



CATIE/PAN Pacific Educational Conference

September 14-15, 2011

Closing Keynote Presentation (speaking notes) delivered by:

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On Thursday September 15, 2011

Vancouver Airport Marriott Hotel

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Social Change and HIV Response in Canada - Speaking Notes

Thanks for having me today! As some of you know, I've been living with HIV for 13 years, and have worked as an activist and community organizer within the HIV response for around that long. Two years ago I entered academia and I am now working towards a master's degree. So now, as with many of you, I cross through various worlds, and do not fit neatly into our defined roles of "community member", "academic", or "researcher". So while I talk, I am coming from a number of perspectives.

Today I am here to talk about the role of 'community' in the HIV response and the increasing need for social change work. I'm going to address some common jargon that we use in our work; I'm going to talk about the unique and vital role of community in responding to HIV. I'm also going to talk about where we I think we are going wrong in our response and some of our current gaps. I'm going to talk about the role of being critical – not for the sake of just being critical, but being critical to advance our thinking, ideas and strategies within the overall response. I am going to ask some hard questions and aim to uncover some assumptions that drive some of our work, assumptions that have the potential to be dangerous and counter to our overall goals. I want to be clear that these are my thoughts. I am open to people disagreeing

with me. I have a deep respect for all of the people in the HIV response and I want to provoke greater dialogue so as to strengthen our efforts.

So community. Using the term community is challenging. While the term community does imply that we are working together, which I like, it is a highly complex term, which is often imposed by outsiders onto groups of divergent people who may only have one thing in common (like being HIV-positive for example). So one of the consequences is that the term community conceals more than it reveals. This is common among much of the jargon we use in the HIV to describe groups and populations.

For example, lets look at the proliferation of use of the term PHA (or PWA) often used within our community-based HIV response. For me the uncritical use of these sorts of acronyms to describe populations always misses something. The use of PHA seems to me to assume that people living with HIV are a homogenous group with the same needs and experiences. While using terms like PHA makes our jobs easier, it also creates false assumptions about who we are looking at and the people we are working with. People living with HIV are widely diverse with divergent needs and lives. Spelling out this diversity is essential to ensuring that we are representative, relevant and realistic in our responses. My PHA identity, as a white, somewhat middleclass gay man is not the same as others in this room let alone around the world and therefore this puts limitations on what I am able to say or do when acting in representative roles.

This is the same for the acronym MSM, which despite many critiques and it being often inaccurate as an epidemiological term (which is its origin) is still widely used today in a lot of our work. The critiques of MSM being that the term relegates the gay male identity to one that is solely based on sex and completely ignores the years of activist struggle to ensure that the human rights of gay men are recognized. But as the HIV response is heavily regulated by medicine and science we have ended up adopted the use of epidemiological terms and acronyms for many things.

The reason I bring those two jargony terms up in my talk about community and social change is that I hope one thing we can take away from my rambling is the idea that we need to be continually questioning and critical in our work to respond to HIV. We can often and easily reproduce forms of oppression that we are trying to counter without knowing that we are doing this, and this is very easy to do with language.

So going back to community, despite being hard to define, community, civil society, activists, advocates, recipient populations, non-governmental organizations and more – who could all be described as “community” have a vital and unique role to play in ensuring we appropriately respond to the growing HIV and Hepatitis C crisis in Canada and around the world. This is because community-based actors are the ones who can leverage grass-roots based progressive social change initiatives that are founded in the lived experience of those most

affected by HIV. This has been the case historically in our HIV response, when governments and funders wouldn't listen, people living with HIV and those who loved them developed their own supports and interventions to fill the void. Activist pressures lead to increasing recognition and accountability on behalf of decision-makers. But just because this amazing social change work happened in the past and has brought us all to where we are now, it does not mean it is happening today.

After almost 30 years into this epidemic we know a hell of a lot about how to end the spread HIV and Hepatitis C. We do know what we need to do to turn these epidemics around in Canada. We have many effective tools and strategies, frameworks and a huge number of assets, leaders and resources. But for some reason we are not doing a large part of the work that we need to do. These viruses are still spreading.

Activists and community folks have known what we need to do to end HIV for a long time. Ugandan activist Beatrice Were once wrote:

“...as a woman living with HIV, I am often asked whether there will ever be a cure for HIV/AIDS, and my answer is that there is already a cure. It lies in the strength of women, families and communities who support and empower each other to break the silence around AIDS and take control of their sexual lives.”

Were is speaking from a context where the primary mode of transmission is through heterosexual sex and where women are most vulnerable. But her sentiment is applicable in Canada where we also know what we need to do to end HIV. But just because we know doesn't mean it is happening.

(Present diagram) To be comprehensive and have the greatest impact this is what I propose our response should look like, a balance of research, services and social change efforts to progress forward. But in fact our Canadian response today looks like this. (Present diagram)

As a result we are failing on a whole bunch of levels. Let me explain by using the education sector, and drug policy as case studies to highlight this gap in knowledge and action.

Education Sector:

We have known for a long time that we need comprehensive sexuality curriculum in our schools that includes a focus on sexual diversity and addresses homophobia. But we have widely failed at implementing this consistently or effectively in Canada. At a basic level, HIV used to be taught more than it is today, and studies show that we have actually lost ground, as HIV transmission knowledge among our students is lower today than it was in the 90s.

For myself, I was infected with HIV just after graduating from high school, and while school was the primary place I got sexual health

information, none of that information was relevant to my lived experience as it was completely hetero-focused. And my generation is the high school cohort who apparently had greater knowledge of HIV than students today. Action to address this gap in the education sector would require advocating the Council of Ministers of Education for policy change to develop consistent sexual health curriculum across all the provinces. But this hasn't happened and we are failing to ensure this human right is realized.

Drug Policy

We know that ending the war on drugs, viewing drug use through a public health, not a criminal lens and ensuring the provision of harm reduction interventions to people who use drugs leads to decreased HIV and Hep C transmission rates. Here is some evidence. Some more evidence, oh and some more evidence. But what we have learned is that there are limits to where all the great science can take us.

Our Federal leaders and institutions are not supporting or carrying out this work. As a result we are losing ground in our epidemic. An example of this failure is the Public Health Agency of Canada. While at a community level we understand harm reduction as a staple public health program. Our national Public Health institution is not allowed to acknowledge or practice this most basic tenet of public health. Politics has prevailed despite how much science we promote.

Props to all those working to produce this great data, but without a systemic and resourced advocacy force to push back against ideologically driven policy-makers, the right to health for people who use drugs is still not realized. Another fail.

So that was my cursory overview of a few social change gaps in our response. But why are we failing in these areas and why are there these gaps around addressing social change?

(Neo-liberal constraints slide) Well, our range of options, our possibilities and our imaginations are limited because of a number of factors constraining our efforts:

Neoliberalism and the bio-medicalization of everything.

HIV is the first global epidemic to come about under the neoliberalism. As a result, our response efforts have been continually constrained to fit within this ideology. One that favours individualism, competition, efficiency, corporate rationalities, privatization, decreased spending on social services such as health and education.

An ideology opposed to addressing social and structural issues that drive HIV. This kind of thinking doesn't value human rights, because human rights are not a commodity that can be traded in the market. Neo-liberalism views people as rational agents who live in a vacuum, a view that simplifies HIV risk and responsibility. Which is why

approaches trying to change individual behaviour have dominated for so long. If they would only just use condoms, right?

This world order also makes us compete for less and less money, which leads to credentialism and can co-opt community voices so that the status quo can be maintained.

I recently presented a similar presentation at the Canadian Association of HIV Researchers Conference held in Toronto. At the presentation, a panel of 5 different “experts” were asked how they would end the HIV epidemic by the year 2020. I was the only person on the panel without a Dr. in front of my name. The reason I point this out is because for me it nicely illustrates what forms of knowledge are privileged in the response to HIV. So with HIV scholar Dennis Altman as inspiration let's use how our HIV conferences are structured as an example of how we model the HIV response in regards to our priorities. If you have ever been to the CAHR conference, or the International AIDS Conference you will be familiar with this.

(SLIDE: quote from Altman)

Basic Science comes first, then Clinical Science, Epidemiology and Public Health, then the last Social Sciences.

The hierarchy favouring basic, clinical and epi **“has come to suggest that this is the natural way of conceptualizing the epidemic... which**

has the effect of other topics, particularly with political or cultural content appearing peripheral”.

Moving on, those familiar with conducting research will know that when looking at how to undertake a research project we should let the question drive the research method and not the other way around. But with the HIV response the prescribed methods are predetermined as defined by what fits within neoliberalism and biomedicine and does not challenge them.

In Canada, we have around 120 community-based organizations that work on HIV. Most of these are called AIDS Service Organizations. Have you ever questioned why we have so many organizations that only provide services or conduct research?

Imagine for a minute that we had this many AIDS Social Change Organizations. If our efforts were dedicated upstream at the root causes of social inequality, at challenging harmful public policy and government inaction. This is not meant in disrespect to the many amazing people who do vital work in these organizations.

So I'm sure all the EDs in the audience are saying: "Well Alex, we can't do advocacy work because we are not allowed to". And yes this is true; a majority of our organizations can't even say the word advocacy let alone do this work.

There is the 10% advocacy rule, meaning that organizations with charitable statuses can only use 10% of their budgets on advocacy work. But this rule is intended to maintain the status quo and inhibit the very work I am calling for. So if the 10% rule isn't working for us then we should work to change it. Or we should develop a new mechanism to systematically fund advocacy and social change work in our response. We can do better and we can be more creative.

We can't take our existing response and funding for granted. This is becoming especially true in the political climate in Toronto. You may have heard of our Mayor Rob Ford who is actively dismantling an innovative network of social services, including HIV prevention and harm reduction programs, which includes funding to many AIDS service organizations in my city. These programs had been developed and fought for for many years by the community-based response to HIV. Now we are at risk of losing these supports. Another moment where concerted advocacy efforts are needed, something that the Toronto response is currently struggling to figure out how to do, as there has not been a focus on this type of work for many years. This attack in Toronto on our response efforts should not be seen as an anomaly, and I think we all need to prepare for more of these attacks on our work in the future.

An example of successful activism is Ontario's drug coverage program, the Trillium Program. There is this myth in Canada that we have universal health care, but in fact each province covers the cost of

expensive treatments for conditions for HIV very differently, and coverage is patchy at best. In Ontario, our program is very good, and Trillium today covers the cost of my \$1700.00 a month HIV meds. I'm not completely familiar with the insurance program in B.C., but I know you have something similar. Anyhow, today many people take this program for granted in Ontario. But why does this program exist? Because of AIDS ACTION NOW fought our government in Ontario using direct action activism and disrupting our provincial legislature to get attention and put pressure on the government at the time to make this happen in the 1990s. This is something that not many people know about, but think for a minute about that and imagine what the resulting health outcomes have been because of this great piece of social change work?

[Slide] To progress in our efforts we need to reflect on how the regimes of neoliberalism and bio-medicine we can end up reproducing harmful practices, which are counter to the goals of this response. We also need to be conscious of how we work with each other and the jargon that we use.

To bring it back to the role of community I would like to talk about community and research. I heard that you all did a community-based research workshop as part of this gathering. As a student in training of HIV community-based research at York University, I wanted to talk about some of my thoughts on the current strong focus on community-based research in our response and how this form of research

constructs “community members” and the knowledge that they have or do not have. Within community-based research, as it is practiced in Ontario (I admit my ignorance of current practice in this province, and I know it is practiced differently in different places), but a strong component of the practice is focused on ensuring the Greater involvement of People Living with HIV and AIDS (GIPA) principles are practiced. And to ensure that people are living with HIV are involved their capacity needs to be built.

The practice of capacity building for community members is not exclusive to Community-Based Research. But for the next few minutes I’d like to investigate capacity building in a research context and some of the assumptions that drive this catch phrase and also the underlying power differential between researchers and community members that can be hidden within this concept.

So what do we mean by capacity building and what is unspoken within this catch phrase? Often capacity building is used as a euphemism for:

“It would be so much easier to work with these people if they just had the right skills” or “As a researcher, I have the skills to pull this research project off, but these community folks don’t... lets put them through a workshop”.

So the main assumption underlying “capacity building” is **not** that academic researchers need any capacity building to work with diverse

communities, but instead that the communities themselves are the ones who need to get their skills in check. Academic knowledge is reinforced as legitimate and “community” knowledge is seen as deficient.

For an example of this in practice, let's look quickly at the language used by the Canadian Institutes of Health Research (CIHR), the national funding body that supports a large portion of our community-based research projects. So on a CBR project, if I am a community-member and am part of the study they way CIHR describes me is as a “knowledge user”. As a community member I am then just a user of knowledge, not someone who can contribute in any way to advancing the response, only those with academic credentials or who are attached to a university can produce that kind of knowledge. As a community member CIHR says that I am just a passive object who uses the knowledge created by others who have more “expertise” than me. For me this term in 2 simple words is a great example of the power relations that exist in our HIV response.

So right off the bat, we are approaching the “community” with a view that they are missing something, and that they need our help to fix that. I want to acknowledge that the community and researchers are not monoliths and there are power imbalances within these groups as well. For the purpose of this conversation I will be talking about them as 2 distinct entities.

Now don't get me wrong, I acknowledge that many people living with HIV continually ask for supports to build their skills. Part of being involved meaningfully through GIPA is about ensuring we accommodate the needs of diverse groups of people living with HIV.

[GIPA Slide] But there are two kinds of GIPA, each with different underlying assumptions. There is emancipatory GIPA and there is instrumental GIPA. Often these two forms of GIPA are conflated and people think that if they practice GIPA that automatically they are “empowering” those that they work with.

Instrumental GIPA means that we involve people because it makes our work easier. For example, UNAIDS supports GIPA because according to their policy brief on GIPA, the involvement of people living with HIV makes policies and programmes more “acceptable, relevant and effective”. This form of GIPA doesn't critically challenge or question power structures, but just seeks to include people living with HIV within them so that they work a bit better. But to be included individual people living with HIV have to be made more ‘professional’ to work with.

Emancipatory GIPA is about challenging structural violence, systematic oppression, institutional racism, colonization, homophobia, cisgender normativity, sexism, classism and the many ways in which we are continually marginalized and exploited. GIPA for emancipation is about working towards developing our communities through progressive

social change so that we can realize our own futures as people living with HIV.

By conflating these 2 forms of GIPA we hide the real motivations behind what we are doing. The form of GIPA that seems most pervasive in the research world is the GIPA that works to make processes more effective, acceptable and relevant.

Lets look at the proliferation of the use of peer researchers in the name of GIPA. Peer being euphemism for: “HIV-positive” “street-involved”, “homeless person”, “person who uses drugs”, “trans-person” whatever the focus of research is.

Is using peers in a research project about promoting empowerment and emancipation? Is this promoting progressive social change to address HIV?

Peer researchers are often at the bottom of the decision-making ladder in most research projects, often paid low wages to do the most onerous work. They are asked to speak to others in their situation about events, which have led to their own vulnerability, events which are often traumatizing. I have not heard of a community-based research project that uses peer researchers, in which they are provided access to psychosocial supports despite being asked to re-traumatize themselves continually in the name of getting more relevant data.

And how does training someone who is street involved or marginalized to implement a survey or conduct interviews with their peers provide them with the skills they need to challenge their current reality? As a friend of mine said to me last week: “So now we have all these homeless researchers, they’re still homeless, but now they know how to conduct a survey”. Now I understand that I am being rhetorical here, but I am trying to make a point. Point being that we need to be aware of our underlying assumptions about what is possible with our work, and not conflate emancipation and empowerment with relevance and efficiency. While I’m sure there are cases where being a peer researcher has led to individual personal development for some, but I don’t see how this form of involvement is about emancipation or about advancing our response efforts.

Keep in mind that Canada is the only G8 country to not have a national housing strategy, and we still do not have a national poverty reduction strategy.

Often funding bodies and institutional organizations are the ones who frame the issue of what capacities are needed. And the only capacities that are possible within “capacity building” conversations are those which accommodate those institutions, not ones that challenge their work.

We don’t often ask about building capacities around advocacy, community organizing, community development, and other skills needed to promote social change. We instead talk about workshops on

confidentiality, survey implementation, coding, analysis and Knowledge Translation and Exchange.

As a quick side note, it took me a while to understand what KTE actually was, until it was explained to me as being technocratic new term for something that community members and organizations have been doing for a long time: making research accessible and usable to support their needs.

For example: Activists living with HIV in the late 80s from AIDS ACTION NOW created CATIE as an organization to translate complex treatment information into accessible and useable formats for those who needed it most.

And back when I was at Positive Youth Outreach (the support program run-by-and-for young people living with HIV), around 9 years ago, we worked closely with CATIE to make new research on treatment more accessible to young people. As a result we worked on developing a youth-friendly workshop that included up-to-date treatment information for our members. We didn't need capacity building to do this work we just did it.

These are examples of do-it-yourself KTE led by the "community" to fill our own needs.

So while I am excited that researchers are being encouraged to build in relevant dissemination activities into their work through KTE. This term can be seen still as just the repackaging of a practice that people living with HIV and other communities have been practicing for years. But through repackaging, KTE now becomes a technocratic practice that requires expertise. To get this expertise we now need capacity building. And then communities are told they are missing yet another skill and unequal power relations are reinforced.

So, often we don't examine critically how we as researchers and institutions predetermine what is possible when we talk about capacity building and engaging community members. Instead we look at the individual community member and think of how we can transform that person to make our work more acceptable, relevant and effective.

But when we think about capacity building we don't question the increasing obsessive credentialism we are pressured into as a result of living in a capitalist society. We don't question the bureaucratization and professionalization of the HIV response. The process which has destabilized grassroots movements and leadership of people living with HIV seeking emancipation in favour of institutionalizing ourselves within the non-profit industrial complex. A complex, which now forces people living with HIV to compete within a capitalist model as neo-liberal entrepreneurial agents fancying up our résumés and seeking jobs.

We don't question the dreadful human rights situation in our country and the denial of the right to health to many people from marginalized communities, which makes it near impossible for many of us to meaningfully participate and be engaged as researchers, go to school, work in ASOs, join academia or get jobs in NGOs.

We don't question why we have such a strong focus on researching communities, getting grants, filling out endless CIHR ResearchNET online applications, and getting our name on articles in journals instead of focusing on advocacy efforts to change the lives of our communities and/or those we work with. We don't question often these things.

So wrapping up: To turn around HIV around we need to acknowledge the constraints we are under and reflect on how they can create greater inequities for us, and limit what is possible in our work. We need to constantly question our practices and ensure that they are aligned with our overall goals.

[Slide with photos] I am envisioning a better world in which equity and rights were our goals as opposed to maintaining our funding and not wanting to offend anyone, a world where our response values and supports sustainable social change work.

When I talk about social change, I am talking about working to challenge harmful policies, laws, and practices that those in power are inflicting on our communities. I'm talking about working to end poverty,

challenging homophobia, and doing antiracist and decolonizing work. I'm talking about realizing basic human rights, rights that are still out of reach for lots of Canadians.

Social change work is hard, scary for some, and not always popular. But it is a vital component of what we need to do if we want to honestly and appropriately change how we are responding to HIV in this country. We need to be brave. We need to reorganize our resources and we need slowly chip away at the systems constraining our work. Pretty easy right?? Lets get to work.

Thank you.