The History of Indigenous HIV – People, Policy and Process

by

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Abstract

In this time of truth and reconciliation, an Indigenous health research question was asked, responded to, and interpreted by people whose genealogy includes Cree, Blackfoot (Piikani), Kwakwaka'wakw, Stoney and Métis. Indigenous HIV in Canada is described from the point of view of those who live with and give voice to this issue.

The story line is set with the vibration of the heart, felt as the sound of the drum, moving through decades of colonizing process and practice. The drum beat is the consistent cadence of the "Prisoner's Song", bringing forward the story of two Alberta Métis boys who were hanged in the 1940's. Through historical data analysis and comparisons of current policies, systems and methods of handling Indigenous peoples, a perpetual cycle of colonialism is revealed.

Using a braided life story narrative, two of the first Indigenous (First Nation) people to publicly disclose their HIV status, are woven into the timeline of the HIV response in Canada. Kecia Larkin and Ken Ward share their select experience to bring light to issues that have been almost silenced. The story line is expanded to include the influence of legislated identities, community organizing, policy impacts and the discourse of health systems in addressing issues affecting People of the Land.

From the rich song and story lines, evidencing the strength of oral translation of Indigenous knowledge, a rhythm of resilience unfolds. Considerations for health programs and policies are introduced through the concepts of surface culturality and reflective vision.

Preface

This thesis is an original work by Denise T. Lambert. The research project, of which this thesis is a part, received research ethics approval from the University of Alberta Research Ethics Board, Project Name “History of Indigenous HIV - People, Policy and Process TITLE”, No. Pro00063367, August 8, 2016.

Dedication

This is for Dez, the love and light you share in this world has helped guide me, all ways.

Acknowledgments

There are so many levels of gratitude to express. First, for the gift of this life, the seen and the unseen, shared by the Creator. I am grateful to the teachers in all forms, those who have gone before and those yet to come, that help me understand love is our greatest medicine. Seeking to understand this connection is the key driver in my life.

Through my beautiful mother Lena, my connection to water, language and land is maintained; coupled with the teachings of my late father Roy, strength, compassion, and the ability to meet challenges are central to who I am. My parents provided the basis of love, tolerance and ambition shared with my sisters, Delores, Mamie and Maureen, who encourage family development. For my children, Chelsea, Sierra, Jolene, Naomi and Nathan, thank you for understanding the work and commitment needed to achieve your aspirations and for “creating a lifetime of entertainment”. To my grandchildren, Noah and Graysen, this is one part of a legacy left to you for the future.

Kecia Larkin – thank you for getting to know me, like me and love me. I have been most thrilled sharing “Critical Thinking” skills and having you use them on me and others to bring light to the dark, voice to the silenced.

Ken Ward – my brother, we have been through feast and famine, down gravel roads, pavement and ditches. I am grateful that you believe in me, trust me and love me. These are gifts not extended by blood but through your gentle spirit.

For those patient individuals who have watched my academic evolution with interest and concern, I extend my thanks for your guidance, questions and support. To my supervisory committee - Dr. Stan Houston, Dr. Malcolm King and Dr. Fay Fletcher – you provided the braid of strength and understanding I needed to get this work done.

Finally, the support of Kimamow Atoskanow Foundation, the community of Paul First Nation, my close friends and mentors - you have believed in the best possible part of me. I hope that those who named me in the traditional way are seeing my path unfold as they envisioned it would. Sâkihitowin ~ Aroha Pumau

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INTRODUCTION

The Human Immunodeficiency Virus (HIV) is having a significant impact on Indigenous[1] (inclusive term for Aboriginal, First Nations, Métis and Inuit) peoples. Despite this, there has not been a comprehensive narrative of distinct Indigenous contributions and challenges in this field over the last 30 years.

Through traditional Indigenous knowledge exchange and authentic connection, this research will bring the story of two long term survivors of HIV to light and include community developed responses to address prevention, care, treatment and support focusing on the geographical network between Alberta, Saskatchewan and, when relevant, other jurisdictions.

A discourse analysis of the HIV portrayal of Aboriginal / Indigenous peoples in health policy and system literature will be conducted highlighting Indigenous community participation and perspectives. A description of how Indian Health Policy (1979), Justice and Corrections policies and broader colonial policies affect the health and response to HIV for Indigenous peoples will be presented.

Research Question

How have Indigenous peoples' knowledge and history of colonization impacted the experience of HIV for Indigenous people? The need for this project was established by asking people who had lived the experience what was important to them. It was generally understood that the current HIV narrative, and specifically the Indigenous HIV narrative, was missing key pieces.

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[1] Aboriginal, Indigenous, First Nation, Métis, Inuit, Indian or People of the Land will be terms used interchangeably unless specified within citation, context or source.

Research Objectives

- Document contributions of Indigenous leaders in HIV from 1985 - 2015
- Provide discourse analysis of HIV among Indigenous peoples in Canada
- Weave cultural literacy and relevance into current system approaches
- Identify and analyze policies that affect the health of Indigenous peoples

Background

Historically, the lived experience of Indigenous peoples has been quite silent. In many Indigenous communities, oral and cultural traditions serve to keep the stories of the past alive and advise on the direction for our future. Recently, the Truth and Reconciliation Commission (TRC, 2012) brought the voice of residential school experiences to the forefront.

Specific to health, the onset of the Human Immunodeficiency Virus (HIV) within Indigenous communities in Canada has connected past trauma to a modern experience. Through this research project, two stories of lived experience with HIV are examined. The policy background that frames these stories is presented. Wise practices for community health initiatives is provided.

Scope

This project will focus on two long term survivors of HIV, one male and one female, both diagnosed in 1989. Their life stories will be the central focus of the project, as well as their interface with the education, health, social services and justice systems. Literature was reviewed from 1985 - 2015 to outline the terminology and discourse used to address Indigenous health and specifically HIV issues.

I will briefly outline the historical timeline for HIV as described through the stories. The issue of “over-representation” is framed within the context of the historical backdrop of Indigenous peoples. Existing and potential solutions will be contrasted with the evidence available to date.

Methods

A mixed methods approach was used for this project placing Indigenous methodologies at the centre. This is described as the cultural protocol and supports central to all aspects of this project. Oral history or life story narratives of Indigenous Peoples are a significant and relevant method of sharing knowledge as described by Smith (2012), “Intrinsic in story telling is a focus on dialogue and conversations amongst ourselves as Indigenous peoples, to ourselves and for ourselves” (p. 146). Oral life story interviews were conducted with two respondents. The stories were transcribed and woven into the process and policy parameters most significant to Indigenous peoples in Canada. This was supported through an archival document review.

Life story as a research methodology aligns well with lifting community voices to the level of being heard and recognized, recorded and retrievable. “Indigenous people versed in their culture know that sharing a story in research situates it within a collective memory” (Kovach, 2009), as part of honouring the contributions of people that were not interviewed, we are including memories.

Procedures

Appropriate cultural protocols were extended to both participants establishing ethical cultural space and accountability to the key participants, Ken and Kecia, and the community they are part of. Additionally, meeting the ethics requirements of the academic research institutions was completed. Once all ethics approvals were in place, individual stories were recorded and transcribed. Both participants met and considered shared experiences. For Indigenous research, it is critical to ensure that cultural protocols are adhered to. In this sense, all the steps for this thesis have been framed through a culturally literate process. While there are limitations to this method, it speaks to the belief that the Creator is forgiving and accepting of each stage we are at. Intentions and actions through all stages of the research process were grounded in ceremony and guided by select Elders, from ideation through to completion.

It is also critical for me to state that each iteration of Indigenous research, knowledge seeking, translation and acquisition is as diverse as the individuals who are on the learning journey. Some stages of learning can be analyzed and others remain unseen and unstated. With many forms of Indigenous cultural learning, interactions are dependent on the teacher and the learner. My mother is fluent in the Cree language and is rich in traditional teachings, but there came a legislated break in our Indigenous learning cycle with the onslaught of the Indian Residential School. I acknowledge my limited Cree language and cultural knowledge in this process.

PEOPLE

Creation Story

Protocol in my world is tied to acknowledgment of my place or life view. My ancestral roots are Cree and French. I place myself in contemporary Indigenous worldview recognizing and validating history and moving forward with a view of revitalization. Indigenous is the first identifier I use to reflect international recognition of "*People of the Land.*" Aboriginal is a Pan-Canadian identifier of First Nation, Indian, Métis and Inuit peoples. My teachings are blended with cultural strengths, academic conventions and political discretions. These teachings have transformed into skills that I actively use in the Canadian criminal justice system, health care system and now educational system.

Growing up, I fit the identity of Métis, Cree mother and French father. I knew from early on this was a distinction from both worlds, native and non-native. It was a struggle. My first Indigenous activism began in 1981 when I attended a youth camp and subsequent health march. We walked from the legislature building in Edmonton to a rally at what was then called the Kinsmen Field House. It was a demonstration to assert the health rights of Aboriginal people. I did not realize at the time that this would be a lifelong fight.

At the time of this graduate work, my grandfather or essence of, materialized again. I was doing my undergrad at the University of Alberta when I was contacted by the department of ethnomusicology. They possessed a taped recording of my grandfather that they wanted my mother's permission to use on a CD for the Smithsonian series.

The story I was told at that time was that my grandfather had been recorded singing a song while out on the Red Pheasant reserve in Saskatchewan in the 1950's. The song had been found in archives and the department wanted to share it. The song was apparently about two young Métis brothers who had been charged with murder. While in the courtroom, so the story goes, the judge told them that if they sang a song they would be free to go. It is told that one brother sang and the other didn't, yet they were both hung for the offence anyway. It is a tragic story that the department felt warranted a place on the CD.

I asked them to send the file to me. I received it on my computer and then asked my mom to come and sit close by to listen to it. I didn't give her warning about the content. As she heard the song play she began to cry and said, "That is the song my dad used to sing when I was a little girl." I felt sad and was more moved by the background to the story. I asked her what the song lyrics meant; she said a very vague and loose translation was "Once I am gone I will be free". She agreed to its inclusion and the song formed part of the Smithsonian compilation and my grandfather, William Burnstick, received credit for it within the CD sleeve (Dalen, 2006). Although his community connection to Paul First Nation was mixed up with Alexander First Nation, both have family connection for me.

The name of the song is "Prisoner's Song." It is fitting that it forms part of my research as it speaks my interest in situational vulnerability. What intrigued me most was the possibility of freedom or exoneration that the young men were promised. I wanted to find out more and acknowledge how our oral history does withstand time despite not forming part of the written record. Further to this was the relationship that Métis and other Indigenous people face within the systems they interact with.

Offenses in Nature

I was curious about the Métis boys in the “Prisoner’s Song.” I did an initial search on the internet and found the Desjarlais boys, who fit the description. It appeared the story was real as both were named in an Edmonton Journal series that discussed hangings in Alberta. There was limited detail but I did find that the offence had taken place at Monday River, near Conklin, Alberta (Pruden, 2011).

My instinct told me that this was a trap line incident. It may have been my sensitivity to traditional land use mapping, with trap lines being a resource area for hunting and trapping that moved my assumption. I sent a note to an archivist at the Provincial Archives to try and find Monday River. I was asked for more information and so provided the names and few notes I had about the offence. A file was found and I went to the Provincial Archives of Alberta to review it (Rex vs. Desjarlais, 1944).

It turned out that there were two court files. I spent time reviewing and copying documents that held key points in the story. Within the court files there were numerous exhibits, statements and letters from the court. It provided a segmented chronology of the offence time, location and processes that were followed.

My instincts were somewhat confirmed in the transcribed court text, which was typed on see-through onion skin paper. A comment was recorded about the defendant saying, “stay away from my trap-line” (Rex vs. Desjarlais, 1944). In one document marked as an exhibit, it appeared as though the statement was written in Cree syllabics. I kept a copy of this for use as a powerful reminder about contrasting language, policies and interpretations. For as we see in the HIV history, presentation of information is critical to make a case for appropriate action. Very graphic black and white photos reminiscent of that time on the frontier were also included in the file.

I observe the parallels in policy and process between the court of that period and the positioning of HIV action today. In the justice system, there is a judge, a crown prosecutor, a defense lawyer, witnesses and the defendant. Similarly, for HIV resource allocation there is a department or agency, a review committee, a proposer and interest groups. The decisions made about who to fund ultimately affect the lives of people.

It may seem unclear why I bring the song and the story into the thesis. I believe it provides a temporal relational gauge of reference—that is, how history is considered, past, present and future. Currently, there is an environment of support for bringing past truths forward. The Royal Commission on Aboriginal Peoples (1996) recommended the establishment of the Truth and Reconciliation Commission (Truth and Reconciliation Commission of Canada, 2015a). We have also had the United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP) interpreted in various forms. The two recent documents (TRC and UNDRIP) attempt to ensure that Indigenous rights and voices are visible or are heard in the current political context (United Nations, 2008).

When I say political, it is delving into the realm of resource allocation right from natural resources through to the concept of intellectual or traditional Indigenous knowledge and land rights. There are various levels of Canadian and Indigenous governance which these documents inform. Now the challenge within each of the different disciplines, including community based research or any type of Aboriginal or Indigenous component within a program, is the uneasiness felt by various Indigenous or Aboriginal groups about how we as people are being represented. The concept of voice is critical to how our issues are stated and how decisions are made in the public eye.

By telling the story of the two young Métis men, I describe how they were in a traditional land area, on a trap-line, trapping furs and living off the land. When they came in contact with the white man, and in this case, it was a Norwegian man, who was on the trap line and traveling through the same area that these boys were trapping, a conflict ensued. It is very difficult to decipher how that conflict arose and the subsequent outcome, which resulted in immediate death for the white visitor and delayed systemic death for the two Métis boys.

Within the mainstream justice system, the two boys were charged with murder. They went through the various stages of “justice.” The details of what happened at that time are only based on the written record, which was the power holder and served as the evidence for many different types of decisions. In this case particularly, the decision was whether the males, the teenaged boys, were guilty or not guilty. This justice system adjudicated outcomes based on who was present in the room.

Who did the arrest and the investigation? Who were the crown prosecutors, the judges, the lawyers and the people who may have sat on the jury? These questions come into play in a time when Aboriginal people were spoken about in a derogatory fashion or what would be called a “racist manner” in today’s context. It’s important to frame the history of Indigenous peoples and the significance and importance of clear voice and representation. There are similar questions being asked in today’s context. Who is speaking on behalf of who? Who receives the benefits directly?

I now shift to using the health care system for our frame of reference for current policy, particularly within the field of HIV. The descriptor of identifying voice has shifted from Aboriginal to internationally recognized Indigenous Peoples (IP). There are several layers in terms of that voice that again create serious discomfort among community members. While there are some commonalities in terms of overarching statements about health disparities, there is still a grave concern for how the issues, positions and experiences of Indigenous Peoples are being translated at the policy and decision-making level.

The voice of Indigenous people, particularly those living with HIV in this instance, are often molded to meet extrinsic needs, such as for an organization or project. In a few instances, I have the permission to share discrete voices, as I have gained trust and permission to do so. This has been created through the development of long term meaningful relationships central to Indigenous methodologies. This is a great responsibility and a treasured right. Wilson (2008) describes how “the person is put into relationship through mutual friends or even through knowledge of certain landmarks, places or events” (p.84).

HIV Specific Relationality

For this research, I selected two individuals to approach and seek their perspective on the history of HIV within Indigenous populations in Canada. There is limited written history on the contributions of Kecia Larkin and Ken Ward, both identified as First Nation and publicly disclosed living with HIV. While many newspaper articles and audio-visual resources exist, a shared telling of their story and contributions as told by them personally does not exist.

Retrospective recall, or looking back to remember, is the context of the story I will share. It is my place within the story that will tie many elements together. Despite the purpose of some research methodologies to create an objective account of the process, I am using research or personal reflections of my involvement in the HIV movement to create a joint Indigenous narrative with the life stories of Ken and Kecia. This process strengthens the selected story lines being conveyed at a point in time.

We are related by this time in history. Our involvement in the HIV movement was unplanned. The connection and relationships we have made are significant and warrant the privilege of being on paper. More than that, the bond created and the responsibility to each other is unmatched by academic conventions. Memorialized by Elder Joe P. Cardinal are the words, “Love is our strongest medicine.” There is no greater relation.

The Storylines

The storylines, as we refer to them on the land, connect and separate as time goes on. This weaving, I believe will strengthen this narrative, much like the teaching of the sweetgrass braid. Central to this teaching is the belief we are stronger together, each contributing to a greater purpose. By taking apart the personal stories of Ken and Kecia and putting them back together with additional written and oral perspectives, a more complete and complex narrative is created. The story lines reflect personal truth, strength, resilience and power, like a blade of sweetgrass, one side is rough and one side is smooth, joined together with others they have a deep purpose.

The views I publicly shared over 20 years ago reflect my then naive understanding of colonialism. This caption references a whole person approach, a need for spiritual teachings and reference to the past.

> When we deal with HIV or AIDS, it is important to view how this will affect our whole life: physical, mental, emotional and spiritual aspects of ourselves as well as financial, psychosocial and other dimensions. The greatest lesson learned in the fight against HIV/AIDS from this perspective is the strengthening of spiritual foundations. We have to acknowledge there is something greater than ourselves involved here. We can learn from the health history of our people to secure the future for our children. (Lambert, 1993)

The deeper meanings of these comments are coming to fruition now. Time has allowed me to further gauge the actual depth and complexity of HIV infections among “People of the Land” or Indigenous peoples. In North America, signified as an ancestral tie to the First peoples of Turtle Island and other countries, ties to rivers, mountains and land.

Identity is complex. The distinctions of Indigenous or Aboriginal identity in Canada are important as certain benefits are extended to some groups and not to others. With respect to responsibility for health services, identity and jurisdiction become even more significant.

They’re Coming

In many traditional Indigenous narratives, there is reference to the prophecy we held that “new” people would come to this land. As this became reality, the terror of “they’re coming” became relevant in many contexts. From parents trying to hide their children so they didn’t have to go to residential school, to the perpetual presence of social workers or police, there exist deep set beliefs about our people being taken.

Milloy (1999) outlines the prevailing belief at the time of colonization, through assimilative attempts and system development, the “noble savage” discourse provided the rationale to “do unto them” for they are “sunk in ignorance and superstitious beliefs” (p.25). There is major evidence to indicate that the tactics used included disorientation to reorientation, savagery to civility, and numerous resets of “children’s cultural clocks” from the seemingly wild to ordered life (p.36).

As the politicians realized that the object of their actions, “Kill the Indian, Save the Man”, were not going to succeed as planned, other transitory approaches were required. Methods of containing and controlling Indigenous people were established.

To move through the legislative process quickly, Milloy (1999) summarizes the steps that were taken to further the assimilation agenda of Prime Minister Sir John A. MacDonald:

> In subsequent legislation, the Indian Acts of 1876 and 1880, and the Indian Advancement Act of 1884, the government took for itself the power to mould, unilaterally, every aspect of life on the reserve and to create whatever infrastructure it deemed necessary to achieve the desired end – assimilation through enfranchisement, and eventual disappearance of First Nations. (p.21)

Legislated Identities

Stepping back for a moment into my personal educational experience, a significant signpost and moment of guided learning occurred in 1982. I was completing my Social Studies 30 course under the tutelage of Mr. B. Shahi, at the Onoway High School in Alberta. I recall Mr. Shahi impressing on my then 16-year-old mind that I must be acutely aware of current events. The repatriation of the constitution, emphasized with the banging and underlining of words – white chalk on blackboard, must be known and understood. This occurred at a time, that in retrospect, I view as another awakening of the Indigenous Activist in me. I was trying to complete my studies and not sure where I fit in the Indigenous schemata, only knowing awkwardly that I did.

The Canadian Constitution in 1982, Section 35 (1) reads, “the existing aboriginal and treaty rights of the aboriginal peoples of Canada are hereby recognized and affirmed” (Carr-Stewart, 2001, pp. 135 - 136). The agreement to exchange land for certain rights and provisions is at the centre of political debate today. Caught between the grassroots movement of Idle No More (Kino-nda-niimi Collective, 2014) and the overarching colonial aims of the Federal Government are the people, recognized as Indigenous or not. Idle No More has raised the awareness of unmet needs and unfilled obligations, blatantly evidenced by media, academia and social activists alike.

The influence of mainstream colonizers on Indigenous peoples was realized through the Indian Residential Schools (IRS). As the home conditions and circumstances of Indigenous peoples were judged by settlers and settler values as inadequate, systems stepped in to pick up the slack. Concepts of illegitimacy, excessive procreation, poverty and alcoholism as described along the “neglect spectrum” (Milloy, 1999, p.213) warranted the creation of child welfare, day schools and hostels to take care of the educational needs of children.

I will focus on two points regarding the IRS. One is the policy direction that was established and how it is perpetuated today. Second, the human effects of colonial actions on Indigenous peoples, specifically connecting these effects to the lived experiences of Ken and Kecia.

The Indian Residential School is described as “the most extensive and persistent colonial system – one that marginalized Aboriginal communities within its constitutional, legislative, and regulatory structure, stripped them of the power of self-government, and denied them any degree of self-determination” (Milloy, 1999, p.9). Most aspects of Indian life, including IRS were regulated and controlled through the Indian Act. This included the criminalization of ceremonies that were viewed to strengthen the people, such as the Sundance and Potlatch.

With this legislation, ceremonies and the foundation of resiliency and community were disrupted. Milloy (1999) describes how parliament quietly dropped the criminal sanctions for participating in the Potlatch and Sundance in the 1951 version of the Indian Act (p.197). These two ceremonies are directly connected to the cultural backgrounds of Ken and Kecia, from a tribal perspective through to their individual experiences with traditions. Additionally, Section 87 of the Indian Act (1951) made it possible to extend provincial "legislation for the protection of dependent, delinquent and neglected Indian children" (Milloy, p.216), which connects to the existing systems of child and family services. All aspects of private and public life were affected including traditional ways, political structures and economic practices (Milloy, p.21).

This profound legislation formed a comprehensive tactical approach to removing ceremonies critical to the health of Indigenous peoples. I doubt that the early government strategies had the foresight to see what the long-term implications of this policy would mean. The banning of spiritual practices through Indian policy was in place for 75 years. Today utilization of traditional ceremony is a healing practice interrupted. The disruption of cultural teaching and learning is an essential part of the reconciliation and reclamation calls to action. Generations of Indigenous people have been affected by loss of culture. Culture is recognized as a determinant of health. Until we can create the opportunities to truly apply cultural learning and healing, we are missing the mark - the goal of optimal health for all.

Integration as a process and policy direction is documented as far back as 1946. Integration "would in the end be substantially less than the cost of establishing" and operating an exclusively federal system (Milloy, 1999, p.194). While at that time it was about residential and day schools, the policy follows to 2014 with the Canadian federal government health approach to integrating health issues such as, HIV, hepatitis C, sexually transmitted infections (STI), addictions, mental health, tuberculosis and aging. At the same time, setting boundaries about how distinct Indigenous populations will receive support to enact integration is at the centre of jurisdiction and funding debates. Milloy makes a statement that rings true today, "integration was inspired by financial rather than philosophic first principles" (p.195).

So, it Starts

In 1985, I was working with Native Counselling Services of Alberta as a Native Courtworker, housed within the Edmonton Remand Centre. My role was to interview Native people who were primarily in conflict with the criminal justice system. I learned first-hand of situations and lifestyles that brought people into the correctional system.

My job existed by virtue of one man, Chester Cunningham, who recognized that Native people who were in conflict with the law required assistance and information to ensure that matters they were facing were dealt with fairly. Often people I would interview in cells did not understand the judicial process, were too shy to speak up and had been mistreated previously.

On the personal side, I started in this role at age 17 while exploring my own way of life in the city. Having been raised in a rural setting, my experience in Edmonton included rude awakenings with alcohol, drugs and sex. In one instance, I was unknowingly gifted with what was then termed a sexually transmitted disease, chlamydia. I recall having to go to the STD clinic on 109 street and Jasper Avenue, where I was herded through an anonymous waiting area. While sitting in that room I distinctly recall picking up a pamphlet on AIDS. I had heard of it, but it was not until I was in that setting that I realized it could have happened to me. The same way that I was infected with chlamydia, was the same way I could get AIDS.

Once I went through the shameful treatment process and relationship reflection, I realized that the people I socialized with and those I worked with in the remand centre needed the information as much as I did. I had learned about people injecting Talwin and Ritalin (T's and R's) without comprehending what that looked like and was schooled on the sex trade by pushers and workers alike. The early days of AIDS awareness raising were done by add on, casual and matter of fact conversations with people I met.

One of the first formal group presentations I made was at the old Fort Saskatchewan Correctional Centre to the Native Brotherhood group (1987). Both the old jail and the program are no longer utilized. The old Fort, where many people were hanged for criminal offences, was replaced by the new Fort. The Native Brotherhood and Sisterhood groups were shut down or revamped as the issues with gangs increased and the use of cultural programming was reduced.

The early days of Aboriginal programs were distinct with a strong level of honour and recognition for the role of culture. In what some teachers have described as a cultural revitalization period, recognition was given to the history and struggle of Indigenous peoples. The honouring of sacrifices made by our ancestors came to the forefront. In the early 70's, many incarcerated individuals and advocates went to activist lengths such as hunger strikes and sit-ins, just to ensure access to cultural programming, including smudging and ceremonies. Sadly, policy and activism changed as did Aboriginal programming.

I worked within the criminal justice system from 1983 to 1988, working my way up from frontline worker to supervisory positions. It was during this time that I was introduced to the concepts of self-awareness and culture. In truly reflecting on this introduction to healing, I knew there were challenges that had been faced by my parents and grandparents with respect to poverty, addiction, mental health and discrimination.

Shifting forward, I realized that to be more useful, I had to continue my education. Changes to the Indian Act and awareness of the wrongful enfranchisement of my mother, I was able to move from my Métis identity into an Indian identity. This was a transition only on paper at that time, as I maintained my connection to the land and practices that I had been raised with on what is termed the “road allowance.” This space was recognized as the unifying place between Métis and Indian peoples during times when they could not reside on reserves. It is a space in between legislated identities. My connection to and ultimate purchase and acquisition of land was necessary to maintain my distinct ancestral connection, despite legislation or the identity wars that continue. Being Indigenous is tied to my land base.

Identities

It is important to discuss/acknowledge the diverse views on the identity issue. Wilma and James Burns, sister and brother in law to Clare Burns from James Smith First Nation in Saskatchewan, became involved in the early start of the HIV movement. James shared with me that “Indigenous is just another way to get rid of us, to weaken the Treaty obligation – I am not Indigenous, I am Indian … Treaty Indian. When we use these other terms, it takes away from the legal relationship” (J. Burns, personal communication, April 20, 2016). There is a time and place for fluidity, to assume situational identities. Being Treaty Indian or a Métis with status or no-status, depends on the situation I am placed in. Identity can serve distinct purposes.

Indigenous peoples in Canada have been subject to many definitions, from personal through structural or system levels. Legislation governing Indians has changed from the early 1850’s to present day. The debate over sexual discrimination was described by Saunders (1984) as the “single most contentious issue in Canadian Indian policy” (Furi, Wherrett, Canada, & Canada, 2003). The range of identifiers of Aboriginals include but are not limited to First Nations (Indian); Métis (Half-breeds); Inuit (Eskimo); and related terms of Indigenous all seeking to define who we are as People of the land. The introduction of Bill C-31 in 1985 attempted to improve the problematic Indian Act legislation. Issues continue to arise, “Indian status and band membership raise fundamental social and political questions about what it means to belong to a community and who has the right to determine membership” (Furi & Wherrett, 2003). The effects are compounded when there are limits to who can claim Indian status under these changed rules. Discrimination continues to exist. Bill C-3, entitled *Gender Equity in Indian Registration Act,* adds additional complexity to untangling the consequences of identities imposed by the federal government (Hurley, Simeone, & Canada, 2010).

In attempting to catch up to the modern rights based approach to governing, Canada has created more confusion for Aboriginal people. The design of new policies and legislation attempting to define Aboriginality or Indigeneity appear arbitrary or at the whim of leaders, further complicated by the identity that is being sought to control.

For Métis people, identity can also be determined by the community driven and official electorate. There is a disconnect between self-identifying as Métis and being recognized by locals, settlements, associations or councils as having membership.

Perspectives

To demonstrate the impact of varied policy and legislation, as documented in the literature, I will share the stories of Ken Ward and Kecia Larkin. Turn taking in the text has been determined based on the content of their life story transcripts. (Kecia's words are in regular font and Ken's words are in italics).

Kecia Larkin

> It wasn't until... it took a year to getting all the documentation but I was finally able to join membership with my dad's band who happens to have control over their own membership and what that means is instead of the department (department of Indian Affairs) deciding who gets to be a band member the band themselves have set up their own system for deciding who is going to be a band member. However, that system is really poorly flawed because a) you have women that are non-native who gained status by marrying a native man who are living on-reserve with status and then you have this system that insists you be 50% Blackfoot in order to be eligible for status with my band which is Treaty 7 Piikani and there is really no way to prove how much blood a person actually has that is Blackfoot unless you did a test that would geographically recognize what and who each person is and that is impossible to do. So, it's a reversal of it's very it's a very flawed system it's a very flawed process. There is stigma and prejudice attached to it I believe it is wrong I believe it violates people's' human rights on some level because the process isn't complete it only applies to certain people. Now, if you've been a band member there since the day you were born it's not an issue. Even the fact that when you're granted being a native person with your status number, if you live off reserve you are disenfranchised from your land, your culture, your people, your food, the politics and you're not your voice is completely excluded from any decision making - You have very low ownership you have very low influence to change anything your voice literally doesn't count. (Kecia)

The diverse viewpoints of Indigenous peoples create tension and conflict in many situations. Opinions exist on most every Indigenous or Aboriginal issue that is identified. The focus is primarily political, that is, who gains or loses support within a particular construct or discipline. The debates and critical reasoning skills presented in public are at times questionable. It is possible to have First Nations people for example, that despite being registered to the same band, are on opposing sides of issues. There is no consensus to define which perspective is relevant in which context.

In the late 80's, there was a shift for the federal government of Canada to transfer health programs back to First Nations. Numerous programs were developed to assist in building the capacity of nations to control their own health programs. I was accepted in the Athabasca University and Yellowhead Tribal Council certificate program called Health Development Administration (HDA). My dedication to AIDS activism was strengthened through the academic learning process. In conjunction with three other students, the "Native AIDS Project" sample research study was implemented. This was my first experience with community based research (1988 - 1990). It was this action that opened the door to many other initiatives.

I continued to do more awareness workshops with youth in First Nations communities, service providers serving Aboriginal people and with my peers in school. It was during this period (1988) that I met David Nelson, a social work student in the same building that I was in. David heard about my efforts and one day introduced himself to me. He said, "I know someone who just found out they have AIDS and it would be great if you could meet him. He is from Enoch." That moment changed my life.

Ken Ward

> *I want to go back to the time of the diagnosis living in Enoch here in Alberta in December 28, 1989. Our local doctor here came to a residence where I*

> *reside at with my brother. And at the time I was suffering from a hangover but needless to say he knocked and asked for me and informed me that I was diagnosed with HIV. I wasn't at all understanding what that meant. Clearly. Uh like when he mentioned AIDS uh that's when I succumbed into feeling really withdrawn and perhaps somewhat traumatized from trying to deal with the reality that I had this disease.* (Ken)

I had been talking about AIDS for about 4 years at that point with little impact. People felt it was important yes, but significant no. To have an individual actually living with AIDS was sadly what I needed to move awareness forward faster. I did not realize that this also meant the support aspect of my work was about to start. David advised me that this person was going to make his diagnosis public at a health rally in Edmonton. The rally was being organized by the Alberta Indian Health Care Commission to address changes that were being made to health services and benefits.

> *I remember coming here to Enoch and my mom is, she’s not an activist but her friend Helen G. had informed her that there was this rally that was going to be held in Edmonton at the Continental Inn and it was about our treaty rights and our health rights and for me when she’s tells me this she says “My boy you better, you better go and listen because you’re on the sickness (and she used to call it HIVE you got HIV (HIVE). What about those pills? And who is going to take care of you and pay for that?*
>
> *And I thought well ‘Maybe she’s right’. So I decided that my own accord to be able to look at my brother Glen and I says well you know what I was to support the rally (that rally) so I insisted with Glen and coaxed him, into walking from Enoch to that rally in the city of Edmonton together just symbolic I don’t know why but something inside me said let’s do this walk bro and uh despite his objections but he did with his old cowboy boots and cowboy hat and uh but uh we made the walk and you know I was getting close to the rally uh apparently uh my mom let it go the secret to Helen and said can you keep an eye on my boy because he has that new sickness. And Helen or someone got wind of that and told the media that someone from Enoch is coming to this rally and it was a good example or something to highlight in support of the rally in health care and treatment so they kind of capitalized on that.*

> *The media got wind of it like wild fire all the local media uh CTV, ITV, uh the Edmonton Journal *clears throat* and uh as I was getting closer to the rally uh I was getting really afraid because it was unknown to me that they knew about it and then they asked me to come up in front and this rally we had natives from the three treaty areas the six, seven, and eight were there. I remember Nancy Potts uh gosh there was so many of them Rufus Goodstriker, uh Frank Large I think and uh some from Paul band and as I was coming close I was urged to say a few words at the mic in the parking lot. Doreen D. was there from Kairos house was there because she was aware I was doing this.*
>
> *And as I got closer to the mic I said, 'My name is Ken Ward and I'm from Enoch and I have HIV'. My speech was very, very limited because I was dealing with 'What were they going to say?' or 'How were they going to treat me there?'. Um I felt really afraid and maybe that where you came in and witnessed. Denise was there. Uh I don't know who this lady was but she stood in the background *laughs*. And uh I said I'm here to support for our rights because our health was slowly being cut away our benefits. And I uh need to add a voice and guess I needed to illustrate that this I have this sickness and we need to be aware of this.*
>
> *As I finished went towards Helen G. and I believe my kokum Jenny Papin and my mom and we were standing/sitting with the elders from all treaty areas and someone had an eagle feather. And they came up and gave me my first eagle feather and that was March 22 of 1990. (*Ken*)*

This rally occurred at the Continental Inn in Edmonton, Alberta. I attended the rally in great anticipation, hoping to meet this man and even more to have the issue of AIDS in the public eye. I didn't get to meet the man formally that day, but I did witness the transfer of an Eagle feather from an Elder to a man named Ken Ward and heard him tell his truth about his diagnosis to the leaders and rally participants who gathered on that day. It was a time of symbolic interaction.

> *The teaching of the feather itself I knew a little about it because I was ignorant of my culture but I knew I was told it meant a sacrifice, courage, respect, love. So many values that they were telling me about it and I started to get emotional and uh I realized that uh that feather was symbolic to opening, it was like a key opening to my journey as to where I'm going to*

> *go. Uh…. I held that feather once it was done with the rally and of course the interviews then it became like a whirlwind uh but not only locally but nationally.* (Ken)

Community Organizing

Soon after, Ken Ward, Elsie Paul, David Nelson and I met at Elsie's apartment in Edmonton, Alberta, to talk about how we could take further action on this issue. We agreed to organize an exploratory meeting and formalize a plan. Ken and I had delivered letters to key organizations asking them to attend a meeting.

> *But in that time in March and that it didn't sit well with me and I believe that's where Denise and I connected and we talked. And I can't recall how I met David or Elsie or Marlene but there was in that time something needed to be done. Needing to form some kind of group here in Alberta and we met at Doctor Anne Anderson's on 124th street and we looked at the realities and then um AIDS network also became the agency then that responded and Barry Breau and David Fitzgerald all the staff at that time uh opened the door to us to begin the process to begin the discussions to where can we go with this? Uh we didn't name 'Feather of Hope' as of yet uh but we knew we had to do something. We needed to form some kind of coalition or society we talked about it but in the meantime what is it that we really need to do um. We all knew that this illness was going to really impact our community, it was. There was a very strong feeling about it and consensus and I certainly wanted to you know we had our first elder was Dr. Anne Anderson contributed so uh as we talked about this where/what direction we need to do under the umbrella the AIDS Network of Edmonton embraced us. We had no money, nothing to start with so we kind of piggybacked on their means of a little bit of money or some space a meeting space to discuss some plan and then we started looking for money for dollars and Health Canada was our target to be able to get some core funding. I can't remember how much it was * laughs for a few seconds ** (Ken)

Feather of Hope

The first organizational meeting was held at the Dr. Anne Anderson Cultural Centre in Edmonton, AB. The people that attended were in support of formalizing our efforts and were the first executive of the Feather of Hope Aboriginal AIDS Prevention

Society. That was 1990. It was the AIDS Network of Edmonton Society and Health Canada – Medical Services Branch who first provided resources to support our efforts in Alberta.

I attended a conference in Whitehorse, N.W.T. in May of 1990. I had completed my HDA program. I met a group from Saskatchewan at that conference who were very interested in the AIDS information I was sharing. I applied for a job that summer with Battlefords Indian Tribal Council and began working as a Community Health Director in October 1990. My connection to the Feather of Hope in Alberta shifted to focus on a similar action in Saskatchewan. Through my new network, I began to meet people who were living with or affected by AIDS. I quickly organized a Feather of Hope Society Incorporated (FOHSI) society with the first board member being Bob Mike, an amazing two-spirit man from Beardy's reserve.

> *The demand became a lot more insatiable because it was the first time that they had a native that went public with/about his diagnosis in Canada. I may not be the first native to be diagnosed but whoever it was before me was probably living you know in the closet. And stuff like that, but publicly I went I became the first native with that notoriety or that title. Uh so the demands of other communities and reserves across Canada wanted to hear who I was and my story. So I...my time was getting consumed quite a bit but it ignited a fire wind or other it's like a domino effect and the other people started to speak out a lot more.* (Ken)

The need for more Feather of Hope chapters was identified. There were limited leaders moving the issue forward. By January 1991, the FOHSI organized one of the first support gatherings in Canada for people living with AIDS and those who were their supporters. Significant to this action was the attendance of Leonard Johnston and Frederick Haineault, the founders of what would become Healing Our Spirit in British Columbia. Jean-Paul, Del, Tom, Bob, Ken, Fiki, Wilma, Flora, Lillian, Roger, Diane and a few other people attended the Queen's House of Retreat in Saskatoon, SK (1991). This gathering was in a church-like setting yet was balanced with Indigenous ceremony.

> *In Saskatchewan, we had our retreat at the Queen's house at Saskatoon at I believe our first if not western Aboriginal Persons living with HIV/AIDS (APHA) gathering and names of course I think Allan Kennard was getting involved at that time too and Ken Bird of course Denis and we were we had our first retreat there and we talked about initiatives and what our needs were. Those gatherings were a lot more like family than anything else. What we really needed was peer support to be able to acknowledge all of us in western Canada because Flora Mike was still alive and that's Bob Mike's mom and of course James and Wilma Burns, Ernie Mike as well.* (Ken)

In the same month, a National Native conference on AIDS was held in Vancouver, British Columbia (January 1991). Another unifying moment occurred. Ken Ward was on a panel with other individuals diagnosed with AIDS, including Kecia Larkin and Leetia Geetah. This was the first time I heard Kecia speak; she was 18 years old and recently diagnosed.

> *I think the biggest thing was that when... on a national scale though I went to the Canadian Native Friendship Centers. I can't remember which annual conference they had there. It was a national conference but I finally got to see Kecia Larkin because she came on main stream about that time too, in BC, and she became the first woman at that time called Aboriginal woman/First Nations woman that went public so there was slowly was little trickle of faces and especially when it came to a woman. I was really feeling excited a because she uh she at that time she was very outspoken and very honest and very real and uh I respected her then and to meet her at this national conference hosted by the friendship center. And Leetia Geetah was on the panel as we were sitting on a panel and Leetia was I think Inuit country up north the role players were slowly coming into light here pardon me*. (Ken)

The impetus for many other grassroots programs came at this time. Connections to community-developed action are often linked to organizational history timelines:

> The AIDS Task Force began in 1991 after two First Nation people from Nova Scotia attended an AIDS conference in BC. They were very concerned about the effect this disease may have on their home communities, so influenced others to

> educate First Nation communities across Nova Scotia about HIV and AIDS. Fifteen First Nation communities across the province quickly joined forces to begin their fight against AIDS forming the ‘Nova Scotia Mi’kmaq AIDS Task Force’. All the Atlantic Provinces have since joined the cause. You may know us to be the Atlantic First Nations AIDS Task Force. However, since May 2000 our organization is now known as Healing Our Nation's. (Healing our Nations, 2016)

Returning to Saskatchewan, several Tribal Councils became active in promoting community response to AIDS. The first Saskatchewan AIDS Conference was held in Saskatoon, March 21 to 23, 1990. The second annual Saskatchewan Native AIDS Awareness Conference was held May 15 to 17, 1991. The theme of the second conference was “Striving Together, Protect our People, Stand as One Against AIDS.” There were over 400 people in attendance. It was at this conference that Flora Mike and Ken Ward presented me with an Eagle Feather to support the work I was doing in the community. Speakers included Clare Burns, Bob Mike and Kecia Larkin. Local support gatherings brought family members together with those living with AIDS.

A Native American man named Randy Lewis, of the Seattle AIDS Prevention Program, became active in community awareness. There was a teaching tour organized with Randy, Kecia and I travelling to several communities in Southern Saskatchewan. It was during this time (1991) that Kecia and I became acquainted.

A youth conference was organized in North Battleford entitled “Living in the 90’s.” I brought speakers out from AIDS Saskatoon and included people living with AIDS such as Bob Mike and Denis Scanie, another leader from Cold Lake First Nation, to share their stories. There were over 200 youth in attendance at this two-day conference.

> *And when Denis told me about uh his story about chief and council how they wanted to buy him out and leave his reserve and how Denis Scanie stayed and fought and kept his little home. I believe it was a trailer but he got the support from his sisters. It certainly impacted me about discrimination and stigma. But having people especially also First Nations dying on the streets and I guess having no place to go. That’s where I saw my role as sort of like brushing the lands and clearing there to create some understanding of you know we will be all right and you know but the fear*

> *was being infected by touching someone or hugging somebody your sharing their plates and you know*. (Ken)

Denis told his personal story and AIDS Saskatoon spoke of what I was to learn were contentious issues, sex and condoms. Once the Youth Conference was concluded and we were starting to put materials away and clean up, an Elder from Poundmaker's Reserve asked to speak to me. He shared his concerns about the information that had been given to the youth. He felt that it was too much for them and that it would make them have more sex. I listened out of respect and because I was responsible for organizing the session.

> *I didn't realize the work that we were doing no matter how much risk that we were going to go to those communities because again there's still the myths and beliefs of some communities about touching and mosquitoes and you don't talk about sex so you don't talk about traditional spiritual ways or you'll offend the community but we knew in our hearts that we had to bring this out to the forefront because we were learning a lot more about this illness that you know you can get infected by having sex you know and uh the movement for needle use and drug use was slowly being introduced but I think the biggest thing right now was the large focus for now was on sex transmission. But we broke that barrier and we broke it with sensitivity and respect that uh we didn't we've never been ousted by communities or elders or church going people. They embraced us in the sense that they wanted to know more about it. The whole thing about condoms yes, we brought that awareness but trying to create an understanding was a biiiiiiiiggg issue over back then because some believed that you're talking about condoms and talking about sex that you know that you're promoting sex. And our message was done is a way that was delivered "no we are promoting healthier lifestyles and healthy ways of not getting infected". That was a big thing, that was and I found it some of the northern communities where I went on my own that was a big challenge. You know? Cause there a lot of denominations out there no disrespect but it's how you deliver the message that will help create an understanding you know. (*Ken*)

The discussion I had with the Elder from Poundmaker's Reserve I will say, was not a light conversation; I was quite shaken by it. George Benson, my cultural mentor from Red Pheasant reserve (1935 – 2016), who was present on that day, came to me months later and said that even though that old man was hard on me, I had taught him something. George had heard him speak in a workshop with Elders, and tell them that it took a young woman to help him realize that we must talk about issues that were usually secret or private like our sexuality. The future held the opportunity to divulge the even bigger traumatic secret of the Indian Residential School.

Upon my return to Alberta, I discovered there were many changes to the services provided for Aboriginal people, specifically in AIDS programs, projects and services. There was also a shift in the approach of the Feather of Hope Aboriginal AIDS Prevention Society (FOHAAPS) program. One of the aspects of the program focused on the Treaty right to health, and while important was questioned as FOHAAPS was utilizing government funds. There were many views on how health and cultural issues should be approached.

Health is a very political issue. The governance structure of the FOH changed, which included the focus of services to prevention programming through a train-the-trainer approach. While this was suitable for some of the needs, it became clear that the support people living with AIDS/HIV required was not being provided. Numerous mainstream organizations were attempting to address Aboriginal specific needs with varying degrees of success. The access or location of offices, relationship between “client” and provider, Aboriginal approaches adopted and the type of resources allocated to specific interventions affected the access, availability and relevance to what were described as high-risk populations—centered in this category were Aboriginal people.

Healing Our Spirit

> *We also had some influences with Healing Our Spirit because I remember the office I can't I don't know if it was 1990 or 91 that I got a call from Leonard Johnston and Frederick Haineault but Leonard called and said how did you*

> *guys start 'Feather of Hope'? *laughs* and I told him how we wrote this proposal and we had 10 grand I believe and um I think we did another one for 30 grand we started building and he says can you send us a copy? So, we can kind of use that to start Healing our Spirit and I said sure and we faxed it. In that time Kecia was becoming this *laughs* gal that certainly had a you know it was those three there in BC really stood out in my mind at that time that became the real activists in their own right*. (Ken)

Ken is central to the development of the Feather of Hope Aboriginal AIDS Prevention Society in Alberta. As a co-founder, Ken recalls sending information about the Feather of Hope to British Columbia, where Leonard Johnston and Frederick Haineault wanted to start a similar program. The B.C. organization was formed and called Healing Our Spirit (Marsden, Clement, & Schneier, 2000). Kecia was a member and a former employee of Healing Our Spirit. Ken worked with both organizations.

> *I believe un Earl King Fisher then came into the limelight at that era and uh we became a family of our own in a sense in the western provinces. Uh if we needed a speaker or we needed somebody we would pick to teach a workshop we would give them a shout to be able to accommodate. If I can't do, we can just rely on someone else but we certainly knew our roles and respected our roles. And we weren't territorial we just went in as a family uh in the west. I think we even blew some of them away and if we look at James and Wilma here looking at me here in Saskatoon I think their AIDS Conference for instance their first one there. They see this little white, blond blue-eyed guy wearing Indian regalia trying to look native. But the thing was that uh they embraced me and they adopted me as their family. And they became significant as my support in Saskatchewan as well as the Mike family uh the Mirasty's and also Sandy and Hilliard were instrumental and then Donna who was diagnosed with Hep C at the time uh she was the poster woman for Hep C. uh her mom was a big support for her but also with me for uh she used to make me neck bones whenever I would tease her about it *laughs* *Denise laughs* But they adopted me. Emil Bell was another one at that time Emil certainly was an activist on his own right as well with his own concerns were women on the streets of First Nations were working the streets but he was connected through Donna but he became my brother and uh. Kingfishers Nellie of course through Earl. They all adopted me there as part of their family. James and Wilma are still surviving and Sandy and Hilliard is still surviving.* (Ken)

With family and friends, and quite significantly through the efforts of Ken Ward, we created a safe space. Initially we met in my parents (Roy and Lena Lambert) home, which proved to be quite busy and overflowing with energy and people. One day Ken and my late father Roy were in the yard looking at a large shed that my dad used for storage. The idea grew between these two to create another space, ensuring that there was some division between the family home and the common home or the centre as we now refer to it.

Kimamow Atoskanow Foundation

> *Sandy Beach was my introduction to the Lambert family uh. And of course, this woman who looked like a social worker back then brought me back to Sandy Beach to meet her folks uh driving her little white truck thought she was going to kill me. Oh well I thought die of an accident instead of AIDS I thought what the hell. But I think that whole thing of feeling of really touching the waters and living mainstream was a big thing for me. I remember going up that big old hill really afraid of how her family would really accept me. That's why I was kind of keeping my distance when I met Mishi Donovan. I can't recall what year that was but uh it was kind of cool because I was sleeping downstairs with these two wild and kind of crazy women. They'd jump on my mattress like little kids. But the one thing that stood out there were that AA meetings out there with her dad with Roy and it was really interesting and I remember Sobriety was really important to me at that time and I was sitting on the steps of the house the big old' house and there was an old pigeon shed and Roy and I were having a cigarette and you know I look at him and I say and he was talking about AA meeting at the house and I said how come you don't fix that old pigeon shed. And I was really amazed at how Roy took to it like wildfire cause all he had in there was just junk but that's his treasures you know including that pigeon shed. But the thing about it was people in the program all came together if not around here to as far as Calgary contributed materials and built this one portion of the pigeon shed*. (Ken)

Over the course of the summer and fall of 1991, volunteers removed junk from the old shed, cleaned and reinforced the shell of the building, painted and furnished the space. There was no plumbing or electricity, so an outhouse was set up and a long extension cord from the main house brought electrical power to the centre. There was a range of activities including healing circles most often facilitated by Lorraine Sinclair of the Mother Earth Healing Society and access to traditional ceremonies conducted by Elders from Cree, Saulteaux, Sioux and Navajo Nations. Central to these activities was the participation of people living with AIDS/HIV.

> *It was at that time/era that Silver Sage started it time of birth and in that time "Feather of Hope" was really faltering. And what really frustrated me at that time was looking at a pamphlet and it looked like 15 services and programs they could offer and said how realistic was that? I questioned it and I says you know they are getting a lot of money for this. And I questioned the validity of how what like is going on over there *laughs*. Because I chose to step away from it because of this new takeover. I wasn't too comfortable in what I was saying. I felt good to a point where David Desjardins was there but then he passed on and he was second director and it changed hands evolving to something different and from me I remember back then in the program Keep It Simple you but with all these programs how are you going to maintain all the wonderful thing I mean are you really and how many services are given to support for our people who are diagnosed.*
>
> *Well I didn't want to get involved in the politics at that time but then as it evolved and then shut its doors it was the end of funding. They yanked our funding out. And I kind of senses there was something wrong with it and I still question to this day this accountability but then they get this lawyer to back them up and you know make it sound all official and stuff like that but I know that I really believe that nobody really questioned it and that people in the community at the time asked me why didn't you say something or do something. You were a part of that you know.*
>
> *But I remember one of the Elders saying you know let it be let it takes its own course. Because it was you guys you started Feather of Hope and the work that you've given to the people in these communities and whatever support you offered at that time. Feather of Hope still lives. It's in with the people who received your support and your services. Then I left it at that even though my sister Denise *laughs* walked out. It hurt me it bothered me to know that and to the day it still does and I'm trying and ok I can't be vindictive, I can't be you know. Because what helped each day I think was Silver Sage and the whole thing about this Kimamow Atoskanow Foundation with was like reliving the Feather of Hope at the house the big*

> *old' house and sandy hill about Silver Sage and we had dreams about that place so that kind of eased my wounds and I realized yeah this lady knows what she's doing (hahaha) you know it's not 'we're walking away from this it's just that we that change is good in a way*. (Ken)

During one ceremony, a female Elder from Big River, Saskatchewan, shared her spiritual insight about the place and named it "Silver Sage," recognized today as Silver Sage Centre. As the number of people participating in activities increased, there was a need to become more formalized. A core group emerged and it was decided to incorporate as a non-profit society with a focus on healing and wellness. The first name was the Silver Sage Cultural Society.

We quickly learned from a key male spiritual leader that this was inappropriate. This was one of the clearest teachings I ever received and it rings true into so many aspects of what I do even now. The message was unwavering; it is important to separate the spiritual / cultural components from what is construed as business or white man's ways. I am challenged in two ways at this point in the narrative.

First, I have not identified the spiritual leaders, the Elders, who contributed so essentially to our history. I have not received their permission to identify them. I have also left out key aspects of the ceremony, the naming and the teachings to protect their integrity. This purposeful exclusion leads to the next challenge, that is, the description used of white man's ways from the male Elder. This may be construed by some as a racist, separating the white from the Indian, but I believe it is the resistance speaking. The powerful resistance that both the male and female Elders have taught is critical to our survival and ultimately our thrivance.

Once we learned that our zeal in becoming incorporated had seemingly disrespected our cultural teachings, we moved to change our name. The result became "Sandy Beach Kimamow Atoskanow Foundation," translated from Cree to English means "we all work together." The name established our connection to the land, to the people, in Treaty 6 territory and inclusive of the road allowance.

National Efforts

I co-facilitated workshops in Ahtahkakoop First Nation for Youth in 1992. I remember vividly the gift I was presented. It was a print, an interpretation of the “End of the Trail” picture; in the background was the seemingly defeated and weary warrior bent over on a horse, but in the foreground, was a strong warrior with arms raised and a pipe in his hands. The picture still hangs in my mother’s home as a constant reminder that despite the challenges we have had on the trail, we will thrive.

My teachers from Saskatchewan, Clare Burns and Bob Mike, passed away in 1991 and 1992 respectively. Clare was the first person I read to in a hospital, because his eyesight was gone and Bob taught me to overcome my fear of casual transmission of HIV (i.e. a kiss on the cheek). I remember travelling with Ken Ward’s late mom, Lillian, to Bob’s funeral. She was one of core supporters of our grassroots efforts.

> *We are the pioneers back then you know of HIV and AIDS in moccasin country. You know I have old videos and old interviews with people and I’m very grateful to like Clare Burns and Bob Mike you know bits and pieces that are on hand you know these old documentaries and stuff like that that I finally had their courage to go through because it was going to be painful that I was going to grieve some because they’ve then past many times where I’ve felt very lonesome because I didn’t have that camaraderie that brotherhood and that sisterhood of that sense of purpose. Not to coin or plagiarize or anything but I think we were the idle no more movement on HIV/AIDS community back then, it wasn’t for profit. It was for purpose. I believe we honored and still do in our own way to this day.* (Ken)

It became clear that the organization of Kimamow Atoskanow Foundation (KAF) was viable in the eyes of government funders. KAF applied for small grants in the amount of $1,500.00 from the Provincial AIDS Program in Alberta focused on care and support. By contrast, the Feather of Hope (Alberta) was receiving funding from the Medical Services Branch and the Provincial AIDS Program. Initially, there was a spirit of cooperation; that changed when ideologies and approaches began to clash.

> *Well we put a lot of energy and when I say we it was part of Feather of Hope towards the ending part but Kimamow you know working in the prisons and corrections was a big thing for me. Uh having to you know attest that I was going to all and that includes repeat visits to these correctional institutes uh it was that time I started helping a little bit as a resource for protective safe house in Edmonton for young girls who were in the sex trade and the Edmonton young offenders. Uhh my role there was the education component but also just telling my story for other possible inmates who were diagnosed uh if it was in the group setting in their units or on a one to one basis. So, we certainly had a lot more exposure than any other agency I believe AIDS service organization with the corrections at that time I can also attest that with Kimamow the longest serving board members in Canada's history that's still are today its board members from its birth. Uh we've lost a couple or a few that have contributed in some form or fashion uh to me that a big historical note that they're not being accredited for and that frustrates me all these board members they became a huge part of this with their wisdom and their care. Such as doing contributing their lifestyles and their research whatever that may seem like. Uh to me that's what it meant that's what it is. That well, it's a lifetime commitment, I was to give. And to this day how many people can really say that*? (Ken)

There were many people concerned about how HIV/AIDS would impact our distinct communities. Despite differences in opinion or approach, individuals would come together to work on the issue. We did not always agree, but we did make the effort. It was clear that limited funding availability strained the relationships.

I began working on projects that were federally funded. With the National AIDS Strategy, numerous projects were happening across the country (Canada, 1991). In 1991, the National Aboriginal Persons with HIV/AIDS Network (NAPHAN) was introduced. This was a small group of Aboriginal People living with HIV/AIDS (APHA) that were brought together to discuss issues and potential actions to address HIV/AIDS in Aboriginal populations across Canada. This group was the rarely discussed predecessor to what is now known as the Canadian Aboriginal AIDS Network (CAAN). The initial focus of NAPHAN was on increased care and support for persons living with HIV/AIDS. There was a shift in approaches to include a strengthened prevention component by CAAN.

> *I believe in 91 we engaged with 7 aboriginal national aboriginal APHA's if I can recall was uh: Darcy from Toronto - 2 spirited, Ken P, Clare Burns, Myself, Tom J., we met in Toronto and Jay Wortman, Dr. Wortman was instrumental and I can't remember the other two but there was seven if not a couple more who were a part of this gathering in Toronto to talk about it. And at that time again back in 91 /92 but we met in Toronto and we called ourselves the NAPHAN National Aboriginal Persons with HIV/AIDS Network on a national level we had Art Zoccole there, Roger P., and uh we had some lady at that time from the Inuit nurses or somewhere I can't recall her name. *chuckles*. But we had about maybe 5 national agencies or reps join us there and to talk about this at a national level what is it that we really need as APHA's. What's the purpose of this national body? And I remember really exclusively that it was advocacy, support and the other thing was education and awareness. We need to refine those to and there was another one, another piece to this but that would be our vision is to be able to become a national voice a representational body.* (Ken)

> And you see it the way it's set up with these AIDS service organizations you take the Canadian Aboriginal AIDS Network for instance which was one of the recommendations from NAPHAN one of ninety some odd it wasn't oh CAAN and we're done now the shows over NO that was one mechanism just one. It wasn't supposed to be everything but somehow, they have become rich with research dollars they've become international you know internationally recognized. (Kecia)

Other relevant action included the work of the Joint National Committee on Aboriginal AIDS Education and Prevention (Canada, 1990) and the Joint National Committee on Prisons and HIV in Canada, (Jurgens & McGill Centre for Medicine, Ethics, and Law, 1993). It was during this time that the Medical Services Branch encouraged regional leads to bring Aboriginal counterparts to the meetings with them. This was my new experience of being mentored and assisting government in finding Aboriginal voice.

International Indigenous HIV

Significant developments occurred in 1992. This was to be the celebratory year of Columbus "discovering" the Americas. It became a grounding in resistance and was endorsed as the "International Year of Indigenous Peoples." Worldwide there were activities that pushed against the mainstream agenda to celebrate what we as Indigenous Peoples recognized as genocide.

I attended a history making event in Aotearoa (New Zealand) in March 1992. The "First International People of the Land Coming Together HIV/AIDS Conference" was organized by the Te Roopu Tautoko Trust. This was my first International Indigenous HIV conference experience. There were Indigenous people from around the world integrating the stories of loss of culture, language and identity with hope for a changed future. I believe this was before the determinants of health and population health discourse became popular.

Today, we have the International Indigenous Working Group on HIV/AIDS (IIWGHA) which has established a presence at the global level ensuring that Indigenous issues are on the agenda of every International AIDS Conference (IAC). This process formalized in Toronto in 2006 with an Indigenous Pre-conference, a practice that has followed with each subsequent world AIDS conference. Kecia Larkin delivered the closing plenary for the Toronto IAC, with her daughter Rakiya by her side.

Global to Local

In July 1992, Healing Our Spirit Worldwide, a conference celebrating resilience and practices of Indigenous people, came to Edmonton. I made a presentation on "Addictions, Abuses and AIDS" that deepened my understanding of trauma and health. We hosted a cultural exchange evening with people from Africa, Aotearoa (New Zealand), and South and North America at Silver Sage, strengthening our International connections.

I continued to participate in HIV/AIDS projects including one with the Edmonton Social Planning Council to create exit kits for federal female inmates and another with the Canadian Native Friendship Centre to organize a community conference. There is significant yet sporadic action occurring.

The Provincial AIDS Program through the Government of Alberta initiated a variety of projects to address the complex dynamics of behavior and populations. One example is the Non-Prescription Needle Use Project (McHutchion & Alberta, 1996), known as the NPNU from 1995 to 1998.

Similarly, a joint project between Alberta Health and Medical Services Branch was funded for the development of the Alberta Aboriginal HIV/AIDS Strategy (AAHAS), (Canada & Alberta, 2001). I worked as a consultant on the strategy with a project team representing key stakeholders to develop a mechanism to address HIV/AIDS among Aboriginal peoples in Alberta.

Note the identifier, Aboriginal, which included representatives from Treaty 6, Treaty 7, Treaty 8, Métis communities and representatives from Health Canada and Alberta Health and Wellness. The advisory committee also included Elders Joe P. Cardinal and his wife Jenny, who were the spiritual teachers at the core of this work.

Tree of Creation

Through the Northern Alberta Working Group and the Southern Alberta Working Group on HIV/AIDS, regular meetings were organized to bring community people and frontline workers together to create a strategy. The main outcome of this strategy was the development of a nature based model named the “Tree of Creation,” which continues to be used today to address issues facing People of the Land, now recognized as Indigenous in government discourse.

Learning through the eyes of the community increased my own personal development, I had to move beyond the constraints and conventions written within a corporate statement of work to get cultural and spiritual guidance. While every protocol that was suggested by the advisory committee was adhered to, including the minimum, opening and closing prayers at meetings, I had to go further. The wholistic understanding and approach that was gifted to me through the “Tree of Creation” conception and birthing was life changing. Moving through the stages of hopeful expectancy that there would be a recognizable and healthy approach created was not a surface pen to paper effort. It invoked a depth of understanding that frightened me as I felt inadequate to take such a role on with my limited spiritual and cultural knowledge.

The model came to life in May 1996 at Nakoda Lodge in Morley, Alberta. People in attendance physically modelled the elements of the tree as a teacher. This included healthy and unhealthy trees, identified by the placement of cut-out images of roots and leaves and individuals standing to represent both. We worked through confirming values and beliefs that were central to the work we do. These core values included: Life/Family; Sharing; Respect and Honesty. There was no adherence to a set number of spiritual laws or teachings; they came from ranking what people felt was important to hold on to in all our work. Included in the model was the past. The past included occupation of lands; government directions to deal with Indians, Natives, Aboriginals, Métis, First Nations, Inuit or what other current term was popular; alcohol abuse; violence; and, of course, HIV/AIDS. There was a fear then that promoted the distinct need to address AIDS/HIV. It was an urgency that communities were ill-equipped to deal with, particularly as the issue touched on sexuality, morality and disease. The “Tree of Creation” is a long-standing, recognized approach to integrated health.

A document was drafted in 1998 to bring the lessons and result of this project together. The style of writing and content was not accepted as conducive to the aims of both levels of government. There was an external independent writer hired by the project sponsors to create a new document outlining the process and findings. It was interesting to hear that the writer was directed to “sanitize” the document, meaning that all action attributed to my personal “touch” or approach was to be removed to make the document objective and aligned with the rigour of the day. If community members stated that I was helpful in specific ways, the information was subject to removal of my name and success attributed to the overall project. The resultant strategy was completed with a variety of technical goals, objectives and activities pleasing to the government of the day (Canada & Alberta, 2001). It took years to complete and was not implemented.

One of the recommendations that came out of the AAHAS was to have streamlined funding so that communities and community groups would not have to go through so many “hoops” to access funding. It is interesting to note that the funding model created by Health Canada, AIDS Community Action Program and Alberta Health (and Wellness), called the Alberta Community HIV Fund (ACHF) attempted to do this.

There is a saying in Indigenous community circles about the tactics of government and how they use funding as a way to get Aboriginal groups fighting amongst themselves. This has sadly been a part of the Indigenous HIV movement. Based on observations in Alberta, funding has also become a method of controlling a variety of community agencies. I believe that the “joint” funding model oppresses the efforts of Indigenous agencies.

The Feather of Hope operated from 1990 to approximately 2007, although this time frame varies depending on the source of the information. There are several versions about the details of the organizational closure. I attempted to attend an annual general meeting in its final year and was not allowed to attend. Staff indicated that one day they showed up at the office and the doors were closed. Funders indicated that the reporting requirements were not met. Years later upon speaking with the former management of the organization, I was advised that it was an executive decision to close because the money being offered to the organization through the Alberta Community HIV Fund was not enough.

My recollection of that period is that I advised the Feather of Hope executive that Kimamow Atoskanow Foundation would be making an application to the Alberta Community HIV Fund, to meet needs that were identified by communities we worked with. In what I believe was an honest attempt to “work together,” I was advised that I should be prepared for a “competition.” The decision makers of the day advised that the $100,000 allocated to Aboriginal funding would be split between KAF and FOH. As it turned out there was an allocation of $50,000.00 that the FOH did not take. This is a point of contention where funders indicated requirements and reporting were not met and the organizational representatives argued that it was just not enough to operate on.

While the Feather of Hope closed its doors, Kimamow Atoskanow Foundation was advised that the additional funding would be available to KAF, AIDS Calgary and AIDS Network of Edmonton Society through a proposal process. I met with both groups, but was struck by the imposing position of both. One of the executive directors offered to apply for and manage the funding since Aboriginal organizations had “demonstrated they cannot handle the money.” I thanked both groups for speaking with me and advised them that we would submit a proposal on our own. We submitted and we succeeded in receiving $100,000.00 for that funding cycle and were on “trial.”

Sadly, for the duration of the funding in Alberta and similarly at the National level, non-Aboriginal groups have received significant funding to address the “Aboriginal” problem. This occurs along the continuum of prevention through to care, treatment, support, research and evaluation. What is historically problematic with this approach is the is limited accountability back to the community being “served.” Appropriate identity is a factor in this issue. Identifying information is needed at so many levels. It is not only ethnicity, it is also type and status of disease, gender, location and familial connections to start.

KAF received “conditional” funding from the ACHF for two funding cycles. In 2007, the organization submitted a funding proposal that went “outside” the prescribed amount. The submission to ACHF argued that $100,000.00 was not adequate for the geographical area, the province of Alberta, nor for the complex needs of Aboriginal populations. KAF also identified the incestuous structure of the ACHF. The community planning committees of that period, who were also board members of recipient organizations, decided or commented on who should receive funding. Additionally, information about the comparative allocations of mainstream AIDS Service Organizations (ASO) and Aboriginal organizations was critiqued. The process was unfair and flawed. In the proposal feedback comments, anonymous at that time, KAF was described as “subversive” and not following the prescribed guidelines. These comments prefaced a conversation with the funding committee.

I recall that I was doing a number of presentations at the school in Calling Lake, Alberta and I had arranged to use the phone for the call to discuss KAF. There were likely four or more individuals on the speakerphone from the offices of Alberta Health and Health Canada. This conversation served as a pivotal point in KAF’s existence, particularly in exercising autonomy and establishing the right to exist.

The members on the line advised that KAF would not receive operational funding, but that ACHF was prepared to provide $18,668.00 in “transitional” funding. I asked what they meant by that and it was described to me as assistance for us to transition out or to close our doors. I was shocked, and upon sharing with my board, was told to tell them tactfully what they could do with their money. I was also directed to tell them they do not govern our community based organization or approaches.

Subsequently, despite applying each funding cycle, KAF has not received any financial support from ACHF for our work over the last 10 years. KAF has been successful in securing project funding from other sources during the same period, including the Public Health Agency of Canada and direct grants from Alberta Health. In keeping our mobile and land based initiatives operating for 25 years, we currently have no financial support from the Alberta government or FNIHB in this region.

It is significant to note that between 2010 and 2016, the Alberta Community HIV Fund has consistently allocated from $60,000.00 to $76,000.00 to another Aboriginal organization, whose primary mandate was housing and yet has shifted to meet ACHF criteria. This demonstrates a pattern for one joint government funding committee, that is, not to support or build capacity among Aboriginal governed organizations, rather to ensure that the funding and structures of mainstream organizations are kept in place. There could be a complete critique of this approach, but it is not the purpose of this thesis. The main issue is that Aboriginal organizations have been consistently underfunded and there has been no shift in decision making criteria or a judicial review of the decisions made by this funding consortium to date. The goals of the funding are to increase capacity but it is questionable whether this can be assessed. It is even more concerning that the evaluation process for determining how well Aboriginal needs are being met is non-existent, unavailable or non-participatory.

It is frustrating to continue attempting to convince or even work within the related structures of the Alberta Funding and Policy Consortium, now called the Alberta HIV, HCV and STBBI Consortium or the Alberta Community Council on HIV given the obvious resource disparities and often discriminating approach of these mainstream entities. Even the argument that more "Aboriginal" people are working within these organizations does not erase the fact that they are not governed by Indigenous people, despite autonomy being one of the key actions in the policy environment of reconciliation. Of relevance is the TRC Calls to Action, Number 18:

> We call upon the federal, provincial, territorial, and Aboriginal governments to acknowledge that the current state of Aboriginal health in Canada is a direct result of previous Canadian government policies, including residential schools, and to recognize and implement the health-care rights of Aboriginal people as identified in international law, constitutional law, and under the Treaties. (Truth and Reconciliation Commission of Canada, 2015b)

> I've had this for so long and now I'm thinking in my life because of the way that the AIDS movement is now on many levels I don't even know if I want to be a part of it anymore. I don't with what I know I wish I didn't know to be really honest. I really wish I didn't know that people embezzle money from other sick people. I didn't know that we would be pitted against each other. I didn't know that I didn't have to be friends with every single positive person.

I'm just figuring that out now. I don't have to be everybody's peer, I don't have to like everybody and now that I'm starting to step back from that way being I have more peace of mind than I've had in a long time. I'm not angry. I'm not irritable. I know it's because I just don't put myself around that stuff that I just can't comprehend that it's just .. It's just the ineffective, policy that people don't even honour half of the time. You know the way I look at policy I look at process, it's all about relationship and it's all about trust. I mean if it was if those were Indigenous values it would be people, it would be called something else and it would look very different. I don't think people realize in this movement how I don't know if people really grasp how important it is to create policy. To really have that grasp on what it means. (Kecia)

So, what we're missing, we're missing the Laverne Monette's who informed not just informed, educated and gave the information from a legal standpoint. We don't have that anymore. We don't have people explaining to somebody when they sign up for their membership that as a board member your board members are legally bound and if you have concerns this is what you are supposed to do. Call the funder. If you can't get through to the organization, right? And just that basic information is so empowering for people to know they have a choice they have a voice they can create change even if it is a policy or something small like a resolution to them that can be a huge their life work. And that's part of what we talk about when we talk about mentoring and building capacity and all these fancy words like knowledge users and it's like why can't it just be people helping people why does it have to be like a terms of reference before we can just build a basic relationship between each other, build a strong foundation of a team that works well together and we just do the work. Why does it have to be committee after committee and then these different decision makers and then we got to go back to this and it just causes so much unnecessary work on lots of different levels and energy. (Kecia)

So sometimes we really as people are the last priority, we're the last item on the agenda because of so much other work to be done that we need to inform as people living with HIV. So, when we go places we're not there to enjoy each other's company that happens after everything. We're there to do the work for the organization. We're there to make them look good, we're there to do work, we're there for own reasons too, our own agendas. In an ideal world, I'd like to say that we're making changes and we're doing big things and look at this, but when I really look at it you know there's only been a few ground-breaking things that have happened in the last 30 years. A lot of it is grassroots driven, it's not what the big huge organizations have done. (Kecia)

> Yeah maybe they've done research, but it's the people who have informed that research that's the sweat off the brow. It comes from those people that have informed that research but they are the last people who are ever acknowledged on the research paper. And they are never told that. Never told that.
> Even in the community based research that I'm doing now kind of reeks of some of that smell. They want to decolonize and use these buzzwords and different and I can coin shit until the cows come home but they don't want PAW[2] they don't want change. (Kecia)

> At the end of the day and I know how much time I've put into this movement. I was there when the first AIDS service organizations started Healing our Spirit, Feather of Hope, travelling across Canada to these different places, Ontario that had already started which an AIDS Strategy in the early 90's yk like they were already engaging their leadership, they were already leading the way and how many different strategies have we written for different provinces that are just sitting on the shelf for aboriginal people. What I don't understand is how the rationale is of spending all the money on that for something that is pointless only to bring in these other strategies that have had no community input no community engagement and who sat up and thought of this ridiculousness yk like that's to me the danger is that the direct exclusion of the positive voice in leadership of HIV and AIDS prevention of HIV and AIDS care, treatment and support. (Kecia)

Healing Our Spirit (HOS) operated from 1993 to 2015. Kecia Larkin was instrumental in having Aboriginal Peoples Television Network (APTN) Investigates do a special on the closure of Healing Our Spirit. This organization continued to receive funding despite not completing required reports and changing its organizational designation from not for profit to a corporation. Many steps were taken by Aboriginal Persons living with HIV/AIDS to attempt to address these concerns (APTN, 2015). The investigation continues into the closure of HOS.

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[2] PAW was created by Kecia Larkin and is an acronym for Positive Aboriginal Woman or Positive Aboriginal Warrior

Anytime that we're not at the table means that someone else is speaking for us and I don't want someone speaking for me. I would rather be heard directly. I would like to be heard directly but for me to be heard directly I need to know which organization I need to align with because there's only so many that are actually have people who are really actually doing some of this work in their own provinces to the calibre that it needs to be or at least striving to be. And when you find those groups if you're not geographically in the same area well guess what you can be a member but you don't get to play in the sandbox all you are is a number for the next proposal that's all. And it doesn't negate the need for us to have these important memberships with our organizations across Canada because we need them. (Kecia)

We need the support, we need the voice, we need the hope and really that's what I kind of see happening with a lot of the HIV positive people that I've known for a long time yk a lot of them have walked away from engaging with any of these organizations because they're not doing the work they're set up to serve themselves they're set up to take care of their own needs they're set up to yk participate in everything without engaging community and there's nobody there to say hey that's not okay or to question it or to critique it. It's individual members and honestly be really truthful if you are not the right person or if you are the right person and you say the wrong thing you are black balled you are excluded you are not allowed to play in the sandbox because it's easy enough for you to submit an application for the AGM but it doesn't mean you're going to get chosen it takes one person to say no not them I've seen it happen I've seen it happen with ... and I've seen it happen at CAAN I've seen it happen at OAHAS yk because they're not there for the community. (Kecia)

When people who are there for the community start speaking up about that incongruency, well the best way to shut them up is give them a job or blackball them. So, if they see you as useful well they'll hire you but if you're too much of a rabble-rouser and a good leader well then you just get black balled and sometimes you go away and just stay away. Why would you want to put yourself in that situation where people don't give a shit about you? That's really what it is. And I don't know who created that policy or process but it seems to be a norm these days. It seems to be acceptable. It seems to be unchallenged. It seems to be perpetuated to the point where organizations are literally shut down and nobody says Boo. Nobody questions oh why did Healing our Spirit shut down why did Feather of Hope shut down – gee there are people legally responsible for this oh where's the police oh we don't talk about that in our community oh we don't have people

> who have embezzled we don't have people who commit crimes oh we don't have predators we don't have any of that we're perfect we got it all figured out. (Kecia)

While each province has distinct approaches to funding, there have been several iterations of Aboriginal funding at the national level, specific to HIV/AIDS. With each of the National AIDS Strategies released, approaches and priorities have shifted. Currently, we are in a transition phase from one type of funding model to another. There has been a shift to bring HIV and Hepatitis C funds into an integrated fund commonly referred to as Sexually Transmitted Blood Borne Infections (STBBI).

At this point, I will clarify that the funding for HIV programs for First Nations on-reserve is separate from funding for Aboriginal or Indigenous people off-reserve. This distinction is important and links back to the historical context that was presented earlier which speaks to the difference in health care for Métis and First Nations individuals, complicated by the federal – provincial jurisdictions.

It is also extremely problematic, at many levels, that there is limited accountability or adequate performance measurement systems in place to assess the return on investments or to clearly account for where funding is being spent. There are levels of secrecy or perhaps selective disclosure to leadership to ensure "confidentiality" and not center out certain communities, organizations or individuals who benefit from funding. Even with a unanimous resolution from the Alberta Assembly of Treaty Chiefs to support resource allocation for harm reduction, blood borne infections and sexually transmitted infections, KAF did not have the capacity, tolerance, or time to navigate the FNIHB bureaucracy.

Alberta is unique with the co-management health structure that brings representatives from Treaty 6, 7 and 8 and FNIHB together to make funding decisions. The weakness, in my view, is that leadership changes usually every 2 years; the health technicians have diverse responsibilities; select First Nations and tribal councils receive specially designated funds, in part due to their financial accountability; and even when evaluations of the co-management structure have suggested that alternate models are required to align with self-determination and nation autonomy, the status quo remains (FNIHB, 2016).

In February 2017, the First Nations Health Consortium was contrived, funded through the Alberta Co-management structure, aiming to implement “Jordan’s Principle” in Alberta (APTN, 2017), a way to mitigate jurisdictional disputes over funding for First Nations children. This another example of distinct approaches for Indigenous peoples.

The policy shift towards the formal adoption of an integrated approach to addressing Sexually Transmitted Blood Borne Infections (STBBI) has impacted the funding model now in play in Canada. Through the Public Health Agency of Canada, we have moved from the Non-Reserve First Nations, Métis and Inuit HIV Project Fund to the Community Action Fund. This shift in approach and priorities is affecting all organizations who address HIV and proposed work within the new STBBI framework.

Now within the HIV movement, characterized as organizations, individuals and communities who have acted to increase awareness, care, treatment and support, there is hesitation and anticipation in the air. Funding arrangements have been altered and will impact how the next 5 years (2017 – 2022) of work unfolds in communities. The integrated approach, a replication of sorts from the federal government, is being played out in the health field. Despite proposal submission deadlines being set and met last fall, organizations like KAF, who have gone to the second level of review, do not have negotiated or approved contribution agreements in place as of March 31, 2017 despite April 1, 2017 project start dates. The fact is contribution agreements were not signed until August 2017, with no funds flowing until these are processed. This is the ongoing reality of health resources for Indigenous peoples. We are given strict deadlines for documentation and reporting; this is not reciprocated. We are assured that funds will flow and they eventually do in what is described by community organizations as the “feast and famine” cycle, a haunting reminder of historical colonial starvation tactics.

It is refreshing to note that cultural prevention programming, associated protocols and costs are being more openly considered and accepted. A shift to outcome based reporting also gives Indigenous organizations another opportunity to describe success on our own terms.

POLICY

To transition from personal experiences in the HIV movement to policy, I will provide a current description of policy and the policy making context as well as a reflection on past colonial policies and their continued manifestation and influence on Indigenous health today.

Within the HIV sector, I have observed the move from opinion or anxiety based allocation of resources to evidence based or evidence informed decision making. Emerging issues, such as the initial identification of AIDS/HIV in 1982 to the current African analogy in Saskatchewan with respect to HIV “rates” (CBC, 2015), are more likely to receive resources quickly. The policy making process which directly influences the allocation of resources or funding specific to an issue can be timed based on the coinciding “attack” rate whether from an infectious disease perspective or public health emergency, through to the level of public outcry about matters of significance. There are some relevant criticisms of evidence based decision making to note. Central to this research is the question of what information is privileged in decision making processes.

Constructs of Policy

Defining public policy is stated by Marchi, Lucertini and Tsoukias (2016) as decisions which involve citizens are public decisions. Government (federal and provincial) are more frequently being held accountable for the allocation of public resources, which follows to the level of the organizations who access public resources, including not for profit or non-governmental agencies through various funding programs.

Smith (2003) includes criteria to consider in public policy including the scope or the number of people affected; the intensity or the magnitude of the impact; and the time, whether it has been an issue for a long period of time or not. These factors determine if a policy “appears and remains” on the policy making agenda. Two types of policy are referenced, reactive and preactive. Reactive is signified by media attention or reacting to crisis, while preactive refers to strategic action. “It is very rare that formal policy development is genuinely proactive” (Smith, 2003, p.10).

Based on literature reviewed by Marchi et al. (2016), there are six main characteristics of public policy: 1) the power relations between different stakeholders; 2) the different institutional levels; 3) the duration over time; 4) the use of public resources; 5) the act of deciding (including deciding not to decide); and 6) the impacts of decisions. Marchi et al. further present a chronology for policy making that includes agenda setting, policy formulation, decision making, implementation and evaluation (p.18).

Decisions about policies and programs are informed by evidence or proof of need. The existence of multiple evidences; the multiplicity of factors influencing policymaking; and the contingent character of evidence (Marchi, Lucertini, Tsoukias, 2016) are considerations expressed that distinguish between what is hard/objective and soft/subjective evidence. For policy, the type of evidence that is privileged or of what counts as valid knowledge is examined. For Indigenous peoples, the manner in which evidence is produced, translated and shared, remains a key challenge to ensuring our experiences and perspectives are included in decision making.

The idea that power, people and politics have been overcome to the point “where research replaces policy, and experts/technicians replace politicians” are influenced by several factors: “Experience, expertise and judgement; Resources; Values; Habit and Tradition; Lobbyists, Pressure Groups and Consultants; and Pragmatics and Contingencies” (Marchi, Lucertini, Tsoukias, 2016, p.30). This is demonstrated quite clearly in today’s political environment, where political parties have changed (conservative to liberal), and so have policy platforms. We are able to use “harm reduction” discourse and practice without naming it something more palatable. Despite the shift in government, the bureaucrats who have been employed in the civil service or varied departments, remain the same. Many of the old regime still tow the colonial line.

As the participation of Indigenous citizens has increased in the policy development cycle, so has the inclusion of Indigenous knowledge. To introduce how knowledge inputs are utilized in the policy cycle, five models are presented: knowledge driven; problem solving; interactive; political/tactical; and enlightenment. In the knowledge driven model, “research leads policy in a sort of scientific inevitability”; in the problem-solving model, “research priorities follow policy issues”; in the interactive model, “there is no position of influence”; in the political / tactical model, “research priorities are settled by the political agenda”; and in the enlightenment model, “they contribute to the comprehension of the context in which the policies will act” (Marchi, Lucertini, Tsoukias, 2016, p.31). Today, we see the attempts at inclusion of diverse stakeholders in determining policy, which has not been the experience historically of Indigenous peoples.

The policy development cycle presented above provides a framework for the analysis of health-related policy that has driven and negatively impacted Indigenous peoples. I will lead into the colonial policy section of this thesis. Policies determine the allocation of resources and the course of action that will be taken or not taken in specific circumstances. Indigenous peoples have struggled to be viewed as equal citizens, rather than as subjects or wards of the government, needing to be taken care of. Colonial policy was legitimized externally by the “Crown” and settlers. There is a distinct policy process that prevails for Indigenous peoples in varied resource allocation processes. While the development of Treaties with Indigenous people was a high-level policy, that is nation to nation, there are variances as to how this has been implemented. We now have a recently collected set of “evidence” that speaks to the exclusion of Indigenous peoples in the trauma policies developed to colonize the lands that became Canada. Trauma was encouraged and directed at our communities through various forms of state apparatus.

Aboriginal Problem

From the time of contact, there has been an issue with "*People of the Land.*" The existence of people, human life, interfered with the colonizing process. Taking the land and the lives of Indigenous peoples were achieved with the introduction of varied legislative documents including the investment in the "Terra Nullius" paradigm, roughly translated as "barren land with no civilization": "the patterns of domination and oppression that continue to afflict Indigenous Peoples today throughout the world are found in numerous historical documents such as the Papal Bulls, Royal Charters and court rulings" (Castanha, 2015). Great investments were made in creating the "savage" discourse. Eurocentric belief systems overran the fact that pre-existing nations had viable political, educational, social and health care organization.

Indigenous people remain a "problem" in numerous settings and are kept in place through a variety of colonial policies including the Indian Act and various legislative frames for justice, health, education and child welfare as examples. One of the most unrelenting and often unwritten practices is the privileging of voice. Taking on or assuming Indigenous identity is pretentious. There are various instances where non-Indigenous or individuals working with Indigenous peoples are using positions to validate their "speaking on behalf of" role. Further to this, the "identity fraud" exists when individuals do not identify their genealogical connection or the authority to speak on behalf of communities, populations, organizations or even a personal perspective. Historically, many non-Indigenous people have jumped onto the "Indigenous bandwagon" for a variety of reasons. This practice is no longer acceptable, yet still tolerated where no contestation exists, particularly in some funding areas.

As individuals and organizations have assumed the right to speak on behalf of Indigenous Peoples, without questioning their authority or capacity to do so, the attention paid to Aboriginal health, education, justice and social issues is courteous at most. There are minimal sources of evidence outlining progress to improving health, education, justice or other life outcomes for Indigenous peoples. More often the language of “over-representation” serves as the appropriate sanctifier of action with limited input from Aboriginal people and even less specificity between distinct groups.

Modifications are required to many systems and approaches in Canada dealing with Indigenous peoples. There is often disdain observed in suggesting this. The mentality of “just get over it” still exists. Until foundational issues like Aboriginal and Treaty Rights or authentic “representation” at all levels are addressed, we are faced with life “as is.”

Deliberate Action and Inaction

Clearing the Plains (2013) is an apt title to describe what happened to Indigenous peoples through disease, starvation and other tactics of the emerging government prior to the dominion of Canada in 1867, and can be analogous to action today. Details are provided about how communities used complex strategies to manage the resources available to them on the prairie landscape.

Virgin soil epidemics (VSE) were described as a way to understand the severity of early disease outbreaks, whereby a “pathogen infects a population for the first time” and “no one has acquired immunity from enduring the sickness, and the entire population can be infected” (Daschuk, p.12). Many of the issues identified by Daschuk surrounding contact and colonization include aspects of Indigenous life that are still affected today. Transportation routes, economic trade and development, alcohol use and venereal disorders are mentioned as “effective vectors of disease” throughout the text (p.13). Of note, as early as the 1700’s, “the ‘authority’ in the Athabasca included a slave traffic in women” (p.50).

Colonial policy advancements in land settlement and treaty negotiations were assisted by infectious diseases such as smallpox, influenza, tuberculosis and measles, as did moving Indigenous people from a mobile existence to a docile population, contained and controlled. Without access to traditional food sources, people starved. It is stated that “dominion officials tailored their response to the famine to further their own agenda of development by subjugating the malnourished and increasingly sick Indigenous population" (Daschuk, p.100). The Canadian Pacific Railroad became a matter of National interest as did the signing of Treaties. Sadly, "the government was unapologetic for its use of starvation to complete the occupation of reserves" (p.127). The *Saskatchewan Herald* wrote in the Spring of 1885 that "their policy seems to be comprised in these six words: feed one day, starve the next" (p.151). A state endorsed policy to address starvation was implemented.

> For over a century, the Canadian government's residential school policy took some 150,000 First Nations, Inuit and Métis children from their families, communities, culture, land, sense of self and security and put them in schools jointly run by the government and religious orders. (Matsunaga, 2016, p.25)

Indian Residential Schools (IRS), Indian Day Schools and Indian Industrial Schools were state sanctioned apparatus to remove children from home and family. They included obliterating any healthy connection to culture and community including use of language, ceremony and tradition. The long-term effects that IRS have had on Aboriginal peoples are evidenced by the *Royal Commission on Aboriginal Peoples* (2011) and the *Truth and Reconciliation Commission* (2014).

Education policy was one of a series of government policies, whose purpose was to create permanent communities, taking people away from life on the land and through the IRS, taking children away from parents. "Through education, a people's connection with their culture, which was the land, their physical health, and spiritual balance was to be ruptured" (Milloy, 1999, p.254).

Land development was an obscure notion to Indigenous Peoples in pre-settler times, yet the settlers had very clear views on how the land would serve their needs. A place was needed to settle, a piece of land necessary to build a life. The historical influence of colonization is diminished and misunderstood as evidenced by written

Canadian history that clearly wrote off Aboriginal people. There has been a colonial policy from the time of contact that continues to be enacted today. This is the reality our community in its diversity is struggling with today.

Despite rhetoric of change, Indigenous peoples' history in Canada has not been critiqued, including the language of vulnerability as it relates to health. As the settlers were building a life, they were also taking life away.

National Interests

Boldt (2000) in *Federal Government Policy and the "National Interest"* indicates that "the idea of national interest is an artificial construct" (p.267), a policy paradigm for Indian Affairs in Canada. It creates the illusion of "national homogeneity" and that the "government policies are designed to promote those interests" (p.267). "On the contrary, 'Indian Policy', has always been, and is today, a design for sacrificing Indian interests for the general Canadian good", (p.269) that is, the "national interest'. Such was the case with the Indian Act (a policy for government control), the Treaties (a policy for acquiring Indian lands), extending the vote (a policy for undermining Indian Nationhood), education (historically a policy of 'civilization')" (p.269).

A range of beliefs about Indigenous capacity exists, "Indians lack the mechanisms and resources to penetrate the closed political, bureaucratic and corporate doors behind which the national interest gets defined" (Boldt, p.273). This is further maintained "despite political tenancies being too brief, the national policy paradigm, such as the Indian Act, are constantly applied even after the turnover in government occurs" (p.279). Boldt further describes the ultimate goal of government as the elimination of all institutional arrangements that set Indians apart from Canadians. Included with this are the bilateral agreements between provincial and federal governments for education, health, welfare and other services to Indians. For Métis populations, these are often described as trilateral agreements.

Boldt describes structural integration as a two-phase government strategy of which firstly, the “traditional Indian social systems (e.g., traditional forms of self-government, redistribution and sharing, custom and spirituality) were displaced by forcibly imposing Euro-western political, economic, legal, and social structures and norms on communities” (p.280). The second stage involves phasing out the Indian Act and the DIAND and a segregated system of institutional structures for Indians by incorporating Indians into existing provincial and federal systems. Being helped by the migration of Indians to urban centres, the federal government institutes a number of assistance programs to “lure” Indians off reserve, that is, in order to have access to services, Indians must leave the reserve (Boldt, 2000, p.281). We can see the attempts to change terms politically by the name shifting that occurs both in identifying Indigenous groups and the organizations that serve them.

Stated Resistance

Many attempts were required to ensure Aboriginal and Treaty rights were assured in the Canadian Constitution and Charter of Rights and Freedoms. Serving as the foundational stance that all Canadians are embraced with, there are challenges to ensure representation is encouraged, maintained and supported. Marge Friedel (1936 - 2011), a well-known and respected Métis Elder from Alberta states in *Expressions in Canadian Native Studies* (2000):

> Métis women firmly believe that for the constitutional process to reflect a true Métis women’s involvement it must ensure that our voices are heard, that our experiences are understood and that our expectations are given a respectful and responsive hearing. Aboriginal women have been and continue to be discriminated against by the unaccountable male dominated political organizations. (Green, p.330)

With the move to “representative voices,” governments are challenged to ensure that community perspectives are heard and that one organization cannot speak for all.

Numerous discriminatory policies and legislation were created by the Indian Act and related legislation, many which are still in effect today. The *British North America Act, 1867* celebrates its 150-year anniversary in 2017. The British North America Act (BNA), passed by the British parliament, was a declaration to unite all parts of Canada into one self-governing federation. Within the BNA Act, "the federal government was assigned in Section 91:24, the power to legislate for Indians and their property" (Milloy, p.20).

Identities of Indigenous people in Canada have been subject to many definitions, from personal to structural and system levels. Legislation governing Indians has changed from the early 1850's to the present. Distinct issues have been raised with respect to the identity of women. Douglas Saunders (1984) described the debate over sexual discrimination in the Indian Act as the "single most contentious issue in Canadian Indian policy" at that time. (Furi & Wherrett, 2003, p.4). With the introduction of Bill C-31 in 1985, this amendment to the Indian Act attempted to rectify the problematic legislation. Issues continue to arise: "Indian status and band membership raise fundamental social and political questions about what it means to belong to a community and who has the right to determine membership" (Furi & Wherrett, 2003, p.6). The effects are compounded when there are limits to who can claim Indian status under these changed rules. Discrimination continues to exist.

Bill C-3, entitled *Gender Equity in Indian Registration Act*, dealing with discrimination from Bill C-31, adds additional complexity to untangling the consequences of imposed identities by the federal government. (Hurley & Simeone, 2010). In attempting to catch up to the modern rights-based approach, Canada has created more confusion and conflict for Aboriginal people. The design of new policies and legislation appear arbitrary or at the whim of leaders.

Policy is often developed in an environment with a view for change to address a problem or issue. "Public policy is the broad framework of ideas and values within which decisions are taken and action, or inaction, is pursued by governments in relation to some issue or problem” (Smith, 2003, p.5). In contrast, policy perpetuation more adequately captures the lack of real policy reform that could address inequities in health, socioeconomic status, education and justice for Indigenous peoples.

> And there are some bad habits that have been learned because if you don’t have – if you don’t have an anti-oppression policy that means you have a policy of oppression. If you don’t have policy around TB prevention that means you have a policy promoting TB. So, it’s not so much about what is said sometimes it’s about what is not said. It’s about what is missing from that. What isn’t being talked about? (Kecia)

> I think some of the stuff that happens wouldn’t fly; it would actually be called kind of criminal. But because we look able bodied and we’re talking and we appear healthy it’s like oh it doesn’t seem important to address other what seemed to be insignificant health policies like tuberculosis. How are we responding to tuberculosis? Well guess what we’re not. We have no policies. We have no standard. We have no way whatsoever to screen people that we’re in contact with for TB. Culturally given some of our intimacy habits of kissing on the mouth or sharing cigarettes or whatever, it would seem logical to implement tuberculosis testing, education, awareness, make sure you’re healthy before you come around all these immune-compromised people but guess what Nope. I brought it up for one of the national research projects and because I was at a national CAAN event one year and someone had active tuberculosis and I had a puff of a joint with them and fucking freaked me out and it happened again at AIDS Vancouver Island they called and said someone came into the lunchroom with active TB and we’re notifying you and when I brought it up for the family gathering, the response I got was it‘s too hard for people and we don’t want people to feel burdened and boop boop boop the research is much more important than preventing tuberculosis that’s kind of what I heard. Yet there are other organizations that have tuberculosis policies and have for over 15 years and it’s not an issue. Its chest x-rays your doctor signs off and says you’re healthy and ready to go and why aren’t you getting a TB test once per year. Shouldn’t that be part of education and awareness? We’re just not going to talk about it. We’re just going to brush it under the carpet even though it’s one of the mandates – it’s one of our mandates. So even though it’s part of the mandate and even though there is evidence to prove that it’s important there’s no rational there to implement it because none of the paid

> staff has gotten tuberculosis yet. So, I'm kind of hoping somebody gets tuberculosis then it will become a big issue. Then it will happen for us. So, that's an example of a really fucked up that I really don't like being and I don't want to expose myself anymore to shitty policy that compromises my health and safety and that has consistently happened with a lot of organizations. (Kecia)

The Indian Health Policy of 1979 introduced by the Federal government remains. It has existed for an extended period of time without significant change and is still used to direct health policy for First Nations and is not likely to be changed substantively.

> In September 1979, the Honourable David Crombie, then former Minister of Health and Welfare, issued a statement representing 'current Federal Government practice and policy in the field of Indian health.' Crombie declared that the 'Federal Government is committed to joining with Indian representatives in a fundamental review of issues involved in Indian health when Indian representatives have developed their position, and the policy emerging from that review could supercede this policy.` The policy statement was preceded by intense lobbying by Indian bands and organizations to repeal restrictive service guidelines introduced in September 1978, to correct abuses in health delivery, and to deal with the environmental health hazards of mercury and fluoride pollution affecting particular communities. As an indication of good faith the objectionable guidelines were withdrawn, to be replaced by professional medical or dental judgement, or by other fair and comparable Canadian standards. Two commissions were subsequently established: one, under Justice Thomas Berger, to inquire into methods of consultation which would ensure the involvement of Indian people in decisions affecting the provision of health care to them, and a second, under Dr. Gary Goldthorpe, to inquire into alleged abuses in medical care delivery at Alert Bay, British Columbia. (Castellano, 1982, p.114)

It is my belief that the transformation of Indigenous health, education, social, justice and related issues, cannot occur within systems that perpetually frame the deficits of Indigenous peoples. I have observed the maintenance of problematic, deficit-based policies and interventions, guaranteed a funded space despite the lack of utilization focused evaluation or impact assessment. The observation I deliberately make in all policy discussions is, who holds the power or keeps the gate?

PROCESS

Factors that influence how we address specific health issues are often framed in statistical language that identifies priority areas. This is a complex and debatable area within Indigenous HIV. I will review several sources and perspectives of HIV program information available in Canada. Connecting this to the people and policy sections is critical to ensure that Indigenous voice and experience are brought to the forefront.

I am framing the themes of the life stories within this section as a four-stage process. I have plotted this on a teaching circle, similar to some quadrants of a medicine wheel. The teaching circle provides placement for the four thematic areas of this life story research process.

It is my intention to demonstrate that we each take a place within the circle, a basis of this model. It speaks to our connectedness and to our individual realities. I will utilize portions of the life story of Ken and Kecia, enhanced with examples from the literature reviewed, personal observations, organizations and community experiences.

Language of an Epidemic

At the outset of this research, one of the concerns with respect to HIV and Indigenous peoples was the Saskatchewan HIV epidemic. “Analysis of disease incidence by person, place, and time is used to determine if an epidemic is occurring” (Aschengrau & Seage, 2014). In Saskatchewan concerns were raised over the number of Indigenous people diagnosed with HIV compared to other populations and varied responses were implemented.

The most recent information from the Public Health Agency of Canada is that "the average annual rates of reported HIV cases per 100,000, (2011 to 2015), are Saskatchewan (14.3); Alberta (6.2); British Columbia (5.6); Manitoba (7.2); with the average Canadian rate (6.0)" (PHAC, 2017). For the same period, reported HIV cases by Indigenous Peoples groups include the following: First Nations (74.7%); Métis (8.4%); Inuit (0.1%); and unspecified (16.8%). The PHAC shared an information slide that indicated 1 in 2 HIV infections among Indigenous people was attributed to injection drug use (PHAC, 2017).

With respect to HIV and Aboriginal people, the Public Health Agency of Canada (PHAC) repetitiously states that "Aboriginal people also continue to be over-represented in the HIV epidemic in Canada." (PHAC, 2012, 2014, p.2). The basis for this statement from both the *Summary: Estimates of HIV prevalence and Incidence in Canada, 2011* and the subsequent 2014 document, compare census information with new infection rates by Aboriginal and non-Aboriginal populations.

For the 2006 Census comparison, Aboriginal peoples comprised 3.8% of the total Canadian population. The new infection rate (incidence) was calculated at 12.2% also stated as, "the overall new infection rate for Aboriginal peoples is 3.5 times higher than among the non-Aboriginal population in 2011." (PHAC, 2012, p.2). For the 2011 Census comparison, Aboriginal peoples comprised 4.3% of the total Canadian population. The new infection rate (incidence) was calculated at 10.8% also stated as, "the overall new infection rate for Aboriginal peoples is 2.7 times higher than among the non-Aboriginal population in 2014." (PHAC, 2015, p.2).

It is a necessary to consider the positioning of numbers and identities in classifying the status of an epidemic. Data has several weak spots in the translation to programs and services. As we bring the population focus to Aboriginal people, the issue of criminal justice system involvement is significant.

Numbers and Positions

The Canadian census of 2006 provides the following demographic information: “There were 1,172,790 people who identified as an Aboriginal person – that is, North American Indian (First Nations people), Métis and Inuit. Within the Aboriginal population, 60% were First Nations people, 33% were Métis, 4% were Inuit and 3% were of multiple or other Aboriginal identities.” Within the article *Health at a Glance,* it is stated that “monitoring the health of Aboriginal groups, however, is limited by a lack of data” (Gionet & Roshanafshar, 2013).

The Population Specific Report HIV/AIDS Status Report - Aboriginal Peoples (2010) is the source utilized as it contains the most current published data specific to the Aboriginal population that ensured Aboriginal input was included.

> Aboriginal peoples made up about 3.8% of the total Canadian population in 2006. This includes nearly 60% of Aboriginal people who self-identified on the census as First Nations, 33% as Métis and 4% as Inuit. The Aboriginal population is growing more quickly than the non-Aboriginal population; it grew by 45% between 1996 and 2006, almost six times faster than the non-Aboriginal population. The Aboriginal population is also younger than the non-Aboriginal population. The median age of the non-Aboriginal population is 40 years, compared to 27 years for the Aboriginal population. Various health measures (e.g., life expectancy, rates of chronic and infectious diseases) indicate that the health status of Aboriginal peoples is generally poorer than the non-Aboriginal population. (Public Health Agency of Canada, 2010)

Surveillance data presented indicates that Aboriginal populations are overrepresented in HIV and AIDS statistics in Canada. The main route of HIV infection among Aboriginal people is injection drug use:

> Injection drug use accounts for more HIV infections and AIDS cases among Aboriginal women than Aboriginal men. Between 1998 and the end of 2006, injection drug use was the exposure category for 53.7% of HIV-positive test reports among Aboriginal men and 64.4% of HIV positive test reports among Aboriginal women. (Public Health Agency of Canada, 2010, p.24)

Compared to the non-Aboriginal population, Aboriginal women and youth are particularly affected by HIV/AIDS. Data completeness presents a challenge for Aboriginal populations because of limitations in data collection and reporting across provinces and territories. In addition, Aboriginal people may face additional challenges in accessing HIV testing, including fear of test results, feelings of shame, fear of racial discrimination from health care providers, and lack of pre- and post-test counselling, as well as broader systemic barriers, including lack of trust in health care professionals and other service providers (Public Health Agency of Canada, 2010).

The common terminology used to describe HIV infections among Aboriginal peoples is “disproportionately over-represented” based on a comparison of population proportions. The Public Health Agency of Canada states, “the number of people living with HIV (including AIDS) continues to rise, from an estimated 64,000 in 2008 to 71,300 in 2011” and “an estimated 6,380 (5,160 to 7,600) Aboriginal people were living with HIV (including AIDS) in Canada at the end of 2011.” At the outset, Aboriginal peoples as an ethnicity, are the only group distinctly defined and described in many documents.

The epidemiological discourse lies in explaining why my community, diverse as Indigenous/Aboriginal, is a population most vulnerable to HIV. My key frustration has been with the simplicity of statements which do not adequately describe how we can be labeled so slightly and be expected to deal with “disproportionate overrepresentation” HIV infections. There is a need to provide the epidemiological frame within specific contexts. Given that community level understanding about “rates” is varied, placing the data into terms of relevance for individuals, communities, organizations and government is critical. Clearly communicated information that incorporates and explains distinct epidemiological terms and the potential implications for people and programs would assist in generating meaningful responses. Hysteria and fear-mongering occur in the absence of understanding and critical thinking opportunities. There are more frames of reference to consider in describing “Indigenous” over and under representation.

The PHAC (2010) report confirms that HIV/AIDS within the Aboriginal population is closely linked to a variety of factors and determinants of health, which influence the population’s vulnerability to HIV/AIDS. Research described in this report indicates that Aboriginal people experience higher rates of poverty, violence, harmful substance use, homelessness and incarceration. I would add traumatic childhood events, based on the life stories presented, are all factors which place the population at increased risk of exposure to HIV infection. The PHAC report also emphasizes the ongoing impacts of racism and the multi-generational legacy of residential schools as key factors that impact on the vulnerability of Aboriginal people to HIV infection (PHAC, 2010).

Raphael (2009) describes Aboriginal status as an unexplored social determinant of health that “represents the interactions of culture, public policy, and the mechanisms by which systemic exclusion from participation in Canadian life profoundly affects health” (p.7). This stance represents a view by some practitioners and sadly community leaders, which fails to consider that Aboriginal status is not the key issue; it is the practices, life choices and situational vulnerabilities that affect health.

Barriers to accessing appropriate culturally sensitive health services and information remain an issue for this population. Racism, stigma and discrimination continue to affect the quality of life and health outcomes of Aboriginal people living with, and vulnerable to, HIV/AIDS. In addition, HIV/AIDS-related stigma and discrimination, including homophobia within Aboriginal communities can reduce access to health care, including HIV testing, care and treatment, and reduce social and family support for Aboriginal Persons living with HIV/AIDS (Public Health Agency of Canada, 2010).

Of significant relevance is Aboriginal youth where “almost half (48%) of the

Aboriginal population is made up of children and youth aged 24 and under" (Public Health Agency of Canada, 2010, p.6). This demographic raises attention as the need for accessible youth designed services to address HIV and related health issues is lacking. In addition, "between 1998 and 2006, Aboriginal females made up nearly half (48.1%) of all new positive HIV test reports among Aboriginal people, whereas only 20.7% of positive HIV test reports were reported among non-Aboriginal females for the same period" (Public Health Agency of Canada, 2010, p.21) critically highlighting the need to consider tactics that appropriately reach and serve women, youth and children.

Within the Population Specific Status Report, it was highlighted that of critical importance are the culturally relevant approaches to HIV/AIDS prevention, care, treatment and support for Aboriginal populations. Evidence identifies cultural reconnection as an important source of strength and resilience for APHAs, and as an important aspect of successfully preventing HIV infection (Public Health Agency of Canada, 2010, p.91). Statements such as "cultural reconnection" strike me as "catch all" phraseology, where everyone says it, but have no idea what it means to implement.

In a recent project submission, I used cultural prevention knowledge to describe activities that we would undertake. Very quickly I was asked to describe "this cultural prevention knowledge that you speak of," to which my unstated response is, "wouldn't you like to know?" There comes a time for cultural resistance, autonomy and skill in defining program elements without giving away the sacredness of the intentions.

Cultural reconnection will be different for each person. For me it is the ability to learn about and embrace your self-defined meaning of culture. Where I stand and how I behave in varied contexts come from the teachings that I have received. When considering the behaviours that contribute to increased exposures to STBBI, it is important to determine the source of these behaviours, learned, required or imposed. The intervention of cultural reconnection may be as simple as modelling the use of protocol when seeking the advice of an Elder or preparing for ceremony at an individual level. Within systems it may be the adoption of inclusion or community critique of practices that offer responsive and relevant cultural connection to people or place.

For Indigenous people to truly participate in initiatives that are relevant, understanding how colonial practice still plays out is critical. A critique of approaches is necessary by people who recognize the overt and subtle agendas of colonial discourse.

An example of the conflict between approaches is exemplified by the reproductive and sexual health agenda often imposed by dominant system service providers and sadly by some of our own community workers. I have observed mainstream providers point out the problem of Aboriginal teenage pregnancy without understanding the cultural beliefs that underlie this phenomenon. The ability to give life to life, as a woman of childbearing age can do, is considered a gift. Dominant campaigns have focused on the “just say no” to sex, drugs or other maladies. This approach has been adopted by some Aboriginal specific programs. It is my opinion that the adoption of this approach has been detrimental to Indigenous knowledge and further stigmatizes young Indigenous woman. There are cultural teachings being brought forward that are strength and support based approaches to pregnancy.

The *Federal Initiative to Address HIV/AIDS in Canada* identifies Aboriginal people as one of eight key populations at risk of, or disproportionately affected by, HIV/AIDS (Canada, & Public Health Agency of Canada, 2004). There are several government references made to the vulnerable circumstances that Aboriginal people are found in (Public Health Agency of Canada, 2010, p.76). While these are general strategic documents for use by all HIV stakeholders, it is problematic in that the discourse is created and endorsed by government, making it acceptable to reference this material. Statistics display the over-representation of Aboriginal people and HIV infections; yet frontline workers are left to create interventions with little practical understanding of the complexity of issues.

Current approaches to creating integrated Sexually Transmitted Blood Borne Infections (STBBI) strategies and action plans, provincially and federally, perpetuate the vulnerable, disproportionately over-represented discourse aimed at Indigenous peoples.

I have stated publicly that this is not a well thought through frame of reference for our community. Positioning information in this manner maintains the status quo of “us” and “them” which emphasizes a difference not truly a willingness to understand. The lack of understanding supports the belief that Indigenous peoples are difficult or hard to reach, on the margin somewhere and less likely to attain health or adopt health seeking behaviours. In contrast, as an Indigenous practitioner, I easily engage with people from our diverse communities. The question I ask to mainstream stakeholders is, “how have you attempted to engage Indigenous people?”.

Stigma and Discrimination

Obvious on the colonial canvas we maintain is the forward statement of *Empathy, dignity and respect: “*Many Aboriginal people don’t trust – and therefore don’t use - mainstream health care services because they don’t feel safe from stereotyping and racism” (Health Council of Canada, 2012).

It has been my experience that many dominant or mainstream or white privileged initiatives speak down to Aboriginal people maintaining the negative portrayals including lack of education or inability to understand basic facts about HIV as the reason that HIV infection rates continue to increase. Overuse of the descriptor “disproportionately over-represented” in all social pathologies continues with little critique as to the deeper meaning. At the core of stigma and discrimination is the concept of being “marked.”

We are in a time where this action is under increased scrutiny which may impact the pace of HIV prevention, care, treatment and support efforts. If there are no places for us to discuss and debate wise practices or culturally informed interventions, it is no wonder that the deficit-based, hard-to-reach and at-risk discourse is maintained. We do not publicly describe ourselves as such and it may be time to find different descriptors which acknowledge historical trauma and ongoing oppression. This leads to another difficult conversation related to stigma and discrimination.

Vulnerability

The frame of vulnerability is not explicit or bound by any agreed to definition. This level of ambiguity is dangerous and often met with disdain by the "named" vulnerable and alternately an obvious discomfort upon questioning those who are "naming." I have asked professionals to describe what they mean when they say vulnerable populations. Being considered vulnerable implies a level of helplessness and the okay to "save" a population. The term is loaded with sensitivity. Indigenous groups and/or communities continue to elevate "talk back" or resistance to identifiers that may be deficit based rather than strengths based. In most human service disciplines, there is a practice of naming individuals as disadvantaged, marginalized, vulnerable, at risk or high risk, which is somehow supposed to assist in the design of programs, policies and services.

There is a deeper historical narrative that is necessary to reveal to provide context for the vulnerability frame. While this narrative may be contentious, it speaks to the current sentiment of many Indigenous / Aboriginal peoples who having reflected on historical wrongdoings are seeking recourse through intentional deliberation. What follows is a brief history of issues relevant to the framing of current HIV and justice system challenges.

When an individual is dependent on another person, such as a child to a parent or as in the case of many Indigenous people, dependency on the state, vulnerability exists. When the state changes its policy, the effect is ultimately felt by populations and individuals. An example of this is in the collection and interpretation of identity data. The collection of ethnicity data can be problematic given the range of identifiers Indigenous Peoples have.

Relating the issue of vulnerability to HIV, the issue of identity returns particularly as it relates to the discourse of "meaningful engagement" or participation as promoted by federal and provincial levels of government, further evidenced by the ambiguous construct of the "duty to consult" with Aboriginal people on matters that will have a direct impact on quality of life. The question of who is consulted and which perspective is heard again is influenced by identity.

The lens of vulnerability is often from the outside looking into Aboriginal communities. Reversing this view and resisting this depiction will benefit communities. I recently stated in a large meeting that if people use terms like “vulnerability” or “at risk,” I would question them. One of the meeting participants asked to speak with me after and asked what I meant by this. I explained that the context or situation is important. I asked if they traded places with a person living on the street or an active injection drug user, would they be vulnerable? Who would handle the situation better? Vulnerability is context and temporal specific. It is not a static condition and should not be treated as such in policy and practice.

It is realistic to imagine improved health outcomes for Indigenous people. What is required is vision and application of appropriate policy and resources to achieve this state. At a basic level, good food and clean drinking water is needed. At a chaos level, saving lives from suicide or overdose, requires immediate attention. In the middle of the spectrum, the STBBI pendulum swings back and forth with varying speed, with the momentum affected by media or community champions, sporadic at best.

Decolonization Really Calls to Action

I want to focus attention not on the colonial state apparatus that still affects numerous aspects of Aboriginal life, but rather on the challenges of decolonizing systems and approaches that have been deemed beneficial to Indigenous people. Decolonizing methodologies or strategies have become the “in” approach. When considering current theoretical and political perspectives demonstrated by Indigenous peoples, self-governance, economic development, healing and environmental protection are a few central themes for change.

Matsunaga (2016) unravels the transitional justice framework, an instrument of which is the truth and reconciliation commission (TRC). The TRC process in Canada serves a purpose both internally to Canada and Indigenous peoples and externally to the world. There is a caution provided and that is not to confuse decolonization with reconciliation. With what is described as the “presently unfolding social and political dynamics where survivors and their experiences must be handled and addressed with respect,” it is suggested that attention be given to their uses (Matsunaga, p.31).

So perhaps at first glance, the TRC Calls to Action may serve a purpose, that is, reconciliation. A closer, in-depth critique, of the concepts of decolonization and reconciliation reveal that at a basic level these two concepts do not serve the same purpose. Reconciliation is about action and used in accounting terms to balance the books. To reconcile implies that there can be balance. Decolonization on the other hand, I believe at the core, is returning the land or making spaces for original peoples.

Of vital importance, a view of current policies all framing approaches and funding models stem from “calls to action.” If “people/institutions” fail to critique the policy implications of these constructs of reconciliatory discourses, the foundational issue of “land is life” is not addressed: “It muffles those Indigenous land-centred and resurgent voices that express anger or rage at colonial rule – past and present – by reducing these expressions to the effects of the residential schools’ legacy” (Matsunaga, p.26).

Similarly, the appropriation of Indigenous knowledge because it sounds good or seems like the right thing to do serves a limited purpose. On the surface, it may appear “culturally appropriate”, but without the depth of teachings, the full essence is lost. Speaking directly into the HIV movement, attempts have been made to bring culture as prevention to the centre of our work. The challenge is that assessing the effectiveness of these interventions is loaded with ambiguity and interpretation. As I outlined earlier, methods and intentions of sharing information or cultural teachings are sensitive and require protocols that may not be written.

Criminalization

Often in social, health and justice disciplines, the terms “over-represented” and “disproportionate” are used to set up rationale for action. Much weight is given to these two words that rarely critique its full context and meaning. The elements of HIV non-disclosure and incarceration rates are compounding data that will highlight the potential problematic implications the criminalization of HIV may have for Aboriginal / Indigenous peoples in Canada.

While HIV has only established itself as a known blood-borne pathogen over the last 30 years, it has taken a firm hold in Aboriginal peoples. The ongoing jurisdictional challenges between levels of government and service providers attempting to address disparities of First Nations, Métis and Inuit peoples will not be solved quickly. HIV infection rates and incarceration rates of Aboriginal peoples will be compared.

There are some considerations that are raised which merit mention. Several sources are outlined that point to the problem of Aboriginal incarceration. It is noted that the problem is not equally distributed through Canada, and that it is primarily restricted to the Prairie Provinces. There is insufficient data to identify the main causes of over-incarceration but mention of factors such as poverty or low income, lack or irrelevance of education, unemployment, youth population, alcohol and substance abuse, loneliness, community fragmentation and other socially disadvantaged backgrounds are key contributors to the problem. What is noted as significant is that “Aboriginal offenders commit more offences against the person, which are generally considered the more serious category of offences, and have longer prior records” (Stenning & Roberts, 2001, p.150).

LaPrairie (1990) points out that for two decades the starting point for discussing Aboriginal people and the justice system looks to “over-representation.” She explains that percentages are used for the number of Aboriginal people in correctional facilities in Canada compared to their proportion of the general population of Canada. This is a similar method used in describing new HIV infections among Aboriginal peoples discussed earlier. Differential treatment by the criminal justice system, differential commission of crime and differential offence patterns are three explanations that may overlap as to why there is the “disproportionate” representation of Aboriginal people in corrections. The context is further examined by considering how the discourse plays into two different agendas, one being the need for a parallel Aboriginal system and the second is to turn the focus towards the systems instead of looking at societal disparities between populations.

In response to and as a supplement to the arguments within the Stenning and Roberts article (2001), two "mis-recognitions" are provided by Cairns (2002). The first mis-recognition has to do with the absence of political, cultural, intellectual and constitutional systems from the analysis. What is suggested is that the distinct attention to Aboriginal within federal legislation emerged within a "culturally conducive, intellectual climate." (Cairns, p.55). Mention of the defeated *White Paper, 1969*, illustrates how an overt assimilation policy shifted to the inclusion of "existing aboriginal and treaty rights of the aboriginal people of Canada" within the 1982 *Constitution Act*, and s. 25 of the *Canadian Charter of Rights and Freedoms*, which protected Aboriginal, treaty or other rights or freedoms of Aboriginal peoples from abrogation or derogation by the *Charter*. (2002, p.56). He asserts that this context provides the rationale of distinction in sentencing that is not the same as, perhaps, with Black Canadians. Recognition that the *Criminal Code* is federally enacted is mentioned and leads into the second mis-recognition that issues are Pan-Canadian.

The question that is raised speaks to a specific placement of the statement regarding over-representation. The *Criminal Code* is applied across Canada but the over-representation issue is relegated primarily to the three Prairie Provinces. This negates the language of a pan-Canadian approach that is often used. In addition, it takes away from focusing issues where they need to be. Conversely, the over-representation of Aboriginal people is not shared equally across Canada and requires interpretation and analysis that reflect the unique characteristics of location and community. Urban and rural differentiations have not been considered extensively.

Using the contextual factors presented, I believe there have been no standard legal or policy solutions attempted within the criminalization of HIV for Aboriginal people.

The approach to addressing this concern is fragmented. The definitions of Aboriginal peoples and the level of government responsibility are unclear. While health is considered a provincial jurisdiction, the fiduciary relationship between the Crown and Treaty or First Nation and Inuit people exists. The relationship between the Crown and Métis peoples is not as fixed. Similarly, with policies that address health or education, the debate over jurisdiction, priority initiatives and "excellence" are debatable.

Four Thematic Areas

Using the teaching circle or medicine wheel approach, the named themes provide some logical sequence to the complex information being presented. The thematic areas are Stay Alive, Survive, Strive and Thrive. These themes shape the lives of many Indigenous and non-Indigenous people alike and were derived in part with conversations I have had with my family to establish a frame for living in this time.

Stay Alive

This theme transcends time and the experience of Indigenous peoples. As outlined earlier in this thesis, IP were devastated by virgin soil epidemics, the result of no immunity to new pathogens. As colonial policy took hold, the confinement of IP on reserves, coupled with a depleted food source, the buffalo, IP were starving. Staying alive meant surrendering the land and giving in to the dominion "charity." Various descriptions of the culture of violence existed including "a well-known oblate, father Lacombe who was known for coercive conversion including confinement, food deprivation and corporal punishment" (Milloy, 1999, p.46).

Ken and Kecia bring their personal context to the theme of staying alive. It manifests in diagnosis of HIV, trauma and intimate knowledge about the future life of HIV.

> *I thought about death because that's what the doctor had said I had 6 months to 10 years to live.* (Ken)

When I was first diagnosed there was talk about let's put them on an island let's mark them so we all know who has it wanting to take away our privacy and our human rights and expose us without looking at the other side of the coin. (Kecia)

The federal government has made this such a low priority that it sickens me to look at the statistics today of HIV in Canada and I say this because all through 90's before antiretroviral before the triple therapy combination before all of that epidemiologist HIV positive people frontline workers government were all sitting at the table together trying to look down the tunnel look down the rabbit hole and try and predict what this was going to look like in the first nations community and everybody agreed for over 13 years that when this reached our community it was going to be the next epidemic. It was going to be the next smallpox. It was going to be the next diabetes. It was going to be the next Spanish flu and what are we seeing today – we see these high rates of HIV infection among a wide range of Canadians but unfortunately our people have gotten it just like it was predicted. Now that's documented. Those are documents. Those happened. Those were not "we're sitting around a campfire telling stories we're not sitting and trying to look in a glass ball" there were educated people who went to school to study epidemiology that were going "what are we going to do when it gets here?". Not if, but when. And we're just trying to stay alive in the early nineties. They're telling us oh you're going to die there were people dying left right and centre literally dying in their wheelchairs trying to give their last fucking presentation because they know the urgency they know the damage that this was going to do. We saw it early. We tried and tried and I thought when I found out that this happening to me it's going to happen to back to somebody else back home because everybody comes to the city everybody partied. (Kecia)

I did pass out and I woke up in skid row in Edmonton and it was at the Travelodge and that's when I passed out and that's when I woke up and that guy there was three of them and one guy sitting behind beside me with me inside and I woke up totally naked and the guy forced himself on me and uh you know he threatened to kill me if I said anything. He raped me which seemed like for hours and when he finished he went to another bed or whatever and I waited and I waited and I remember him lying there and I was standing over him and I was angry and but I was mostly afraid because I was just kinda I was mostly traumatized. (Ken)

> *My one trip to Vancouver when HIV started hitting the streets there it was really incredible because people were just nodding off or dying on the bar table just literally and we didn't know what it was back there we heard about it but we thought it was just the party city that doesn't sleep but then all of a sudden when that came to the streets and came into the clubs and stuff like that it was really profound*. (Ken).

> Even the drugs kids use today are so different from what I grew up with and the consequences are so much more dangerous and how do you explain that to your children how do you grasp the potential for them to be sucked into that lifestyle. And I've seen other kids fall into that lifestyle and yk and end up with HIV at 20 years old at 23. It's like man are you ready for the ride kid? 'Cause it's one helluva ride. And most people aren't like me. They're not out there. They didn't plaster themselves on television oh I have HIV and I'm going to travel around and talk to people and I'm I don't even know why I'm alive still. (Kecia)

> *Living at Kairos House certainly ignited a lot about my own mortality yet I remember you Denise coming and you talked about it you said I remember your words to this day you said, "You better leave here because you're dying with them." And that triggered I was starting to succumb to that I er really wanted to surrender here I got to get out of here*. (Ken)

> I know one guy who has pancreatitis 5 times and they don't follow the protocol. They don't take him off his meds, they don't put him on bedrest, and they don't put him on liquid diet. They don't do any of that. They let him eat. They give him his medications. They put him on prednisone or those steroids. And I finally had to tell them do you know that if you get pancreatitis you can die and of course they never told him how serious it was and they fed him. I sat in the hospital and I had to tell them you don't realize how serious this is and they just kind of minimize it and glosses it over like oh well you know that doctor. (Kecia)

Talking back or resistance, was historically met with unquestioned sanctioned consequences. Historical records describe the public hanging of dissidents including Louis Riel. Today, Indigenous community members focus on several issues: Missing and Murdered Indigenous Women (Girls, Boys, Two-Spirit, People); the fentanyl crisis; child welfare; and systems of justice. Staying alive is a mantra I share with my family and friends, that is, be aware of your surroundings and circumstances, as the odds you will be harmed are great.

Survive

Many childhood experiences described by Ken and Kecia, speak about carrying on despite numerous challenges. The exposures to trauma in childhood, youth and adulthood, impacts each of us differently. The manner in which we deal with pain, hurt, shame, rejection or abuse is the critical factor in survival. For many people, using substances to escape “reality” is common. Given that this research was not focused on dealing with intergenerational trauma directly, I mention it to acknowledge its pervasive existence and manifestation in our community.

> I was born to a native mother and a native father full blood and I was born without status because my mother married her first husband who happened to be non-native and she was automatically stripped of her rights as a native woman and she couldn’t live on the reserve and my father who was native was unable to somehow benefit me and give me status so I had to fight to be reinstated to be get permission from the federal government when I was aging out of the ministry for children and family services at the age of 18. (Kecia)

> *I was in this void and my ass hurt and my pride right but I dug in his wallet and took whatever money he had and I just ended up from downtown and I don’t remember walking aimlessly just on the South Side where that Whyte avenue and where that bridge connects trying to understand what happened um …… (PAUSE……………………………….) that was the biggest biggest hurt and trying to understand that as a kid was really traumatic for me but I knew I had to I had to go home or something so I phoned social services or some agency to come to a pay phone, I don’t know how I dialed it but I was put on the bus the greyhound and I got back to St. Paul. I got shit from my parents but carried that and I didn’t want to tell anybody in St. Paul and started rebelling more and more and I thought about suicide and I tried suicide so many times in that time when I was 13, 14, 15 and I started acting out a lot more*. (Ken)

I have forty-five years that I've spent on this earth and I am a mother too I've been HIV positive for 27 years and from the time that I was born to now I have been a part of a variety of systems and situations and places in my life where I recognize my own colonization and my own struggles to somehow manoeuver these places that I was never taught about. (Kecia)

I tell this to people why I became an alcoholic and drug addict at 13 and suicidal. It was just before just around when I was 16 my foster parents couldn't handle me so I was put in a home the La Roques where they had a receiving home for kids in crisis or something and they were just going to hold me there to figure out what to do cause I had this charge on me so it was in that place that I was in the basement I had the room down there and I found solvents, and bleach and shit like that comet and I remember mixing a cocktail and started drinking it and I was caught and brought to St. Theresa hospital where they pumped my stomach and I remember my brother Marvin coming to see me and I thought I would kind of get some kind of comfort but I remember his words you're fucking nuts you're crazy.

You know that didn't help and once I started getting better I had to go to court and Judge Marshall Hopkins Sr. was there and he looked at my juvenile rap sheet and stuff like that and at that time Gordon S. who was the executive director and I can't remember my social worker's name but he looked at the social worker and gave him shit (laughs) don't you see this kid's got a lot of emotional problems and looking at the reports from the RCMP he's got a lot of mental issues here so that's when they sent me to Alberta hospital for a month for a psych assessment and I faked it at the Alberta Hospital I think that's when one flew over the cuckoo's nest came out …. But ah that's once I was done they said that's where they placed me in a foster home and when they said that in the court I just kind of ya I'm outta here I'm free I'm free from all that, that's what I thought right so after Alberta Hospital I was put into Acadia house for about a year. (Ken)

I was very open in my video. I did a video that was distributed to Canada throughout Canada about my story and in my story, I talk about… a guy didn't want to use a condom and was going to give me that extra money after being positive you might consider that I just didn't care. (Kecia)

I have 101 excuses why I should still contain but it's not an addict or somebody like that especially when you're trying to fight for sobriety and being clean and you are dealing with so many crises at so many times can be overwhelming and you do it the softer way trying to commit suicide by popping pills or drink yourself to death. (Ken)

I go back to waking up in pain where I can't walk I wake up to not enough morphine or I need something else to help with the breakthrough pain where the quality my life is not important it seems and I have to be the one to appeal to the government I have to have the right wording I have to have the right doctor who is willing to work with me to write the letter. (Kecia)

I believe from me being able to survive those first five years was really crucial to really find my sense of purpose in my role in this movement. (Ken)

So when I started losing my friends to AIDS and you know and you really lose you lose and what's left is grief you know I've never dealt with the grief cause it hasn't stopped people are still dying were still losing I'm still losing my friends I'm still losing people to this and I just sit and I think sometimes all that travelling and all that time we spent and look what's happened look what's happened to our people yk they just don't get it and there's so much yk to say about that the leadership that's failed us because they've refused to barely even pass any type of resolutions as leaders to halt this. (Kecia)

I think the other part is of even surviving this long it has I can't go I'm dying with this sickness, I'm dying from a broken heart probably but you know I think speaking in these workshops and conference I do regret I didn't realize I was going to live this long and I kinda wish maybe I would perhaps have kids maybe one or two they would have been grown by now I rely on is my extended family like yourself, my nieces, my nephews, my godchildren to see them grow is a blessing so I can't discount that sometime I feel like a wounded healer or warriors for us old timers because we had to endure so much and I had to endure so much of so many people who have passing on in the movement, if not beyond contributing to Silver Sage or Kimamow, in our journeys it is that learning to deal with unresolved grief or survivors grief is a big thing. (Ken)

When I moved to Victoria I couldn't find a dentist for years so my teeth went to crap which made me sick and there's all kind of scientific data out there that says especially for people living with HIV that oral health care is directly care is directly tied to heart disease and the type of infections that you get from bacteria in your mouth can kill you but for some reason the college of dentists don't seem to think that that's something they need to honour and in my mind that doesn't make any sense because when you go to medical school your ethical duty is to do no harm do something but don't do harm

> and these policies are just papers of harm these delisting saying you know you can only have so many Tylenol 3's because you Indians use too much or you can't have because you Indians use to mush we are always scrutinized over everything we do and often that is played out not only at the federal government level it is played out in the medical system where 9 times out of 10 if you end up in an emergency person in Canada and you're recognized as an aboriginal person it's automatically assumed that you are drinking or that you're a drunk you're automatically assumed that you're pregnant you're automatically assumed that you're drug seeking and that you're not intelligent and I've experienced this so many times that I expect it. (Kecia)
>
> *So around 18 and like that I was no longer a ward of the government so not knowing where I fit in I just ended up on the streets of Edmonton trying to find my own identity and that whole thing about being raped was a real mindbender for me because I didn't know whether I was Gay or bisexual or straight but I tried to fit in with different pockets and of walks of life if it wasn't people on the street it was the gay community if it wasn't bikers or rounders you know I just wanted to find out where I fit in it was until I was 21 I realized it was getting really intense I started getting lost within myself I started using. My drug of choice was mescaline and cocaine I would always mix that or T's and R's*. (Ken)
>
> Lots of safety especially with women, predatory behaviours I'm just going to say rape. I know that rape has happened; I know that women have been abused, I know people have done self-harm to themselves, I know the drug use that happens at these conferences, I know all of the horrible ways people have to cope and live unfortunately. Because there aren't safe places for people to go, they will go where they can. (Kecia)

Assumptions about identity have had implications for the validity of "voice." In the HIV movement, we have had decades of non-Indigenous people speaking on our behalf. This is, in part due to the "research" or "work experience" they possess through us. No one questions the problematic privilege or the absence of an Indigenous response. It is not lived Indigenous experience that speaks; it is perhaps with good intention, contrived.

Strive

With the historical process thus outlined, it is “safe” to say that IP are predisposed or inclined to believe that systems created through policy have not been beneficial to the life and health of a population. I use population in this context to describe and be inclusive of First Nations, Métis, Inuit, non-status, Aboriginal and Indigenous peoples, inclusive for the purpose of speaking in specified generalities. I leave the distinctions between populations for the politicians and bureaucrats to debate.

Despite ongoing colonial challenges about land, resources, jurisdictions and priority issues there is a progressive form of action taking place. In 1990, I copied a definition on a flash card and it continues to guide my work. The definition by Rubin and Rubin (1986) reads, “Community development involves local empowerment through organized groups of people acting collectively to control decisions, projects, programs and policies that affect them as a community” (p.6). Development, engagement, participatory action, consultation and relational accountability are descriptors that speak to inclusionary practices. Relational accountability is described in *Research is Ceremony* (Wilson, 2008).

Survivors of the IRS have moved past testimonials and compensation packages, beyond barriers and deficits, to the place of working towards meaningful participation and improved life situations. There are still inequities, but they are gradually being overcome.

Moving beyond pain and suffering is achievable with connection and supports. Progress may be delayed by policy timing and individual life circumstances. Striving is constantly seeking to achieve better outcomes in all areas determining health including education, socioeconomic status, income, culture, as examples.

> *I managed to go to school and that’s where I went to Vic Comp 126 that was one of my biggest plusses Vic Cop performing arts theatre and I did my 2 years but I still was a ward of the government but even though I still had some emotional problems it was getting a little more bit more severe at*

Acadia House so this other group home it was called Project 72 Ironically it was run by Catholic Social Services ironically that's where Kairos House was and today is and Project 72 is for hard at risk kids to do intensive group therapy and stuff like that but in a sense it was kind of helpful for me because I was learning a little more about myself even though intense self-evaluation and evaluation of others awareness of self and others and all these personal things about learning to develop who you are as a person but I felt really safe and clutched on to them and that's why I knew I had to speak out be very frank about why and how I got you know I started using. (Ken)

So I went trying to get my mental health medication refilled that the doctor from Oak Tree had prescribed me only to find out that the doctor wouldn't prescribe it and I was suddenly discontinued for my clonazepam and I went through three days of some pretty fucked up shit. I was losing my mind and I went to the hospital trying to get help and nobody would help me nobody. (Kecia)

You know I did do some personal accomplishments I think writing the book of poetry was from Lena your mom was a big inspiration from her to me that I do have something to offer and that book came out 1997/1998 the same time as the documentary came out with 'the long walk' but I took her advice and I'm proud to say at least I've got one like Chief Dan George did and that was a trip and uh… Being on council for a short stint but still to be acknowledged in this community despite my diagnosis that was breaking a barrier. (Ken)

Then I got sick with this stomach bacterium called h. pylori and it's really common among native people. I didn't know this but it's very common apparently and I had bacterial overgrowth so I stopped eating I lost a bunch of weight like 50 pounds. I literally wasted away to nothing. I was getting no intervention whatsoever from them. And when I started phoning and freaking out because I was scared they really treated me like I was out to get them. They treated me like I was abusing them. And I was just crying out for help. I went down a really dark path after that. Because nobody would help me. I lost a few pounds I couldn't eat I was I had an aversion to food. When I did eat I was like in excruciating pain and it just got worse and when I'd phone and try and get help they wouldn't investigate. At one point I was admitted to St. Paul's hospital they were going to have me see a gastroenterologist, a pain doctor, a neurologist and get a whole bunch of tests run and one of the doctors from Oak Tree (4256) that didn't like me

> and I didn't like her she didn't enter in any of the proper paper work so I was stuck there for 5 days and all they did was test me for hepatitis c they never did anything for me. And it was because of that one doctor. She didn't like me so they'd send these different people in and they basically told me I was depressed. And then they sent me home. So I went for a long time without any pain medication I went for a long time without being sick and I lost my mind. I ended up getting metadol from my friend who knew how much pain I was in and he gave me it's basically methadone for pain and it was the only thing that worked when I got pain medication I was able to walk I could go outside I was with my family I was able to do stuff and unfortunately my friend couldn't continue giving me his pills cause he would of got in a lot of trouble if he had got caught so he took a huge risk to help me but it got me dependent I became dependent on the methadone and when I realized that I was dependent I was getting sick because I didn't have an metadol. So I had to go to the streets and ask people that I knew if they knew where to find opiates I wanted methadone ideally but I would have settled for morphine would have been my second choice but instead I had to buy ……. I had to buy heroin. I had to buy heroin a few times and I remember the first time having to go look for it, it was early out early in the morning cause they only have a certain time that they're out selling their opiates and stuff it's like 7 in the morning and you go downtown to our place and I don't know anybody and I hadn't bought anything on the streets in Victoria and I'm freaking out and I got to buy fucking heroin and I just feel like like a fucking junkie but I just remember the relief the relief I had after I got it into me I could walk again I didn't feel like I was sick my hands stopped shaking and I'd have to wake up at a certain time just to keep it in my system and that was my life I started buying methadone. (Kecia)

> *At this point at in my longevity I don't know if I have a purpose even in this community so I'm just kind of living day by day hiding from bill collectors of money mart and payday loans too old to become a prostitute and I don't want to prostitute myself for other people to get funding to fill their pockets with these silly organizations the politics of HIV/AIDS has really ripped my heart apart.* (Ken)

What may be insignificant in the life of one person may mean the world to another. There is no external gauge that can be assigned to measure success. It must come from within. For policies and systems, it is different. We must take the time and make it a priority to create relevant instruments of assessment.

Thrive

This stage of the process is the realization that change is possible, a central tenet of harm reduction. Often, recognition and validation of influences that affect wellness are required. This forms the rationale for appropriate, Indigenous designed assessment tools and traditional diagnostic tools that assist in defining what is needed to achieve, in this instance, improved health outcomes or improved quality of life.

> *To this day it's all there in the corner of my mind I look for the little things to try to inspire me just to keep my sanity or just to keep my sense of hope. There were so many things that were significant that I need to look at or think about. But I think the biggest part is you have become the biggest candlelight in my life, because you were there from the get go, your dad, your mom, your family and Vern and Lorraine Sinclair was significant. and Mishi, you know Silver Sage was my hill of hope and the people then and now who have contributed including Eva. So against all odds of living today with HIV AIDS in this world is still not as smooth yet and in today's times it's the politics of HIV/AIDS that I really find distasteful you know I see some true colors of people who are in it locally and nationally that's why I opt out to stay away from that. The only thing that I do value that they can never take away is my memories of the people I once knew including D. J. Everyone has a significant role, so I can't feel guilty about that, but it was a privilege so*.... (Ken)
>
> *I agree I think the most significant thing is that I don't have a large circle of friends. I choose not to. Only small. Very small. My family's small. Even my immediate family isn't as close. As yours and Kecia's are. To watch the girls grow and Rakiya and Owen and Kecia's old man you know they're growing to but to able to feel a sense of belonging. And you know what. I can't stop that in my head with that old pride. And that's all I need. (*Ken)
>
> I have to say that my kids have really been my inspiration. My children even though like I didn't really grow up consistently with my parents, my mom, I was sent off to different relatives at different times, I've never really felt like I've had a home and it really hasn't been until I've had my kids that I feel like I have a home. Trying to break these cycles that bring us into these systems is my goal for my children. So yk for my children to not be caught up in the health care system is okay preventing HIV, eating healthy, teaching them about smoking and sexual health and abuse and yk anything

that will potentially harm them. To washing your hands properly and then if I want my son or my daughter to stay out of the justice system they need to know the law, they need to know their human rights, they need to know how the law works, and they need to make good choices and there's no guarantee that my child children are going to make good choices, there's no guarantee that they are going to be HIV free, there's no guarantee that there's going to be a good outcome for their life, you know it's a crapshoot and you just try and do your best. (Kecia)

I used to know what to do and I didn't know where to go I saw over 12 different doctors, some of them a few times in a row like in the emergency rooms and I'm not eating I'm wasting no one's helping me I'm in a lot of pain yk and just denied denied denied denied denied constantly and that went on for almost 2 years and I finally told a friend of mine yk I was at my wits end and I just said I can't live like this anymore I'm really scared and really ashamed and she gave me the email to this doctor and he was a lifesaver because he didn't treat me like a drug seeker and he believed me and yk I haven't looked back since yk since I found him. (Kecia)

It certainly has gave me time to think last night about where does it all need to go and this interview was certainly touching base, grounding and looking at that was then this is now and it's really important and really crucial I thought that there are definitely segments that really needs to be talked about in terms of for me is looking at addressing how the politics and colonialism affects the HIV and the AIDS movement because it affected me personally in my personal life but also in the larger realm of working in this kind of social delivery of services of HIV and AIDS certainly does have a bigger impact that we need to address that it certainly has another point I thought about was the looking at the old wave and the new wave of the Aboriginal families affected by HIV and AIDS that there needs to be a much more stronger focus but we need to certainly recollect and bring back some of those families who have since passed on in their roles that needs to be presented in a fashion that we as pioneers as I say with Kecia, Denise and myself but there are other pioneers that are neglected that need to be mentioned their roles and theirs contributions to this movement what I thought about this morning about it was all for me the whole experience was certainly helping me to look at where I need to go and what I need to do to contribute and one of the biggest things that I thought about was if it's not the workshop trails certainly applicable of being selective applicable or who is doing the work or another way is through print I thought of the three of us *doing a short story book compilation of this three – brother sun sister moon sort of thing we need to be able to document something in a book form that will be part of the history as well in a printed manner. I strongly feel that we owe it to ourselves and to our families but we also owe it to the community as large especially the ones who are newly diagnosed need to get in touch and to read some personal stories about what our experiences are, what we've learned and where we need to go it certainly created generated a lot of thoughts of why as I said a little prayer for the ones just recently passed on most notable note is how parents or families I can't emphasize any stronger words how much we need to acknowledge them in some way so hopefully there would be some kind of special day a national Aboriginal AIDS Awareness day that we have profiles and we do it in a panel of some sort sharing our experiences of these people as one of Kecia's videos said words to live by certainly fits this by people who have recently passed on I think that is a phase two of what's been offered It's a really good experience I really want to elaborate that I felt really at peace from waking up this morning I felt that some sense or that I am giving something that is worthy in a respectful way and honored*. (Ken)

To be really honest you know I see a future I see hope I see us having to pass this torch on now to our younger generation and they are picking up the work they are doing it in a good way but we need to start mentoring more people to disseminate this knowledge that we have that I think binds us to HIV and binds us to stigma so the Indian Health Policy for instance you know is affecting our people today because there is no legislation that protects us and that will support us we have to deal with the federal government ourselves especially if you are off reserve and don't have a land base and there is huge gaps between on reserve and off reserve and I think those are important things to look at as well because even though life in community is hard there is still a land base a culture base there's still something there whereas for a lot of us urban aboriginal people who have left the communities or who have been forced to leave the communities because they are not safe you know we've ended up becoming urban Aboriginal people and disconnected from our own communities and languages and food and that really has a direct impact on my health and it has a direct impact on the health of my family and there is no way around that experience. (Kecia)

There is no way to change that except to become independently able to buy my own health insurance that will allow me the benefits and privileges that are given to many Canadians that who have health care under the same government I my mind's really on just policy right now and I'm having a hard time focusing on the heart stuff and I'm happy that I was able to talk about that yesterday and I felt the need to go a bit deeper and talk about our community and the division that has been thrust upon us because of because of money the nepotism, the colonialism, the old boys club, the dyke dynasty, the isms that have we've had to fit into these models as opposed to them fitting into our way of life and our way of thinking and our way of being which is decolonizing and we haven't even decolonized basic language around sexuality and these deficit based models that were constantly being sort of labelled as and you know I'd really like to look at how we can help our communities survive despite these you know the Indian Act is always going to be there and how do we raise our children and the next generation to live within that reconcile and still thrive in Canadian population. (Kecia)

What I think a lot of people don't realize is when you live on the reserve and you live in that isolation and you come off of the community and you come out of the reserve you have what a lot of immigrants experience which is a culture shock and it's not recognized as that because we've always been so mobile and it's natural for us to transient and that's what they've basically labelled us as transients, like were vagrants, but this is our way of life is to be on the move to be doing to you know go to different land bases and do different things with different people that is in our blood and in our genetics and I think that need for us to connect and that need for us to survive is what has been our strength and what has brought us together to do things that were impossible which for a lot of people they won't do unless there is money on the table we've done a lot of things outside of the box we've had to be creative in order to engage our communities properly and in a way that I know funders would probably freak out at but this is the way that it works for us and what they don't know is not going to hurt them as long as what's on the paper meets the needs and makes them happy. (Kecia)

But in the same breath why do we have to act like my people did and potlatch in the winter time just because there is no Indian agents around why can't we do these things out in the open without having to kowtow to the government and always be like paternalistic towards us like we're incapable of our own sovereignty of our own health these are very political issues but these are the issues that our children need to know they need to know their basic human rights so that they can exercise those things and if they don't have two feet grounded firmly in both worlds and prepared for those you know that's where we are failing them and where we need to step up our work now and go beyond the 101 and start having real conversations that are difficult and challenging about politics about you know the state of our government and teaching our children you know how the government works and that they're not ever going to be allowed to just do what they need to do on their own they're always going to be in the back pocket of the government or always have the government trying to gain from their skin colour and from their race and its profiling in many ways I see it as racial profiling the breaches of our privacy that continually exist are unconstitutional it really concerns me the lack of confidentiality that our communities still can't grasp and being able to look at how we can move resources around without asking for more money we need to look at redistributing how the money is now doled out. (Kecia)

I'm looking at these important roles and actions from reserve level that we need to come to terms with acceptance we need to be able to help and assist and that includes people in prisons people coming out of the institutions how many of communities are out there who have stigmatized and labelled people coming out of prisons? and they are kind of set them in their corner and they have no opportunity for growth or to be able to find a job or go to school very simple means of these kind of supports what happens is that they ultimately fall into the cracks and heading back into prisons we are not resolving it we are more or less encouraging this problem to continue so we need to take on ownership. So I'm looking at a little keen on speaking on things that will help to reduce the numbers I don't believe in this ground zero philosophy what I do believe in is being honest from the reserve setting – how can I how can we keep our numbers low or down in Enoch and by providing such an open understanding and caring community to be able to be non-judgmental honouring the values of that needs to be done culturally that needs to be done wholistically we need to approach this and continue this but if we don't address these areas and especially if we don't make peace with TRC and embrace that we are still going to allow this to continue it will still have people who are being crack, crystal meth, and we're still going to have many people going back to prisons. For me I think each community has the responsibility in what changes that they take is up to the community to define and I see that there needs to be some work with this coincides with TRC including the missing and murdered indigenous women and girls that all in connects with this whole circle and how it all relates to each other and it all boils down to those simple values but we need to identify where our weaknesses are. So where do we go with this HIV and AIDS in reality is reduction of numbers of new infections. (Ken).

Moving through this cyclical process, forward or back, and bringing choice truths to written word, creates some risk, for the teller, reader and writer. These narratives are only part of a much greater story. They can be taken apart and analyzed through many distinct levels. This is the style of complexity that permeates all aspects of Indigenous life. There are truths that can be revealed, the seen and unseen, yet it is never complete. It will always evoke emotion and hopefully inspire well intentioned action.

(Problematic) Relationships

At the outset of this research, it became very clear to me that this story-seeking was not just to fulfill academic requirements. This is a significant effort to capture key stages in the development and contributions, for and by Indigenous peoples, to the HIV movement. It represents only a segment of Indigenous participation in the history of HIV. Despite this limitation, it creates a space for our long-term HIV leaders to be honest and state quite bluntly the reality of this participation.

When I started to focus my attention on HIV, over 30 years ago, I was quite naïve and gleefully unaware of the power intricacies of relationships, personal and professional. I was taken to meetings that I realize now were token efforts to show that Aboriginal people were “participating.” Interestingly, this action still occurs. I have developed a sense to recognize the interplay of power and control within the HIV and broader health agenda. The idea that some relationships along this journey may become strained or “problematic” was not an early realization. It has taken the strengthening of my voice and understanding to see how speaking out and critical reasoning makes some people uncomfortable.

I am a skeptical optimist, in that I want to believe “things” will change, yet perhaps know too much about the depth of colonial thought, trauma and subsequent practices, to truly believe it. I have heard some Elders say, “Not in my time,” and sadly this may be true for me. Despite this, I will note a few areas of concern.

A persistent focus on the politics of identity exists, which undermines action in two ways. One is the improper, assumed or fraudulent identities that individuals take on, either to garner or hinder support for efforts. It is difficult enough to have non-Indigenous people "(wo)manning the ship," inclusive of the gender inequities and positive / negative binaries of disease, but representation is always contentious. For Indigenous peoples, the adequacy of representation should be questioned. I find the attempts to divide resource allocations by Aboriginal interest group or politically specified labels alarming.

Second, this chaos inherited from legislation and government interference plays out relentlessly in varied fields including epidemiology, community-based research, social sciences and health systems. The constant bantering about jurisdictional issues and priority populations takes away from very central issues. Today, relevant questions are about access to point of care testing for HIV and Hepatitis C, or who is covered for what treatment, in what province, and with what criteria. This gets even more complicated with a variety of "strategies" to reduce the viral load in diverse communities.

There is no centralized system of gathering and evaluating data that determines if the "target" populations, often Aboriginal peoples, have ever been reached adequately, if at all, by programs intended for them. Surveillance data is gathered in some areas and not in others, a key challenge is the ethnic identifier, is it self-identification, or does an Indigenous person have to verify their status through sanctioned identification? The global program operative of "Know Your Status" can take on an entire different meaning.

As we have learned more about the intricacies of HIV transmission, it brings challenges to public health in the manner that we deal with "populations." Given the heightened awareness of stigma and discrimination, coupled with the ambiguous definitions of decolonization and subsequent attention paid to Indigenous peoples, there is an air of "caution" in naming targets, priority populations, core transmitting populations, populations of interest or key populations. However, look at most calls for proposals and you will see youth, women, men who have sex with men, current or previously incarcerated individuals, injection drug users AND Aboriginal people, often as the only ethnicity specified. It is also common to find a “qualifier” hidden in the footnotes that indicates the data is subject to many limitations.

Finally, the relationship of culture to practice in a variety of human service disciplines is another area where problems arise. This is particularly evident when “surface culturality” is at play. I was unsure if the word “culturality” existed or if I had just created a new descriptor for how not to develop Indigenous programming. I did some preliminary word searching and found variations including inter-culturality. The meaning that I assign to surface culturality is the extension or action attempting to respect and include Indigenous traditional culture in contemporary operations. This is done so it appears as if the action is culturally authentic.

Given that culture has many components and diverse understandings, I define it as the values, beliefs, traditions, guiding principles, protocols, natural laws and ceremonies that bring these elements together, particularly for “People of the Land.” Culture has been described to me as the manner I conduct myself in, based on where I am standing in the world. Maintaining the integrity of the range and levels of Indigenous cultural practices I have been taught is my cultural discipline. I acknowledge I am a beginner in cultural Indigenous learning. It is through understanding the steps or stages of this learning that I can comment on or critique, to a respectful degree, that which others may be sharing.

Central to this stance lies the problematic relationship potential. It is one view over another; one teaching compared to another; an adapted versus an original teaching; one medicine to another; and so the variances continue. While matching the student and the teacher is important, connecting bloodlines, family histories, earned right and witnessing of cultural proficiency often clarify the debate of who is entitled to share what and at what level. The problem lies in the questioning and the response to “Who are your teachers?”.

When considering relationships, it is important to determine if it is healthy or unhealthy, deep or superficial, contributing to or taking away, from the purpose of being united or together. Bringing culture into practice means more than hanging a dreamcatcher or pricey piece of Indigenous art on the wall or naming a project with an Indigenous “flavour.” It is the full recognition and appreciation for the energy required to bring cultural energy and knowledge forward.

CONCLUSIONS

HIV is a part of our community and is recognized as an entity that has a life force. This is the spirit that we are encouraged to greet, respect and learn from. I have seen people take offense to the idea that we must respect HIV. To truly deal with the manifestation of HIV and its results in our communities, informed Indigenous leadership is required at all levels, personal, professional, cultural, political and social.

Recognition and assertion of where Indigenous knowledge and healing practices are best utilized, requires cultural critique. There have been numerous shifts in knowledge translation; to truly connect to the source of power in culture, language and authentic traditions must be explored. Sharing traditional Indigenous knowledge is best considered within an ethical cultural framework.

For Indigenous people, colonialism has severely impacted cultural and spiritual practice. This is most evident and relevant to HIV when fundamental religious beliefs about virtue or sin and right or wrong become the frame of reference. I have witnessed community elders describe HIV as the great sin and that people who have it must have committed a wrong and are being punished. On the opposite side, I have observed community members demonstrate acceptance and inclusion of people living with or affected by HIV. Being able to discern and address between helpful or harmful attitudes and practices, racism, stigma and discrimination are qualities needed in the health field.

For action to have more than a surface response, it is necessary to look at the strategies and tactics that move beyond a particular view of the problem. Janet Smylie’s chapter “The Health of Aboriginal People” (2009) states:

> Although all of the classic socio-economic determinants of health (such as income, security, employment, education, food and shelter) apply to Indigenous populations, there is evidence that the societal processes of European colonization are a fundamental and underlying determinant of health. (p.280)

It is within this context that strategies and policies would ideally be developed and rated through the creation of a relevant assessment process.

When considering the constructs of policy as outlined by Marchi, Lucertini and Tsoukias (2016), the privileging of evidence was a key factor in policy formation. If we review existing literature, the poor health outcomes of Indigenous people are well documented. The political process is also being critiqued for its acceptance and promotion of systemic discrimination and racism.

There is recognition that the health policies for Indigenous people set one group against another with respect to the perceived benefits of varied identities. Within the Indigenous leadership camps, advocacy for improved health is limited to a specified population, First Nation, Inuit or Métis. The missing piece is a willingness to work together. If we could move past the legislated identities and achieve “health for all” that would be the visionary position.

Having suggested strategies, I qualify this point with the criterion of utilization, relevance, autonomy and representation. At a very basic level, the question must be asked, “Who is going to utilize or access this strategy, service or project?”. Determining who is the driver behind the action or activity, and being transparent about the purpose is critical. A key practice of non-government organizations (NGO’s) in Canada is to establish Aboriginal Advisory Committees housed within mainstream organizations. This ensures the funding stays within the dominant organizational structures, limiting organizational development at the Aboriginal community level where capacity is needed most. Aligned with capacity is the economies involved; if we are not hiring Indigenous peoples, benefits are not extended where they are needed most. The approach of providing “gifts” or “honoraria” does not balance out this inequity. Applying a similar concept of “surface relationality” is useful in this context.

Reserves, residential schools and jails were legislated systems that continue in similar forms today. With the intention of altering a people, education, justice, child welfare, corrections and social assistance programs demonstrate the “problem” or “need” that has not been resolved. Smylie (2009), indicates, “abysmal statistics which reflect levels of family violence, suicide, alcohol and other substance abuse in Aboriginal communities today”, while excluding specifically HIV/AIDS, is a common deficit based portrayal.

If we are considering the discourse of reconciliation as the way forward, it may be time to review and place value on what has been taken away from Indigenous people. If the national agenda was less focused on fossil fuels and more focused on improving the Indigenous reality or life situation and reconciling in a financial sense, progressive action could occur. It would mean dismantling or reducing the state apparatus that manages the “Indian” problem.

Consider all the resources that are used to contain the problem, then imagine if the solution was to look at the human return on investment. This idea of giving back what has been taken is truly reconciliation in action. To coin an industry term, the change must occur upstream if it is to have any effect downstream.

REFLECTIVE VISION

Rather than completing this research by offering recommendations, neatly arranged, in order of priority, I will offer a vantage point aptly described as “Reflective Vision.” To understand my choice in words, I will provide a nature based analogy. My mother often speaks about her grandmother and how in bad weather, she would always “look for that little piece of blue sky.” If there was a little piece of blue sky, she would say in Cree, “wewasiskwun,” meaning, it is going to clear.

Imagine driving in a storm, with the dark clouds and heavy rain, so blurred is your line of sight that you contemplate pulling over until the storm passes, but you keep going. You have a destination to get to. Then you glimpse that “little piece of blue sky,” perhaps just a sliver, but it inspires hope and relief that you will get through this. Further along there is a faint outline of colour, which gradually gets clearer. You can now see distinct colours bursting on a rainbow. In that moment, there is clarity. Your purpose and direction have been rewarded with a display of Creator’s magnificence. A brief glance into the rear-view mirror and you see the storm is still there, but you came through it. This mirror, a reflective vision, confirms what is behind us historically. We can choose to stay in the storm or see the blue sky.

Implicit to the design of Indigenous solutions and possibilities is the philosophy or tenets of self-determination or self- governance. This is directly connected to the systems, community, organization, departments or disciplines that address all matters of humanity. It speaks to the ability to determine the course we are taking, as opposed to letting someone else steer us.

Further to this is the understanding that personal and interpersonal relations require healthy practices, that is being able at a minimum to recognize and empathize with conditions that are not acceptable for anyone. Internal health is synonymous with personal healing. Within Indigenous communities this broad concept of healing is multi-generational, ambiguous and difficult to measure. Due to colonial teachings and practices, our Indigenous views have been disrupted. It is time to re-create and envision what health or success or wellness means through our own eyes and on our own terms. This message has been repeated and requires Indigenous tailored action recognizing the systems and environment we are part of.

> Currently, the situation, and very often the plight of Indigenous peoples, should act as a mirror to mainstream Canada. The conditions that Indigenous peoples find themselves in are a reflection of the governance and legal structures

> imposed by the dominant society. Indeed, what the mirror can teach is that it is not really about the situation of Indigenous peoples in this country, but it is about the character and honor of a nation to have created such conditions of inequity. It is about the mindset of a human community of people refusing to honor the rights of other human communities. The gaze staring out from the mirror is the mindful look of Indigenous humanity standing as it is with substantial heritage. This heritage acts as the standpoint from which Indigenous peoples gauge and view the unfolding of the Canadian state. Philosophically, there is an expectation from our children and grandchildren that we resolve these issues and to leave them a better world than the one we found. (Ermine, 2007)

Whole person approaches to health are recognized by some as the way forward. Integral development can be described at a personal level through a wholistic map linked to: Spiritual development (getting a name, attending ceremony, picking medicines); Mental development (learning traditions, practices, language, philosophy); Emotional development (giving and receiving love, describing feelings, heart talk); and Physical development (self-care, nurturing, diet, discipline) with each action centred in a distinct cultural space. It is the extension of self to family and other relationships that becomes evident in work and community life. A key limiting factor in implementing whole person development models is access to adequate resources.

No longer do I see the provision of clean needles and condoms as the only means to preventing the spread of HIV. I am seeking to understand how the “evidence” that guides policy and practice is sometimes the safe surface approach. Only doing what is minimally necessary, referred to as the band-aid response or quick fix, is where just enough assistance is provided for people to get through their particular crisis or circumstance, yet fails to unravel the deeper issue that requires attention.

Service providers who work in community can support personal and inter-personal growth by creating safe and therapeutic environments, incorporating varied levels of the integral approach. This is necessary for both the individual seeking help and the individual providing the help. Moving from the current silo systems or individualistic programs into collective systems or integral programs would be a major shift in practice. Community program providers can take apart systems or policies that keep people down and begin to focus on strategies that bring people up, whether in personal wellness, socio-economic, or education status. Through a truly engaged process, community members can indicate which policies or actions are oppressive and work cooperatively to change them.

Indigenous diagnostic tools, built upon cultural literacy, are needed to assist in the selection of relevant and appropriate actions to address health disparities, inequities and ideally Indigenous aspirations of health. Going forward, as Indigenous practitioners or as distinct service providers, we can co-create ways to support, strengthen and critique our efforts mindfully working towards change that benefits Indigenous peoples.

Our Greatest Medicine

All I am, all I have, I take forward in this world, realizing time is precious and as Joe P. Cardinal taught, “Our greatest medicine is love.” If not for the essence of human life, shared in love, I would not have experienced this journey. I have brought forward the song line and the stories to demonstrate that voice, historical and contemporary, well sounding or obtrusive, have a place. This place is central to change. It is vital.

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