

# Leading the Way: The Evolving Role of Aboriginal HIV and AIDS Research in Canada

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Know your HIV status: Get Tested!

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## Honouring

The territory of  
the Gadigal  
people of the  
Eora Nation.

Elders past and  
present.

Our loved ones



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## Self Location



- Blood lines and family ties
- Involvement began in 1995,  
formalized in 1997
- Regional and then National work

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## Acknowledgements

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## The Context in Canada

- 3 distinct populations – First Nation, Inuit and Métis
- Over representation in HIV and AIDS diagnoses.
- An epidemic with key modes of transmission through IDU and increasingly heterosexual contact
- Community leadership with Aboriginal HIV and AIDS organizations from sea-to-sea-to-sea
- We are STILL HERE – culturally grounded, supported by Elders, working in a good way



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## Canadian Aboriginal AIDS Network



Head  
Office  
British  
Columbia

Research  
and Policy  
Unit  
Nova Scotia



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## Our Story

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## Background

- CAAN began to engage in HIV and AIDS research in 1998.
- Capacity Building and research have evolved in parallel
  - Harm Reduction
  - Summer Training Awards
- Community-based Research framed an opportunity for transition from key stakeholder to leadership

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## Our Journey Begins

### Key considerations:

- Commitment to Aboriginal leadership in response to HIV and AIDS in Canada
- CAAN's membership and Board maintained a vision to maximize opportunities through our national structure
- Research began with programmatic document review regarding Harm Reduction to our first research project investigating APHA Care, Treatment and Support needs



## Our Journey continues

- Initial dependence upon Allied researchers with full academic credentials
- Developing organizational capacity to manage funds
- Developing staff member's credentials
- Dissemination Project to create our Journal
- Evolving capacity building through full time staff position(s)



## Beginning to Take Leadership

- Grant writing
- Sub-grants allocated from universities
- Holding meeting, planning and dissemination grants at CAAN
- Developing catalyst grants to support larger projects
- Refining the capacity building roles of full time staff



## Turning Points

- Indigenous researchers begin to enroll in and/or complete PhD studies
- Dr Charlotte (Loppie) Reading continues to work closely with CAAN as a faculty member
  - Indigenous leadership is fully entrenched
- Several PhD candidates presently nearing completion
- Outreach continues to engage more Indigenous researchers



## The AHA Centre



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## Research Grant Timeline

- Harm Reduction
  - Addressing Homophobia
  - Care, Treatment and Support
  - Youth Experiences of Testing
  - Stigma
  - 2-Spirit Women's Experience of Homophobia
  - Depression
  - Relational Care (Cultural Competency)
  - Women's Experience of Sexual Violence
  - Impact of Alcohol Use on Access to Care
  - Stable Homes, Strong Families
  - Family Matters
  - Refining the Research Response: A Strategy
- Research Technical Assistant > Community-based Research Facilitator
  - Enhancing Dissemination – Formed CAAN's Journal

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## Our Time

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## What have we learned about research?

Process matters!

- Culture and ceremony
- Relationship
- Creativity
- Collaboration
- Reflexivity
- Reciprocity
- Strengths-based

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## What have we accomplished?

- Indigenous community capacity to lead research is recognized
- GIPA and MEPA - standards for community engagement have been raised
- Research has contributed towards legitimizing experiences
- Stigma is addressed by telling people's stories
- Individual lives have been transformed
- Member organizations have reports to reference



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## Youth Leadership in Research

- Open the door and move over!
- Youth in Research statement
  - Engagement
  - Nothing about us without us!
- Youth are leading research
  - Informing youth roles in prevention
  - Responding to the language of risk
  - Mentoring



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## Responding to Aboriginal Women's Health

- Supporting an Aboriginal women's research agenda
- Research designed to investigate Aboriginal women's vision of their health energizes a National response
- Aboriginal Women's Research Initiative is formed
  - Ownership in the research process



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## What have we learned through our research?

- (Re-)Connecting with culture is consistently identified as important for well-being.
- Care, Treatment and support needs of APHAs emphasize traditional Aboriginal Health and Wellness services:
  - 61% of the APHAs use or need traditional Aboriginal services such as Elder counsel, ceremonies, medicines and sharing/healing circles.
- The relationship between HIV and depression is diverse, complex and interconnected. For many participants, HIV and depression went "hand in hand" but depression was also linked to broader community issues such as poverty, unstable housing, fostering/adoption, cultural disruption and substance abuse.
- Violence and HIV are closely interwoven for many Positive Aboriginal Women. Women's exposure to violence is rooted social determinants, including racist sexism, disadvantaged socio-economic conditions, punitive social services and lack of access to opportunities and support.
- Cultural competency is important, relationships are at the core
- APHA Leadership is strategically fostered through policy, mentorship and training that is grounded in local context and linked together.



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## Our Future

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## Refining the Research Response

- Collectively, our plan is to create, disseminate and implement a strategic research agenda in response to HIV and AIDS in the Indigenous community.
- We will identify:
  - What research is most needed and what has been done already?
  - Where research is most needed
  - How to design our research
    - incorporating Indigenous research methodologies,
    - Options to apply Western methodologies in a good way

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Thank you!

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