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ASSHH presentation 2013

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Abstract Title: 'Being Professional': Living With HIV And The Tensions Of 'Community' Location

The aims of my discussion is to trace the historical trajectory of how the community-based HIV response in Toronto, Canada has been socially organized over time and how, why and in what contexts people living with HIV have or have not been engaged, the practices of engagement, and the underlying principles of engagement, and examine what some have labeled “professionalization” within the context of the dynamic AIDS Service Organizations (henceforth ASOs) in Toronto.

When these organizations first developed, they were dually focused (to address prevention new HIV transmissions, and to support people through end of life care). Today the focus of these organizations has shifted have many complex and sometimes competing focuses including encompassing poverty mitigation, harm reduction, settlement and immigration work, street outreach, online outreach, micro-finance, self-esteem workshops and capacity building, community-based research, and addressing sexual violence among many others.

People with HIV have extremely complex interactions with ASOs. Roles for HIV-positive people have gone from being fought for and negotiated to being thought through strategically with policies, codes of conduct and detailed procedures.

While there was some research work in this area (notably Dennis Altman, Roy Cain, Robb Travers, Gary Kinsman, & Charles Roy), there has been a paucity of knowledge examining the nuances of ‘why?’ and ‘how?’ specifically Toronto

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ASOs are shaped the way that they are today. In many cases, the structures, management and organization of ASOs that we see today have been ‘taken for granted’ as being just the way they are – or as natural and somewhat static – despite the fact that these organizations are all less than 30 years old and have been developed through deliberate decisions, moments of conflict and have been fought for and planned.

With this approach to historical tracing, I am working to counter what Gary Kinsman has called the “social organization of forgetting”, stating:

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So this project is an act of remembering the past in order to better understand the current context facing ASOs in Toronto, Canada. This is a project guided by compassion and generosity towards a movement in which I am a committed and active actor.

In relation to issues of organizational “professionalization”, there has been limited research in this area as well, research where available, has helped illustrate the potential impacts of the process and has given us a snap shot of how this process can act as a barrier to ethical principles of participation of HIV-positive people. As a result, discussions in the Toronto-based HIV sector have often focused on “professionalization” as a negative process, and one described as acting as a real and/or perceived barrier to what is known as the “meaningful engagement” of people with HIV in the response to AIDS.

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I propose that conceiving of professionalization as solely a bad or negative process has not allowed for a depth of analysis in understanding why or how

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notions of “professionalization” came about in the first place and what factors have acted as conditions of possibility to allow for this phenomenon to flourish.

Methodological approach:

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It must be recognized when discussing these roles people living with HIV, that this group is not a monolith. People in this study represented a diversity of races, genders and social classes.

Context & Definitions

I want to start off by providing some context on the milieu within which this project took place. As of 2010 there are 45 AIDS Service Organizations across the province of Ontario focusing on providing services to a wide range of populations based both on geography or other demographic categories.

Organizational profiles

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Initially many organizations formed in the late 1980s and early 90s with decentralized structures and were inspired by feminist organizing and also lesbian and gay resistance struggles to counter homophobic police and state violence. ASOs all quickly acquired charitable status (a state regulated legal organizational mechanism) to support broader fundraising efforts. As a result, certain policies and procedures were required around financial accountability and now these organizations are formalized hierarchical and bureaucratic entities (Cain & Todd, 2002; Cain, 1997).

As the nature of HIV has shifted many of these organizations had to change in order to serve a growing diversity of populations and emerging needs faced by people living with HIV (Cain, 1997; Cain & Todd, 2002; Miller & Greene, 2005).

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The increasing demand for a wide variety of complex services has necessitated the hiring of highly trained staff to undertake what is known as case management, programmatic research, evaluation and more. These factors have contributed to many tensions and pressures on these organizations to remain relevant to those who they are intended to serve, while being accountable also to the funders and various new constituencies (Altman, 1994; Miller & Greene, 2005). These tensions are part of the work that this small project examined.

Despite this wide range of service in Ontario, new HIV infection rates have risen by over 67% since 1999 (Ontario Ministry of Health and Long-Term Care, 2008). In Toronto itself, the city I focused on, this city has approximately 18,000 people living with HIV with around 71,000 living in Canada as a whole. Canada itself has concentrated epidemics among various populations (gay men, women, trans people, aboriginal people, people who use drugs, and people from endemic countries).

So what do I mean by Bureaucracy and professionalization more specifically? Bureaucracy results from a larger social trend towards rationalization or the “rational-legal authority” and has been defined as a process where an organization begins to develop a “division of labour, hierarchy and authority, written rules and regulations” (Meyer & Brown, 1977, p. 364) and is necessitated by a monetary economy, and widespread literacy. Formalization relates to the internal changes that occur as a result of bureaucratization. As defined, formalization “gives rise to hierarchical differentiation and differentiation to delegation of decision-making authority” (Meyer & Brown, 1977, p. 365). Meyer and Brown have noted, “the extensiveness of formal procedures in bureaucracies is due in part to the historical era in which they were founded and in part due to the subsequent effects of the environment” (Meyer & Brown, 1977, p. 365). In other words, pressures external to organizations are what lead to them bureaucratizing and developing formal processes.

There is a wide range of sociological research conducted on social movement organization, development and trajectory. The processes, causes and consequences of bureaucratization, formalization and “professionalization” have been documented in the civil rights, women’s pro-choice, Palestinian rights, and Indigenous sovereignty rights social movements, among others. For many of these social movements the trajectory is similar. Grassroots social movements such as the civil rights and pro-choice movements transform over time from voluntary and activist-driven responses to become stable professions for those involved, leading to expert and manager-led, hierarchical organizational formations that have not-for profit and charitable statuses in order to be eligible for greater pots of funding.

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Most often within the literature focused on the HIV response the term “professionalization” is used to describe the multiple processes of that transform organizations. As Ng states: **“Professionalization is a process which transforms non-capitalist forms of organization into hierarchical ones”** (Ng, 1996, p. 211) and Central to professionalism discourses is the notion of ‘service’ through which people are constructed as clients and their cases are managed through a professional management discourse. In *Living and Serving 2: 10 Years Later*, a study on the involvement of people living with HIV in the Ontario HIV response, “professionalization” is defined as including a number of characteristics, including, roles in organizations increasingly requiring formal levels of expertise and training, and the valuing of professional credentials over lived experience (Collins, et al., 2007, p. 24).

One assumption guiding this work is that there is a benefit derived from participatory principles of inclusion for people living with HIV in the response to

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HIV and AIDS. Participation and engagement have been understood as leading to the increased self-determination and emancipation. But as with any participatory principle, methodology or practice, there are critiques that the complex nature of power is not adequately addressed (Kothari, 2001) and can lead to disempowering results. I am active in also critiquing participatory paradigms, and understand the participation can often be aligned with neoliberal self-actualizing notions of active citizenship and can be driven by corporatist managerial logics. However, in the beginning of the epidemic, decisions about the lives of people living with HIV were being made by scientists and politicians without any consultation from those directly affected by the emerging epidemic despite calls for the opposite. So I name this assumption to address the problems with it, while also understanding its necessity.

Professionalization & conditions of possibility: social, political, economic & cultural factors

Quickly, I wanted to touch on a number of the conditions of possibility that I, and others have identified which could be understood to drive professionalizing, formalization and bureaucratizing practices. With this I have also identified a number of outcomes of these drivers. I am not attempting in any way to prove causality between the drivers and outcomes, but rather elaborate a number of both broad and specific concepts that has been described in literature and in outcomes of my research as shaping the AIDS organizations we see today. I am also not claiming that there was ever any static organizational “state of nature” wherein original ASOs were utopian places of inclusion for all, and where there was a perfect balance – a balance that has now been interrupted. These organizations have always been dynamic and have experienced these tensions. This is something that is perhaps obvious for us in the social sciences and humanities, but within ASOs themselves, the mythical ASO of the past can

remain a pervasive concept. Conversely, an unquestioning of the structures and social organization of ASOs of today is equally as pervasive

Factors & conditions

- Need for funding, access, and quality sustainable services
- Biomedical ways of knowing and the medicalization of HIV
- Neoliberalism
- Financial coercion and funder priorities
- Social service sector norms
- Internal organizational factors

With the neoliberal project, one that is aimed at reducing the state and managing self-governing individuals and populations, Jennifer Wolch (1990) documented the impacts of neoliberal policy on the non-profit sector in the 1990s, including the systematic downloading of services onto communities in the ideological attack on the welfare state creating a voluntary sector organizations which are “outside the political system but still subject to state control” (Wolch, 1990). Wolch hypothesizes that “the transformation of the shadow state apparatus could ultimately shackle its potential to create progressive social change” (Wolch, 1990). While we can understand neoliberalism to promote a logic of individualism, hierarchical organization and depoliticization, we can also see that unionization is a factor which acted to codify certain formalizing and bureaucratizing practices driving organizational change. In some cases moments of organization turmoil (such as poor management, staff firings, and boards of directors perceived as out of touch with the "community") were documented as ultimately leading to increased stability for staff. Unionization occurred across all of the organizations I studied, and mostly took place over the course of the 1990s and was a sector-wide phenomenon.

Outcomes

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- Organizational stability, sustainability & security
- Marginalized & the reproduction of discrimination & oppression: PLHIV are transformed into “cases”
- Depoliticization & inability to address complex social & structural issues
- Privileged is reproduced: some PLHIV get jobs, benefit & gain access

Despite their diversity and differences, PASAN, ACT and Black CAP all followed a very similar trajectory to growth and formalization. When examining growth it must be understood that growth is not meant to imply progress or evolution. Many of these organizations are still very much on shaky ground financially, and can be chaotic places to work, with limited supports for staff and volunteers. So while growth and formalization has led to organizations expanding in size and function, this must be understood as measured with the realities of community-based work in the voluntary sector.

Additionally, not all community-based HIV organizations grow in this fashion. Three years ago, Ontario’s organization run by-and-for women living with HIV – VOICES of Positive Women - was forced to close its doors due to loss of funding from the provincial government.

Internal factors such as the development of staff codes of conduct has led to discursive and material boundaries being implemented between staff and people who access services, which has resulted in workplaces being regarded as more formal. Among those that I interviewed, formalizing of organizations was contrasted with the feeling that they had lost an original ‘family’ or ‘grassroots’ or ‘political’ nature. The contrast between ‘grassroots’ or ‘family’ and being ‘corporate’ or ‘formal’ was indicated as both a dichotomy, but also understood by some as a necessary division. In describing the past ‘family’ nature of organizations, it was noted that staff in the past invested very heavily in the lives

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of people who accessed services (i.e. such as attending a service user's funerals, going on hospital visits, attending the birth of children, having people for Christmas dinner etc.). A shift away from this way of working was illustrated as a loss for some, but a loss that was necessary to ensure the sustainability of staff roles in the long-term and was aimed to assist in preventing 'burnout'.

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Staff, including people living with HIV talked about the increasing complexities of what it means to be "professional" within a community-based setting.

Today, for many staff living with HIV in these organizations there is a dual and competing pressure imposed onto them. They are expected to be simultaneously 'community' located, while at the same time 'professional' in a workplace environment. These concepts were often addressed as competing with one another. This dual expectation was highlighted as being unfair to expect from one individual and was highly complex to navigate.

In the some instances, caring and compassionate staff with HIV were contrasted against others who were 'professional'. So the underlying assumption by some seems to be that 'compassion' and 'professionalism' cannot co-exist, and leads to the question: do we stop being compassionate when we are professional?

Staff with HIV spoke about the lived experience they brought to their positions as being invaluable and ensured their programs were relevant. With lived experience also came an assumption that staff living with HIV brought 'compassion', 'understanding' and 'commitment' to their positions at a level greater level than those who were not living with HIV. The consequences of these processes are that through bureaucratization and formalization,

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organizations have worked to compartmentalize tacit lived experience and render it as a commodity in AIDS work, ensuring that it is performed just as any another skill when needed or useful for the organization or funder. This logic of exploiting tacit lived experience as a skill in the workplace is also deployed in the name of relevance and effectiveness for peer programs (where most people living with HIV are employed).

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It was also noted that due to the highly personal and emotional nature of living with HIV and simultaneously working in HIV there was a difficulty for some in distancing themselves from their positions at work. All of the staff living with HIV interviewed first came to ASOs as volunteers or to access services. The complexity of blurring lines between job positions and peoples lives was addressed as an unsustainable way of working in the long-term and one that led to burnout in the past. In terms of mitigating the negative impacts of this issue, ASOs have developed codes of conduct which act as discursive managerial devices to regulate time and space to establish social distance between staff and clientele.

This was noted as being very challenging to navigate for staff with HIV, as their lives and emotions can be highly intertwined with the ASOs within which they work. In addition, Senior Managers (some of whom are also living with HIV) also have the challenge of ensuring that staff adhered to these policies. Additionally, while being difficult to negotiate, these formalized processes were also described positively as resulting in sustainable staff workloads and outlining clear guidelines, expectations and supporting job security.

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These protocols have had implications for how people who access services engage with ASOs. Such as staff being perceived as having less time for people who access services and their interactions being increasingly formal in nature. More rules are imposed and staff doors are less open to people using services, despite the hiring of more staff and the expanding of programs.

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The use of language was addressed as having the potential to limit the roles of people living with HIV who access services in organizations. The term “client” was identified as disempowering and as constructing a limited beneficiary role onto people. The use of this term was noted as clinical and a professional way to create client/staff boundaries, which ‘othered’ populations of people who accessed services in ASOs. Despite this, these terms were often still used.

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It was also noted that people living with HIV who were involved in leadership roles within organizations were often privileged and savvy. This was stated as complicating participation, as participation and access to staff positions was only available certain kinds of people living with HIV – the ones who already have access to privilege and had savvy around the ins and outs of non-profit organizations. So the people who have greater access and privilege can end up working in ASOs or moving on in the world, while other people without such access become “cases” to be managed by ASO workers.

Conclusion

In conclusion, some of these findings will be nothing new for those of you who work with similar organizations – but I hope that through reflecting on how we

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have come to the place we are at, this work can help inform future directions to improve how ASOs and people living with HIV work together.

This work encourages greater reflection on the complex expectations and embedded assumptions placed onto people living with HIV within the community-based sector— either perceived or real - could help ensure that the changing nature of HIV work actively supports and works to realize their dynamic lives and needs.