FASD in a Canadian aboriginal community context—an exploration of some ethical issues involving the access to FASD service delivery

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Prenatal exposure to alcohol, PEA, has been shown in both animal and human research studies to have a deleterious effect on many aspects of development particularly neurodevelopment. [1] Brain injury from the PEA can affect learning, memory, attention, language and social behaviour.[2] Recent research also indicates that prenatal exposure to alcohol can result in changes to hormonal functioning and disruption of HPA system that affects cortical production and stress response regulation.[3]

Fetal Alcohol Spectrum Disorder (FASD) is the name given to describe the spectrum of effects due to pre-natal alcohol exposure. Primary diagnostic conditions along the FASD spectrum include Fetal Alcohol Syndrome (FAS) Partial Fetal Alcohol Syndrome (pFAS) and Alcohol Related Neurodevelopmental Disorder (ARND). [4] Secondary conditions or disabilities related to pre-natal exposure to alcohol were first recognized in the research literature by Streissguth.[5] These are exacerbated by the absence of diagnosis and subsequent accommodations for the FASD disability at home and in the community. Socio-economic factors and environmental adversity play a significant role in the clinical expression of both the primary and secondary conditions.[6,7,8, 9] FASD is recognized as a permanent and significant disability that can affect functioning throughout the lifespan.

Older youth and adults, especially those who lack FASD diagnostic health services and disability accommodation, often have problems with depression, suicide, panic disorders, addictions, incarceration, and institutionalization.[10] Children`s problems include learning and behaviour dysfunction that (in the absence of recognition and support) often lead to school disruption: suspension, expulsion, early school leaving and addictions and trouble with the law. [11]

Despite these findings many babies born in Canada are still being exposed to alcohol in-utero. Research indicates that approximately 15% of women in all of the Canadian provinces reported that they consumed alcohol during their pregnancy. [12] This rate may be higher since 62.4 % of women report that they drank in the 3 months prior to pregnancy recognition. [13] Overall rates of alcohol consumption among aboriginal women seem to be lower than in the general population but binge drinking, associated with greater fetal risk, is reported to be more prevalent among aboriginal women who do drink. [14] Published research on prenatal alcohol consumption in aboriginal communities in Canada is limited but a few community studies have indicated that prenatal alcohol use may be problematic among some populations. [15,16]

Population	Population	Prevalence Rate	Population FASD
Canadian[17]	35,540,400	3.6%	1,279,454
Canadian Births[18]	383,822	3.6%	13,818
Aboriginal [19]	1,400,685	3.6%	50,424
Aboriginal Births[20]	33,616	3.6%	1,210

Epidemiological data regarding the incidence of FASD in the Canadian population is lacking. We have not yet established a mechanism for surveillance or national capacity for screening and diagnosis. The incidence in Canada was previously approximated at 1% of the population based on US data of 9.4 per 1000. [21] New US data from a large population study indicates considerably higher rates. Researchers reported an updated incidence estimate of 3.6%.[22] Actual incidence rates of FASD among Canadian aboriginal populations are unknown but using the new general population estimates many thousands of aboriginal people are affected and lack services.

Projected Rates of FASD

In much of Canada access to FASD health service delivery is limited but in aboriginal communities, access to FASD health service delivery is especially problematic. There are no multi-disciplinary diagnostic FASD teams in all of Nunavut and limited access in Yukon and NWT although team diagnosis is recommended by Health Canada and the Canadian Guidelines for Diagnosis [23] A 2007 report on Inuit Public Health published by the National Collaborating Centre for Aboriginal Health at the University of Northern British Columbia noted: [24]

> FASD has been identified as a pressing health issue facing Inuit communities. Interviews with representatives from each of the northern regions identified FASD as one of the major issues they were concerned about in their region.

There also may be some health inequalities within indigenous populations. Stakeholders in Inuit communities reported that Inuit communities receive a disproportionately lower portion of FASD Federal funding than other aboriginal groups in Canada for FASD. They noted the general lack of Inuit-specific planning, programming, and resources for FASD specific activities. [25] Across all regions the following priorities were identified in regard to FASD health service delivery.[26] [27]

- Lack of diagnosis
- Lack of follow-up and coordination following diagnosis
- Lack of intervention and family support services after diagnosis to assist diagnosed individuals and their families
- Lack of alcohol counselling and harm reduction services for women
- Lack of training of health professionals and lack of health staff in the communities
- Lack of staff training for community members to assist them in implementing FASD-related programs and services
- Lack of services and staff for FASD-affected offenders in Corrections including adult diagnosis
- Lack of culturally specific FASD strategy and approach to diagnosis, prevention and intervention

Without diagnosis, appropriate interventions in educational and social systems are limited or lacking. This would suggest an increase in associated FASD secondary disabilities. Research on the incidence of secondary FASD disabilities in aboriginal communities is unavailable-- since this data depends upon primary recognition and diagnosis and this continues to be a problem in all regions.

According to Statistics Canada (2011) there are 94,400 people living in the Atlantic provinces of Canada (Newfoundland-Labrador, Nova Scotia, New Brunswick, and Prince Edward Island) who are Aboriginal.[28] Using the recent prevalence general population estimate of 3.6%[29], we can project that ~ 3398 Aboriginal people in Atlantic Canada need FASD health services at this time. In 2011, there were only 10 diagnostic slots in Atlantic Canada.[30] At the present time, with the opening of the New Brunswick FASD Centre of Excellence, capacity increased to approximately 30; but most of these diagnostic slots do not serve the aboriginal population. 99% of the aboriginal population affected by FASD in Atlantic Canada do not have access to FASD health services in terms of diagnosis and disability accommodations treatment.

The lack of access to FASD health service delivery in aboriginal communities may be negatively affecting the health and well-being of indigenous people living in these communities. It also is contrary to Canada's ethical and legal obligations as expressed by international covenants as well as by the Canadian Charter of Rights and Freedoms.

In 1948 Canada was also a signatory to the UN Declaration of Human Rights affirming in Article 25 the rights of everyone to adequate medical care as well as support in the event of a disability. [31] In 1966, Canada was a signatory to the UN International Covenant on Economic, Social and Cultural Rights, ICESCR, which also recognized the right of everyone to medical care. In Article 12 of the covenant there was special mention of services to ensure: prevention and treatment, the healthy development of the child, and the creation of conditions that would assure medical services.[32] The ICESCR was ratified by the Canada in May of 1976 committing the government in law as well as in principle to the human rights principles of the covenant. [33] In December 1991 Canada also ratified the Convention on the Rights of the Child (CRC).[34] Article 24 of the CRC specifically mentions the responsibility of states to 'ensure that no child is deprived of his or her right of access to…health care services' that further 'states shall strive to ensure that no child is deprived of his or her right of access to such health care services (and) shall pursue full implementation of this right. The CRC also recognized its obligations to mothers to ' not only take appropriate measures….to ensure the provision of necessary medical assistance and health care to all children…..(but also) to ensure appropriate pre-natal and post-natal health care for mothers.' [35]

Research has determined that FASD is a brain based disability but outcome can be improved by early diagnosis, a stable and supportive home and appropriate treatment and accommodations. In Article 23 of the CRC Canada also affirms its obligations to provide all children with a disability the special accommodations that are needed without charge if parents lack resources and that services 'should be designed to ensure that the disabled child has effective access to and receives education, training, health care services, rehabilitation services, preparation for employment and recreation opportunities.'[36]

Like many developmental disabilities FASD is permanent and requires life-long support and accommodation. Section 15 of the Charter, signed into law 1982, clearly indicates Canada's legal responsibility to provide access and accommodation to for people with physical or mental disabilities of all ages without discrimination.[37] The nature of this commitment is more specifically articulated in the UN Convention of Rights of Persons with Disabilities—signed by Canada in 2007 and fully ratified in 2010. This Convention affirms the rights of all people to access, accommodation and support in event of disability. Specific mention in the convention is made of many areas of life including: Justice (Article 13), Education (Article 24) Health (Article 25): [38] The convention clearly states provision should be made of services that work to prevent secondary disabilities:

> Provide those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities, including among children and older persons;

The Convention also notes 'the difficult conditions faced by persons with disabilities who are subject to multiple or aggravated forms of discrimination on the basis of race, colour…… language……indigenous or social origin…… age or other status.

The disadvantage faced by an Aboriginal person with an FASD disability is exacerbated by the already significant gap they have to traverse in health, education, housing, and all other determinants of health. According to the 2014 UN report of the Human Rights Council:[39]

> The health of First Nations, Inuit and Métis people in Canada is a matter of significant concern….significant gaps still remain in health outcomes of aboriginal as compared to non-aboriginal Canadians, including in terms of life expectancy, infant mortality, suicide, injuries, and communicable and chronic diseases such as diabetes. The health situation is exacerbated by overcrowded housing, high population growth rates, high poverty rates and the geographic remoteness of many communities, especially Inuit communities in the north.

Socio-economic status is one of the biggest risk or protective factors to the clinical manifestation of the FASD condition. [40,41] In 1987 a group of researchers compared the offspring of upper middle class and lower class women with controls. The study population all had chronic drinking problems and similar prenatal alcohol consumption when pregnant yet the incidence of FAS in offspring was 4.5% for upper-middle class mothers vs. 70.9 % for lower-middle class mothers. [42] There were significant differences in rates of intellectual deficiency but more importantly in areas that could not be attributed to post-natal environment, such as a significant reduction in head circumference and growth, as well as increased congenital malformations.

In 2010, Canada became one of the signatories of the United Nations Declaration on the Rights of Indigenous Peoples.[43] In doing so Canada affirmed its indigenous peoples' 'equal right to the enjoyment of the highest attainable standard of physical and mental health'. Canada also agreed that they would 'take the necessary steps with a view to achieving progressively the full realization of this right' (Article 24). Special note was taken in the document of the need to protect the rights of people with disabilities. 'Particular attention shall be paid to the rights and special needs of indigenous elders, women, youth, children and persons with disabilities in the implementation of this Declaration (Article 22). [44]

Despite its ethical and legal responsibilities lack of access to FASD diagnostic services means lack of identification and subsequent lack of eligibility for provision of disability accommodation in school and community. The 2014 UN report of the Human Rights Council notes that despite conditions funding levels in aboriginal communities for education, health and social services continue to lag far behind. [45]

The challenging behaviors of youth and young adults who may be affected by prenatal exposure are often perceived to be intentional because they have not been identified through the medical system as having a disability. FASD behaviors can become more challenging as individuals grow into adulthood without support and accommodation. Secondary disability research indicates that without early diagnosis and support 60 % of individuals with FASD begin to get into trouble with the law.[46] Research indicates that many individuals with FASD end up in the revolving door of the criminal justice system (CJS) where they are punished for behaviors that have less to do with criminality than with their disability. [47]

The criminal justice system in Canada has no process in place to screen or assess FASD. Forensic psychiatrists are not often trained nor always available to diagnose this, so unless the diagnosis is brought into the court individuals with FASD do not get appropriate consideration or accommodation within the CJS for their disability.[48]

To remedy the situation regarding the lack of FASD service delivery Health Canada implemented FASD initiatives beginning in the early 2000's. [49] First Nation Inuit Health or FNIH's FASD Program and PHAC's (Public Health Agency of Canada) FASD National Strategic Projects Fund are the basic components of Health Canada's FASD Initiative introduced in the 1999 Budget.

PHAC's FASD National Strategic Fund has been responsible for advancing a number of important FASD projects and Canada has become well-known throughout the world for its ground-breaking work in the FASD knowledge, research and practice. [50] They funded a wide range of projects including development of : Clinical Practice Guidelines for Diagnosis of FASD [51], Alcohol Use and Pregnancy Clinical Practice Guidelines for physicians[52]; a 'National Screening Toolkit for FASD,[53] Prevention statements, Adult diagnosis statements, development of a national prevalence plan, economic analysis and research funding through Canada's FASD Research Network and NeuroDevnet.

Despite the success of PHAC's National FASD initiative, actual service delivery at the community level in Canada has not improved significantly. In 2011, Clarren and Lutke report that the clinical capacity in Canada to diagnosis was 2288 while the number of people projected to be affected by FASD was 1,279,454. [54] [55] Canada's specific legislation dealing with healthcare, the Canada Health Act (1985) [56] shares the responsibility of running the Canadian medical system between levels of government. The provinces/ territories have been given the primary responsibility for health service delivery while the federal government through Health Canada provides direction, research and support. [57] So despite PHAC's direction, there was no real change in provincial health policy and practice.

Health services for aboriginal people are provided through more complex arrangements between the provinces or territories, the federal government and aboriginal communities. Often there is confusion as to the responsibility of each of these in relation to the funding and the delivery of particular health services. The federal department that has the specific mandate for aboriginal health is FNIH (First Nation and Inuit Health). While an Aboriginal right to health care has never been specifically acknowledged by the federal government or decided in the courts, the courts have clearly recognized the fiduciary responsibility of the government towards aboriginal people. FNIH's mandate is to:[58]

- Ensure the availability of, or access to, health services for First Nations and Inuit communities;
- Assist First Nations and Inuit communities address health barriers, disease threats, and attain health levels comparable to other Canadians living in similar locations; and
- Build strong partnerships with First Nations and Inuit to improve the health system.

Most of the health services for aboriginal people, however, are delivered by the provinces or territories where the people reside whether off or on reserve. FNIH`s 'un-insured benefits program' is supposed to fill in the gaps by covering health services that are not provincially insured i.e. dental services, eyeglasses or medicine. This program could provide the framework to fund FASD diagnostic services but at this point in time there is only project support (not core funding) for FNIH's FASD program. The actual focus of the program has been on prevention through mentoring services and support for women, although the stated objectives of their program are broader:

> 1) Reduce the number of babies born with FASD; and 2) support children (age 0-6) who are diagnosed with FASD and their families to improve their quality of life. [59]

When FNIH's FASD program was first launched in the early 2000's there were three eligible priority areas: Asset Mapping, Diagnosis (Formation of Multi-disciplinary team), and Mentoring (PCAP, Parent Child Assistance Program).

Amidst this context, one community based FASD multi-disciplinary diagnostic team, the Eastern Door, was established in Atlantic Canada through the FNIH's call for proposals in the early 2000's. The Eastern Door Team, is an aboriginal community based diagnostic team, that's been operating since 2005-6; it was used as a model for the New Brunswick FASD Centre of Excellence that opened in 2012.[60] The Eastern Door is actually the result of successful tri-partite collaboration between the federal government, the provincial government and the community. It would not have been possible without the funding provided by FNIH's FASD Program for training and team coordination, but the in-kind provincial services of physician and OT and the special needs accommodation services offered post-diagnosis by the FN on reserve school were also essential.[61] The Eastern Door is unique in the development of culturally based tools for screening, diagnosis and intervention and the participation of traditional healers in the diagnostic process. After the Eastern Door was operating for a few years a satisfaction survey was sent to the families who had accessed services; the satisfaction rate was over 90%.[62] One of the birth mothers who was able to access FASD services in the community speaks of her experience with diagnosis and then after as accommodations were put in place and he child began to learn: [63]

> When she was a baby I didn't understand why she would you know when she would get angry she would bang her head on the floor……like constantly…..she didn't know how to say how she was feeling… so just for…for not to get hurt I would put my hand on her head, where she was pounding her head, and so she wouldn't get hurt……
> At first I dreaded going and didn't know….didn't want to know….but I put all those feelings aside and I said this is for her…… She asked me a lot of questions and I just answered them in my honest way as best as I could…what I know…but she helped me figure out a lot of stuff in my head…about it…just talking to her it was a relief….for me…that it had a name….the doctor told me that this is what it is and then what they were going to do and every word he was saying after that…it was lifting my spirits and then things started going more easier after that and both of us…and she started to learn and when she first started reading a book I cried…I never thought she would read a book……and I was so happy…when she graduated high school----all that, because of that, the diagnosis, it made my life easier---

Despite its success, the Eastern Door funding from FNIH has been reduced to a point that it now does not even cover the salary of the team coordinator. The original plan was to begin to offer adult diagnosis and to expand in order to allow nearby FN communities to access diagnostic services as they have requested.[64] Instead, one of the health center administrators recently had to restrict Eastern Door services because of inadequate funding from FNIH. FNIH removed diagnosis as one of the funded components in their FASD program since they consider medical diagnostic services to be the responsibility of the province.

Because of the limited funding in the provinces for the development of multi-disciplinary diagnostic teams an individual's access to FASD diagnosis in aboriginal and non-aboriginal communities has depended upon the practice of individual physicians. These health professionals are funded through provincially insured health plans and they face a number of challenges in providing diagnosis. Twenty years ago the Public Health Agency of Canada commissioned a survey of pediatricians and family doctors to explore their level of knowledge and attitudes to FASD in light of the lack of access to FASD diagnostic services. One of the most important issues for them was lack of training. Over half reported that they lacked the training to diagnose FASD. A few had never even heard of the condition.[65] Some of the physicians reported that they had considered FAS as a diagnosis but also admitted they never made reference to the condition in their case notes because they were uncomfortable with the issue.[66] Physician lack of FASD training and knowledge continue to be a problem. Physicians also continue to report that they are uncomfortable asking about alcohol use in pregnancy and they do not have the resources needed to deal with the issue. [67]

In 2007, the *Lancet* published an article written by British pediatricians entitled 'Fetal Alcohol Syndrome: law and ethics' that suggested that diagnosing FASD poses a conflict for physicians. [68] They write that they are caught between 'the right of the individual to know the likely cause of their disability against emphasising the mother's potential sense of guilt, thereby probably damaging the relationship of mother and child'.[69] Despite this conflict the authors conclude that ethically it is only by 'reliably making the diagnosis can more effective interventions be offered to affected individuals'. But there are practical barriers to FASD diagnosis that affect their offering FASD diagnostic services.

FASD diagnosis is time-consuming. It requires interviews with the birth mother, information from other specialists and coordination of care. Physicians report that there are no provincial FASD billing codes that would enable them to charge for the services that are required. [70]

The provincial government however, could choose to supply FASD billing codes for individual physicians as well as resources for the coordination and development of FASD diagnostic teams. Health officials justify the continuing lack of FASD service delivery in terms of a risk-benefit or cost-effective analysis (i.e. the cost of FASD diagnosis is high; there is no cure for FASD, and FASD interventions are expensive to provide. [71]) This economic approach to health service delivery would appear to have no ethical basis in light of the principles that health professionals and policy makers agree should guide health care policy and practice. Beauchamp and Childress first articulated these in the 1970's and they are now widely accepted by most health professionals and their regulatory bodies: [72]

1. Beneficence—Policy and practice that has the best interest of the other in mind
2. Maleficence—Policy and practice that above all 'does no harm'
3. Justice— Policy and practice that is fair and that promotes equality among individuals
4. Autonomy— Policy and practice that allows for the right of each individual to have freedom of choice

In our society cost-effectiveness/cost-benefit analysis in healthcare has become identified with the ethical principle of beneficence. This is based on an interpretation of John Stuart Mill's philosophy of utilitarianism. Mill proposed that decisions, by individuals or the state, should be made on the basis of what will do the greatest good for the greatest number of people.[73] In Utilitarian terms, 'Beneficence' would then be equated with an action that brought the greatest benefit to the greatest number of people. In making policy decisions the theory is that there is a need to balance the economic benefits of a certain course of action with the risks it entails to achieve results.

Given this framework, the decision to provide access to FASD diagnosis and intervention would be based on analyzing and weighing the probable risks and benefits that would be incurred. Health care decisions are often guided by tools such as QALY (Quality Adjusted Life Year), that are used in cost effective analysis to calculate the value for money of a medical service---in terms of the quality and the quantity of life lived after the service/intervention. Below is a chart outlining the risks and benefits associated with FASD diagnosis.[74]

<u>RISKS AND BENEFITS ASSOCIATED WITH FASD DIAGNOSIS/SERVICE DELIVERY</u>

Risks	Benefits
Lack of appropriate interventions after diagnosis	• Interventions provided anyway—Diagnosis means more appropriate ones • Diagnosis leads to shift in focus of interventions • Diagnosis leads to better resource allocation • Diagnosis needed in research to help improve outcome
Stigma and labeling	• Diagnosis leads to understanding of disability

	• Shift from individual being a problem to having a problem • More effective interventions • More autonomy as individuals with FASD are supported and empowered
Diagnosis and interventions are expensive in a time of scarce resources	• Research indicates diagnosis and intervention works to prevent or ameliorate secondary disabilities • Secondary disabilities lead to great economic costs • Appropriate interventions mean less recidivism in CJS • Providing mothers with FASD services and support for their disability means improving the lives of their children
FASD diagnosis is not cost-effective. Health resources could be used on health conditions that would serve more people and have more impact	• Diagnosis and support means improved relations to self, to family, world---Mi'gmaw ethical concept 'Nogemag' • Increased well-being for individual, family and community—Greek ethical concept 'Eudaimonia'

The economic implications of FASD have been studied extensively in recent years, and the research indicates that using a cost-benefit analysis it would actually be more effective to deliver FASD health services despite the initial expense.[75] Despite this research, the political will that drives policy is lacking at the provincial level. As Michael Foucault pointed out, ethical principles are socially constructed. [76] Who decides what benefits are of value and what risks are worth taking? Who decides what "quality" means to an individual or group who may have entirely cultural different values. Who decides the groups that should benefit by the decisions that are made? For instance, we would never consider refusing health services to children with inoperable brain cancer, although by cost effectiveness analysis the QALY score would be low. Extensive health services for Autism Spectrum Disorder have been provided in most regions after much lobbying by upper middle-class parents, yet services for FASD (a similar developmental condition that is perceived to affect only the aboriginal population or the marginalized) are non-existent. Public health policy and professional practice are affected by prevailing politics and perceptions and interests.

Policy makers would have a different set of priorities if the issue of FASD service delivery was instead considered using the framework of Aristotelian ethics where 'Eudaimonia', happiness, harmony and well-being, is the 'end' or purpose of human life and of virtuous and ethical action.[77] This concept is similar in a sense to the M'igmaw aboriginal concept of Nogemag—well-being in relationship to self-others-creator. From a Mi'gmaw perspective health and right action should be considered in context of the balancing and harmony of the whole.[78]

One of the most important issues that need to be addressed when considering the provision of FASD services in an aboriginal community context has to do with a certain resistance within the aboriginal community to the way FASD is framed in the present medical model. Often this is posed as an issue about lack of culturally sensitive norms or assessment tools, but the issue is deeper than this. Noel Milliea, one of the traditional healers who are part of the Eastern Door Diagnostic team, suggested a different way of looking at FASD by framing it in relation to a circle (rather than a grid) and considering it as a system disorder as well as an individual one. In traditional terms the disorder we now call FASD might be considered as 'a disordering'. There is a breakdown in relationship between mother and child that has to do with the breakdown of social relationships to self, family, community and larger society.

When the condition of FASD is framed in this way there is no stigma involved to the affected individuals, the mothers, families and communities. This is not the case when FASD is considered through the lens of the present medical model. In the medical paradigm FASD as it is constructed tends to be perceived as the ‘fault’ of the mother. One particular article discussing FASD and ethics published in a physicians’ journal reported:[79] ‘by exposing the fetus to a teratogen the mother is causally, and arguably morally, responsible for the outcome.’

This way of thinking stigmatizes the mother and so leads to resistance in terms of accessing FASD diagnostic services for her child or disclosing pre-natal alcohol use (even if she drank before she knew she was pregnant or was told by her physician that moderate drinking wouldn’t harm her child). In Canada, the aboriginal population as a whole now carries the ‘stigma’ of FASD because in Canada FASD is widely believed to be primarily an aboriginal problem.[80] The ethical implications of this kind of mis-information are serious as it has hindered progress and empowerment by generating resistance and discomfort within the aboriginal community itself. The Ontario Federation of Indian Friendship Centres reports that the stigma associated with FASD and aboriginal people is working to silence aboriginal voices about FASD. [81]

> This erroneous characterization has not only negatively affected the mainstream understanding of Aboriginal health and community, but has also inhibited the progress of FASD research and strategy development…….

The reality is that adequate FASD service delivery is a serious health problem in both aboriginal and non-aboriginal communities in Canada; however, aboriginal communities (and individuals living in them) are particularly disadvantaged because of the `disproportionate hardship that they experience in relation to the social determinants of health` and the lack of access to the services they need:

> Colonization and assimilation practices have resulted in high rates of mental illness, addiction, homelessness, poverty, unemployment, incarceration, poor physical health, and community and familial dysfunction….Many individuals do not have access to the holistic services that would help them to cope with the social isolation and experiences of violence and abuse that can arise from these issues. Together, these consequences of a shared history of trauma embody the underlying, or ultimate, causes of FASD in Aboriginal communities, and must be addressed with culturally appropriate methods that foster cultural reintegration, personal and collective healing, and positive change. FASD is a product of socioeconomic status rather than race or culture and as long as a national or provincial strategy does not exist…….Aboriginal people affected by FASD will go without the culturally appropriate, wholistic, and self-determined supports and resources that they need to ensure positive health outcomes and an optimal quality of life. [82]

Therefore, Canada’s ethical obligation to provide resources for system based FASD diagnostic and intervention services in aboriginal communities is clear, as is its legal obligation to accommodate for the FASD disability. However, there are further considerations. Naomi Adelson pointed out that system inequities in Canada in regard to aboriginal health are the root cause of health disparities.[83] In this light FASD service delivery to aboriginal people-whether diagnosis, prevention or intervention-implies a system focus and also identifies a system responsibility. This is true for both indigenous and nonindigenous populations in Canada. Prevention and healing of FASD has much to do with Canada’s ethical and legal responsibility to actively work together at all levels of government to create healthy systems. This would, in turn, help provide access to culturally informed FASD diagnosis services and to the social, economic, physical and spiritual accommodations that are needed by affected individuals and families to deal with the disability.

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[12] Health Canada. Canadian Perinatal Health Report, 2003. Ottawa: Minister of Public Works and Government Services Canada, 2003. TABLE F1.3 Rates of maternal alcohol consumption by province. pp159

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[14] Statistics Canada. 2001 Aboriginal Peoples Survey See also Statistics Canada. Canadian Community Health Survey – 2000/01. Retrieved from: http://www.statcan.ca/english/freepub/82-221-XIE/00502/tables/html/2156.htm In Nunavut it is reported that 51% of women drink alcohol compared to 74% of women in the general Canadian population. 30 % of those 12 years and over who do drink in Nunavut, binge drink 5 or more drinks per occasion compared to only 20.1% binging in this way in general Canadian population

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[20] Aboriginal Birth rate Information: Retrieved from Statistics Canada : http://www.hc-sc.gc.ca/fniah-spnia/pubs/aborig-autoch/stats-profil-atlant/index-eng.php#a621 In 2011 the aboriginal population was 1,400,685. According to Stats Canada the crude birth rate is 24 births/1000 population. We can project that there are roughly 33,616 babies born a year.

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[23] Salmon A, Clarren S. (2011) Developing effective, culturally appropriate avenues to FASD diagnosis and prevention in northern Canada. Int Jour Circ health 70:4 There are diagnostic teams in Whitehorse and Yellowknife but most of Canada's north continues to lack FASD service delivery

[24] National Collaborating Centre for Aboriginal Health,"State of the Knowledge: Inuit Public Health "University of Northern British Columbia, 2007; Prince George, BC.

[25] Ajunnginiq Centre, Fetal Alcohol Spectrum Disorder: An Environmental Scan of Services and Gaps in Inuit Communities. Ottawa: Ajunnginiq Centre, National Aboriginal Health Organization. 2006

[26] National Collaborating Centre for Aboriginal Health ,"State of the Knowledge: Inuit Public Health " University of Northern British Columbia, 2007; Prince George, BC.

[27] Results of Asset Mapping and Medicine Wheel Community Development Workshop—Elsipogtog First Nation, NB (2004)

[28] Retrieved from: Statistics Canada: *www.statcan.gc.ca/daily-quotidien/140926/dq140926b-eng.htm*

[29] May, PA, Baete A, Russo J, Elliott AJ, Blankenship J, Kalberg WO, Buckley D, Brooks M, Hasken J, Abdul-Rahman O, Adam MP, Robinson LK, Manning M, Hoyme HE (2014) Prevalence and characteristics of fetal alcohol spectrum disorders Pediatrics Nov;134(5):855-66. doi: 10.1542/peds.2013-3319

[30] Clarren, S., Lutke, J., & Sherbuck, M. (2011). The Canadian guidelines and the interdisciplinary clinical capacity of Canada to diagnose FASD. J Popul Ther Clin Pharmacol, Vol 18((3)), e494-e499.

[31] UN Declaration of Human Rights (1948) Retrieved from: www.un./org/en/documents/udhr/
Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing, and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control. (Article 25)

[32] UN International Covenant on Economic, Social and Cultural Rights (1966): Retrieved from: *www.who.int/hhr/Economic_social_cultural.pdf*
Recognizing 'the right of everyone to the enjoyment of the highest attainable standard of physical and mental health"(including) provision for the…….a. healthy development of the child; b. prevention, treatment and control of epidemic, endemic, occupational and other disease (and) c. creation of conditions which would assure to all medical service and medical attention in the event of sickness**. (**Article 12)

[33] Canada Heritage-Reports on UN human rights treaties and other documents: ICESCR. Retrieved from: http://www.canadianheritage.gc.ca/eng/1357136859881/1357137099645

[34] Canada Heritage-Reports on UN human rights treaties and other documents: Convention on the Rights of the Child (CRC). Retrieved from: http://www.canadianheritage.gc.ca/eng/1357136859881/1357137099645

[35] Ibid

[36] Ibid

[37] Canadian Charter of Rights and Freedom of the Constitution Act. Retrieved from: http://laws.justice.gc.ca/eng/Const/Const_index.htmlSection 15. (1) Every individual is equal before and under the law and has the right to the equal protection and equal benefit of the law without discrimination and, in particular, without discrimination based on race, national or ethnic origin, colour, religion, sex, age or mental or physical disability

[38] Convention on the Rights of Persons with Disabilities. Eighth session, New York, (August 2006) Retrieved From: http://www.un.org/disabilities/convention/conventionfull.shtml

[39] United Nations General Assembly-Human Rights Council 27th Session (July 2014) Report of the Special Rapporteur on the right of indigenous people: The situation of indigenous people in Canada; Retrieved from: http://www.ohchr.org/EN/Issues/IPeoples/SRIndigenousPeoples/Pages/SRIPeoplesIndex.aspx

[40] Abel, E., & Hannigan, J. (1994). Maternal risk factors in fetal alcohol syndrome: provocative and permissive influences. *Neurotoxicology and Teratology*, *17*, 437-443. See also Abel, E. (2004). Paternal contribution to Fetal Alcohol Spectrum Disorder. *Addiction Biology*, *9*(2), 127-33.

[41] May PA, Gossage JP. Maternal risk factors for Fetal Alcohol Spectrum Disorders: not as simple as it might seem. Alcohol Res & Health. 2011; 34:15–26. [PubMed: 23580036]

[42] Bingol, N., Schuster, C., Fuchs, M., Iosub, S., Turner , C., Stone , R., & Gromisch, D. (1987). The influence of socioeconomic factors on the occurrence of fetal alcohol syndrome. *Adv. Alcohol Subst. Abuse.*, *6*, 105–118.

> 'There was highly significant difference in the incidence of FAS offspring between upper middle and lower class alcoholic mothers, 4.5% versus 70.9% respectively. Mean weight, length, and head circumference at birth in children of upper middle class alcoholic women was -ISD, those of lower class alcoholic women fell into -2SD. All other parameters, congenital malformation rate, failure to thrive, mental retardation were also significantly greater in children of lower class alcoholic women (p less than or equal to .01)'

[43] United Nations General Assembly-Human Rights Council 27th Session (July 2014) Report of the Special Rapporteur on the right of indigenous people: The situation of indigenous people in Canada; Retrieved from: http://www.ohchr.org/EN/Issues/IPeoples/SRIndigenousPeoples/Pages/SRIPeoplesIndex.aspx

[44] Canada became a signatory to the Declaration in 2010; but in 2007 when the Declaration passed by a vote of 143 countries in favour to 4 against Canada was one of only four countries in the world that originally voted against it. The other countries are: Australia, New Zealand and the United States—countries that have large historically disadvantaged indigenous populations.

[45] United Nations General Assembly-Human Rights Council 27th Session (July 2014) Report of the Special Rapporteur on the right of indigenous people: The situation of indigenous people in Canada; Retrieved from: http://www.ohchr.org/EN/Issues/IPeoples/SRIndigenousPeoples/Pages/SRIPeoplesIndex.aspx

[46] Streissguth AP, K. J. (Ed.). (1997). *The Challenge of Fetal Alcohol Syndrome: Overcoming Secondary Disabilities*. Seattle: University of Washington Press.

[47] Conry, J., & Fast, D. K. (2000). *Fetal Alcohol Syndrome and the Criminal Justice System*. Vancouver: Fetal Alcohol Syndrome Resource Society.

[48] This may change with the recent addition in the DSM-5 of the condition, ND-PEA, Neurodevelopmental Disorder-Prenatal Exposure to Alcohol.

[49] PHAC's FASD Initiative is described on their website: http://www.phac-aspc.gc.ca/hp-ps/dca-dea/prog-ini/fasd-etcaf/funding-fonds/index-eng.php FNIH FASD program is described on the Health Canada website: http://www.hc-sc.gc.ca/fniah-spnia/finance/index-eng.php

[50] Ibid. The objective of the FASD initiative is to develop: 'practical tools for community-based programs and health and allied professional (with the goal) to reduce the number of alcohol-affected births and to improve the outcomes for those affected by FASD….(by providing) knowledge and evidence, knowledge translation and exchange, leadership, co-ordination, and collaboration, systems capacity development, and evaluation.'

[51] Chudley, A., Conry, J., Cook, J., Loock, C., Rosalas, T., & LeBlanc, N. (2005). Fetal alcohol spectrum disorder: Canadian guidelines for diagnosis. *CMAJ*, *172*((S suppl)).

[52] Carson, G., Cox, L., Crane, J., Croteau, P., Graves, L., Kluka, S., Wood, R. (2010). Alcohol Use and Pregnancy Consensus Clinical Guidelines. JOGC, S1-S32.

[53] CAPHC. (2012). *National Screening Tool Kit*. FASD Toronto: CAPHC.

[54] Clarren, S., Lutke, J., & Sherbuck, M. (2011). The Canadian guidelines and the interdisciplinary clinical capacity of Canada to diagnose FASD. J Popul *Ther Clin Pharmacol*, *Vol 18*((3)), e494-e499

[55] Universal access to medical care is not a specifically mentioned as a Charter right. Canadian Charter of Rights and Freedom of the Constitution Act Retrieved from: http://laws.justice.gc.ca/eng/Const/Const_index.html Section 7 of the Charter has been used in successful legal challenges to guarantee access to health services

[56] The Canada Health Act (1985) Retrieved from: *laws-lois.justice.gc.ca/eng/**acts**/c-6/page-1.html*

[57] Health Canada: Retrieved from: http://www.hc-sc.gc.ca/hcs-sss/index-eng.php
`Health Canada's mandate is to help Canadians maintain and improve their health..... Health Canada's responsibilities for health care include setting and administering national principles for the health care system through the *Canada Health Act* .....Working in partnership with provinces and territories, Health Canada also supports the health care system through initiatives in areas such as health human resources planning, adoption of new technologies and primary health care delivery

[58] FNIH Retrieved from: http://www.hc-sc.gc.ca/ahc-asc/branch-dirgen/fnihb-dgspni/index-eng.php

[59] Health Canada Archived content: Retrieved from: http://www.hc-sc.gc.ca/fniah-spnia/finance/agree-accord/prog/index-eng.php

[60] NB FASD Advisory Committee Final Report 2010. The NB Centre of Excellence was first operated by Moncton Family Service and is now being managed by VON Canada. When they are fully operational they are able to do about 20 diagnosis a year and the Eastern Door team can do about 10 diagnosis.

[61] The community school provides the psychologist, speech pathologist, and social worker for the team. The school also provides accommodation services in the school after diagnosis. The school program is funded by AANDC, Aboriginal and Northern Development Canada (Indian Affairs) through its special needs funding. This funding was not available until the children were diagnosed with FASD.

[62] EHWC Evaluation 2008

[63] Interview with Bev Sanipass- 2010--Eastern Door Video.

[64] NB FASD Advisory Committee report. 2009. A consultation meeting was held with FN health center administrators and community health professionals. There was consensus that they wanted the Eastern Door Center made into an aboriginal center of excellence to serve their communities.

[65] Nanson, J., Bolaria, R., Snyder, R. E., & Morse, B. A. (1995). Physician awareness of fetal alcohol syndrome: a survey of paeditricians and general practitioners. *CMAJ*, *152*, 1071-76. (2% of physicians had never even heard of FAS. Of the 98% remaining who had some knowledge of the condition less than 50% felt able to diagnose it)

[66] Ibid

[67] Carson, G., Cox, L., Crane, J., Croteau, P., Graves, L., Kluka, S., . . . Wood, R. (2010). Alcohol Use and Pregnancy Consensus Clinical Guidelines. *JOGC*, S1-S32.

[68] Mukherjee, R., Eastman, N., Turk, J., & Hollins, S. (2007). Fetal alcohol syndrome: law and ethics. *The Lancet*, *369*, 1149-1150.

[69] Ibid

[70] Gander FASD conference. 2000 Physician Session facilitated by Dr.Ted Rosalas. Goose Bay physicians' session at the hospital (2001)

[71] Notes from Big Cove Wellness Committee Inc. In attempt to get diagnostic services in FN community as well as in the province members of the Wellness Committee met with representatives from the department of health and hospital medical services in a series of meetings from 2004-2009.

[72] Tom L. Beauchamp / James F. Childress: (2008) *Principles of Biomedical Ethics.* 6th ed. Oxford University press, 2008 6. Aufl., Oxford University Press, 2008,

[73] Mill, John Stuart. *Utilitarianism, On Liberty, Considerations on Representative Government.* London: Everyman, 1993

[74] Cost effective analysis and Cost benefit analysis are distinct. Cost benefit analysis has to do with monetary savings and cost effective approach with what appears to be a more qualitative approach. This distinction is not important for the purposes of this analysis

[75] Stade, B., Ungar, W. J., Stevens, B., Beyen, J., & Koren, G. (2007). Cost of fetal alcohol spectrum disorder in Canada. *Canadian Family Physician*, *53*(8), 1303-1304.

[76] Foucault, M. (1984). *Foucault Reader.* (P. Rabinow, Ed.) New York: Pantheon Books. See On the Genealogy of Ethics: An Overview of Work in Progress (pp. 340-372). Also Politics and Ethics. (pp. 373-380)

[77] Aristotle. (1941). Aristotle. Nichomachean ethics. In Aristotle, & e. McKeon R (Ed.), *The Basic Works of Aristotle* (pp. 935-1126). New York: Random House. The word *Eudaimonia* (εὐδαιμον-ία) literal English translation in Liddell and Scott's Greek lexicon is 'prosperity, good fortune, opulence, happiness' but the word as a concept used by Aristotle holds much more meaning than the simple English translation.

[78] Discussions with elder Noel Milliea The English translation of the word *Nogemag* is 'all my relations' but the concept holds much more meaning than the simple English translation.

[79] Mukherjee, R., Eastman, N., Turk, J., & Hollins, S. (2007). Fetal alcohol syndrome: law and ethics. *The Lancet*, *369*, 1149-1150.

[80] When we were lobbying in NB to get provincial FASD diagnostic services I was asked to give an FASD 101 presentation to a group of provincial ministers including Health, Education, Social Welfare and Aboriginal Affairs. During discussion period that followed one of them commented that they thought FASD was only a problem of aboriginal people—he wasn't aware that it was a health issue for others.

[81] Ontario Federation of Indian Friendship Centres Toronto, Ontario (2013) Fetal Alcohol Spectrum Disorder: a Position Paper. Retrieved from: www.ofifc.org

[82] Ontario Federation of Indian Friendship Centres Toronto, Ontario (2013) Fetal Alcohol Spectrum Disorder: a Position Paper. Retrieved from: www.ofifc.org

[83] Adelson, N. (2003). The embodiment of inequity: Health disparities in Aboriginal Canada. *Canadian Journal of Epidemiology and Community health*, *57*, 254-8.