

# The Power of Western Scientific Language: Reclaiming *N'ginaajiwimi* For Indigenous Peoples

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# Presentation Outline

- Acknowledgements
- Social and cultural location
- I'm going to share three stories with you ...
  - The power of Western scientific language
  - What's accomplished?
  - Recommendations for resisting
- Example: 2SHAWLS

# Acknowledgements

- The **traditional territory** of the Mississaugas of the Credit, the Anishnabeg, the Chippewa, the Haudenosaunee, and the Wendat peoples. Today Toronto is home to many diverse First Nations, Inuit and Métis peoples.
- Thanks also go to ....
  - Doris Peltier
  - Dr. Earl Nowgesic

My people never knew or had any position in life except the face of the earth—stretching away from them in all directions forever. And they lived there laterally—on one level with each other and all things. They looked up only to trees and eagles... [and] by reading our own footprints we could always tell where we had come from. In fact, we had no future. In our language, the closest word we had to future was sort of an arc or circle. Our going was part of the arc of a circle. So was our coming (Pelletier [Wawashkesh]: 11).

*Haudenosaunee*

“There is always a story that frames the nature of research.’ Hence, [our] research inclination or [our] way of knowing [is] directly/indirectly related to [our] position in the story” (Dunbar Jr., 2008, p. 89) .

“Indigenous people in Canada recognize that it is important for storytellers to impart their own life and experiences into the telling. They also recognize that the listener will filter the story being told through their own experience” (Wilson, 2008,p.32) .

# Kettle Point First Nation



# Stony Point First Nation (i.e., Aazhoodena)





# Grandparent's Home (Stony Point)





# Family



# The truth about stories ...

- The truth about stories is that's all we are
- You can't understand the world without telling a good story
- If you want to change the world, tell a different story
- 'Stories are wondrous things ... and they are also dangerous'

*(Thomas King, 2003)*

# A poor history of research ...

- **Research** is “probably one of the  *dirtiest words* in the  *Indigenous world’s vocabulary* ” (Smith, 1999, pp. 1).
- Damaging, harmful, insensitive, intrusive, and exploitive (Henry et al., 2001)
  - Academic driven vs. community relevance
  - Convenient data sources
  - “Researched to Death”
  - “Helicopter” or “Parachute Research”
  - Focused on deficits rather than strengths
- Used as a tool by the colonizer to justify racist and assimilation policies (Saini, 2012)

“Through [the cold language of science], politicians and policy makers find it easier to turn away from what suffering does to a person’s humanity. [...]By adopting a morally ‘dispassionate’ and cold-calculating style of writing, social researchers may even find themselves unwittingly allied to the interests of those whose positions of power and privilege that are maintained at the cost of doing violence to large numbers of people.”

*(Wilkinson, 2006:430)*

“Portraits of Indigenous sickness and misery act as powerful social instruments for the construction of Indigenous identity. Epidemiological knowledge constructs an understanding of Indigenous society that reinforces unequal power relationships; in other words, an image of sick and disorganized communities can be used to justify patterns of paternalism and dependency.”

*(O'Neil, Reading & Leader, 1998, pg. 230)*

# Manifest Manners: Narratives on Post-Indian Survivance (1994)

“By **controlling the self-image** and imaginatively reinventing viable ways of being Native through [language], post-indian warriors **defy the impositions of the dominant culture** and, most importantly, define their identities for themselves: **‘touch’ themselves ‘into being with words’**” *(McKegney, 2007, pp. 139; quoting Vizenor by Coltelli, 1990: pp.160)*



# Caveat

- Our use of language is Influenced by my *Anishinaabae* identity
  - Respectful of diversity

# Context (1 of 2)

- Indigenous peoples are disproportionately represented in Canada
  - Represent “5.0% of the Canadian population ... and yet an estimated 6,180 Indigenous were living with HIV (including AIDS) in Canada in 2018 (i.e., 10.0% of all prevalent HIV infections)” (CATIE, 2018).
- Seventy-two percent of all Indigenous people living with HIV have an AIDS diagnoses
  - Later diagnosis (Stokes, Pennock, & Archibald, 2006)
  - Slower uptake of treatment (Wood et al, 2006)
- Higher morbidity (i.e., more illness) and mortality (i.e., higher and earlier deaths)

(Lima, 2006)

# Context (2 of 2)

- **Psychological distress** (*Indigenous vs. non-Indigenous*)
  - More experiences of depression (4 to 5 times higher) (*Kirmayer et al 2000; Manson et al 1985*)
  - Higher rates of suicide (3 to 5 times higher) (*Health Canada, 1998; Kirmayer et al 1992*)
  - Higher rates of drug/alcohol use (*Hirschfeld et al 1990; Gray et al 2001; Jacobs & Gill, 2001*)
  - Subjective experiences differ (i.e., appear similar but not identical) (*O'Neil, 1996; Cain, 2011; Cain, 2012*)
- **Ways to reach out and help are comprised** (*Cain, 2011; Cain, 2012*)
  - Under represented in HIV/AIDS mental health research in Canada
  - Under represented in the development of interventions
  - Care can be poorly designed to meet cultural needs

# Issues (1 of 3)

- Language shapes how we think about Indigenous peoples and HIV infection (McKay-McNabb, 2006; Lavalley & Clearsky, 2006; O'Neil, Reading and Leader, 1998)
  - Stigmatizing / used to justify continuing control
  - Detrimental to Indigenous identity, wellbeing and survival
    - Indigenous youth hold fatalistic views about the future (Larkin et al, 2007)

# Issues (2 of 3)

- Language is used to sustain medical colonialism and health inequities for Indigenous peoples (Brown et al, 2012)
- Language influences medical practitioners' knowledge and assumptions about Indigenous peoples (Browne, 2005)
  - Intertwined with dominant social stereotypes and were sometimes expressed as fact even when they conflict with egalitarian ideals

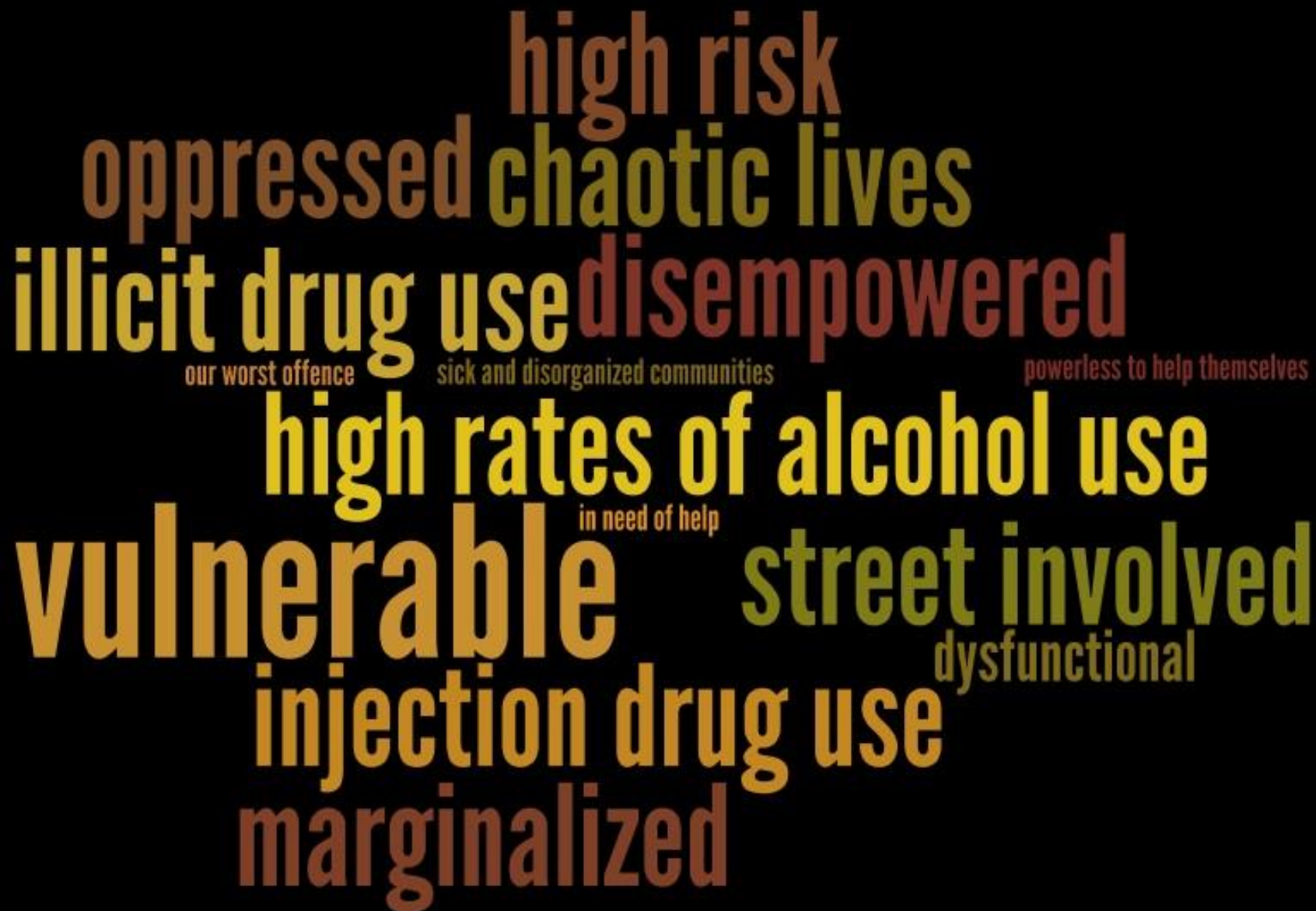
# Issues (3 of 3)

- Potential consequences when we ignore language in research
  - Contributes to stigmatization and marginalization
  - Vulnerability in research has not been clearly or uniformly defined
  - Barriers affecting HIV/AIDS researchers' ability to conduct clinical trials with pregnant women, prisoners, and children, for which the regulations specify additional protections  
(Sengupta et al 2010)
- Indigenous peoples sometimes adopt this language to describe themselves



# Description

- A team of scholars and community members have been meeting to begin work
  - Two face-to-face meetings
  - Collaborate online via email
- Conducted a preliminary literature review (n=23) of Indigenous HIV literature in Canada
  - Critical discourse analysis
  - Grouped words and findings of studies
- Plans include working with a team of Indigenous scholars and community members to further this work



A word cloud on a black background featuring various social and health-related terms. The words are arranged in a dense, overlapping manner. The colors of the words range from dark brown to bright yellow. The largest words are 'high risk', 'oppressed', 'chaotic lives', 'illicit drug use', 'disempowered', 'high rates of alcohol use', 'vulnerable', 'street involved', 'injection drug use', and 'marginalized'. Smaller words include 'our worst offence', 'sick and disorganized communities', 'powerless to help themselves', 'in need of help', and 'dysfunctional'.

high risk  
oppressed chaotic lives  
illicit drug use disempowered  
our worst offence sick and disorganized communities powerless to help themselves  
high rates of alcohol use  
vulnerable in need of help street involved  
injection drug use dysfunctional  
marginalized

# over-represented

generalizability  
oppressed  
later diagnosis  
P Value  
disproportionately effected  
slower uptake of anti-retroviral medication  
marginalized  
higher morbidity  
mortality rate three times higher  
inference  
die sooner  
objective  
standard deviation  
Aboriginal ancestry correlated with HIV-positivity  
vulnerable  
lack access to HIV treatment  
risk factor more illness  
hazard ratio  
non-compliant  
validity  
bias  
shorter survival times  
meta analysis  
frequent users of emergency room departments  
attributable risk  
less access to experienced physicians  
confounding  
evidence based  
disempowered

colonization vulnerable

income and income distribution  
early childhood development  
health services  
Aboriginal status  
social safety net  
racism  
unemployment and job security  
disability  
social exclusion

food insecurity  
employment and working conditions  
colonialization  
gender  
race  
housing  
education

disempowered  
oppressed  
marginalized

# Lessons Learned

- Double-speak (Fiske & Browne, 2006)
  - Simultaneously support principles of inclusion, equality, meaningful involvement etc. while paradoxically describing them in the literature as 'discredited medical subjects'
  - Further oppresses, marginalizes, discredits and makes vulnerable
  - Engenders fatalistic attitudes and beliefs

# Recommendations (1 of 2)

- To decolonize the language of HIV in research
- To use language that emphasizes our reality as Indigenous people
  - Ways of being
  - Ways of knowing



# Recommendation (2 of 2)

- Leave space that cultivates deep listening and appreciation
  - Do we perceive beauty? Do we stop to appreciate it? Do we recognize beauty in unexpected contexts?
  - Actively search for beauty and strength in ways that are balanced against broader socio-structural challenges impacting Indigenous health

knowledge is handed down ancestors  
 adjusts to changing conditions  
 shpendan e-aawiyin dibaadendizowin  
 Métis  
 ajichaak minodaapin kina gwaya experiential  
 aakwa'ode'ewin naagadawenim g'jichaag  
 Home Land First Nation reciprocity dynamic language dream oral  
 boonigi'odetaagwewin connection  
 e-zhitwaayin zhi-bimaadizin holistic  
 the winged ones sacred  
 the two legged creatures  
 need to walk on the land to know it  
 consensus adaptable  
 Inuit cosmology Indigenous-centred  
 respect sacred teachings  
 kinship those that crawl  
 mnaadendan bimaadiziwin zaagi'idizon nda-mino'daapinaan e-aawiyaanh  
 distinct revelation diversity  
 E-zhitwaayin zhi-bimaadizin visions responsibility  
 giizhendawin dreams Minodaapin kina gwaya survival  
 I can only tell you what I know  
 self-determination  
 oral teaching  
 story bwaajigewin  
 cultural wisdom  
 timeless truths  
 miikaan culture intuition traditional teachings  
 mashkoziwin the four legged ones  
 spiritual wisdom of Elders  
 n'ginaajiwimi  
 Anishinaabae

# **The Two-Spirit HIV/AIDS Wellness and Longevity Study (2SHAWLS), Ontario, Canada**

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**Randy Jackson, David J. Brennan, Tony Nobis, Art Zoccole, & Georgi Georgievski**

**Denver, Colorado  
October, 2015**

# 2SHAWLS: Background

- Concern about over-representation of HIV infection affecting two-spirit communities in Ontario
  - Higher rates of illicit drug use, poverty, housing challenges, etc.
  - Higher rates of illness and death
- Even though clients came through the door in crisis, aware that many two-spirit men were doing well living with HIV
- Hence, 2SHAWLS
  - Resisting racism, homophobia, colonization and gender violence against two spirit men
  - How do we design services that support two-spirit men's health, wellness, their resiliencies?

# 2SHAWLS: Western Resilience

- Western understanding of resiliency
  - Resiliency is commonly understood as individual and a “positive adaptation despite adversity” (Fleming & Ledogar, 2008)
  - Criticized as placing the sole responsibility for healing upon the individual (Lavalley and Poole, 2010; Newhouse, 2006)
  - Lacking sensitivity to social and cultural contexts (Kirmayer et al 2009)

# 2SHAWLS: Indigenous Resiliency

- Connected to the broader socio-cultural environments of Indigenous peoples (Fleming & Ledogar, 2008)
  - Is relational, focused on connection, the health of a community to provide, and is something learned/put into practice/shared through culture (McGuire, 2010)
  - “Resilience [is] not just an individual’s capacity to cope with adversity but [is] also the capacity of the person’s community to provide the health resources necessary to nurture and sustain well-being, providing individuals opportunities to access health resources in culturally relevant ways” (Liebenberg et al, 2008: 2)
    - Access to and use of Elders/Traditional Healers
    - Use of ceremony and spiritual practices
    - Family, peers, community
    - Language

(Isaak & Marchessault, 2008; McIvor et al 2009)

# 2SHAWLS: Goal / Objectives

- To better understand the factors, skills, resources, knowledge and practices that contribute to **two-spirit men's** health and **well-being** living with HIV

# 2SHAWLS: How did we do this?

- Comprehensive (**scoping**) review of the literature
  - A rapid gathering of literature in a given policy or clinical area where the aims are to accumulate as much evidence as possible and map the results
  - Attentive to ways the literature described use of decolonizing and indigenous methodologies
- **Focus groups** with two-spirit men
  - Re-envisioned as **sharing circles** (i.e., Anishinaabe)
  - Adapted and made culturally sensitive and appropriate for two-spirit men



# 2SHAWLS: Findings

- Participant Demographics
  - Two-spirit and living with HIV for 10 or more years
  - Indigenous status (First Nation = 12; Métis = 2; Inuit = 0; Total = 14)
  - Age (32 and 61 years of age; average age = 46; Age n/a = 2)
- Seven **truths of resiliency** for two-spirit men living long-term with HIV
  - (1) Worldview, (2) Finding One's Strength, (3) Walking Towards Balance, (4) Recognizing True Power, (5) *Mino-bimaadiziwin* (living the way of a good life), (6) Self-care, and (7) Living Our Truth

# 2SHAWLS: Worldview



**What we believe  
about the world**

**Note:** The petroglyphs are an artistic interpretation of each of the paths/truths of resiliency (Earthlore, Ottawa, Ontario).

# 2SHAWLS: Finding One's Strength



**Accept and work  
with challenges in  
a good way**

# 2SHAWLS: Recognizing One's True Power



Connecting to  
community for  
healing

# 2SHAWLS: Walking towards Balance



**Putting  
community  
connection into  
action**



# 2SHAWLS: Mino-bimaadiziwin



Journey to “living  
the way of a good  
life”

# 2SHAWLS: Self-Care



Sustaining the  
journey of  
“living the way of  
a good life”

# 2SHAWLS: Living Our Truth



Accepting and  
learning to live  
with our whole  
selves



# 2SHAWLS: Discussion of Findings

## Our findings:

- There is a story we rarely hear: *resiliency occurs in the lives of Two-Spirit men living long term with HIV*
- Resilience is not found in a linear progression through the Truths but is rather about locating and using these truths as a map to guide
- Resilience is grounded in the values and perspectives of one's culture
- Resilience is also acting on these values and beliefs

# Last Thoughts ...

“In a fractured age, when cynicism is god, here is a possible heresy: **we live by stories, we also live in them.** One way or another we are **living the stories planted in us** early or along the way, or we are living the **stories we planted—knowingly or unknowingly—in ourselves.** We live stories that either give our lives meaning or negate it with meaninglessness. If we change the stories we live by, quite possibly we change our lives.”

*(Ben Orki, 1997)*

WHAT THE WORLD NEEDS IS A TEAM OF  
SCIENTISTS, PHILOSOPHERS & SHAMANS.  
WORKING TOGETHER, NOT AGAINST EACH  
OTHER.