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Student Placement at the AHA Centre, a project of CAAN

Michael Parsons

INTRODUCTION

This paper talks about my progression as a researcher and Knowledge Keeper who does research within ceremony. This started with a Gender and Wellness grant and continued when I started my field placement for my bachelor's degree in social work. CAAN supported me as I wrote my first grant proposal *THE NINE GENDERS: A Traditionalist's way of organizing Indigenous gender and interpreting gender through an Indigenous worldview* in 2019.

SITUATING MYSELF

I do not believe there is such a thing as objective writing—as we write, we expose our biases—therefore, I first need to situate myself as an Indigenous Knowledge Keeper. I began my path to social work education in 1985 when I was studying at Mount St. Vincent University. In 1986, I was diagnosed with HIV/AIDS and given 6 months to live. Learning I was HIV positive was so traumatic that I went to Ecuador to die with my then partner. As we experienced immigration problems, we sought out a *Quechua* (a subset of the Inca dynasty) medicine man whose medicine had an extreme impact on my disease track. Upon return to Canada, I tested HIV negative at the Hassle-Free Clinic in Toronto. \

Many years later, when I was dating a man from the Tsuut'ina First Nation while living in Vancouver his mother gifted me an eagle feather and sweetgrass which had an impact on my spiritual progression as I was crossing Canada. When I got home to Nova Scotia, my aunt saw the eagle feather and sweetgrass and told my mother to support my path in these ways as it would be where I would find the strength to fight this disease. My mother then told me her father was Indigenous and when my father arrived, he told me his great grandmother was a witch (medicine woman) in Stephenville Crossing Newfoundland. These were the first times I had heard of my Indigenous heritage.

In February 1997, I started a solo cross-country tour to raise awareness for the 5-year National AIDS Strategy. While on this journey I met a Cree man with whom I had an instant and powerful mutual attraction. When I was diagnosed with full blown AIDS, he took me to his home in Sturgeon Lake, Saskatchewan where his stepfather ended up adopting me as his son. This is how I was adopted into the Cree Nation.

On my father's side, I am a Jackatar. The Jackatars were originally formed when the Irish Jacktar slaves dove off the boats while in the waters off Bay St. George Newfoundland, swam to shore finding Biotic women with whom they formed a new Indigenous métis nation. My grandfather on my mother's side also had Biotic ancestry from one of the ones who washed off the red ocher to escape the hunt. Biotic people lived their lives covered in red ochre which was

the only way they were able to be identified. Once they washed it off, they blended in with the rest of society some with a darker complexion, but many Biotic people could pass as white.

Through my maternal Grandmother I am English. She was born in St. Anne Slums Nottingham, England around 1904. This is my heritage and speaks to the ancestors who walk and work with me.

PRACTICUM PLACEMENT

CAAN (Canadian Aboriginal AIDS Network) is a national network for AASOs (Aboriginal AIDS Service Organizations) and IPHAs (Indigenous People living with HIV/AIDS). CAAN was incorporated in 1997 to address the higher rates of HIV infections and instances of AIDS within Indigenous communities. I became involved in CAAN because I was alone (without peer support) and living with this virus in Atlantic Canada. I am an Indigenous person, but I am not First Nations. There is a strained relationship between Indigenous people in Atlantic Canada, so I was not accepted at the AASO here. I turned to CAAN because through the organization, I was able to connect with other IPHAs which is important because it feeds my spirit with the energy we create when we are together. Generally speaking, I get to engage with this energy once a year at the CAAN AGM.

I chose to do my placement at CAAN because of my long-term community involvement and the relationship I have with Renée Masching, the Director of Research. Renée and I met 24 years ago when she was the Executive Director at the Atlantic AASO. This relationship has had its ups and downs. As an activist, Renee and I have found ourselves on opposite sides of many issues, however she has always been able to distinguish between me and the issue. Renee has included me in the work in many ways over the years. She knew that I was very much alone here in the Atlantic where my peers were concerned and so she oftentimes reached out to include me in AASO activities and programs. I always had support within the traditional Indigenous community. My support as I have been living with this virus has been heterosexual men on Reserve, family and my best friend.

My placement at CAAN has seen me do many things. I started volunteering at CAAN in the early 2000s, long before my placement began. In 2019, I applied, through CAAN, to attend an Indigenous Gender Ideas Fair co-hosted by the Canadian Institutes of Health Research (CIHR) and the Kahnawake Mohawk people. My application was successful, which meant I was able to attend the event which took place in Montreal, June 2019. When I started my placement at CAAN September 2019, I was supported to be the Nominated Principal Applicant on a CIHR research proposal for funding based on a teaching I received from the ancestors called the 9 Genders. In this role, I took the lead on pulling the research team together, proposal writing and submitting this proposal on October 1st, 2019.

The next thing I did as part of my placement was to join the CTN (CIHR Canadian HIV/AIDS Trials Network) C4 (Cross Core Community Engagement) working group where I contributed my community voice. I also represented the Atlantic on the IPHA Leadership Standing Committee (ILSC), a committee of CAAN, during my placement. The ILSC provided CAAN

with guidance from the IPHA first voice. I am on the GIPA Homefires team which is a research project looking at how we can inform the GIPA (Greater Involvement of people Living with HIV/AIDS) principles from an Indigenous Leadership perspective. GIPA is a UNAIDS principle that realizes the rights and responsibilities of people living with HIV, including our rights to participate in decision-making processes that affect their lives (<https://www.unaids.org/en/resources/presscentre/featurestories/2007/march/20070330gipapolicybrief>). I was on the writing team when this grant was being prepared to be submitted to CIHR, and I advocated for a critical policy analysis to be included in the proposal. Since the new year and in preparation for conducting the critical policy analysis, I have been familiarizing myself with Indigenous methods of doing research. I have read 7 books concentrating on what it looks like to do research within Ceremony.

THEORETICAL PERSPECTIVE

Decolonizing research as described by Vanessa Simonds and Susanne Christopher in *Adapting Western Research Methods to Indigenous Ways of Knowing* has become the norm for Indigenizing western research methods. However, in a research meeting I attended in 2019, we were talking about moving beyond decolonizing research to research which is done in the old ways before colonization impacted on our people. I see our old ways of knowing and doing being brought into the present by embedding research in Indigenous ceremonies. When we look at how community decisions were made in the past—information was gathered, issues were debated, chiefs were named, business was done participatorily and within the context of the tribe and everyone had a chance to voice what they wanted to give voice to, everyone had a chance to listen with a deep understanding of what was being discussed, and the ancestors were able to impact on the discussions within that circle—we can see how Lavalee (2009) evokes all of this and more, in her Circle Theory. Circles are one of the ways that we include our ancestors. Within a traditional circle, the ancestors are invited in—in a good way—and are able to participate through the voices of the participants in the circle. According to Lavallee, L:

The circle represents infinite life, whereas the four quadrants can represent teachings such as the four races: black, white, yellow, and red. The teaching here is that all races are equal, all are related, and all are interconnected. The story of one cannot be understood outside of the story of the whole. Another teaching of the medicine wheel concerns health and well-being. Health is the balance between the physical, emotional, mental, and spiritual: the four quadrants of the medicine wheel. Health also involves balance with others (family, community), with the environment, and with Mother Earth. Balance is sometimes depicted through interconnecting circles. (2009 p 24)

In western ways of knowing and doing we are taught about objectivity and positivism where facts are ascertained through a deductive method of inquiry, by reducing data over and over until we have the bare building blocks from which we start to build what we know to be an empirical truth with the blocks available. While in Indigenous ways of knowing and doing, we build what we know within a circle from voices and knowings of each person adding to what has been said by the ones who spoke before them. Also, knowings, or messages received from the ancestors,

impact on their voices to have input into the gathering of knowledge within this inductive process (Tuiwvai Smith, 1999).

PRACTICE STRATEGIES PERSPECTIVES

Coding data is a way that transcribed data from interviews, focus groups etc. is rearranged from a narrative into themes that help to answer the research question or make sense of what is being shared in a systematic way. Coding separates the narrative into individual pieces where original relationships are broken, assigned themes that relate to the research and then are re-organized during a reductive process. In data analysis undertaken with community researchers in the Crow First Nation, for example, community researchers were uncomfortable with the analysis process because “They shared that having scattered categories and breaking apart people’s stories loses the meaning and the understanding of the whole picture and purpose of the story. Moreover, it felt like a violation of the Crow culture because there is always a bigger purpose of the story that is lost when it is broken up into themes,” (Simonds and Christopher, P. 2187 2013.)

Starblanket et. al. (2019) have developed a way of coding data where relationships are not broken where themes are taken from the raw data with relationships attached. Referencing Iwasaki & Bartlett:

The CCDAP [Collective Consensual Data Analytical Procedure] method calls for collection of data via open ended questions during focus groups and interviews. Collecting data via open-ended questions is effective for Indigenous community-based research and ensures participants and community leaders share information in a culturally appropriate manner (Kovach, 2010). The goal after transcribing the interviews, sharing circles, or focus groups is to place key phrases or words of the interviews into several columns. In this process, a panel of experts, community members, participants, Elders, Knowledge Keepers, and the researchers are gathered together to do the collective data analysis. The panel could be as small as 3–4 people or as big as 20–25. Together, the panel will discuss the placement of the key phrases or words into each column based on the similarity of each key phrase or word. After the data are clustered into columns, the panel may easily identify patterns or themes (2006). (2019 P.3)

Dr. Bourassa’s team, with the help of Devin Dietrich (a data analyst for the Native Women’s Association of Canada [NWAC] and a research associate for the Centre for Rural and Northern Health Research), sought to streamline and digitize the process in order to more effectively sort and code the data from several different research projects and to reduce the time it took to perform it. The process was broken down into data collection, data pre-analysis, data digitalization, data reduction and display, and conclusion and verification.

The CCDAP method as developed by Dr. Bartlett et al.:

The first step in streamlining the process was to have the data undergo a rough thematic analysis prior to the collective data analysis. This preanalysis is done using the software NVivo (v. 11), a qualitative data analysis software. Importing the data in NVivo also helps in accessing the large volume of data (especially quotes) in a matter of seconds. This is particularly helpful with the writing process and with developing the various products that are outcomes of the research projects. Transcriptions from interviews, focus groups, or sharing circles are imported, and each quote is grouped into a “node.” Typically, the title of the node would be the question that is being asked during the interview, focus group, or sharing circle. Hence, the same questions being asked during several interviews, focus groups, or sharing circles are brought together and grouped into their respective nodes. Thus, engaging in a more responsible way of data collection which respects the traditional ways of knowing and doing of Indigenous peoples. This is a good way for me as it includes some western technology while protecting the indigenous roots. There are also some western ways of data collection which can be adapted in Adapting Western Research Methods to Indigenous ways of knowing which would be valid for me to use as I am as western as I am Indigenous. (2007 Pp.4,5)

While I was doing my second-year research course, I ended up getting into problems with the team I was on due to the direction the project was taking and what I felt needed including, so I separated from the group at the behest of the professor and did the rest of the project on my own. Through the research I did on that project, I discovered Indigegogy—an Indigenous pedagogy coined by Cree Elder and educator, Stan Wilson. “Indigegogy is a wholistic approach to learning that . . .uses Indigenous knowledge, literature and scholarship and is centred on land-based education. Indigegogy engages Indigenous methodology such as circle work and lifts up traditional teachings, ceremonies and practices. Indigegogy is a decolonizing practice that builds on the resurgence of Indigenous ways of knowing, teaching and learning,” ([Centre for Indigegogy | Wilfrid Laurier University \(wlu.ca\)](#)).

Through conversations with Dorene Bernard, a Mi’kmaq Elder who did her Master of Social Work through Sir Wilfred Laurier University, I learned that Dorene has based her resistance work as a Water Walker on the principles of Indigegogy which, in her opinion goes much further than, but includes an educational methodology in learning, teaching and knowing. According to Dorene, Indigegogy encompasses our ways of being, thinking, doing, and provides a way of working within the concept of Indigenous wholistic development. Indigegogy also encompasses the ways in which we seek direction from the ancestors to be able to do things in a good way.

RESEARCH IDEOLOGICAL PERSPECTIVE

My ideological perspective connects to my Indigenous world view. Living my life according to Spirit is my ideology. As an Indigenous person I have a two-way connection to my ancestors and to my spirit helpers, and it is through them that I make decisions on how I do my work and what work it is that I do. This is clearly represented in the following.

The focus of my Social Work practice, and therefore, my Social Work placement at CAAN, was research. One of the challenges I face is working through questions I have with regard to where the emphasis lies for me: does it lie with ceremony, or with research when it comes to integrating the two in practice?

In the Nine Genders project, I embedded research within ceremony. As a pipe carrier, practicing ceremony is how I interact with the world (Parsons 2019), so it is only logical that I would do research within ceremony. By doing the research in ceremony, we will reduce the possibility of harm by not triggering Indigenous participants as much who have a connection to their traditional ways of knowing and doing.

The Nine Genders research project starts with a sweat where the pipe will be lifted and will be handled in a way to be a continuous pipe ceremony lasting four days until the final sweat when the tether which keeps the ceremony (and people in it) attached to the spirit world will be severed by the conclusion of the ceremony. The circles that are held in the teepee is where data collection will happen. Day 3, drum and basket making workshops will give participants a chance to make their gift from the project to take home. Day four will begin with a sweat, and the ceremony will end with a community feast. The entire event will be a four-day continuous ceremony.

It is important that I use decolonizing methodologies but even better, if the researcher can use Indigenous methodologies. Research needs to be about the community and the primary focus needs to be 'do not harm'. Within an Indigenous methodology a comfort may be created for Indigenous participants. As Indigenous people, we talk about being researched to death and about helicopter research where promises about sharing the data are made by researchers who are never heard from again. These past research projects make it hard for researchers who are doing things with a focus on community. Sometimes communities have a hard time shaking off the experiences from the past. By centering culture in Indigenous research, a relationality will be entrenched with a reciprocity that will lead the community to understand that gifts to the community will be forth coming.

FIRST VOICE INTERPROFESSIONAL DYNAMICS

Within First Voice I am having an impact in two ways. I am the Atlantic representative on the IPHA (Indigenous Person with HIV/AIDS) leadership standing committee for CAAN (Canadian Aboriginal AIDS Network) and I am in a First Voice role with CTN (Canadian Institute for Health Research HIV/AIDS Trials network). I am a person from community from outside of the organization. At the beginning of my placement with CAAN, I applied for an apprentice role on the CAC (Community Advisory Committee) at CTN which will give me knowledge on how research proposals are deconstructed and scored by a review committee, in addition to many other skills and knowledge. At the time of writing this paper, I have been accepted as an apprentice on the CAC.

In my work at CTN, I am on a team which has just grown from a six to seven-person team. While we were a six-person team we held a community engagement workshop where several

objectives were voiced by community members. One of the things voiced was that since we are doing our work on Turtle Island, we should build an Indigenous framework in to the CTN C4 team. We have had several calls since the workshop where I attempted to bring up the framework and there has been no uptake. This may be because they have no idea where to even start to look for an Indigenous framework that would work in this context.

In an effort toward reconciliation, CTN has begun to open their in-person meetings with the C4 team in a Good Way. As part of that opening, they always make arrangements for a smudge. I am suggesting that the smudge ceremony would represent the Indigenous framework because this is a decision CTN makes over and over again—to open their meetings following this cultural protocol.

Another first-voice role I have, is on the [GIPA \(Greater Involvement of People living with AIDS\) Homefire](#) research project, led by CAAN. The GIPA Homefire research team has almost 80% first voice representation which is very important because we are exploring what Indigenous GIPA and Indigenous leadership looks like. With a high representation of first voice, we can be assured that we are getting as many of our bases covered as possible.

IN AN IDEAL WORLD

First voice is not just about having the HIV voice represented, it is also about the diversity of voices in everything that we do. For example, if we can look at representation of gender, geographical representation and whether we have representation from the four main communities: First Nations, Inuit, Métis (Red River) and métis (non-Red River) then we have created a stronger, more inclusive way of doing our work. We need to ensure we include trans-masculine and trans-feminine voices. We also need to include the 2Spirit community in our research, understanding two spirits physical male and two spirits physical female and two spirit non-binary are representations that are important to honour. We need cis-gender women and men on the team because these are important voices to have represented as well. We need to keep an eye on the data to see where the new trends for infections are so that we can engage people from those communities. We also need to be mindful of how many academics we have on the team and whether they are respectful of the first voice. We need representation on the basis of age, youth representation, and within youth, gender parity. We also need to pay attention to income parity—how many of the people are working and how many are subsisting on community services, band subsidies or band welfare.

Past and present impacts of Colonialism such as the residential school legacy and the 60s Scoop are but a few areas that we need to look at when it comes to first voice inclusion and diversity. CAAN does try to honour diversity as much as possible. This is proving to be difficult as diverse populations are hard to find, and funding to bring people together in order to have that diversity is not there either. There are a lot of barriers that prevent us from having the diverse representation we need to be doing truly good work. We need to strive for the best we can do, given the circumstances we are working within.

CONCLUSION

In this paper, I have been able to identify the progress I have made as a researcher and Knowledge Keeper through my placement at CAAN. I have moved towards understanding research in ceremony to the point of being able to develop a research project proposal and engage in employment with CAAN as a co-coordinator of the GIPA Homefire Project where I've also been able to bring ceremony into that project on many occasions. It is starting to look like I am developing the beginnings of a career through doing research within ceremony.

REFERENCES

- Ellers, Steve., (2016) Refuting Denzin's Claims: *Grounded Theory and Indigenous Research*
Retrieved From: <http://groundedtheoryreview.com/2016/12/19/refuting-denzins-claims-grounded-theory-and-indigenous-research/>
- Kovach, M. (2009). *Indigenous Methodologies, Characteristics, Conversations, Contexts*.
University of Toronto Press.
- Lavallee, Lynn., (2009) Practical Application of an Indigenous Research Framework and Two
Qualitative Indigenous Research Methods: *Sharing Circles and Anishnaabe Symbol-
Based Reflection*. International Institute for Qualitative Methodology Retrieved From:
<https://journals.sagepub.com/doi/full/10.1177/160940690900800103>
- Parsons, M (2019) https://www.nspirg.ca/wp-content/uploads/2019/09/Margins_2019_web.pdf
- Simonds, V.; Christopher, S. (2013) Adapting Western research Methods to Indigenous Ways of
Knowing. *American Journal of Public Health*. (Vol 103, No. 12 Pp: 2185 – 2192).
- Smith, L. T., (1999) *Decolonizing Methodologies, Research and Indigenous Peoples* Zed Books
Ltd. London and New York. Twelfth impression 2008 Malaysia.
- Starblanket, D., Lefebvre, S., Legare, M., Billan J., Akan, N., Goodpipe, E. and Bourassa, C.
(2019) Nan[^]atawihowin [^]Acimowina KikaM[^]osahkinik[^]ehk Papisk[^]ici-Itascik[^]ewin
Ast[^]acikowina [*Medicine/Healing Stories Picked, Sorted, Stored*]: Adapting the
Collective Consensual Data Analytic Procedure (CCDAP) as an Indigenous Research
Method
- Wilson, Shawn., (2008) *Research Is Ceremony Indigenous Research Methods*. Fernwood
Publishing Black Point Nova Scotia and Winnipeg Manitoba