

“It’s like there’s this glass ceiling”: Exploring the benefits and tensions of operationalizing the Meaningful Involvement of Women Living with HIV/AIDS (MIWA) in the design and delivery of HIV/AIDS services

A. Carter^{1,2}; S. Greene³, V. Nicholson⁴, N. O’Brien⁵; M. Sanchez⁶; A. de Pokomandy⁵; M.R. Loutfy⁷; A. Kaida²; CHIWOS Research Team

1. BC Centre for Excellence in HIV/AIDS, Vancouver, Canada, 2. Simon Fraser University, Burnaby, Canada, 3. McMaster University, Hamilton, Canada, 4. CHIWOS Study, Vancouver, Canada, 5. McGill University Health Centre, Montreal, Canada, 6. ViVA, Salt Spring Island, Canada, 7. Women's College Research Institute, Toronto, Canada

BACKGROUND

The **Meaningful Involvement of Women Living with HIV/AIDS (MIWA)** is a key feature of women-centred care, yet little is known about transforming MIWA from principle to practice.

Study Objective: To explore the benefits and tensions that emerge for women living with HIV as they traverse multiple roles as service users *and* service providers in their care communities and the impact this has on their access to care and overall health.

Identifying and mitigating unintended consequences of MIWA must be considered as peer participation in care gains prominence in Canada and worldwide.

METHODS

The Canadian HIV Women's Sexual and Reproductive Health Cohort Study (CHIWOS) aims to evaluate the impact of women-centred care among women with HIV across Canada.

As part the formative phase, Peer Research Associates (women with HIV who received training in community-based research) conducted 4 focus groups with women with HIV (n=28) in three urban centres of British Columbia, Canada: Vancouver, Victoria, and Prince George.

Focus groups were conducted between Aug-Oct 2011, lasted 2-3 hours, and were audio-recorded, transcribed verbatim, and thematically analyzed.

RESULTS

Participants represented diverse communities: 50% identified as Caucasian and 39% Aboriginal; 25% identified as LGBTQ; 65% were 31-50 years; and 43% and 32% had drug use and sex work histories, respectively.

Women described accessing peer-driven services, highlighting the informational, social, and emotional supports associated with care driven by lived experience. Emerging more prominently, however, were women's reflections on engaging as peer workers within their care communities. While involvement varied (e.g., peer navigators, board members), most were volunteer rather than paid positions.

RESULTS (continued)

While women experienced benefits of MIWA in the form of capacity building, mentorship, and ownership, several tensions emerged as their role shifted from service user to service provider within organizations.

TENSIONS THAT EMERGE WHEN WOMEN BECOME INVOLVED IN THE DESIGN AND DELIVERY OF HIV/AIDS SERVICES: (See Figure 1)

1. Being required to choose between remaining service users or becoming paid employees.
2. Being positioned unequally as providers who are good enough to volunteer yet not good enough for paid work.

3. Serving as a resource for organizations but without equal representation, ownership or control throughout levels of decision-making.
4. Confronting organizational attitudes that espouse empowerment yet fail to fully acknowledge women's capacity to contribute in practice
5. Needing transparency around having women living with HIV working in organizations while balancing the need to protect HIV status confidentiality

CONCLUSIONS

Organizations need to implement policies that ensure that the pathway to women's meaningful engagement and leadership in the design and delivery of HIV/AIDS services is unobstructed and that their health and access to care is uncompromised in the process.

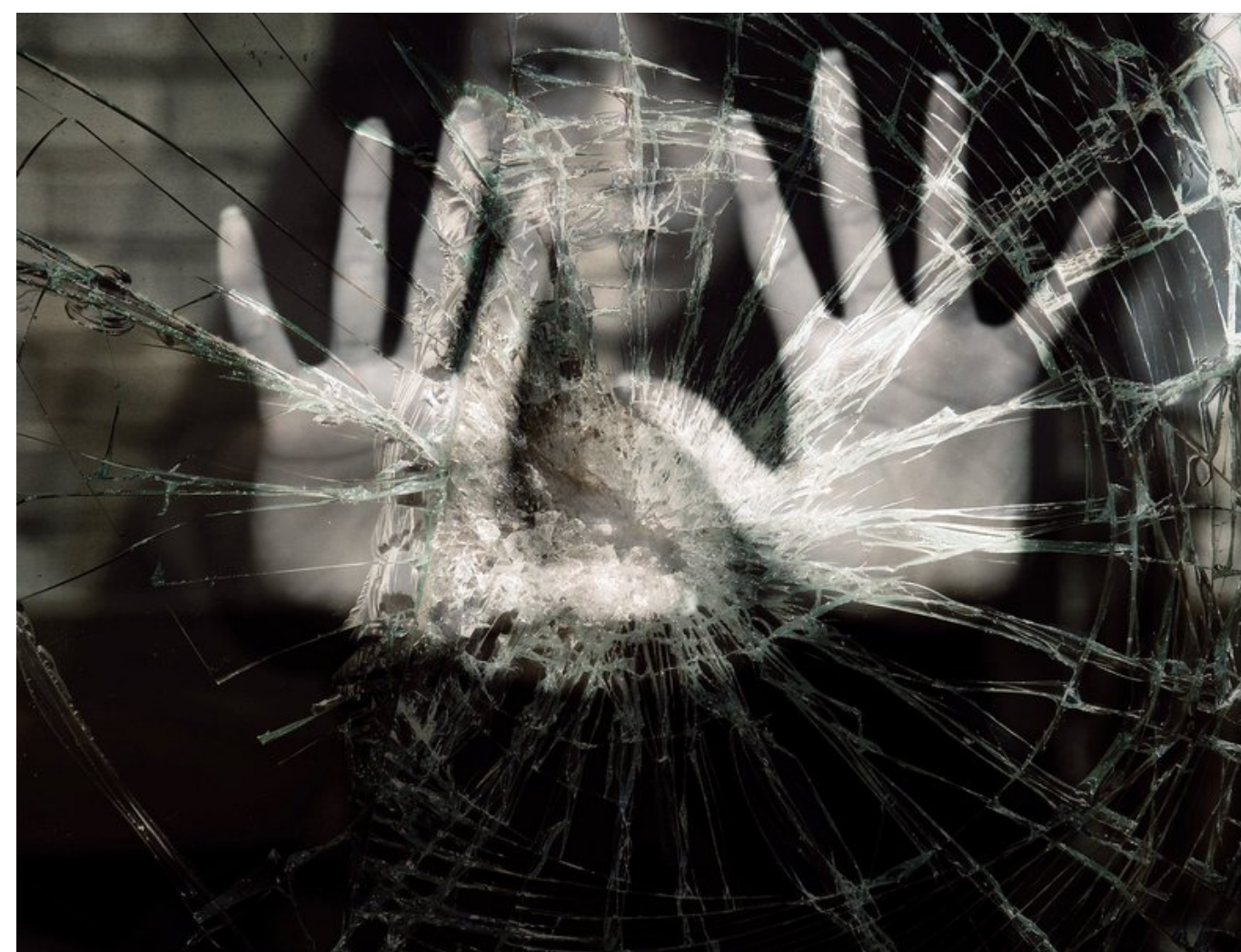
ACKNOWLEDGEMENTS

We gratefully acknowledge all of the women living with HIV who participate in CHIWOS, the national team of co-investigators and collaborators, the national Steering Committee, the provincial Community Advisory Boards (CABs), and the CHIWOS Aboriginal Advisory Board (CAAB-PAW). CHIWOS is supported by:

Figure 1. Tensions that emerge when women become involved in the design and delivery of HIV/AIDS services

Tension 1:
“We had X-group. I started that group. But, I felt very uncomfortable, that because I access their Food Bank I can never work there. And because of that, I stopped doing it. It was like I’m wasting my time. It’s ridiculous.. You can never really get into the system.. just because you are HIV-positive.”

Tension 2:
“They will not hire anybody who is accessing.. X’s Health’s Programs. So, if you access the Food Bank you can volunteer there. They’ll take your hard work on a volunteer basis. I’ve got a resume that I could get a job there as a support worker, no problem. But because I’m accessing the services, I have to be out of the Program for two years, which makes no sense whatsoever.”



“That’s a clear indication that X-Institution doesn’t follow GIPA principles.. It’s very disturbing.. It’s like there’s this glass ceiling.”

Tension 3:
“Every time I walk in that door I’m paying somebody’s salary and they’re able to write another grant because I fit into many demographics.. but I have no control over how they use my membership.. no control over whether they hire positive people, Aboriginal people..”

Tension 4:
“They just seem to have this mentality of, oh those poor people. We’re going to help them. We’re going to give them all these services but we’re not going to recognize their ability to help themselves. There’s no empowerment.”

Tension 5:
“I feel like there needs to be more openness.. it’s very secretive who on the Board at X-Institution is HIV-positive.. I’m just not up for that kind of a place where there’s this big, secretive thing happening.”



BRITISH COLUMBIA
CENTRE FOR EXCELLENCE
in HIV/AIDS



UBC



SFU



McGill University Health Centre



the CTN
CIHR Canadian
HIV Trials Network



le Réseau
Réseau canadien
pour les essais VIH des IRSC



Ontario HIV
Treatment Network



Ontario