Promising practices in the engagement of people living with or at risk for HIV in rural Canada

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Research Questions

• What helps or hurts meaningful involvement in rural AIDS Service Organizations (ASOs)?
• How is this experienced by those who are further marginalized?
• What practices help support meaningful involvement in rural ASOs.
Meaningful Involvement

The commitment to ensuring that voices of all members of the population of interest are heard.

Participating as equal partners in decisions about policies and programs within ASOs
Background

• GIPA/MIPA
  – International support
  – National support
  – Local Support
ASOs in the Maritime Provinces

- 17 ASOs in total
- Frequently lack resources
- May serve fewer than 12 PHAs
- Often share programs
- Clients may be transient
- May provide other services such as needle exchanges
- Do not all have provincial funding
Methodology

• Community-based research
• Initial training workshop for PHAs
• PHA-led interviews
• Thematic Analysis
• Photo-voice
• Two day strategy workshop
Participants (Interviews)

- 35 people who were HIV-positive or who were at risk of acquiring HIV
- 16 staff or volunteers of ASOs
Photovoice

• A qualitative, community-based research strategy in which participants take pictures of the phenomenon under study.
Participants (Photovoice)

- Eleven participants trained in photovoice process
- Asked to take pictures of what meaningful involvement in an ASO looked like for them.
- Three participants completed the process
  - Selecting
  - Contextualizing
  - Codifying
Research Findings

• Many people did not know what GIPA/MIPA meant.

• People sometimes stopped volunteering because of stigma or because they believed, they did not fit into the organization.

“It’s the stigma down here. People/gays are not accepted. I’ve heard of a lot of gay bashing here before I came down here.”
Research Findings

• People who became meaningfully involved did this because they wanted to help other people and for personal reasons

“I lost my partner of twenty years nine years ago and I was really involved with the AIDS committee of [city]. I was involved with them for about four years and I volunteered about forty to fifty hours a week because when my lover passed they helped him out quite a bit in the hospital and stuff. It’s kind of pay back for that.”
Research Findings

• Some people did not become involved because the ASO was closed when they had an opportunity to attend, they did not have a way to get to the ASO, and/or they needed baby sitters.

“Some people are just busy. Most days various organizations are only open during office hours. Like for example, for me, if I wanted to go to (the ASO in town) right now, I’m working. But even times when I’m not working I have a child and I have a family and it’s only open nine to four. I can’t necessarily run up to TOWN and access a service.”
Research Findings

• Some people did not volunteer because they lived in a small community and did not want other people to know about their business

• “I don’t think people want to see their cars parked out front or in the back because somebody is going to see.”

• In this little town I didn’t tell anybody because it would have been... suicide... I mean I could have lived with it, it’s just that everybody else put the fear of God in me ...
Research Findings

• Some people believed that ASOs could do a better job of involving aboriginal people, people who come from other countries, people who did not speak English, and injection drug users.

“Meaningful involvement is advocating for changes around social inequities, prevention education with young people, and hospital visits”
Recommendations

• ASOs use technology effectively so that people who do not want to go into an ASO can become involved.
• People be provided with transportation in order to attend activities at their ASO.
• Peer mentoring be instituted or strengthened.
• People be made more aware of volunteer opportunities through outreach activity.
Thank-you!