

BREAKING THE GLASS CEILING: THE MEANINGFUL INVOLVEMENT OF WOMEN LIVING WITH HIV/AIDS IN THE DEVELOPMENT AND PROVISION OF WOMEN-CENTRED CARE

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BACKGROUND

The Meaningful Involvement of Women Living with HIV/AIDS (MIWA) is a key feature of women-centred care. This study sought to explore women's desires to become peer leaders in their care communities, the

structural barriers they face, and the tensions that emerge from involvement. Identifying and mitigating consequences of MIWA must be considered as peer participation in care gains prominence in Canada.

METHODS

The Canadian HIV Women's Sexual and Reproductive Health Cohort Study (CHIWOS) aims to measure and evaluate use of women-centred care among women living with HIV across Canada. As part of the formative phase aimed at better understanding 'women-centred care', Peer Research Associates (PRAs; women living with HIV who received

training in community-based research and focus group facilitation) conducted 4 focus groups with women living with HIV (n=28) in Vancouver, Victoria, and Prince George, BC. Focus groups were conducted between August and October 2011, and were audio-recorded, transcribed, and thematically analyzed.

RESULTS

Participants expressed strong desires to become involved in and provide expertise and leadership to the services they access. However, women identified a lack of clear organizational policies that recognize women living with HIV as not only recipients of services but as valued volunteers, employees, partners, and leaders within organizations.

STRUCTURAL BARRIERS IMPEDING PEER INVOLVEMENT:

- Organizational prejudice against hiring their own clients
- Disempowering staff attitudes towards women's capacity to contribute
- A lack of remuneration and recognition for contributions

TENSIONS THAT EMERGE WHEN WOMEN BECOME INVOLVED:

- Being transparent about having women with HIV working in organizations yet wanting to protect confidentiality
- Securing funding through use of women's membership and efforts yet giving women no ownership over policy/programming decisions
- Having women contribute to an improvement of services to which they are then given limited access as staff members

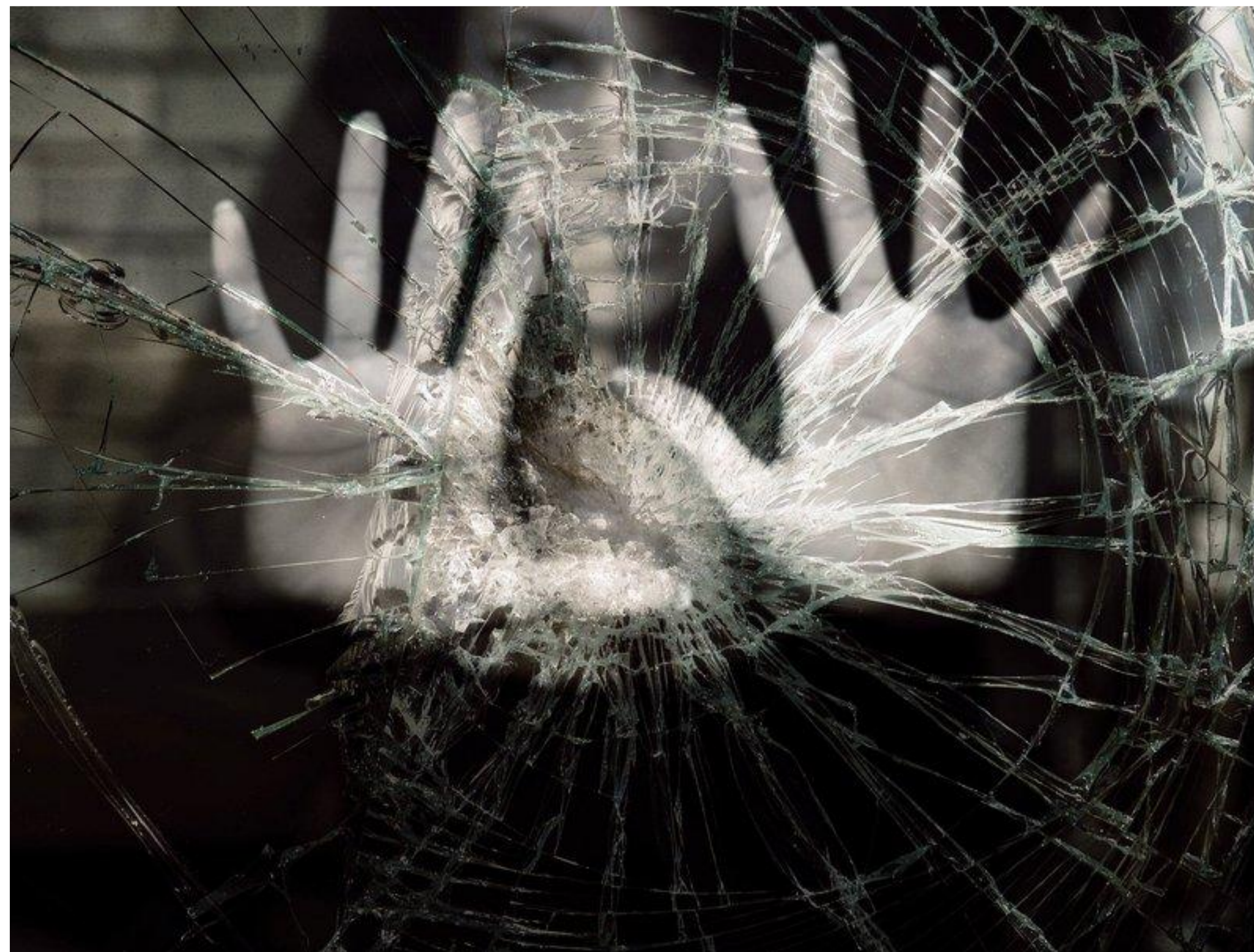
This yields an 'HIV peer engagement glass ceiling' that keeps many women from reaching their full leadership potential in their communities.

BARRIERS:

"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."

"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."

"I'm expected to put in volunteer hours. I see a couple of my neighbours, they drive them like slaves. They work like dogs and don't get a penny for it. They don't get recognition. They don't even get a cake or something on volunteer day."



"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."

TENSIONS:

"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."

"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.."

"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."

CONCLUSIONS

Organizations striving to operate within a women-centred care model of care need to implement policies that include a commitment to MIWA. However, there is an urgent need for successful strategies that mitigate barriers/tensions and facilitate women's involvement. Meaningful user engagement in care may contribute to more effective services and improved health for women with HIV. This will be evaluated in the next phase of CHIWOS, which will enroll 1,250 women with HIV in Canada.

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CHIWOS is supported by:



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