

THE FUTURE OF THE HIV MOVEMENT: SOME CLUES TO FORECAST CHANGE.

A brief literature scan (October 2008)

Introduction

This is not a comprehensive scan, it provides some general clues of where the HIV movement is heading. It can be used to jumpstart and support a dialogue about the future of the HIV movement in British Columbia. We encourage you to distribute it and use it in your organization strategic planning sessions.

In North America services for individuals with AIDS came about mainly from grassroots pressure and organizations. This pressure came from vocal groups consisting of those afflicted with AIDS and their families and friends. Most of those afflicted with AIDS early in the epidemic in North America (late 1970's) were gay males. There was great stigma attached to those with AIDS by religious organizations and the heterosexual population in general. At that time the affliction resulted in illness usually with extreme suffering leading to an untimely death.

Thousands of AIDS service organizations (ASOs) sprung up in North America. The fight for services and treatment by gay militant groups such as ACT UP resulted in such actions as the Government of the United States paying for all drugs and treatment for PWA. Non-medical services in both the U.S. and Canada were usually carried out by non-government organizations. In Canada these usually were not-for-profit. By the late 1990's three major changes have given the HIV movement its current state:

1. In North America, HIV was becoming statistically more prevalent in injection drug users, economically disadvantaged heterosexual minority groups, women, and aboriginal communities; the focus of non-profit work, government services, and research shifted from gays (including bisexual and transgendered persons) to those groups.

2. In North America, improved drug therapies changed AIDS from a life-threatening syndrome assuring significantly shortened life expectancy to an "episodic disability" with intermittent periods of wellness and illness (aging with HIV became a possibility)

3. Governments, funding agencies and individual donors are requiring greater accountability from ASOs. There is more competition for funding and less money in slowing economic times. Long term planning with defined measurable goals is critical for an organization's survival and growth.

In view of the rapidly changing nature of a) AIDS with treatment, b) populations affected and c) funding patterns ASOs must review the needs of the populations they are serving and the significance and effectiveness/efficacy of the services they are providing.

CLUES FROM A BRIEF REVIEW OF LITERATURE

1. Organizational Change

There are a great number of articles on organizational change in the non-profit social service sector. The larger studies and those more relevant to HIV services are cited here.

The Nonprofit Sector Research Fund of the Aspen Institute listed projects funded in 1996 (see Appendix B). Even over ten years ago questions were being asked about the future relevance of nonprofits in their present form. In that year Kramer¹ in his article “Nonprofit Organizations in the 21st Century: Will Sector Matter?” summarizes his project as follows:

The blurring of the boundaries between government, business, and the nonprofit sector during the last 25 years has made obsolete the traditional distinctions between public and private. New types of hybrid organizations have emerged, aided by the policies of privatization.

Twombly² studied the effects on nonprofits in the US during a period of significant welfare reform (1992-1996). He found that there was a large growth in the non-profit sector – most pronounced in the social service sector. He stated the implications of his study as follows:

The limited impact of AFDC programs on the deaths of nonprofit human service providers suggests that many of these groups maintained an adequate level of capacity to meet organizational commitments and client needs. Indeed, many human service nonprofits successfully navigated changing contracting systems during this period. In their study of the finances of a panel of human service nonprofits in 13 states, De Vita and Twombly (1997) determined that the majority of groups had revenues that exceeded expenditures from 1992 to 1996. And while some nonprofits failed during this period, *it appears that their deaths were related more significantly to organizational factors than to socioeconomic conditions or policy changes*. For example, spending by local governments on social welfare; the size and organizational density of local social service systems; and the population of the metropolitan region were not significantly related to the closures of nonprofit providers in urban areas.

Twombly study leaves some interesting questions and a pertinent conclusion quoted as follows:

These findings leave unanswered the questions of whether the growth in the number of social service providers during this period led to more effective or accessible services to those in need, or whether the rapidly increasing size of the human service sector produced a set of organizations that can address the social and economic problems of the hardest-to-serve populations. Moreover, whether nonprofit providers changed their operational strategies during this period to become more akin to for-profit organizations, or varied the quality and quantity of the services, are additional questions to be explored. Nevertheless, the analysis suggests that rapid growth in the human service sector will help to provide low-income residents with a greater array of options to meet their needs.

Chambre (1999)³ studied redundancy, third party government, and consumer choice: HIV/AIDS non profit organizations in New York City. The article “addresses two questions: (a) Why were

so many new nonprofit organizations in New York City created to “fight AIDS?” and (b) What are some consequences of this phenomenon? Drawing on redundancy theory as a partial explanation, it also considers the role of racial and ethnic politics and the impact of government contracting on the formation and growth of community-based organization. *For clients, the effect has been paradoxical: financial support of a large number of organizations led to a complex and fragmented delivery system offering some clients a range of choices but decreasing access for those less able to navigate a complex system.*

Gelb⁴ in her article “Organizational Change and Transformation Success, Survival and Decline among Feminist Groups in the 1990s” writes:

The 1980s marked a major turning point for feminist groups searching for ways to be activists in the face of mounting opposition, financial difficulty, and their own aging. ...women who had been active in the 1960s and 1970s did not abandon their political commitments, but instead found new ways to cope with political challenges, thus allowing feminist movement organizations to survive the 1980s and experience renewed fervor and growth in the 1990s.

There is plenty to learn from feminist organizations and a number of questions: How has the women's movement redefined organizational success? What particular characteristics of the women's movement have sustained the continued success and survival of the movement over time? To answer these questions, researchers interviewed and observed executive directors, board members, and staff from eight national women's organizations, including: Wider Opportunities for Women (WOW), Women's Equity Action League (WEAL), Project on Equal Education Rights (PEER) and National Coalition Against Domestic Violence (NCADY).

The research findings included the following:

- * Successful organizations have been able to fill a unique niche in the movement, establishing clear group identity and issue focus. Coalition building has also helped groups maintain a collective identity and promote survival.

- * Movement organizations share a commitment to continued renegotiation of power relations and goals among all decision-making participants, including board, staff, and program participants.

- * Organizations have diversified funding sources, moving away from sole reliance on predominately federal or foundation sources to other donors. Membership-based groups have sought to increase individual contributions.

- * *Rather than deradicalizing, women's advocacy/lobbying groups have expanded the feminist agenda and their commitment to social change, service, and diversity.”*

2. Changing Nature of AIDS

a. Changing Demographics of PWA

In Canada, the pressure to attend to ethnocultural diversity is increasing. Hamers and Downs (2004)⁵ when reporting on the changing face of the HIV epidemic in Western Europe, state: “Migrants from countries with a high prevalence of HIV/AIDS, notably sub-Saharan Africa, bear a disproportionate and increasing share of HIV throughout western Europe and, in most countries, account for the majority of heterosexually acquired HIV infections diagnosed in recent years. Prevention, treatment, and care must be adapted to reach migrant populations.”

At the International Conference on AIDS Fownes (2002)⁶ reported on “The role of an AIDS service organization within Aboriginal communities.” The issues were reported as follows:

In Canada, HIV and AIDS is devastating Aboriginal peoples. Aboriginal peoples are 5 times more likely to have AIDS than any other Canadian, and 25% of new HIV infections in 1999 were among Aboriginals. Within community-based programming specific to Aboriginal communities, consider the following: Acknowledgement that community members are the experts of their own experiences. Current lack of accessible and culturally appropriate information on HIV and AIDS. Responsibility of agencies to collaboratively address HIV and AIDS with the Aboriginal community. The diversity inherent within the Aboriginal community. The need for ASO's to have role clarification and boundaries within the collaborative process.

A report in *The Body: the Complete HIV/AIDS Resource* (2008) shows new organizations arising due to the changing demographics of AIDS. Reporting on “What’s happening at AIDS service organizations across Canada (Pacific region), two new groups are discussed as follows:

New grassroots initiatives mentor positive women leaders. In spite of excellent services for HIV-positive women in British Columbia, opportunities for these women to be leaders in their own communities have been few and far between. Until now. Two new grassroots initiatives – the Positive Advocacy Project of British Columbia (PAPBC) and SAHWANYA for African women living with HIV -- are by positive women, for positive women[...]PAPBC members currently include Aboriginal women, recent immigrant women, urban and rural women and women living in Northern B.C., the Interior and on Vancouver Island. SAHWANYA is run by and for African women living with HIV in the B.C. Lower Mainland. It first began meeting in June 2007. It was formed because African PWAs may be dying in Vancouver not from lack of access to HIV treatment, but from isolation: ‘It is difficult for immigrant and refugee women to integrate because of poverty, illness, language barriers and stigma in their communities’. Women who have recently arrived in Canada and who speak little English often have difficulty gaining access to services.

There are long-standing reminders that organizations not only need to rebrand and restructure to become appealing and accessible to a diversity of consumers, but they also need to examine their professional values and best practices. In addition, ASO need to continue to reflect on their stigmatized status; it may not have disappeared, it may have only changed. Cain (1994)⁷ in summarizing his paper on “Managing impressions of an AIDS service organization: Into the mainstream or out of the closet?” states:

Organizations, like individuals, can be discreditable and potentially stigmatized. This can affect both the members of the organization and its operation. This study examines how workers in an AIDS service organization in Ontario, Canada, manage its public image as a way of dealing with the stigma which surrounds much of their work. Using data from in-depth interviews with staff members and volunteers, the study describes worker concerns about the appearance of being too closely associated with the local gay and lesbian community and documents some of the strategies they employed to manage the organization's public image.

Cain's paper concludes with a discussion of the relationship between organizational impression management and viability in the context of the stigma and uncertainty which surrounds the HIV epidemic." Cain study behooves us to continue discussing who ASOs need to serve and how much they need to change or stay the same to appeal, attract and effectively serve specific groups affected by HIV.

b. Changes in the Nature of HIV with Treatment

In 2006 the headline of an article in the Epidemics section of Terra daily read, "HIV Life Expectancy Now Normal." Ed Susman⁸ wrote:

A decade ago, when a doctor diagnosed a patient with an infection caused by human immunodeficiency virus (HIV) -- the microbe responsible for AIDS -- that individual faced a bleak and short future. The disease was usually advanced, the treatments were limited and a patient's life expectancy was in the neighborhood of about two years. Today, I can tell my patients with HIV that they can have a normal life expectancy," said Stefano Vella, director of drug research and evaluation at the Institute Superiore di Sanita in Rome [the equivalent of the Canadian Institutes of Health Research, CIHR].

Of course, there are some caveats: the chief one being that a patient has to take the prescribed medicines faithfully (adherence); another, that patients have access to treatment.

Dr. Joseph McGowen⁹ in responding to a query in The Body regarding aging with HIV states:

Recent data indicate that life expectancy is approaching HIV-uninfected rates. It is about two-thirds of HIV uninfected overall, but much of the difference may be driven by people who lack access to treatment or can't maintain an undetectable viral load.

Many questions emerge when the possibility of using HAART as prevention, not only as treatment is put on the table. In addition, local British Columbia scientific research at the Living Well Lab (Friends For Life 2005 – 2008) shows a promising and close relationship between HIV medical treatment and complementary and alternative medicine (CAM) that must carefully considered by ASOs. It may be the case that CAM has come to replace the often neglected "spirituality" aspects of managing HIV.

c. Funding Pattern Changes for Services to PWA

In the article cited above, Kramer¹ stated, "...public funding is often separated from service delivery through contracting with nongovernmental organizations. Because conventional theories and concepts applying to the nonprofit sector may no longer be suitable for this new mixed economy, this project will suggest new research paradigms to understand better the structures and operations of nonprofit organizations and inform social policy."

More than other syndromes and illnesses, AIDS funding in Canada seem to depend on the moral attitudes and philosophy of political parties in power. Connor¹⁰ wrote in the Toronto Sun:

AIDS organizations are using the federal election to try to get Ottawa to restore about \$12.7 million in annual HIV/AIDS funding that was cut by the Conservatives. The Liberals, NDP, Green and Bloc say in a questionnaire that they endorse restoring the funding in HIV/AIDS social supports. The Conservatives did not respond. 'Many Canadians take the measure of our country based on how we treat our most vulnerable citizens,' said Monique Doolittle-Roma, executive director of the Canadian AIDS Society. "Funding for AIDS programs is an important factor in that measurement and one to which all parties made a unanimous commitment in 2005 – it's a promise they should honour. 'Since the signing in 2005 of an all-party agreement, which provided for \$85 million annually in AIDS funding, government support has been cut by an Angus Reid poll done for the national AIDS organizations shows that 91% of Canadians want AIDS funding maintained or increased'.

Statistics Canada¹¹ (2004) in the Canada Survey of Giving, Volunteering and Participating reported that Canadians donate generously in both money and time. The survey found that: "Nearly 8 in 10 (78) Canadians aged 15 and over made at least one donation to charitable and nonprofit organization in 2000. On average, those who donated contributed \$259 each, for a total of \$4.9 billion."

However, the same survey found that in British Columbia:

The majority of charitable donations and volunteer hours came from relatively small proportions of the British Columbia population. Findings from the Survey indicated that the top 25% of donors (who gave \$191 or more during the year) and the top 25% of volunteers (who volunteered 198 hours or more during the year) accounted for 81% of the total value of donations and 71% of the total number of volunteer hours in British Columbia, respectively. This concentration of support has important implications for charitable and nonprofit organizations. The sector's dependence on a small percentage of the population for the bulk of support can be viewed as an area of vulnerability for the voluntary sector. Any reduction in donations and volunteering among British Columbians who provide either the bulk of charitable donations or the majority of volunteer time could result in a substantial decline in the availability of these two key resources to the voluntary sector. *These findings serve as a reminder for British Columbia's nonprofit charitable organizations to foster, and sustain the relationships that they have with existing donors and volunteers.*

SUMMARY AND CONCLUSIONS

In this brief scan of some of the literature on organizational change a large number of articles were found. Only a small number were cited because no major differences or conflicting findings stood out. Therefore, typical studies and articles most pertinent to PWA non-profits were selected.

The review indicates that most organizations and movements undergo change over time. In the case of ASOs change is occurring or is being forced to occur because of a shift in the populations being affected by AIDS, changes in the nature of the syndrome itself with good treatment and changes in the way service organizations are funded and the amount of money being distributed by governments or donated by the public.

Gelb⁴ listed ways in which organizations such as the women's organizations reinvented themselves to stay strong and relevant in changing times. One of the most interesting findings was in the study by Twombly² which indicated that *factors internal to an organization rather than external forces such as lack of funding or competition from other agencies seem to destroy organizations.*

Moreover, it was found that while increasing the number organizations serving PWA may create more choice; it was also more difficult for clients to navigate the system to find the services most suited to them. As HIV increasingly affects different populations some with limited education who may not be fluent in English/French, increasing the number of organizations may actually decrease the ability of many PWAs to receive the help they need.

The literature also discusses other factors ASOs must consider when making changes such as the stigma attached to the syndrome due to how it is usually contracted, sexual activity or drug use, the stigma attached to the gay community by new groups now being increasingly infected with AIDS, and the withdrawal of the gay community from ASOs which at one point heavily funded, volunteered at and fought for funding and services in the early stages of the epidemic. The latter may now become less involved in the organization in terms of funding and volunteering due to both the changing nature of population being affected and the changing nature of the syndrome itself with good treatment.

However, in spite of the changes that are occurring and might have to occur to ASOs, it appears that government and non-government funding will continue well into the future as reflected by the generous donations of the Canadian public and the support of most political parties.

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