



INDIGENOUS PERSPECTIVE ON BUILDING INCLUSIVE AUTISM PRACTICES

Grant Bruno
PhD Medical Sciences Student
Department of Pediatrics
University of Alberta
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Autism Ontario Webinar



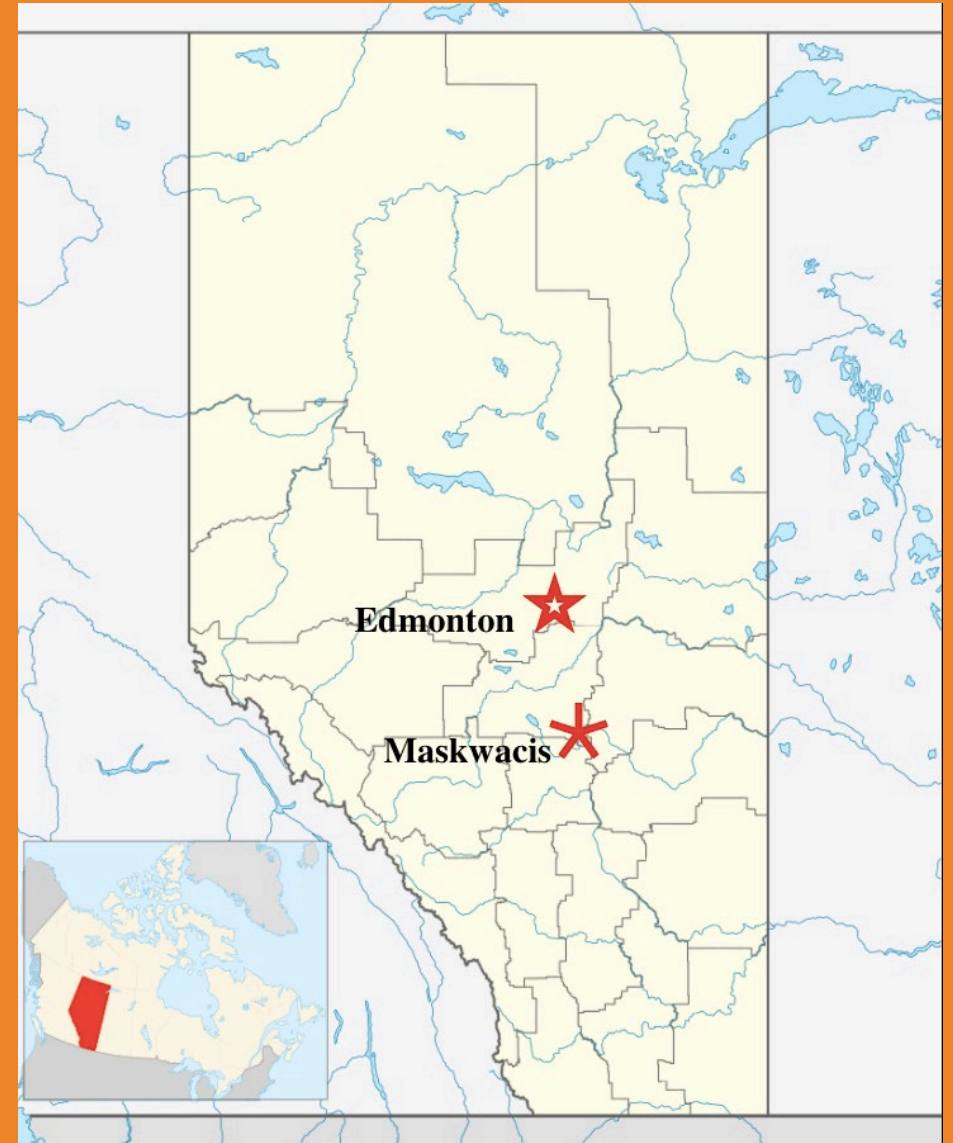
“It is not who are you but whose you are”

Connections to okimaw papasteyo (Chief Woodpecker) and okimaw mistahi maskwa (Chief Big Bear) who both lived in the 1800's

First generation residential school survivor. Both *nôkomak* (grandmothers) and my mother went to Hobbema residential School

Registered member of Samson Cree Nation (one of the reserves that makes up Maskwacis).

The four reserves of Maskwacis are Samson, Ermineskin, Louis Bulls and Montana



MY EARLY STORY



- Father to four children - three sons and a daughter, two of my sons are on the autism spectrum
- My children guide me
- First generation university grad
- Have been conducting research in Maskwacis for 8 years

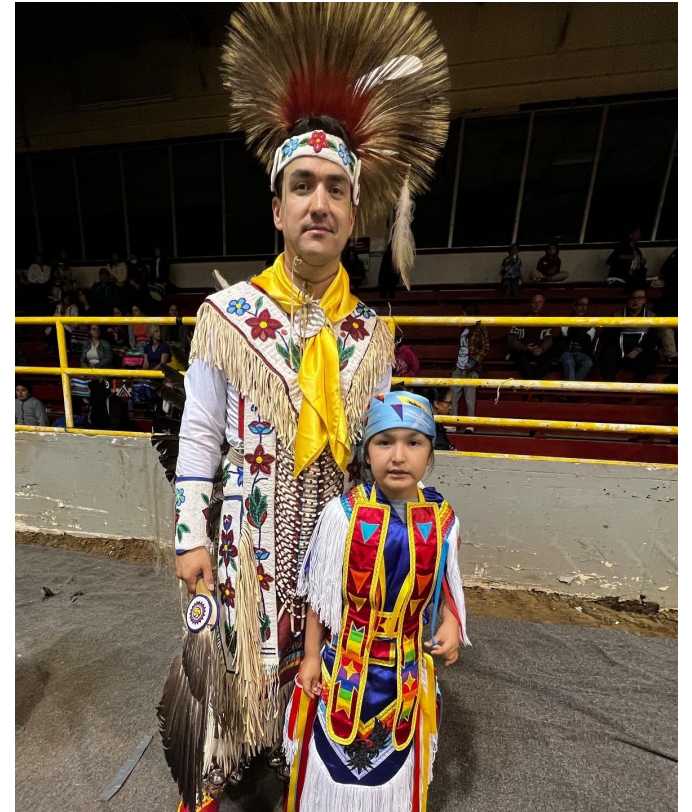
AUTISM TERMINOLOGY

- Constantly evolving
- Identity first language - Autistic person (instead of 'someone with autism')
- Autism rather than Autism Spectrum Disorder (ASD)
- Use of neurodiversity lens – acceptance first
- I do not consider myself an expert on autism

"Autism isn't something a person has, or a 'shell' that a person is trapped inside. There's no normal child hidden behind autism. Autism is a way of being. It is pervasive; it colours every experience; every sensation, perception, thought, emotion, and encounter, every aspect of existence. It is not possible to separate the autism from the person – and if it were possible you, the person you'd have left would not be the same person you started with." Sinclair 1993 p. 1

INDIGENOUS TERMINOLOGY

- Section 35 of Canada's Constitution recognizes three distinct groups - First Nations, Métis, Inuit
- Approximately 1.4 million Indigenous people today
- Vast differences in language, geography, and experiences
- Terms such as 'Indian' 'Aboriginal' 'Native' are used anymore, Indigenous is appropriate, but it is best to get more specific such as tribal or family affiliation



INDIGENOUS DEFICIT DISCOURSE

“Deficit-based research can contribute to stigmatization when problematic health issues are repeatedly characterized in the context of a specific population. Additionally, when any given health deficit is repetitively associated with **Indigenous** Peoples through research, there is risk of stereotyping. Unfortunately, due to a lack of critical exposure in education and media, deficit based research given without proper framing can perpetuate negative characterizations of **Indigenous** Peoples”

Bryant et al 2021

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DSM-5 AUTISM DIAGNOSTIC CRITERIA

A. Persistent **deficits in social communication and social interaction across multiple contexts, as manifested by the following, currently or by history (examples are illustrative, not exhaustive)**

- **Deficits** in social-emotional reciprocity, ranging, for example, from **abnormal** social approach and failure of normal back-and-forth conversation; to **reduced** sharing of interests, emotions, or affect; to **failure** to initiate or respond to social interactions.
- **Deficits** in nonverbal communicative behaviors used for social interaction, ranging, for example, from **poorly** integrated verbal and nonverbal communication; to **abnormalities** in eye contact and body language or deficits in understanding and use of gestures; to a total **lack** of facial expressions and nonverbal communication.
- **Deficits** in developing, maintaining, and understanding relationships, ranging, for example, from **difficulties** adjusting behavior to suit various social contexts; to **difficulties** in sharing imaginative play or in making friends; to **absence** of interest in peers.

DISABILITIES AND COLONIALISM

Forced removal of children

Loss of kinship, language, and culture

Medical colonialism

Inequitable access to healthcare and services

Imposed westernized views

Mentally Incompetent Indians

Powers of Minister generally

51 (1) Subject to this section, all jurisdiction and authority in relation to the property of mentally incompetent Indians is vested exclusively in the Minister.

Particular powers

(2) Without restricting the generality of subsection (1), the Minister may

- (a)** appoint persons to administer the estates of mentally incompetent Indians;
- (b)** order that any property of a mentally incompetent Indian shall be sold, leased, alienated, mortgaged, disposed of or otherwise dealt with for the purpose of
 - (i)** paying his debts or engagements,
 - (ii)** discharging encumbrances on his property,
 - (iii)** paying debts or expenses incurred for his maintenance or otherwise for his benefit, or
 - (iv)** paying or providing for the expenses of future maintenance; and
- (c)** make such orders and give such directions as he considers necessary to secure the satisfactory management of the estates of mentally incompetent Indians.

Property off reserve

(3) The Minister may order that any property situated off a reserve and belonging to a mentally incompetent Indian shall be dealt with under the laws of the province in which the property is situated.

R.S., c. I-6, s. 51.

Indian Act of 1876

PHD RESEARCH

- Recently a systematic review was done with a focus on ASD in Indigenous communities at the international level, and the findings outlined an “urgent need for ... resources to be dedicated to support research for Indigenous and First Nations people across the lifespan with ASD (Shochet et al., 2020)
- Strength-based and decolonizing methods (using *nehiyaw* worldview)
 - Community led partnership with Maskwacis Education School Commission
- Action oriented – producing films, parent support group, sensory/autism friendly cultural events

PHD STUDIES

Study 1 – Scoping review

- 24 articles found total
- Research in this area is low quality and often not done in partnership with Indigenous communities

Study 2 – Traditional understandings of autism

- Engaging with Elders traditional knowledge keepers
- Early conversations see autism as a gift

Study 3 – Community perspectives of autism

- Done in partnership with Maskwacis and the Six Nations of the Grand River
- Allow families to tell their stories of challenges and success

PHD RESEARCH: EARLY FINDINGS – THE NEGATIVES

Misinformation

Obstacles to
getting a diagnoses

Families have to
leave the reserve
for better access
to services

Band politics get in
the way

Missed
opportunities for
interventions

Apprehension
when working with
the provincial
government

Funding does not
equate success

Urgent need for
evidence to justify
decision making

Reserves are not
friendly to
disabilities

PHD RESEARCH: EARLY FINDINGS – THE POSITIVES

A lot of interest

Acceptance first

Autism can be
viewed as a gift

Inspiring allyship
stories

Families are really
trying

Kinship supports

Cultural continuity

Jordan's Principal

Opportunities for
share learning for
Indigenous health and
Autism researchers

Language as Foundation

awâsis

as noted earlier, is a child or rather “a small animate being,” “a small travelling spirit,” or “a small spirit engaged on a human journey.”

nikâwiy

refers to “my mother.” This term honours a child’s relationship to their birth mother and it recognizes the sacred role a child’s mother holds in bringing them into the human world and giving them the gift of life.

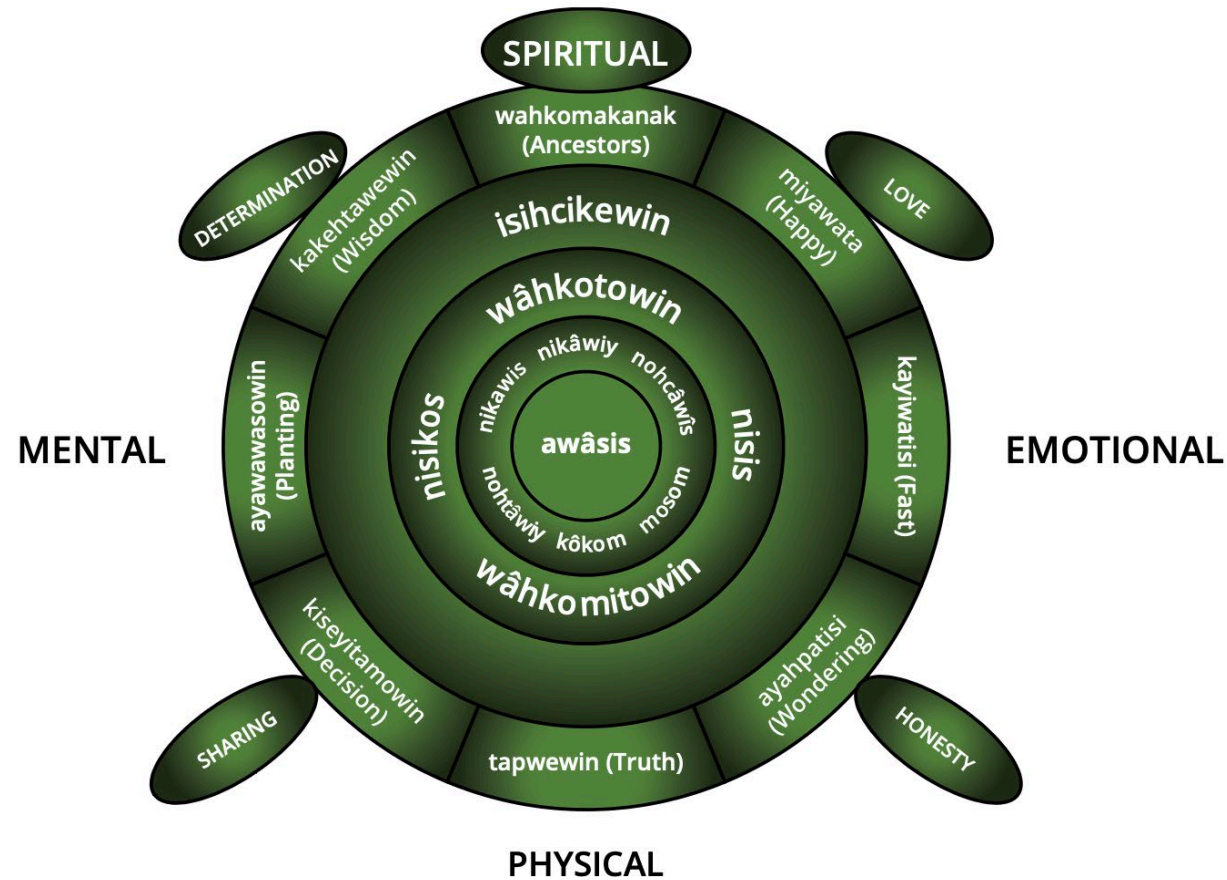
nohtâwiy

is the relationship term for “my father.” Similar to above, this term honours a child’s relationship to their birth father.



Figure 1

The Turtle Lodge Relationship Mapping Image



Makokis et al 2019

Indigenous parenting

DECOLONIZING AUTISM



ka-kamawaci-iyinisit (meaning: given a unique quiet spiritual intelligence)

pihtos-mânitonihk-iyinisit (meaning: given different way of thinking in its own spiritual intelligence)

ê-mihkosit pihtos mânitonicihkan (meaning: given different way of spiritual thinking)

ê-mihkosit pihtos ê-si-waskawiht (meaning: given the gift of moving a different way or being (characteristic/behavior))

DECOLONIZING AUTISM

Sometimes viewed as gifted

- Encourages unconditional acceptance

Neurodiversity is not new

- Nehiyawak (Plains Cree) have been practicing neurodiversity for centuries

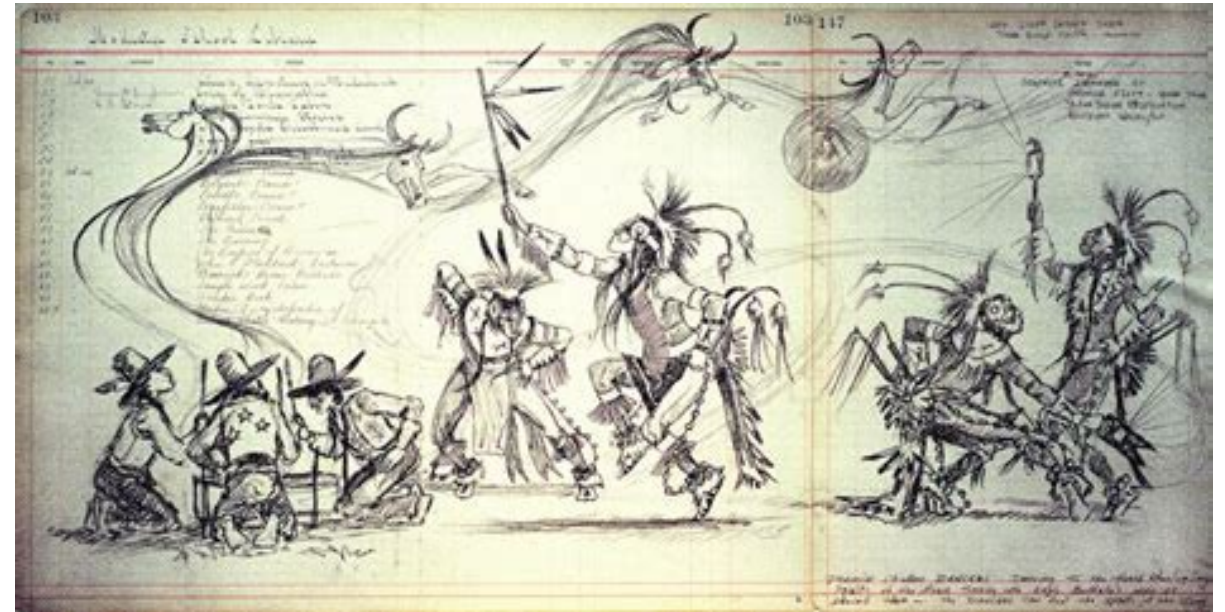
Ceremony

- Can give the individual purpose
- Inclusive

On the land services and assessments

Sensory friendly cultural events

At the heart of decolonization is healing



HOW TO SUPPORT FIRST NATIONS FAMILIES

What can I do to support families?

- It is all about relationships/connection (wahkotowin)
- Become trauma informed/post traumatic growth
- Lean into discomfort/uncomfortable conversations
- Look upstream for solutions
- Meet the families where they are at
- Walk a mile in their moccasins
- Beware of performative reconciliation
- Be flexible and patient



THE GIFT OF BEING DIFFERENT – A SHORT DOCUMENTARY

Ay hiy (thank you)

Supervisors:

Dr. Lonnie Zwaigenbaum

Dr. David Nicholas

Committee

Dr. Sean Lessard

Elder Francis Whiskeyjack



MASKWACIS EDUCATION
SCHOOLS COMMISSION



women & children's
health research institute



Fondation
Brain Canada
Foundation



Réseau pour transformer
les soins en autisme

Transforming Autism
Care Consortium

