THE FUTURE OF HEALTH CARE: LESSONS FROM THE AIDS MOVEMENT

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The 1990s are seeing health care systems scrutinized and rethought at many levels. In Windsor and Essex County, the District Health Council is directing a reconfiguration of health care which is couched in the highly optimistic terms of a "Win/Win Solution." However, the major dynamic driving this rethinking of health care delivery is actual or anticipated cutbacks in government funding.

The AIDS movement has important lessons to contribute to debates about the future of health care. The activist response to AIDS has produced a challenge to the established social relations in health care. The central focus of the AIDS movement has been to promote the control of people living with HIV/AIDS over their own bodies and lives. This has meant challenging the power of experts (such as doctors) and state officials to decide what is best for those affected by HIV/AIDS. This challenge has been accomplished through various forms of collective mobilization.

There is much of value to be learned from this challenge to the health care system. There is also, however, reason to fear that the wrong lessons will be learned in the present context. The AIDS movement was not about developing 'community-based' alternatives to the medical system. People living with HIV/AIDS need extremely expensive high-technology medical care as well as a variety of community-based services providing information, support, education, and advocacy. There is a great danger that policy-makers will use the rhetoric of the AIDS movement to put a progressive gloss on a straightforward reduction of services.

People living with AIDS in the early years of the epidemic faced blame, rejection, condemnation, inaction, and indifference at the highest levels of the health care system and the state. They organized, along with others affected by the epidemic, to struggle against that response. It would be the ultimate disservice to this mobilization to use it as a cynical justification for cutbacks to health care services. The real
lesson of the AIDS movement is not about the effectiveness of community-based services, but rather about the relationship between health and social justice.

The AIDS Movement — Official Inaction

The AIDS movement developed as an already politicized community mobilized to confront the epidemic in the face of official inaction. AIDS was first constructed as a syndrome in 1981 based on the reporting of clusters of cases of PCP and KS among gay men in New York and San Francisco. From the outset, AIDS was constructed as a 'gay disease.' Indeed, one of the early names given to the syndrome was GRID (Gay Related Immune Deficiency). In more popular terms it was known as 'gay cancer' or 'gay plague.'

The construction of AIDS as a 'gay disease' had an enormous impact on its development. The initial official response by governments in Canada, the United Kingdom and the United States was silence and inaction. The early years of the epidemic (approximately 1981-1985) saw virtually no government action in the areas of treatment, prevention or advocacy for people living with HIV/AIDS, not even in the limited form of official pronouncements that identified the problem. Many sources argue that this initial phase of inaction was connected to the construction of AIDS as a gay disease which would do no damage as long as it didn't bridge over into the 'general population.'

The silence of this period was broken only for bouts of 'just say no' moralizing. AIDS was presented as the symptom of a moral problem, to be treated by campaigns which promoted rectitude through fear. Early British AIDS campaigns, for example, employed dire images of death to show the dangers of AIDS, yet offered no concrete advice on how to prevent infection except to avoid 'promiscuity.' Gay men were told to avoid sex rather than how to have sex safely. This reflected an attitude that gay sex was something that could (and perhaps should) be avoided. It is difficult to imagine a similar injunction against heterosexual sex.


Of course, AIDS is not the first medical condition to be approached in moral terms. Early in the twentieth century, tuberculosis was regarded as an indicator of 'moral degeneration' among the working classes in the urban centres of Britain, Canada, and the United States. AM Brandt discussed the parallels between early AIDS campaigns and those mounted against sexually transmitted diseases at the time of World War I. This moral dimension to public health campaigns has generally focused the blame for ill health onto those who suffer from it, shifting the spotlight away from the social conditions which promote ill-health (such as poverty) or the gaps in health care delivery.

The response to AIDS in terms of inaction combined with 'just say no' moralizing is very much connected to the construction of it as a 'gay disease'. From the earliest days, AIDS was associated with an 'epidemic of blame' which has impaired prevention and treatment endeavours. Preventive efforts have been hampered by an unwillingness to speak frankly about gay sex (or sexuality in general) combined with a resilient belief among heterosexuals that a 'gay disease' could not infect them through straight sex. Treatment has been impeded by the persistence of AIDSphobia, the irrational fear of AIDS. The rational fear of AIDS, based on the use of effective measures to block the known routes of transmission, can help combat new infections. In contrast, the irrational fear of AIDS leads to various forms of 'quarantine' based on totally unfounded fears of casual contagion.

AIDSphobia has been remarkably resilient despite improved AIDS education. This resilience can be explained largely in terms of the correlation between AIDSphobia and homophobia, prejudicial attitudes against lesbians and gay men. Studies show that individuals with anti-gay attitudes are far more likely than others to have irrational fears about HIV transmission.

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The construction of AIDS as a gay disease has been maintained despite many kinds of evidence to the contrary. Cases of AIDS were identified among people who were not gay in the very early days. Scientific knowledge of the routes of transmission for HIV clearly shows that unprotected heterosexual intercourse is a high risk for both partners. The vast majority of cases worldwide (75 percent according to the World Health Organization) result from heterosexual transmission. It is still true in Canada that the gay male community has been the most affected by AIDS, but it is only through homophobia that this statistic is transformed into a myth of heterosexual immunity. Anti-gay attitudes underlie the deeply-held belief that 'normal' sex is somehow inherently safer.

Community Mobilization

The construction of AIDS as a gay disease has had tragic consequences. The lives of people with HIV and AIDS are made far more difficult by the presence or anticipation of discrimination and irrational fears. Many people have been infected when that might have been prevented through effective intervention. Others carry on with unsafe activities with the false assurance that their 'normalcy' will save them.

At the same time, the development of AIDS in an already politicized community has led to important mobilizations in response to official inaction. These mobilizations, which I collectively label the 'AIDS movement', have ranged from informal networks through which people living with HIV/AIDS share knowledge about treatment to formal organizations which offer services (like the AIDS Committee of Windsor) or concentrate on political action (like AIDS Action NOW or ACT UP). The AIDS movement first developed in lesbian and gay communities, usually drawing on the skills and perspectives of people who had some experience in advocacy, community-building or political organizing.

The significance of the development of AIDS in an already politicized community goes beyond the presence of a skills base and an inventory of existing organizations. The AIDS movement built on the legacy of previous struggles for lesbian and gay rights. This legacy contributed to the development of an orientation to issues of health and illness, particularly around issues of the state, medical expertise, and the importance of collective action.

First, the AIDS movement developed with a somewhat oppositional approach to the state. The struggle against various forms of state
regulation has been a central feature of the lesbian/gay movement. People who had fought against censorship and police harassment were unlikely simply to trust the goodwill of states that would not even recognize their rights or their relationships. Certainly, the AIDS movement has made demands on the state (for funding and services) but it has generally opposed measures that would increase state power over people living with HIV/AIDS (such as reporting by name the people who test HIV positive to public health authorities).

Secondly, the AIDS movement has been highly critical of 'experts' in general and medical practitioners in particular. Through much of the twentieth century homosexuality had been pathologized, treated as an illness. It was only in 1973 that the American Psychiatric Association removed homosexuality from the list of mental illnesses. People were unlikely to hand themselves over without reservations to a medical system that until quite recently had been trying to 'cure' them of being gay.

Thirdly, the lesbian/gay movement had taught people the importance of collective action. The contemporary lesbian/gay movement grew out of the Stonewall riots in June 1969. The gains that lesbians and gays have made since Stonewall can be attributed to the militancy and activism that have shaped the movement at its highest point. This experience in building a social movement provided a framework for responding to the AIDS crisis. AIDS could not be approached as an individual medical problem to be dealt with only through health care. Only a collective response could challenge the inaction and the prejudice that confronted people living with HIV and others affected.

Challenging Health Care

The accomplishments of the AIDS movement have been crucial for people living with HIV/AIDS and others affected. The first accomplishment was the invention and popularization of safer sex education. The seminal 1983 pamphlet "How to Have Sex in an Epidemic" by Berkowitz, Callen and Dworkin is regarded as the first serious guide to the safer sex practices that are commonplace today. These practices


did not originate with public health officials, who in the early period had focused basically on anti-sex and anti-promiscuity messages. The safer sex message was carried into the community by AIDS organizations who developed innovative, appropriate, and erotic ways of disseminating it in a variety of situations. The result was one of the most successful behavioural change campaigns in public health history. The use of safer sex among members of the gay male community is impressively high, even if there is still important work to be done in certain areas.

The second important accomplishment of the AIDS movement was the development of a network of support and advocacy services for people living with HIV/AIDS. AIDS service organizations across North America formed support groups and offered other services such as case management. Buddy systems linked people living with HIV on a one-on-one basis with trained volunteers who could help in a number of ways ranging from daily chores to personal discussion. AIDS service organizations acted as advocates for people living with HIV/AIDS in their dealings with the health care system, government services and other institutions. This has contributed to breaking down the isolation of people living with AIDS, provided a single point of entry to the wide variety of health and social services that may be required and challenged discrimination in treatment and service provision.

The third area of accomplishment for the AIDS movement has been in the dissemination of treatment information. AIDS-related medical conditions are particularly complex as they consist of a whole range of opportunistic infections developed in response to immune deficiency. It is a tremendous challenge for anyone to keep on top of this very wide range of medical problems as well as ongoing treatment developments. People living with HIV/AIDS often learned more from informal folk networks of peers than from their doctors. These networks have been formalized and it has become a major priority for AIDS services to get useful and accessible information into the hands of people living with HIV/AIDS.9

A fourth accomplishment of the AIDS movement has been winning demands for improved funding and services. Following the period of official inaction, the late 1980s and early 1990s saw a tremendous increase in funding to AIDS services as well as the release of

9See, for example, the impressive self-help publication, M Whitehead, and B Patterson, Managing Your Health: A Guide for People Living with HIV or AIDS (Toronto: Community AIDS Treatment Information Exchange and The Toronto People Living With AIDS Foundation, 1993).
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experimental treatments and other important changes. The AIDS movement succeeded in placing considerable pressure on governments, drug companies and other organizations. These improved levels of service are certainly at risk as the wave of cutbacks sweeps through health, education, and social services in Canada, the United States and elsewhere.

Finally, the AIDS movement has succeeded in developing new ways of grieving appropriate to the memories of people who have died from AIDS-related causes and to those they leave behind. This has included the development of innovative forms of memorial service for individuals as well as public projects such as the AIDS quilts in the United States and Canada and the AIDS memorial in Cawthra Park in Toronto. At their best, these memorials have combined specific recognition of individuals who have died with a general sense of community loss, particularly in lesbian and gay communities where the losses have been devastating. They are often secular in tone, reflecting the diversity of the communities who have most directly felt the losses and the exclusion that members of these communities have felt from traditional religious institutions.

These accomplishments add up to a challenge to the social relations which shape health care in contemporary society. The AIDS movement has used collective action to increase the power of those whose health is at stake over their own bodies and lives. This has meant making the resources and information available to people affected so that they can make choices about treatment and prevention. The emphasis on the active role of those whose health is at stake is demonstrated even in the terminological preference for the label 'people living with HIV/AIDS' rather than 'AIDS victims' (implying passivity) or 'AIDS patients' (describing only a specific location in medical relations). 10

The debate about HIV testing in the late 1980s and early 1990s provides an important example of the challenge mounted by the AIDS movement. 11 At that time, AIDS organizations generally supported anonymous testing which would permit people to find out their HIV status without providing identifying information that could be reported to public health officials. The test was exclusively for the use of the people being tested, permitting them to control completely information concerning the results. The AIDS movement argued that anonymous


testing would provide the conditions under which more people would come forward to get tested as the first step in a process of taking control over their health.

Public health officials often opposed anonymous testing. They tended to support procedures compatible with the reporting of HIV-positive cases. They wanted to know who was infected to permit the tracing of previous sexual contacts and to monitor safer sex practices. AIDS activists fought against the use of these traditional public health practices on the grounds that they compromised the privacy and safety of people living with HIV/AIDS. They were concerned that these procedures might drive people underground, creating a situation where it was preferable to forego testing in order to avoid the intrusion of public health officials. In Ontario, the AIDS movement won on this issue and anonymous testing is now available at numerous locations across the province, including sites in Windsor.

None of this would have been possible without the support and participation of committed individuals within the health care system. The AIDS movement has, to a large extent, approached the health care system as an outsider, but it has relied the work of insiders in many areas. In cities across North America particular doctors and nurses invested tremendous time and good will in the up front learning required to assist with the medically highly complex treatment of people living with HIV. The AIDS movement has not necessarily been anti-medical, though it has certainly been highly critical of the health care system and the medical establishment.¹²

The AIDS movement did more than fill the vacuum left by official inaction. It developed an approach to health care that challenged established social relations in medicine. The movement's origins in the lesbian/gay community contributed in crucial ways to this approach. Yet this has also raised issues as the face of AIDS changes. It could be argued that a coalition model has been followed (with more or less success) in work with other politicized communities (women, ethno-cultural communities). This has certainly created stresses and strains and battles about priorities, though it has also produced some very useful programs that have taken the AIDS movement's approach in appropriately adapted forms to new communities.¹³ The issue of how

¹²There is a current within the AIDS movement which is avidly anti-science and therefore anti-medical. The debates about the relationship of the AIDS movement to science and medicine lie outside the parameters of this paper.

¹³There has been a specific debate around the 'de-gaying' of AIDS: E Rofes, "Gay Groups vs. AIDS Groups: Averting Civil War in the 1990s," Outlook 2, no.
this model relates to communities who are not organized and politicized (e.g. injection drug users) or those outside the parameters of organized communities (e.g. men who have sex with men but do not identify as gay) remains an important one which has not been fully addressed.

Health Care and Control

The AIDS movement is not the first to mount such a challenge to the relations of health care. There are notable parallels with the women's health movement and the struggle for workers' health and safety. In each of these cases, health issues emerged in an already politicized context with pre-existing forms of organization. The women's liberation movement of the 1960s produced the women's health movement, while health and safety struggles have been connected to workplace organization, particularly unionization.

The struggle for information played an important role in these movements. The women's health movement saw the publication of important sources such as the book, Our Bodies, Ourselves, which aimed to educate women so that they could take charge of their own health. The 'right to know' has played an important part in health and safety struggles, where workers demand accurate information about the risks associated with dangerous materials or situations. As well, each of these movements has gone beyond the right to know to demand the power to act. Unions have fought for the right to refuse unsafe work. Women's organizations have fought to develop the basic services (abortion clinics, women's health centres) required to offer women genuine choices.

Each of these movements has developed some embryonic form of the politics of health 'from below.' The central feature of this set of politics is an emphasis on people taking control over their bodies and lives through collective action. It is a challenge to the idea that health comes 'from above,' through the actions of the state or the medical system. Certainly, the struggle for health 'from below' necessarily includes demands for full access to comprehensive health care services.

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4 (1990): 8-17. Critics such as Rofes argue that the AIDS organizations have been ditching their lesbian/gay identities in order to 'pass' as health agencies. These critics see a broader focus for the AIDS movement, not as a step in the direction of inclusiveness but rather as a capitulation to homophobia.

14 These parallels are explored in detail in Sears, "Contradictions," 41-42.

It also includes demands about the way these services are organized, challenging the power relations implicit in the medical model, such as the control exercised by experts. It goes demanding a role for 'consumers,' a very popular term in health care planning drawn from the market place which describes the place of individuals in the purchase of commodities. The model of shopping does not place sufficient emphasis on the idea of people whose health is at stake as activists on their own behalf.

It is important, in the current context, to distinguish health-care-from-below from health-care-on-the-cheap. The critique of the social relations of health care can be appropriated to serve as window-dressing for cutbacks. That is certainly what happened through the program of psychiatric de-institutionalization in the 1970s and 1980s. Governments took up the language of community-based alternatives as they shut down repressive psychiatric institutions. They did not seriously engage in the development of alternatives and in the end people wanting or needing help for mental health problems were left with fewer available services. Paul Martin's 1995 budget makes it very clear that we are facing a context of cutbacks in which it is logical to suspect that any shift in the organization of health care delivery is simply a way of packaging service reductions and lay-offs.

People living with HIV and AIDS have benefitted from top quality hospital care as well as community services. No number of buddies, support groups, or case managers can replace good hospital treatment and care for those who need it. The aim has been to improve access to medical services, not to erode them. No amount of treatment information can replace the diagnostic and therapeutic skills of medical professionals. The aim has been to challenge the experts' monopoly on knowledge, not the existence of experts.

The final lesson from the AIDS movement concerns the limits of health care. It is possible to challenge and improve health care, to make demands for full access to comprehensive health care under the control of those whose bodies and lives are at stake. It is possible to win some victories that lead to genuine reforms However, these reforms can only go so far in a society based on inequality.

For people to be truly healthy, we need a healthy society. On a global scale, poverty is the sharpest indicator of risk for HIV infection.

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( the poorer someone is, the more likely he/she is to be infected ). The 1990s are seeing an intensification rather than reduction of poverty on a global scale. People living with HIV/AIDS will suffer from deep cuts in health care and social programs as well as the erosion of international assistance and chronically high unemployment. The return of public health threats such as cholera and tuberculosis is a sign of a world where absolute poverty is on the increase.

Poverty is not the only manifestation of inequality that is related to ill-health. Discrimination against lesbians and gays has contributed in many ways to the spread of HIV infection, whether through official inaction or the false reassurance among heterosexuals that they could not catch a 'gay disease.' Sexism contributes to ill-health, for example making it very difficult for women to insist on safer sex practices. Racism contributes to the chronic neglect of the health needs of people of colour and aboriginal peoples.

The control over our bodies and lives cannot be achieved through good health care alone. It requires an exhaustive challenge to social relations of inequality at every level of society. The AIDS movement has offered a number of important lessons about what health is and how to obtain it. It has produced important developments in services and programs. It has shown the importance of collective action in the struggle for health. The ultimate lesson of the AIDS movement, however, is that the struggle for health is at the same time a struggle for social justice, against all forms of inequality and discrimination.

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17Sabatier, Blaming Other, 4.