immune system as damaged as it was, other people were more of a danger to him than he was to them.<sup>2</sup> Until then, Canadian press coverage was often guilty of distortion in the coverage of the epidemic, but most large-city dailies were beginning to incorporate a sympathetic human face into their coverage as the location of stories shifted from the U.S. to the home front.

The Vancouver and Montreal groups began to offer counselling and referral services to those who were sick, as well as to the worried well -- in these early stages overwhelmingly gay male. Safe sex print materials and awareness programs were soon to develop, often taking advantage of the gay bars in the downtown cores of the two cities. In the early years, the leadership of AIDS groups was often provided by gay professionals in the health care fields, but the paid staff starting to grow during this time, especially in Toronto, sometimes came from backgrounds that entailed extensive gay activist experience.

In some communities, the burdens of providing supports for people with AIDS were overwhelming. AIDS clinics were slow to develop, and those who feared illness or who were sick often needed referrals to doctors who knew about the disease; gay men who were sick often wanted to know which doctors were gay positive. The counselling needs entailed in becoming infected and sick were enormous, not least because the stigma associated with AIDS often risked jobs, friendships, and family supports. In most cities and towns, gay men seeking counselling expected little support and sympathy from groups and services outside the gay community itself, and AIDS groups with paltry funding had to struggle to keep up with the demand.

There was growing concern among AIDS workers in the gay community that the disease would provoke widespread discrimination and oppression. In such cities as Toronto and Montreal, there was widespread suspicion that state authorities were determined to roll back what few gay liberation gains had been won since the early 1970s, this suspicion grounded in the reality of police raids and criminal prosecutions. This wariness of state authority and fear about popular homophobia raised the profile of human rights issues in the fight against AIDS, one of several concerns which brought community groups into head-on collision with the officials in charge of governmental

response, particularly at the federal and provincial level.

These concerns were not always at the forefront of AIDS community work. The size of the gay community in Toronto, the substantial amount of gay organizing in the recent past, and the relatively cordial relations between segments of the organized community, created more potential in that city's AIDS organizing for dovetailing services for people with AIDS on the one hand, and the development of a critical agenda on the other, although in the early days even the AIDS Committee of Toronto seemed preoccupied with an image of respectability which tempered its criticisms of public authorities. In AIDS Vancouver, too, there was increasing concern about political issues beyond public education and the provision of services to people with AIDS. As with ACT, political issues and anti-government critiques were more likely to come from paid staff than from members of the board, but in the Vancouver case, there was more concerted resistance to that kind of political agenda among directors.

Even from this early period, the Montreal case had distinctive features. The Montreal Gay Association's committee on AIDS (the Montreal AIDS Resource Committee -- MARC-ARMS) was formed a year later than the Toronto and Vancouver equivalents, and led mostly by members of the city's anglophone minority. A few of its founders, like a number of the staff at ACT and a few at AIDS Vancouver, had years of experience in gay activist politics, but they did not have the widespread connections and constituency base that the other groups had. The increased coverage given to AIDS in North America's English-language press, both gay and mainstream, had to fully penetrated to the Quebecois gay population, most of which seemed to believe that AIDS was a risk only to those who travelled frequently to the U.S.. Particularly among the city's gay francophones, there seemed to be a general political complacency, and a low level of awareness of AIDS issues remained through this period.

By the end of February 1985, the total number of cases in Canada had reached 183, 148 of them gay. The gay press across the country seemed more and more filled by stories about men in Canada and the U.S. living with sickness and confronting the likelihood of death. Community groups now included the Edmonton AIDS Network, the Halifax Gay Health Association, in addition to the older groups in Toronto, Vancouver, and Montreal. Most were growing rapidly and straining under the burdens imposed upon them.

## **Local Governments**

Local governments in Toronto and Vancouver might well have been expected to respond early to the epidemic emerging in their midst, and in Toronto certainly there were some policy developments. But in general, during this first period funding levels provided for AIDS-related activities were modest, and were generally kept low profile, out of the political limelight, and well within established administrative routines. At the beginning, there seemed only modest recognition that AIDS required any approaches different from those used for other public health issues.

By June of 1983, there were fifteen cases of ARC and eight of AIDS in Toronto, and Toronto's public health officials began taking the epidemic seriously. By June, the Department of Public Health delivered its first report on the disease to the local Board of Health, suggesting a program that included a public education component, one which would inform the gay population about ways of avoiding infection, and the and one which would attempt to allay fears among health care workers and in the rest of the general public. The program envisaged close collaboration with a community health clinic with established credentials in the gay community -- the Hassle Free Clinic -- securing its important role in education and diagnoses. The city's coordinator of

community health information made it clear that the education campaign would emphasize that AIDS was not caught easily, since it required intimate contact and the exchange of body fluids. Departmental representatives made a point of making themselves available to the media, helping to increase the factual accuracy of media reporting. But the program still had only a paltry budget of about \$10,000, and even though substantial staff time in addition to that was being devoted to AIDS, the local Medical Officer of Health seemed wary of allowing AIDS to suck up too many of his department's resources.

By 1985, the sheer demands of AIDS work were taking up well over \$100,000 in the City's Public Health Department staff time. In mid-year, the metropolitan level of local government in Toronto gave the AIDS Committee of Toronto \$40,000 in emergency funding, though the upper tier municipal government was generally not nearly as engaged in AIDS-related work as the city government. Vancouver's city council had become the first major local government to provide funding for a community group, giving AIDS Vancouver \$50,000 in June. This was one of the first instances of local governments recognizing the need to go beyond normal procedures, the pressure in the Vancouver case being increased by the unwillingness of the provincial government to assist.

### **Provincial Governments**

Despite their central role in health, the provincial governments generally side-stepped the AIDS issue in this first period, Ontario having the only health ministry to move significantly into program development. Although British Columbia was the first province to make AIDS a "reportable" disease (followed soon by Alberta and Ontario), the Social Credit government undertook no other measures. By mid-1983, the provincial health ministry had said nothing in recognition of the seriousness of the problem, and in the words of one specialized medical practitioner at the time, "It's pretty hopeless with the present minister." (TBP, July-August 1983, p. 12).

The Quebec government, too, did little. It was the first province to establish an AIDS advisory committee, which it did in 1982, but little in the way of special programs emerged. There was a strong predisposition to believe that the decentralized health care apparatus was perfectly poised to deal with just about any health care issue, and there was no readiness to believe that AIDS was sufficiently unusual to warrant fine tuning of that system.

Ontario's Conservative government established a Provincial Advisory Committee on AIDS in July 1983. The Advisory Committee, though, was composed exclusively of medical professionals, and it did little to raise the public profile of the disease or to take measures to contain it through public education, being more preoccupied with physician-related referral services. The province established a \$500,000 research fund in July, but by the fall that seemed a very modest sum indeed. A major research project being put together at the University of Toronto was asking for \$2 million, and its principal investigator was expressing frustration at the modesty of Canadian funds available for research.

### **National Developments**

The first sign of activity at the federal level was in the LCDC, in which three or four staff members began committing a part of their time to establishing a system of national surveillance for AIDS in late 1981 and early 1982. In May of 1983, the federally-appointed Ad Hoc Task Force on AIDS held its first meeting, as an advisory



committee reporting to the LCDC, but it was given permanent status only in August, and renamed the National Advisory Committee on AIDS (NAC-AIDS). Even then, it was to meet only three of our times a year, and maintained a low profile in its early years. It was composed mostly of medical clinicians and researchers, without representation from public health spokespeople or representatives from high risk groups. More money was being made available for research during 1983, the Health and Welfare department's research commitment during the fiscal year starting in April amounting to \$300,000. (By then, one important research project on gay men was under way in Vancouver, and another focusing on haemophiliacs was undertaken in Montreal.) In general, however, the small federal "policy network" that developed around AIDS was dominated by physician-trained epidemiologists and medical researchers -- people who believed that the only really important work to be done, until the specific micro-biological facts were known, was in tracing the spread of the disease. There seemed no conception that there were issues in public education which needed thinking and funding.

In February of 1984, the federal Health Minister (Liberal Monique Begin) announced a \$1.5 million addition to her ministry's funds to investigate and trace AIDS, this in addition to a half-million dollar grant from the Medical Research Council to a Montreal-based research project in haemophiliacs. But this was to be spread over four years, a paltry commitment. Some research funding came from the National Health Research and Development Programme within the Ministry of Health, but there was no perceived need even among health officials to expand that programme's funding. In the 1983-84 year, \$250,000 was made available, a figure which may appear small but was, in the view of one official, "all that the market would bear." Only twelve research proposals were submitted to the program during that period, and eight were approved. Researchers across the country still seemed unsure whether the field was a fruitful one to enter, many of them seeing it as risky. That perception may have been partially rooted in fear of being identified with a gay-related issue, but hesitations were no doubt reinforced by the slowness of federal granting agencies to entice research with major funding programs.

In the spring, when the viral agent responsible for AIDS was identified, microbiologists working with and for the LCDC in Ottawa became more actively engaged in AIDS related work, developing procedures for testing for the presence of the virus, but then as before, the agenda being set within the Health Ministry was being set by medically-trained researchers and practitioners with a relatively narrow vision. At a time when there were 3000 reported cases of AIDS in the U.S., when the growth pattern in Canada was mirroring the American with only a few years delay, and when public misconceptions of transmission were disturbingly evident, the director of the LCDC, Dr. Alistair Clayton, was trumpeting the fact that a fact sheet on AIDS was being prepared for health care professionals and the public, with projections of a mere 250,000 being distributed across Canada.

Through the first half 1985, to a large extent though to the autumn, the eerie silence and relative inactivity of most public authorities continued, and for much of the year press attention waned. An official in the Health Protection Branch of the federal Ministry of Health and Welfare described the National Advisory Committee as meeting "periodically" and portrayed the scientific work of the LCDC as "percolating along." By then, he said, they knew a lot about how the disease was transmitted -- through sexual activity and blood transfer, and they were moving towards more elaborate testing procedures, for example, to screen blood. There was a modest recognition that there were "social" issues raised by the disease, but little policy attention devoted to it within an administrative apparatus preoccupied with tracing, with regulatory control, and with

biomedical research.

There was a small exception to this trend, which emerged in mid-year. AIDS Vancouver became the first community group to receive funding from the federal government, through the Health Promotion Branch of the Ministry of Health and Welfare. This was a part of the Health bureaucracy quite different in its culture and its priorities from the Health Protection Branch. There was more preoccupation with public health here, and more preparedness to raise critical questions about traditional public health models. There was a system of regional offices and a culture which made some allowances, though still modest ones, for recognizing the role of community groups in public education. The decision to grant \$150,000 was helped by the relatively progressive attitude of officials in the Vancouver regional office of Health Promotion, and also by Pat Carney, an influential Conservative cabinet minister who represented a riding with a substantial gay population, and had herself more forward-looking ideas on gay-related issues than most of her colleagues. The Health Minister at the time, Jake Epp, was still disinclined to show any interest in the issue, though, so for a time the AIDS Vancouver grant stood in isolation.

## **Assessments**

Here were the germs of striking polarization. Most of the public officials engaged in AIDS-related policy making and service delivery systems were operating from a very narrow vision of appropriate governmental response, often a vision lodged within a traditional medical model of how to respond to disease. At the federal level the agenda was being set up officials within the LCDC, itself lodged within one of the most traditional branches of the federal Health Ministry -- the Health Services and Protection Branch. This was a part of the Ministry most retentive of the coercive regulatory patterns developed in response to epidemics in the nineteenth century, and the few officials charged with responding to AIDS seemed to see absolutely no need for changes in well-established structures and routines. The disease seemed to them to be manageable within the operating procedures already in place. Most officials, at all three levels of government, believed that it was appropriate and advisable to keep the response to this disease out of "politics." There was little pressure on ministers at the federal and provincial level or city councils and boards of health at the municipal level to change fundamentally either the level of funding given to health authorities or the management and delivery systems being used to handle AIDS.

Within a few of the community groups bearing most of the burdens in responding to the crisis, on the other hand, there was a quite different view. Although there were still many gay men who were complacent about the epidemic, those who were working with AIDS community groups often knew people who were sick, either in Canada or in the U.S.. They were all too familiar with what was happening in New York and San Francisco through personal contacts and reading gay press. They were generally concerned to avoid panic, but they were intensely aware that insufficient attention was being devoted to the epidemic by their own communities, and more notably by government officials. Here there was a preoccupation with educating the public, and in particular targeting gay men with safe sex information. The campaigns being developed for gay men were calling for some change in sexual practices, but resisting the moralistic revival of monogamy or abstinence that so often seemed to surface in mainstream commentaries about avoiding infection.

In May, the first national conference on AIDS was held at Montreal, organized by a number of Montreal groups and institutions, and financially supported by the National Advisory Committee. It brought together AIDS community workers from across

the country, and resulted in the formation of the Canadian AIDS Society -- a national coalition of AIDS support groups designed to lobby the federal government for more funding and public education. There was lots of criticism of government inaction, although Dennis Altman, speaking to the conference on the basis of considerable experience in the U.S. and Australia, was struck by the "politeness" of Canadian community group representatives. "It strikes me as an outsider that you could do with a lot more anger. We have a right to be angry."<sup>3</sup>

### July 1985 - June 1988: Conflict and Ad Hoc Response

The July 25th announcement that Rock Hudson had AIDS escalated media coverage and intensified public attention as much in Canada as in the U.S.. Although Rock Hudson's homosexuality became publicly known in the next couple of months, the first word of his illness instantly increased fears that the disease would spread beyond the existing high risk groups. By August, when the major American news magazines and Canada's largest equivalent were headlining AIDS and Hudson stories, the disease was being characterized as "the number one health menace."<sup>4</sup> A Globe and Mail editorial on August 17th commented in the following terms:

The public's awareness of Acquired Immune Deficiency Syndrome (AIDS) increased following actor Rock Hudson's dramatic disclosure that he, like thousands of people around the world, had contracted the disease. People who had no contact with AIDS sufferers saw the virus attacking a man they had "known" for years, and were startled by its visible wasting effects. The publicity hasn't been a uniform blessing -- fears are such that the Los Angeles City Council felt compelled to pass an ordinance banning discrimination in restaurants, housing and employment against people with AIDS -- but it has made the public realize that it can't dismiss the syndrome as somebody else's problem.

Not long into the autumn, newspaper stories began carrying word of increased scientific concern about the spread of AIDS into the heterosexual population.

As of July 4th, the LCDC recorded an accumulated total of 248 AIDS cases in Canada, up from 97 cases one year previous. Of the total, 102 cases were in Ontario, 84 in Quebec, and 45 in BC; overall, 76% were gay or bisexual. Exactly three years late, in early July 1988, there were 1809 cases in Canada, of which 713 were in Ontario, 529 in Quebec, and 368 in BC. Between 80% and 83% were gay or bisexual.<sup>5</sup> There was, in other words, a seven-fold increase during this period, with the geographic and "risk" activity profile remaining strikingly stable.

It was during this period that a number of governments at all three levels of jurisdiction made their first major commitments to policy development and funding. This was also a period of dramatic community group growth and diversification, in the midst of which emerged strong radical gay voices prepared to confront the inadequacy of government action with harsher words than ever and more militant tactics. The range of issues over which conflict appeared broadened considerably, such that by mid-1988 all of the issues now being debated were on the table, including anti-pwa and anti-gay discrimination, HIV testing procedures and controls, drug testing and releasing, community group funding, public education priorities, styles of medical care, and methods of public health regulation. In some respects, the battle lines already drawn up between the traditional medical and epidemiological establishment on the one hand, and gay-dominated AIDS community groups on the other were hardened, but during the 1985-88 period, a number of public officials and agencies emerged into a reformist "public health" middle ground, prepared to recognize the legitimacy of community

groups and the vital significance of high profile public education programs. Just as the community group network dealing with these issues was diversifying, at times with open conflict between groups having distinct political priorities, so to the governmental actors with a stake in AIDS diversified, and at times conflicted with one another.

## Community Groups

Through the 1985-88 period, community groups continued to bear the brunt of the burden in responding to AIDS, and to the extent that governments involved themselves, the agenda was considerably influenced by community group pressure. In mid-1985, groups dealing with AIDS existed in a number of Canadian cities, often containing medical practitioners or researchers who were either gay themselves or had large gay practises. In the larger cities, the backbone of these groups came from gay men and lesbian volunteers. Some of them, although not usually a majority at this stage, came to AIDS work with substantial experience in highly-politicized gay activism. Although the gay dominance of AIDS organizations often gave community groups a critical perspective on the responses of governments and epidemiologists to the spreading epidemic, particularly in Toronto and Montreal, many of the people in leadership positions were reluctant to voice that criticism too loudly or angrily. There was an emphasis, partly born of necessity, to provide service to those affected by AIDS, a concern to build the factual base so that anxious questions could be addressed competently and calmly. There was also an interest in appearing respectable in order to lure government policy makers and funding agencies on side. But as the issues being raised in AIDS debates broadened, more radical voices emerged from within the community group network, widening the gap between community group representatives on one side and the policy makers informed by traditional medical and epidemiological perspectives on the other. The strength of community groups overall was increased during this period by an expanding volunteer base, still largely within gay and lesbian communities, and by increased government funding contributions.

### Toronto

Throughout the period from 1985 and 1988, Toronto community organizing was in a much healthier state than community organizing anywhere else. Toronto had the largest number of people with AIDS, and the AIDS Committee of Toronto remained by far the largest AIDS community group in Canada, offering counselling services, public education programs, and political advocacy. In 1985-86, its budget was \$428,000, almost twice the year before, and almost five times the year before that. Government grants accounted for almost two thirds of the total, (the province accounted for 50%, the City of Toronto 25%, and the rest from the metropolitan government of the Toronto area, and from the federal government. There were now several paid staff, most of them experienced in or knowledgeable about the previous years of activist organizing by gays and lesbians against attacks on it by the police and censors.

The enormous workload imposed upon ACT by the dramatic increase in public concern about AIDS added to the frustration and anger felt by a number of its staff and volunteers. By 1986, disagreements over priorities began to emerge. Although the Board of Directors had always been ready to criticize governments for downplaying AIDS, and had some highly-politicized members, several Directors were cautious professionals who sought to uphold ACT's "respectable" image. This occasionally produced some estrangement from segments of the gay community politicized and

radicalized by attacks on it in the recent past. As the strains increased, a number of directors most uneasy about a more politicized direction left ACT to set up the Toronto AIDS Drop-In Centre, although it never rivalled the parent organization in size and public profile. The shuffling of Board members and the enlargement of a paid staff - with quite elaborate connections through the city's gay community - secured ACT's importance in AIDS organizing and tempered criticism levelled against it. In this way, Toronto groups avoided the sort of dissension in AIDS organizing which seemed to be growing in Vancouver and Montreal.

By 1988, ACT's budget was close to three quarters of a million dollars, and although it remained the dominant AIDS community group in Toronto, it was no longer the only game in town. The PWA Coalition was formed in early 1987. Operating first out of a basement, and then an apartment, its focus was the provision of services and financial assistance to people who had contracted AIDS. The group became well known within a short time. The burdens placed on it were enormous and discontent soon emerged about the group's inability to meet the demands of PWA's. The result was a reconstitution of its leadership later that year, and a renaming to PWA Foundation. However, internal dissension remained through 1988, in large part a function of the paucity of funds. The group as a whole, though, remained in contact with ACT, and decided from the outset not to duplicate services. The Foundation was not engaged in public education, or very much in advocacy, but focused instead on offering financial assistance to PWAs and helping them to get back into the world. Its relatively apolitical stance did not create unusual tension with other groups in the city, apart from the generalized anger often experienced by PWAs in the first stages of coping with the disease. When PWAs would go to the Foundation -- and they would often go there first -- staffers would often plug them into relevant ACT services.

Casey House, a twelve-bed hospice for AIDS patients opened in October 1987, was another part of its AIDS network which developed during this period. Initial discussions about setting up such an institution began with a subcommittee of ACT and writer June Callwood. A massive fundraising campaign was launched both within the gay community and the more fashionable "Rosedale" set, a campaign that substantially increased the respectability of AIDS-related work and care. The province made substantial funds available for the purchase and renovation of the house, and committed \$2.3 million a year in operating grants. It was a gold-plated pilot project for the government, and signalled a major increase in provincial commitment to the fight against AIDS, although in the view of some policy makers outside Toronto, it was such an expensive facility that it could never serve as a model for anywhere else.

The Safe Sex Corps (later the Safe Sex Project) was founded by the Toronto-based Canadian Organization for the Rights of Prostitutes to mount educational and prevention programs among female and male prostitutes in the city. Initial funding came from the AIDS Committee of Toronto, although eventually, in mid-1988, the city provided additional funding, followed by money from the province. From the beginning, the project was supported by and remained in touch with the gay-dominated AIDS community groups.

The last major organization to emerge during this period was Aids Action Now! Drawing on an enormous reservoir of activist energy and anger about political inaction, Aids Action Now! added a militant political wing to the community group constellation in Toronto. The group, which first started meeting in late 1987, was most angry about treatment issues, believing that the medical and public health establishments were concerned only with the not-yet-infected. They raised concerns about the difficulty or impossibility of obtaining new promising treatments for AIDS, the narrow and exploitive methodologies used in drug experimentation, and the inadequacy of patient care in

Toronto hospitals. The group quickly grew in size and sophistication, and soon began high-profile demonstrations against government representatives.

From the beginning, the relationship between AAN! and other AIDS groups in Toronto was a cordial one. Certainly there was some impatience with ACT and PWA for their caution in joining or sponsoring demonstrations, but generally speaking, there was a recognition on both sides that each group had a distinct and mutually-complementary role to play. The anger in tone and militancy in tactics employed by AAN! added weight to ACT's lobbying for greater funding for AIDS work, and encouraged those in ACT who sought for that organization a higher profile political role. AAN!'s tactics, in fact, increased the perception among some provincial and local policy makers that ACT had to be dealt with as a legitimate representative of AIDS community interests. Even though ACT itself had moved towards a more activist stance, it was seen as moderate in comparison to the new kids on the block.

### Vancouver

Community group organizing followed quite a different, and more difficult, path in Vancouver. As in Toronto, the burdens placed on groups increased many-fold during the 1985-88 period, but in Vancouver, government funding did not increase correspondingly. AIDS Vancouver was the first community group in Canada to receive federal funding, a mid-1985 grant of \$150,000 coming largely as a result of the group's early formation and of its influence of the local Conservative MP, Pat Carney. The group also received local funding, starting with a 1985 grant of \$50,000. But this group and others formed during this period suffered from the resistance of the provincial government to community group funding, and the low level of local funding. As in Toronto, a PWA group formed, but at its base there was more substantial discontent about the work of AIDS Vancouver than was felt by Toronto PWAs about ACT. Vancouver's oldest community group suffered from organizational weakness as well as from a political moderation and caution which separated it from much of the city's activist gay community.

Through this period, the group still offered a range of services to a large number of the sick and worried. In 1987, its Housing Committee launched McLaren House, a geared-to-income five-bedroom home for people with AIDS. The group developed well organized counselling systems, home care worker networks, and speakers lists. When the province finally launched an AIDS education campaign, in early 1988, requests for speakers increased six-fold. Most of its publications were aimed at gay men, although it also worked on materials for street youth, prostitutes, and heterosexuals.

AIDS Vancouver was always more cautious than its Toronto counterpart. Vancouver's gay community had certainly faced a homophobic right wing provincial government in recent years, but they did not have the scale or police and censor attacks experienced by their counterparts in Toronto and Montreal. The people who went into AIDS community work, then, were not as often formed by gay activist experience of the sort which would engender political anger. Gay organizing, too, had not been sufficiently intense in earlier years to develop the networks of connections which have so marked gay organizing in Toronto. Added to that perennial underfunding, and AIDS Vancouver became even more nervous about giving offense to actual or potential funders than the early boards of ACT in Toronto. The caution of the group's board of directors extended to prohibiting the executive director from public criticism of governments and from organizing an AIDS Vancouver presence in the city's annual gay pride festival. Tension and disarray peaked in 1987, and the next year was consumed by tortuous re-organization. A great deal of gay community trust was lost in the process, though by 1988 there were signs of the group re-gaining some of its

footing.

Canada's first PWA Coalition formed in Vancouver, and from the outset its relations with AIDS Vancouver were not as cordial as those in Toronto. It was a much more political group than the PWA Foundation in Toronto, and more likely to be critical of AIDS Vancouver for not being political enough. Despite that, it was the first Canadian PWA group to receive funding, getting \$27,000 from the federal government in 1986-87 and another \$38,000 the following year. PWA has been active in exploring alternative and experimental treatments for AIDS, raising at a relatively early stage some of the issues raised by Aids Action Now! in Toronto. Two activists from PWA met the Health Minister in mid-1986 to press him to authorize the release of experimental drugs on compassionate grounds, and it was largely as a result of pressure from the Vancouver PWA Coalition in the fall of that year that AZT was released.

### Montreal

The political divisions within and between Montreal's community groups were even more severe than in Vancouver. Montreal's largest AIDS community group -- the Comite SIDA Aide Montreal (C-SAM) -- was founded in September 1985 and soon replaced MARC-ARMS as the most prominent AIDS community group in the city. C-SAM received its first grants in the fall of 1986, the largest from the Health Promotion Branch of National Health and Welfare, and a modest grant from the provincial treasury. Its 1986-87 budget was \$170,000, less than half ACT's budget in Toronto. By the 1987-88 fiscal year, it received \$150,000 from Ottawa, \$100,000 from the province, and office space from the City of Montreal. By then, it coordinated the work of close to 200 volunteers, and had a staff of five. However, financial hardship contributed to internal dissension which was exacerbated by French-English tensions and by the relative weakness of gay political networks prior to AIDS organizing.

As had been true from the beginning, a disproportionate amount of the leadership for AIDS organizing came from anglophone gays, but most of C-SAM's services were in French. An English-speaking faction broke away partially for that reason, forming AIDS Community Care Montreal in 1987, which remained a quite small group. Another split resulted in the formation of the Montreal PWA Coalition in late 1987 - a reaction to long ideological debates with C-SAM over whether PWAs were simply the recipients of services or full-fledged members with rights. The group developed a political mandate more similar to its Vancouver than its Toronto counterpart, though it did not get the government funding that both of those groups received during this period. Relations with the parent group, with which the PWA Coalition retained formal ties, remained tense for a considerable time. A certain amount of resentment arose, as well, from C-SAM's tendency to attempt serving all needs for all affected populations. In trying to do as much as it did, the group developed only limited services in any one area, and only limited expertise. And in part because of a fear that the emergence of any other AIDS community group would jeopardize its already limited government funding, C-SAM also became defensive of its turf, reluctant to offer any assistance to fledgling groups.

A substantial number of the Montrealers affected by AIDS were Haitian. The Group Haitien pour la Prevention du SIDA was formed by two nurses in 1985, and grew to become an umbrella group for a number of associations and agencies (Groupe Haitien pour la Prevention du SIDA). It received its first federal grant in mid-1987 -- a two-year grant of \$132,000 from the federal Health and Welfare Ministry -- and its first provincial grant -- \$40,000. There was little in the way of systematic dissension between groups formed to cope with the disease in that population. However, there

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was little familiarity and great cultural distance between the Italian and gay networks. Group Haitian does work with C-SAM, but with a quite different set of challenges and dilemmas, and "cultural" understandings.

### Establishing a National Network

Whatever the weaknesses in AIDS organizing in Vancouver and Montreal, the sheer proliferation of community groups strengthened that particular voice in the broader policy debate in Canada. The Second Annual AIDS Conference was held in Toronto in November 1986, bringing together representatives of AIDS community groups across the country, along with some research specialists from the National Advisory Committee on AIDS. By then, AIDS community groups had developed in several new centres, including St. John's in Newfoundland, Ottawa, London, Windsor, and the Cambridge-Waterloo area in Ontario, Regina, Calgary, and Edmonton on the Prairies, and Victoria on the West Coast. The workload facing such groups continued to mount, with more and more calls from worried people outside high risk groups, and the bulk of work was still carried by volunteers, the overwhelming majority of them gay and lesbian. Funding was still uneven and often non-existent, although it was clear that even as late as this AIDS community groups were substantially more on top of what was needed for public education than most government officials.

The Canadian Haemophiliac Society became active in AIDS-related education and advocacy during this period. The organization had been involved in 1985 discussions about testing the country's blood supply, although its first major educational campaign was launched only after major federal funding came in 1987. By that time, it was clear that the infection rate among Canada's 2,000 haemophiliacs was high (about 42%), and that a number of the preventive and treatment issues that were emerging within other AIDS community groups would have to be addressed within this organization's own membership and clientele.

During this time, membership in the Canadian AIDS Society, the network of community groups formed in 1985, grew significantly. However, CAS had yet to establish an office in Ottawa, or hire permanent staff. Geographic distance, the paucity of resources, and the pivotal role of provinces and municipalities made the formation of a significant federal presence difficult.

### City Governments

In Canada's three largest cities, the response of municipal government to the dramatic increase in AIDS cases during the 1985-88 period varied enormously. In Montreal, both the city and metropolitan governments have essentially no public health mandates, so little was asked of them and little delivered, except for the provision of free office space to community groups.

In the other two cities, health officials and public health nurses were thrust quite quickly into the front lines of the epidemic, and a number of positive policy developments were effected. There was a tendency, however, for policy developments to be low key, public health administrators often delaying a push for major programmatic innovations for fear of lack of political support.

By the end of this period, Vancouver authorities had developed a progressive policy to protect its own employees (including police and fire departments) against discrimination on the basis of HIV infection or AIDS. The city had also given money to community groups - \$50,000 to AIDS Vancouver in 1985, for example.

Municipal health officials were not particularly locked in to traditional medical and public health models, so the city's initial responses tended not to be locked within



purely regulatory, "policing" models. This created political room for the funding of community groups and for contracting out some services to such groups. Initial funding came from the city's Social Planning Department, but when they sought a shift of such responsibilities to the Health Department, there was a general willingness to take the program on. During this period, Vancouver's Medical Officer of Health became an increasingly public voice, arguing against discrimination on the basis of HIV status or AIDS, and criticizing the provincial government to which he reported. In 1987, the city's mayor established and chaired a task force on AIDS, providing Dr. John Blatherwick with political support for the preparation of an AIDS plan in early 1988, one that entrenched a substantial program of support for community groups, and for educational programs directed at all city employees.

Toronto's city health authorities responded somewhat more comprehensively to the AIDS epidemic in their midst, though with only modest resources. Even though the City of Toronto's Department of Public Health had developed a master plan on AIDS in 1983, officials were inclined to keep its profile low, not commit major budgetary resources to it, and to keep the AIDS issue out of city council politics. In fact, the formal budget allocated to AIDS in the first couple of years reached about \$50,000 in 1985, although the time devoted to the issue by staff whose salary was not included in the figure was pushing the effective budget substantially over that time. At the time that public attention escalated in 1985, the demands placed on the city might well have been unmanageable, but about that time the provincial government increased its own involvement and somewhat reduced the pressure on local authorities, particularly with respect to educational programs aimed at the general public.

There was much that was progressive in the way the City's officials worked. There was considerable support for deferring to community groups in educational and prevention programs. In 1985-86, the city provided its first major grant to ACT, essentially a purchase-for-service arrangement. This was a departure for the department, illustrating one of the many ways in which AIDS pushed public health officials beyond the bounds of their standard operating procedures. There was a lot of concern for educating public health staff in the city, particularly for addressing homophobia and discrimination. Among some staff and managers of the department there was a degree of recognition that AIDS was different from most of the diseases handled by public health -- that the routines for testing and reporting and contact tracing would not necessarily hold.

But the Department was still dominated, during this period, by management which adhered to standard public health responses to communicable diseases. As issues dealing with testing for HIV and reporting seropositivity arose at the end of 1985, tension arose with community groups. The department disbanded its advisory committee which had representatives from the major community groups. The controversies around testing and reporting made it, in the opinion of one staffer, too "cumbersome." Relations with community groups were exacerbated by the man appointed to manage the city's AIDS programs -- a man with a rough style and an approach completely locked into traditional public health thinking.

In 1986, the city's Board of Health acquired a new chair who would bring AIDS into the political arena and dramatically increase city commitment, this despite the fact that reformers on city council constituted only a minority. Jack Layton was a progressive city councillor representing a downtown ward with a large gay population. By the end of the year, the Board had an AIDS sub-committee, and Layton presented his own master plan to the Board of Health, recommending the expenditure of between \$2 and \$3 million. To the surprise of the Board, and of public health officials, no one around city council attacked the plans or its dollar figures as outrageous, thereby giving

the department significant political space. At least in Toronto, AIDS had clearly become the sort of issue which moved even the most right wing local politicians to support major funding. Once officials took a look at the programming that was recommended, the projected costs were doubled to \$6 million for a thirty-month plan, half of that to be a re-allocation of existing staff.

The final plan did not commit much money to community groups, reflecting a desire to have city officials undertake most educational and preventive programming. The top managers of the department, including the AIDS manager, were still tied to relatively traditional public health models. But the community grants were increased after some political pressure was applied, and the long process of increasing the flexibility of public health officials began. When a new Medical Officer of Health was appointed in 1988, the man chosen was someone much more critical of existing public health and medical models. In the interim, the city's public health department acquired a reputation for having several staff with much more "radical" attitudes toward public health units than other province's health units. This change in perspective would soon be reflected in AIDS programming.

One of the ways in which civic authorities assisted the local population in learning about and defending itself against AIDS was through the financial support it provided to the Hassle Free Clinic, providing men's and women's health services in the heart of the gay ghetto of Toronto. Long before the province allowed even limited anonymous testing, such testing was available at Hassle Free in a gay-positive and generally-non-judgemental environment, officials at various levels of government apparently turning a blind eye.

## **Provincial Governments**

### **Ontario**

A 1985 Ontario election resulted in the Liberal Party taking office (with the support of the social democratic NDP) after forty-two years of Conservative rule. The new government, for strategic reasons at least, was portraying itself as reformist, and the dramatic increase in public concern about AIDS made a step-up in provincial initiatives almost inevitable. On September 25th, the Ontario Health Minister announced a \$100,000 grant to the AIDS Committee, and a \$200,000 budget for the education of health practitioners and the general public on AIDS, to be administered by an Ontario AIDS Public Education Advisory Panel (OPEPA). The grant to ACT was only half of what they asked for, and the administrative commitment to OPEPA was unclear, but AIDS community workers sensed a somewhat more progressive attitude in this new government. Still, mistakes were being made. Late in 1985, the Health Minister (Murray Elston) publicly acknowledged that a Toronto school teacher had AIDS, embarrassing the Health Ministry and the government by breaking the pattern of confidentiality already in place for this and similar diseases. There was little community panic around the issue, but the gaff intensified concern within the department about public awareness.

OPEPA represented an important break from earlier consultative committees at the federal and provincial level. Rather than being dominated by clinical and research specialists, it brought together medical scientists, doctors with large gay practises, public health officials, government administrators, Red Cross officials, and AIDS community group representatives. There was considerable energy and commitment in the group, and a recognition that no leadership was coming from the federal government.

Within the provincial Health Ministry, there continued to be a "business-as-usual"

approach to AIDS. Officials resisted granting OPEPA even so much as one full time staff member, believing instead that the Committee's work could be absorbed into existing departmental routines. In the view of one committee member, Health Ministry officials were still dominated by a culture which pretended that AIDS didn't exist, and which recoiled in the face of any gay-related issues. Until then, Evelyn Wallace was the only official given over to AIDS work in the ministry. "She was it!" In the view of a community activist in Toronto, the Health Ministry's officials in those days seemed to feel that as long as the epidemic was limited to gay men, there was no urgent need for resources. The AIDS Committee of Toronto was perceived as offering service only to gay men, and not needing provincial funds for that purpose. The homophobia among officials was "not very veiled." Only in the face of AIDS spreading among heterosexuals was the ministry moved to act. Even then, the inclination was to give money to public health authorities and not to community groups. The Ministry's Communication Branch, obviously central to any public education program, was most resistant to taking the issue seriously and granting the committee resources. At first, any calls to the ministry dealing with AIDS would be referred to the already beleaguered members of OPEPA, as if officials simply did not want to have to talk about it.<sup>6</sup>

In autumn 1985, OPEPA's members were convinced that they had to prepare information for health professionals and the public, and get it out fast. In the view of one of its members, OPEPA's work from 1985 to 1987 formed the backbone of AIDS education work across the country, apart from the work already undertaken within gay communities. Material first emerged in late 1985. Printed and audio-visual materials were produced in seven languages. Pamphlets were eventually distributed to three-and-a-half million households. This educational material generally de-emphasized risk groups, and focused on risky behaviour. The target was heterosexuals, largely because of the committee's belief that the gay community was already very aware of the disease and of appropriate sexual precautions. The same principle was applied to the development of curricular materials on AIDS in late 1986 and early 1987, in a high-speed cooperative venture between the Ministry of Education and the Health Ministry, taking six months to accomplish what would normally have taken three years. There was growing recognition in both of these ministries that school teachers and public health nurses were going to have to start talking to school children about sex in ways that they have never contemplated before.

There were limits on the explicitness of the message transmitted through official provincial materials. The approval process within the Ministry of Health for printed and audio-visual materials destined to have the provincial government "trillium" on them was complex and restrictive. Most OPEPA members recognized the value of explicit materials, and soon developed the view that a prominent place should be reserved for explicit materials targeted to particular groups. When substantial money began to flow in the direction of provincial educational programs, OPEPA recommended that a portion of that money go to community groups, who could then (as they had in the past) produce more explicit materials.

In 1987, the provincial government took over the AIDS hotline -- originally the idea of the AIDS Committee of Toronto, and for a time operated by the City of Toronto. In that year, the province also increased its overall funding for AIDS, providing significant grants to the regional health units across the province, and establishing an AIDS section within the Health Ministry. In January of the following year, the province funded the establishment of AIDS outpatient clinics in a number of Toronto hospitals.

During the 1985-88 period, the BC provincial government remained in the hands of a right wing government, resistant to taking on AIDS as a priority issue, and reluctant to sanction any educational materials that used explicit messages or which came even close to "condoning" homosexuality or other supposedly immoral behaviour. Nevertheless, some progressive measures were adopted.

The most significant step taken by the province during this period was the appointment of Dr Michael Rekart as its AIDS "point man" - in the Sexually Transmitted Disease Division of the B.C. Centre for Disease Control. Rekart had at his disposal a relatively forward looking set of policies and procedures on STD's going back to the 1960's. and before. In the view of a number of observers, he was able to use those policies to maximum effect without raising controversy. A "street ? program" that had been developed for substance abuse in the 1960's, for example, was expanded for AIDS education and counselling. The STD division had much less of the traditional public health baggage that still permeated the most influential divisions of the Ontario Ministry of Health.

The political constraints imposed by a Social Credit Leadership widely considered homophobic, though, was considerable. B.C. was the province in Canada not to pay for AZT. The Community groups received next to no funding from the province, although by the end of this period the government was channelling some needed project - specific funds to groups through the city. In all of the premier's and the health minister's statements through this period, there was a clear reluctance to assist any gay-identified group or initiative. The homophobia was as blatant as among any senior government politicians in Canada, and did much to reinforce negative popular stereotypes.

In October 1985, BC became the first jurisdiction to establish free province-wide testing and counselling. A special AIDS Testing/Counselling Clinic (ATEC) was established by the Health Ministry's division of Sexually Transmitted Disease Control. In B.C. as elsewhere, part of the pressure to establish distinct testing sites came from the Red Cross, which feared that the imposition of across-the-board blood supply tests would attract people from high risk groups to the blood donation system in order to determine their own status. ATEC staff asked for a name and address, but not for proof, thus permitting widespread use of pseudonyms. This less-than-fully-rigorous system was installed after AIDS Vancouver representatives convinced public health officials that no one would show up for testing at a clinic were names would be on file. What allowed for a certain amount of flexibility on this matter was the fact that although the province was the first to make AIDS a reportable communicable disease, the normal reporting regulations did not apply to seropositivity.

In 1987, a highly controversial amendment to the Health Act introduced in 1987. The language, though ostensibly directed towards improving control of recalcitrant ? patients, was quickly evaluated and condemned in the context of AIDS. It gave medical health officers powers of sanction up to and including quarantine to restrict those likely to expose others to HIV or AIDS. Given the long incubation period of HIV, such powers could confine someone for a very long period indeed. Other provisions threatened the confidentiality of those who had been tested for antibodies or those who had participated in AIDS research at Vancouver's St. Paul's hospital.<sup>7</sup> Some changes were made after protests from various quarters were registered, although there are still some fears that the new powers of quarantine are excessive, and the protections for confidentiality insufficient.

Limited steps were taken to protect against discrimination. The Public Service Act was amended in 1987 to insert AIDS-related policies. However, the protections against discrimination were not thoroughgoing, since they accommodated unreasonable

refusals to work with HIV+ employees.<sup>8</sup> Fortunately, in 1988, the BC Council of Human Rights interpreted the province's Human Rights Code as protecting those with AIDS or with HIV antibodies against discrimination in the same way that those with disabilities were protected -- a decision much like those made by other human rights tribunals in the country, including Ontario, Quebec, and the federal Human Rights Commission.

The Ministry of Health launched an AIDS education program for the public in 1985-86, and within two years, the budget for it reached \$800,000. By the fall of 1987, household mailings had gone out to 1.2 million homes, a toll-free AIDS information line had been established, and materials had been prepared for health care workers. Generally, the educational materials were thought "tame" by observers outside the province, using such themes as "Be Responsible . . . For Life." The province also directed school boards to develop AIDS-related staff and student policies. At a cost of \$4 million the Ministry of Education developed a Family Life Programme for grades 7 to 11, at a cost of \$4 million. Although condoms are discussed (much against the instincts of the provincial premier), sexual abstinence is emphasized, as it is in a number of other provincial school programs. Extra precautions were taken : parents were allowed to remove their children from the program and the decision to address such topics as homosexuality was left to individual school boards. None of the curricular guidelines and directives cover Roman Catholic separate schools.

The government did appoint a Provincial Advisory Committee on AIDS comprised of medical practitioners. Even as late as 1987-88, the Committee received only \$300,000 funding, to support its own operations and the costs of the governments AIDS information line. The government's commitment to research is equally modest, the province's Health Care Research Foundation and its Medical Services Foundation awarding grants totalling \$115,000 for AIDS-related research between 1985 and 1988. The BC government is less generous in the provision of drugs to people with AIDS than any other province. AZT is provided free of charge only to those with incomes low enough that they are eligible for welfare.

## Quebec

In most respects, Quebec lagged significantly behind Ontario in developing a budgetary commitment to AIDS, and in developing substantial public education programs. Even B.C. moved more quickly in some fields. There was a strong tendency for government leaders to assume that the province's existing health care system would adequately care for those who were sick and dying with AIDS, and that little additional work needed to be done. Quebec was the first province to establish an AIDS advisory committee (in 1982), the Comite SIDA-Quebec, but its membership was largely from the medical profession, and its mandate relatively narrow. It was reorganized and expanded in 1986 to broaden participation and expand its range of activities to include public education, the provision of information to health care workers, and the monitoring of the spread of HIV/AIDS. But for the 1986-87 fiscal year, the provincial government's total budgetary commitment to AIDS, apart from \$1.1 million for the Red Cross to test blood, was \$619,000. During this whole period, the provincial government was facing significant budget deficits and was tightening the screws on virtually all departments. The political leadership of the Health and Social Services Ministry was also in the hands of right wing practising Catholic -- Therese Lavoie-Roux -- who seemed to want to avoid the issue, particularly in its public education implications.

The Comite SIDA-Quebec was replaced in 1986 by a five-person AIDS Task Force, as part of a broad-ranging action plan. The task force was to report back to the Minister of Health and Social Services after consulting throughout the province and

beyond. In the spring of 1988, the task force recommended increased research funding, increased education programs (especially for high risk groups), greater protections against discrimination for HIV-infected people, opposition to mandatory HIV testing except for the blood supply and tissue donations, increased support for community groups, greater availability of condoms, and the provision of an integrated system of care and financial support to HIV-infected persons (including home care, day care, and foster care).

Steps were taken by several agencies to ward off discrimination. In 1985, the Ministry of Education directed school boards to ensure that no child be deprived of education because of HIV or AIDS, that medical information available to the school be kept in strictest confidence, and that any evaluation of risks to other students be the responsibility of the community public health department and not the school. In 1986, the Ministry of Health and Social Services directed local community health and social service centres, hospitals, and other health-related institutions and nursing homes to ensure that no one suspected of being HIV+ should be excluded. The Quebec Human Rights Commission had not waited for a case to appear before it, adopting a policy document which treated HIV infection and AIDS as protected under the Charter of Human Rights and Freedoms as a disability.

In 1986, the Public Health Protection Act was amended to add AIDS to the province's reportable disease, but an explicit decision was taken not to require reporting for seropositivity. In fact, amendments stipulate that any information which might allow for the identification of an infected person may not be revealed to anyone but that person, and this provision overrides any other provisions in the Health Protection Act or other acts. There are provisions allowing public health authorities to order someone with a specified contagious disease to undergo treatment, but so far there is no talk of those provisions being invoked for AIDS. In general, there are very strict controls on confidentiality, with the effect being official sanction of anonymous testing.

The provincial government launched a major public education program in 1987, dealing with all sexually-transmitted diseases, but HIV/AIDS in particular. It included a substantial radio and television ad campaign in French and English, targeted to young adults and adolescents and using well-known entertainment stars. A province-wide information line was also established that year. The development of AIDS-related curriculum has been slower to develop, and by 1988 there was no province wide direction on the matter, although the Protestant School Board of Greater Montreal (serving a majority of the province's anglophones) had developed programming, in cooperation with C-SAM.

Starting in 1988, the province was establishing AIDS action teams in community health centres (CLSC's) most affected by AIDS -- two of them in Montreal, one in Quebec City, one in Sherbrooke. The teams are meant to act as a link between community health centre staff, community health departments, and hospital centres, dealing with information and prevention programs, testing, and counselling. The earlier development of the CLSC network across the province has shaped the province's strategy along a number of fronts, giving more ready access to local communities and making health services more easily accessible to local populations. The decentralization of many aspects of health delivery, resulted in quite uneven policy and service development, even within the Montreal area. In addition, the confidence of provincial health and social service authorities that they were able to deliver services at the community level has often led them to ignore or disparage the work of community groups, to spurn any suggestions that Quebec's health care system suffered from inadequacies.

Between 1985 and 1987, the Health and Social Services Ministry spent \$2.2

million on AIDS-related programs. Over half of that went to the Red Cross Blood Transfusion Service, to pay for blood screening. Of the rest, \$345,000 went for the operation of the Comité SIDA-Quebec, about \$560,000 for testing and diagnosis, and only \$185,000 to community groups. A further \$2.8 million was allocated in August 1987. There was a third of a million for community groups in that budget, with the province tending to match federal funding for the major AIDS groups, but this was a far cry from the accelerating funding program which Ontario had launched. The low level of funding exacerbated in-fighting in Montreal community groups in fact, reinforcing the fear that the emergence of new groups would jeopardize the money allocated to C-SAM. There was also little priority given to research. The Fonds de la Recherche en Santé du Québec allocated about \$54,000 to AIDS-related projects in 1987-88, although a program providing about \$100,000 to pay for indirect costs associated with research had been available to three hospitals in Montreal.

In this critical 1985-88 period, then, all three provinces were forced to act on AIDS. Ontario committed the most resources, and developed the most elaborate and best-designed public education programs. It also had the best relations with community groups, though it was by no means speedy in developing systematic funding programs for them. Though by 1988, health officials in B.C. were using established procedures to useful effect in the AIDS field, they were hampered by overtly hostile politicians. Quebec seems to move quickly on some fronts during this period, but their strategic development was often hampered by inconsistency across a decentralized system, and by inattention to the role of community groups.

## **Federal Government**

Until 1986, there was little in the way of public initiative on AIDS-related issues at the federal level, apart from relatively low-profile epidemiological work. Even in the field of research, in which the federal government had the largest budgetary flexibility, there was little activity. By early 1986, the paucity of funding for AIDS research was becoming painfully obvious. In the words of a Globe and Mail reporter,

Canadian AIDS researchers are ready to quit. While researchers in the United States are running to join the well-financed and politically popular effort to cure, treat or simply understand the mechanism of acquired immune deficiency syndrome, few Canadians see it as a growth area. In the United States, one federal agency alone provides \$120 million for AIDS research. . . . Canadians working in the field, most of them in Montreal, say they have access to far less money and political support. . . . Several top Canadian researchers say they and their colleagues are on the verge of abandoning their work or going to France or the United States because pleas to provincial and federal officials for special funds for AIDS work fall on deaf ears. (22 April 1986)

To that point, public research funds for AIDS totalled \$2.3 million from the federal government, \$68,000 from the provincial government in B.C., and \$517,000 from Ontario. One Montreal researcher estimated that such funds constituted merely one tenth of what was needed.

Federal officials, though, were still arguing that research proposals were not coming forward. Of the more than 300 grant applications sent this year to the National Health Research Development Programme (with an annual budget of \$20 million), only eight were on AIDS. The Medical Research Council had a much larger budget, of \$151 million, and the relatively modest \$1.2 million going to AIDS was largely a product of the small number of grants. No new grant proposals had been sent to the Council, and only two projects asked for extensions. A large number of researchers still

seemed to feel that there were risks in committing to AIDS work -- that it was a field that could make a career, but one that could just as easily break it. The disease was still perceived as affecting marginal groups, and less attractive as a result. In such a climate, those who were interested seemed to need a sign from the federal government that their work was considered important. The grants system then in place was not one that directed research in particular directions, and there seemed no particular interest in changing routines for AIDS. (In contrast, social science research funding from federal agencies was becoming increasingly attracted to the notion of stimulating research which accorded with national political strategies.)

It was only in 1986 that the federal government provided its first major budgetary commitment to AIDS. On May 1st, the Health Minister announced a five-year, \$39 million plan, in part responding to the recommendations made by the parliamentary standing committee on Health and Welfare. The vast majority of this was for research (\$23 million), to be directed by the National Health Research and Development Programme. For the first time, there was significant money provided for community grants. Approximately \$4 million to the Health Services and Promotion Branch, which established the AIDS Community Action Programme (ACAP).

Of the \$39 million, \$3.7 million was given over to the development of national educational programs, but these were to be put together not by the ministry but by the Canadian Public Health Association, itself a very conservative organization whose leadership was firmly lodged within very traditional conceptions of public health regulation. At this stage, the government still seemed to be of the view that AIDS education was controversial, and that keeping programs at arms length was safer than keeping the public face of AIDS education in-house. Between \$600,000 and \$700,000 was assigned to the first year. As Colin Soskolne cynically suggests of this allotment,

Some comparisons are in order. The United Kingdom, with less than half the per capita AIDS problem, devoted the equivalent of about CAN \$40 million to education in the same fiscal period. A second comparison is also enlightening. The government of Canada allocated \$12 million to educate the Canadian public about its free-trade initiatives.<sup>9</sup>

The CPHA, at the time, did not seem to feel that this level of funding was particularly inadequate. Surprisingly, its central headquarters still appeared uncertain itself how big the problem was, and what measures to counsel to contain the epidemic. The \$3.7 million dollars seemed to them an enormous budget for health promotion. The organization's caution was evident in its first work in producing print materials. After drafting a brochure with the word "condom" in it, the organization sent it to the Health Ministry for approval, something which would never have occurred to AIDS community groups being funded by the government. Eventually, but only after long delays, the CPHA decided to go ahead without approval. In mounting a national campaign, at least the CPHA had learned that a certain degree of explicitness was in order, but in developing public service announcements, it soon ran into difficulties using the word "condom." CBC executives, along with the Canadian Association of Broadcasters, argued that the general public was not ready for that kind of thing, and delayed things sufficiently that even Jake Epp's office was obliged to intervene.

Eventually (much too slowly, in the judgement of some observers), the CPHA put together a "national brochure," a video for high school students, and a curriculum for elementary school students (the latter becoming quite popular across the country). Earlier on, the CPHA started up a program of information meetings in various regions of the country, in some cases the first such meetings. A number of the provinces with low incidence of AIDS had undertaken no educational programs on their own, waiting for a lead from the federal government or simply choosing to ignore the epidemic as



something affecting only large cities.

At the federal level, most of the control over AIDS programs remained with the Health Protection Branch, which retained its "regulatory" mind-set. In this scheme of things, there was little priority attached to the development of national public education programs, and little interest in recognizing the legitimacy of community groups.<sup>10</sup> May 1986 saw not only the first major federal funding for AIDS, but also the establishment of the National AIDS Centre, with a mandate to "coordinate and facilitate AIDS related activities nationally, to perform a policy support role, and to provide recommendations on funding priorities." But the office was still lodged within the LCDC, and the person chosen originated from within Health Protection.<sup>11</sup> That whole branch retained a paternalistic culture, and many of the officials in it resisted acknowledging that AIDS constituted a major public health crisis. In the view of one insider, the culture which dominated the branch retained considerable distaste for dealing with unconventional sexual issues and with anything to do with homosexuality. And although some officials of the Branch and of the ministry as a whole believed that the resources given over to AIDS remained woefully inadequate, the man in charge at LCDC, Alistair Clayton, seemed disinclined to press administrative superiors and political masters for substantially greater commitment, apparently believing that the range of activities currently under way in the ministry was sufficient.

By the second half of 1986, pressure was being applied on the federal Health authorities on another dimension of the AIDS epidemic -- the release and acquisition of new experimental drugs. In June, two activists from Vancouver met the Minister of Health to speed up his ministry's approval of new AIDS-related drugs, and to allow for early release on compassionate grounds. The Health Protection Branch was resistant to such proposals, largely on the basis of fears that unanticipated side effects could injure or kill patients.<sup>12</sup> The Branch was still feeling the affects of having approved Thalidomide in the 1960s, much of its caution aimed at avoiding a similar disaster. Even the suggestion that people suffering from acute stages of AIDS would be willing to sign waivers to prevent law suits seemed not to move Health Protection Branch staff. Officials were also operating, to some extent, at the mercy of pharmaceutical companies, who sometimes avoided even applying for approval in Canada because of the relatively small market for prescription drugs, although in fact the government can play an encouraging role in cases where it perceives a need. Experimental trials did get started for AZT early the next year, probably spurred on by pressure from the Vancouver PWA Coalition.

The larger issue being posed pitted AIDS community groups against the established testing and releasing procedures used by the federal Health Ministry, shaped by rigid procedures and standards that had never been seriously challenged before. Part of the difficulty lay in the limited number of laboratories in which clinical tests could be conducted, in turn a product of inadequate funding. But a more serious problem lay in a drug release program devoted exclusively to research questions and long term results, and not at all to the treatment of people currently ill and dying. The research was heavily tilted towards "double-blind" trials, in which people facing immanent death could well be placed on placebos rather than on promising drug treatments. Because such trials were often the only method of obtaining experimental drugs, people with AIDS were being effectively coerced into trials. A full-fledged critique of such research methods was not evident yet, but the seeds were being planted.

The government's view was made evident in coverage of the issue by the Globe and Mail on June 27th. Paraphrasing Michael Davis, head of the Infection and Immunology Division of the Health Protection Branch, the Globe story commented as

follows:

In Mr. Davis's powerful opinion. . . most [drugs] have been discredited by premature announcements of favourable results. . . . "One simply cannot take every little idea, even if the drugs are available" from the manufacturer. "You'd have total chaos. You'd be killing people off left and right." Mr. Davis said he must balance the needs of patients dying today of AIDS against the projected needs of the thousands of Canadians expected to develop the disease. The government cannot hand out drugs that have not been proven effective, or whose effectiveness is outweighed by the toxicity and which will kill patients, even those who will die nonetheless, he said. The consequences would be that researchers and manufacturers would prematurely abandon further studies of drugs once considered initially promising in unfavourable results are announced too soon for confirmation or retesting.

In the case of AZT, even before trials began in early 1987, American authorities announced the drug had proven effective in slowing the progress of HIV, and that it would soon be released. Canadian people with AIDS were already inquiring about obtaining drugs through American connections. This increased the pressure on federal Health officials, who announced in November that AZT would be available very soon through doctors, rather than just through clinical trials [?].

In another encouraging development at the national level, the Canadian Human Rights Commission indicated in May of 1988 that the Canadian Human Rights Code protected those with HIV or AIDS from discrimination, under provisions dealing with disability.

## Assessments

Throughout the 1985-88 period, AIDS had an extremely high profile in the press, stories about it appearing almost daily in the press. City authorities in Toronto and Vancouver stepped up their activity during this time, particularly in the 1987-88 period. Increases in provincial government activity were uneven. The most disturbing tendency during the mid-1980s was the slowness of the federal government and its agencies in developing innovative responses to the AIDS crisis. A number of epidemiological programs had in fact been put into place, and some move towards increased funding for research was in evidence. But most of what the federal Health and Welfare authorities did was reactive and not proactive. The officials who were in the administrative command posts most relevant for AIDS were generally locked within a cautious and traditional medical model, one increasingly under attack from reformist public health spokespeople as well as from AIDS community groups.

AIDS community groups proliferated and grew during this period, and many of them received their first government funding. In some places, this allowed for the stabilization and expansion of paid staff of such groups. Although the growing role of public funds in local community work introduced the risk of cooptive relationships with funding agencies, the primary impact appears to have been the strengthening of political voices. Not all of those voices were uniformly radical in their critique of government policy (or its lack), but as the networks between community groups grew, the voice was clearly critical. By the end of this period, the groups providing most of the "front-line" services to AIDS-affected people were joined by other political voices, organized as PWA Coalitions or as Aids Action Now! or as ACT UP, some of them expressing more anger than ever.

The issues raised by community groups broadened in the few years leading up to 1988. More and more, groups came to be critical of a traditional medical model

which highlighted regulation, which accentuated the fear of irresponsible behaviour, which downplayed the role of patients and non-professionals in making policy, and which focused on protecting the uninfected much more than on caring for the sick. They were also critical of the tendency within large parts of the medical establishment and of health bureaucracies at various levels of government to treat this crisis as just another epidemic of contagious disease, avoiding the peculiar characteristics of HIV and of the risks of discrimination against the communities most at risk. Those most influenced by the traditional medical model, in fact, were explicitly resistant to any attempt to dovetail a concern for gay rights with attention to AIDS. Gay rights, in this view of things, was an entirely separate matter.

The issue of testing for HIV antibodies, and especially about what to do with the information derived from testing, clearly reinforced the opposition between the two sides. It was an issue which symbolized the conflicting priorities which had already emerged over other matters. By the end of 1985, the HTLV-3 antibody test was made available to everyone in Canada. The initial purpose of the test was to test the blood supply, which from November was being fully screened for antibodies, but increasing numbers of people in high risk groups were talking about taking the test.

One of the fears expressed by gay community representatives was that a testing procedure developed for blood would become widespread as a tool for screening out people. Fears about compulsory testing for certain kinds of employment (for e.g. in the armed forces) were prevalent, and the insurance industry was already starting to require testing for "suspicious" insurance applicants. Another fear resulted from the reporting procedures being put into place by some public health authorities. Ontario established a policy of requiring that the name of anyone emerging with a positive test be given to the local medical officer of health. The move was unequivocally supported by Dr. Alistair Clayton of the federal LCDC.<sup>13</sup> Even though little was known at the time about the likelihood of a person testing positive going on to develop full blown AIDS, readily-available testing "kicked in" the traditional public health preoccupation with its classic control mechanisms -- identifying the sick, tracing their contacts, ensuring their adherence to restrained behaviour. To community groups, this sort of preoccupation was drawing attention away from the more important work of public education. Because of the extra stigma associated with AIDS, beyond that linked to other diseases, the fears of discrimination made compulsory reporting that much more fearsome. AIDS community groups argued, with some reason (and eventually with evidence) that the lack of anonymity in testing would inhibit gay people (and others) from taking the test.

The issue of drug testing and release also brought AIDS groups and the federal government's most powerful health officials into conflict, although on this issue a number of medical practitioners in contact with large numbers of AIDS patients sided with the community groups. Health officials, and most health researchers, held to a scientific model and to a conception of AIDS patients which allowed little flexibility for drug release, even in cases where drugs were shown to have promise in American experiments. The issues were far from clear cut, but the arguments being put by community groups generally fell on uncomprehending ears. The release of experimental drugs on compassionate grounds was finally forced upon federal authorities, but only because community groups and individual PWAs threatened underground importation of AZT from the U.S..

As the number of PWAs increased, and as promising treatments proliferated in the U.S., the community groups paid more and more attention to issues of treatment and not just public education and counselling. One of the issue areas which came to receive increased attention was that of palliative care. In 1985, AIDS Vancouver was

pressuring political authorities to provide funding for a hospice providing care and accommodation for up to twenty-five people suffering from AIDS, and soon thereafter, the work which ended up in the establishment of Casey House began in a sub-committee of the AIDS Committee of Toronto. By 1988, the Quebec government, in cooperation with the City of Montreal and a charity coalition in the city, established a residence for twelve people with AIDS. This was not an issue which polarized opinion as much as the others, since it did not strike as much at the heart of established health policy and administrative routines.

Throughout this period, there were of course continuing differences in perspective on the importance of community work in combatting AIDS. The traditional medical model so influential in Ottawa downplayed the significance of the work already done by community groups, and steered away from such groups for the delivery of programs being debated or put on stream. Community groups were starting to get funding at the local and provincial level, and even at the national level, but often in the face of opposition or disdain from the most powerful branches of the health bureaucracies at each level.

The political struggle over AIDS policy during this period, though, did not involve simply the opposition between two camps. Over this three-year span, a new voice was being heard in some venues -- a reformist public health voice that was critical of the medical establishment and of traditional public health responses to epidemics. This was a perspective which in general attached much more significance to the rights of patients and to the work of community groups, and which in the particular case of AIDS recognized that traditional regulatory practises were doubly inappropriate. Such perspectives were becoming evident with the federal Health Ministry's Health Promotion Branch, which had some experience in funding community groups and in conceiving of public health in broad social terms. It was also evident in some local health units, most notably in the City of Toronto. It was not a perspective very evident in the leadership of the Canadian Public Health Association, but even within that quite conservative groups there were critical voices emerging from below.

Throughout most of this period, the perspective which dominated most government policy making at all levels was the traditional regulatory medical model, but the strength of critical voices from both of the other perspectives, each bolstering the other was growing. The conflict would come to a head in 1988.

### **1988 - 1990: Pressure for Comprehensive Government Strategies**

The oppositional pattern pitting community groups against traditional medical and public health officials has continued in the period since 1988, but with reformist health policy makers becoming more prominent in debate over AIDS policy. Even federal policies began taking more account of traditional perspectives on the epidemic.

When, in May 1988, the Toronto-based AIDS Action Now! burned the federal Health Minister Jake Epp in effigy, they helped launch a new stage in AIDS policy in Canada. It was not the sort of thing often done in Canada, and Epp's wholesome small-town image made the act that much more dramatic. The visual image it created was instantly etched in the minds of health officials in Ottawa, and it acted as a signal to government players in AIDS policy across the country. It accelerated the preparation of federal programs, and helped ensure that Epp would no longer be Health Minister at the next major cabinet shuffle. The attempt by officials in various levels of government to keep AIDS within standard operating procedures and out of politics was now doomed.

AIDS was now an unavoidable policy issue. And what was becoming more

evident during this period, in contrast to most of the preceding periods, was that getting involved in AIDS as a policy issue was a "winner". The climate of opinion around AIDS, although not without its negative components, made the increase of programmatic attention to AIDS politically popular. Politicians came to realize that they could attract support in the press and in the electorate by announcing progressive policies and increased funding for AIDS. Administrators came to recognize that they could increase funding for their directorates and branches by developing AIDS-related programs.

Even though governments were assigning more and more staff to AIDS policy development and AIDS service delivery, this was still a period in which the political agenda was being heavily influenced by AIDS activists, particularly by gay activists. This was a period when community groups grew to be even stronger and more confident than they were, particularly in Toronto, to some extent in Vancouver, and at the federal level. The Canadian AIDS Society was developing into a significant player in the federal policy making system, by 1990 working with a Health Minister much more open to discussion of AIDS than his predecessor.

While all of this was happening, the medical personnel on the front lines were becoming more and more overloaded with cases. Of these, the general practitioners with large gay practises were the most beleaguered. Philip Berger may well have the largest number of AIDS-affected patients in the country:

I had been seeing gay male patients for a long time before the AIDS virus began to affect them. I became sensitized to their situation because of the rights violations committed against them. So, I had a fairly large population of gay patients. . . . The word got around that I was knowledgeable about "the gay disease." There are now another twenty, twenty-five doctors in Toronto who are knowledgeable, and patients who are infected tend to go to these doctors. That's one of the problems in this whole epidemic: there's only a very small number of doctors seeing most of the patients. And we had to educate ourselves, by listening to our patients, reading the medical literature, attending international conferences. There was no one to sit there and tell us about it.

[The] pressure is there from all sorts of angles. We see men between the ages of twenty and thirty-nine die of a disease which has no cure. There's much more of a gut link, than with someone who's seventy-five and has a terminal disease -- not that I'm less sympathetic with the seventy-five-year-old, but I can identify more with younger men. A second source of pressure is the amount of work involved in taking care of patients. They have tremendous physical and emotional needs, and they need to be guided through the social system to obtain legal aid, welfare, lower OHIP premiums, or hospital services. Thirdly, keeping up with medical knowledge is very, very difficult. . . . What's more, it seems everybody wants us to do research for them. Clinical investigators testing new drugs or social scientists who traditionally have not approached us, general practitioners, are soliciting our cooperation because of our knowledge of AIDS and our experience with AIDS patients. . . . Another part of this "volunteer work" involves being consulted by government policy-makers. That is something new for them; they used to consult only people at very high levels. . . . And there's the political side, the lobbying and the intervention by our group of doctors [Toronto HIV Primary Care Physicians Group], putting pressure on the government policy makers to get moving, which, as you know, they haven't done.<sup>14</sup>

Between the mid-1988 and the end of 1989, seven of approximately 30 Toronto doctors with large AIDS case loads have left their practices. According to one of them,

"I just can't treat everyone who wants to be seen by me, none of us can. Every day I have to turn away one or two patients who call looking for a physician. I feel like I'm working in the middle of a war zone. Most of my patients know someone who had died. Recently I had three patients die in one week. I usually have one a month."<sup>15</sup>

## Community Groups

In 1988, the Canadian AIDS Society obtained office space in Ottawa and recruited its first full time executive director -- Richard Burzinsky, a gay AIDS activist from Montreal. More funding was available from the Federal Centre for AIDS, allowing for the organizational stability and the concentration of skill required to establish a legitimate lobbying presence in Ottawa. In the spring of that year that a national conference on AIDS was organized, for the first time, with the cooperation of CAS, the Federal Centre for AIDS, and the Canadian Public Health Association. It brought many of the principal actors in AIDS politics together, although without there being much sign of consensus on the major issues that had already been placed on the public agenda.

The stabilization of CAS allowed its staff to develop more understanding of the Health Ministry, and to develop ties with sympathetic staff in various branches and directorates. Even within the most "militaristic" directorates, there were sympathizers, some of them gay, some of them critical of rigidity in their branch and intent on doing something to help. Within the Drug directorate, within other parts of the otherwise rigid Health Promotion Branch, various administrators in lower levels or middle management positions were receptive to CAS inquiries and suggestions, taking risks in order to cooperate.

Over the next two years, CAS leaders and staff learned how to "work" the Health Ministry and Parliament Hill, although still not recognized as fully legitimate by a number of officials (particularly in the Health Protection Branch). When a new minister arrived in the portfolio in early 1989, quite cordial relations developed with him, and many activists began to temper their criticism. The organization developed two discernable styles. Some CAS members were groups preoccupied with social service delivery and were therefore comfortable with that being the dominant thrust of the national organization. On the other hand, CAS remained heavily influenced by gay activist voices with a policy agenda still significantly at odds with dominant health officials in Ottawa. The most influential figures in CAS remained closely tied to local community groups such as C-SAM and ACT, some of them more than ever prepared to declare their gay identity.

Contributing to this latter influence were the role of PWAs, most of whom seemed ready to press the CAS to take more radical stands, especially on treatment-related issues. In 1989, a National Coalition of People Living with HIV was formed by people with AIDS who wanted to remain independent of CAS out of a sense of marginalization within it. A 1990 annual meeting of CAS helped to ensure much greater PWA representation, which may well have lowered the level of discontent or unease.

CAS's relationship to the Canadian Public Health Association remained extremely cool. The federal government had given the CPHA a prominent role in launching national public education programs, but in the eyes of most AIDS community groups, the organization had never been a constructive partner. It got involved in national AIDS conferences only in 1988, and yet in the lead-up to the 1990 conference it was suggesting that CAS was no longer needed. The CPHA also turned away a proposal from CAS that more PWAs in its AIDS work. By this time, the CPHA was producing a range of educational materials, but in the eyes of many AIDS activists the

materials were too cautious, too slowly produced, and processed without any attention to the importance of cooperating with other groups working in the field. The leadership of the CPHA is also seen by most other activists in AIDS as heavily compromised by its close relationship with the federal Health Ministry.

### Toronto

The AIDS Committee of Toronto had much the same character as CAS, its staff and leadership increasingly insinuated into local and provincial policy networks, though many retained a political agenda sharply at odds with some of the most powerful AIDS officials in the city and province. As ACT became larger, more publicly funded, and more diversified in its services, the potential existed for it to have become more bureaucratic and more conservative. By 1990, it had a budget of \$2 million, up to thirty full-time equivalent paid staff, 400 volunteers -- all of which marshalled to deal with about 500 AIDS-affected individuals a year. It was having to think increasingly about management systems, job evaluations, fiscal control, and so on. All of this could have opened up a gulf between itself and other AIDS community groups in the city. Some PWAs and gay activists certainly have felt that ACT is too mainstream and cautious, some of AAN!'s members, for example, wanting to establish services parallel to ACT's. But in fact the relationship between ACT and the more radically-activist AAN! have remained friendly, and in most ways mutually complementary. ACT resisted the sort of shift towards "professionalism" that required specialized academic degrees for staff or managers, and more than ever it linked itself visibly to the gay community. A 1989-90 strategic planning exercise, in fact, ended with a clear declaration that ACT was a gay organization, certainly open to all and ready to serve any need asked of it, but clearly lodged within the community which effectively gave it birth.

AIDS Action Now! continued its active role in criticizing all levels of government for inaction or inappropriate action. Its critique of the federal drug testing and releasing routines became more and more comprehensive, and its policies routinely became the policies of CAS. It was AAN! which first developed a proposal for a national treatment registry for AIDS, and the idea was quickly adopted in other AIDS community group networks.

The PWA Foundation received its first major government grant in late 1988. The \$75,000 from the federal government supplemented employment grants, as well as the by-now substantial fundraising in Toronto's gay community. Eventually, funds came from three levels of government, and allowed for hiring up to ten staff to deal with a client load which eventually increased to 600. This seemed to reduce the dissension and discontent within the organization, although some AIDS activists perceived a shift towards professionalization and even more apoliticism. Throughout the changes at the Foundation, however, its leadership retained close contact with ACT, assisted by its location in the same building. There has been more potential for tension with AAN!, but that has been largely averted by AAN!'s determination to direct its criticism at governments rather than at other community groups.

Other groups and projects were joining the local AIDS community group network. Groups of gay Asians and blacks, for example, formed to develop their own public education and support services. Prostitutes were continuing in their efforts to spread safe sex practises among prostitutes. The Ontario AIDS Network emerged during this time. It brought together representatives of twenty-two AIDS community groups across the province, taking advantage of travel grants from the provincial government to hold quarterly meetings. It allowed the larger and more experienced groups to help the smaller and newer groups, and it helped forge a common front on a range of policy issues. A network of executive directors also emerged, although it is not clear whether

the network yet constitutes an important advocacy voice in provincial policy debates. The OAN does not have that much clout in the provincial capital, but its primary function has been to strengthen each group within its own constituency, and adds to the overall pressure on all levels of government to take the agenda of AIDS community groups seriously.

### Vancouver

Vancouver's AIDS community groups were continuing to face more serious underfunding than their Toronto counterparts, the provincial government still refusing to provide much in the way of financial support. Even as late as 1990, AIDS Vancouver had a budget and paid staff only about one-quarter the size of ACT's. In 1988, AIDS Vancouver was undergoing a major reorganization, too, with substantial turnover in staff and directors. The loss of gay community confidence during earlier crises continued during this period in which service delivery and public profile were impaired. The re-constituted organization began regaining some standing during 1989 and 1990. Those leaders who had been most cautious in their determination to remain respectable and avoid criticism of government had mostly left. A degree of political caution remained, however, particularly because the need for additional funding increased the need to curry provincial government favour. That in turn maintained a contrast in political styles with the PWA Coalition, and retained a degree of distance in the relationship between the two organizations.

The PWA Coalition was the fastest growing AIDS organization now. It was receiving almost as much funding from the city and the federal government as AIDS Vancouver, and despite its more aggressive political style, was regarded as the more competent of the two. By 1990, its half-million dollar budget was equal to that of the organization from which it had split. It took on a number of service and educational functions that might have been performed by AIDS Vancouver, though some attempt was made to avoid duplication. As it had from its beginnings in 1986, the group devoted considerable energy to treatment issues, both in its advocacy work and in its provision of services to PWA.

In 1990, though, some disagreement about advocacy style was emerging within the Coalition. A splinter group formed ACT-UP during the summer of that year, modelling itself on its American counterparts just as the PWA Coalition had modelled itself on its New York counterpart three years before. ACT-UP used aggressive and dramatic techniques to criticize not only the provincial government, but the otherwise much-praised St. Paul's Hospital.

Though a degree of division still characterized Vancouver's AIDS groups, which by 1990 included the McLaren House AIDS hospice, a BC AIDS Network had been formed at the instigation of the PWA Coalition. This was an informal group bringing together a wide range of community group representatives and some staff members of government agencies interested in AIDS issues. Not yet a political lobbying group, the Network has brought diverse groups into closer contact. It should be emphasized, too, that the substantive political agendas of the major community groups in Vancouver and beyond have not much differed on the major issues: to the extent that differences persist they centre on questions of tactics.

### Montreal

The sense of common political agenda is less applicable to Quebec community groups. The higher proportion of AIDS cases from non-gay populations, especially Haitian, is an important contributor to the distinctiveness of the Quebec case, but so is linguistic and cultural distinctiveness of Quebecois. In Quebec, AIDS community



groups are still plagued by internal divisions and by a relatively insecure funding base. ACT-UP has now joined the small constellation of groups, once again with anglophones disproportionately in the lead. That may well produce tensions with C-SAM, which has over time attracted more francophones among volunteers and staff. There are some signs of a more cooperative spirit emerging, and in 1990 a province-wide coalitional network was being established (La Coalition des Organismes Communautaires Quebecois de Lutte contre le SIDA). But there are still turf wars and resentments between the various community groups working on AIDS. There are also differences in political style, perhaps sharper than in Toronto.

Montreal community groups still suffered from organizational weakness or from a duplication of services. C-SAM was still the largest group, with an annual budget of about half a million dollars and a large volunteer pool providing services for up to 700 people. But late in 1989, the organization began major convulsions with the firing of the director and resignation of many other leading figures. The period of fundamental reconstruction continued through 1990, at the cost of considerable confidence in the larger community and with government agencies. The PWA Coalition was still suffering from drastic underfunding, still hampered in its community fundraising by the slowness of most of the local gay population to take AIDS as seriously as their Toronto or Vancouver counterparts. ACT-UP had seized a certain amount of the political initiative in AIDS community work, but its committed membership remained modest in numbers.

For Canada as a whole, the community group voice was at its strongest at the Fifth International Conference on AIDS in Montreal. The June 1989 conference attracted enormous numbers of researchers, medical practitioners, policy makers, and activists from across Canada, and the activist voice was significantly bolstered by the presence of ACT-UP representatives. The conference, and the protests mounted by AIDS activists, attracted a great deal of press attention, disillusioning some scientists, but substantially increasing the political pressure on federal and provincial governments.

### **City Governments (Toronto and Vancouver)**

By mid-1988, the city councils of Toronto and Vancouver had approved comprehensive AIDS strategies, accommodating a number of community group concerns and continuing to fund major groups directly. Both cities had developed programs for the education of their own employees, and both had developed programs to prevent the spread of AIDS among IV drug users.

The city council and Board of Health in Toronto had already been set on a highly interventionist course on AIDS since 1987. In late 1988, a new Medical Officer of Health was appointed to head the Department of Public Health, signalling something of a shift in the direction of the department. Perry Kendall represented a more reformist view of public health than his predecessor, and was less at odds with community group representatives. The manager of the city's AIDS programs was still a substantial thorn in the sides of community groups, seeming intent on retaining the city's control over as much AIDS programming as possible. But by 1990, there were signs that even Fred Ruff was re-thinking the role which community groups could play in such programs as needle exchanges.

Much of the gay-related AIDS programming was channelled through established AIDS community groups. Some of the city's managers were uncomfortable with what they perceived to be a lack of accountability in offering services through such groups, but the support given to such groups remained in place through this period. In the downtown area, there was also an increase in the city's own AIDS-related public health

services, with additions to the ranks of public health nurses. Indeed, the opportunity to hire a significant number of the new staff allowed for a greater diversification in the staff more generally, since the city was hiring gay male PHNs and nurses from non-white segments of the population.

The city also established a needle exchange program available to IV drug users in 1989. A number of city hall staff and most community groups argued that such a program would be successful only if offered through groups already insinuated into the community, but the public health managers' preferences for in-house programming prevailed. The program has enjoyed some success, although there are now indications that even the most reluctant managers are prepared to add supplementary exchange program (and needle-cleaning-kit program) through community groups. Here too, the public health authorities in the city seem open to the suggestion that AIDS cannot be squeezed into the pre-established routines for other diseases.

Toronto is most clearly ahead of other local governments in its public education programs. There is widespread support in the Public Health department for a proactive public education program which targets specific populations, and which uses messages as explicit as particular communities will bear. There are AIDS educators in some of the subsidized housing projects, for example. The city's Medical Officer of Health proposed installing condom dispensers in city schools, for example, and by the end of 1989, the city's public school board had agreed to place them in all high schools. Public health staff have begun participating, alongside PWAs, in schools education programs, often providing guidance for teachers having to apply the province's AIDS curriculum.

In much of the city's AIDS programming, the traditional rules of public health have been stretched or broken. A lot of new money has gone into AIDS, a lot of new strategies for dealing with community groups have been developed, and a number of new ideas about how to stop the spread of disease have become largely accepted. In 1989, the Board of Health unanimously supported the establishment of clinics with anonymous testing, and although in public the city's health officials were uneasy with that decision, in private there was some shift in perspective. There is still a preference for non-nominal testing among most of the staff, but a preparedness to recognize the legitimacy of the concerns that form the basis of the community group demand for complete anonymity. The political gap between AIDS community groups and public health officials is therefore much narrower at the city level than it is at either the provincial or federal level.

Vancouver's Health Department was never given the budgetary explosion that its Toronto counterpart obtained under Jack Layton, but its programming during the most recent period did receive substantial support from city council, and was less hampered by a legacy of traditional public health thinking. The city was the first in Canada to establish a needle exchange program to combat HIV infection among IV drug users. Though building in some ways on the practices already used in the provincial street nurse program, the needle exchange proposal was sufficiently public that the provincial government wanted nothing to do with it. The city established it early in 1989 with its own funds, eventually assisted by the federal government. Unlike Toronto, Vancouver was clear from the outset that such a program would be best contracted out to a community group, and high usage rates since the beginning have confirmed the wisdom of that decision. In 1989, the Health Department initiated a program of AIDS education for all 6000 city employees (police and fire included). The program of workshops was unlikely to have affected more than a fraction of the police force, but it may well have been effective in other divisions and within the Health Department itself.

## Provincial Governments

The contrasts in policy style and substance between Canada's three largest provincial governments remained largely intact in the period since 1988. What was different was that even the most conservative of provincial politicians were being forced to acknowledge publicly the seriousness of the AIDS epidemic.

### Ontario

By the end of March 1988, the Ontario government had spent a total of \$19.5 million on AIDS programs, starting with half a million in 1984-85 and increasing that to \$11 million in the most recent fiscal year. AIDS outpatient clinics at five Toronto hospitals received increased funding, and of course the government had committed major funding to Casey House. The province was by now committing substantial resources to AIDS research, having spent \$2.8 million up to early 1988. Substantial funds, too, were being made available to the Red Cross to cover the costs of blood screening, and the costs of AZT were rising fast. By the end of 1989, the province had also established a treatment unit to administer aerosolized pentamidine for people who were HIV+.

The bulk of the \$7.1 million given to the Health Ministry went to local health units, a substantial amount of it for public education. In the spring of 1988, the province also established an AIDS hotline, taking over from the City of Toronto's information line, in turn an inheritance from the early years at ACT. The infusion of funds into AIDS programming at the end of 1987 had also led to the establishment of a more systematic community group funding program. The budget for this program was \$1.4 million in the 1988-89 fiscal year, and grew to \$3.7 for 1990-91.

As was the case with the City of Toronto, giving funds to community groups was a new departure for the Health Ministry. In fact, a special AIDS section established within the Public Health Branch of the ministry has been generally considered as somewhat deviant from the normal routines and culture, and somewhat suspect for that reason. The prevailing culture is somewhat similar to the traditional epidemiological and medical model prevalent in the Health Protection branch, although perhaps not quite as strongly resembling a policing approach to disease. When Richard Schabas, the province's Chief Medical Officer of Health, recommended in early 1990 the reclassification of AIDS as a "virulent" disease to grant powers of quarantine to health authorities, he confirmed the worst fears of activists about. This statement, in combination with his earlier argument that sex with a condom is unsafe, accentuated fears among AIDS community groups that his office would abuse the reclassification. His opposition to anonymous testing further widened the gap. Those views appear to be dominant in the Public Health Branch, and may be even more widespread in other parts of the Health Ministry. The AIDS "manager" for the province -- Evelyn Wallace -- is another official held in low esteem by most area community group leaders, and she may in fact share some of the health care professionals' distrust of community activists. Nevertheless, she is considerably more flexible on some issues than her superiors and many of her colleagues outside the AIDS Section.

When, at the end of 1988, the Health Ministry organized a "consensus" conference on AIDS, bringing together researchers, community group representatives, public health officials, and other policy makers, division was at least as apparent as agreement. As had always been true at the federal level, the issues which struck most directly at traditional medical and public health models of controlling the spread of disease were the most contentious -- issues having to do with anonymous testing, with drug testing, and the like. The conference may well have introduced some important

players to one another, but it fell far short of developing an integrated policy network on AIDS.

In 1989, the province established the Ontario AIDS Advisory Committee (OAAC), in the place of the previous Provincial Advisory Committee (OPACA) and its education sub-committee (OPEPA). The expanded membership of the new committee ensured strong representation from community groups and primary care physicians, giving voice to individuals and interests sharply at odds with the norms which prevailed in most parts of the ministry. That, combined with the arrival of a new minister intent on being well-briefed on AIDS, opened up some opportunities for change. In April 1990, for example, the province approved the establishment of anonymous testing at selected sites across the province, as part of a study of the issue.

### British Columbia

In B.C., the province's most important AIDS official had less problematic relations with community groups, with a perspective on a range of issues less at odds with them than existed in Ontario. The problem continued to be the Social Credit politicians at the head of government. Only in the spring of 1990 did provincial authorities even begin a consultative process as a preliminary to the establishment of a provincial AIDS strategy. In 1989, one of the province's Social Credit ministers likened AIDS to a self-inflicted wound, and the Health Minister then suggested that some people's lifestyles have "invited" the disease. B.C. remained the only province charging people for AZT, and still made only modest contributions to the work of AIDS community groups. Some political shift was apparent, though, even in B.C.. A new Health Minister was appointed in 1989, one who was not as personally resistant to sexual or gay-related issues. The matters which most divided community groups and the government were actually being debated within the government, with some signs of movement.

### Quebec

There were a couple of important changes in Quebec during this period. In 1989, Marc-Yvon Cote replaced Therese Lavoie-Roux as Health and Social Services Minister after the September 1989 election, and from the beginning established a new tone with respect to AIDS. He seemed much more comfortable talking about the whole range of issues implicated by AIDS, and seemed to have an ear open to a wider range of voices. Earlier that same year, the Quebec government centralized all of its AIDS-related responsibilities in the Centre Quebecois de Coordination sur le SIDA, and instructed it to coordinate programs, not only with the various agencies in the decentralized health care system, but with community groups. The government committed itself to spending \$7 million a year for the next three years on AIDS. In the 1989-90 budget, about \$1 million was given to community groups (less than a third of the Ontario figure for the 1989-90 fiscal year), a figure which was to include funding for a new AIDS shelter in Montreal.

Still, the establishment of the Coordination Centre did signal a new departure for Quebec, and a number of initiatives long delayed by governmental inaction were under way by 1990. For example, there had been considerable reticence about the development of AIDS programs in a few of the province's Catholic school boards, particularly the Montreal Catholic School Board. But by 1990 the Coordination Centre was cooperating with the provincial Education Ministry in developing programs that would be imposed on school boards across the province.

## Developments at the Federal Level

Despite the creation of the Federal Centre for AIDS in 1987, and the commitment of \$39 million for a range of programs, trouble loomed on the horizon for the Minister of Health and Welfare. Critics were growing in their demands for government action, and for the development of a coherent national strategy, becoming more accomplished in their tactics. In part, this reflected the changing and growing demands of the AIDS epidemic itself. Anger with the federal government peaked in the late 1980s, contributing to the pressure to remove Jake Epp as minister and replace him with Perrin Beatty, a far more receptive and aggressive colleague.

The first sign of trouble emerged in early 1988, when a key member of the National Advisory Committee on AIDS, Norbert "Nobby" Gilmore, resigned in frustration. Although federal officials and politicians often pointed to NAC-AIDS as the government's key advisory body on AIDS issues, in reality it reported only to the Federal Centre for AIDS and not directly to the minister, and had neither the resources nor the strategic location to develop and press for policy change along the full spectrum of issue areas engaged by AIDS. NAC-AIDS was still seen by key officials as having an advisory role only on medical and scientific issues, and as having an essentially apolitical role in the process.

The next major development, as already indicated, was at the May 1988 National Conference on AIDS, sponsored jointly by the Federal Centre for AIDS, the Canadian Public Health Association, and the Canadian AIDS Society. It was, by all accounts, a tumultuous event. AIDS Action Now! spear-headed protests which culminated in the burning in effigy of Jake Epp -- an incident that received extensive media coverage. Dr. Alistair Clayton, the director of the Federal Centre, tried to express his sympathy with protesters by marching with them at one point, and by committing his life to the fight against AIDS, but his inaction and obstructionism in the years leading up to that moment gave neither his words nor his actions credibility.

The government now seemed to recognize that some damage control was needed on the AIDS front. In June 1988, less than two months after the National Conference, the Health Minister announced that an additional \$129 million would be committed to AIDS, spread across a five year period. In January of the following year, following a late 1988 federal election, Jake Epp was replaced as Health Minister by Perrin Beatty, who was personally more comfortable with the issues presented by AIDS (as well as with abortion, another high-profile issue at the time). He was a young minister widely rumoured to have prime ministerial ambitions, so much was at stake in his putting the AIDS house in order.

In May 1989, the AIDS Community Action Program (ACAP) was announced, channelling a total of \$4.7 million to community groups. It was during the same month that the Treasury Board (the cabinet committee responsible for managing the civil service) produced its AIDS guidelines for managers and employees, although it is not clear that Beatty had a hand in the policy. In June, the new minister addressed the Vth International Conference on AIDS in Montreal, and used the occasion to promise that his department would produce a national strategy on AIDS before the end of the year. This announcement took his officials by surprise, and some of them felt that he was caving in unreasonably to community group demands. They felt the same when Beatty acquiesced to several Members of Parliament asking for the pursuance of the AIDS issue through the development of an ad hoc parliamentary committee, a relatively unusual procedure generally thought by government members to be hazardous.

Changes also occurred at the Federal Centre for AIDS, reflecting an increase in sensitivity to the social and community dimensions of the disease. Although the

Centre's director remained unconvinced of the importance of those issues, several staff with experience in dealing with community groups were hired, partly to administer grants to national groups. At about the same time, the mandate of NAC-AIDS was expanded to include advice on behavioral, ethical, and legal issues, and its membership expanded to include PWAs and representatives from community groups.

In October 1988, the Health Ministry received a working discussing document from a team of consultants commissioned to assist in the development of a national strategy. The document, though, was widely perceived as inadequate, and its preparation seen as having delayed unnecessarily the preparation of a strategy. The impatience fuelled by this delay was increased by delays in community group funding early the following year, adding further pressure on officials to develop something that could be labelled a national strategy as quickly as possible, though it was soon clear that nothing would be ready before the summer.

When a delay in the delivery of a strategy first became clear, late in 1989, the Ad Hoc Parliamentary Committee on AIDS decided that it would produce a report proposing what might constitute the components of a national strategy. The committee, which had started as an informal group of over twenty members from both the House of Commons and the Senate, had coalesced into a more formal and determined body. The minister could have neutralized the ad hoc committee by establishing a standing committee, which would have had a clear Conservative majority on it -- one unlikely to have embarrass the government -- but the risk of being seen to have muzzled a new forum for debate was probably too great. The committee initiative public hearings in March 1990, and a number of community group representations were made.

Through this period, the Canadian AIDS Society was loudly critical of the government for its low level of AIDS funding and its delays in producing a national strategy. Tensions were intensified when Beatty and his officials were slow in responding to calls for a boycott of the VIth International Conference in San Francisco - a boycott to protest discriminatory U.S. immigration policy that was by then supported by the Canadian Public Health Association, the Canadian Red Cross, the City of Toronto, the Ontario government, and other groups and agencies. The federal government, though, was wrestling with the embarrassing fact that Canadian immigration policy had its own restrictions, though not enforced as vigorously as the American. The government's reluctance to stand on a relatively "easy" issue dampened hope among community groups that policy towards AIDS in general would improve.

In early June, the Ad Hoc Parliamentary Committee released a report which was favourably received by a number of AIDS activists. Confronting a Crisis was critical of the federal government for the inactivity of a Federal/Provincial/Territorial Advisory Committee, which had not met since Beatty was appointed Health Minister. Greater inter-governmental cooperation was called for in a number of areas, including public education programs and drug policies. It called for the inclusion of sexual orientation in the Canadian Human Rights Code, the development of programs for federal prisons, and the creation of a national treatment registry, an idea originating with Toronto's AIDS Action Now!. It also called for a broader mandate for NAC-AIDS, one which would include political advocacy. The Health Minister was no doubt displeased that the report would increase expectations about the impending national strategy, particularly because of its recommendation of a four-fold increase in AIDS funding.

Already, though, administrative changes were being effected within his own ministry to raise the profile of AIDS. Richard Di Cerni, a senior official thought to be a trouble-shooter and problem-solver, was appointed early in 1990 as Senior Deputy

Minister, with responsibility over AIDS policy. His previous position at the Department of the Secretary of State entailed oversight of funding programs for community groups in a wide range of fields, a number of them touching on human rights and minority rights issues, so that his appointment was a clear signal that relationships with community groups were to receive a higher priority than they had in the past. An AIDS Coordinator Office was established to report directly to Di Cerni, its primary objective at the outset to provide better coordination between the various branches and directorates within the ministry working on AIDS, including the Federal Centre for AIDS, the Health Promotion Branch, the Drugs Directorate, and the Medical Services branch, as well as with agencies outside the ministry. That staff person, too, came from Secretary of State, with extensive experience working with community groups.

The long-awaited announcement of a national strategy occurred on June 28th, at the annual meeting of the Canadian Public Health Association. A specific commitment of \$7 million was made to the creation of a national treatment registry, an idea pressed hard by AIDS community groups which sought the establishment of a system by which information about treatments could be exchanged and elaborated. Though still in its infancy, the idea was included proposal was adopted in large measure to create a sense of innovative action. The minister's announcement also included the creation of a Clinical Trials Network to induce drug testing by pharmaceutical companies, although in fact the Network had first been announced months before. The strategy also indicated a substantial increase in funding for community groups, including the Canadian AIDS Society. A number of AIDS activists and government officials at the provincial and local level expressed cautious approval of the general directions taken in the strategy, in part because the language used in the announcement included comfortable references to "gay" and "lesbian," and spoke warmly of the contributions made by community groups to the AIDS fight.

But to the disappointment of many, no new money was added to the federal government's AIDS budget. Funding for the programs that were specified was simply re-allocated from other areas, some of it from research and education programs. The failure to add new money raised some doubts about Beatty's clout within the Conservative cabinet, and the strategy's increased attention to community groups struck some as intended to coopt those groups or temper their criticism of the federal government. It is widely believed that the minister must secure additional funding from cabinet colleagues well before the expiry of funding presently committed, in the 1992-93 fiscal year. There will also be pressure to add enticements to pharmaceutical companies to test new drugs in Canada, and to alter the Emergency Drug Release Programme in ways that accommodate both the concerns of ministry officials and the interest of community groups in compassionate drug release. A number of observers expect most policy moves to be largely symbolic, deflecting criticism more than initiating major new programs. One such step, having largely symbolic significance insofar as AIDS is concerned, is the amendment of the Canadian Human Rights Code to include sexual orientation, a matter within the jurisdiction of the Justice Minister but apparently supported by the Health Minister.

## **Assessments**

During the late 1980s, AIDS continued to occupy a prominent place in newspapers and on television, with the public eye on the one hand still harbouring fears about the disease and on the other hand still identifying the disease as affecting only homosexuals and IV drug users. One of the most significant changes during this most recent period, though, was an increase in the preparedness of politicians to deal

with the issue in public. Indeed, a number of strategically-placed politicians came to the view that they could no longer afford in electoral terms to remain silent, and that it was imperative to take action and to be seen to take aggressive action on AIDS. The shift in perception came in part from the strategies and improved organizational skills of AIDS community groups such as CAS, AIDS Action Now!, and PWA groups across the country.

On the front lines, the pressure on primary care physicians was increasing. The caseload of those doctors who had developed some expertise in AIDS was extremely high and growing. Patients were living longer, too, and needing a wider range of treatments and care. HIV/AIDS patients were becoming more informed, and were more and more prepared to challenge health care professionals. Physicians in the field were being faced, then, with an increasing number of burdens and challenges, made heavier still by the overwhelming amount of paperwork associated with obtaining experimental drug treatments. The national treatment registry was a long-overdue policy development designed to meet some of the difficulties faced by medical practitioners, although it is still too early to know how helpful it will be.

During the late 1980s, the most dramatic policy changes occurred at the federal level. Much energy of AIDS activists had been directed at the Minister of Health and Welfare in the years leading up to 1990, and some signs of movement appeared soon after the appointment of a replacement for Jake Epp. Administrative changes and the announcement of a shift in policy direction in the national AIDS strategy indicate a federal recognition that more had to be done on AIDS. The departure of Alistair Clayton from the Federal Centre for AIDS late in the summer of 1990 sent a further signal to the same effect.

### Conclusion.

One of the most remarkable features of the 1981-1990 period has been the growth of gay-dominated AIDS organizing. At the beginning of the epidemic, substantial fears were expressed in Canada and elsewhere that the recent gains in gay rights would be rolled back by a New Right re-invigorated in its attacks against gays and lesbians by the spread of disease. Equally strong fears were expressed that AIDS would decimate the gay community, and demoralize it. The cost in human lives has in fact been staggering, though nothing on the scale of the United States. But the epidemic has strengthened gay and lesbian community organizing, attracting to AIDS work people who had never been involved in community organizing, and developing skills on an unprecedented scale.

The high gay percentage of Canada's AIDS cases has intermingled gay and AIDS organizing inextricably, and in a number of ways the need to combat disease and fears about sickness have raised the profile of a number of gay-related political issues. The entrenchment of protections against discrimination on the basis of sexual orientation have gained more support than ever, not only amidst the general public, but among politicians of varying political stripes. The extension of federal human right protections to lesbians and gays is now a real prospect; three years ago it seemed not to be. School educators in a number of Canadian cities now talk to their students more frankly than ever about AIDS, and in some cases about homosexuality, though resistance on that score remains substantial.

The most important contribution of AIDS community groups, however, has been to challenge the established ways of dealing with sickness and epidemic. The initial responses to AIDS in a number of provincial governments, and the continuing response of the federal government until 1990, fit into a traditional model of health care delivery



that had been used on countless epidemics in the past. For the first time, public authorities now confronted a well organized community and an articulate, well organized group of people with AIDS. The community response was not always in a single voice, but over time, the diverse voices began complementing one another, the whole ensemble gaining considerable support in the media and among reformist politicians and bureaucrats. A number of public health officials in such cities as Toronto and Vancouver and in some provincial capitals soon recognized that the traditional responses would not work for a disease that affected the gay community the way this one did. Standard operating procedures dealing with testing, with confinement of patients, with public education programs -- all were challenged by AIDS community groups. The traditional focus on the not-yet-infected, to the neglect of the presently-sick -- that too was successfully challenged and a certain balance restored. While at first the epidemiological character of the disease may well have constituted a set-back for reformist public health thinking in this country, the work of gay-dominated community groups helped in the medium term to strengthen that kind of reformism.

In characterizing the evolution of AIDS policy as a confrontation with traditional practices in the medical and public health establishments, it is important to recognize that governments have not been monoliths. There have been heroic figures lodged within all three levels of government who have fought to change the way AIDS was being treated. There have been some who have found considerable flexibility in public health apparatuses and used existing procedures to good effect. Some officials kept working in a low profile way, within existing procedures, to avoid what they feared as a political backlash, and they may well have been astute in doing that. An enormous variety of participants in the process of making or administering AIDS policy now recognize the length of the delays in responding to the epidemic. Some delays came from officials finding comfort in traditional bureaucratic routines. "The Federal Centre for AIDS," as one official commented, "always went through the right channels, and ducked the issues."

The failure of political leadership around AIDS in a number of key Canadian jurisdictions has been notably, most obviously at the provincial level in British Columbia and at the federal level. In the last few years, those politicians who have pretended that they could completely ignore the issue have become a small minority. Health ministers in Ottawa and Victoria are now having to speak about AIDS, and are talking of policy directions that would have been unthinkable two or three years ago. The motivation in some cases is personal contact with the disease. What is remarkable in the Canadian setting, however, is that political expediency now virtually requires attention to AIDS. More and more politicians in health-related ministerial portfolios now appear to believe that AIDS is inescapable as a major policy issue, and that to pursue policy in this area without taking account of community group views and interests is extremely dangerous.

The federal system has sometimes made for confusion and lack of coordination. On the other hand, the involvement of three levels of government has provided openings for community groups and has provided opportunities for innovation in policy. Provincial and local governments have to some extent learned from one another in their AIDS policies, and some have felt impelled to outdo rivals in other regions or at other levels of jurisdiction. The unevenness in regional response has meant that people with AIDS in some parts of the country are less well served than others. The medicare system imposed by the federal spending power, though, has reduced the unevenness in medical care, leaving fewer PWAs to fall through the cracks than, for example, the United States.

The struggle over AIDS policy has brought a large number of groups and agencies into often conflictual relationships with one another, sometimes cooperative. The shift in policy over the first decade of the epidemic has been largely a product of the confrontation of large scale forces. But it has also entailed heroic acts by individuals in strategic locations, sometimes working with subtlety out of the public limelight, some of them thrust for the first time into the limelight. Some officials and politicians have confronted their own homophobia and their own prejudices about health care delivery in the process of working on AIDS policy issues. People living with AIDS have often found themselves taking charge of their own lives and their own medical care, taking active speaking roles instead of playing the passive recipients of expert advice and care.

1. Toronto Star (11 August 1983), p. A15.
2. Globe and Mail (12 September 1983), p. 9.
3. The Body Politic (July 1985), p. 13.
4. Quoted from Newsweek by Rick Bebout in an October 1985 story in The Body Politic, p. 31.
5. 80.3% of cases arose from homosexual or bisexual activity; and additional 2.5% of cases came from people who used intravenous drugs and who engaged in homosexual activity.
6. Over time, attitudes within the Health Ministry shifted to some degree. Later, even the Communications branch recognized the need to equip themselves to deal with public inquiries.
7. Stan Persky, "AIDS and the State," This Magazine. As Persky comments, opposition to at least the most draconian of the amendments came from the BC Civil Liberties Association, from researchers at St. Paul's, and from the staid BC Medical Association.
8. AIDS Research Program, McGill Centre for Medicine, Ethics, and Law, Responding to HIV/AIDS in Canada (Toronto: Carswell, 1990), p. 4-3.
9. Soskolne, "A Canadian Retrospective on AIDS," p. 23.
10. Soskolne, "A Canadian Retrospective on AIDS," p. 21.
11. The office was overseen by a committee of assistant deputy ministers, to ensure that it had a department-wide mandate, and to some extent this oversight balanced the influence of the LCDC's director,
12. The Body Politics (August 1986), p. 15.
13. The Body Politic (December 1985), pp. 15-16.
14. "An Interview with Philip Berger, M.D.," Grail 5, no. 1, pp. 21-2.
15. Toronto Star (23 December 1989), p. 1