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Human dignity and engaging social epigenetic studies of FASD in Tribal communities within Canada

*First International on the Prevention of FASD
Edmonton, Alberta, September 23, 2013*

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UNIVERSITY
OF MANITOBA

In the spirit of respect, our research team acknowledges this country as belonging to the Indigenous Peoples of Canada.

Our team is grateful for this opportunity to speak in this territory of the First Peoples.

We honor those that came before us, those that are with us today, and those who are the future.

I am from the territory of the Ojibway people, who signed Treaty 1. I am from a rural community, close to where Treaty 1 was signed. I live in Winnipeg near the Forks, where two rivers come together, a traditional territory, a diverse ecosystem where tribes gathered to trade to share, to grief, to laugh, to live.



Discovering the Epigenetic Signatures Associated with Fetal Alcohol Spectrum Disorder

Nominated Principal Investigator: Davies

Project Leads: Hicks, Fainsod, Rastegar, Del Bigio, Elias

Discover a “FASD Epi-Code” based on reliable biomarkers that exist in different animal models of FASD.

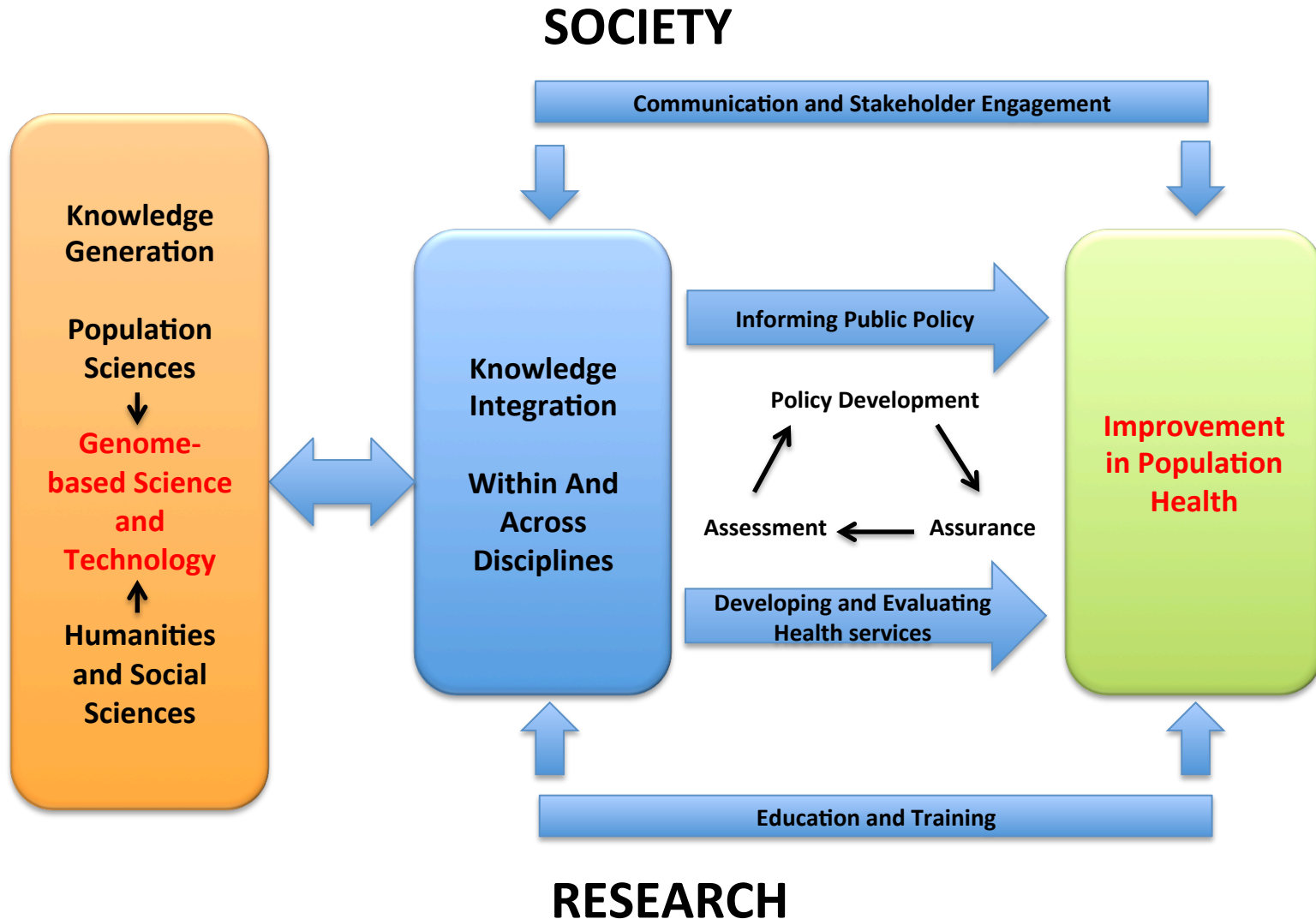
Validate the code in human brain tissue to confirm that the biomarkers discovered in cell culture, knock-out mice, and frogs, is conserved in affected individuals.

Informed by animal models and human brains, develop a validation human community cohort for investigating changes in living people.



The Public Health Genomics Enterprise (Bellagio Model)

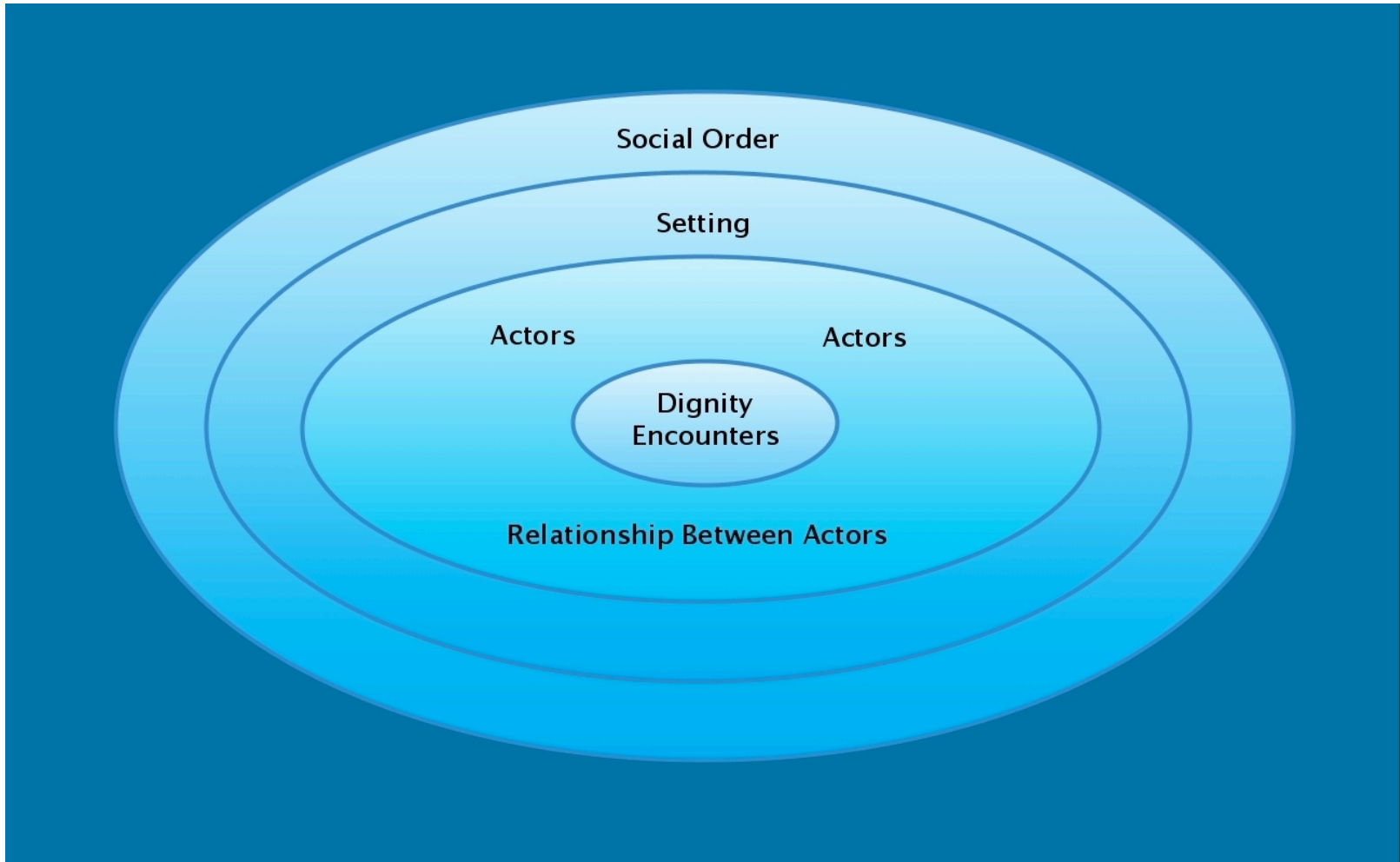
Source: Bellagio Statement. Genome-based Research and Population Health, Report of the expert workshop held at the Rockefeller Foundation Study and Conference Center, Bellagio, Italy, 14-20 April 2005



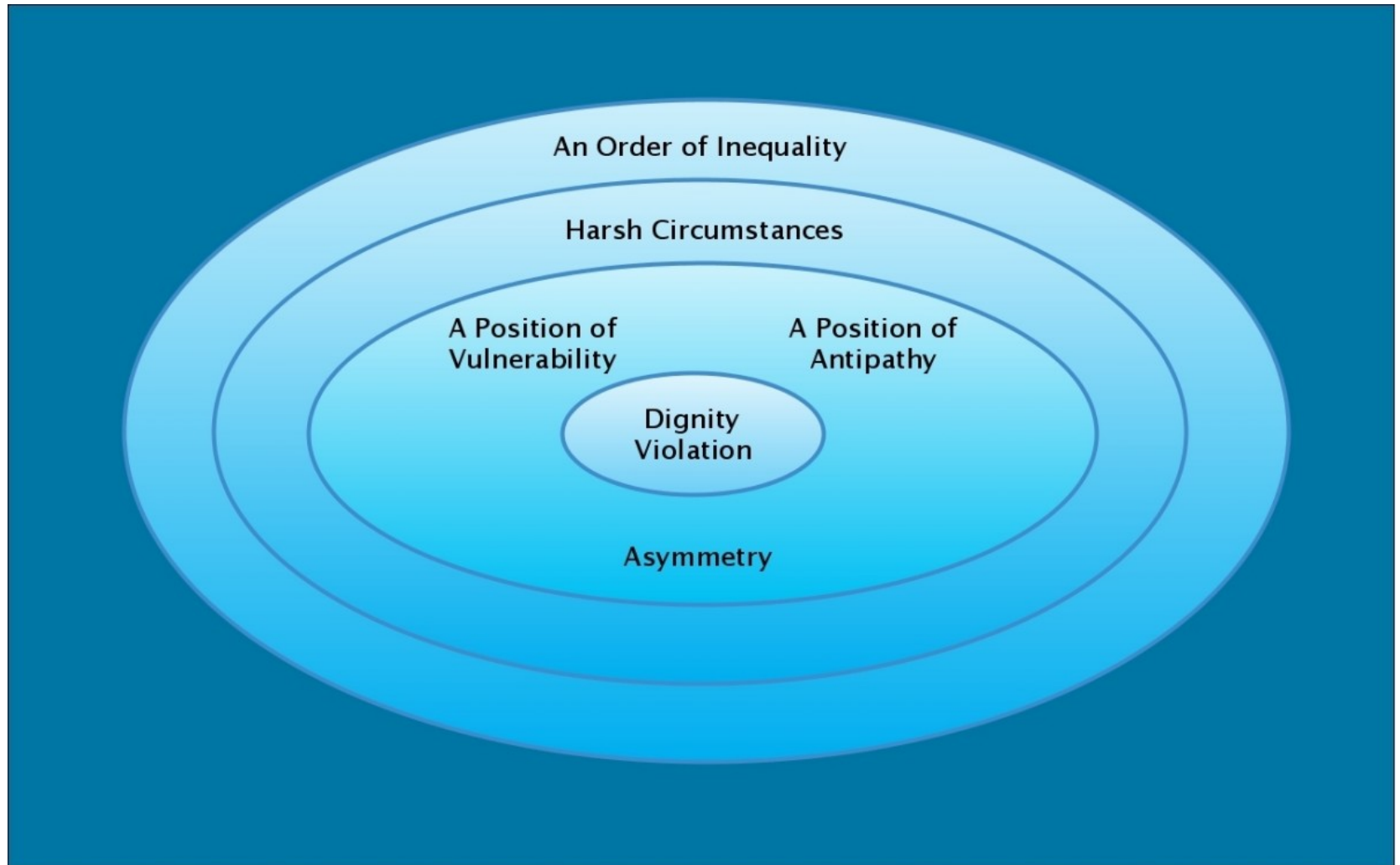
Adding human dignity to the Model

From a qualitative study of individual experiences of dignity and the participants understandings of the meaning, impact, and consequences of those experiences (Jacobson, 2009)

Conditions of the dignity dimension of an interaction



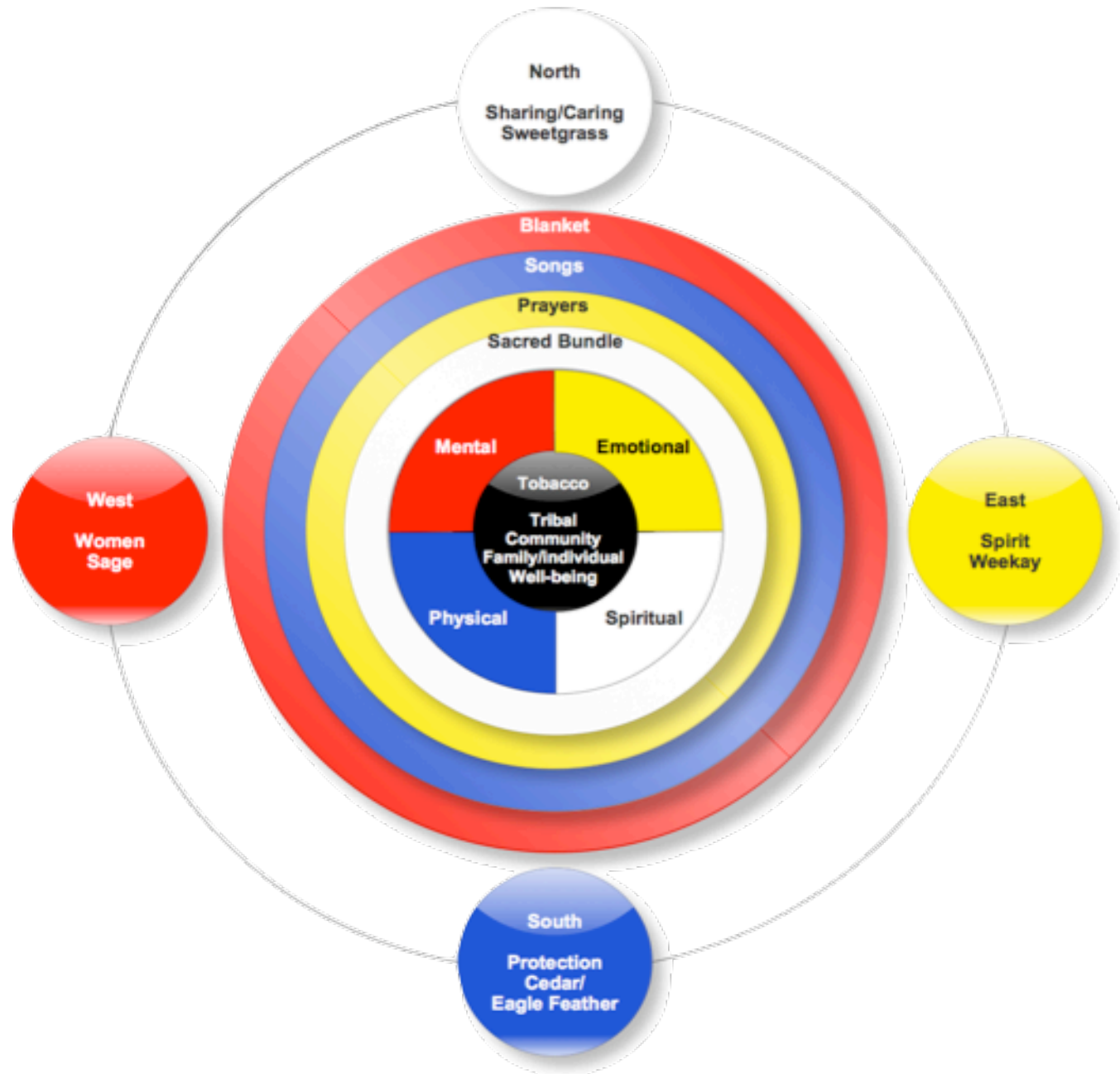
Portrayal of dignity violation



Portrayal of dignity promotion



- Research solutions are generated in First Nations space guided by traditions representing north, south, east and west to advance the mental, emotional, physical and spiritual health of community members, on and off reserve.



Translating to the Community

- A research team, comprised of leading researchers in clinical, biological and social determinant research.
- Roundtable forums and workshops were held, with First Nation community time prioritized, local, provincial, international.
- Attended and presented at tribal community meetings, side by side with tribal community health directors.
- Supplemented by formal and informal discussions also occurred, followed by academic-community partner reviews of research funding applications.
- Respectful dialogue was key, resulting in the following.

TRANSLATING TO THE COMMUNITY: FUNDED SOCIAL EPIGENETIC STUDY Design and Implementation Plan

YEAR 1-5

Team Planning Meetings (Y1-5)

Network Meetings (Y1-5)

Ethical Review and Approval (Y1)

Survey Development and Pilot (Y1)

Develop standard operating procedures for data and sample collection, sample processing, and storage (Y1)

Data collection, entry and management tools/systems (Y1-2)

Formalize Advisory and Management Committee (Y2-5)

BioBank Stewardship Model (Y5)

Data access, authorization, and publication protocols for researchers (Y5)



Survey



Data



iMac



Shared BioBank Administration



Data Access Application Process



Authorization



Researchers



Researchers



Researchers

YEAR 2 - 5 Data Collection and Processing

Y2n=125

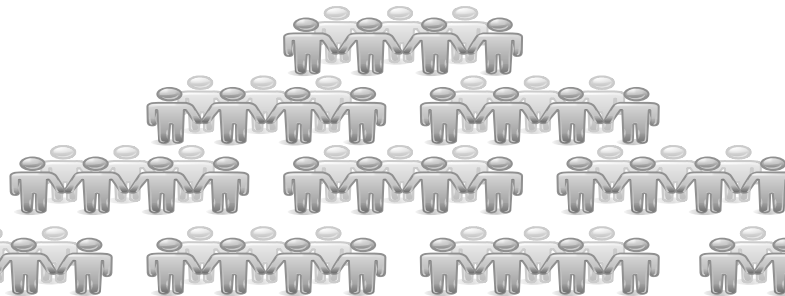
Y3n=125

Y4n=125

Y5n=125



FASD Clinics
Primary Health Care Clinics



SERDC
Communities

SAMPLE

100 Children with FASD

100 Siblings/Children FASD

100 Children Controls

100 Parent FASD Controls

100 Parent Controls

YEAR 1 - 5

Network Partnership Building to Expand Cohort

Funding Proposals for Cohort Expansion and Data Analysis



LESSON 1

Solidarity, built over time, advances dignity in research

- Policy or practices, including research, developed and aimed, should support and advance respect for human dignity, and by necessity and central to the undertaking, engage and embrace an affected population (1).
- We worked with the SERDC in developing the application and asked what we can do to support respect for human dignity.
- Together, we were mindful.
- **Targeting** populations, through research, when imposed by outsiders, can result in distorted images of people's way of life, how they live their life, why they do what they do, to name but a few.
- **Cultural safety is paramount.**
- **Populations are NOT “persons or things against whom criticism or abuse is or may be directed”**

1. Brant Castellano M, Reading J, “Policy writing as dialogue: Drafting an Aboriginal policy statement: Ethical conduct for research involving humans,” The International Indigeneous Policy Journal, Vol 1(2).

LESSON 2

- Success, in our developmental activities, occurred within the context of self-determination.
- We had to be mindful and vigilante.
- Communities, regardless of their origin, will resist external examinations and representations of health.
- Research programs, developed as a fundamental right within autonomous institutions, is key to successful outcomes.

LESSON 3

- We built a relationship to make a positive difference.
- Successful relationships require dialogue as a conversation between equals.
- We treated the space between the communities and scientists as “ethical space” where dialogue and ethical engagement of different knowledge systems was able to occur.(2).
- We created that space, we are obligated to maintain it.

2. Ermine W, Sinclair R, Browne M, Kwayask itôtamowin: Indigenous research ethics, Saskatoon, SK: Indigenous Peoples' Health Research Centre, March 2005.

LESSON 4

- We mutually thought ahead for the next generations, as every deliberation we consider will have an impact.
- The teaching we received were simple.
- We need to look and listen for the welfare of “whole” people.
- We cannot view only the present - the existing.
- We must consider the unborn, including preconception, we must think about generations.

LESSON 5

- We were open to a wholistic approach as that was critical to understand the extent, magnitude and solution of an issue.
- We built a partnership /collaboration model.
- We were not afraid to step out of our comfort zone.

Winnipeg Free Press - ONLINE EDITION

Feds used native kids as guinea pigs

Manitoba reserves among test sites

By: Alexandra Paul and Bob Weber

Posted: 07/17/2013 7:53 AM | Comments: 0g | Last Modified: 07/17/2013 10:31 AM | Updates

[Enlarge Image](#)

A nurse takes a blood sample from a boy at the Indian School, Port Alberni, B.C., in 1948, during the time when nutritional experiments were being conducted on students there and five other residential schools. (LIBRARY AND ARCHIVES CANADA / THE CANADIAN PRESS)

CHIEF MAY HAVE BEEN VICTIM

THE chief at Norway House Cree Nation had a sinking feeling when he learned Tuesday that hungry aboriginal children in his community were the country's first unwitting subjects for nutritional experiments decades ago.

NEW historical research that hungry aboriginal children and adults were once used as unwitting subjects in nutritional experiments by Canadian scientists has outraged indigenous academics and scholars in Manitoba.

"Alongside residential schools and the atrocities of the Indian Act, the starvation of First Nations communities for bureaucratic 'research' is another violent chapter illustrating the legacies that separate indigenous and nonindigenous peoples," said Niigaanwiwedam James Sinclair, assistant professor of native studies at the University of Manitoba.

In Guelph, Ont., Ian Mosby, the researcher who uncovered details about one of the least known but perhaps most disturbing aspects of government policy toward aboriginal people immediately after the Second World War, called it "the hardest thing I've ever written."

Mosby — whose work at the Guelph University focuses on the history of food in Canada — was researching the development of health policy when he ran across the strange science, he told The Canadian Press.

Government documents revealed a long-standing, government-run experiment that came to span the entire country and involved at least 1,300 aboriginals, most of them children.

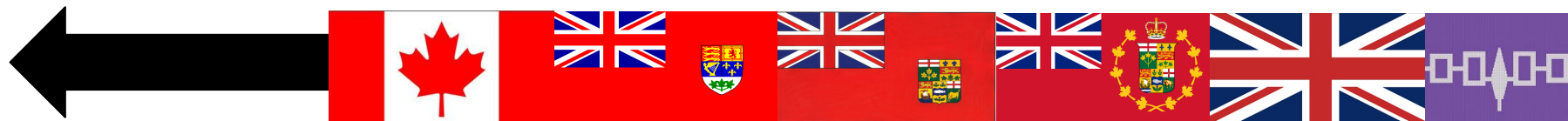
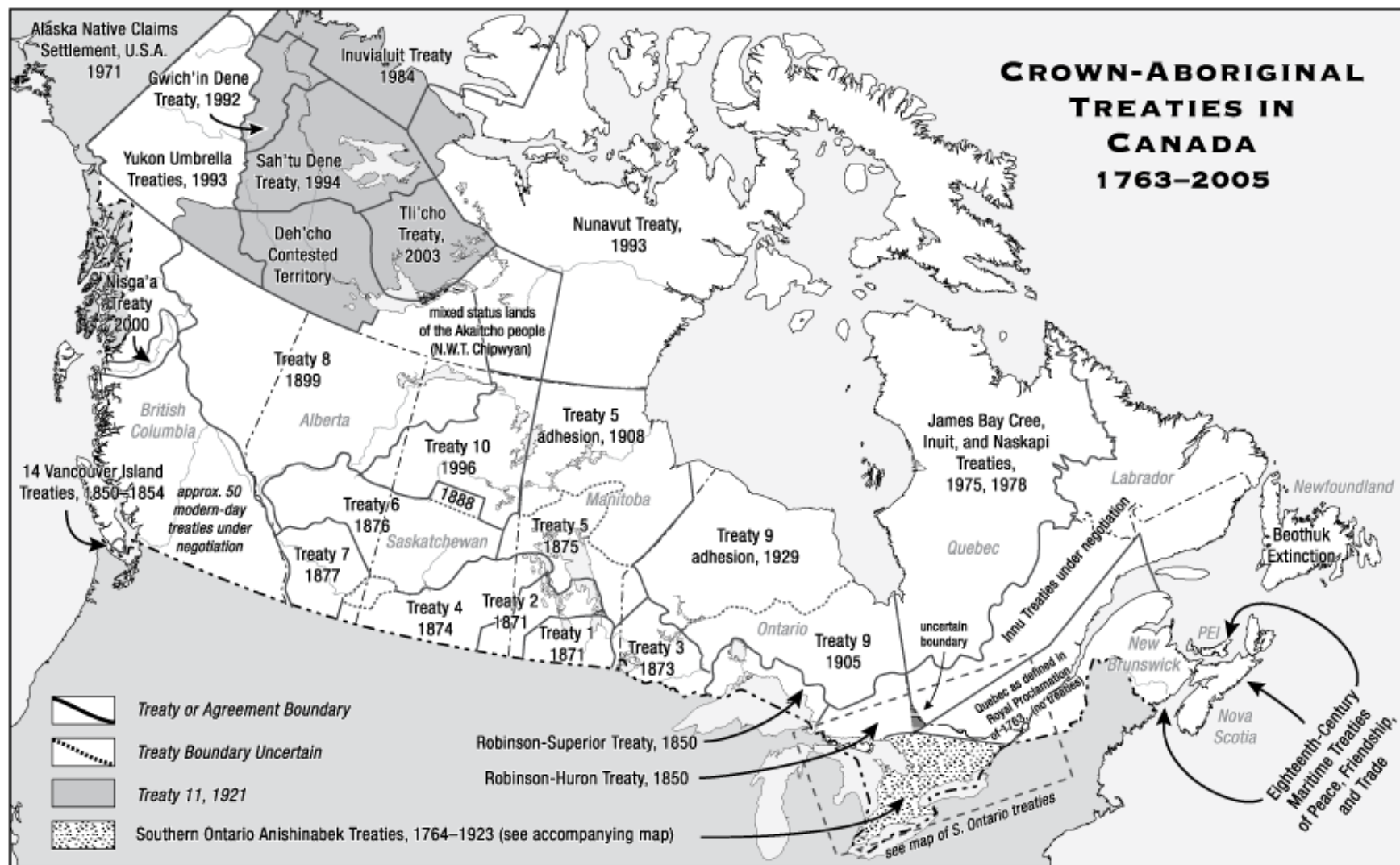
It began with a 1942 visit by government researchers to a number of remote reserve communities in northern Manitoba, including places such as The Pas and Norway House. Mosby's study covered the decade between 1942-1952 but there is no indication when the practices actually ceased.

Scientists found people who were hungry, beggared by a combination of the collapsing fur trade and declining government

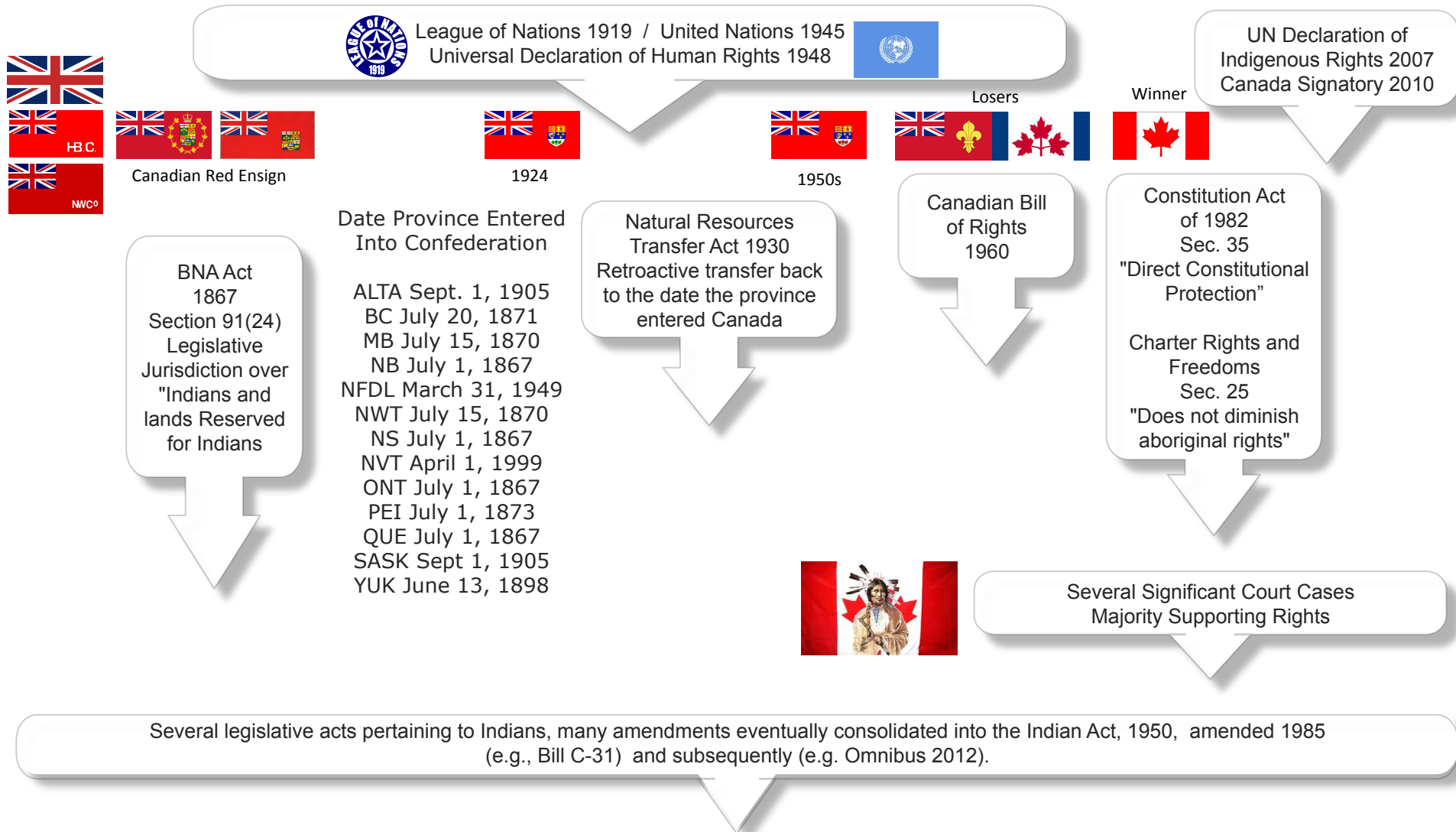
"This is a reminder of a disgusting

In our design and implementation process we will have cultural safety training

Pre-and-Post Confederation Treaties



A legacy of colonization, post-colonization



Instruments & structures of colonization, post-colonization

Legislative Acts and Policies Pertaining to Indians Administrated and Enforced By Federal Departmental Agencies

Dept. of the
Secretary of
State
1867 - 1869

Dept. of the
Secretary of
State for the
Provinces
1869 - 1873

Dept of the
Interior
1873 - 1880

Dept. of Indian
Affairs
1880 - 1936

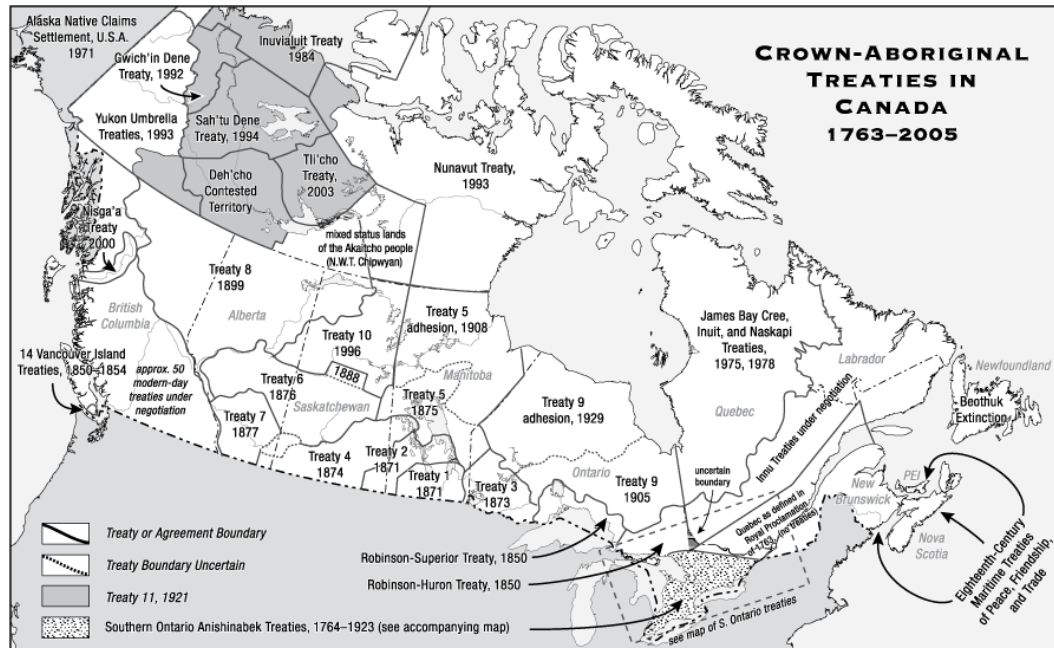
Dept. of Mines
& Resources
1936 - 1950

Dept of
Citizenship
& Immigration
1950 - 1965

Dept of Northern
Affairs &
National
Resources
1966

Dept of Indian
Affairs &
Northern
Development
1966 - 2011

Dept. of
Aboriginal Affairs
& Northern
Development
2011 Present



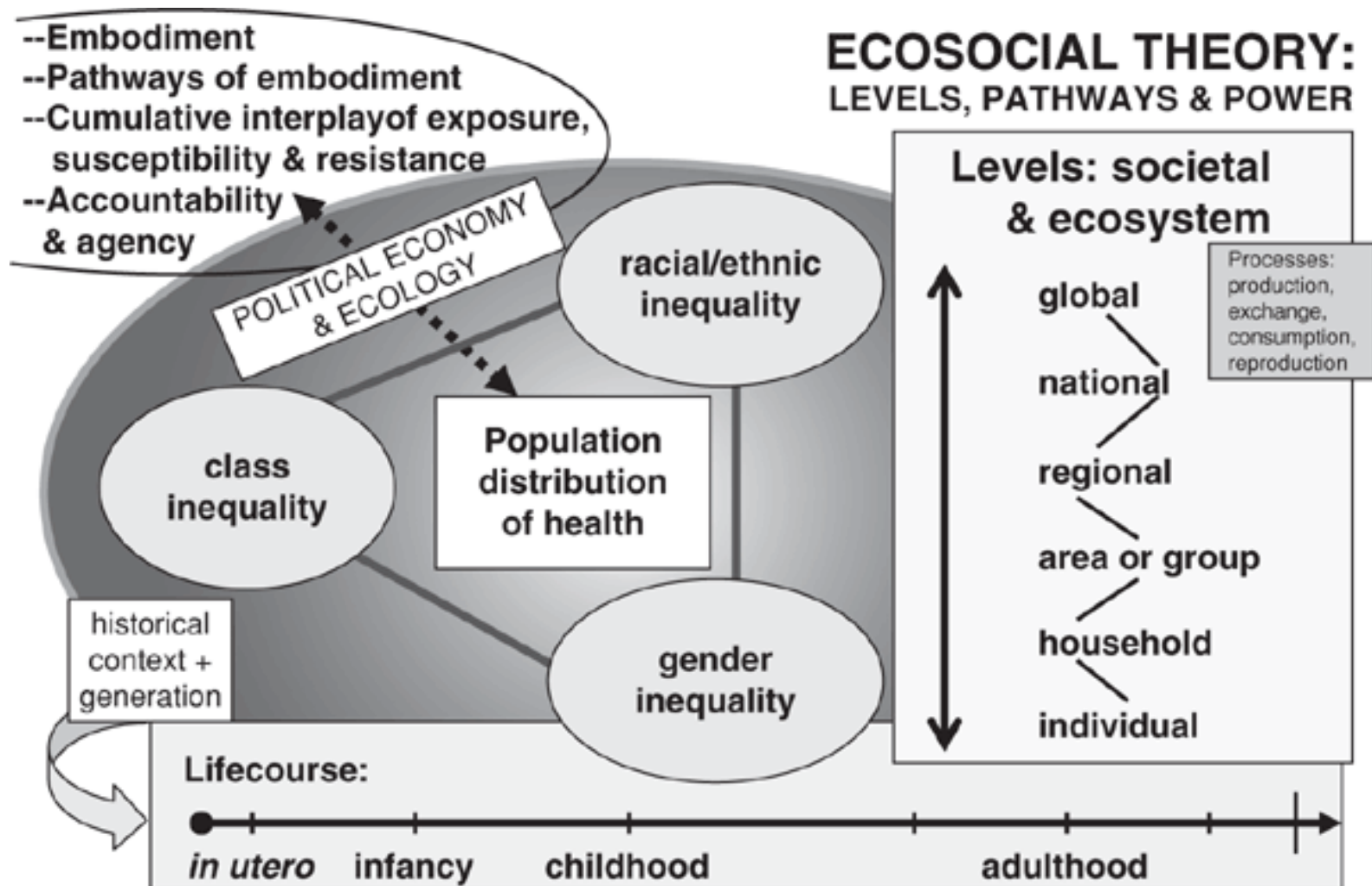
Residential School System



A legacy of the Residential System, etched into the landscape, etched within the body



Embodiment and determinants of health (Krieger 2011) and avoiding stigmatizing risk discourses (Lupton 1995)

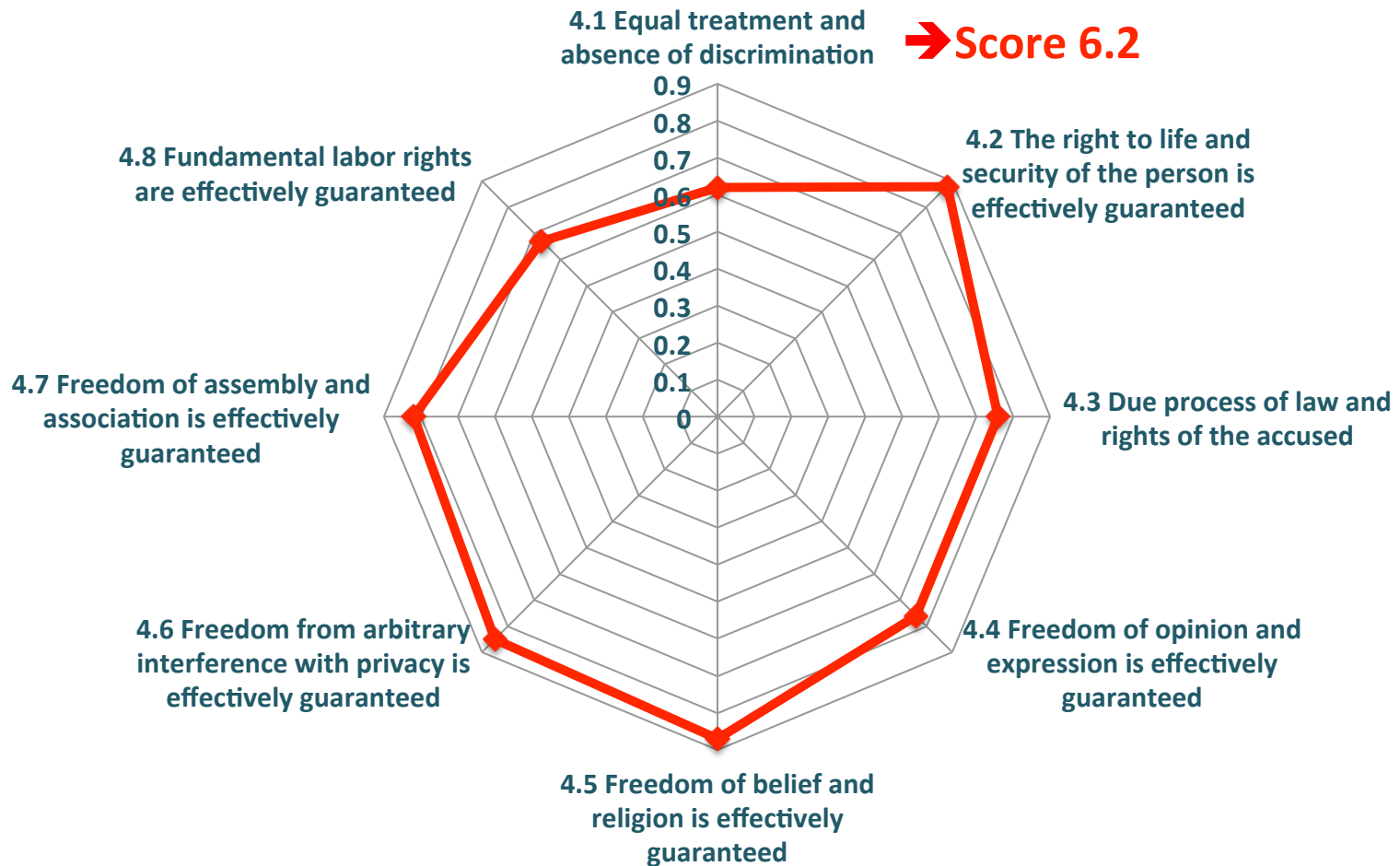


Intergenerational loop, perpetuating poor health, a social epigenetic phenomenon

Using research to end discrimination

Canada's World Justice Index Score

(World Justice Index 2012)





ONE WOMAN CONNECTING,

with the sun and the moon.

Two rays of sun flowing into each hand, Claiming Health, Claiming Wellness

*Jackie Traverse, First Nations, Woman, Artist,
University of Manitoba School of Fine Arts Graduate*