Critiquing the AIDS Bureaucracy: An Open Letter to the Canadian AIDS Society

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We are writing this open letter to the Canadian AIDS Society (CAS), as activists and researchers involved in the work of HIV prevention and services with regards to trans people in Canada. In so doing, we wish to express our profound dissatisfaction with how CAS engages in its work. In particular, we feel based on our dealings with CAS that it offers little meaningful consultation with the communities it is supposed to serve, and that CAS refuses to be accountable to its communities and their real needs.

Below is a detailed account of our interactions with CAS regarding their work on trans people and HIV, followed by a series of questions and proposed actions related to CAS and the broader AIDS bureaucracy.

We write this open letter as a way to ask some critical questions about the current state of the AIDS bureaucracy. We invite others to reflect on these issues with us. The future of meaningful action in the field of HIV/AIDS depends on such critical reflection.

History on this issue at CAS

This letter emerges from CAS's recent initiatives to engage in work on trans people and HIV in Canada. Let us be clear from the outset that we applaud initiatives to address these issues, too long overlooked and ignored in many AIDS service organizations. Inadequate attention to trans realities is perhaps especially ironic given that the Public Health Agency of Canada estimates an HIV seroprevalence rate of 27.7% among trans women in North America: a rate that surpasses any other population (PHAC, Population Specific HIV/AIDS Status Report: Women, page 51). Because of the high rates of HIV in some sections of trans communities in Canada, as well as the profound marginalization of trans people, we feel that it is important that any such work in this area engage trans communities from the outset and be linked to our real needs in daily life.

In the spring of 2011, CAS organized a symposium on the situation of women and HIV in Canada (Towards the Development of a Coordinated National Research Agenda for Women, Transwomen, Girls and HIV/AIDS in Canada, from which emerged The Gathering of Spirits: Canadian Women, Trans People and Girls' HIV Research Collaborative Initiative), and included trans women in this event both as speakers and as participants. We welcome such efforts insofar as they provide a place for trans women to identify their own needs, to outline processes for future work in this area, and to network with other women working in the field of HIV across the country.

In early winter of 2011, we learned that CAS was preparing a grant application to seek funding from the Public Health Agency of Canada. The objective of the grant would be to engage in a needs assessment of trans people and HIV, notably through an online survey and key informant interviews. The project included plans for a national advisory committee of HIV-positive trans people, and sought to develop relevant educational fact sheets in order to sensitize member organizations of CAS to the realities of trans people and HIV in Canada.

We learned of this grant application because CAS asked some of us for letters of support, as researchers and front-line community organizations. Some of us elected to provide such a letter, some of us declined that invitation. We expressed grave concerns, however, about the process (or lack thereof). When we verified on the ground with activists and service providers in this area, we learned that they had not been involved in conceptualizing this grant proposal, its objectives, or its activities. We found this situation striking, since the initiative did not seem to come from trans communities.

In addition, in discussions with CAS with regards to the PHAC grant, we learned that CAS had secured a grant from the pharmaceutical company ViiV for a project on trans people and HIV with basically the same objectives, activities and deliverables as the proposed PHAC grant (the ViiV grant was in the amount of $15 000). We found it disconcerting, to say the least, that a national organization was able to secure funding from a pharmaceutical company for national work on trans people and HIV when the leaders we know working in this field across the country had no knowledge of such an initiative.

Our primary objection to this work, raised in conversation with CAS as of January 2012, speaks to the relevance of the proposed project. We repeat that reflection and action on trans people and HIV in Canada is welcome. But we insist that such work needs to be driven by trans communities, especially trans people living with HIV. We did not feel, nor do we currently feel, that a general "needs assessment" of trans people in relation to HIV is a political or research priority. This information is already available in a number of forms: we can think of the resources, data and publications of Trans PULSE (http://transpulseproject.ca/) and Getting Primed (www.queertransmen.org) in Ontario, the educational resources on trans people produced by Vancouver Coastal Health (http://transhealth.vch.ca/resources/library/), the guidebooks for trans people and service providers created by ASTT(e)Q that are available in French, English and Spanish (www.astteq.org), or the recent pamphlet distributed in English and French by the Interagency Coalition on AIDS and Development (www.icad-cisd.com/pdf/**HIV**_and_**Trans**_Communities_EN.pdf*).* In both English and French, then, there is ample information available on the situation of trans people and HIV in Canada, and some educational resources already exist. This is not to say that further work is not required, it is simply to state that a needs assessment has already been done in recent years.

Meetings and communications with CAS

Subsequent to our discussions with CAS during the PHAC grant application process, we took the initiative to request a meeting with CAS to discuss our concerns. We asked for such a meeting in good faith. At this meeting held at the end of March, we raised several issues:

1) the process chosen by CAS was not reflective of genuine community engagement. The leaders we know on the ground were not involved in conceptualizing this project, although some individual trans people (who remained unnamed by CAS during that meeting) may have been consulted. During the meeting we discussed the principles of GIPA (Greater Involvement of People with HIV/AIDS) and OCAP (Ownership, Control, Access and Possession) and identified links between the ways "marginalized" communities need to be approached in relation to research. We communicated our perspective that the process at CAS was backwards: instead of working with a community to identify its priorities and seek financial support to help realize these, CAS sought and secured funding with the intention of then getting the community (or at least individual trans people) on board. CAS representatives communicated to us that such a process was common at the organization, and that CAS was often confronted with the dilemma of engaging communities after funding was secured;

2) an online needs assessment was not, in our view and experience working with trans communities over many years, the most appropriate way to go about getting the relevant information - particularly when reaching trans people most affected by HIV/AIDS. An online survey of trans people conducted in France, for example, yielded very little data on sex trade workers and as such represented a biased sample (« Transsexuel(le)s : conditions de vie, santé perçue et comportements sexuels, résultat d'une enquête exploratoire par internet », CRIPS Ile-de-France et Act Up-Paris, Bulletin Epidémiologique Hebdomadaire (BEH) n°27, juillet 2008);

3) any work to be done ought to prioritize or at least seriously consider employing trans people, given the difficulties trans people have in employment, as well as the complexity of the issues involved, and;

4) our experience with funders, including PHAC, is that funding bodies are often flexible with changes in the operationalization of a particular project, provided that the overall objectives are met. We expressed a willingness to work with CAS to explore the possibility of using the funding in a manner that would be more relevant to trans people in Canada, notably a national community-led conference, while respecting the objectives of secured funding. There has, after all, never been a national gathering of trans people in Canada.

At that March meeting, CAS representatives stated that CAS has "an obligation to employ our own employees" and that the original work plan proposed (online survey and key informant interviews) "needs to go forward". Nevertheless, CAS did express a willingness to collaborate with us, including the possibility of a memorandum of understanding with a community agency active in trans health.

We learned that CAS had been successful in its PHAC grant for the trans/HIV national project ($43 000 for the first year of the project; we were not informed if there is additional funding for subsequent years). We wrote to officially propose that the funding be used for a national conference on trans people and HIV, and that community facilitators would be hired and trained in three cities (Vancouver, Montréal and Toronto) to engage people across the country leading up to this conference. The meeting would involve forming a national network to work on these issues, establish a framework to respond to HIV in trans communities in Canada, make recommendations in terms of the rights of trans people in community-based initiatives, and determine facilitators and barriers to accessing HIV treatment and services for trans people in local communities. It was underlined that the experiences of trans women and HIV positive trans people should be a key focus of the work, and that the conference and all work activities would reflect the impact of HIV on trans women. Subsequent to the conference, the Coordinator would work with a national committee in order to develop and distribute relevant resources for ASOs (AIDS Service Organizations) across the country. We proposed either that CAS hire this individual directly, or that an understanding be secured with a relevant trans health project or trans community organization to hire the Coordinator.

In this letter of May 2012, we reiterated our deep concerns about the process to date at CAS. In our view, community AIDS work needs to involve the community at all stages, including at the conceptual, development and financing stages. We clearly stated that if CAS disagreed with this view of community work, then we would request a meeting with the Board of Directors to discuss these issues – which extend far beyond the topical issue of "trans people and HIV."

In June 2012, CAS responded with agreement that a national conference with regards to trans people and HIV is a good idea, and expressed an openness to apply for funding for such an endeavour. The staff person of CAS who was to undertake this project had left CAS, and CAS communicated to us that the agency was now prepared to hire a trans person to undertake this work. This job was advertised and filled in the summer of 2012.

Despite these statements, CAS indicated that it had consulted with its funders and had to "reiterate the need to deliver the needs assessment we had been funded for." CAS repeated that the need for such a project was identified at its March 2011 "Gathering of Spirits" meeting, and that there had also been "concrete requests made by others in communities in Canada." We still find it more than curious that the appeal to such "concrete requests" as evidence of community consultation is vague, with no specific details of individuals, agencies, leaders, cities or even geographic regions cited.

Moreover, two of us were present at the "Gathering of Spirits" event, and although we both concur that there was a need to engage in further work on trans women, at no point was there an identification of an online needs assessment as something desirable as a future course of action in this area. The report of that meeting certainly mentions the need for additional research on trans women and HIV, but does not specify a needs assessment. We note with interest that the final report further indicates that there was great reflection at CAS on the importance of community involvement at all stages of research. On the question of participation, the report states:

> Participants emphasized that community involvement must begin during the early stages of research formulation (including question identification), so that they are engaged in designing the research, and to ensure it responds to community's questions, concerns and lives. It was noted that researchers need to recognize the capacity of community stakeholders. (see http://www.cdnaids.ca/research-agenda-

> for-women).

Elsewhere, the CAS report underlines:

> … the importance of having all stakeholders included on the research team, the need for diversity, importance of involving the community early in the development of research questions, and including both allies and dissenters. Other important principles were meaningful engagement, transparency, greater horizontality (getting out of silos), capacity building, acknowledging and addressing power dynamics, and careful definition of "community." (http://www.cdnaids.ca/research-agenda-for-women).

Finally, in discussing concrete steps to encourage good research, the CAS report from the "Gathering of Spirits" meeting in March 2011 contends that:

> More consultation is needed to set the research agenda, to hear about research priorities, avoid duplication and create opportunities for coordination, and seek community input. (http://www.cdnaids.ca/research-agenda-for-women).

While the above document produced by CAS seems to say all the right things about how to do research that is meaningful and relevant, the actions of CAS with regards to trans people and HIV tell a very different story. In our view, there has been no meaningful engagement of the community, little or no involvement of trans people in identifying the research priorities, questionable transparency, and no accountability whatsoever.

We wrote CAS again in July 2012 to indicate that we found their response unsatisfactory. We reiterated our objections to their methods, as well as our deep concern about the lack of any genuine community engagement in this work. We also expressed our faith that, in our experience, funders are committed to supporting initiatives that promise success and that engage communities at every step along the way. We were clear that we remained open to working together but not within a "business as usual" model; we seriously question the relevance of the proposed online needs assessment. In addition, we communicated that we may respond publicly on this issue.

Principles in Practice ?

On its website, CAS outlines a number of *Community Action Principles* that drive its work, as well as the work of its member agencies (see www.cdnaids.ca). Such principles include:

Empowerment – ensuring that people living with HIV/AIDS "are directly involved in the decisions that affect their lives, and in the organizations that serve their needs"

Greater Involvement of People Living with HIV/AIDS (GIPA), as defined by UNAIDS

Accountability – "recognizing the need for organizations to be accountable to the communities in which they are rooted."

We do not find CAS's work in the current situation to respect any of these principles. Although CAS may have consulted with some trans individuals in preparing its grants on trans people and HIV, this is not the same as a commitment to genuine community consultation (or engagement) that would empower trans communities. The substance of the grants prepared did not involve any meaningful direct involvement of trans people in the work identified. Having a national AIDS organization write up a grant to do work that has already been done, without having involved the main actors working in this field in the conception of the objectives and activities, and then dismissing objections raised, can hardly be considered empowering.

Moreover, the involvement of PHAs in this work is questionable; the leaders in regions across Canada with whom we spoke were unaware of CAS's work in this regard. If, in meeting with CAS early on, we were provided information and evidence that the initiative was truly supported by a variety of trans people and relevant organizations across the country, if there was clear involvement of at least one major trans health project at all stages of the work, then we would not necessarily be writing this letter.

And finally, when we met with CAS to suggest that they needed to engage in work which was more relevant to the realities on the ground, we were repeatedly told (in March, June, July and in an email written by the Executive Director in August) that CAS was going to go ahead and execute its plan of work. While we certainly recognize that we as three individuals do not represent the diversity of trans communities in Canada, we all gave of our time, energy and expertise to meet with CAS and to suggest that they were off track in their approach. With the best of intentions (perhaps with unrealistic optimism), we were hoping to meet with CAS to do more relevant work, and felt that this was especially important since CAS did not have solid links with many of the leaders and organizations working in this area across the country. To disregard the concerns we raised given our experience in this field, at the same time as being unable to offer any concrete demonstration of community involvement in the conception of the project, is far from a practice of accountability. CAS maintains that it is open to collaborating with us and others to secure funding for a conference – but only after it proceeds with its funded grants. This is nothing but business as usual in the AIDS bureaucracy.

Questions We Still Ask Ourselves

Throughout our communications with CAS, we are confronted with a number of questions time and again. We don't have any easy answers, but we think the questions themselves are worth thinking about:

- How exactly does it happen that trans women have the highest HIV seroprevalence rate of any population in Canada, the national AIDS organization does not substantively address the issue until 30 years into the epidemic, and the initiative proposed is not based on any meaningful consultation with members of trans communities across the country ?
- Would CAS proceed in this way with communities of drug users, sex workers, or gay men? If so, is that something we should be happy about? If not, why has CAS

chosen to initiate work on trans people differently than work with other populations?

- How exactly can national AIDS organizations obtain funding for work on trans people without demonstrating that there has been meaningful consultation with trans communities?
- Even if we consider that CAS got off on the wrong foot, developing a project that is not based in people's needs and that does not reflect political priorities, is it really that difficult to sit down with communities to ask what would work, and if there might be a way to use the funding available?
- Even if we as three individuals are not representative of trans communities across Canada, in the absence of any strong evidence of trans community involvement in the work proposed by CAS, would it not be wise for CAS to think about *beginning* with community consultation, and using the funds for this purpose?
- Are funders really not able to offer some flexibility in terms of specific activities to be carried out, provided the objectives of a grant can still be met?
- Should ASOs simply implement grants because the funding is there?
- By what process can communities hold agencies accountable?
- Should HIV funding be contingent on the ethical inclusion of affected communities?
- By what standards can we evaluate community engagement?

Why This Letter ?

Why write this letter and send it out publicly? We are more than aware that we risk making some waves. We are more than aware that our own reputations may be put into question. We're not saying we have all the answers: maybe we're just angry AIDS activists with no good reason to be angry. Maybe we're not right on this.

Nevertheless, we've decided to make our objections public because we think that these kinds of practices are common. And we think it is time to instil a culture of critical reflection in AIDS work. We think it is time to ask some tough questions even if they may ruffle some feathers.

We have a number of objectives in making this letter public:

- We think that spending $58 000 in one year, in order to produce information that we already have, is politically irresponsible. Trans people, especially trans people living with HIV, deserve better.
- We want to raise critical questions about how ASOs function. Sadly, we see the current situation as exemplary of how many ASOs work: they prioritize their own funding needs, even if the project has little relevance to the people it is supposed to serve. Securing and administering grants are the business-as-usual of this industry. HIV-positive people and marginalized communities are deprioritized, and invited to "collaborate" with the implementation of AIDS work that has already been defined without them, in order to ensure that these agencies receive ongoing funding.

- We want all of us working in the field to think critically about what we mean when we take about "community" and "community engagement". CAS maintains that it is committed to Community Action Principles. But our experience in working with CAS since December 2011 is far different. Preparing grants and workplans without any real meaningful input from trans people, and then promising to get the community on board once the funding is in place, does not, in our view, reflect principles of empowerment, GIPA, or accountability.
- In the future, we want people working in ASOs to think twice before engaging in these kinds of practices.

We are certainly not removed from the AIDS industry, and we recognize that we benefit from it, as researchers, activists, frontline workers, and students. In the past and or present, we have secured paid employment, have had travel expenses paid to attend conferences and yes, we have given a great deal of volunteer labour to the AIDS movement. While we are certainly inside the AIDS industry, we remain committed to engaging in work that is relevant.

And we think – perhaps quite boldly given the current climate – that if AIDS funding only exists to perpetuate ASOs without actually creating prevention, services or research based in people's real needs, then quite simply, ASOs should close up shop.

What Can You Do ?

In sending out this letter, we're asking you to think critically about the situation presented here. We repeat, we do not think we have all the answers, and we may not even be "right" on this. The issues, in our view, are more complex: they are fundamentally about the way that AIDS work has been transformed over the last thirty years, such that many in the field place funding applications, deadlines and administrative imperatives above the real needs of PHAs and communities affected by HIV/AIDS.

We hope others will share, exchange, and engage in a dialogue about these issues. We are less interested in whether others agree or disagree with us. We are interested in fostering a culture of serious reflection in AIDS work. This letter is one effort to help all of us think carefully and critically. To that end, we invite you to:

- Share this letter with your colleagues and friends
- Organize a specific meeting with your entire team – including management, administration and the board – to discuss the situation we have presented and to think about it in relation to your own organization
- Imagine what the work of AIDS organizations would be without funding
- Think about how and why AIDS organizations were established in the 1980s, as well as how and why they continue to exist today
- Consider if grants determine the work of ASOs. If so, is this the real work that needs to be done?
- Identify instances when ASOs have refused grants they received. In such cases, what was the context and reason for so doing?

- Discuss the relevance of funding national AIDS organizations if and when such organizations are not accountable to the communities they supposedly serve
- Imagine, develop and share strategies to displace the AIDS bureaucracy

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Currently, CAS is soliciting individuals to participate in its national advisory committee for its work on trans people and HIV. All three of us have decided not to pursue any collaboration with CAS on this matter. We leave it to other trans people, PHAs and activists across Canada to evaluate whether that committee is a good place to invest their time and energies, as well as whether the work of said committee will produce results that are relevant to trans people infected and affected by HIV.

Collectively, we've been responding to HIV/AIDS for more than 30 years. Perhaps in that time, we have somehow lost sight of the people, lives and needs that once drove our work and action. Perhaps in our good will to have successful and strong organizations, our focus has narrowed to administrative and funding issues, and we have somehow squeezed the real people, and the real issues, into (or out of) bureaucratic boxes. Perhaps how we are doing our work, collectively, is no longer in sync with everyday people and their needs.

This open letter is an invitation – to all of us – to think critically about the best ways to engage in collective action. This letter is an invitation to move beyond the AIDS bureaucracy.

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