An Evaluation of a Program Supporting Indigenous Youth Through their FASD Assessment

by

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Abstract

This dissertation was a program evaluation of a three-year program focusing on the intersection of health, justice and child welfare in relation to FASD where holistic, culturally-informed support services are provided to justice-involved Indigenous youth before, during, and after FASD assessments. *Fetal alcohol spectrum disorder* (FASD) is a diagnostic term used to describe the resulting neurodevelopmental impacts of prenatal alcohol exposure. Not only is FASD a health concern, but FASD is also a concern within justice and child welfare. There are several areas where an individual living with FASD may experience difficulties navigating the justice system and advocating for themselves. Children living with FASD are also more likely to be wards of child welfare agencies. At the heart of this Program, the focus is on exploring, revitalizing, and nurturing cultural connections and Indigenous identity. The scope of this evaluation focused on a formative and process evaluation which aimed to garner information for program improvement. A total of six Program staff and management and three Program advisory committee members participated in evaluation interviews developed by the evaluator, and 65 Program stakeholders participated in a program needs assessment survey. Evaluation data collection tools were developed in a participatory manner with the Program manager and staff. Qualitative data were hand-coded using thematic analyses. Findings from the evaluation showed the strengths of Indigenous youth living with FASD are plenty, yet also underscored the many challenges they face in accessing services and being supported. Several needs emerged from the evaluation, including needs around brain-based services, public awareness and education, culturally-informed services and professionals, holistic support, and access and exposure to culture and identity. Evaluation findings showed that the Program is reaching the right youth and the holistic design was perceived to be effective. While the Program rolled out differently than designed, adaptations were necessary to address the needs of those being served. Findings also highlighted that the Program is contributing to community level changes in stigma, and increases in cultural connections and identity among youth. Findings from this evaluation are informative for the Program in moving forward as several recommendations for program improvement were developed.

Keywords: Program evaluation; holistic support; Indigenous; FASD; young offenders

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Chapter 1. Introduction

This dissertation provides a summary of the program evaluation of a three-year program focusing on the intersection of health, justice and child welfare in relation to FASD, where holistic, culturally-informed support services are provided to Indigenous youth before, during, and after FASD assessments. The first section of this dissertation describes the background literature, and the evaluand. The second section of this dissertation reviews the evaluation approach, including the evaluation focus and evaluation questions. This is followed by a review of the methodology used, including the measures, procedure and analyses utilized. The remaining portion of this dissertation highlights the evaluation findings, and presents recommendations and next steps for the Program, followed by a structural analysis of the authors experiences throughout her graduate career.

1.1. Terminology

In Canada, the term Aboriginal refers to the first inhabitants of North America and includes three distinct groups of Indigenous people, each with their own unique culture, language, and traditions (*Royal Commission on Aboriginal Peoples Report* [RCAP], 1996). These three groups of Indigenous people are First Nations, Inuit, and Métis. In describing each of the three Indigenous groups, it is important to acknowledge the vast diversity within and between each group.

The term First Nations refers to Indigenous people who are neither Métis nor Inuit. Indigenous people who are of First Nation ancestry have also been referred to as status

or non-status Indian[1] (as outlined in the *Indian Act*; Indigenous and Northern Affairs Canada, 2015; RCAP, 1996). While First Nation is the contemporary and preferred term, the term *Indian* is the language used in legal documents, policies, and government statistics (RCAP, 1996). Inuit people refer to Indigenous groups who inhabit the arctic regions of Canada; most Inuit reside in 53 communities through the most Northern region of Canada, including Nunavut, Nunavik, the Northwest Territories, and Northern Labrador (Inuit Tapiriit Kanatami, 2016). In Inuktitut, the word Inuit means *the people* (Indigenous and Northern Affairs Canada, 2015). Finally, the term Métis refers to Indigenous people who are descendants of Indigenous women and European fur traders of the 18th century (Métis Nation, 2016; TAL, 2016).

1.2. Context

1.2.1. Indigenous Worldview

In Canada, there are over 600 First Nations and over 60 Indigenous languages (Statistics Canada, 2015a). According to the National Household Survey in 2011, Indigenous people represent 4.3% of the Canadian population, of which 46.2% are Indigenous youth under the age of 25 years old. Of the 4.3% of Indigenous people in Canada, 60.8% identify as First Nation, while 4.2%, and 32.3% identify as Inuit and Métis, respectively (Statistics Canada, 2015a).

In British Columbia (BC) specifically, Indigenous people represent 5% of the BC population. Like the national statistics, the younger Indigenous population is growing, where Indigenous youth under the age of 25 years old represent 44.49% of the BC Indigenous population. In BC, 68.4% of the Indigenous population identify as First Nation,

[1] Status Indian refers to First Nation individuals who are federally recognized as registered under the *Indian Act*. Registered (status) Indians are entitled to certain services and rights. Everyone registered under the *Indian Act* is issued a certificate of Indian status with a unique registry number providing information about band membership (Aboriginal Affairs and Northern Development Canada, 2013). The term *Indian* will be used in reference to government policies (such as the *Indian Act*) or in direct quotations only.

while 0.4%, and 30.3% identify as Inuit and Métis, respectively (Statistics Canada, 2015b; BC Stats, N.D.).

While First Nations, Inuit and Métis peoples are distinct groups, there are commonalities with respect to the worldviews held by Indigenous people. Though the medicine wheel is not a pan-Indigenous concept, the four directions teachings it represents resonates with many Indigenous people. The four components of the medicine wheel can represent (Poonwassie & Charter, 2001):

- Direction: east, south, west, north
- Life giving element: earth, wind, fire, water
- Race: yellow, red, white, black
- Season: winter, spring, summer, fall
- Well-being: mind, body, spirit, emotion

With respect to health and wellness, when the four components of well-being are not in harmony, wholeness is broken and there is greater risk of poor health; it is important to walk in balance among all of the elements, honouring the principles of holism, togetherness and connectedness (Marshall, Marshall, & Bartlett, 2015; Mussell, 2006). Indigenous people also have an intricate connection to the land. Dr. Bill Mussell (2006) notes that, as Indigenous people, we are to honour and respect all things of the Creator, such as land, the resources from the land, and human life. The land does not belong to mankind, the land provides resources for humans to share (TAL, 2016). Elders are highly respected within an Indigenous worldview; Elders have the oral history and share their wisdom through storytelling, the primary mechanism for instruction, guidance and cultural and spiritual knowledge transmission (Marshall, Marshall, & Bartlett, 2015; TAL, 2016).

1.2.2. Colonial History

Pre-Contact and First Contact

Indigenous people in Canada have endured a long history of colonization through the Indian Act, reservation systems, residential schools, and the sixties scoop,[2] all of which operated with the goal to assimilate a culture of people. Before the arrival of European settlers, Indigenous people were self-governing nations, there was extensive trade networks within and between nations (RCAP, 1996; TAL, 2016). Contact between European and Indigenous people occurred as early as the 10th century, though it was limited to the eastern Atlantic provinces (RCAP, 1996). In the 1500s Europeans started to settle and establish colonies in North America (TAL, 2016); though, Indigenous and non-Indigenous settlements developed mostly in isolation. By the 17th century, Europeans came to the Atlantic provinces by the thousands (RCAP, 1996).

When Europeans first settled in North America the relationship between Indigenous and non-Indigenous people was relatively peaceful; Indigenous people were commercial partners with non-Indigenous people in the fur trade and were strong military allies (Campbell, 2008; RCAP, 1996). However, as the number of European settlers increased, the Aboriginal population decreased due to diseases to which Indigenous peoples had no immunity (e.g., smallpox and influenza). Furthermore, as the number of European settlers increased, so did their desire to control the land and resources (TAL, 2016). In 1763, King George III established a legal framework for Indian Department officials via the Royal Proclamation. The purpose of this framework was to preserve peaceful relations between European settlers. This proclamation acknowledged Indigenous peoples' right to occupy traditional territories, but it also declared that trade was to continue according to Royal British regulations and that the British Empire was responsible for protecting Indigenous people and their lands (e.g., from expropriation); representatives of the King were to negotiate with Indigenous people about land through agreements called treaties (TAL, 2016). Should the land be ceded through these treaties,

[2] The sixties scoop represents a period of time between the 1960s and 1980s where an estimated 20,000 Indigenous children were removed from their families and placed in non-Indigenous foster homes, and placed in the child welfare system, being adopted out to non-Indigenous families (Tait, 2003).

Indigenous people were to receive payments (e.g., money, equipment, reserve land) and rights (e.g., education, hunting, fishing). If the land was un-ceded, European settlers were not to settle on it, as it rightfully remained Indigenous land. Many nations ceded, out of good faith, but even lands that were un-ceded were taken by settlers, and the Canadian government failed to meet the conditions stated within the treaties (TAL, 2016). This Royal Proclamation of guidelines for settlement in North America was later used by British leaders to lay claim to North America (Belanger, 2010).[3]

Following the War of 1812, the British Empire and the United States established a peaceful relationship, in turn affecting the relationship between the Indigenous and non-Indigenous people of the British Empire in Canada. The *Royal Commission on Aboriginal Peoples* Report (RCAP; 1996) identifies this as a historical event signalling the beginning of a period of displacement and assimilation: "the fur trade and traditional harvesting economy declined in importance and the need for Aboriginal nations as military allies waned, and soon Aboriginal people were living on the margins of the new colonial economies, treated less and less as nations worthy of consideration in the political councils of the now secure British colonies" (p. 141). As such, the period of cooperation between the British Empire in Canada and Indigenous people stopped; in the Maritimes the cooperation stalled by 1780s, in Ontario by 1830, and in British Columbia by 1870 (RCAP, 1996).

The next section will briefly review key historical events related to colonization and assimilation efforts of the British North American and subsequent Canadian government.

Displacement and Assimilation Efforts

The Indian Act: The *Indian Act*, originally passed in 1867, is a federal legal document within Canada that oversees and regulates all matters pertaining to Indian status, bands, and reserves. The *Indian Act*, which is still in existence today, has undergone several amendments, though remains relatively unchanged since it was first

[3] The British Empire reframed its relationship with Indigenous people from a protection of Indigenous rights stance to a guardian role, protecting its wards – Indigenous people were no longer seen as equals with rights to land, but rather the policy morphed into a policy focused on civilizing Indigenous people (Belanger, 2010).

passed (RCAP, 1996). The *Indian Act* was generated under the assumption that Indigenous people were inferior and in need of protection, civilization, and assimilation with Euro-Canadian ways (RCAP, 1996); this legislation elucidated that it was no longer an option to be an Indian and in order to be civilized, an Indigenous person was required to disenfranchise their heritage (Belanger, 2010). As part of this legislation, Indigenous people have been subjected to various oppressive measures, including attacks on traditional culture, alcohol prohibition, and the implementation of Indian agents who enforced the rules outlined in the *Indian Act* (RCAP, 1996; The Truth and Reconciliation Commission of Canada, 2013) Table 1 outlines the various ways in which the daily life of Indigenous people were governed and restricted by the *Indian Act*.

Table 1: Indian Act Amendments

Indian Act Amendments	
Date Enacted	***Amendment***
1880	- Getting a university degree results in automatic enfranchisement
1881	- Selling agricultural produce is illegal without permission from Indian agent
1884	- Three or more Indigenous persons (treaty, non-treaty, or mixed-blood) together was an offence of breaching the peace or making riotous threatening demands on a civil servant
	- Potlatch and other ceremonies banned
1905	- Power to remove Indigenous peoples from reserves near towns
1911	- Power to expropriate land from bands without consent
1914	- Require permission to appear in traditional regalia in public
1920	- Residential school attendance now mandatory. Penalties for parents who refused to send their children
1927	- Illegal to raise money to hire a lawyer for land claim purposes against the government
1933	- Canadian officials now have power to arbitrarily enfranchise an Indigenous person if they meet criteria
1941	- Selling furs and wild animals is now illegal without permission from your Indian agent. Also not allowed to wear 'costumes' in any dance, show, stampede or exhibit without permission
1951	- Potlatch no longer banned
	- Central registry created
	- Bill c-31 passed o Bands can now control band membership o Reversal of Indigenous women being forced to give up status if married non status man

(Belanger, 2010; Brasfield, 2001; Gray, 2011)

Ban on Traditional Culture. As stated in the Royal Commission on Aboriginal Peoples Report (RCAP, 1996), "In 1884 the official policy turned from protecting Indian lands from non-Indians to protecting Indians from their own cultures. That year amendments to the *Indian Act* prohibited the potlatch and the Tamanawas dance" (p.291), with prohibition of the Sundance to follow the very next year (RCAP, 1996). It became a criminal offence and illegal to participate in a potlatch[4] or to appear in regalia.[5] Furthermore, traditional hunter-gathering practices were restricted off reserves, which could lead to fines and imprisonment. The rationale for these restrictions was that Indigenous traditions were obstacles to civilization and assimilation (RCAP, 1996).

Alcohol Prohibition. With respect to alcohol prohibition, the policies in the Indian Act made it illegal to sell alcohol to Indigenous people, and a punishable offence for an Aboriginal person to be intoxicated. Revisions to this section of the Indian Act in the 1950s permitted an Indigenous person to possess alcohol in public, but it remained an offence to be in a state of intoxication (Campbell, 2008; RCAP, 1996). The 1874 federal legislation of alcohol prohibitions outlined in the Indian Act was the start of unique offences applicable solely to Indigenous people (RCAP, 1996). As a result of this prohibition on alcohol, which only applied to Indigenous people, drinking was often consumed rapidly and in secret. In an interview with an Indigenous person about alcohol, Maracle (1993) reports a story recalled from one individual:

> When it was against the law for Indians to drink, that's where it all started, this drinking going out of control 'cause when somebody bought a bottle of wine, you don't want the police to find you with that open bottle because you're gonna get fined or you're gonna go to jail. So when they get that wine, they'll pass it around to finish that bottle so there's no evidence. That happened a lot on the street in town. That does a lot of damage to the person when they drink it all at once. So not many people learned how to be sociable drinkers. They want to drink that wine up because of the law. When it became legal, it was just like

[4] Potlatch refers to a ceremony among Northwest Coastal people that marks important events (e.g., births, deaths, the appointment of Chiefs, giving of traditional names). The ceremony, which is publicly held within the community, has spiritual and cultural significance and often involves a process in which goods are gathered and given away (Belanger, 2010; Gray, 2011)

[5] Regalia are special dress attire worn for specific occasions (e.g., gatherings, dances, ceremonies). Regalia should not be called costumes, nor should they be appropriated by mainstream society. Styles of regalia vary by region; for example, woven cedar is specific to the Northwestern Coastal people, while the Métis sash is specific to Métis people. Some regalia are sacred; therefore, it is important not to touch or handle regalia without permission.

> opening a bag of candies to children, you know, they run for it and they went out of control and everybody just sat in bars. (Maracle, 1993, p.47)

Reserves and Dislocation. In Canada, there are over 600 reserves; reserves are for status Indians (Gray, 2011). The reserve system dates back to before the Constitution (formation of Canada 1867). As mentioned above, the Royal Proclamation of 1763 was originally created to protect the land rights of Indigenous people from expropriation; this legal framework also required the negotiation of treaties with First Nations. Despite this proclamation, large amounts of land were taken prior to signing the treaties in order to create reserves or to give/sell land to non-Indian people (Gray, 2011).

Over the years, the government tried to get bands[6] to agree to relocate. In 1962 the government threatened to withhold funding and cut off benefits to two villages in BC. As a result of this coercion, the two voted to move. The government promised improved housing, health, education facilities, and economic opportunities if they agreed to the move and they did so in 1964. These promises were not fulfilled. When they arrived, only three houses were ready, despite there being 100 people. Many ended up living on boats, but were not given proper anchorage, so the boats were damaged. Furthermore, they faced discrimination by surrounding communities, which limited employment. The government burned down the communities they originated from to stop them from moving back; consequently, those who were coerced into relocating became depressed, living in unhealthy living conditions, community cohesion eroded, and people started drinking (RCAP, 1996).

The Residential School System and Child Apprehension: In addition to the *Indian Act*, Indigenous people also endured the government-funded, church-run residential school system as a method of civilizing and assimilating Indigenous youth.

The residential school system operated from 1870 to 1996 (Truth and Reconciliation Commission of Canada, 2013) with mandatory attendance beginning in 1920 (Brasfield, 2001). Like the *Indian Act*, the rationale behind the residential school

[6] The *Indian Act* Replaced traditional governance models with elected or appointed male band councils (Gray, 2011). This act was another means of displacing power from Indigenous women (e.g., loss of status and disempowered women; TAL, 2016).

system was to assimilate Indigenous people through education. As part of this system, children were taken from their families and communities and were placed for extended periods of time in boarding schools. At the schools, children were punished for speaking their ancestral language, practicing cultural and spiritual practices, or even acknowledging their cultural heritage (RCAP, 1996; Tait, 2003). The government philosophy for the residential school system was to assimilate and civilize every last Indigenous person until there were no more Indigenous people. This was to be done through education (Gray, 2011). Some of the effects of the residential schools included not knowing one's family, not learning how to parent, not knowing one's own culture, turning to harmful coping strategies, and passing effects to subsequent generations (Morrissette, 1994; RCAP, 1996; Tait, 2003). A 1907 medical report, which shed light on the conditions and experiences of children in residential schools, was swept under the rug. In this report, the author warned that 15-24% of all children in residential schools were dying due to malnutrition, disease, and poor living conditions. These warnings were ignored by the Canadian government (Gray, 2011).

By the 1950s, there was slow shift away from the residential school system, first with the elimination of mandatory attendance, followed by the elimination of church involvement (Morrissette, 1994). As the slow process to phase out residential schools was underway, an additional means of assimilation was enforced, by displacing Aboriginal children into non-Aboriginal families. This new wave of assimilation is often referred to as the sixties scoop, which spanned roughly 20 years from the 1960s to 1980s (Johnson, 1983). While the practice of child apprehension for the purpose of assimilation has diminished, there continues to be an overrepresentation of Indigenous youth in the child welfare system (Sinha, Trocmé, Fallon, & MacLaurin, 2013).

The White Paper: In 1969, the government of Canada issued a white paper on Indian policy, which would eliminate federal responsibility for status Indians, their treaty rights, and protecting reserve lands. In the paper, the dismantling of the *Indian Act* was proposed. The stated purpose of this proposal was to eliminate *Indian* as a legal status so that Indigenous people could have equal status, equal rights, and not be dependent on the Canadian government. There was enormous opposition to the white paper as Indigenous people viewed the paper as another means of assimilation and were reluctant

to see it repealed as their rights and protections are in the document; consequently, the government withdrew its proposal in 1970 (RCAP, 1996; TAL, 2016).

The remaining portion of the literature review will focus on the impact of colonization, with particular attention to *Fetal Alcohol Spectrum Disorder* (FASD), youth justice involvement, child welfare involvement, and contemporary Indigenous culture.

1.2.3. Impact of Colonization

Various adverse effects of the Indian Act, residential school system and child apprehension practices have been documented throughout the literature (e.g., alcoholism, suicide, loss of identity and language, altered parenting skills, loss of a natural connection with Creator, harmful coping strategies, and not knowing one's family; Gray, 2011; Morrissette, 1994; Proulx, 2003; RCAP, 1996; Tait, 2003; TAL, 2016). Indigenous people in Canada are faced with many adversities in several areas of life, many of which are interrelated, having a cumulative impact as each stressor influences the presence of the others.

In terms of health issues, rates of chronic diseases such as diabetes, *acquired immunodeficiency syndrome/human immunodeficiency virus* (AIDS/HIV) infections, heart disease, and FASD are disproportionately higher among Indigenous people (Burd & Moffatt, 1994; Canada Public Health Agency, 2005; Health Canada, 2013; Reading, 2009; Sibbald, 2002). Poor and chronic health illness can impact various aspects of a person's well-being (Reading, 2009). Health stressors among Indigenous people are not limited to chronic health issues, as mental health stressors are a reality for many Aboriginal people as well. For instance, Indigenous people, in particular First Nations, experience depression at rates well above the national average (i.e., 12% and possibly higher versus 7%; Government of Canada, 2006; Kirmayer, Brass, & Tait, 2000). A serious mental health issue that is overrepresented among Indigenous people is suicide (Government of Canada, 2006; Kirmayer et al., 2007). Suicide is a tragic reality for Indigenous people, in particular First Nations and Inuit. For instance, suicide rates are twice the national average for First Nations, while the rates are 6-11 times the national average for Inuit, possibly the

highest suicide rates in the world. Many of these suicides are committed by Indigenous youth (Government of Canada, 2006).

Furthermore, Indigenous people in Canada are faced with poverty and economic issues. While poverty and economic instability are concerns for many people in Canada, the issue of poverty and financial instability is particularly alarming for Indigenous people. For instance, according to the First Nations *Regional Longitudinal Health Survey* (RHS) 2002/03, Aboriginal people living on reserve indicated that their housing conditions were substandard, as they live in overcrowded homes, their homes are in need of major repairs, they lack access to garbage collection services, and some live in homes without electricity, running water, appliances, and operable toilets/septic systems (Assembly of First Nations, 2007). In BC, Indigenous people earn less than non-Indigenous people (BC Stats, N.D.), and the wage gap is particularly disproportionate for Indigenous women (BC Provincial Health Officer, 2011; BC Stats, N.D.; Pérusse, 2008). Furthermore, the disparity of attaining a university degree is staggering between Indigenous and non-Indigenous people in Canada. According to Statistics Canada (2011), 9.8% of Indigenous people in Canada have a bachelor degree or higher, compared to 26.5% of their non-Indigenous counterparts.

Alcohol use and misuse is a complex and stigmatized issue for Indigenous people in Canada. A commonly held public stereotype is the 'drunken Indian' stereotype about Indigenous people as alcoholics (CBC News, 2014). Thatcher (2004) explains that "the phrase 'drunken Indian' reflects one of the most common and enduring ethnic stereotypes not only in Canada but in North America as a whole" (p. 15). While some have suggested that there is a genetic predisposition to alcoholism, and that Indigenous people are unable to metabolize alcohol, there is no scientific evidence to support this myth, and there is no evidence for the existence of a genetic trait that lead Indigenous people to drink excessively; Indigenous people metabolize alcohol at the same rate as their non-Indigenous counterparts (Campbell, 2008). In fact, more Indigenous people abstain from drinking than the general population (The First Nations Information Governance Centre, 2012), and alcohol abuse among Indigenous people does not exceed the national rate (Assembly of First Nations, 2007). Despite not exceeding the national rates of alcohol abuse, alcohol misuse has nonetheless been a self-identified problem among Indigenous

organizations, chiefs, and communities as alcohol-related deaths among First Nations communities are six times higher than the general population (Assembly of First Nations, 2007). Like the history of child apprehension, alcohol consumption has its roots in Canada's history of colonization and assimilation efforts.

The impacts of colonization, particularly the residential school system, have not only impacted those who directly endured the systemic efforts of assimilation, but continue to impact subsequent generations (Gray, 2011). For those who attended residential school, the impacts continued beyond their time in the schools and stayed with them into their adult years, and oftentimes, the impacts were transmitted to their children and grandchildren (TAL, 2016). This transmission of the impacts is often referred to as intergenerational trauma. For those who suffer the effects of trauma, when left undealt with, the subsequent behaviours and traumas become normalized and are passed to the next generation, contributing to a cycle of trauma (Menzies, 2007).

Fetal alcohol spectrum disorder, criminal justice system involvement, and continued child apprehension are three interrelated areas that are contributing to the cumulative impact of adverse outcomes among Indigenous people. These three areas will be discussed in further detail as they are directly related to the Program being evaluated in this dissertation.

Fetal Alcohol Spectrum Disorder

Fetal alcohol spectrum disorder (FASD) is a diagnostic term used to describe the resulting neurodevelopmental impacts of prenatal alcohol exposure. Up until 2015, the term FASD was not used as a diagnostic term itself, rather it was considered an umbrella term used to describe a range of behavioural, physical, and cognitive deficits; FASD was an umbrella term in which different diagnoses could be made (i.e., FAS, pFAS, ARND; Chudley et al., 2005; Poole, 2008).

The terms used to describe the resulting neurodevelopmental impacts of prenatal alcohol exposure, and the related operationalisations along the spectrum, have evolved since the first documented case in 1968 by French doctors Lemoine and colleagues. Table 2 below highlights the changes over time. The updated 2015 Canadian guidelines for

diagnosing FASD and revisions to the former 2005 Canadian guidelines stemmed from research involving infants, youth, and adults living with FASD. As such, with the revised guidelines, new nomenclature was introduced, terms were renamed, redefined and further clarified, and specific diagnostic criteria from the 2005 guidelines were removed. For instance, growth delays is no longer a diagnostic criterion, as it was with the 2005 guidelines. Furthermore, the diagnoses that can be made under the 2015 Canadian guidelines differ from the 2005 guidelines. Instead of the three diagnostic categories under the umbrella term (i.e., diagnoses of FAS, pFAS, ARND), now, under the 2015 guidelines, a diagnosis of FASD may be made with or without sentinel facial features (i.e., short palpebral fissures, smooth and flat philtrum, thin upper lip; Cook et al., 2015; see Table 2).

Table 2: The Evolution of FASD Terms Over Time

Year	Term	Details	
1968	No term	- French doctors observe patterns of facial features in children whose mothers drank during pregnancy (Astley, 2004; Streissguth, Barr, Koga, & Bookstein, 1997)	
1973	Fetal Alcohol Syndrome (FAS)	- North American dysmorphologists observe the same pattern of facial features, in addition to growth and developmental delays (Jones, Smith, Ulleland, & Streissguth, 1973)	
1978	Fetal Alcohol Effects (FAE)	- The term FAE was coined to explain FAS without the full range of symptoms (e.g., confirmed alcohol exposure, but with only some of the physical characteristics; Streissguth, 2007; Burgess & Streissguth, 1992)	
2005 Canadian Guidelines	Fetal Alcohol Spectrum Disorder (FASD)	- An *umbrella term* to describes the constellation of behavioural, physical, and cognitive effects from prenatal alcohol exposure (PAE; Chudley et al.; Poole, 2008)	
		Three diagnoses can be made:	
		FAS	- 1 growth delay - 3 dysmorphic facial features - 3 central nervous system impairments - PAE can be confirmed or unconfirmed
		Partial FAS (pFAS)	- grow delay not necessary - 2 of 3 dysmorphic facial features - 3 central nervous system impairments - Confirmed PAE
		Alcohol Related Neurodevelopmental Disorder (ARND)	- Growth delay not necessary - Dysmorphic facial features not necessary - 3 functional central nervous system impairments - Confirmed PAE
2015 Canadian Guidelines	Fetal Alcohol Spectrum Disorder (FASD)	- A *diagnostic term* to describes the constellation of behavioural, physical, and cognitive effects from prenatal alcohol exposure (PAE; Cook et al., 2015)	
		Two diagnoses can be made:	
		FASD with Sentinel Facial Features	- 3 sentinel facial features - 3 or more neurodevelopmental domains impaired - PAE confirmed or unknown
		FASD without Sentinel Facial Features	- 3 or more neurodevelopmental domains impaired - PAE confirmed

People who are diagnosed with FASD encounter primary and secondary disabilities associated with brain functioning and behavioural challenges. Primary disabilities are functional deficits, such as memory, judgement, communication, resulting from central nervous system injuries (Streissguth et al., 1996), while secondary disabilities are behavioural symptoms of their underlying disabilities; these behavioural symptoms are preventable and can be improved with appropriate intervention and environments (Centers for Disease Control and Prevention, 2016; Wemigwans, 2005). In their longitudinal study on alcohol and pregnancy, Streissguth and colleagues (1996) identified six secondary disabilities, including:

- 90% of their sample experienced mental health problems
- 60% of their sample experienced disrupted school experiences (e.g., dropping out, suspensions)
- 60% experienced trouble with the law
- 50% experienced a form of confinement (e.g., in-patient treatment, incarceration)
- 50% exhibited inappropriate sexual behaviours
- 30% experienced alcohol and/or drug problems

FASD has been described as an invisible disability, as most of those living with FASD have no observable physical characteristics (Streissguth et al., 1996). Furthermore, the disabilities and behavioural symptoms associated with FASD vary between those living with FASD and each person living with FASD will present differently. While FASD is a lifelong disorder, the effects change as an individual ages into adulthood (Burd et al., 2003; Health Canada, 2003). Given the varied nature of disabilities in brain functioning, and varied behavioural symptoms, adolescents and young adults living with FASD will benefit from holistic support in terms of their complex needs (TAL, 2016).

Criminal Justice Involvement and Child Apprehension

Not only is FASD a health concern, but FASD is also a concern within the area of justice and child welfare. It has been well documented throughout the last 25 years that

Indigenous people are disproportionately overrepresented in the criminal justice system when compared to non-Indigenous people (Bell & Crutcher, 2002; Bonta, Lipinski, & Martin, 1992; Bracken, Deane, & Morrissette, 2009; Dauvergne, 2012; LaPrairie, 2002; Rudin, 2005; Sapers, 2012).

In terms of FASD and justice involvement, associations between delinquency and prenatal alcohol exposure have been established throughout the literature (e.g., Caley et al., 2005; Lynch, Coles, Corley, & Falek, 2003; Nash et al., 2006; Streissguth et al., 1996). There are several areas in which an individual living with FASD may experience difficulties navigating the justice system and advocating for themselves, including waiving their rights during police interrogations, self-reported false confessions, and fitness to stand trial (McLachlan, Roesch, Viljoen, & Douglas, 2014; Roach & Bailey, 2010; Roesch, McLachlan, & Viljoen, 2016).

Indigenous youth are also overrepresented in the child welfare system. For Indigenous people, child welfare is an issue that dates back to a period in Canadian history when the government adopted and enforced a policy of assimilation. While rates of child apprehension was at its peak between 1960s-1980s (referred to as the Sixties Scoop), there continues to be disproportionate rates of child apprehension of Indigenous youth (Blackstock, Cross, George, Brown, & Formsma, 2006; Trocmé, Knoke, & Blackstock, 2004). According to the 2011 National Household Survey, nearly half of children under age 14 in foster care were Indigenous children (48.1%). Furthermore, 4% of Indigenous children under 14 years old are foster children versus 0.3% for non-Indigenous children under 14 years of age (Statistics Canada, 2015a). Moreover, children living with FASD are more likely to be wards of child welfare agencies (Fuchs, Burnside, Marchenski, & Mudry, 2005).

Indigenous Culture

Despite all the efforts to eliminate Indigenous culture and “killing the Indian in the child,” there were many ways in which Aboriginal people resisted the various assimilation policies. For instance, in BC, Indigenous people practiced their culture, such as potlach, in secrecy despite the bans imposed by the Indian Act (Gray, 2011), and many students ran away from school as a form of resistance. Even with the knowledge that running away

caused extreme punishments and even death, students still ran (Tait, 2003). Further, an additional form of resistance included speaking one's Indigenous language, as children met in unsupervised areas to speak their Indigenous language, and when supervisors were near, the children switched from their Indigenous language to English (Tait, 2003). This is particularly important as language is an integral component of Indigenous culture; as Tait (2003), explains, "when a language dies, the world dies, the world it was generated from breaks down too" (p.52).

Though there were many attempts to keep languages alive, ultimately many survivors lost their ability to speak their Indigenous languages. While the number of Indigenous people who speak their Indigenous language has declined in the last 100 years, there is currently a revival of Indigenous people learning their language. This revitalization can in part be attributed to the healing movement; Indigenous people have been reconnecting with cultural roots as a means of healing (Legacy of Hope Foundation, 2011). In terms of healing, it is a process, it is long-term, and it starts with the individual and expands to include the community as the community can also be impacted by intergenerational impacts, such as poverty, ineffective parenting, abuse, grief, and health issues (Legacy of Hope Foundation, 2012). Gray (2011) notes, "Ironically, the creation of reserves ultimately acted against the government's attempts at assimilation as First Nation people were able to maintain somewhat insulated communities and a land base from which to retain our culture and communities" (p.58).

Culture is important when talking about Indigenous people. Indigenous culture is thought to be the solution to healing. The very fact that Indigenous people fought to maintain and subsequently revitalize their culture, despite the efforts of the government and churches to strip the culture away, speaks volumes as to the importance of culture to Indigenous people. Harris and McFarland (2000) identified specific factors that can be protective for Indigenous people, including: spirituality, culture, family, traditions, celebrations/recreation, and health and medicine. Conversely, Indigenous youth who are less connected with cultural practices have been found to be 4.4 times more likely to misuse alcohol (McIvor, Napoleon, & Dickie, 2009). Furthermore, Indigenous youth who are culturally connected or in the process of exploring their cultural identity have been shown to be at less risk in terms of risk for violent offending compared to Indigenous youth

who are have low cultural connections. Perhaps, Indigenous youth who are highly connected to their culture, or exploring their identity are better equipped in navigating difficulties faced, and engaging in less risky behaviours (Rogers, McLachlan, Viljoen, & Roesch, 2014). Not only does a connection with one's own culture protect against adverse outcomes, but involvement in cultural traditions can also contribute to prosocial behaviours (Whitbeck et al., 2002). The benefits of spiritual practices and traditional activities, such as smudging and sweat lodge ceremonies, can have transformative and positive impacts on individuals (McIvor, Napoleon, & Dickie, 2009). For instance, Indigenous youth in BC youth custody who indicated that they speak a traditional language at home (16%) also indicated that they had positive future aspirations and goals (Smith, Cox, Poon, Stewart, & the McCreary Centre Society, 2013), further indicating the importance of cultural involvement, in particular language.

1.3. Fetal Alcohol Spectrum Disorder

FASD Outside of Canada

Despite the misconception that FASD is an Indigenous specific problem, implying that there are genetic risks for those with Indigenous ancestry (Chudley et.al, 2005), the fact is FASD is neither genetically linked to Indigeneity, nor is it an Indigenous-specific problem. In fact, FASD can be seen worldwide as the first documented case of FASD was by French doctors in 1968 (Astley, 2004; Streissguth, Bar, Koga, & Bookstein, 1997). A recent meta-analyses of prevalence rates among 10 countries found substantial differences in prevalence rates of FASD, seeing the highest prevalence in South Africa, with 113.22 per 1,000, followed by Italy, the United States, and Canada (47.13, 33.5, and 30.52 per 1,000 respectively; Roozen et al., 2016). However, as with many meta-analyses, interpreting findings should be taken with caution due to the differences between studies and methodology. Furthermore, there is an additional layer of complication with meta-analyses involving FASD, as there are inherent limitations of assessing and diagnosing FASD in itself, which complicates the interpretation of meta-analyses.

South Africa

As noted above, South Africa has one of the highest prevalence rates of FASD worldwide (May et al., 2007; Roozen et al., 2016; Viljoen et al., 2005). While Roozen and colleagues (2016) found a pooled-prevalence of 113.22 per 1,000, May et al. (2013) found estimates ranging from 135.1 to 207.5 per 1,000 in first graders in the Western Cape Province, with highest rates being in rural impoverished areas (May et al., 2007, 2013). Interestingly, while Canada and the United States see more cases of ARND, South Africa has the highest rates of FAS, and pFAS (May et al., 2016).

There is a pressing need for public awareness and education around alcohol consumption during pregnancy in South Africa. In an attempt to understand what men and women in an urban township of Cape Town, South Africa believe about the use of alcohol during pregnancy, and how alcohol effects a developing baby, Eaton and colleagues (2013) surveyed patrons of alcohol establishments. Their study found that, many did not believe alcohol consumption during pregnancy was harmful, but rather, many men believed alcohol during pregnancy was safe. Further, both men and women believed alcohol was not harmful to the fetus, and 40% of pregnant women disagreed that pregnant women should abstain from alcohol. Community-level interventions aimed at increasing knowledge around FASD and shifting social norms have been shown to be effective in South Africa (Cherisch et al., 2012). While South Africa has the highest prevalence of FASD in the world, compounding the difficulties is the limited access to clinicians in some communities, and the lack of physicians who are trained to recognize and diagnose FASD (O'Connor et al., 2014).

Assessing and diagnosing FASD poses several challenges due to a level of subjectivity in assessing cardinal facial features. As such, the importance of normative data cannot be discounted, as applying non-normative data on populations can have implications on diagnoses. Given the complex nature of diagnosing FASD, a population-

specific lip and philtrum[7] FASD diagnostic guide was developed in South Africa, which acknowledges facial differences across racial groups (Hoyme et al., 2015).

Italy

On September 9, 2011, Italy celebrated FASD Awareness Day for the first time (Pichini et al., 2012). The first study to determine the prevalence of FASD in Italy focused on school-aged children. In this study, the authors found the prevalence of FASD was 20.3 to 40.5 per 1,000 (May et al., 2006). While the 2006 study was the first among school-aged children in Italy, the first national cohort study focusing on prenatally exposed newborns in Italy was completed in 2012, and showed a total prevalence of 7.9% across seven sites, ranging from 0% in Verona to 29.4% in Rome (Pichini et al, 2012).

Studies on FASD in Italy have also focused on maternal factors related to having a child living with FASD. Studies have found educational differences between mothers with children living with FASD and the control group (May et al., 2016), and differing drinking patterns between mothers of children living with FASD and the control group (Ceccanti et al., 2014). Mothers of children living with FASD have been found to have lower levels of education, report higher levels of drinking behaviours currently and prior to pregnancy, and mothers of children living with FASD were more likely to endorse solitary drinking (Ceccanti et al.; May et al., 2016). Furthermore, a study focusing specifically on drinking behaviours in Italian mothers before and during pregnancy found that of the 34.8% of the sample who were drinkers prior to pregnancy, only 5.5% abstained upon learning of their pregnancy, with more women abstaining the older they were (Bonati and Fellin, 1991).

Public awareness and education around alcohol consumption during pregnancy is also needed in Italy, particularly among women of childbearing years, and medical professionals. With respect to practice and awareness of FASD among medical professionals in Italy and Spain, it was found that despite awareness of the dangers of

[7] As noted above, a diagnosis of FASD can be made with sentinel facial features. The sentinel facial features include: (a) short palpebral fissures where the length of the individual's eyes are short and give the appearance of small eyes; (b) a smooth and flat philtrum which is the area between the nose and the lips; and (3) a thin upper lip (Cook et al., 2015)

consuming alcohol while pregnant, 50% of the Italian paediatricians, and 40% of the Spanish paediatricians allowed women to drink wine or beer during their pregnancy. Furthermore, it was found that neonatologists and paediatricians had low confidence with respect to diagnosing FASD, citing inadequate training (Vagnarelli, García-Algar, Falcon, et a., 2011).

Australia

National prevalence rates on FASD are unknown in Australia (Australian Institute of Health and Welfare, 2015). Several factors have been identified which contribute to the challenges around determining the national prevalence rates, as there is a lack of knowledge around diagnostic criteria among health professionals, and there may be reluctance to diagnose FASD due to the stigma associated with the label (Burns, Breen, O'Leary, & Elliott, 2013). Furthermore, there are variations in how data is collected, and consequently there is incomplete data that is being collected. For instance, while Australia has a state prevalence data system, which includes a birth defects registers, only four states are included, and data on alcohol consumption during pregnancy is not consistently collected (Burns, Breen, O'Leary, & Elliott, 2013).

Despite there being no national prevalence data, a recent study focused on patterns of maternal alcohol use among Indigenous women in Western Australia. Invited to conduct the research by the community, this study found that rates of maternal alcohol use among Indigenous women parallel that of the general population (59% of those sampled consumed alcohol during pregnancy). However, while the rates of alcohol consumption during pregnancy were equivalent among Indigenous women and women in the general population, the quantity and frequency of alcohol consumption were elevated for Indigenous women in this study; 4% of the non-Indigenous women in the general population reported drinking 5 or more drinks per occasion during pregnancy, while 47% of the Indigenous women in this study reported consuming 5 or more drinks per occasion during pregnancy. The author notes, that these patterns necessitate interpretation within historical context (Fitzpatrick et al., 2015).

Latin America

Few studies regarding FASD have come from Latin America. The exceptions are Chile and Brazil. A study in Chile looked at demographic and descriptive statistics of mothers and children living with FASD and found that mothers in their study consumed more alcohol during the period in which they conceived and discovered their pregnancies, and only 14.1% of the mothers abstained upon learning of their pregnancy (Kuehn et al., 2012).

Children in care are at higher risk for FASD, often due to circumstances that bring them into care in the first place (e.g., neglect, parental substance misuse). In a meta-analysis to determine the prevalence of FASD in children in care, inclusive of foster care and orphanages, a pooled prevalence of 169 per 1,000 (16.9% was found, ranging between 109 to 238 per 1,000 (Lange, Shield, Rehm, & Popova, 2013). In another meta-analysis focusing on foster care, authors reported a range between 305 and 520 per 1,000 prevalence of FASD (Ospina & Dennett, 2013). A study exploring the rates of neurodevelopmental disorders and FASD in a Brazilian orphanage, found that nearly half of the children in the orphanage had mothers who abused alcohol, and 17% of children living in the orphanage showed signs of FASD, while 50% were found to have neurodevelopmental disorders (Strömland et al., 2014).

Lack of awareness

There is a general lack of knowledge and awareness of FASD and the impacts of alcohol consumption while pregnant. In Israel, this lack of awareness can be seen particularly among physicians and medical personnel who attend to pregnant women. Consequently, consuming alcohol is frequent among pregnant Israeli women (Senecky, 2012). Senecky notes there is a need for awareness and education around the risks of consuming alcohol while pregnant, and FASD, not only with the general public, but also within the medical profession. In Poland, it was found that many women are not aware of FASD. It was also found that 29% of Polish women who have been drinking in the past 12 months have been doing so while pregnant (Borkowska, 2012).

A Profile of FASD within Canada

In Canada and the USA, the prevalence of FASD is estimated to be between 1 in 100 for Canada, and 2-5% for the United States (May et al., 2009; Stade et al., 2009). While it has been estimated at 1 in 100, Clarren and colleagues (2015) note the number of new diagnoses made in Canada each year is unclear (Clarren et al., 2015). Several factors limit the ability to establish the true prevalence of FASD in Canada, including clinical capacity, accessibility of assessment services, and stigma associated with receiving a diagnosis of FASD (Aspler et al., 2015). With respect to Aboriginal people, the prevalence of FASD in Indigenous populations varies greatly depending on the study, however the pooled prevalence of FASD has been found to be 2 per 1,000 (0.2%). In a recent meta-analysis, the authors found that prevalence rates were higher for Indigenous youth in corrections (26.9%) versus community samples (0.17%; Ospina, & Dennett, 2013).

With respect to the effects that FASD can have, these include growth delays, dysmorphic facial features, and central nervous system impairments, that can vary greatly in terms of the combinations and severity (Nicholson, 2008; Pacey, 2008). Clarren et al. (2015) notes that there is no common profile of the functional impairments or deficits, and the symptoms of FASD manifest differently within each individual. When it comes to the effects of FASD that youth face, research has found that youth living with FASD are often faced with mental illness and substance abuse (OFIFC, 2013), trouble with the law, victimization, institutionalization, unemployment, ADHD, executive functioning, abstract reasoning, language disorders, learning disorders (Chudley et al., 2005; Clarren et al., 2015). For Indigenous youth living with FASD, the Ontario Federation of Indigenous Friendship Centres notes that Indigenous youth are also faced with disconnection from their culture, social and cultural isolation, histories of trauma, systemic racism, and a lack of belonging (OFIFC, 2013). Most frequently, following a diagnosis of FASD, clinicians recommend support programs and services, such as social and life skills programs, mental health and legal services, speech and language therapy, and educational supports and modifications (Clarren et al., 2015).

The effects of FASD are life long and continue into adulthood. As youth living with FASD become parents themselves, they are also faced with challenges around memory, impulsivity, planning, emotional regulation, addictions, housing instability, and a lack of supports and services (Rutman & Van Bibber, 2010). With respect to service utilization, youth living with FASD are more likely to be hospitalized than the general population, or those with asthma. When hospitalized, for those living with FASD, it was more frequently due to mental health concerns versus respiratory concerns and injury for those with asthma and general population. In terms of prescriptions, individuals living with FASD are eight times more likely to be prescribed psychostimulants, and six times more likely to be prescribed antidepressants compared to the general population (Brownell et al., 2013)

Given the complex challenges, needs, and services that individuals in Canada living with FASD require, the projected annual cost to support those living with FASD, based on the estimated prevalence of 1 in 100, is $5.3 billion dollars (Stade et al., 2009), while Clarren, Salmon, and Jonsson (2011) report the annual costs for health services at $2.1 billion. These estimates are inclusive of direct and indirect costs of social services, specialized education, health care, and justice and legal costs (CanFASD, 2012). Narrowing specifically on youth custody costs, the direct costs for youth with FASD in Canada between 2011 and 2012, aged 12 to 17, has been calculated at approximately $17.5 million dollars (Popova, Lange, Burd, & Rehm, 2015).

In 2006, the province of BC provided 10 million in funding to non-profit organizations with the objective of improving the lives of those living with FASD through education, prevention and programming (George & Hardy, 2014). While there are efforts to educate and increase awareness of the effects of alcohol consumption during pregnancy, evidence to support the effectiveness of such campaigns are lacking (Ospina, Moga, Dennett, & Harstall, 2011). In fact, it has been argued that awareness campaigns around FASD may inadvertently contribute to the stigma and blame towards mothers who consumed alcohol during pregnancy; the awareness campaigns do not include the various social factors contributing to alcohol use during pregnancy (e.g., limited access to health care centres; poverty). The use of the language that it is ‘one hundred percent preventable’ unintentionally sends the message that mothers are personally responsible, which does not account for systemic or social factors, and negates society’s contribution to the issue

and their responsibility to address the larger social problems (Bell et al., 2016). In BC, there are four provincial initiatives, including assessments and diagnosis for children under the age of nine; a key worker and parent support program; the provincial outreach program for FASD which educates teachers on strategies for teaching youth living with FASD; and a cross-ministry provincial plan called *Fetal Alcohol Spectrum Disorder: Building on Strengths. A Provincial Plan for British Columbia 2008-2018*, with commitments from ministries (George & Hardy, 2014).

Misperceptions, Stigma, and System-Level Barriers

The presence of inconclusive research around safe levels of alcohol consumption during pregnancy, such as research failing to show neurodevelopmental effects as a result of mild-to-moderate alcohol consumption during pregnancy, is leading the public to believe that drinking while pregnant is acceptable (Chan & Koren, 2013). This misconception is further exacerbated by medical professionals who do not refute the need to abstain from alcohol while pregnant, and rather note that mild drinking is okay. For instance, in a study on the knowledge and perceptions of medical students and residents, it was found that roughly one-quarter of pre-clinical medical students stated it was safe to consume one drink per day during a woman's pregnancy (Elizabeth et al., 2007). As noted in their study, this is contrary to the US Surgeon General's stance on the dangers of alcohol consumption during pregnancy, stating that "no amount of alcohol consumption can be considered safe during pregnancy" (US Surgeon General, 2005). There also exists a misperception around the timing of alcohol consumption, such some believe that consumption during the later stages of pregnancy is less harmful to the developing baby (Chan & Koren, 2013).

Despite self-reported acknowledgment of the seriousness of FASD, all health professionals in a study in Australia believed that consuming small amounts of alcohol while pregnant was not likely to cause harm. One health professional in this study commented, "I think the problem is too much alcohol, real alcoholics. That can cause brain injuries. We learnt about Foetal Alcohol Syndrome as part of midwifery training. But I think it is an issue in Aboriginal women'' (Crawford-Williams, Steen, Esterman, Fielder, & Mikocka-Walus, 2015, p. 332). Finally, there is this misconception that FASD is an ethnic

issue, that there is a biological or genetic predisposition among Indigenous people, which is unfounded and false (Chudley et al., 2005; OFIFC, 2013; Tait, 2003).

In Canada, of the FASD diagnostic categories, research has shown that ARND is the most frequently diagnosed (83.7%), followed by pFAS (13.5%) and FAS (2.1%), and as such, many of those living with FASD do not have dysmorphic facial features, consequently making the disorder invisible (Clarren et al., 2015). Due to the invisibility of FASD, those living with FASD are often stigmatized by those they come in contact with. Oftentimes, youth are misunderstood and labelled as lazy, disobedient, disruptive, unwilling to comply, or uncooperative, rather than experiencing difficulties related to brain injury (Farsai, 2010; OFIFC, 2013; Stewart & Glowatski, 2014). These stigmatized perceptions can impact a youth's ability to make friends and achievements academically (Bell et al., 2016). Furthermore, the stigma associated with FASD has implications for youth being excluded from programming, as systems are using information around FASD as exclusionary criteria (Masotti et al., 2015). This stigma of being non-compliant, can lead to parents living with FASD to not seek supports or assessments due to fear of being labelled as an incompetent parent and having their children removed from their care (Rutman & Van Bibber, 2010).

The stigmatized perceptions of FASD being an Indigenous-specific problem has led to stereotyped discussions around diagnoses, where symptoms that suggest ADHD have been attributed to different disorders depending on the ancestry of the youth. For instance, discussions around ADHD symptoms tended to be attributed to FASD in Indigenous youth, while not in other populations (Oldani, 2009). Further, in a study of health professionals in Australia (e.g., general practitioners, obstetricians, midwives), health professionals were asked about their knowledge of FASD and adherence to government guidelines. It was found that health professionals in this particular study held perceptions about FASD that contribute to stigma associated with FASD. For instance, comments made by general practitioners and midwives in this study included, "Could I actually delineate what the adverse effects are? Well no I can't actually describe that, I could google it and tell you all about it. I know that they are funny looking kids and I think they have got retardation problems and developmental problems but certainly couldn't describe a lot more'" (Crawford-Williams et al., 2015; p. 331).

Stigma around FASD knows no bounds, as youth are not the only ones impacted by FASD, and different groups experience the stigma including biological parents, adoptive and foster parents, communities and society at large (Bell et al., 2016; Corbett, 2014). Biological mothers with children living with FASD can experience stigma related to personal responsibility and blame, and there are perceptions of mothers being unfit parents; the diagnosis in itself is stigmatizing given that it documents the mother's role in prenatally exposing a child to alcohol (Aspler et al., 2015; Bell et al.). Furthermore, there exists the perception around negative life trajectories for those living with FASD, where the life of someone living with FASD will be filled with crime, drugs and alcohol (Bell et al.). In one study, despite officers expressing an understanding of the intersection between behaviours associated with FASD and justice involvement, they felt as though FASD should not be a mitigating factor (Stewart & Glowatski, 2014).

Youth who are living with FASD are also faced with systemic barriers, as the system in which they are navigating is complex and challenging. To begin with, the differing funding policies serve as a barrier for both youth living with, and parents of children living with FASD, as there exists unequal funding between foster, adoptive and birth families (Farsai, 2010; OFIFC, 2013; Rutman & Van Bibber, 2010). Depending on whether you are a foster parent, adoptive parent, biological parent, or extended family caregiver, the funding for support varies significantly. Foster parents have access to home support workers and respite care, while biological parents and extended family caregivers are left paying out of pocket for the same resources and supports (OFIFC, 2013; Rutman & Van Bibber, 2010). Supports that are available to those living with FASD through community living BC require that the individual have an IQ less than 70 to receive support such as supportive housing (Farsai, 2010). Ultimately, foster families are allocated the majority of the supports and funding compared to adoptive parents and biological parents (Farsai, 2010). Furthermore, when it comes to youth in conflict with the law, there is a lack of alternatives to incarceration for those living with FASD (Stewart, 2015). There is an explicit need for specialized courts such as mental health courts, and diversion programs to expand their mandates to address the needs of those living with FASD (Burns, 2015).

Those living with FASD could benefit from an array of services and supports, yet, the services and supports that they need are often fragmented, operating in silos (Farsai,

2010; Masotti et al., 2015; OFIFC, 2013), plagued with staff who do not understand FASD fully enough to understand the implications for learning (Farsai), or include strict guidelines and policies that are incongruent with the needs of those living with FASD (OFIFC, 2013). Masotti and colleagues (2015) explain that there is a lack of services in rural and First Nations communities, and the waitlists are increasing, while resources are insufficient.

Furthermore, access to assessments has been identified in the literature as a barrier, in that access to both assessments and diagnoses are both limited and lengthy in process (Aspler et al., 2015; Masotti et al., 2015; OFIFC, 2013). Burns (2015) further notes that access barriers are not limited to assessment and diagnoses, but also extend to disability supportive programs and supportive housing.

Linked to issues around a lack of awareness, the medical system is not immune from misperceptions around FASD, and consequently, deficient practice. For instance, one study found that there was resistance among health professions around prevention of FASD, as health professionals resisted having discussions with their patients around alcohol consumption (Crawford-Williams et al., 2015). Furthermore, a study on practices of hospital medical students and residents found that medical students were more likely than resident physicians to screen women for alcohol consumption during their pregnancy (Elizabeth et al., 2007). Ultimately, there are gaps in knowledge about FASD throughout the various health professionals, and the lack of professionals trained on FASD serves as a barrier to early diagnoses (Masotti, Longstaff, Gammon, Isbister, Maxwell, & Hanlon-Dearman, 2015; OFIFC, 2013).

Needs of Those Living with FASD

The following section describes the complex and interconnected needs of those living with FASD, including needs around: awareness, training, education, diagnoses, support, and culture.

Awareness, Training, and Education: Individuals living with FASD need trained and educated professionals on matters related to FASD. When it comes the training and education, there is a need for culturally informed and sensitive education for health professionals on various aspects of FASD, ranging from the causes, contextual factors,

the effects, the importance of prevention, and the cross-cultural occurrence (Crawford-Williams et al., 2015). Training and education within the justice system has also been identified as a need among police, judges, lawyers and correctional staff (Masotti et al., 2015; Stewart, 2015). For example, officers in a study expressed interest in learning how to effectively interact with individuals living with FASD, and information on how their behaviour is impacted by FASD; officers indicated that they wanted more information so they can manage situations at the front-line (Stewart & Glowatski, 2014). Perhaps a standard curriculum could be developed for professionals who will undoubtedly come in contact with individuals living with FASD (OFIFC, 2013). There is a need to educate those who will be supporting youth living with FASD by raising awareness of FASD and the youths' need for support at a brain-based level (Kyle, 2016). Brain-based support can be in the form of acting as an "external brain" for the youth, where parents, teachers and support workers help the youth in areas where there are deficits related to their brain injury. For instance, external brain support can include supporting executive functioning, such as supporting them with emotional regulation strategies, memory strategies, or flexible thinking (Green, 2007).

Raising awareness broadly among the general public has also been identified in the literature as a need. For example, a more accurate depiction of FASD in Canada where Indigenous specific images are not used was noted as a necessary step to combat the misconception that FASD is an Indigenous issue (Bell et al., 2016; OFIFC, 2013). Some have recommended that awareness campaigns be tailored to specific audiences, such as how men, community, and families can prevent FASD (Bell et al.). Beyond the dangers and effects of prenatal alcohol exposure, there also needs to be public awareness around the underlying socioeconomic, and system-level factors that contribute to mothers drinking while pregnant (OFIFC, 2013).

Diagnostic Needs: For those living with FASD, receiving a diagnosis is critical as it is a prerequisite for supports, such as special education, funding, persons with disability allowance (Farsai, 2010; Masotti et al., 2015). Following the assessment and subsequent diagnosis of FASD, youth need recommendations that are basic, individualized, and realistic; for instance, despite a recommendation that youth living in supportive housing throughout adolescents and adulthood, supports and services are removed upon reaching

age of majority (Farsai, 2010). With respect to diagnosing FASD, Farag (2014) explains that currently, some countries use the relaxed Institute of Medicine (IOM) diagnostic criteria, while others use the strict 4-Digit Code, while others are using the Canadian guidelines, which is a harmonization of the two. The variability in diagnostic guidelines has led to inconsistencies in prevalence rates. In order to achieve consistent incidence and prevalence reports throughout regions, a global standard for diagnoses is needed.

Support Needs: Individuals living with FASD have complex, multi-system needs that necessitate holistic and integrated support, as the combination of secondary and primary deficits increase the complexity of care required. The multi-system needs include, health, mental health, remedial education, medical, social services, such as supportive housing, legal support and food bank supports (Brownell et al., 2013; Clarren et al., 2015; Farsai, 2010; Popova et al., 2015; Thanh, Moffatt, Jacobs, Chuck, & Jonsson, 2013). Given the wide range of assistance from multiple service systems that youth living with FASD need, it is not unreasonable that these youth also need a collaborative and holistic wrap-around approach to care as they move from childhood to adulthood (Masotti, Longstaff, Gammon, Isbister, Maxwell, & Hanlon-Dearman, 2015). The need for support does not stop as a youth becomes an adult, but rather, lifelong and sustained support is needed into adulthood (Farsai, 2010). Furthermore, from a systems-level policy perspective, there is great need for supports to be available based on functional needs rather than IQ related criteria (Rutman & Van Bibber, 2010). In BC, *Community Living BC* (CLBC) has broadened their eligibility for funded support services beyond their criteria of having an IQ score two standard deviations below the mean (100), and have established a second streams for those living with *autism spectrum disorder* (ASD) and FASD. However, in this additional stream specific to those with ASD and FASD, there remains a fixed and arbitrary adaptive functioning cut-off at least three standard deviations below the mean (Greenspan, Brown, & Edwards, 2015).

With respect to education, appropriate learning environments are essential for youth living with FASD, as one size does not fit all (Farsai, 2010). For instance, accommodations to learning styles and behaviours are critical for success; as Duquette, Stodel, Fullarton, and Hagglund (2007) found that accommodation such as homework assistance and permission to leave the classroom when feeling overwhelmed and

frustrated was a key to success. Additional modifications and accommodations include a focus on positive reinforcement (Green, 2007), and learning approaches that are experiential and hands-on are needed (Rutman & Van Bibber, 2010). Focusing on the whole child, such as their physical, mental, emotional and social well-being, and building capacity within the school, among staff and personnel have also been identified as a priority for students living with FASD (Pei, Job, Poth, & Atkinson, 2013). Additional support needs of those living with FASD include approaches that come from a strengths-based and empowering place of working (OFIFC, 2013), and respite care coverage to assist families in coping with the challenges of raising a child living with FASD (Farsai, 2010; OFIFC; Olson and Montague, 2011).

Given the multiple systems that youth living with FASD require, cross-sectoral integrated services are needed (Burns, 2015; Masotti et al., 2015). Green (2007) notes that a system of integrated supports is essential for successful outcomes, though there are barriers to integrating systems, such as awareness and training on FASD among both medical and non-medical service providers. Furthermore, privacy policies limit the ability of different sectors from communicating (Masotti et al.).

Cultural Needs: Culture and healing is needed for Indigenous youth and families living with FASD (Farsai, 2010). Furthermore, Indigenous youth and families living with FASD need services and supports that are culturally appropriate and culturally safe, that foster cultural restoration, healing and historical circumstances that contextualize FASD in Indigenous communities (Farsai, 2010; OFIFC, 2013; Rutman & Van Bibber, 2010).

In terms of what has been identified as working well for those living with FASD, the literature has reported that relationship-based approaches where staff are non-judgemental, holistic programs that are culturally based and address the individuals needs holistically, service providers who are knowledgeable on the complex issues and needs of those living with FASD, and one-on-one support (Rutman, 2013). Parenting programs focused on parenting a child with FASD have been shown to reduce behavioural problems of children and youth living with FASD. Neurocognitive therapy and attention training has also improved skills within school aged children living with FASD (Australian Institute of Health and Welfare, 2015).

1.4. About the Evaluand

The Program

The Program that is the focus of this evaluation is a 3-year project that provides holistic, culturally informed support services to Aboriginal youth referred for a FASD assessment by youth probation officers in the Lower Mainland. The Program is unique in many ways. First, it is a partnership between an Indigenous organization and a non-Indigenous medical agency that provides FASD assessments. Second, the Program is not necessarily a FASD program, nor is it a justice program; rather, it happens to be a Program that works with a population of young Indigenous people who are both living with FASD and involved in the justice system. At the heart of the Program, the focus is on culture – on exploring, revitalizing, and nurturing cultural connections and Indigenous identity.

The Program provides intervention specific to justice and culture to Indigenous youth, their families and communities, when youth are referred for assessments and throughout their justice involvement. Furthermore, with one female and one male worker, the Program assists youth, family members, and community with respect to rehabilitation of the youth and reintegration within a cultural context.

Program Purpose and Objectives

The objectives of the Program are multifaceted, and aims to:

- ✓ Create an awareness of the association between an FASD diagnosis, co-existing substance use and other life harms, and justice involvement among Indigenous youth;
- ✓ Develop strategies for Indigenous youth assessed for FASD in order to facilitate successful navigation through both the assessment process and the justice system;
- ✓ Reduce the number of Indigenous children living with FASD from being removed from their family and community.

See Appendix A for the program logic model, which outlines program inputs, activities, target groups, and desired outcomes.

Truth and Reconciliation Commission of Canada

In June 2015, the *Truth and Reconciliation Commission of Canada* (TRC) released its summary report, followed by the release of the full report in December, 2015. The full report is six volumes, and details the colonial history, the legacy of the colonial history, and puts forth 94 calls to action. The Program is a timely response given the recent calls to action specifically to address gaps in services for Indigenous youth living with FASD (TRC, 2015). The TRC called to action the following justice and child welfare activities related to FASD:

- Better management of the harmful consequences of FASD
- All levels of government (i.e., federal, provincial, territorial) to prioritize and acknowledge the need to address and prevent FASD alongside Indigenous communities. More specifically, through:
    - Culturally appropriate programs
    - Providing increased resources and powers to courts and communities to ensure the proper diagnosis of FASD and appropriate community supports for those living with FASD, and
    - Appropriately evaluating and measuring the effectiveness of FASD programs
- More programming in Indigenous communities that address addictions and FASD
- Keeping families together in culturally appropriate environments
- Cultural competency training for social workers
- Transparent reporting about Indigenous children in care, and
- Transparent reporting about evaluating effectiveness of interventions

Chapter 2. Evaluation Approach

This section will discuss the evaluation approach taken in this project, including methodologies and principles that guided the evaluation. This section will also discuss the evaluation focus, objectives and questions.

2.1. Indigenous Methodologies

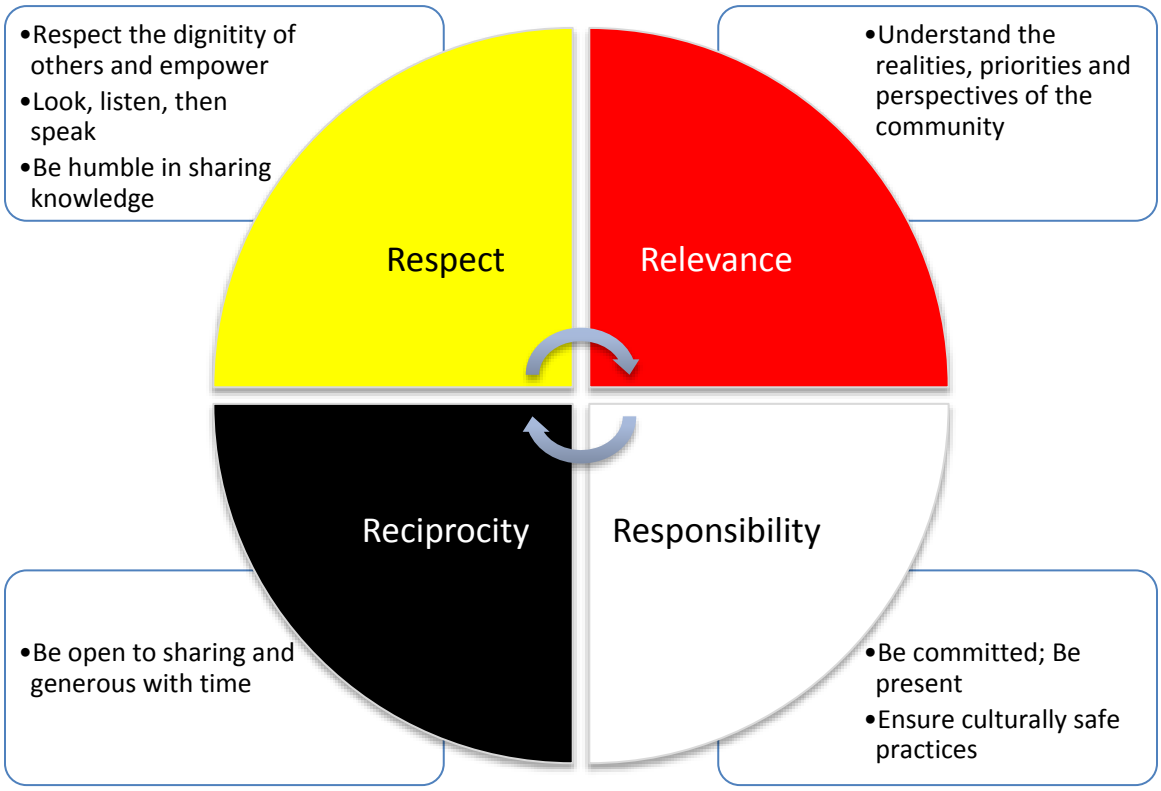
Indigenous methodologies are relational in that they are more than a "how-to" set of guidelines, as there are inherent values and principles rooted in the approach. Principles and values within Indigenous methodologies operate to strengthen communities; sustaining and upholding Indigenous voices and knowledge, rather than exploiting Indigenous people and their knowledge (Kovach, 2009; Ormiston, 2010). Furthermore, Indigenous methodologies challenge power imbalances and the dominant colonial discourse, destabilizing the status quo (Morgensen, 2012; Ruwhiu & Cathro, 2014).

In Indigenous methodologies, the study or agenda is set by Indigenous people, who determine what needs to be studied and what questions are pertinent (Kurtz, 2013; Ruwhiu & Cathro, 2014; Smith 1999). The lens with which one operates is also essential to Indigenous methodologies, as this has implications for contextualizing and interpreting findings. As such, knowledge that is shared by individuals and interpretation of findings ought to be kept in context, and reported in a meaningful manner (Kovach, 2009; Ruwhiu & Cathro, 2014). Finally, Indigenous methodologies are based in reciprocal relationships where there is continual consultation with Indigenous stakeholders throughout the process. As such, Indigenous methodologies are also holistic in nature, infused throughout the entire process from conception to completion (Kovach, 2009; Kurtz, 2013).

This evaluation will be guided through the application of the four "R's" as articulated by Kirkness and Barndhart (1991), and the seven values of Indigenous research as articulated by Ruwhiu and Cathro (2014). The following section highlights the principles of

the 4 R's for Indigenous methodologies, in which the seven values are embedded (see Figure 1).

Figure 1: An Application of Indigenous Methodologies



The Four R's

The four R's and seven values are guiding principles that informed and shaped the evaluation.

Respect: The principle of respect centres around respect for the beliefs, values and differences among different Nations and Indigenous groups; to respect Indigenous knowledge and ways of knowing, and to reflect on what is being seen and heard. Ruwhiu and Cathro (2014) further elaborate that the principle of respect includes values around respecting the dignity of others, while empowering Indigenous people in the research process; building face-to-face relationships and being humble while sharing information. Finally, respect includes listening first and speaking after.

Relevance: The principle of relevance centres around the use of methodological frameworks and ways of knowing that will contribute to knowledge that is relevant for Indigenous individuals, communities, and Nations. In order to do so, Ruwhiu and Cathro (2014) emphasize the need to understand the realities, priorities and perspectives of the Indigenous communities one is working with.

Reciprocity: The principle of reciprocity is rooted in the sharing of knowledge throughout the process so that the results will be useful to Indigenous youth, families, and communities. Furthermore, reciprocity includes meaningfully sharing findings with all stakeholders identified (e.g., participating organizations, agencies, advisory committees, project participants, academic and non-academic communities). Ruwhiu and Cathro (2014) also note that reciprocity is relational in that one ought to be open to share back, and be generous with time.

Responsibility: The principle of responsibility focuses on those completing the research or evaluation, where the researcher or evaluator ensures culturally safe practices, and reports findings in a culturally responsive and meaningful manner that will provide relevant information regarding the directions for the future health and well-being of Indigenous youth, families, and communities.

The OCAP Principles

In addition to the 4 R's and 7 values outlined by Kirkness and Barndhart (1991) and Ruwhiu & Cathro, (2014), this evaluation also acknowledged the role of the OCAP principles: *ownership, control, access, and possession* (First Nations Centre, 2007; Schnarch, 2002; Schnarch, 2004). The principles of OCAP are reflective of self-determination as it is applied to research; it is about Indigenous focused research for and by Indigenous people (First Nations Centre, Schnarch, 2004). The principles of OCAP concern all aspects of information in research, from the creation of information, collection and management of information. Each principle is detailed below:

Ownership: The principle of ownership concerns the relationship that a community or individual has to the information that has been shared, where the information collected

is owned by a community or group in the same way an individual owns their own information.

Control: The principle of control concerns the rights of Indigenous communities and groups to their knowledge and information throughout the entire research process, from conception to completion, including how the information is managed.

Access: The principle of access also concerns the rights of Indigenous communities, groups and individuals to have access to information about themselves.

Possession: The principle of possession is more literal than the relational principle of ownership. Possession concerns where the information is stored and protected. While data can be owned by one party, and possessed by another, there are risks involved when trust is not firmly established (First Nations Centre, 2007; Schnarch, 2004).

The importance of Indigenous methodologies, including the 4 R's, the 7 values, and the OCAP principles, cannot be understated when conducting research in Indigenous communities. With a legacy of bad research in Indigenous communities, there is a reluctance to participate in research (First Nations Centre, 2007). Given that many Indigenous communities are small, the impacts of bad research reverberate through a community at a magnitude unlike it would mainstream society, which is large enough to withstand the impacts (Schnarch, 2004).

2.2. Participatory Evaluation

Participatory evaluation is an approach to social inquiry that complements Indigenous methodologies. Not only do participatory evaluation approaches involve collaborative cooperation between the evaluator and program stakeholders, where program staff are involved in the decision-making with respect to the evaluation (Israel, Schulz, Parker, & Becker, 1998; Rossi, Lipsey, & Freeman, 2004), the approach also intersects with social pedagogy that promotes the improvement of social outcomes for marginalized and oppressed groups (Chouinard, Milley, & Cousins, 2014). The collaborative component of participatory evaluations can be seen in the team approach,

where program stakeholders are involved in the planning, and execution of the evaluation. Program stakeholder involvement in the evaluation is particularly beneficial as their input works to ensure the evaluation is responsive to the needs of the program, creates buy-in, and produces results that will be useful (Rossi, Lipsey, & Freeman, 2004). Furthermore, participatory evaluation approaches are particularly essential when working with Indigenous communities, as the approach facilitates relationship building, gives equal weight to the different ways of knowing, and gives voice to those who contribute to the evaluation (Fletcher, 2003; Kurtz, 2013).

2.3. Evaluation Focus

Formative and Process Evaluation

There are several approaches to conducting evaluations, depending on the information the funder and/or the program is pursuing. For this particular project, the scope of the evaluation focuses on a mixture of aspects from both a formative evaluation, as well as a process evaluation. Formative evaluations focus on garnering information for program improvement. Typically, findings from a formative evaluation are useful for program planners, funders and oversight boards with respect to how and where they can improve the program (Rossi et al., 2004). Similarly, process evaluations speak to information relevant to funders and program planners, focusing on whether the program was implemented as planned; what worked and what did not work in implementing the program as designed, and what the design the right model to implement (Harris, 2010; Rossi et al.). Rossi et al. (2004) explain that "[i]t is not unusual to find that programs are not implemented and executed according to their intended design" (p.56). In assessing the implementation of the program, process evaluations may also consider the context, whether the program is meeting a need, satisfaction levels, and as such, makes recommendations on activities and operations (Harris, 2010). As a means to establish whether the program is meeting a need, the first evaluation activity that is fundamental to program planning and program evaluation is to conduct a needs assessment. As such, the scope of this evaluation also focused on a needs assessment to determine the extent to which the program was meeting demonstrated needs, and to identify areas for program improvement. Rossi et al. (2004) explain that a program cannot be effective if the services

are unrelated to the social problem, or if there is no need in the first place. A needs assessment has been described as a systematic approach to identifying social problems, such as gaps between the current state and desired state, with the goal to support informed decision making around programming (Watkins, Behrens, & Meiers, 2012). Understanding the extent of the problem is integral to a needs assessment, where the evaluator determines the nature, magnitude, and distribution of the social problem or condition (Rossi et al., 2004). Rossi et al. further explain that from an evaluation perspective, a needs assessment demonstrates the need for a program, such as whether or not it is responsive to the current needs of a target population, but furthermore, a needs assessment can inform the program around the need to restructure or expand. A total of five steps are delineated in conducting a needs assessment (Rossi et al., 2004):

1. Who will use the needs assessment findings?
2. Who is the target group of interest?
3. What are the needs, problems, and solutions?
4. What are the recommendations?
5. Who to communicate the findings to?

2.4. Evaluation Questions

With the goal of achieving sustainability, the overall objectives of this evaluation were to gather feedback on the process and implementation of the Program, in addition to conducting a needs assessment, which is an integral starting point for program planning and evaluation. Program evaluation is a way to share knowledge, lessons learned, and program successes, whereas a needs assessment can help broaden perspectives and enhance programming to ensure needs are being met. Based on the evaluation objectives, the evaluation questions are as follows:

1. What are the needs of Indigenous youth and families living with FASD to best serve them?
2. How effective was the design and delivery of the Program?

3. To what extent has the Program been implemented as planned?

4. What are the outcomes of the Program?

5. How have partnerships contributed to the success of the Program?

6. What lessons learned have emerged that can be used to improve the efficiency of the Program?

Chapter 3. Method

3.1. Participants

Program Staff and Management

A total of six individuals directly involved in the Program participated in an evaluation interview, including the family support worker, two Program managers, two executive directors, and one director. The family support worker is an Indigenous woman whose role within the Program is to provide both youth and their families support throughout the FASD assessment process (before, during, and after). Furthermore, as part of her role within the Program, the family support worker provides holistic support to preserve families, preventing children from being removed from families and placed in the foster care system. As this Program is the result of two organizations working together in partnership; each organization has a Program manager. The Program manager of the current Program being evaluated is an Indigenous woman whose role is to support and guide those working directly with the Indigenous youth within the program. The Program manager of the non-Indigenous assessment agency is a non-Indigenous woman who is passionate about the field of FASD. The executive director of the Indigenous partner organization is an Indigenous woman who works in the field of Indigenous justice. The executive director of the non-Indigenous assessment agency is a non-Indigenous woman who is passionate about FASD.

Needs Assessment Stakeholders

A total of 65 stakeholders participated in the needs assessment focusing on the needs of Indigenous youth and families living with FASD (Note: the needs assessment survey and procedures around recruitment are detailed in the procedure section 3.3.). Stakeholders including Indigenous and non-Indigenous organizations, service agencies, and community members with an interest in supporting Indigenous youth living with FASD. A majority of the needs assessment stakeholders self-identified as Indigenous, being from the Vancouver Island region, and working in an organization or service agency that

provides services and supports to Indigenous youth and young adults living with FASD. Table 3 below provides additional descriptive and demographic details.

Table 3: Needs Assessment Respondents' Descriptive Data

Descriptive	% [Count (*n*)]
Self-Identify as	
Indigenous	79.4% (27)
Non-Indigenous	20.6% (7)
Region	
Northern Region	26.5% (9)
Vancouver Island Region	47.1% (16)
Vancouver Coastal Region	17.6% (6)
Fraser Salish Region	5.9% (2)
Interior Region	2.9% (1)
Connection to FASD	
Parent or loved one of an Indigenous youth living with FASD	21.5% (14)
Working in the field of supporting Indigenous youth or FASD	44.6% (29)
Both a parent/loved one, and working in the field of supporting Indigenous youth or FASD	6.2% (4)
Other (e.g., researcher, addictions counsellor, living with FASD)	27.7% (18)

Furthermore, just over half of the needs assessment stakeholders noted that they work for an Indigenous organization (51.6%; *n* = 33). Of the stakeholders who completed the needs assessment in its entirety, they identified several sectors in which they work, including the non-profit sector (20.6%; *n* = 7); health sector (14.65%; *n* = 6), social services and support sector (14.71%; *n* = 5), government (11.76%; *n* = 4) and medical field (5.88%; *n* = 2). Others also identified fields of work such as: tribal council, education system, lands, student, and security (28.6%; *n* = 10). Of the 65 stakeholders who participated in the needs assessment survey, 34 completed the survey in its entirety for a completion rate of 52.3%.

The Program Advisory Committee

The Program is guided by an advisory committee comprised of five leaders in BC with varied expertise, including expertise in justice related Indigenous matters, expertise in FASD, and expertise in Indigenous and holistic health. A total of three of the five advisory committee members agreed to participate in an evaluation interview (one female, two male). Advisory committee members have been experts in their respective fields for many years, with one advisory member having 20 plus years of experience as a Pediatrician, another advisory member having 25 years of experience working in an Indigenous justice capacity, and the other having 40 years of expertise in Indigenous holistic health.

Youth Project Participants

A total of four Indigenous youth involved in the Program expressed an interest in participating in the evaluation of the Program. However, I was not permitted access to interview the youth who expressed an interested in participating. This will be discussed in further detail in sections 5.2 and 5.5.

Despite not having access to hear youth participants' feedback on the Program, demographic information was made available. With respect to describing the youth receiving services the Program provides, a total of 91 Indigenous youth have been involved in the Program since its inception in 2014 (57 males; 34 females) ranging from 12 to 19 years of age ($\bar{x}$ = 16). Of the 91 Indigenous youth on the caseload of the Program, a total of 55 were active, while 36 youth were referred but support services were not provided, as the youth were unreachable. Despite being unable to reach the 36 youth, the Program continued to work on those youths' files, as they were connecting with probation officers, social workers and legal guardians. Of the 55 youth who were actively involved in the Program, a total of 12 youth reconnected with their cultural community (21.81%), and 47 participated in cultural activities with the Program workers (85.45%), of which many had multiple cultural contacts with the Program workers.

Family and Legal Guardian Project Participants

A total of one social worker and two family members of youth involved in the Program expressed an interest in participating in the evaluation. However, I was not permitted access to hear the feedback of the social worker and family members. This will be discussed in further detail in sections 5.2 and 5.5.

3.2. Measures

Needs Assessment Survey

Following an evaluation-scoping meeting held with the Program management and host partner agencies, I developed a web-based survey for Indigenous and non-Indigenous organizations, and community members with an interest in supporting Indigenous youth living with FASD, which aimed to garner a greater understanding of the needs of Indigenous youth and families living with FASD in the province of BC. The needs assessment survey consisted of 13 open-ended questions. The development of the needs assessment questions was rooted in the five steps of conducting a needs assessment as outlined by Rossi, Lipsey, and Freeman (2004): Who will use the findings?; Who is the target group?; What are the needs, problems, solutions?; What are the recommendations?; and To whom will the findings be communicated? The purpose of the needs assessment was to demonstrate the need for the Program, and the extent to which the Program is responsive to the current needs of the target population the Program is serving. As such, the scope of the needs assessment was focused on highlighting the current landscape for Indigenous youth and their families living with FASD, and their needs with respect to their cultural needs, assessment and diagnostic needs, care and family needs, justice needs, co-existing substance and life harm needs, and ultimately, the need for the Program (see Appendix B for the needs assessment questions).

Program Staff and Management Semi-Structured Interview

A semi-structured interview for Program staff and management was developed by myself, and revised with input from the Program manager. The semi-structured interview aimed to gather information on the needs of youth participants in the Program, in addition

to information on the process of implementing the Program, outcomes, and lessons learned. The semi-structured interview consisted of 30 questions, most of which were open-ended questions, and were developed to address the broader six evaluation questions posed earlier (see section 2.4). The broader evaluation questions are rooted in the evaluation rubric for actionable answers for real-world decision makers developed by Jane Davidson, an internationally recognized evaluation specialist. In her evaluation rubric, Davidson (2009) explains that evaluation questions ought to focus on the following several aspects to produce actionable answers: the quality of the program's design and delivery, the implementation of the program, the outcomes' value and relevance to community and the organization, barriers and successes in implementation, and lessons learned about what went wrong, what went well. As such, each of the questions in the staff and management semi-structured interview were proxy indicators of the broader evaluation questions (see Appendix C for the evaluation interview questions).

Advisory Committee Semi-Structured Interview

A semi-structured interview for the Program's advisory committee members was developed by the myself, and revised with input from the program manager. The semi-structured interview aimed to gather information on the current landscape, including the needs of Indigenous youth living with FASD, and the extent to which the Program was meeting those needs, and the objectives the Program set out to achieve. The semi-structured interview consisted of seven open-ended questions (see Appendix D for the evaluation interview questions).

3.3. Procedure

A participatory evaluation approach to the evaluation was taken. Program staff and management were instrumental in the formation of the evaluation; together the project staff and management and I worked to develop the design of the evaluation, as they assisted in forming the evaluation scope, approach, evaluation questions, and development of evaluation instruments to ensure the findings would be relevant to them.

With respect to the stakeholder needs assessment, I contacted Indigenous listservs, contacts, and organizations in BC, inviting them to participate in the web-based survey. As part of the invitation, I introduced myself, my Nation, and the purpose of the needs assessment, noting that their feedback would be used to inform an evaluation of a Program working to support Indigenous youth and their families living with FASD. In my request to Indigenous listservs, contacts and organizations to participate, I also asked them to forward the survey to colleagues and contacts who could speak to the matter at hand (e.g., the needs, gaps). Prior to participation in the needs assessment survey, participants were informed of the purpose of the needs assessment, and were informed that they had the option to refuse to participate or withdraw at any time without penalty. Participants were required to agree to participate before they could begin. Due to the nature of the questions (some were tailored to family members, some were tailored to professionals) individuals were informed that they might not be able to speak to all of the questions and to answer those that they felt they could. One person did not agree to complete the needs assessment survey and therefore was directed to the final page, in which they were thanked. The needs assessment survey was available from April 15, 2016 to June 15, 2016. For their participation, participants were entered into a draw in which they could win one of twelve prizes, including one $250 gift card from Apple, one of two $100 gift cards from Apple, or one of nine $50 gift cards from Apple.

Program advisory members were recruited with the assistance of Program management. Recruitment was done via facilitated contact methods, as a means to facilitate confidentiality. All five advisory members were approached by the Program manager and invited to participate in the evaluation. The Program manager informed me that three of the five advisory members were interested in participating, and in turn provided me with their contact details. For those who expressed an interest in participating in the evaluation, I reached out via email to introduce myself, describing my Nation, the purpose of the evaluation, and to establish a time to meet by phone or in-person to conduct the evaluation interview. Advisory members were also provided with the evaluation questions in the body of the email. One interview was completed in person, while the remaining two interviews were completed over the telephone. On average, the interviews last 1 hour and 19 minutes (ranging between 43 minutes to two and half hours). In line with the OCAP principles and Indigenous methodologies, evaluation interview notes were

emailed back to the interviewees, as the notes contained their words and they belong to the interviewee. Interviewees were invited to review their notes and provide additional details, delete or modify their words.

With respect to the Program staff, management, and executives' interviews, I contacted them directly to invite them to participate in the evaluation interview. As with the process used in the advisory committee interviews, interview notes from the Program staff, management, and executive interviews were also emailed back to the interviewees, with an invitation to review their notes and provide additional details, delete or modify their words.

3.4. Analysis

This evaluation closely aligns with what Creswell (2013) describes as an intrinsic case study, where the focus on the evaluation of the Project was to understand and describe in detail factors related to a unique case. Alternatively, the needs assessment portion of this evaluation focused on understanding a specific concern (e.g., the needs of Indigenous youth living with FASD), and as such, aligns with the phenomenological study, where a common understanding among several individuals was sought (Creswell, 2013).

The raw data were cleaned and prepared for analyses (e.g., typos were addressed, data were sorted according to the source, and coding document was prepared to organize the codes and themes). With respect to analyses, qualitative data were hand-coded using thematic analyses, grounded in what Creswell (2014) describes as "essence coding" in which portions of the content are coded by ascribing an essence. Furthermore, an inductive framework was applied in this evaluation, where patterns and themes were coded as they emerged, being built from the bottom up, and coded into more abstract units (Creswell, 2014). For example, I did not begin with a theory or assumptions, but rather, I remained open to themes that emerged. However, as I have completed previous research on several of the topics related to this evaluation (e.g., FASD, strengths and resilience, cultural connections and enculturation) and I have lived experience as an Indigenous person, I was not free from preconceptions, and therefore some level of deductive coding was likely present. With respect to the coding process, two additional

coders were recruited with expertise in program evaluation assisted early in the analyses of the needs assessment. Both coders are Indigenous and have graduate degrees; one a PhD in psychology with over 20 years of experience conducting program evaluation and research, and the other a master's degree in public health with six years of experience conducting program evaluation. Both coders are also experienced in conducting qualitative data analyses. The two coders were provided with a synopsis of the literature on FASD, the objectives of this Program, and the rationale for the needs assessment (i.e., to identify needs of Indigenous youth and families living with FASD to inform the extent to which the Program is meeting those needs, and identify areas for the Program to further their focus). For the initial six questions, coding was completed as a group, discussing the essence of the data line or sentence, and generating emergent codes. Creswell (2014) highlights the issue around whether or not analyses should be coded based the essence that emerges from the data, based on pre-determined codes (e.g., a codebook), or a combination of both, and concludes that "the traditional approach in the social sciences is to allow the codes to emerge during data analysis" (p.199). In coding the data, each line, sentence, and paragraph was reviewed by myself and additional coders, and codes were assigned. In this evaluation, the qualitative data analysis process included: sentences being manually chunked, then coded, tallied, then themed and tallied once more. For example, if one respondent says that youth need "someone who will help the youth through all the systems and support their understanding. Someone who will stand up for them and fight for their rights", this would be coded into two distinct codes: *navigators* and *advocacy* and each would be assigned a count (*n*) of one. Following the coding of all responses to the question, the codes were categorized according to a theme, such as ***support***, and each code contributes to the count (*n*) of that theme. In reporting the findings, themes are bolded and presented in aggregate, whereby the count (*n*) represents a number of different codes that emerged from the thematic analysis. Following the analyses where codes and themes were identified, findings were reported, and cross-cutting themes were identified and discussed.

Chapter 4. Evaluation Findings

4.1. Program Needs Assessment

As a needs assessment is a systematic approach to identifying social problems, understanding the current state, desired state and the many needs in between is an integral step. This section will first highlight findings on the current state for Indigenous youth living with FASD, including their strengths, and services available and missing, and will then findings related to the needs of Indigenous youth living with FASD will be provided.

Current State

The strengths of Indigenous youth living with FASD are plenty. Too often, discourse around the topics of Indigenous youth, justice involved youth, and FASD evoke a deficit-based conversation. Rarely is the discourse rooted in a strengths-based manner, where strengths can be leveraged. As such, needs assessment respondents and advisory committee members were asked to share from experience, or speak in general about the strengths, gifts, and positive qualities of Indigenous youth living with FASD. Most frequently, needs assessment respondents and advisory members highlighted youths' **positive intrinsic characteristics and qualities**. Needs assessment respondents frequently spoke about youth living with FASD as being ambitious, gentle, carefree and easygoing, and resilient and focused, while advisory committee members highlighted youths' wise spirits, friendly and pleasant demeanour, and perseverance and willingness. Comments included:

- *Characteristics around something that might be perceived as perseverating; they can turn that into a strength if honed with supports. Had Michael Phelps focused on the fact that he has ADHD instead of his swimming, he wouldn't become the fastest swimmer in the world. We need to turn around characteristics that are part of FASD.*

- *They're always happy. It doesn't take much to make them smile. They have unique ways of processing and understanding information they are taking in, and get so excited when they do understand. They are open to learning new ways to absorb information provided … as the saying goes: 'not trying*

harder, just trying differently.' Teaching new ways to make their life easier to navigate always seems to be welcome.

Staff and management interviewees were also asked to speak about the strengths and gifts of Indigenous youth in the Program. While some of the interviewee's noted that they do not work directly with youth in the Program, they were able to speak broadly about the youths' strengths based on what they have heard from Program staff and management. Most frequently, staff and management interviewees also highlighted the **positive qualities and characteristics** of the youth as strengths, noting that the Indigenous youth in the Program are resilient despite the trauma and adversity they have experienced, and they are thoughtful and caring. Staff and management interviewees also noted that the youth are well-spoken and are good at communicating, and despite their day-to-day struggles they remain committed to their lives and to their culture. Additional qualities that staff and management interviewees indicated as strengths included the leadership qualities of the youth, their sense of humour, their desire to be a part of something important, and their protective and loyal nature. One interviewee commented that "We are family to these young people; they say if you have a problem with her, we're not working with you." It was also noted that the youth in the Program are self-aware; they know when someone has their best interests in mind or when they are being mistreated. Comments from staff and management interviewees included:

- *What blows me away is, you read people's stories before you meet them. And all through youth justice, they have a history of trauma, you kind of read through them, hear behavioural symptoms of their FASD and trauma and you expect pretty hardened people, and usually they are in lots of ways when they come through, but when you break through the harder outer shell and get better relationships with them, you see their thoughtfulness, how they reach out to care for another person and their resilience.*

- *When we look at family histories, and who our families were, and the place our families held in traditional communities, I would expect more than not, that you would find that those youth, despite having FASD and brain damage in 3 brain domains (which is significant), that they have these leadership qualities and personalities and you'd find that would be their traditional role in family and community … that is something that our people believe in have always believed in, you can see that with [the] youth [in the Program].*

Table 4 below provides more details of the strengths and gifts identified by staff and management interviewees, needs assessment respondents, and advisory committee members.

Table 4: Positive Characteristics of Indigenous Youth Living with FASD

Respondent	Count (*n*)		
Needs Assessment Respondents			
Positive Qualities and Characteristics	45	- Ambitious nature, such as their eagerness to help, engage, and work - Gentle and kind way of being - Carefree and easygoing (e.g., willing try anything) - Perseverance and determined (e.g., especially with traditional singing, dancing, and if at own pace) - Resilient - Focused - Content with who they are: "he is who he is. And he is okay with that"	- Sense of humour - Desire for change - Big hearts and caring - Honest - Helpful and generous - Happy - Friendly, likeable - Forgiving, not holding grudges - Smart in unique ways - Sensitive - Dependable - Polite - Patient
Advisory Committee Members			
Positive Qualities and Characteristics	14	- Intelligent, intuitive and "wise, like an old spirit" - Friendly and pleasant - Perseveration and perseverance; willing to try despite repeated failures - Funny - Loving; "generous of spirit"	- Protective and loyal - They see the good in others - Articulate - Observant - Thrive under structure and discipline - Dedicated to culture
Staff and Management			
Positive Qualities and Characteristics	16	- Resilient - Thoughtful, caring - Well-spoken and good communication	- Committed to their culture - Leadership qualities, protective and loyal - Sense of humour

In speaking about the strengths and gifts of Indigenous youth living with FASD, needs assessment respondents, staff and management interviewees, and advisory committee members also highlighted **youths' skills and abilities** as strengths. Needs

assessment respondents noted that many youth living with FASD are creative, and have artistic skills (e.g., drawing, musically inclined). Furthermore, they noted that many youth living with FASD are athletic, good with teamwork and are technologically savvy. Staff and management interviewees also spoke about the youth in the Program as being creative in terms of art, music, and crafts, in addition to youth being skilled at building things. They also noted that many youth in the Program are athletic and good story tellers, while advisory committee members highlighted Indigenous youth living with FASD as being skilled in dancing, singing, physical strength, and creativity. One interviewee commented, "The strengths are many; they are organized, but not the way society expectations are; they are artistic, and musically inclined. When the expectations are broken down in smaller increments, the goal is possible." It was also noted by staff and management interviewees that the strengths of the Indigenous youth in the Program are individual and unique to each person; and the strengths and gifts of the youth will emerge when the youth feel safe, commenting:

- *I think that the strengths and abilities, we are only beginning to see in our youth. Given time, opportunity and resources, they have strengths we don't know about and are only starting to surface when they feel safe, when they have a safe place to be. We haven't found the depth and breadth of youth strengths. They have a tremendous amount of strengths and abilities. They aren't a separate group of people in our communities or society, like everyone, they have strengths and challenges.*

In speaking about the strengths and gifts of Indigenous youth living with FASD, needs assessment respondents also highlighted youths' connectedness, and cultural strengths (e.g., spiritual and traditional), noting that Indigenous youth living with FASD have strengths when it comes to being culturally connected, and connected to family and community. Comments around the strengths, gifts, and positive qualities of Indigenous youth living with FASD included:

- *It is a spectrum and a disability; it's a spectrum of disability and it's a spectrum of gifts … In our aboriginal community, our strengths lie in who we are, cultural values, ceremonies, and relationships. I think all of those are strengths that can be built upon.*

- *They all have gifts to focus on. Those involved in culture, traditions or spirituality have been the most successful. Various skills are abundant.*

Table 5 highlights the skills and abilities of Indigenous youth living with FASD.

Table 5: Skills and Abilities of Indigenous Youth Living with FASD

Respondent	Count (*n*)	Details
Needs Assessment Respondents		
Strengths: Skills and Abilities	11	- Creative and artistic (drawing, colouring, musically inclined) - Athletic - Good team work - Creates own way of understanding thins, takes longer to complete things but they complete it - Technologically savvy (e.g., IT equipment, games, phones)
Staff and Management		
Strengths: Skills and Abilities	7	- Creative: artistic, musically inclined, crafts - Skilled at building things - Athletic - Story tellers
Advisory Committee Members		
Strengths: Skills and Abilities	5	- Skilled dancers, singers - Physical strong - Creative

Acknowledging the strengths of Indigenous youth living with FASD is essential given the barriers they face. Staff and management spoke about the stigma youth living with FASD face, such as being labelled as masterminds of crime or labelled as the leader of the pack. Interviewees noted that often, youth living with FASD are seen as bad apples with issues around social relationships. Not only are youth faced with stigma, but youth in this Program were described as some of the most vulnerable youth in BC, who are also faced with a deficit-based system where the culture of the system is to focus on the challenges.

Available Supports, Services, and Programs

Needs assessment respondents were asked what supports, services, and programs were available in BC. Respondents offered a variety of support and services available, including: FASD-specific supports and services, services for parents, services for youth and children, employment services, holistic health services, mental health and

suicide support services, justice services, substance misuse support services, assessment services, school supports, cultural services, professionals and housing supports. Respondents frequently spoke about FASD-specific supports, such as FASD key workers and FASD workers within Indigenous organizations or health authorities. Further, respondents noted that there are also FASD resource centres that offer programs and services specific to FASD.

Services for parents were also highlighted by needs assessment respondents, as they spoke about the networks and support groups for parents, and supports that the Friendship Centres offer parents and families. With respect to employment services, respondents spoke about job search services such as BC job search, and employment counselling and training services that support employers to hire those with disabilities, or focuses on vocational training. Holistic health services were also identified by respondents as being available, noting that health authorities have intensive care management for mental health, health, legal and are open to alternative cultural and spiritual practices. Mental health counseling and *Aboriginal suicide and critical incident response teams* (ASCRIT) were also identified by respondents as services and supports available. Table 6 highlights the many supports and services identified by needs assessment respondents.

Table 6: Supports and Services Available for Youth and Families Living with FASD

Supports and Services Available	Count (*n*)	Examples
Needs Assessment Respondents		
FASD specific supports and services	9	- FASD workers and FASD support workers within Aboriginal child and youth mental health services, within the health authority, and at friendship centres - FASD resource centres and FASD societies that offer programs and services, like White Crow Village, or Circles of Cedar
Services for parents	6	- Networks and groups for parents, such as Aboriginal FASD caregiver groups, or primary caregiver support groups Friendship centres that support families, they offer holistic support for families
Employment services	6	- Job search services and employment counselling and training services

Supports and Services Available	Count (*n*)	Examples
Needs Assessment Respondents		
Holistic health services	6	- Health authorities are open to alternative cultural and spiritual practices
Mental health and suicide support services	6	- Mental health counseling - Aboriginal suicide and critical incident response team (ASCRIT) and crisis lines for Aboriginal people
Justice services	5	- Justice supports and programs, such as ISSP, community justice programs, justice advocates and navigators, and Indigenous people working in the justice system
Drug and alcohol support services	5	- Drug and alcohol counselling and programs
Child and youth services	3	- Child development centre and Urban youth centres
Assessment services	3	- Diagnostic centres, such as Asante Centre or Sunny Hill
School supports	3	- Schools knowledgeable about FASD, and schools who are aware of the educational needs of those with FASD
Cultural services	2	- Tribal school in one particular community
Professionals	2	- Neuropsychologists and pediatricians
Housing supports	2	- Mainstream housing supports
Interpersonal supports	1	- Such as healthy relationship programs for Aboriginal people
Daily living supports	1	- Such as *community living BC* (CLBC), supports with home care and life skills

Needs assessment respondents also provided comments about the availability, and limitations of services and supports. In doing so, the following themes emerged: quality of support, funding, timing, service operations, follow through, and staff burnout.

With respect to the **quality of support**, respondents noted that often, workers are unresponsive to requests, and do not have the skill level needed to work with youth and families with FASD. One respondent commented, “We have an FASD worker … but they have not responded to our request for services and appear to not have the skill level needed to work with youth or families” while another commented, “Most programs are available, but the question is ‘How effective [are] the programs and supports?’” **Funding** also emerged as a limitation to services and supports, as services are often underfunded or the funding for diagnoses are limited to youth in care. With respect to **timing**, one respondent summed up the limitation by expressing, “There are waitlists. Endless

waitlists." In terms of **service operations**, it was noted that the nine-to-four hours of operation that most services operate under is a limitation and barrier for supports; FASD is twenty-four hours a day, every day of the year, and more supports are needed after hours. Finally, needs assessment respondents spoke about the lack of **follow through** at schools where individualized education plans were not followed through with and the concern around staff burnout. One respondent noted that staff are being overworked, commenting, "We don't have anyone really educated to deal with FASD besides counselors. The counselors here are pretty much doing everything... or expected to do everything and it ends up burning them out. More resources are needed!" Given the barriers, respondents noted that the following are needed in communities: More resources, more FASD specific agencies, services and support after hours, and long term housing.

Program advisory committee members were also asked what resources, services or supports exist in BC to support Indigenous youth living with FASD. They spoke about the Program, FASD specific services and supports, such as community outreach workers, FASD key workers, support groups for FASD parents, and an FASD mentoring program called SOAR. Advisory members also spoke about Indigenous specific supports, such as housing supports, justice supports, and programs offered at the Friendship Centres. One advisory committee member commented, "there are so many generic services for FASD from various health regions, and these work for Aboriginal and non, but specific for Aboriginal, I'm not aware of any outside of [this] Program." Table 7 highlights the respondents and advisory committee members' feedback on the availability and limitations of services and supports in BC.

Table 7: Availability of Services and Supports

Theme	Count (*n*)	Details
Needs Assessment Respondents		
Quality of support	5	- Unresponsive workers, who lack the skills needed to work with FASD
Funding	2	- Underfunded services and funding specific to youth in care, not youth in the community or living with birth families
Timing	2	- Endless waitlists
Service operations	2	- Standard daytime hours of operation do not always work
Follow through	2	- Lack of follow through at schools with IEPs
Advisory Committee Members		
FASD specific services	4	- Community outreach workers, FASD key workers, support groups for parents, and an FASD mentoring program
Indigenous specific services	3	- Indigenous housing supports, Indigenous justice supports, and programs offered at the Friendship Centres
The Program	2	- A program to support justice involved youth before, during, and after an FASD assessment

Missing, But Needed Supports and Services

Needs assessment respondents were also asked to speak to what supports and services are missing in their region, yet needed. In doing so, the following themes emerged: support, programs and activities, services in general, FASD specific service, access to FASD assessments, public awareness, and housing. Most frequently, respondents spoke about **supports** missing from communities, but needed. More specifically, respondents noted that housing supports and housing are needed in communities, as well as respite support for parents of youth living with FASD. School, assessment, and drug and alcohol supports were also noted by respondents. Finally, respondents also noted that family supports, such as group supports for families and supports that bring or keep families together are needed. **Programs and activities** were also highlighted as being needed in communities, such as cultural and land-based groups, programs or camps for youth, or social groups for youth. Parenting programs was also noted as a needed program for those who are living with FASD and have children. More specifically, it was noted that these parenting programs need to be taught in a way that is brain-based and specifically geared to learners living with FASD. Furthermore, programs

that focus on developing life skills, such as self-regulation of emotions, cooking, and laundry were noted as needed programs.

In speaking about services and supports that are missing, but needed, respondents also highlighted a variety of **services** that are needed, such as employment and training, treatment centres, mental health beds in hospitals, and counselling services. One respondent spoke about the limited counselling services available, while another spoke about the circuit health system in their community, which limited the availability of doctors and nurses in their community. With respect to **FASD-specific services and programs** respondents noted that oftentimes they have to leave their community for resources for FASD, and as such, more resources for FASD are needed. Others noted that FASD supports that are culturally responsive or specific to Indigenous youth are lacking but needed. One respondent commented:

> - *We have no FASD agencies in this area specifically geared to Aboriginal youth, it is very much needed especially given the current FASD agency is NOT familiar with the First Nations complete history going back to colonization, assimilation, residential schools.*

Further, respondents spoke about alcohol and drug programs not being equipped to deal with FASD, and there are no treatment centres or programs that are specialized in working with those living with FASD; respondents noted that FASD-informed treatment is needed. In terms of **access**, respondents also noted that clinics need to be closer to communities, as “Assessments and diagnoses are very expensive trips to Vancouver.” One respondent also noted the need for community awareness around FASD as this is currently lacking. Table 8 highlights the supports and services missing but needed and the frequency at which each theme emerged.

Table 8: Supports and Services Missing, But Needed in BC

Theme	Count (*n*)	Details
Needs Assessment Respondents		
Support	23	- Housing supports and housing - Respite for parents of youth with FASD - School, assessment, justice and drug and alcohol supports - Family support groups
Programs and activities	11	- Culture and land-based programs and activities - Social groups for youth - Parenting programs for those who have FASD and have children - Life skills programs
Services	9	- Employment and training services - Holistic health supports and services - Treatment centres - Mental health beds in hospitals - Counseling - Health professionals
FASD specific services and programs	8	- Resources for FASD within communities - FASD supports that are specific to Aboriginal youth living with FASD - Employment services, where employment programs help those with FASD gain employment, but reaching out to employers - Alcohol and drug programs specialized in FASD or youth - Parental supports for parents of youth living with FASD
Access to assessments	5	- Clinics closer to communities - Funding to receive an assessment
Awareness	1	- Communities need to know and be aware of FASD

Advisory committee members also spoke about what services and supports are missing but needed, including the need for supportive housing, restorative justice, rather than incarceration, and workers who are trained on FASD and brain injury. For instance, one advisory member commented:

> *Drug and alcohol workers understand addiction, but not brain injury and FASD. It's setting them up for failure. They don't have the training or understanding of FASD … there's a lack of training on FASD, more focus is on addictions.*

Other services and supports that advisory committee members said are needed in BC included FASD specific programs and services, role models who are living with FASD, mentoring programs where someone can assist with daily tasks and set them up for success, and parental support and advocacy groups. One advisory committee member noted the need for a working group for FASD, commenting, “we need a coordinating body to bring all the strands [services] together to work effectively; like a working committee on FASD.”

Needs of Indigenous Youth Living with FASD

Respondents who participated in the needs assessment were asked to describe the top needs of Indigenous youth living with FASD in order to live their best life. Respondents provided various comments, which were coded and grouped into various themes/categories of needs. A total of thirteen themes emerged as the top needs, including needs around supports, services, education, awareness, culture, belonging, housing, health, environmental conditions, skill development, finances, recreation, and internal needs. Most frequently, respondents highlighted the need for **supports**. For instance, respondents spoke about youth needing a healthy support network of friends, family and community that surround the youth. Furthermore, respondents elaborated that supports need to extend beyond the youth but also support the whole family. Emotional support was also identified as a need, where youth need guidance and patience. Respondents also indicated that youth need advocates and advocacy support, specifically around the judicial system. Additionally, support needs identified by respondents included the need for positive role models and mentors who can help youth build health relationships and steer them in the right direction. Support needs also included support in gaining and maintaining employment. Finally, respondents spoke about the need for day-to-day supports, and support will need to be life-long as FASD is a life-long condition. As such, respondents indicated the need for youth to have strategies that support independent and successful living as young adults and support as they age out of the system.

Respondents also emphasized the need for **services**, noting services such as assessments, brain-based services (e.g., services that acknowledge limitations due to

brain injury and make accommodations, such as dimming lights, reducing audio), family-focused services, and individualized services for youth and services that are rooted in Indigenous culture. With respect to assessments, respondents spoke about the need for timely and professional assessments and diagnoses that fully assess the youth's capacity and for services to consider the recommendations from the assessment and diagnosis report. Furthermore, respondents spoke about the need for external-brain services that support executive functioning, and respite and support services for families. With respect to individualized services, respondents noted the need for services to be adapted at school and at work in order for youth to succeed. Grounding services in culture was also noted by respondents, where they indicated the need for Indigenous-focused healthcare services that are holistic and grounded in the concepts of the medicine wheel, where cultural perspectives are included in the planning of services.

In describing the top needs of Indigenous youth living with FASD in order to live their best life, respondents also emphasized several needs that were categorized under the theme of the **education system**. While most of those who spoke about the need for education in general, others provided more details around education system needs, including the need for the education system to recognize that youth living with FASD require additional support, and youth need access to supports both at the elementary and high-school level. Respondents also highlighted the need for stability in the school environment, the need for schools to implement intervention strategies, and schools that are self-paced education and trauma-informed.

Public awareness of FASD was also noted as a need. Respondents highlighted the need for the public to be aware of FASD, specifically around the behaviours that accompany FASD, the differing levels of functioning, and the invisibility of the disorder. Furthermore, respondents identified the need for those who will be interacting with youth living with FASD to be informed on how they can deal with the behaviours that accompany FASD. For instance, the team of service providers who work with youth living with FASD ought to understand the differing needs and learning styles of those living with FASD. Specifically, respondents identified specific target groups that ought to learn about FASD and how to deal with associated behaviours: Parents and family members, teachers and school personnel, employers, justice personnel (e.g., lawyers, judges, RCMP, youth

probation officers, and correctional officers), frontline workers, such as alcohol and drug counselors and support workers, and first responders. One respondent commented that "FASD is a family disability, all family members need to have education on the disability to be supportive." Finally, in terms of public awareness of FASD, it was also noted that youth need for FASD to be recognized from the community in the same manner autism is recognized, and that people need to see the person first, not the disability.

Culture also emerged as a need for Indigenous youth living with FASD to live their best life. Many respondents noted the need for Indigenous youth living with FASD to have cultural connections, and cultural identity as an Indigenous person. They also noted that working with Elders, learning traditions, and having access to their community's culture if they live in the city are needs of Indigenous youth living with FASD. Finally, respondents spoke about the need for youth to have opportunities to explore their culture in a safe and meaningful way with other Indigenous people. Respondents also spoke about youth needing a **sense of belonging**. For instance, they need to feel loved unconditionally, and to feel accepted, safe, and secure, with a safe place to go. In addition, respondents noted that youth living with FASD need to feel supported from their community and loved ones.

The need for **housing** also emerged as a theme, where respondents spoke about the need for supportive housing (e.g., dependent or semi-independent housing), low income and stable housing, and housing with assisted living where support workers assist in daily routines. Needs assessment respondents also emphasized the **health** needs of youth, noting youth need to have a regular healthy diet with nutritious foods, and adequate sleep. **Environmental conditions** were also noted as a need by respondents, as they spoke about youth living with FASD needing structure and stability in their life, both at home and at school. For instance, respondents spoke about the need for substance-free homes, adult monitoring, and the need for routine structure in their lives.

Needs around **skill development** were also noted as important for Indigenous youth living with FASD to live their best life. In particular, respondents emphasized the need for programming that focuses on building life skills, social skills, self-worth, self-esteem, and communication skills specifically around emotions. Respondents also identified **financial** needs of youth living with FASD, as they require financial support,

secure income, and a financial safety net. The need for disability funding was mentioned frequently. Respondents also highlighted **recreation and leisure** needs, particularly around physical activity and appropriate social outlets. Finally, three respondents noted that youth living with FASD need to know their own gifts, strengths and capacity to success. For instance, respondents noted that youth living with FASD need to be provided with opportunities to succeed. Table 9 below highlights the top thirteen needs identified by respondents

Table 9: Top Needs of Indigenous Youth Living with FASD Identified by Needs Assessment Respondents

Theme	Count (*n*)	Details
Top Needs		
Supports	38	- Personal support networks, emotional support, advocacy supports and support strategies, support through the criminal justice process and restorative justice, a strong family unit and community, positive and accepting role models and mentors, supports around gaining and maintaining employment, and supports for independent living
Services	30	- Brain-based services, family-inclusive services, and Indigenous-specific services
Education system	26	- System that recognizes the needs, provides stability and opportunities
Public awareness of FASD	24	- Public awareness of FASD, what it is, behavioural implications, and strategies for interactions
Culture	18	- Cultural connections, cultural identity, access to culture, and spirituality
Sense of belonging	15	- To feel loved, accepted, safe and supported by communities and loved ones
Housing	15	- Supportive housing, stable housing, with assisted living
Health	13	- Access to nutritious foods, a healthy diet, adequate sleep
Environmental conditions	13	- Structured and stable environments, repetition and monitoring
Skill development	12	- Life skills, social and communication skills
Financial	9	- Financial support, such as disability funding, and a secure income and financial safety net
Recreation and leisure	7	- Physical activity, appropriate social outlets, and an understanding of what activities they are interested in

Theme	Count (*n*)	Details
Top Needs		
Intrinsic needs	3	- To know their own gifts, strengths, and capacity to succeed and given time to be process information
Issues Youth Face		
Policy issues	5	- Lack of assessment options, length of assessment process - Pushed through the education system - Having to be involved in the justice system to access services and diagnoses - Inadequate services where workers do not follow through
Barriers	5	- Regular school system does not work - Lack of resources in isolated communities
Impacts of FASD	3	- Misunderstood by teachers and justice officials as "trouble makers" - Often living in social isolation - Parental sense of failure in raising their child

In answering this question about the top needs of Indigenous youth living with FASD, respondents also highlighted several issues that youth living with FASD face, including issues around: policy, barriers faced, and impacts of FASD. With respect to **policy issues**, respondents spoke about a lack of assessment options, the length of the assessment process being too long, and having youth pushed through the education system which limits their ability to achieve their full potential. One respondent commented:

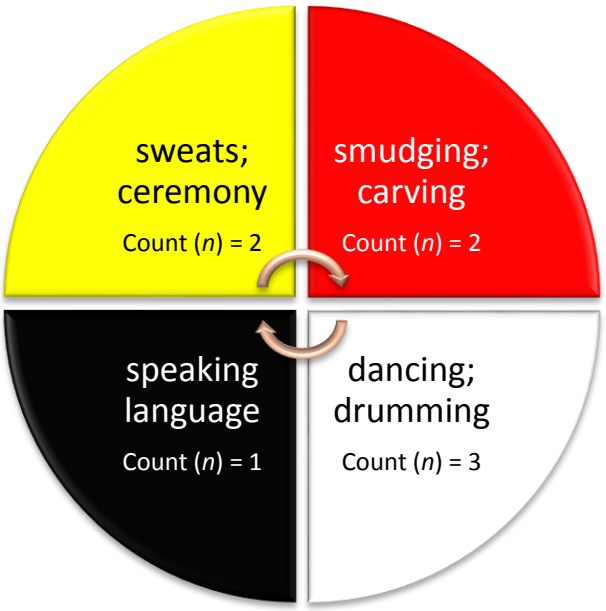
> *Most often children/youth with FASD do not get diagnosed until they are involved in the criminal justice system.*

With respect to **barriers faced by youth living with FASD**, respondents spoke about the regular school system not working for this population of youth. They also noted that they were either unaware of resources available or there was a lack of resources and programs in isolated communities. The **impacts of FASD** were also mentioned by respondents. For instance, respondents spoke about the impacts in terms of stigma, where youth are often misunderstood and viewed as troublemakers. Additional impacts of FASD included social isolation where youth and young adults live in isolation, and the impacts on caregivers carrying a sense of failure with their youth.

Cultural Needs of Indigenous Youth Living with FASD

Respondents were asked to elaborate on the cultural needs of Indigenous youth and young adults living with FASD. A total of five themes emerged, including respondents' explanations for why culture is important, the need for exposure to Indigenous history and teachings, methods for involving youth in culture, and holistic needs that encompass mind, body and spiritual needs. Most frequently, respondents noted reasons for **why culture is important for Indigenous youth**, such as culture creates identity, belonging, and pride. Furthermore, respondents noted that culture contributes to healing, can build on family, community and nations, and can provide guidance. Respondents also spoke heavily about the need for Indigenous youth to be **exposed to Indigenous history and teachings**. For instance, there was an emphasis on the need for Indigenous youth living with FASD to learn about their culture and history, such as the legacy of colonization, or learning the ways of their nation; receiving Elder teachings on how to utilize the land. It was also noted that there is a need for Indigenous youth to be exposed to their specific family history, as one respondent commented: "Youth need to know where they come from, they need to know some basics about their culture in order to know where they are going and to heal in their healing process." Respondents not only identified what Indigenous youth need in terms of culture, but also provided **ways to involve youth in culture**. Respondents noted the need for access to healthy Elders to guide and support youth, while suggesting that youth be connected with people who will encourage cultural activities and programs. Respondents also spoke about the need to adapt activities based on the family context of the youth, the youth's level of cultural connectedness, and the abilities of the youth (e.g., consider a brain injury perspective, utilizing repetition, visual and audio cues). Finally, taking a strengths-based approach in being culturally supportive was noted by one respondent. Many respondents suggested cultural activities that youth could engage in. Figure 2 provides the types of cultural activities in which Indigenous youth could participate.

Figure 2: Cultural Activities



Holistic needs were also identified by respondents, encompassing needs related to mind, body, spirit, and emotion. For instance, respondents spoke about needs related to *mind*, emphasizing the need for Indigenous youth living with FASD to have a sense of self-identity, a sense of belonging, and a sense of pride. With respect to needs related to the *physical being*, respondents highlighted the need for youth to be connected with land and environment, and the need to be involved in traditions and events for social support. In terms of *spiritually*, respondents spoke about the need for Indigenous youth living with FASD to have spiritual connections and connections to Creator. With respect to the *heart,* respondents noted that youth need support systems within their communities. Table 10 highlights the cultural needs of Indigenous youth living with FASD.

Table 10: Cultural Needs

Theme	Count (*n*)	Details
Needs Assessment Respondents		
The importance of Indigenous culture	27	- Culture creates identity, belonging, pride. Culture heals, and guides individuals
Exposure to history, teachings	19	- Learn about the history of Indigenous people in Canada, their specific Nation and family, and learn about land-based teachings
Methods for involvement in cultural	25	- Access to healthy Elders, adapt activities based on level of cultural connection and their brain-injury, and take a strengths-based approach
Holistic needs: mind, body, spirit needs	18	- Sense of identity, pride, belonging, connections to the land and environment, and connections to Creator
Demonstrated need for culture	6	- Culture and traditional practices are diminishing

Finally, respondents **demonstrated the need for culture**, highlighting that "culture is being lost and forgotten" and traditional practices have become unhealthy when the use of alcohol, drugs, and violence become attached to that practice. The need for culture was also demonstrated by respondents stating that youth who are continuously in and out of care are disconnected from teachings and where they come from due to intergenerational trauma and fragmentation within the Indigenous population.

- *Culture is [important] to young adults as it shows them how we as First Nations live our lives, how to be substance free, and to be close to our ancestors. To teach them how to walk the red road.*[8]

- *Youth with a sense of belonging and understanding of their roots, traditions and cultures are more likely to be successful. Many of these youth were raised in foster care and do not know where they come from nor were guided with daily teachings in life skills.*

Cultural Needs of Families with a Loved One Living with FASD

[8] The term Red Road is a concept that embodies the path to or means of achieving holistic wellness through balanced mind, body, spirit, and emotions. It is the process of reclaiming Indigenous worldviews, ways of knowing, teachings, and beliefs, and ultimately one's Indigenous identity (First Nations Health Authority, 2013; Gone, 2011).

Needs assessment respondents were also asked to speak about the cultural needs of families who have a loved one living with FASD. A total of five themes emerged, including the importance of culture, the need for families to have support, the need for access to culture, the need for families to learn about Indigenous culture, and the need for respect from others. Like their responses for youth's cultural needs, respondents also frequently spoke about the **importance of culture** for Indigenous families, noting that culture is healing, and helps families support their children; culture keeps the traditions, teachings and language alive, while building a sense of pride, dignity and self-identity as an Indigenous person. Finally, culture is important because many families and children are unaware of their family and cultural history because of residential school and the multi-generational impacts. One respondent commented:

> *Because of the residential school experience and multi-generational effects, many parents are not familiar with their roots or culture. It's important to support the parents and family as a whole to help them gain that connection or to support them in getting connected to local cultural events.*

In speaking about the cultural needs of Indigenous families with a loved one living with FASD, respondents highlighted the need for **families to have cultural support**. For instance, respondents noted that families need support from Elders and healers. Families also need support in connecting to their culture, in connecting to community gatherings and ceremonies, and support in helping their children explore their culture. **Access to culture** was also identified as a cultural need for families. Needs assessment respondents noted that families need access to their culture while residing off-reserve, and they need access to healthy culture and access to resources and events about culture. Additionally, cultural needs included **caregivers and families learning about their culture**, such as learning about their ancestry, culture, language, and the history of Indigenous people in Canada is needed. Furthermore, **respect from others** was also identified as a cultural need; Indigenous families need service providers to respect their Indigenous culture and recognize that Indigenous people are diverse, not all the same; Métis and Inuit are often forgotten. Indigenous families also need Canadian society to embrace Indigenous people and their culture. Table 11 highlights the cultural needs of families with a loved one living with FASD, and the frequency which the themes emerged.

Table 11: Cultural Needs of Families

Theme	Count (*n*)	Details
Needs Assessment Respondents		
The importance of Indigenous culture	11	- Culture is healing, supports families, maintains traditions and teachings, and provides identity and pride
Cultural support	9	- Support from Elders, healers, community to connect to culture themselves, and to help their children explore culture
Access	7	- Access to culture while living off-reserve, access to events and resources
Learning about Indigenous culture	4	- Learn about history of Indigenous people in Canada, personal ancestry, and language
Respect from others	3	- Need services providers to respect Indigenous culture, acknowledging the diversity within and between Nations

Education and Employment Needs of Indigenous Youth Living with FASD

Respondents were asked to elaborate on the needs of Indigenous youth and young adults living with FASD in terms of education and employment. A total of nine themes emerged, including the need for: employer awareness of FASD, awareness of FASD within the education system, adapted education, youth empowerment, employment supports, educational supports, support networks, skills development, and self-awareness of FASD. With respect to the need for **employers to have an awareness of FASD**, respondents spoke about the need for employment to be the right fit where the work is suited for the youth living with FASD and their abilities. In doing so, respondents highlighted the need to increase employers' understanding of FASD and related difficulties through training. It was also noted that employers should learn about FASD and the limitations due to brain injury, such as the increased time it may take an individual living with FASD to process instructions. Further, it was noted that employers' ought to learn about how to best work with and support those living with FASD, such as utilizing visual and audio cues as aides, and providing clear, concise and structured schedules. Respondents also spoke about the need for **employment supports**, primarily in the form of supported employment opportunities with external brain services, and job coaching so youth can maintain and thrive in the workplace. One respondent noted that employment

policies could be revised, so that trades programs can accept younger students as early as grade 10, rather than requiring a grade 12.

Respondents also provided their insights on the school needs of Indigenous youth living with FASD so they can live their best life. Respondents highlighted the need for schools to **adapt education to fit the needs of the youth**. More specifically, respondents spoke about the need to find the right program for youth, where schools accommodate and teach according to the youths' differing learning styles. It was also noted that adaptations need to go beyond the curriculum, but rather adapting education for a youth living with FASD needs to be rooted in brain-based and strengths-based approaches. It was noted that youth living with FASD need specialized school programs that are at the youth's pace, that are individualized, and have strategies in place to support learning. Finding the right fit for youth goes beyond their learning needs, but also includes their cultural needs. Respondents spoke about the need to adapt the school system where Indigenous students have liaison workers and cultural support staff to assist them with their education, and provide land-based educational opportunities. One respondent recognized the need for teachers to be culturally informed, understanding the history of colonization for Indigenous people in Canada.

Just as was highlighted with employment needs, when it comes to education, **awareness of FASD within the education system** was highlighted as a need. Respondents explained that school staff and school personnel need to understand FASD and the range of skill abilities; having this knowledge will allow for adapted teaching methods and individual learning plans. Furthermore, having an understanding of FASD will inform school personnel's perceptions of youth living with FASD. Youth living with FASD should not be seen as a problem child, rather they should be taught in a manner that accommodates their learning style (e.g., using visual cues, providing concrete direction). One respondent noted the need for school awareness to extend beyond school staff and personnel, but also saw the importance of raising awareness of FASD among other students in the schools. Comments around education needs for Indigenous youth living with FASD included:

- *It is difficult enough for a youth to navigate through the school system, or workforce without being impacted by FASD. For some youth with FASD it*

can be an extreme challenge to learn and retain information, school systems and employers should be educated on FASD and how it has affected a youth's brain development.

- *Because each person, especially with FAS, learns differently, the school systems needs to find ways to teach not force the youth to conform to academic expectations. Increasing public awareness around FAS will also encourage employers to be more patient with those that need to do things differently but can still accomplish much.*

- *Knowledge of FASD by the school employee and/or employer will go a long way to success of an individual with FASD. This is a difficult area because all individuals with FASD function at different levels. Some will learn in a highly functioning manner in some areas but not others. Employees may also function at a high level in some work places but not others. [Knowing] the individual's strengths and weakness is important to the success of the individual in school and the work place.*

In addition to raising awareness of FASD and the history of Indigenous people in Canada within the education system, one respondent also noted the need for a shift in the educational culture, where the education system becomes trauma-informed, and teachers are compassionate and trained to understand trauma and triggers.

Table 12 below highlights employment and education needs for Indigenous youth living with FASD and the frequency at which they emerged.

Table 12: Education and Employment Needs

Theme	Count (*n*)	Details
Needs Assessment Respondents		
Employer awareness of FASD	14	- Increased understanding of FASD among employers', such as brain injury implications, and how to best work and support those living with FASD
Awareness of FASD within the education system	13	- Increased understanding of FASD among school personnel to allow for adapted teaching methods and informed perceptions of youth
Adapted education	13	- Schools to adapt education to fit the needs of the youth, where teachers accommodate differing learning styles, and is rooted in brain-based strategies
Empowerment	7	- Empowerment to believe in themselves and believe they can be successful
Employment supports	4	- Supported employment opportunities, job coaching, and responsive policies
Educational supports	4	- Hands-on school support workers, bursaries and scholarships, and social supports at school to prevent bullying
Skill development	4	- Support to develop life skills
Support networks	3	- Support networks and social connections (e.g., peer relationships)
Awareness of FASD	2	- For those living with FASD to understand FASD and how it affects the brain
Why education and employment is important	13	- Education is the key to success, and can prepare youth with life skills, socialization, future employment

In addition to providing the needs of Indigenous youth living with FASD, many respondents offered reasons for **why education and employment is important**. Respondents noted that education is the key to success, despite the disability; education can prepare Indigenous youth living with FASD with life skills, and can prepare them for socialization with peers, and future employment. Respondents further noted that employment prepares youth for living independently, and provides a sense of purpose. Finally, support in education and in employment is important due to the stigma that exists; respondents noted that often Indigenous people living with FASD are "shunned by society and tossed aside as non-valuable/non-functioning members of society" and "Discussing FASD with school is embarrassing! I wouldn't bring this topic up with academic advisors, professors, or employers, as it may impact their opinion of me." Respondents offered

barriers to education and employment for Indigenous youth living with FASD, including: when individuals living in remote communities, they do not want to leave for work or school; and often there is social isolation when attending school or work.

Needs of Indigenous Families Supporting their Children and Youth Living with FASD in their Education and Employment

Respondents were also asked to speak about what Indigenous families need to support their children in school or in their employment. A total of four themes emerged, including the need for support from teachers and advocates, system-level needs, awareness, and family involvement in their child's education and employment. Respondents most frequently indicated that Indigenous families need **support from teachers and advocates**. More specifically, Indigenous families need support in terms of follow-up from teachers and liaisons, where the teachers and families work together, and where there is a relationship between families and the core educators in the youth's life. Furthermore, it was noted that families need communication with teachers and liaisons on a daily basis, and need to be aware of the content their children will be learning so they can support the youth at home. One respondent commented, Indigenous families who have a child living with FASD "Need to hear … information about what they will be studying so things can be introduced at home beforehand (i.e., Learning about Egypt; introduce some books at home about pyramids, mummies, etc.)." In terms of educational support, respondents also spoke about Indigenous families needing support workers and advocates, including advocates who will support families in working with the system to ensure the success of their child, as families are not always an expert in FASD matters. In supporting their youth academically, families also need to utilize academic supports such as educational assistants, tutors, or a core supportive educational team. Respondents also spoke about family needs for support from Indigenous outreach workers for when it becomes too much.

System level needs were also identified by respondents when asked what Indigenous families need to support their loved ones living with FASD in their education and employment. More specifically, respondents spoke about families needing an educated education system where the education system is not biased, but rather,

understands the learning needs of a youth living with FASD, and the associated challenges such as reactive situations and meltdowns; not mislabeling the youth as troubled. Respondents also spoke about families needing an accommodating education system, noting that Indigenous families who have a child living with FASD need an education system that will adapt to the youth's needs, and has programs in place that support different learning styles with modified teaching strategies. Finally, respondents spoke about the need for strengths-based approaches, where families hear positive feedback and the strengths of their youth, not just the challenges. **Awareness** also emerged as a theme for what families need to support their children living with FASD in their education and employment. More specifically, awareness of what programs and services are available in their region that can help youth living with FASD with employment, and what supports are available to help their child in school was identified as a need for Indigenous families with children living with FASD. Furthermore, it was noted that families need others to be aware of the limitations and learning needs of their child living with FASD, and how to support their child in learning. Equally important is the need for Indigenous families to have others be aware of the youth's strengths and how to leverage those strengths. One respondent commented, "We need to ensure that adults have a good understanding of the youth's strengths (and how these can be utilized) and the youth's areas of difficulties. Families should also be supported to develop strategies to build on strengths and to help with areas of difficulties." Finally, respondents spoke about the need for f**amilies to be involved in their child's education and employment** and know that they are important to their child's success. Table 13 below highlights needs of families in supporting their youth in education and employment and the frequency at which the themes emerged.

Table 13: Needs to Support Education and Employment

Theme	Count (*n*)	Details
Needs Assessment Respondents		
Support from teachers and advocates	19	- Support from teachers, such as follow up and communication about the youth, and communicating to families what the youth is learning - Advocates who will support families in navigating the education system
System-level needs	12	- An educational system that is educated about FASD and can accommodate the needs of youth living with FASD and takes a strengths-based approach
Awareness	8	- Awareness of the limitations and strengths of the youth living with FASD, and what programs and supports are available in their region
Family involvement	3	- Families need to be involved in their child's education and employment
Barriers	6	- Lack of school supports and communication with parents

In addition to identifying what families need to support their children living with FASD, respondents also identified **barriers** faced by Indigenous parents with loved ones living with FASD, including barriers around the lack of school supports and the lack of communication between parents and teachers. Further, respondents spoke about the **importance of education and employment** for those living with FASD noting that school success will lead to employment success, which will thereby reduce poverty and adverse outcomes.

Substance Misuse and Treatment Needs of Indigenous Youth Living with FASD

Needs assessment respondents were asked to elaborate on the treatment and substance misuse needs of Indigenous youth and young adults living with FASD. A total of five themes emerged, including the need for substance misuse support, the structure of treatment, awareness, the need to break the cycle of substance misuse, and the need for youth to have voice and choice with respect to treatment. Needs assessment respondents frequently spoke about the need for **support**, such as ongoing alcohol and drug support through the continuum of care, with an emphasis on the need for support in getting to treatment centres, and the need for aftercare supports. Respondents also spoke

about the need for positive and sober role models so that youth living with FASD have support to make good choices as well as someone to talk to. Finally, respondents spoke about the need for supportive counselling services and second stage housing that can provide youth with short-term housing between six months to a year, that is safe, affordable and independent. Comments around the need to support Indigenous youth living with FASD in terms of alcohol and drug treatment included:

- *Youth that have been prenatally exposed, and also youth who have grown up in situations where addiction is an ongoing issue require support in making good choices and somebody to talk to for support and guidance.*

- *They fall easily into social circles with addicts and are manipulated into giving up all of their money for the benefit of others. Drugs become the only way they know to fit in, because addicts are who they consider their friends.*

Respondents also spoke about the **structure of substance treatment support**, noting that substance treatment and support need to be responsive to the youth's cultural connections and their brain injury. For instance, respondents noted that treatment and support need to be inclusive of Indigenous culture and spirituality, and trauma-informed, not solely drug and alcohol, and addictions-focused. Furthermore, they noted that treatment and support need to be FASD and brain-injury specific, where treatment is individualized, focusing on individual needs, and not time-oriented, yet more structured than mainstream residential treatment options, all while operating from a harm reduction model.

Respondents also shared that **awareness** is needed, specifically around the impacts of alcohol and drugs; youth living with FASD need to understand the consequences of using alcohol and drugs, and how the latter affect the brain. They also shared that those who work with Indigenous youth living with FASD need to understand that standard residential treatment does not always work for those living with FASD and there is a need to understand the challenges associated with the brain injury through training and develop strategies to work with this population. **Breaking the cycle** also emerged as a need for Indigenous youth living with FASD when it comes to alcohol and drug misuse. Needs assessment respondents noted that the cycle of substance misuse and abuse needs to be broken, and in order to do so, work needs to be done to increase the coping skills of Indigenous youth living with FASD. For instance, one respondent

commented, “Because the FAS brain processes information in different ways, alcohol and drug support needs to find ways to increase a youth’s coping skills; building a more effective tool box to deal with temptations around drug and alcohol use.” Furthermore, respondents noted the need for healing and community cohesion, where community comes together to address the issue of alcohol and drugs within community, and holding dry events in community. Finally, respondents spoke about the need for **youth voice and choice**, where youth have options and choices of which treatment facility to attend; where the youth have the opportunity to choose an Indigenous or non-Indigenous facility or an inpatient or outpatient facility. One respondent commented: “Youth need to have choices around which treatment they chose--whether it be Aboriginal inpatient or outpatient or non-Aboriginal treatment services should they chose that. We can't assume that all Aboriginal youth want Aboriginal services--they need to be asked what they prefer.” Table 14 below highlights the themes that emerged around substance misuse and treatment needs, and the frequency at which the themes emerged.

Table 14: Treatment and Substance Misuse Needs

Theme	Count (*n*)	Details
Needs Assessment Respondents		
Support	17	- Ongoing substance support throughout the treatment journey, positive sober role models, supportive counselling and second stage housing
Structure	12	- Individualized treatment that is responsive to culture, substance and brain-injury needs (e.g., inclusive of Indigenous culture, harm reduction, trauma informed, flexible time requirements)
Awareness	11	- Youth to be aware of the impacts of substances, how they affect the brain - Others to be aware that mainstream treatment may not work due to brain injury challenges
Break the cycle	10	- Increase coping skills, community and personal healing, dry community events
Voice and choice	2	- Provide youth with options for treatment facilities

Needs of Indigenous Families Supporting their Youth Living with FASD with Substance Treatment

Needs assessment respondents were also asked to speak about what Indigenous families need to support their children who might be misusing or abusing alcohol and drugs. A total of three themes emerged, including ways in which families can support their youth from misusing substance, the need for family inclusive treatment and counselling, and respite support. Most frequently, respondents highlighted **what families can do to support their youth**. More specifically, respondents spoke about families teaching their youth about the impacts that drugs and alcohol have on a person, but teaching this from a brain-based level. It was noted that families need to seize teachable moments about drugs, alcohol and harm reduction. It was also noted that families need to provide emotional support and unconditional love to their child. Furthermore, respondents noted that families need to set boundaries and monitor their youth as this intervention may help reduce adverse outcomes. Modeling healthy and sober living was another way in which families could support youth in addressing their substance misuse. For instance, respondents noted that families may need to change their own behaviours and address their own substance use as a means to support youth with substance misuse problems. One respondent commented, “Families may also have to change their behavior to support the youth, it is not always just the youth who has to change.” Finally, needs assessment respondents noted that families need to be aware of their youth’s triggers for substance use and relapse. One respondent commented, “Adults need to be educated around their youth's triggers for abusing or misusing drugs and alcohol. They also need to have an understanding of relapse.”

In terms of what Indigenous families need to support their youth living with FASD from misusing substances, respondents highlighted the need for a holistic approach with **family inclusive treatment and counseling**, where families are included in the treatment program and learn how to support their child so the cycle can be stopped. One respondent commented, “Families need to be included in the treatment program so they understand better why their youth are using and also how to best support their youth.” Respondents also spoke about families needing **support and respite**, such as parent support programs and opportunities for caregivers to have breaks from the associated stresses of raising a

child with FASD. Table 15 details needs that emerged for families supporting youths' substance misuse and treatment journeys.

Table 15: Supporting Substance Misuse and Treatment

Theme	Count (*n*)	Details
Needs Assessment Respondents		
How families can support youth	17	- Teach youth the impacts substances have, emotionally support youth, set boundaries and monitor youth, understand the youth's relapse triggers, and model healthy sober living
Family inclusive treatment and counselling	7	- Families included in treatment to learn how to support youth in their treatment journey
Respite support	3	- Families need parent support programs and breaks from parenting
Barriers	6	- Alcohol and drugs are normalized for some, funding is limited to youth, and there is a lack of knowledge of services

Needs assessment respondents offered several **barriers** that Indigenous families may face in supporting their youth with substance misuse and treatment, including barriers around the normalization of alcohol and drugs in some communities, especially communities where alcohol and drugs are readily available and parents are also misusing alcohol and drugs. Furthermore, the limitations of supports and funding is another potential barrier as most funding is youth-specific, and not for families and/or caregivers who may also benefit from supports. Finally, respondents noted that in some cases, there is a lack of knowledge of services available and stigma may prevent families from reaching out.

Justice Needs of Indigenous Youth Living with FASD

Needs assessment respondents were asked to elaborate on the needs of Indigenous youth and young adults living with FASD in terms of reducing, stopping and preventing future justice involvement. Respondents frequently noted **support** as a leading need to address justice involvement. More specifically, respondents spoke about youth needing family and peer support, where youth are surrounded by healthy friends, healthy activities, and positive role models (e.g., peer role models who have been in similar situations and can provide guidance). It was also noted that family members need to be attentive to the youth's strengths and build on them. Respondents also noted the need for

ongoing support from support groups and support workers who will follow up with youth and act as an external brain. One respondent commented, “Remember that FASD impacts the memory and learning system. Some of what an FASD child learned yesterday, they may not recall today. And alcohol, an FASD child may have a different perception of consequences and may not understand what they have done is wrong.” Professional supports were also identified as a need for youth living with FASD, such as the need for youth to attend counselling, have access to mental health supports, and the need for treatment instead of incarceration. Finally, in terms of supports, it was also noted that youth living with FASD need advocates and liaisons who can explain legal procedures to them.

In responding to the question on the justice-related needs of Indigenous youth and young adults living with FASD, needs assessment respondents also spoke about youth needs at the **community-level**, highlighting the need for holistic supports in the community that focus on mind, body, spirit and emotion. Furthermore, there is a need for reduced stigma and blame on birth parents in the community, and an increase in community awareness and knowledge of FASD. Respondents also spoke about justice-related **system-level** needs of youth living with FASD, highlighting the need for mandatory training of justice system officials and personnel on recognizing FASD (e.g., judges, lawyers, personnel, RCMP, peace officers). Further, respondents highlighted the need for increased use of restorative justice principles and Aboriginal persons’ court models where the justice system understands the context and history of Indigenous people in Canada and the Gladue principles.[9] Finally, respondents highlighted the need for the system to stop removing supports from those with FASD, and the need for integrated and collaborative support for youth living with FASD. One respondent commented “The whole system needs to offer seamless collaborative support mechanisms for youth who are affected by FASD.”

[9] Gladue principles are synonymous with the sentencing provisions in section 718.2(*e*) in the Criminal Code of Canada. The principles, in response to the disproportionate overrepresentation of Indigenous people in the criminal justice system, direct courts to consider alternatives to custody, as well as consider the unique circumstances of Indigenous offenders that brought them before the court (*R. v. Gladue,* 1999).

When asked to speak about reducing or preventing justice involvement, respondents also noted the need for **supervision and structure**. For instance, they noted that youth need adults around to support and monitor behaviours, who will establish boundaries, structure, and provide repetition. **Learning skills and gaining awareness** was also mentioned as a need, including the need to learn life skills around coping with stressors and money management, and gaining self-awareness around what triggers offending behaviours. One respondent commented, “Youth also need education around what triggers their offending (e.g. boredom, drinking etc.) and supports need to be put in place to prevent triggers from hopefully occurring and also coping strategies to help when a youth is triggered (e.g. a coping card in their wallet that they look at when they are bored-with activities like phone mom or friend).” Finally, having one’s **basic needs met** was noted as a need, such as having stable housing, employment and ability to earn an income. Table 16 below highlights the justice-related needs of Indigenous youth living with FASD, and the frequency at which each theme occurred. Needs assessment respondents also offered their perspectives on why there is a need to support Indigenous youth living with FASD for preventing future justice involvement. Comments by respondents included:

- *It is not fair to any unborn child to be burdened with FASD; it is a life time sentence.*
- *Without the support the individual may fall victim to the wrong family member, friend, or group.*

Table 16: Justice Related Needs

Theme	Count (*n*)	Details
Needs Assessment Respondents		
Support	22	- Ongoing family, peer, professional and worker support is needed, as well as positive role models and a focus on leveraging youth strengths
Community-level	11	- Holistic supports in the community, reduced stigma in the community, and increased awareness and knowledge of FASD in communities
System-level	7	- Mandatory training on FASD for justice officials and personnel, incorporation of Gladue court and Gladue principles, and continued supports for youth living with FASD
Supervision and structure	8	- Adult supervision and boundaries
Awareness and skill development	8	- To learn life skills around coping and finances and gain self-awareness of triggers
Basic needs	5	- Stable housing, stable employment, stable income

Needs of Indigenous Families Supporting their Youth Living with FASD who are Justice Involved

Needs assessment respondents were also asked to speak about what families need to support their children who might become involved in the justice system. A total of two themes emerged, including the need for family support and services, and the need for information and awareness. Like the needs of Indigenous youth, families also need **supports and services** while they support their youth in the justice system. Specifically, respondents spoke about the need for support workers, such as navigators, liaisons, and advocates that will assist families through the legal process, but who are also knowledgeable about FASD, youth justice, and Indigenous people. Furthermore, there is a need for continuity of support by trained outreach and court workers. Support groups and programs for parents were also noted as need by respondents. For instance, respondents spoke about the need for a network of families who have children and youth living with FASD, so they know they are not alone, possibly through Friendship centres, and parenting programs that focus on parenting young teens. Respondents also highlighted the need for respite and on call support when the stresses of parenting a youth living with FASD become too much.

Needs assessment respondents also noted that families may need family counselling to resolve their own trauma, work on parenting, and build positive relations with their children. Hands on learning and workshops were also indicated as something needed for families. Respondents spoke about learning opportunities where families could learn strategies to support their children who are living with FASD and involved in the justice system. For instance, families could learn how to support their children not to breach, or how to support their child in coping with their emotions and venting. Finally, with respect to services, needs assessment respondents highlighted the need for culturally competent services where agencies have an understanding of the history of Indigenous people throughout Canada, and subsequent and intergenerational impacts.

Needs assessment respondents also noted that families with youth living with FASD need **information, education, and awareness** when it comes to their youth's justice involvement. More specifically, families need information on the legal system and legal processes (e.g., court process, probation process). Respondents noted that families need to know what happens throughout the legal process, what to expect, how to navigate the legal system, and to understand common legal jargon. Respondents also noted that Indigenous families need contact with the front-line workers, such as youth probation officers, court workers, and counselors, so the family is informed and involved in decisions. One respondent commented that families need "Close contact with the front line workers who may be involved in their child's process. Whether it be the probation offices, court worker or counselor, the parent should always be in the loop and have full access to the child's safety. Once parents begin to have to deal with workers who are not familiar with their child, the frustration begins." Information and awareness on the secondary disabilities associated with FASD was also noted as a need, in addition to the need for families to know their children's triggers for offending. Finally, one respondent spoke about the need for justice-specific resources for families that are community friendly and accessible. One respondent highlighted the **importance of supports for families** with children involved in the justice system, noting that the legal system is confusing and scary for many, and difficult to navigate alone. Table 17 below highlights the justice needs that emerged for families with a loved one living with FASD and the frequency at which they were noted by respondents.

Table 17: Justice Needs of Families

Theme	Count (*n*)	Details
Needs Assessment Respondents		
Supports and services	26	- Support workers, navigators, advocates who will assist in the legal process; ongoing support; support groups, and respite - Family counselling to resolve own trauma and relationships - Hands-on learning (e.g., strategies to support youth involved in the justice system)
Information and awareness	13	- Legal-specific information and awareness (e.g., court processes, probation process) - Awareness of child's triggers for offending, and the challenges associated with FASD

Assessment and Diagnosis Needs of Indigenous Youth Living with FASD

Needs assessment respondents were asked to elaborate on the needs of Indigenous youth and young adults living with FASD when it comes to FASD assessments and diagnoses. In responding, respondents offered feedback on the needs before the assessment, following the assessment, and throughout the entire assessment process. Respondents spoke about youth needing **information and transparency on the process** before the FASD assessment begins. For instance, youth need to know what to expect from the assessment process, and why they are going through the assessment to begin with. Prior to the FASD assessment starting, there is a need for **buy-in and support** from families, communities, and schools who will provide information pertinent to the assessment; further, youth who are about to undergo an assessment should also be asked for their input and if there are cultural initiatives they would like incorporated.

Respondents shared that, following the assessment, Indigenous youth recently diagnosed need **education about FASD**, such as information that will help them understand why they have FASD, how FASD will affect their life, the outcomes of their assessment, and them knowing that them having FASD is not their fault. One respondent commented, "The individual needs to get to know FASD. It may resolve some long standing guilt about themselves and their misbehaviours that keep getting them into trouble. This will teach them that they are not a bad person, but are suffering from an

affliction that happened before they were born. They need to know that there is no cure, but with the right supports, they can successfully cope." The need for **ongoing support and assistance** was identified, such as assistance at school, in community, in applying for disability, follow up support, and support in developing skills to manage the associated challenges. Respondents noted that throughout the entire assessment process, Indigenous youth will need a variety of **support people**, such as specialized workers who can advocate and support them through the process, and a navigator who will ensure recommendations are followed, and who will remind youth to show up for appointments; one respondent noted that youth need to be connected to an FASD key worker as soon as possible before their assessment begins. Other support people youth will need include a team of support workers who can act as an external-brain, and support from family, school and community. Respondents also spoke about the youth and families needing emotional support during the assessment, as FASD is a stigmatized label. One respondent commented:

> *There should be support for FASD child and family. It was a devastating emotional and mental time when I received the results of my grandson's disabilities. It still is somewhat difficult.*

Taking a strengths-based approach was also noted by respondents as a need throughout the entire assessment process. Respondents shared that there needs to be empowerment through a strengths-based approach, supporting the youth to determine their strengths, and encouraging them to try new things. It was also noted that there needs to be professional sensitivity from everyone involved in the process (e.g., medical staff, community workers, school staff). Furthermore, in terms of the assessment process, one respondent shared that the environment where the assessment will be completed needs to be welcoming, and another shared that youth need to be spoken to in a manner that they understand. Finally, Indigenous youth need **resources**, such as a foundational plan that walks them through the assessment process, or a roadmap of reliable and consistent supports in the region. Table 18 below highlights the assessment needs that emerged and the frequency at which they were noted by respondents.

Table 18: Assessment Needs Identified By Needs Assessment Respondents

Theme	Count (*n*)	Details
Before the Assessment Process		
Information about the process	6	- To know what to expect from the FASD assessment
Buy-in and input	5	- Youth, families, communities need to buy-in to the assessment - Youth to be asked if they would like cultural initiatives incorporated
After the Assessment Process		
Education about FASD	6	- To know what a diagnosis of FASD means, and to know it is not their fault
Ongoing support	6	- Support in applying for disability, follow up support, supports to develop skills and individualized strategies
Throughout the Entire Assessment Process		
Support	15	- Specialized workers, navigators, and advocates knowledgeable about the assessment process (e.g., key workers) - Emotional support as FASD is stigmatized
Strengths-based approach	6	- Empower youth to determine their strengths and explore new things
Resources	4	- Assessment plans and a roadmap of services and supports in regions

Needs assessment respondents offered insights around the **importance of FASD assessments** stating that many individuals go unassessed and undiagnosed, which creates invisibility and limits access to supports. There are many barriers to **accessing assessments**, such as the cost of assessments, the length of the assessment process, limited access for those in small communities, and limited awareness of where to go if they need an assessment.

Needs of Indigenous Families with a Youth Undergoing an FASD Assessment

Needs assessment respondents were also asked to speak about what families with a loved one living with FASD need when it comes to supporting their child before, during and after the assessment process. A total of three themes emerged, including needs specific to the assessment process, support needs throughout the assessment,

and awareness needs. Most frequently, respondents spoke about what families need with respect to the **assessment process**. Specifically, respondents noted that families need information about the assessment process, such as what to expect, what the results mean, the implications of a diagnosis, and the benefits of a diagnosis. In speaking about the assessment process, respondents also noted the need for family involvement throughout the entire process, from referral to diagnosis, so the youth and families learn together; families need to be there for the youth throughout the process. Post assessment support from the diagnostic team was also noted as a need for families, as respondents spoke about the need for the report to be reviewed with families, where the families, youth, and clinicians can strategies on next steps. Furthermore, in terms of post-assessment support, families need more actions for the youth and family, and less referrals. One respondent commented, “families need education on the process and the results of the assessment, not just ‘read the report’, but actually go through the report and help the families come up with strategies to support their youth and then, support in carrying out these strategies.” Finally, with respect to the assessment process, it was noted that the assessment pace needs to be done at the child’s pace, not the clinicians’.

Respondents also spoke about the need for families to have **support during the assessment**. They indicated the need for support workers, such as a navigator or worker to help the family and youth through the process; someone connected with FASD key workers to advocate in community and provide support, and someone who can strategize on carrying out the recommendations in the report. Further, respondents indicated the need for support workers who can help fill out the paperwork, and answer assessment related questions. Respondents also spoke about the need for emotional support, such as empathy and patience from others. In speaking about the FASD assessment needs, one respondent spoke about the need for financial support to travel to the assessment clinic, while another respondent commented that connections with other families who have gone through the assessment process is needed. Respondents commented that the FASD assessment is a difficult process, families do not know what to do; it is difficult when given the diagnosis. **Awareness** was also highlighted as a need for families during the assessment process. For instance, respondents spoke about the need for awareness of FASD and how it affects the brain, and the need to relay this knowledge to other family members. Furthermore, respondents spoke about the need for awareness of what

community supports and resources are available in communities and regions, such as family counsellors. Finally, one respondent spoke about the need for families to practice self-care during the assessment process, such as resting and eating a healthy diet. Table 19 highlights themes that emerged when speaking about the needs of Indigenous families who have a loved one undergoing the assessment process, and the frequency at which the themes emerged.

Table 19: Family Needs for Supporting Youth with FASD Assessments

Theme	Count (*n*)	Details
Needs Assessment Respondents		
Assessment process	13	- Information about the process, what to expect, implications of a diagnosis, and benefits - To be involved in the process, from start to end
Support throughout the assessment	11	- Support workers and navigators to support families and youth through the process, who can answer questions and help with paperwork - Emotional support and patience
Awareness	7	- Awareness of FASD to relay knowledge to other family members, such as understanding what FASD is and how it affects the brain - Knowledge of community supports and resources (e.g., family counsellors)

Keeping Families Together and Family Reunification

When asked to speak about what Indigenous families with a youth living with FASD need in order to keep their families together, or what they need in terms of reuniting families, a total of five themes emerged, including the need for support, the importance of support, the need to understand what is in the best interest of the child, the need for culture, and the need to resolve shame around FASD. Needs assessment respondents most frequently indicated the need for **support**. For instance, families need community support, where families and communities work together to support youth with FASD, as "'it takes a village to raise a child.' Every family needs support from the community (agencies), school system, family, friends, peer support groups and an advocate knowledgeable in this area". Indigenous families also need community support from chief and council, and band involvement in child family protection issues. Additionally,

Indigenous families need respite care support to prevent burnout; families need a break from the stress and challenges associated with raising a child with FASD. As such, respondents also noted that Indigenous families also need coping and emotional support services, such as conflict resolution, anger management, addictions services, and Western or traditional counseling services.

In terms of support for family reunification, it was noted that Indigenous families need support workers to assist in the family reunification, workers who understand the difficulties of the family history and how they got to the point where they are. Also, structured contact was identified as a need, such as communication books and scheduled visits. Respondents also noted the **importance of family support**, because families need support just as much as youth. One respondent commented, “The families need to be supported just as much as the youth. No matter how much intervention you do with the youth, they still go back home. We need to work in a holistic way with the whole family and support each aspect.” **Understanding the best interest of the child** was also identified as a need for families. Some respondents noted that families need to understand that there will be circumstances when it is not in the best interest of the child for the youth to be living in the home, and sometimes maintaining or reuniting families is not the best option, particularly when there is abuse or parents are not equipped to care the child living with FASD.

Needs assessment respondents spoke about the need for **cultural activities** that are land-based and rooted in tradition and spirituality, as this will strengthen families and foster belonging. One respondent commented, “Understand that family is medicine. Tradition, culture, spirituality, language are all healthy medicines for our people, and strengthen the family unit. Maintaining strong, healthy connections creates a healthy feeling of belonging.” In addition, respondents spoke about the needs for Indigenous families to **resolve and forgive shame** about FASD within family. One respondent spoke about the need for basic needs to be met in order for family reunification or maintaining the family unit, such as having housing and financial security. Another spoke about system-level needs, noting trauma-informed services are needed, where workers practice in a trauma-informed manner, focusing on the root causes, not the person. Table 20

highlights the three themes that emerged for family reunification and the frequency at which the themes emerged.

Table 20: Family Reunification Needs

Theme	Count (*n*)	Details
Needs Assessment Respondents		
Support	24	- Families need community support (chief and council, band support), agency support, peer support, and respite support - Support workers to help with family reunification
Importance of family support	5	- Families need support just as much as youth need support
Best interest of the child	3	- Understand that there are circumstances when the youth should not be living at home, and family maintenance is not the best option
Cultural activities	2	- Will strengthen families
Resolve shame	2	- Resolve the shame of FASD within families

Program Staff and Management Perspectives on the Needs of Indigenous Youth Living with FASD

In thinking about the Indigenous youth in the Program, staff and management were asked to identify service and support needs of the youth. In doing so, the following five themes emerged: support, basic needs, relationships, culture, self-awareness and self-worth. Most frequently, staff and management interviewees spoke about needs that fell under the theme of **support**. They highlighted the need for support workers who will assist youth in navigating the various systems they come in contact with, and navigators who will explain the system processes. They also spoke about the need for advocates who will fight for their rights and basic needs, but also understand the complex needs of a youth living with FASD. It was also noted that youth need a holistic support system where a support worker or navigator will assist youth in connecting with other supports and resources in the community. In terms of advocacy, it was noted that youth in the Program need advocacy support specifically related to legal matters (e.g., as victims and offenders), and for family court matters (e.g., family foster placements). Interviewees also noted the importance of competent workers who have an understanding of or have

specialized training on the broad spectrum of needs related to FASD, and who also have an understanding of culture. Brain-based supports were also noted as a need for Indigenous youth in the Program. Interviewees explained that youth in the Program need external-brain supports, that is, someone external to the youth in the community to help. Further, interviewees noted the need for brain-based therapeutic interventions, such as interventions that focus on rebuilding brain connections that were broken or pruned in childhood due to trauma (e.g., neglect, violence). This was further elaborated on with the need for trauma counseling, that digs deeper, and gets at the root trauma. One interviewee commented:

> *We are in desperate need of skilled and knowledgeable counseling. [Youth] need skilled and able counselors that can support our youth and families with their trauma issues, and trauma they've experienced, specifically sexual abuse, specifically experiencing a tragic loss in their life (e.g., a loss of birth parent, grandparent, sibling …). So, very specialized counselors who (a) know how to work with youth; we know the brain is not fully developed until 25, and they're youth, and (b) then are knowledgeable around sexual abuse and tragic loss, and can work with complex trauma, not drug and alcohol only, that's not the issue. We need someone who can go beneath the issues and go to the root causes; we need those specialized kinds of counselors to work with youth; if we can address the core, deeply-rooted traumas, it will help flesh out other challenges in the youth's life*.

Staff and management interviewees also expressed that youth need workers who are empowering to the youth; workers who will encourage the youth to live differently, and encourage youth to set and achieve their goals. One interviewee commented, "they can lead negative or positive lives." FASD is a lifelong disorder and support needs are ongoing; support is needed beyond once a week. As such, interviewees noted that youth in the Program need long-term support. One interviewee commented:

> *It's not as simple as an outreach worker once a week; they need someone to dedicate significant time per week. They need support for when they age out. Children should be growing up with support workers who can help them with culture, identity as a First Nations person, and growing up with FASD. It shouldn't be now that you're … in the justice system, here's a support worker.*

Social isolation has been identified as a challenge faced by youth living with FASD. As a means to address this challenge, staff and management interviewees spoke about

the need for youth in the Program to have social support for socializing (e.g., sports, access to social groups) and FASD specific programming. One interviewee noted that there are specific programs for youth living with autism, for youth living with physical disabilities; yet, there are fewer FASD-specific programs available due to the invisible nature of the disorder.

Staff and management interviewees also emphasized that youth in the Program need their **basic needs met**. This includes, having food security, having life skills, such as knowing how to cook, grocery shop, do laundry, care for oneself, and having housing supports. One interviewee noted that while the housing first model is good in theory, it does not necessarily play out that way for youth living with FASD. Other basic needs include transportation, and holistic health needs, such as emotional, spiritual, mental and physical health.

Relationships were also noted as a need for youth in the Program. Staff and management interviewees noted that Indigenous youth in the Program need relationships with caring people they trust and want to spend time with, and they need to have positive adult role models and mentors in their life. **Culture** was also highlighted by interviewees as a need for Indigenous youth in the Program. More specifically, it was noted that youth need cultural activities that build positive identity and spiritual connections, such as prayer over a button blanket. Further, interviewees noted the need for land-based activities to ground and calm youth when they are frustrated. One interviewee commented, “I have high expectations working from a cultural lens, there are no limits on what culture can do. I believe our teachings, our sacred way of being in the world, I believe to my toes that that is the answer.”

Staff and management interviewees also noted the importance of youth in the Program to have a healthy **self-awareness and self-worth** where they have a positive outlook on who they are as an Indigenous youth. Understanding their own needs, their disability, and knowing their personal strengths was also identified as a need for Indigenous youth living with FASD. Comments by interviewees explaining the importance of building positive identity as an Indigenous person, included:

- *I speak of the importance of our youth coming in for an FASD assessment and especially the youth being diagnosed, that they don't equate FASD as being a systemic issue of being First Nation. All of my youth who haven't grown up in their culture, will agree with you, if you say, do you feel that this is your identity as a First Nation person, and you bring up all the negative things that have harmed our people (e.g., residential school, colonization, missing and murdered Indigenous women, the downtown eastside, the Sixties scoop, MCFD involvement, justice involvement, addictions, violence in the home) that's who they see themselves as an Indigenous person; so many youth will deny that they are Indigenous, and tell their other workers that they aren't in some cases, especially if they are sent away for treatment, they tell people at treatment programs that they aren't Indigenous. It's a fear of how they will be treated and if that is your concept of self.*

- *When people have a sense of who they are and where they come from, and when they have a sense of place and identity and connection within themselves, and an opportunity to be validated with how they feel – the possibilities are … there is no limit.*

One interviewee commented that Indigenous youth in the Program need to see their ethnicity represented in the workers, such as seeing Indigenous people working in the systems they are accessing and using (e.g., Indigenous doctors, Indigenous support workers, Indigenous psychologists). Table 21 highlights the needs of Indigenous youth living with FASD identified by staff and management interviewees.

Table 21: Needs Identified by Staff and Management

Need	Count (*n*)	Detail
Staff and Management		
Support	23	- Support workers and navigators who will assist youth through the systems and advocate for their legal and family needs - Holistic support network, empowering workers, and social supports for socializing - Brain-based supports, external-brain supports (e.g., brain-based therapeutic interventions) - Trauma counselling
Basic needs	9	- Food security, life skills (e.g., cooking, laundry), housing, transportation, and holistic health
Relationships	5	- Trusting relationships, and positive role models and adult mentors
Culture	5	- Activities that build positive identity and spiritual connections
Self-awareness	3	- Positive self-identity as an Indigenous person and knowing their own personal strengths
Access to services	2	- Access to medical care is needed
Flexible assessment processes	2	- Provide breaks and allow youth to come and go

Staff and management interviewees also spoke at great lengths about the importance of having youth needs met. They frequently spoke about **policy issues** that contribute to systemic racism and systemic barriers as reasons for why Indigenous youth living with FASD need support. With respect to systemic racism, they spoke about the differential treatment by the justice system that Indigenous youth living with FASD receive depending on whether they are the victim or the offender. For instance, interviewees commented that when a youth is the victim, rarely are the crimes prosecuted, yet when the youth is an offender, the sanctions are harsher, even for breaches. In line with this, interviewees commented that there is systemic institutional racism where orders that are given to youth have nothing to do with the offence at hand, and children are criminalized for returning home. In terms of systemic barriers, staff and management interviewees noted the poor systemic management of youth living with FASD. Interviewees spoke about the system's solution to providing youth with support through imprisonment or having the youth enter themselves into ministry care; otherwise, the supports are difficult to access or unavailable. Interviewees also shared that the very services that are in place to support

youth with disabilities are actually barriers for those living with FASD. One interviewee explained:

> *It's a huge gap with youth aging out and having to sign up for persons with disabilities … The only place you can get disability paperwork is through social assistance. What happens is, they give youth these papers for those signing up, (someone with FASD) and youth lose them. And the youth comes in again and again, and they say you have to fill it out and fax this. So the very service that's there to provide support for your future doesn't understand your needs. I've met people with FASD who haven't been on disability for 7 years because no one in these service offices that are supposed to be providing support understands that he can't do it alone. None of the systems have been designed around it, a lot are designed for physical disability, and they kind of manipulated it to suit people with development designation (so an IQ below 70), but FASD is so much broader than that and many with FASD don't have an IQ below 70, so it really does interfere with the service peoples' ability to provide service.*

Additionally, interviewees also spoke about the systemic barriers around general supports in society not being aligned with the disabilities and complex needs of those living with FASD. Rather, programs that are available, are designed for those with visible disabilities and disorders; FASD is invisible and often goes unnoticed. One interviewee commented that FASD is "an intellectual disability that's invisible, but not recognized … we don't have the supports available that are specialized or specifically geared to, or specific to someone who has that brain damage (intellectual and cognitive disability); it's invisible, so a lot of people don't see it … They were born with it, it's not something they did to themselves, they don't have a choice, yet we don't have any socialized programming specific to youth who are impacted with prenatal alcohol exposure." Further, interviewees explained that mainstream programs do not always work for youth living with FASD.

In speaking about the importance of having youth needs met, staff and management interviewees also explained the importance due to the **stigma** that Indigenous youth living with FASD have to face. Not only do these youth have to deal with stigma related to being Indigenous, but they are also faced with stigma related to their diagnosis of FASD. Staff and management interviewees noted that many Indigenous youth were equating their Indigeneity with negative aspects, such as residential school, missing and murdered Indigenous women, or the downtown eastside of Vancouver. Further, youth are also facing stigma around their Indigenous identity with white and settler

privilege in society; one interviewee explained that society is placing the blame on Indigenous people for the problems they face. For Indigenous youth living with FASD, the stigma is compounded by their diagnosis, as interviewees explained that oftentimes, youth living with FASD are seen as con artists, problem children, and leaders of crime.

Staff and management interviewees also spoke specifically about the importance of specific needs, including relationships needs, competent support workers, advocacy needs, the need for trauma counselling and basic needs. Interviewees explained that **relationships** for Indigenous youth living with FASD are important, as many youth are lacking connections to anyone; they are not living with their families, and have lived much of their lives without those connections. Interviewees also explained that the need for **competent supports** is important for youth living with FASD, because oftentimes, general supports do not have the specialized training and awareness of the complex needs and challenges of those living with FASD. Further, interviewees explained that often, workers do not fully understand the brain deficits and challenges that accompany FASD, and consequently, they are approaching case management of youth in a manner that does not work for the youth, such as speaking to the youth as if they do not have FASD, not understanding that the youth does not understand. **Basic needs** were also identified as important to address, such as adequate housing. Interviewees explained that many youth end up couch surfing or homeless, with no reliable family placements or stable homes. One interviewee commented, “You can’t teach someone to cook if they don’t have access to a kitchen.” Finally, the need for **trauma counselling** was also noted by one interviewee as important as Indigenous youth living with FASD have trauma in their life that they are coping with. Table 22 below details the importance of meeting the aforementioned needs and the frequency at which the themes and needs emerged.

Table 22: Staff and Management's Perspectives on Supporting Youth Needs

Theme	Count (*n*)	Importance of Meeting Needs
Policy issues	10	- Systemic racism, such as differential treatment in the justice system - Systemic barriers, such as poor management of youth, programs not designed for FASD, and services that are intended to support youth with disabilities being a barrier due to paperwork,
Stigma	6	- Stigma is doubled; stigma related to Indigeneity, and stigma related to a diagnosis of FASD
Need	**Count (*n*)**	**Importance of Meeting Needs**
Relationships	3	- Many youth are lacking connections to anyone; they have lived half their lifetime without connections - Many youth are not with their families - Many youth have a many workers they do not want to be around
Competent supports	3	- General support staff do not have the specialized training or awareness of the complex needs and challenges associated with FASD - Not fully understanding the brain deficits, such as understanding that a youth may have difficulties understanding basic things
Housing	2	- Many youth have no reliable family placements or stable homes and end up couch surfing or homeless
Trauma counseling	1	- Severity of traumatic experiences youth are dealing with

The above findings strongly suggest a need for: legal advocacy, education and training for justice officials, specialized workers and support who have an in-depth understanding of FASD, for workers to be educated and trained on FASD, for the system to re-evaluate their policies around support and services, and ultimately, for Indigenous youth living with FASD to have a positive self-identity as an Indigenous person.

4.2. Program Reach

When asked if the right youth were in the Program, all but one staff and management interviewees agreed that that this was the case, while one interviewee was unsure. When asked to elaborate, interviewees noted that the criteria for inclusion in the Program is specific; youth must be referred by youth probation services and must be Indigenous. Further, the criteria for inclusion was also intentional, as one interviewee

commented, “we picked those [criteria] in particular for a reason, because of the intersection between justice and health.”

Staff and management interviewees indicated that there are youth who are not in the Program but should be, as the workers in the project were facing **capacity barriers.** For instance, interviewees spoke about barriers around the ability to take new referrals, as their caseload was at capacity and there was a need to scale back the number of youth in the Program. One interviewee commented, “a lot of youth on the caseload are not getting service the hours they need, the Program hasn’t taken new youth in the last year, all new youth go to [the mainstream programming].” Furthermore, interviewees noted that there are many youth who **do not meet the inclusion criteria of justice involvement** but could benefit from the Program (e.g., community referrals are not accepted). Comments included:

- *Yes, I believe all of the Indigenous youth referred could benefit with connection to our project, because we come from strong cultural lens, so we talk about what does that mean; even listening to our youth, and hear what they’re saying.*

- *There is only one way to gain access to our project, via intersection with justice, and being referred for FASD assessment by youth probation officer across BC. That is the only way youth can access the program … We have community members asking how to get my youth involved, I want to work with that project. We have to say we can’t.*

Barriers for accessing the Program included **caseload capacity** where more youth qualified for the Program than the Program could serve; this ultimately limited their ability to take new referrals. One interviewee noted that **geography** also presented a barrier for accessing the Program; the focus of the work in the Program is rooted in building relationships and connections with youth and families, and as one interviewee commented, “the amount of time to make connections, you can’t do that over the phone, you have to be out in the community, you can’t do a spirit bath if they live in Prince George.”

Table 23: Program Reach Barriers

Theme	Count (*n*)	Details
Staff and Management		
Case load capacity	5	- Cannot take new youth and need to scale back the number of youth per worker - More youth qualify than the workers can take on
Inclusion criteria	2	- Criteria to be in the Project is limited to youth referred by probation services

4.3. Program Design and Delivery

Program Design

Staff and management interviewees provided mixed responses as to whether the holistic design of the project is effective in achieving the objectives. Four of the interviewees said yes, while two interviewees noted somewhat. For those who indicated yes that the holistic design is effective, they explained that the holistic design is effective because of the **nature of youth needs**. For instance, staff and management spoke about the fact that youth needs do not occur in isolation, but rather they are interrelated, and youth needs extend beyond the assessment and diagnosis; youth need support, especially before and after the assessment. One interview noted that when you diagnose a youth, you may very well be diagnosing the family as well, stating:

> *It's so much more than the diagnosis. We never looked at this as just a diagnosis, our whole concept here is if we provide a diagnosis, we have to provide support before, during, and after to these families and individuals because they've experienced so much trauma; to give a sweeping diagnosis and then to send [them] home, it's not healthy. What people don't realize is, that when we diagnose a youth, one youth, we may be diagnosing a family, and then how does that roll out or play out in their homes and community? That's why the support is so important to youth and families to deal with this, the grief and trauma of diagnoses can be huge.*

Furthermore, operating in isolation does not work, as one interviewee commented "if you separate the different needs, that won't work. Compartmentalizing needs doesn't work, [you] have to look from a broader lens, so that wrap approach is really important."

Interviewees who indicated that the holistic design is effective also spoke about the **significance of the holistic design**. For example, one interviewee noted that a result of a holistic approach is that you are not pathologizing someone as sick and others as healthy; rather, the focus is on the system level, not the individual level. Further, a holistic design means that the community is engaged and supporting the program. One interviewee commented:

> *Yes, holistic blanketing a youth and their family; absolutely I do think it's necessary and relevant and a best methodology because it doesn't create patient "x" where one person is what's wrong with something, it looks at the system level, it looks at a healing response that works for community, for family, and doesn't pathologize one person as sick and the others as healthy, or where one person is in need and others aren't, it's addressing the needs, and the health of the entire unit as it functions together in a good way.*

Some interviewees spoke about the **objectives and operations of the Program**, noting the objective is "for these youth to have healthy vibrant lives outside the criminal justice system, and to have some sense of independence, adulthood, and identity, care and love and connection to who they are, and support for that." Another interviewee noted that workers in the Project operate in a holistic manner, "we do everything, getting medical doctors, securing housing, keeping children out of care, making sure there's adequate contact for youth in care with families."

While most interviewees expressed that the holistic design was effective in achieving the objectives, two interviewees were hesitant to say the same. They noted that workers in the Program do not have the capacity to meet the objectives, and that holistic services are what they ideally want, though they are facing **barriers to holistic work with youth**. For instance, interviewees noted barriers around the lack of skilled trauma counselors that can support youth with tragic loss and traumatic histories, and systems that do not work for Indigenous youth. One interviewee also noted that the level of monitoring and advocating the Program workers have to focus on is a barrier to providing holistic work with youth. Comments around barriers included:

> *It's hard to do the in-depth work we need to do with our kids, when we're monitoring, it should be more an education system, but there is such power dynamics at play, and we're not really on top of it … It's unfortunate that*

our program right now has to do so much monitoring (what's this social assistance office doing, what's the plea worker doing), and we know and hear what's happening, the kids call because they know we're advocates for them.

- *If we had that, the holistic service, we would be providing a better holistic and supportive service to our youth and families. We struggle at times to find a home to make sure our families are not homeless, it's been a battle with some ministry workers (Youth Probation, social workers) and having our youth attend Indigenous cultural based drug and alcohol programs, that they're absolutely against it, so how are we doing with finding holistic support? [W]e are struggling.*

Table 24 below highlights the factors that contribute to the holistic design of the Program as well as the barriers to working holistically with youth.

Table 24: Factors Contributing to the Holistic Design of the Program

Theme	Count (*n*)	Details
Staff and Management		
Nature of the needs	4	- Needs do not occur in isolation, youth need support throughout the continuum of the assessment
Significance of the design	3	- Holistic work does not pathologize youth, and focuses on the system level, not the individual
Program objectives and operation	2	- The focus of the program is to see youth living healthy vibrant lives, with independence and identity
Barriers to holistic work	3	- There is a lack of trauma workers, and the program focuses much of its work on monitoring

Program Delivery

In thinking about the original design of the Program, staff and management interviewees were asked what adaptations were made to the Program. Unanimously, they spoke about adapting the **focus of the work**, as the Program rolled out differently than envisioned; the focus is now broader and deeper. For instance, rather than focusing only on how one factor impacts another (e.g., how FASD can contribute to justice involvement), the Program evolved to focus on deeper, root causes of the challenges youth face, such as how intergenerational trauma impacts legal involvement. As such, the Program is more community-focused, rather than assessment focused. Comments included:

- *We originally envisioned [the Program] to be more assessment-focused and it's become more community focused, which I think is a good thing; it reflects the needs of youth. Things that we didn't necessarily build into the original proposal of the program, but are able to offer because of the skillset of the people … And [the] legal advocacy, we built the program around helping the youth understand how their substance use effects their legal involvement, and I think it's much more about how intergenerational trauma has impacted justice/legal involvement. It's been an interesting shift, but an important shift, because that's where a lot of youths' substance use comes from. So I think it's a more important understanding to have, to understand how substance use impacts legal involvement. It's a different approach than anticipated, but it's richer in a lot of ways. I think part of it's the difference between administration and support aspects of the work, I think partly the needs of youth, and partly the skills of workers – it just differentiates itself naturally and it's becomes more community-based, than assessment procedural-based.*

- *The biggest difference of what we're doing on the ground is backing it up before that, we're focusing not just on how your current circumstances impact legal involvement, but how past family and child experiences and development in this way is putting youth in trouble with the legal system. It's more prevention-focused. It's direct, but potentially more impactful.*

One interviewees noted that the focus has shifted in that there is more advocacy and monitoring versus correcting justice involvement, while another explained that the focus of the work has changed in that it is less connected to youth probation services, as it was originally envisioned.

When asked to elaborate on why the focus of the work had changed, interviewees attributed the shift to **real time data** and **staff skillsets**. With respect to real time data, they noted that they originally did not have a clear idea on how the Program would unfold, but given flexibility, the Program has evolved, as it is a living project, "*it's much different from its conception*." They noted that it took time to develop relationships and trust with families and youth, and in the process, they learned the extent of youth needs. As such, the focus of the Program became more broad and deep due to the needs of youth. They also explained that the shift was due to staff skillsets that stood out, such as important cultural knowledge and legal advocacy skills.

When asked for feedback on how the design and delivery of the Program could be improved, staff and management interviewees spoke about improvements to the **infrastructure of the Program**. They shared that the Program should expand in terms of

staff and location, and the Program should also be designed to address the broader needs. It was also suggested that there be more representation of Indigenous people on the medical side.

The Program is guided by an advisory committee comprised of leaders in BC with expertise varying from justice related Indigenous matters, FASD, and holistic health. One interviewee shared that a joint advisory committee, with representation from the executive directors of both agency and organization partners would be beneficial. In offering suggestions to improve the design and delivery of the Program, it was also put forth that a community outreach strategy be developed as a means to increase outreach to community, youth probation services, youth custody services, and educational systems where justice officials are trained. One interviewee explained:

> *I thought we'd have a more formalized relationship with youth probation services than what we have; what we have now is a design of a program from a cultural lens, that hasn't quite yet filtered … our connection to youth probation services is not there yet. They [youth probation services] should know [the Program] and youth custody should know about this program by now, or soon, they should know the relevance. There should be some community outreach to that. I hope to see this in the future. And MCFD, they above all need to know about this program. Where are youth probation officers trained? The program itself should be on the agenda of [the institutions where probation officers are trained] to speak of the program deliverables; and I know [the assessment centre] is reaching out provincially to a larger reach than just the Fraser Valley, it could be that all youth probation officers must learn from a program point of view, if they're required to fill out the [screening] form, they should know about this program, it does have a larger reach.*

Suggestions were also made around utilizing staff expertise and specialities, where the staff with specialized skills and knowledge that fit within the holistic model could be sought, rather than seeking out someone with all of the skillsets and qualities. It was also noted that delivery of the Program prior to a youth becoming involved in the justice system would be great, as one interviewee commented, "It would be great if we were meeting these young people before come into conflict with justice in doing this work. Correctional system and ministry are an industry. How great would it be if the first thing the ministry did was call our program, before apprehension? If the first time there's a worry at home, call the Program instead of apprehending."

Staff and management interviewees also provided suggestions around improving the **operations of the Program**. For instance, interviewees suggested that the Project deliver more workshops, knowledge gatherings and presentations, particularly with justice personnel (e.g., youth probation services, MCFD, the Justice Institute, youth custody). Interviewees also noted that the Project could share updates on progress and statistics with the partner agency, such as sharing updates on youth and family outcomes. One interviewee suggested that the someone from the Program document and share minutes of the advisory committee meetings (e.g., share agendas, recommendations that emerged from the meeting, decisions and outcomes of the meetings), while another noted the need for more time, space, and opportunities to grow the design and delivery. Table 25 below provides a high-level summary of the changes that were made to the original design of the Program, as well as the themes that emerged explaining the changes and suggestions for improvement.

Table 25: Program Adaptations and Suggested Improvements from Staff and Management

Theme	Count (*n*)	Details
Adaptations		
Focus of the work	10	- The focus is broader and deeper; focusing on the root causes of legal involvement and challenges faced - Increased advocacy and more community-based rather than assessment focused - Less connection to probation services than envisioned
Rationale for Adaptations		
Real time data	4	- The program is a living program, with time and flexibility, the program has evolved - Learned the extent of the youths' needs
Staff skillsets	2	- Having strong skills in legal advocacy and strong cultural knowledge
Improving the Design and Delivery		
Infrastructure improvements	8	- Expand staff, location, scope of addressing broader needs - Expand to allow community (non-justice) youth in need of a FASD assessment - More Indigenous representation on the medical side - Joint advisory committee with representation from both organization/agency partners - Development of a community outreach strategy

Theme	Count (*n*)	Details
Operations improvements	5	- Deliver more workshops, training, gatherings with justice personnel - Share Program statistics and updates with partner agency - Document and share advisory committee minutes

4.4. Program Relevance and Satisfaction

Relevance

All staff and management interviewees unanimously agreed that the Program is relevant to the needs of Indigenous youth and families living with FASD. When asked to elaborate, they spoke about the focus of the work within the Program, how the Program workers operate, and the approach of the Program workers as reasons for why the Program is relevant.

With respect to **the focus of the work within the Program**, staff and management interviewees spoke about the emphasis on culture and cultural support and their focus on reaching out to family as important. Interviewees also spoke about the Program being relevant to Indigenous youth and families because of the manner in which **Program workers operate**. More specifically, one interviewee spoke about the balance between being youth-driven with youth input and meeting the objectives (e.g., advocacy, informing youth about residential schools), while another spoke highlighted the fact that the workers in the Program provides stability, knowledge and pride for youth. Interviewees explained that the emphasis on culture and identity as an Indigenous person is particularly important, as oftentimes they are seeing family disconnection, where youth are disconnected from their family, and disconnected from their culture; as such, it is critical for youth to have that positive identity as an Indigenous person. One interviewee commented:

> *The biggest loss we see with youth are that they are so disconnected from family, and from culture. That connection is so important to know who you are.*

The **approach of the Program workers** was also noted as a factor that makes the Program relevant to the needs of Indigenous youth and families. In particular,

interviewees highlighted the Program workers' approach to having conversations with youth about FASD and identity, commenting, "The conversation [Program workers have] with Indigenous youth around FASD probably looks different from the conversation that the [assessment agency] has … when you have so many things toppled on top of you, such as a negative identity as a First Nation person, that conversation needs to be deep." Further, the approach of the Program workers in engaging families and building those trusting relationships was noted as an aspect that contributes to the relevance of the Program. One interviewee commented:

> *The cultural perspective has made all the difference in working with youth and family; they see we really mean this, so they see that and feel it and they start calling. The intimacy that the youth and families, in terms of relationship development, have shared (things that are so sacred to them: trauma, abuses) that they haven't told others, and they have an army of other workers [ministry, probation, social workers], and they haven't developed a trusting enough relationship to share their intimate fears, trauma, challenges, but they're doing it with [this program].*

Table 26 highlights the three themes that emerged with respect to staff and management perspectives on the relevance of the Program in meeting the needs of Indigenous youth living with FASD.

Table 26: Perspectives on the Relevance of the Program

Theme	Count (*n*)	Details
Staff and Management		
Focus of the work	3	- The emphasis on culture and family
How the Program operates	2	- The balance between youth-driven and objective-driven - Provides pride and knowledge for youth
The approach the workers take	2	- The way the workers approach conversations with youth and the way workers build trusting relationships

Staff and management interviewees noted that the focus of the work, the approach the Program takes, and the manner in which Program workers operate is important as Indigenous youth and families are faced with systemic racism, where parenting from an Indigenous lens is dismissed, undervalued, and penalized. Furthermore, the focus, approach and manner in which Program workers operate is important given historical

relationships with the three agencies involved in the assessment process. One interviewee commented:

> *With our Indigenous youth, we have issues with youth not wanting to come to the [assessment agency], because who are the three agencies involved at time of referral? The ministry, the justice system, and health (e.g., the assessment agency); historically, these are agencies that our people don't have a good relationship with.*

All advisory committee members who took part in the evaluation interview agreed that the Program is relevant to the needs of Indigenous youth and families living with FASD, noting the successes of the Program. For instance, advisory members spoke about the successes of the knowledge gathering, and supporting parents in maintaining guardianship. One advisory member noted that the medical assessment centre never had the coordinated follow-up post assessment like the Program does, noting the importance of this post assessment support.

Staff and management were also asked whether or not they thought that Indigenous youth who are in the Program would have done the FASD assessment if the Program did not exist. Responses varied among staff and management interviewees, as two indicated that yes Indigenous youth would have done the assessment, but some would not, while two others stated that most or some would not, and the remaining two interviewees expressed no, they would not. For those who said that some youth would still do the FASD assessment, though some would not, they noted that non-participation in assessments can be attributed to timing, as many youth will disengage for a period of time, but later return for the assessment once they are in a different place in their life.

For those who said no--Indigenous youth would not engage in the assessment if the Program did not exist--they spoke about the history of Indigenous youth engagement in the assessment process. For instance, interviewees compared previous statistics to current statistics of youth who progressed through the FASD assessment, commenting "the centre, they were having problems with kids coming in for an assessment, that's why the project exist; now more [Indigenous youth] are being assessed than non-[Indigenous], it's making a huge difference … It would probably look like what it used to look like." Those who indicated that Indigenous youth would not engage if Program did not exist also spoke

about the systemic history of the agencies involved being a barrier (e.g., MCFD, justice, health), and the engagement of Indigenous youth in FASD assessments could be attributed to the approach that the Program workers take in building trusting relationships with the youth. Comments included:

- *Some families are adamant that they will not do the assessment with non-Indigenous individuals.*
- *The experience is richer for youth because of the [Program].*

In speaking about the relevance of the Program, staff and management interviewees were also asked whether or not they thought that non-Indigenous youth who are going through an FASD assessment would also benefit from the Program. All but one of the interviewees agreed that non-Indigenous youth would also benefit from the Project, while one interviewee was unsure. For those who said that non-Indigenous youth would also benefit from this project, they spoke about the **approach the workers take**, such as the collaboration with medical assessment workers, and the Indigenous lens of Program being applicable across-cultures. One interviewee commented, "Every culture has an Indigenous lens. Europeans had Indigenous people. We all had that." Staff and management interviewees also spoke about the **benefits that non-Indigenous youth would gain** from a program such as the Program which is being evaluated, including an enriched experience, and support in navigating protocols and different systems. One interviewee commented, "I think every youth and family, if they have to go through the justice and medical system, having an advocate that can translate that and support them would be helpful; the cultural support is specific to Indigenous youth". Interviewees also highlighted examples of a minority youth from another cultural background who responded to and benefited from interactions and time spent with the Program workers (see Table 27 below for a summary of the themes and frequency at which the themes emerged).

Table 27: Why Other Youth Would Benefit from the Program

Theme	Count (*n*)	Details
Staff and Management		
Approach the Program takes	3	- The collaborative nature of the Program, and the Indigenous lens applies cross-culturally
Benefits youth would gain	5	- Support in navigating systems, and having an advocate

Satisfaction

All of the staff and management unanimously expressed being satisfied with the Program. When asked to elaborate, three themes emerged as reasons for their satisfaction, including the Program is filling a gap, the partnership and the progress that is being made. With respect to **the Program filling a gap**, interviewees explained that the project did not exist three years ago, but absolutely needed to; and the work that the Program is doing is ground-breaking work, there is no other model like it. It was also noted that the work the Program is doing is filling a need with respect to the connection between justice and health in terms of service delivery. Staff and management also spoke about **the partnership** when explaining their satisfaction with the Program, noting that both organizations are willing, committed, and patient with each other. Interviewees also spoke about the **progress that is being made** in terms of assessments and cultural connections as a reason for their satisfaction. One interviewee commented, "I'm very glad our project is here, if it wasn't here, the kids wouldn't be getting assessment, they wouldn't be given opportunities and experiences, the experiences have ability to fundamentally changing someone's life." Table 28 below summarizes the themes that emerged and the frequency at which they occurred when staff and management interviewees were asked to elaborate on why they were satisfied with the Program.

Table 28: Staff and Management Satisfaction with the Program

Theme	Count (*n*)	Details
Staff and Management		
Addressing a gap/need	3	- Program is doing ground-breaking work, and is connecting justice and health service delivery
The partnership	2	- The willingness and commitment each agency and organization partner brings to the table
Progress being made	2	- Seeing changes in cultural connections and assessments being completed

Though staff and management interviewees were unanimously satisfied with the Program, they also expressed that there are **aspects of the process they are still working through**. For instance, interviewees spoke about the fact that they are still learning in the partnership trying to find balance; it is a work in progress. Interviewees

shared that there remain some barriers to progress, specifically around figuring out the caseload per worker, and explained that finding the right people for the work has limited progress, as there has been turnover of the male position.

4.5. Program Outcomes

Program Outcomes

Staff and management interviewees were asked whether or not they thought there have been changes in stigma around FASD in Indigenous communities because of the work that the Program is doing. Most interviewees said yes, while one interviewee expressed, not yet, though in-roads were being made. Interviewees frequently spoke about changes in stigma around FASD at the **community level**, referencing the success of the community knowledge gathering held in partnership with a local First Nation. They explained that the community gathering had a broad reach, the speakers were impactful, and there were community members and high-level political leaders from the First Nations Health Authority, and First Nations Health Council present. Furthermore, it was shared that the community knowledge gathering developed due to a conversation around FASD with the local First Nation, in which initial perceptions of FASD were viewed differently. One interviewee explained:

> *Definitely. The community knowledge gathering held was in partnership with [a local First] Nation; it happened because of a conversation with the Nation and them being able to look at FASD in a different way, looking at kids in their community causing problems in a different way. [This] Nation is a hard-on-justice community, if you're a parolee, you're not allowed to be there, they don't want criminals in their community. To have them recognize and value the community members having FASD, and we need to support them and we need to change, and to partner and financially support the gathering, because it's something to be spoken about, that was huge.*

Interviewees also spoke about changes in stigma around FASD at the **individual level**, explaining that each youth that workers in the Program interacts with has a support system, and each family and service provider is also learning, commenting "you're not just working with the youth, you're working with family, or service providers or community around them, we're doing things differently, especially coming from strengths-based

approach, so helping them see the beauty of each youth helps reduce the stigma which is quite often the most impactful level, it hits the heart more so."

When asked if there were any outcomes of the Program that surprised them, staff and management interviewees spoke about unanticipated outcomes for youth and unanticipated outcomes related to the process of the Program. With respect to **unanticipated youth outcomes**, interviewees shared that certain qualities of youth were unanticipated, such as witnessing youths' intrinsic motivation to complete the assessment without being told by others, and youths' insight, such as knowing what is best for oneself despite others telling them otherwise. Staff and management interviewees also spoke about the level of youth engagement as an unanticipated outcome, given the intensity of the work. For instance, youth continue to engage in intense ceremony, and intense deep conversations. One interviewee commented:

> *[Program workers] talk on a deep and emotional level and [youth] understand that. These are serious conversations for kids with limited vocabulary and concentration issues, and they sit there and they engage. They want to hear more. They're upset when the time is getting cut off.*

Staff and management interviewees also spoke about **unanticipated outcomes related to the process of the Program**. Interviewees noted changes to the status quo at the assessment centre, noting that the assessment centre has changed some of their process as a result of the Program (e.g., paperwork, celebrating successes). One interviewee elaborated by saying:

> *To be honest, some of [the assessment agencies'] practices have changed too … Even the focus on celebrating successes of completing an assessment, it's stressful, we know it, we always try to be as nice as possible to youth when they come through, but even just paying more attention to them finishing the assessment, and making sure the youth is part of that closure part. We're more intentional about what that means and helping to explain it to the youth more deeply. [The support workers do] that more intentionally – [they have] more opportunity for follow up after diagnosis, so [they're] able to help on that journey a little bit more, we don't have as much of an opportunity to do that but we're thinking about that deeper now. We're trying to be more responsive. That's something the Program did from the beginning. When you have a deeper relationship with the youth, there's no way you wouldn't notice what the impact of the diagnosis is on that youth, when you really know them, you see what the implications are, and to make sure you have that aftercare.*

Interviewees also expressed that the justice component unfolded in a way that was unexpected, with the emphasis on legal advocacy. Though it unfolded in a manner they were not expecting, one interviewee said, “I think we have something to learn from that, to support the person in court, so many of our youth, while waiting for them to come through, they have new charges.” Table 29 below provides a high-level summary of staff and management interviewees perspectives on outcomes that were unanticipated, and frequency at which the themes emerged.

Table 29: Staff and Management’s Perceptions of Program Outcomes

Theme	Count (*n*)	Details
Stigma Related Outcomes		
Community level changes in stigma	5	- The community knowledge gathering held by the Program had impactful speakers and reached community and political leaders
Individual level changes in stigma	2	- Changes in stigma at the individual level radiate outwards to families and communities
Surprising Outcomes		
Unanticipated youth outcomes	4	- Witnessing youth qualities, such as intrinsic motivation and insight - The youths’ level of engagement in the Program
Unanticipated processes	3	- Partner agency changed processes around paperwork and celebrating successes - The manner in which the justice focus unfolded (e.g., the focus on advocacy)

Staff and management interviewees also shared what they were **surprised to learn** through their involvement in the Program, including the depth of challenges Indigenous youth living with FASD face, the length of time it can take for an FASD assessment, and the fact that some youth may age out of the system while they wait for the assessment. Additionally, one interviewee noted being surprised to learn that Indigenous youth who are children in care are not necessarily living in a responsible place, but in reality, they are living in group homes or are homeless and not being supported.

Advisory committee members were also asked about program outcomes and if the Program is achieving their objectives to support Indigenous youth and families living with FASD. In responding, two advisory members said yes, while one said they could not

answer as they were not aware of the outputs. The two advisory committee members who said yes noted that the Indigenous lens and Indigenous work is therapeutic (e.g., blanket ceremony), and the outreach has been a success. One advisory committee member commented, “we’re in the pioneering early stages; what we do now will impact other people.”

Youth Outcomes

Staff and management interviewees were also asked about youth outcomes. In responding, interviewees spoke about several outcomes that stood out for them, including outcomes around culture, pride and identity, trust, and family. With respect to outcomes related to **culture**, staff and management interviewees spoke about youth learning about Indigenous culture, and knowing that ceremony is healing. One interviewee elaborated, stating that a youth “knows ceremony is healing even though he didn’t grow up with it, he participated in a brushing and he was amazed by how he felt after brushing ceremony.” Interviewees also spoke about youth being mindful of spirituality and prayer, and being more connected to culture and spirituality. Interviewees further explained that youth in the Program have learned about the historical trauma Indigenous people in Canada have endured, specifically due to the residential school system. In addition, they also noted that youth in the Program have gained a connection to their Indigenous culture and language. **Pride and identity** was also noted as a youth outcome, as youth are no longer embarrassed to be Indigenous, and have a positive self-identity as an Indigenous person, and their self-esteem has increased, as they are not feeling pathologized as a bad person.

Staff and management interviewees also shared youth outcomes around **trust**, noting that youth in the Program have started to trust the workers, so much so that they are willing to have the workers meet their family, and know to call the Program workers if they need to. Further, youth outcomes around **family** were also identified; interviewees noted that youth are staying with the family unit versus being removed, and youth are involving their family in the Program (e.g., bringing their siblings to ceremony). Interviewees explained that they are witnessing outcomes around empowerment, as youth and parents are gaining their voice and voicing their concerns; “They’re learning how to advocate and have a voice … they’re saying what they want” and they are “voicing their

wants, needs, and concerns." Finally, one interviewee noted that there have been positive outcomes from the legal advocacy, as legal sanctions are now more reflective of the crime (e.g., reduced sentences, home placements, and appropriate probation orders versus placed in the system unnecessarily). Table 30 details the outcomes identified by staff and management and the frequency at which the themes emerged.

Table 30: Youth Outcomes

Theme	Count (*n*)	Outcome
Staff and Management		
Culture	6	- Youth are learning about culture, becoming mindful of spirituality and prayer
Pride and identity	6	- Reduced embarrassment, increased self-esteem and self-identity as an Indigenous person
Trust	3	- Youth trust the workers
Family	2	- Youth are staying with the family unit versus being removed
Voice	2	- Youth are stating their voice and wants

Staff and management interviewees were also asked to rate whether or not youth achieved specific outcomes the Program set out to achieve. Table 31 provides a visual breakdown of interviewee ratings.

Table 31: Achievement of Objectives

Because of the Program	Yes	No	Already there	Do not know
Staff and Management Ratings				
Youth have increased awareness / understanding of how FASD and substance use can contribute to justice involvement	2	0	0	2
There has been a positive change in attitudes and perceptions of FASD for youth and families in the program	4	0	0	0
Youth have increased confidence in accessing services and support needed	3	0	0	1
Youth have increased self-esteem	4	0	0	0
Youth have increased coping skills	4	0	0	0
Youth are more connected to Indigenous culture, traditional teachings, and community	3	0	1	0
Youth know what they need for healing	3	1	0	0

When asked if youth have increased their awareness or understanding of how FASD and substance use contribute to justice involvement, responses were split, with two interviewees indicating yes, and two interviewees indicated that they did not know. When asked to elaborate, those who said yes said that they believed youth have increased their understanding to the best of their ability, given the challenges associated with their disability. Another interviewee noted that the Program will do even better at increasing the awareness within youth once the caseload per worker is reduced, as they will be able to spend more time with youth. For the two interviewees who said they were unsure, they spoke about the project being implemented differently than they had envisioned it, with more focus on cultural connections and Indigenous identity. As such, they were not sure about what conversations were happening within the Program with respect to the intersection of FASD, substances and justice involvement.

Staff and management interviewees were asked if there had been a positive change in attitudes and perceptions of FASD for youth and families in the Program. Interviewees unanimously agreed that there have been positive changes. When asked why, they shared that the Program is lessening stigma and shame around FASD through the conversations that are happening with youth. One interviewee commented, “I think there’s a lot of, ‘yeah you have FASD, but there’s a lot more about you; yes, you have FASD, but it’s not who you are, we can talk about it.’ it dissipates stigma, it’s not to be ashamed of.”

Interviewees were also asked if youth in the Program have increased their confidence for accessing services and supports needed, and most said yes, while one interviewee said they were unsure, providing a mixed response, noting maybe yes, maybe no, that they did not know. When asked to share more, the interviewee commented, “Have our youth gained some strength in advocating more for them self, I’d say yes they have based on work with the Program, would others no, maybe not. They’ve definitely gained internal strength (e.g., knowing something isn’t right, that feeling being stronger), just maybe not noticeable on the outside. Can they go against the system? probably not”

Interviewees unanimously agreed that youth in the Program have increased their self-esteem. They shared that there has definitely been progress, and the self-esteem is

better than what it was, and attributed the progress to the cultural work that the Program focuses on. One interviewee shared:

> *I think that the cultural component helps with that self-esteem. When you make a connection youth can't take that back. When you have a greater sense of who you are, that's validating. It always made sense to me.*

Staff and management interviewees also unanimously agreed that youth in the Program have increased their coping skills, and when asked whether or not they believed that youth in the Program were more connected to Indigenous culture and traditional teachings and community, three interviewees said yes while one interviewee said that youth were already there. Finally, staff and management interviewees were asked whether or not they believed that youth in the Program knew what they needed for healing as a result of their involvement. Interviewees provided mixed responses, with three interviewees indicating that youth were learning what they need for healing. One interviewee shared, "I think they have a better understanding, not that they absolutely have it. There's progress towards that goal" while another shared, the Program worker "took a youth on a hike, and they said it's the first time their heart was beating without being scared. That one insight from that one youth makes me answer yes [they know what they need for healing]." While most interviewees indicated yes, one interviewee said no and added "Does anybody know what they need for healing? We have adults without brain impairment who don't know what they need for healing"; many are unaware of what they need or the underlying traumas. Healing is an abstract and big concept to understand.

4.6. Program Sustainability

All staff and management interviewees agreed that there is a need for the Program to continue in the future. When asked what needs to happen to make the Program sustainable, staff and management interviewees spoke about the need for **funding and buy-in to the Program**. More specifically, interviewees spoke about the need for funder and stakeholder buy-in, where funders and stakeholders hear Program participants' feedback and stories, and can appreciate the issues and need for Indigenous people to do this work. Ongoing and stable funding, rather than annual funding, was also noted as a need for a sustainable program, as there are limits to annual funding. In order for

program sustainability, staff and management interviewees also noted the need for provincial funding beyond the lower mainland, and the need for the Program stakeholders to lobby funders to ensure the Program can be sustained beyond being a pilot project. One interviewee commented, “We need to ensure there’s more opportunity to access this project as an actual program. We need to do more work in lobbying funders to ensure the program is stable and stays – we don’t want the doors to shut, we want the program to be sustainable.” Finally, one interviewee noted the need for a commitment from the MCFD at the minister level to fund the Program was also noted as a need for sustainability.

Staff and management interviewees also spoke about the **infrastructure of the Program** in terms of sustainability, such as the need for more staff, the need to expand the Program in terms of their catchment area, and age criteria, and to develop their own mandate. One interviewee commented, “I think now is the opportunity as we move forward to make this program not just a project, but a program by itself, that it would be funded with its own mandate, that it’s Aboriginal specific. I still see it in partnership with the assessment centre, but one of expanded services.” Further, interviewees noted the need for Indigenous representation at all levels of the Program, where there are Indigenous doctors and clinicians.

In order to be sustainable, it was also noted by interviewees that there needs to be **increased awareness of the Program**. It was suggested that the successes of this Program be promoted as a means to raise awareness through disseminating report findings to the community, funders, and journals. There also needs to be community support for the Program, and in turn, the Program staff and management need to do community outreach for sustainability. Finally, staff and management interviewees spoke about the need to **plan for sustainability**. For instance, it was noted that the staff and management, and executives in charge of the Program need to start thinking about what a longer-term expansion of the Program might look like 5 years from now. One interviewee commented that, “we need time, space opportunities and resources to find our place in this work”; and [we] need the flexibility to be a “living project” that evolves and is never static. One interviewee commented:

- *We may be two years in, but we’re two years into the beginning of something that doesn’t exist anywhere, not in BC or Canada, that we know*

of doing the work we're doing; where there's support for youth and families, for youth and family before, during, after FASD assessment, and we're doing it from a strong cultural Indigenous lens, we have a small family of workers.

Table 32 highlights the themes that emerged when staff and management spoke about what needs to happen to make the Program sustainable, and the frequency at which those themes emerged.

Table 32: Program Sustainability Needs

Theme	Count (*n*)	Details
Staff and Management		
Funding and buy-in	9	- Need funder and stakeholder buy-in via participant feedback and lobbying funders - Ongoing, stable, provincial funding
Infrastructure changes	7	- More staff, expand the Program's catchment area and inclusion criteria
Increased awareness of the Program	3	- The successes of the Program need to be promoted - More community outreach and community support
Dedicated planning	3	- Long term visioning and planning (e.g., 5 years)

4.7. Lessons Learned

Strengths

Staff and management interviewees were asked to reflect on what is working well in the Program. In doing so, they frequently spoke about **how the Program operates** as a component that is working well. Specifically, staff and management highlighted the approach that is used within the Program, where the staff and management operate from a cultural lens, and take the time to explain things to youth and families, using real life examples. Interviewees also highlighted the connections and trusting relationships between workers and youth and families, as intimate relationships are being developed, where youth are opening up to workers. It was noted that the way the staff speak to youth and parents is done respectfully, where the staff are transparent with parents about what they are telling youth. Further, one interviewee spoke about the flexibility of the staff in the Program, in that they are not nine-to-five office oriented and will meet youth when youth

need it. Another interviewee noted that the staff intentionally following up with youth after they have been diagnosed, and explaining their diagnosis to them was working well. Finally, it was noted that the land-based cultural activities that are offered within the Program such as hiking, going to the mountains, and attending a potlach was working well. One interviewee commented:

> *One of the biggest things [the Program] gives youth, is a proper understanding of FASD. [The Program] always ask them, if someone says you have FASD, what does that mean to you? [The] less outspoken youth, say I don't know. [The] more outspoken youth, they say, 'you think I'm retarded' … They don't understand that someone can have FASD and have a high IQ, or be a productive member of society and have FASD. They think you're saying they're incompetent. It's one of the reasons they agree to come in as well – because of the understanding that [the Program] can give them, the gentle way of speaking and explaining FASD to them.*

What the Program focuses on was also identified as something that is working well. Staff and management interviewees spoke about the focus on topics around Indigeneity, such as building pride, positive self-identity as an Indigenous person, historical actions of colonization, systemic racism, and shame, as providing opportunities for youth to learn or talk about it information they already knew. Interviewees also noted that the focus on justice and housing advocacy, and cultural work are working well. One interviewee also added that the focus on supporting Indigenous youth understand FASD in relation to being Indigenous is working well, while another interviewee noted the connections that are being built within families are working well.

The **partnership and collaboration** among Program partnership was noted as an aspect that is working well. Staff and management interviewees highlighted the collaborative effort of the partners to reach out to communities for support and get the word out about the Program, and their efforts to work together to solve problems. Furthermore, they noted that the partners are committed to the partnership and to improving the program. The Program is housed within the assessment centre's office, and one interviewee noted that this integrated physical environment where they have shared space works well, as it allows for efficient problem solving. Interviewees also spoke highly of the staff at the Program, noting that the staff are the **right staff for the Program**. More specifically, interviewees spoke about the staffs' qualities, they are very good at their jobs,

they care deeply about the youth, and they have immense knowledge and spirit. Furthermore, interviewees noted that the relationship among the staff is a contributing factor for the Program working well, commenting that the staff operate as a family and know each other well. With respect to the staff, one interviewee commented:

> *You can see the amazing work she does … She is very unique and very gifted. She has gifts that are just a … to do this work, to do all the … we went through all the areas ideally someone would have in this position and she has them all in spades. You know, compassion, empathy, justice system background and knowledge, ministry knowledge and how it works. We need more people like [her]. The heart she brings.*

Interviewees also highlighted the fact that they are learning about the youths' needs, and getting a deeper understanding of how to serve youth better as something that is working well in the Program.

In addition to speaking about what is working well and the strengths of the Program, staff and management interviewees also shared success stories of the Program. In particular, they spoke frequently about **Program successes**, such as the success of staff in building trust with youth and families, and being their point-person for support. One interviewee commented, "If a youth needs help, they know to call [us at the Program], I know if something happens … if he can't get a hold of mom, he'll call me." They are building trust to the point that youth and families are opening up and asking workers at the Program for help. Other Program successes included the knowledge gathering held with a local First Nation, as they successfully disseminated information on FASD to the community. Further, interviewees noted that the rates of FASD assessments being completed was a success, commenting "The fact that they come in for the FASD assessment, the Program is a great success in that way … having youth come in and complete their assessment, it's a huge success." Interviewees also noted the increased awareness of Indigenous matters among their non-Indigenous partnership as successful.

Not only did staff and management interviewees share Program successes, but they also highlighted **youth successes** because of the Program. For instance, interviewees spoke about the success of youths' response to culture; interviewees are seeing pride in the youth; "they get excited to sew on a sacred item" and they are responding to the spiritual and cultural approach, specifically the work on the Button

Blanket. Interviewees also noted that they have witnessed youth successes in that youth are gaining a sense of cultural identity; they feel safe to be Indigenous at the Program, and are not denying their Indigeneity. Furthermore, youths' commitment to culture was also noted as a success by interviewees, as they noted youth want to practice culture, they are getting up at 5:30 am to go for a Spirit Bath, and are engaged in the entire ceremony. Table 33 provides a summary of the themes that emerged with respect to program strengths, and the frequency at which the themes emerged.

Table 33: Staff and Management Perspectives on Program Strengths and Youth Successes

Theme	Count (*n*)	Details
Program Strengths		
How the Program operates	13	- The cultural lens and cultural approach to working with youth and the focus on building trust and relationships with youth and families - Support beyond nine-to-five - Intentional follow up with youth and explaining the diagnosis
What the Program focuses on	8	- Focus on Indigenous identity, pride, history, and systemic racism - Focus on justice and housing advocacy
Partnership and collaboration	6	- The collaborative effort from both agency and organization partners in reaching out to communities and problem solving - The commitment of each partner to the Program
Program staff	6	- The staff are the right staff, have positive qualities and work well together
Program Successes		
Building trust	4	- Building trust with families and youth, being the person that they reach out to when in need
Knowledge gathering	2	- Successful dissemination of FASD information to community and political leaders
Youth Successes		
Youths' response to culture	2	- Youth are responding to the spiritual and cultural approach, and are proud to work on sacred items
Youth gaining a sense of cultural identity	2	- Youth feel safe to be Indigenous; they do not deny their Indigeneity
Youths' commitment to culture	2	- Youth want to practice culture; and are engaged in ceremony
Youth building skills	1	- Youth are working on budgets and asking help with budgets

Theme	Count (*n*)	Details
Need for the Program		
Importance of the work the Program does	7	- Indigenous youth face stigma from others and within themselves - Indigenous youth face systemic barriers such as having to be in government care to easily access services and supports

Staff and management interviewees also spoke about the **importance and need for the work that the Program does** as Indigenous youth living with FASD are faced with stigma, systemic barriers, misperceptions, and a lack of understanding. In speaking about stigma, interviewees noted that the work of the Program is important especially when youth are equating FASD with Indigeneity, or equating FASD with being dumb. Further, interviewees spoke about stigma in terms of other workers only seeing the deficits of youth and speaking negatively about youth. In terms of systemic barriers, interviewees noted that the current system is not working; there is a catch-22 where youth are faced with barriers of receiving support when they are not currently in care. Interviewees also spoke about misperceptions that workers have about youth, and their overreliance on file information. One interviewee commented, “we don’t need to have an intimate relationship with the files and what’s written, at best, there’s 5% of the youth’s life and trauma they’ve been through actually in that file and if you use that file as the rule for what the young person has been through, you’ll be very misguided.”

Challenges

While staff and management interviewees spoke about what is working well in the Program, they were also asked to share what is not working well. In responding, they spoke about the **operations** as an aspect that is not working well, as the connections with the correct justice providers, such as youth probation services and youth custody services, have not yet been made. Interviewees also spoke about the balancing of program objectives, commenting “[we need to] make sure that we’re linking into the correct justice providers that we need to be connected with, and making sure that justice and culture is balanced out.” The capacity to see youth is also an area in which there are challenges, as one interviewee commented that the “Program with [their] current caseload, doesn’t have the capacity to dedicate a significant amount of time to [youth] in a week” while another

explained “We would need a whole lot more workers, we can barely manage the caseload we have now. Once we get our next two workers in, I still don’t think we’ll be able to take all the Indigenous youth coming through probation. I doubt we’ll still have the capacity … There’s that many [referrals] coming through.” Related to this, staff and management interviewees also spoke about **staffing** as a challenging area. Specifically, there have been difficulties with staff turnover, finding the right fit in terms of the male support worker, which consequently has left the Program with not enough staff. One interviewee speculated why the male position continuously turns over, commenting:

> *We had some trauma training and trying to figure out why is it so hard to get a [male support worker]. [The trainer] did a re-enactment so people could understand the pain of what happened to children in our community. She put residential school survivors in the middle, put mothers behind them, behind them put husbands and fathers, then the rest of people behind. Then, [she] took the children out of the middle of the circle and put them in residential school. They were speaking about the pain the men felt at the outside circle - their role was to protect. In every Indigenous culture, they always say women are going to liberate our people, women will bring us back to our teachings; the reasons for that are around women being life givers, and having a straight connection to mother earth … when you look at that trauma training, what happened to our men in trauma, it’s almost an additional layer of trauma, of course it was very traumatizing for women to have children taken away, our role was to teach our children and pass on community values, but our role wasn’t to protect our whole community as it was for our men, they really did have that warrior role of protecting, our strongest men who went to battle, those men are probably the most effected.*

Furthermore, while staff and management interviewees spoke about the partnership as an aspect of the Program that is working well, they also noted that there are aspects of the **partnership** that are not working well. Specifically, they shared that when it comes to sharing of resources and communication, these aspects are lacking a bit. In terms of communication, interviewees elaborated, noting that there could be more communication between the partner agencies, and that communication from clinicians could be more culturally respectful. Operating from a colonial perspective, where the Indigenous lens is not fully embraced was also noted as a challenge. Despite these challenges, interviewees did note that the relationship between the partner agencies is a work in progress, as one interviewee commented, “Some aspects, we’re still working on that [cohesive partnership]. It’s been a division caused over centuries, things won’t all of

a sudden get better because of an Indigenous and non-Indigenous partnership. But it's changing, there's something they're still tolerating and something's they're valuing." Table 34 provides a summary of the challenges the Program is facing and the frequency at which the themes emerged.

Given these challenges, staff and management interviewees provided some thoughts on what is needed to remedy what is not working, such as increased collaboration and more learning from each other, and continued education with partners regarding what true self-determination, Indigenous-led means from an Indigenous perspective.

Table 34: Program Challenges

Theme	Count (*n*)	Details
Staff and Management		
Operations	8	- Connections with justice organizations/agencies not yet established - Challenges around balancing objectives and the capacity to see youth
Staffing	8	- Staff turnover of the male support worker
Partnership	4	- Resource sharing and communication between the partner agency, organization, and staff is lacking

Partnerships

As the Program is a collaborative effort between two organizations, one being an Indigenous justice organization, and the other being a medical assessment centre, staff and management interviewees were asked to reflect and provide feedback on the partnership and how it has contributed to the success of the Program. A total of two themes emerged, including the heart and commitment each partner has for the work, and the differing expertise and interdependence of the partners. Most frequently, interviewees spoke about factors that fell within the theme of having **heart and commitment to the work**. For instance, staff and management interviewees spoke about the strong commitment from both partners, as both are willing to do the work, not allowing failure, and ready to resolve conflict, demonstrating a genuine collaborative mentality. Interviewees also spoke about both partners approaching the work from the "right place" where they want to do the work, showing openness, and patience. One interviewee noted

that viewing the Program through a long term lens was also a factor contributing to the success of the partnership. This interviewee elaborated:

> *When you go into a committed partnership, particularly in a 3-year project, you think about end date (in terms of funding), but I don't think about the end of the partnership, we are both well committed to seeing this as a long term relationship because we do it well together and we need to build on it.*

The **differing expertise and interdependence** was also noted as a factor that contributes to the success of the partnership. Interviewees spoke about the Program combining different expertise's and skill sets, as each organization in the partnership brings a different knowledge base; the assessment centre is a leader in terms of FASD and assessments, and the Indigenous justice organization is a leader in the field of justice and brings the cultural lens. For instance, one interviewee explained that "We wouldn't be here without them; the whole project is founded on … referrals [originating from their assessment centre]; we couldn't do this work without them. They provide the FASD assessment, but [the Program's] work is much broader than that." Table 35 highlights the themes that emerged when staff and management spoke about the partnerships role in the success of the Program, and the frequency at which those themes emerged

Table 35: Partnership Factors Contributing to Program Successes

Theme	Count (*n*)	Details
Staff and Management		
Heart and commitment	8	- Strong commitment from both partners and collaborative mentality - Approaching the work from a place of openness, patience and desire to do the work - Long-term vision for the program
Differing expertise and interdependence	5	- Different skills sets and expertise are combined in the partnership (e.g., assessments, and cultural knowledge)

Moving Forward

Staff and management interviewees were asked to share the number one lesson they learned through their involvement in the Program. They answered in two ways: either speaking about **what lessons they would share with others** who are endeavouring to implement a program like this, or speaking about their **take-home lesson** from the

Program. Table 36 details interviewees take-home lessons, as well as what information or lessons they would impart on others.

Table 36: Staff and Management Lessons Learned

Take-home Lessons Count (*n* = 7)	**Lessons to Share** Count (*n* = 7)
Staff and Management	
Youth Wants and Needs - Youth want to change; they want a healthy life, they want culture, they want to be involved - Youth need to be in the Program, they need to learn how to live differently, without the chaos	**Use a Strengths-Based Approach** - Focus on supporting youth develop positive self-identity both individually and culturally - Build self-esteem, and build family connections and cultural roots
Need for Community-Level Work - The issue of shame around FASD within Indigenous communities needs to be addressed - More community engagement is need around FASD (e.g., knowledge gatherings) - Aboriginal communities need to buy-in to the Program	**Be Prepared** - Be prepared to understand what it really means to Indigenize a program
Breadth and Depth of Work - The service the staff in the Program provides extends beyond the youth, there are families, nations, siblings on the caseloads as well - The breadth and depth of the work and youth needs	**Be Open and Willing** - Be open and willing to change your perspective and your processes
Failure of the System - There is a lack of commitment from the system in terms of processes and services; it is a job to them	**Be Patient** - Be patient with everyone; with yourself, with the organizations, with the families and youth, with your partner agencies
Staffing Qualities - Knowledge of the kind of person need for the support position (e.g., cultural knowledge, FASD knowledge, grounded)	
Importance of Culture - An assessment process that is in line with an Indigenous worldview is more family sensitive	
Timing - The administration work takes time, in particular, working with the files	

Comments related to lessons interviewees would convey to others, as well as their take-home learning included:

- *Every task should be focused on youth developing a positive self-identity … If I could teach the youth one thing … Teach that they have value. That's the one thing I hope all youth would have.*

- *Be patient – all the way around with yourself, with organizing and getting the project off the ground. Be patient with families and youth. Be patient with partnering with a non-Indigenous organization. Be patient with the host parent agency or if working under an umbrella organization if they don't work under the lens of culture. Be patient with ministry, justice and health workers – I mean it, don't react, be patient, take a minute and take a breath.*

- *I have learned the absolute utter lack of commitment there is in [societies] existing processes to have a youth achieve wellness … Like, really at the systemic level, put away your privilege to benefit the youth. It's very cynical. Just how for everyone, it's a job, youth are a product. It's the absolute lack of seeing youth as a person and not as an inventory. And I don't mean that people aren't good natured, just really, privilege and power still reign when it comes to decision making around youths' lives.*

Advisory committee members were asked to share their thoughts on the Program. In doing so, three themes emerged: thoughts around barriers, thoughts on the importance of the Program, and opinions for next steps for the Program.

With respect to **barriers**, one advisory committee member shared their opinion about the cost of assessments, noting that the government and prison systems will not identify FASD due to the associated costs of assessments. Furthermore, it was noted there is a lack of funding for FASD assessments, while other assessments are covered through the health system. This advisory committee member commented, "It is so expensive for an FASD diagnosis … It costs $5,000. Yet, a diagnosis of Asperger syndrome is free. It's a barrier because disability funding is based on a diagnosis.[10]" Systemic barriers were also noted, as one advisory member spoke about supports for FASD being more accessible for youth in care, or more accessible once a youth is involved in the legal system. They also shared barriers specific to the Program, including the need for more staff due to the turnover of the male staff position, and the lack of resources to

[10] In British Columbia, assessments and diagnoses are provincially funded for individuals under the age of 19 years of age, but not for adults (George & Hardy, 2014).

do the work the Program staff and management want to do. Advisory committee members also spoke about the need and **importance of the Program**. For instance, they spoke about the lack of public knowledge around FASD; despite being acknowledged since the 1970's, the public still does not understand the seriousness of the disorder. One advisory committee member explained:

> *The first description of FASD in North America was in Seattle in 1972-1973. Before that it was France in 1968, but we didn't pay attention to it until the Seattle report in 1973. It's been a long time, but [we] more recently discovered the importance. But still, people don't realize the effect of alcohol on the brain, and people think it's not as serious as it is.*

Further, advisory committee members noted that the Program is needed because youth living with FASD are highly vulnerable to gangs and being victimized. One advisory committee member shared that this Program is a unique program, in that it was conceived ground up rather than being an existing program with Indigenous components tacked on. Finally, advisory committee members spoke about **next steps for the Program**, including the development of partnerships and connections with other resources and supports in the community (e.g., housing supports, food security supports, transportation supports). One advisory member commented:

> *[The Program] can't be everything to everyone. It needs to find its place and connect to other resources and supports in community – they need to develop those relationships. [They] need to showcase and shine light on supports they need, some places have them and some places don't … again it has to be connected to linking up to resources and forming a circle around the youth and family, not just a compassionate year and supporting someone through the justice system.*

Advisory committee members also identified the expansion of the Program as a next step, where a protocol for operation could be developed, and activities and services could be replicated across the province and country. Channelling funding through the TRC was also suggested, as well as reaching out to political supports, such as Justice Murray Sinclair, to raise awareness about FASD in Indigenous communities. Table 37 highlights the themes that emerged when advisory committee members were asked to share their thoughts on the Program.

Table 37: Advisory Committee Members' Perspectives on the Program

Theme	Count (*n*)	Details
Advisory Committee Members		
Barriers	4	- The cost of FASD assessments - Systemic barriers, such as supports are more accessible for youth in care or youth involved in the justice system - Staff turnover and the need for more staff
Importance of the Program	4	- There is a lack of knowledge about FASD - Youth living with FASD are vulnerable to gangs and victimization
Next steps for the Program	6	- Develop partnerships with other community resources/supports - Develop a protocol for operation so the Program can be replicated - Channel alternate funding sources

In moving forward, staff and management interviewees were asked what the Program needs to support Indigenous youth and families living with FASD. In responding, a total of three themes emerged, including the need for staff with specific qualities, the need for more staff, and the need for external workers that the Program works with be both FASD and culturally competent. Most frequently, they spoke about the need for **staff with specific qualities**. Interviewees noted that the Program needs staff that have cultural knowledge and knowledge around trauma. For instance, ideal staff would have a deep understanding of culture, and the different approaches to healing trauma (e.g., Western approaches and Indigenous approaches). Further, it was noted that ideally, staff would also be able to recognize trauma. Interviewees also noted that the they need staff who are a good fit with the Program, such as staff who want to be there, who want to learn, and who have the skills to work with Indigenous youth living with FASD. Ideally, staff that work with the Program need to have a deep understanding of FASD and support from a brain-based level, and should understand the nuances of FASD. Further, interviewees noted that staff that work in the Program need to be stable and healthy, while another interviewee noted that staff that work in the Program would be able to provide holistic support for youth (e.g., emotional support, physical health wellness, and dietary support).

Staff and management interviewees also noted the need for **more staff** to increase the capacity within the Program and reduce the caseload per worker. One interviewee commented, “By increasing the capacity of the program, you’ll have more time to spend with each youth and do that relationship building piece and bring them to appointments. Being able to … have a smaller caseload means more time with each youth – this makes a difference.” In speaking about additional staff, interviewees also noted the need for an administrative support person who can support with files, charting, and ordering. Interviewees also identified the need for specialized brain-based workers, and the need for self-care, such as a wellness plan that is practiced and balanced. One interviewee commented, “there’s a real concern … of burnout, it’s taxing emotionally, physically and spiritually; we need time to ensure [the workers are] not burning out.”

While most staff and management spoke about what the Program needs internally (e.g., more staff, the right staff who have specific qualities and skills), some staff and management also shared what they need from others. Specifically, they spoke about the need for **FASD and culturally competent workers**. They shared that other workers need to be educated and aware of FASD, they need to adapt their style of working with youth to fit the needs of the youth, and they need to have respect for Indigenous culture and knowledge. Table 38 highlights the themes the emerged when staff and management were asked what the Program staff need in moving forward.

Table 38: Program Needs in Moving Forward

Theme	Count (*n*)	Details
Staff and Management		
Staff with specific qualities	13	- Cultural knowledge and knowledge of trauma - Staff that are a good fit, and have skills to work with client base (e.g., an understanding of FASD) - Staff that are healthy and can provide holistic support
More staff	6	- To increase the capacity within the program - Staff that can support administrative duties and staff that are specialized in brain-based workers
Workers that are both FASD and culturally competent	3	- External workers who are educated on FASD and respect Indigenous culture and knowledge

Finally, staff and management interviewees were asked what needs to happen in the field of FASD related work for Indigenous communities in moving forward. All of the staff and management interviewees spoke about the need for **community-level work to raise awareness and reduce shame and stigma**. They shared that there is a need for community dialogue and community awareness on FASD and associated challenges and needs (e.g., crime, alcohol, need for supports). Further, interviewees noted that more community knowledge gatherings need to happen, where the community is educated on the gifts and strengths of Indigenous youth living with FASD, and educated on the root causes of FASD, and the various factors that lead women to drink while pregnant (e.g., drinking to numb pain). One interviewee commented:

> *I think it's stigma. They have to take a look at what exactly is happening in their community around the issue of FASD and communities themselves realizing support systems are needed around FASD. Because I think most believe it's … they aren't addressing it at all. Because right now, it's maybe considered a health issues, or a delegated agency issue, or they see it as an MCFD issue, I'm sure there's still a stigma that if you have a child with FASD, a social worker will come and remove the child … That stigma needs to be addressed. There's a shame factor there.*

Staff and management interviewees also spoke about the need for **Indigenous-led work**, where it is Indigenous people working to raise awareness of FASD, and where Indigenous workers are represented in supports and services (e.g., Indigenous doctors). They also noted the need for an Indigenous approach to work being done with Indigenous youth living with FASD. Recognition of trauma and FASD was also noted as a need for moving the field of FASD in Indigenous communities forward. Specifically, it was noted that there needs to be more recognition of the impact of trauma, and there needs to be more work to increase the field of FASD, as there is a lack of awareness. Finally, one interviewee noted that more proactive outreach by the Program staff and management needs to happen.

Community-work, Indigenous-led work, recognition of trauma and FASD, and outreach are needed as there are a lack of support systems in place for youth and families, and many are unaware of supports that are available in their communities. Furthermore, one interviewee noted that there is a level of shame and stigma for FASD that is similar to the stigma and shame of the Indian Residential school system 30 years ago, commenting:

- *[FASD] is no different than the conversation around Indian Residential School; people weren't talking about it 30 years ago, there was so much shame, fear and stigma around it, and now here we are, people are saying yes I am Residential School survivor, I was sexually abused, I was not best parent, they're taking ownership, and starting on their healing journey by talking about it. I hope to have this conversation around FASD in communities and look at the facts, what's happened, not have it under the carpet (the suffering of residential school in a generation). They're hiding it under the door and sweeping under rugs pretending it doesn't exist when it does.*

Chapter 5. Conclusion

This section will discuss the findings of this project, including cross-cutting themes from the assessment of needs, and implications. This section will also discuss the findings of the Program evaluation, limitations of the evaluation, recommendations, next steps/future directions, and a structural analysis of my reflections throughout the duration of my PhD program.

5.1. Cross Cutting Themes and Implications

The Program is a unique project, being the only program of its kind in BC, perhaps Canada, that is doing the work to support Indigenous youth and families before, during, and after FASD assessments from a strong cultural Indigenous lens. The Program is firmly rooted in Indigenous culture, rather than being an existing project, with Indigenous components added after the fact. Findings from the assessment of needs and evaluation underscore the deficits of those living with FASD, the challenges they face in being supported and accessing services, and the need for the Program. Not only are the findings from this evaluation informative for the Program itself in moving forward (see section 5.3 for recommendations), but the findings also highlight several areas for system-level change and policy revisions. This section focuses specifically on the cross-cutting themes that emerged from the needs assessment and evaluation, and discusses implications for system-level change and policy revisions.

Strengths of Indigenous Youth and Families Living with FASD

The strengths of Indigenous youth living with FASD are plenty. Staff and management, advisory members, and needs assessment respondents all spoke about the many strengths, gifts, and positive qualities Indigenous youth living with FASD possess. Intrinsic characteristics and qualities emerged as a theme across all data sources, where staff and management, advisory members, and respondents all spoke about the youths' eagerness, resilience, honesty, humour, and protective and loyal nature as gifts. These youth are also skilled; staff and management, advisory members and respondents all

spoke about youth being creative, artistic, technologically savvy, and gifted when it comes to building things. Their cultural connectedness, such as their passion and commitment to their culture, was also highlighted across all of the data sources. As stated by one staff and management interviewee, the goal of the Project is to see Indigenous youth and families living with FASD healthy, vibrant, and living their best lives; in order to do so, those who work with and support Indigenous youth living with FASD ought to adopt a strengths-based approach and lift the youth up. The approach that the Program takes is in line with a strengths-based approach; the staff that work with the youth encourage cultural exploration, positive Indigenous identity, and work to build the self-esteem of the youth, rather than focusing on their deficits (e.g., challenges associated with FASD, justice involvement). This focus that the Program has on strengths and protective factors is particularly important, as too often, many services and ministries that Indigenous youth living with FASD are involved in are operating from a deficit-based lens, focusing solely on the associated challenges of FASD (e.g., the behavioural challenges or limitations of the youth). The culture of the system is deficit-based, in that the system is focused on punishing and/or correcting problem behaviours after they have occurred, rather than prevention, or building on existing strengths and actively empowering youth. Too often, strengths and gifts that can be leveraged are overlooked or disregarded. In assessing strengths, professionals can either enhance existing protective factors and strengths or work to build up strengths and protective factors that are absent. The literature supports the strengths-based approach of the Program; Lösel and Farrington (2012) suggest that like risk factors, there is a cumulative impact of protective factors, where accumulated protective factors have a stronger impact on adverse behaviours compared to a single protective factor. Borowsky, Resnick, Ireland, and Blum (1999) found that enhancing protective factors among youth was more effective than just decreasing risk factors. Furthermore, in an implementation study of a strengths-based case management approach with youth runaways, Elizabeth, Walsh, Oldham, and Rapp (2007) noted positive results, particularly when youth developed trusting relationships with the case manager, as they witnessed youth seeking out employment, and engaging in open communication with parents.

The Current State and Needs of Indigenous Youth and Families Living with FASD

In analyzing the data across all of the data sources (e.g., the literature, needs assessment responses, staff and management, and advisory member interviews), it was evident as a cross-cutting theme that the current state for Indigenous youth and families living with FASD is mired by system-level barriers and gaps, such as the education system failing Indigenous youth living with FASD. Staff and management, and needs assessment respondents highlighted that the mainstream education system does not work for youth living with FASD, and youth are being pushed through, or expelled from the system. The literature also noted the education system failing youth living with FASD and the importance of having a fulsome understanding of the associated challenges of FASD. In one study, a mother spoke about the educational system failing her adolescent youth living with FASD, as her youth had been receiving Bs in English, yet was not able to write coherently (Duquette, Stodel, Fullarton, & Hagglund, 2007). The associated challenges of FASD with respect to cognitive functioning (e.g., memory, encoding, planning, attention span), and emotional and behavioural regulation (e.g., mental health problems, hyperactivity, aggression) can have dire impacts educational outcomes if not understood in context (Duquette, Stodel, Fullarton, & Hagglund; Coles, Taddeo, & Millians, 2011; Pei, Job, Poth, & Atkinson, 2013). It is therefore not surprising that a cross-cutting need that surfaced as a theme within this study was the need for **brain-based services**, including the need for educational systems and support services to accommodate the learning needs and behavioural styles of those living with FASD, as one size does not fit all. It is important that programs acknowledge the permanent nature of the disability, which will ultimately prevent continual marginalization, and contribute to positive results (Burns, 2015). While brain-based strategies are key to addressing some of the education failures, there are also larger systemic issues at play with the educational system in itself. As was the case with the Program, there is the issue of being over capacity with respect to caseload numbers, or in the case of teachers, classroom sizes. The number of students within a classroom remains a complaint among BC teachers, noting the classroom sizes are letting children down, particularly those with special needs who require individual attention (CBC, 2016).

Another system-level barrier that was highlighted throughout the evaluation and needs assessment was that the systems and the workers who are the most likely to be in contact with a youth living with FASD (e.g., justice, MCFD, health, education) are not adequately trained or equipped to work with or support Indigenous youth living with FASD. Stewart (2015) echoes this concern, noting that there is a lack of trained frontline justice personnel on FASD (e.g., police, lawyers, corrections, judges). These findings are also in line with results from a national study demonstrating that while Canadian health professionals have an awareness of FASD, they require more education and training to support individuals and families living with FASD (Health Canada, 2005). Furthermore, over 50% of the health professionals in the national survey noted that a lack of training on FASD has limited their ability to diagnose (Health Canada). A lack of training among professionals has implications not only for the quality of service professionals provide to those in need (e.g., inability to diagnose, inability to tailor strategies), but it also contributes to a lack of awareness of the complex needs those living with FASD have. As such, the need for **public awareness and education** emerged as a cross-cutting theme. There needs to be more focus on raising awareness of FASD broadly, while focusing on the message that it is not an Indigenous specific concern, nor is it the fault of the youth living with FASD. Furthermore, there is the need to educate and train professionals who will be in contact with those living with FASD, particularly education on FASD, the associated challenges and limitations, and strategies for working with their limitations. In particular, the need for awareness and training was noted for justice officials and personnel, school personnel and staff, and employers. Moreover, strategies that professionals use with most youth will not necessarily work with youth living with FASD, and therefore, professionals need to understand that it is essential that they manage youth living with FASD differently (Stewart, 2015). Perhaps a standardized curriculum to understand FASD and strategies could be developed for sectors that are most commonly to come in contact with those living with FASD. Having a fulsome understanding of FASD, and knowledge around strategies to support youth living with FASD will ultimately lessen stigma and misperceptions, and produce more favourable outcomes for youth. With respect to system changes and policy revisions, perhaps education ministers could explore embedding the topic of FASD in high school sexual education and health curricula, while graduate programs that train students to work in health, and clinical and social sciences could explore courses specifically on FASD. It is surprising that graduate programs, such as

clinical forensic psychology programs, that are training students who will most likely work with Indigenous people and individuals living with FASD, do not focus on either issue in depth, or at all. With the annual costs to health services at $2.1 billion (CanFASD, 2012), the need for public awareness and education within professional fields around FASD cannot be disregarded.

As stated earlier, the systems and the workers who are the most likely to be in contact with an Indigenous youth living with FASD (e.g., justice, MCFD, health, education) are not only lacking training on FASD, but are lacking training on cultural competence and cultural safety. As such, a cross-cutting theme emerged across data sources with respect to the need for services and professionals to be **culturally informed**, with culturally competent workers that see the value in Indigenous ways of knowing and Indigenous history. For all of the services, ministries, and supports that youth and families living with FASD come in contact with, understanding the history of Indigenous people in Canada is a critical consideration in understanding the presence of FASD, substance misuse, and criminal justice involvement among Indigenous people. As noted earlier in this dissertation, there is a long history of colonization for Indigenous people in Canada that operated with the goal to culturally assimilate all Indigenous people; this history of forced assimilation ultimately has implications for why FASD, substance misuse, and associated adverse outcomes are even an issue. Some progress has been made with several post-secondary schools implementing mandatory Indigenous-specific credits for students (e.g., Lakehead University, University of Winnipeg, Ryerson University, Carleton), pledging to educate students on Indigenous history, treaty rights, and Indigenous-Crown relations (Baker, 2016). While at first glance, this appears to be a great step moving towards reconciliation and culturally safe service provisions, but there remains a concern around whether educators are educated themselves on the content to adequately teach students on the content. Moreover, there remains a concern for the cultural safety of the Indigenous instructors, as Indigenous professors and sessional instructors will need to prepare themselves for white privilege mindsets and resistance. White privilege is a term used to describe the societal privileges that white people have that are not necessarily afforded to non-white people – they are unearned invisible privileges for their dominant status in society (e.g., not being followed by security in retail stores; McIntosh, 1989). McIntosh (1989) states that, “[a]s a white person, I realized I had been taught about racism as

something which puts others at a disadvantage, but had been taught not to see one of its corollary aspects, white privilege, which puts me at an advantage" (p.30). As topics around race, racism, and white privilege can be emotionally charged, it is possible that Indigenous instructors will encounter circumstances where students resist the concept, be unwilling to acknowledge their privilege, and disempower the instructor. As Beeman (2015) states about her experiences teaching race and white privilege as a woman of colour, she "realiz[ed] that the issues [she] was facing in the classroom had more to do with resistance to learning about racism and inequality from a woman of Color than it did with [her] teaching abilities" (p. 16).

Further, across the data sources, the need for Indigenous youth living with FASD to have access and exposure to their **culture and identity** as an Indigenous person was highlighted. Providing access and exposure to Indigenous culture is something that the Program is doing well. Access to culture provides a sense of belonging, pride, identity, and helps with healing. Given the misperceptions of Indigenous people being predisposed to FASD, the importance of culture, positive self-identity as an Indigenous person, and healing is of utmost importance. Staff, management and advisory committee members repeatedly highlighted the positive outcomes for Indigenous youth as a result of the focus on culture and identity in the Program; it would be beneficial to many Indigenous youth living with FASD if the Program further explored their approach and focus as a best practice in supporting Indigenous youth living with FASD. The strengths-based and culture-focused approach is something that many services and organizations could learn from. Mi'kmaw Elders Albert and Murdena Marshall explained that Indigenous people need to recover from cultural starvation, and this recovery starts with utilizing traditional languages and reclaiming stolen spirits (Marshall, Marshall, & Bartlett, 2015).

The evaluation and needs assessment also highlighted system level barriers for biological parents and grandparents of Indigenous youth living with FASD, noting that oftentimes, access to supports for parents (e.g., respite) are limited to foster parents. The fact that unequal funding among biological and foster families was identified as a barrier among needs assessment respondents and advisory committee members, is similar to recent studies which highlight barriers with respect to differential access to home support workers and respite care (Farsai, 2010; OFIFC, 2013; Rutman & Van Bibber, 2010).

Without the supports and respite that parents caring for youth living with FASD require, there is the risk of burnout and hopelessness. Watson, Hayes, Radford-Paz, and Coons (2013) found that parents of youth living with FASD expressed less hope for the future in comparison to families of youth living with Autism, likely due to the limited availability of supports and limited awareness of FASD broadly. As such, it is not surprising that another cross-cutting theme across data sources spoke about the need for **support**, as the impacts of FASD are not solely on the youth living with the disorder, support is also needed for families and communities. Not only does the Program support youth before, during and after the FASD assessment, but the project also extends that support to families, providing the respite needed. The need and importance of supports was also highlighted within the literature, as it has been found that youth living with FASD and families who have proper and adequate supports show long term positive results (Bailey, 2007). However, while the need for supports and multi-system services can contribute to positive outcomes, both advisory committee members and needs assessment respondents within this evaluation expressed that although services and supports do exist for those living with FASD, many are missing, lacking, or suffer from fragmentation, where services and supports are operating in silos. This sentiment has been echoed by representatives of a justice coordinating committee in Ontario who expressed the inadequacies of the systems' response to those living with FASD, noting that the system contributes to instability and poor outcomes for those living with FASD (Burns, 2015). The many systems that youth living with FASD require are not coordinated, but rather, the onus is on the youth themselves to navigate the multiple systems, often without support. As McFarlane (2010) notes, "when well-intentioned agencies and well-meaning staff follow these procedures, it can become system abuse" (p.328). This is in line with one of the most salient support needs noted within this evaluation; the need for youth and families to have justice advocacy and justice liaisons. The justice system is complex enough as an adult without FASD, let alone, youth and adolescents living with prenatal alcohol brain injury. This justice advocacy and liaising is one of the many supports that the Program is tackling with youth.

The Program is contributing to remedying many of the challenges and barriers Indigenous youth living with FASD face, while supporting their needs. Currently, based on

the evaluation findings, the work being done by the Program is addressing the top three needs identified within the needs assessment and are seeing positive outcomes:

- **Providing support services for youth**: The Program offers brain-based, Indigenous-specific and family inclusive services, such as advocacy and navigation through the multiple systems youth living with FASD face.

- **Public awareness of FASD**: The Program works to ensure that those who are interacting with youth living with FASD are aware of FASD and the associated challenges, and has even held a community knowledge gathering.

- **Culture and sense of belonging**: The Program has found that Indigenous youth in the program have gained a sense of identity as an Indigenous person, have made cultural connections, and have gained a sense of belonging and safety within the program.

While the Program has been focusing on supporting the needs of youth, fostering culture and a sense of belonging and raising public awareness around FASD, they are also supporting families throughout the assessment process, and have been faced with capacity issues. Furthermore, in the needs assessment, several additional areas of need emerged, which the Program cannot address all of. For instance, needs around structural changes and environmental modifications within the education system emerged, as well as needs around adequate housing, access to a healthy lifestyle, skill development, and financial support. In moving forward, the Program might consider continuing their focus on the top three needs identified above, but refining their support for youth and families, or consider expanding and further developing their team to provide the wide range of individualized support needs.

Given the current state, the desired state, and the many needs in between, there is evidence to suggest that the Program is meeting the needs that have been noted across the data sources, however the Project cannot address them all and additional work from local, provincial and federal governments needs to occur if the goal is to have Indigenous youth living with FASD living their best and healthiest life (section 5.3 provides specific recommendations for the Program in moving forward).

5.2. Limitations of the Evaluation

As is the case with all research and evaluation, there are several limitations of this evaluation to consider. With respect to the design of the evaluation, this evaluation is merely a snapshot in time of the work being done at the Program; the evaluation only tells the story that the interviewees share from the timeline they wish to share, such as focusing on the most recent successes, or challenges, rather than sharing the several successes or challenges over the three years. In an attempt to broaden the reach of insight on the needs of Indigenous youth living with FASD, an online survey was used. The use of an online survey may be a potential limitation, as it did not provide an opportunity for me to interact and establish trust with the potential survey respondents. This is particularly important when it comes to research or evaluation that involves Indigenous people. Indigenous people have been researched to death, treated as sources of data to take (Castellano, 2004; First Nations Centre, 2007), often not seeing the benefits of the research (Norton & Manson, 1996; van der Woerd & Cox, 2006). As Smith (1999) states, "'Research' is probably one of the dirtiest words in the Indigenous world's vocabulary" (p.1); there is a lot of distrust and reluctance to engage in research (First Nations Centre, 2007). Although no one mentioned it, the focus of the survey on the needs of Indigenous youth living with FASD could have been a limitation, as the fatigue of expressing the same needs over and over may have limited people's desire to complete the survey fully, contributing to a completion rate of 52.3%.

As the Program focuses on providing support to Indigenous youth who have been referred by youth probation services, the files compiled by the Program are populated with *Ministry of Children and Family Development* (MCFD) data and therefore are subject to MCFD privacy and ethics standards and I was not permitted access to the files which contained demographic and descriptive information (e.g., age, gender, Indigenous affiliation). As such, the Program management, agency executives and I designed the evaluation where I would rely on the Program staff to collect demographic and descriptive data. Not having access to files, and relying of Program staff and management to provide demographic and descriptive information, was a limitation for fully describing who the Program is serving.

In terms of implementing the evaluation, there were also limitations around participation in the evaluation. As a means to ensure confidentiality, the Program manager facilitated contact with advisory committee members, which may have been a barrier for evaluation buy-in. Due to the facilitated contact, I was unable to speak directly with advisory committee members to explain the benefits of an evaluation and importance for their voice to be reflected, thus not all advisory members participated in the evaluation. The need for facilitated contact also extended to past staff members, as I did not have their contact information. Due to the need for facilitated contact, I was unable to speak with staff members who had left their position.

While youth and family participants of the Program were originally part of the evaluation plan to provide feedback on the program, regrettably, this evaluation does not include their voices. The resistance from the front line, despite initial buy-in, to include these voices in the evaluation was a limitation to implementing the evaluation as planned. Consequently, this evaluation is imbalanced, privileging the voices and perspectives of those in power: executives, management, staff, and advisory members. Exclusion of youth and family voices from providing feedback on services that impact their lives directly is a concern. Indigenous youth and families already face a system in which their voices are marginalized, disempowering them. Ormiston (2010) notes, “All researchers working in an Indigenous context have an ethical responsibility toward the people, their cultures, and the environment. As part of this process, it is essential to include those who have been marginalized through colonization, particularly the voices of our young people, women and elders” (p.53).

Ultimately, these limitations have implications for understanding the findings of the evaluation, as a comprehensive evaluation was not conducted.

5.3. Recommendations for the Program

The following recommendations are for the Program:

Human Resources

1. **Consider conducting exit interviews should there be future staff turnover.**

    - Capacity emerged multiple times throughout the evaluation as a challenge, of which multiple staff turnovers in the male position was a factor. The Program might consider conducting exist interviews. Exit interviews are an excellent tool to gather feedback on what was working well for the staff, what was not working well for the staff, areas in which the Project can improve from a staffing perspective, and even why a staff member chose to leave their position. Ultimately, exit interviews are valuable human resource tools to gather constructive feedback and prevent future costly turnover.

Program Planning and Sustainability

2. **Consider additional funding to enhance the accessibility of the program to Indigenous youth not involved in the justice system**.

    - This Program aligns with recommendations in the TRC and given the partnership between an Indigenous organization and non-Indigenous agency, this Program in itself is contributing to reconciliation. Seek out funding that is related to implementing the TRC calls to action.

3. **Develop an outreach strategy to improve awareness of the Program among key stakeholders.** Consider:

    - (A) *Creating and implementing an agency engagement strategy:* The need to increase focus on partnerships and engagement with justice personnel and clinicians in BC was noted as an important step in moving forward within the evaluation, as there are justice-related objectives of the original program design that have not yet been achieved (e.g., direct connections with justice services). Furthermore, findings from the evaluation highlighted the need for more Indigenous representation in professions that Indigenous youth living with FASD encounter through their assessment. As a means to increase connections with justice services, and Indigenous professionals, consider:

i. An engagement strategy targeting the Justice Institute of BC, youth probation services, youth custody services, ministry workers, and the Indigenous stream of the UBC medical school (for internship opportunities at the assessment Centre).

ii. Increasing the visibility of Program staff and management with justice personnel and the Indigenous stream of the UBC medical school through presentations and information sessions about FASD and the Program.

- (B) *Creating and implementing a community-organization engagement strategy:* To disseminate information and awareness of FASD in Indigenous communities to organizations that will frequently come in contact with Indigenous youth living with FASD. Consider:

    i. Providing training and/or information sessions on FASD to enhance community organizations' awareness of FASD and awareness of the Program.

4. **Consider a strategic planning session with both partner host agencies and the Program.** Consider:

    - Brainstorming opportunities for how the Program can grow in terms of design and delivery. Consider:

        i. How to balance the objectives of both agency partners, the Program, and the funders (e.g., connections with justice personnel, supportive assessments, cultural connections). Within the evaluation, it was noted that while the program has evolved to be more broad and deep, the justice-related objective to have direct connections with justice services has not yet been achieved.

    - Continue to evolve the Program and treat the logic model and original design as a living document. Programs are meant to meet the needs of those they serve, and as such, the Program should evolve and adapt as the needs of those they serve evolve and adapt. Currently, the Program is focusing their work on the top needs identified in the needs assessment (e.g., support services, awareness of FASD, and cultural identity and connections). However, the support services needs are broad and the Program might consider:

i. Narrowing the scope around support provided: which support activities yield the desired outcomes, and which support activities do not?

- Plan for scaling up, scaling out. Consider:

    i. The development of a 'best practices' protocol that other Indigenous organizations and programs can use to implement similar programs in other areas, such as peer social programs, or justice programs.

    ii. Seeking out staff with specialized skillsets and knowledge that will fit into the holistic approach of the Program (e.g., specialized skills in clinical work, or family advocacy, or justice advocacy).

5. **Develop a sustainability strategy for the Program.** As recommended in staff, management, executive and advisory feedback, consider:

    - Defining Program-specific mission statement, mandate, and core values.

    - Building strategic partnerships, where the Program can leverage funding, financial resources, human resources, and service delivery.

    - A strategy in which funders can be lobbied. For instance, consider demonstrating the need for all levels of government to fund Indigenous health initiatives, and to fund initiatives, such as this Program, that contribute to the TRC Calls to Action.

Program Operations

6. Public awareness and understanding of FASD was a theme that emerged from the needs assessment frequently. It is recommended that the Program **continue to organize and host knowledge gatherings where information on FASD is disseminated as it relates to Indigenous people.**

    - Feedback from the evaluation highlighted the success of the gathering, reaching and impacting community, ministry workers, First Nation Health Authority, and First Nation Health Council.

7. **Continue to deliver the Program with the focus on traditional and cultural support.**

    - As found in the needs assessment and evaluation interviews, Indigenous youth and families are not only faced with the stigma associated with a FASD diagnosis, but there is also a legacy of colonization that is impacting the self-worth and identity as an Indigenous person. For too long, Indigenous people were banned from practicing traditional ceremonies, and the focus on tradition and culture in the Program has been identified as contributing factors to youths' positive self-identity and pride.

    - As building a sense of belonging, identity and cultural connections was among the top themes of needs for Indigenous youth living with FASD, consider incorporating an Elder in residence into the Program to increase youth's exposure to Elders, which may consequently alleviate time constraints faced by staff.

8. **Consider having seasonal (quarterly) meetings between staff, management, and executives of both organizations.** Communication within the partnership of the two organizational partners was identified as a work in progress, where in some respects the partnerships could benefit from more communication. Consider both:

    - (A) *Executive and management seasonal meetings*: Where there is communication between executive directors and management at both organizations. Seasonal meetings could focus on detailed updates on:

        i. Inputs into the Program,

        ii. Program activities,

        iii. Program outputs

        iv. Program outcomes, successes, and gaps.

    - (B) *Management and staff seasonal meetings*: Where Program staff and management and the assessment centre staff and management share findings and program statistics, and learn from each other around what is working well, and what is not working well. Consider lunch and learn meetings where each project shares project successes and best practices.

9. **Consider creating long-term support strategies for each youth and family involved in the Program to facilitate their path towards a positive and healthy life.**

    - All data sources in this project (literature, staff, management, needs assessment respondents) spoke about the need for others to act as an "external-brain" as support for youth living with FASD. As FASD is a lifelong disorder, the need to sustain positive outcomes is important, and given that the Program is a pilot project, they might consider developing long-term support plans for youth and families as they exit the Program so youth and families can sustain the positive impacts made thus far. Factors to consider include:

        i. Supports youth and families can access in their region.

        ii. Indigenous organizations and agencies in their region that they can reach out to.

        iii. Detailing strategies used within the Program that can be used outside of the Program (e.g., connecting with the land, grounding techniques).

Organizational Partnership

10. **Consider holding in-house team building activities to further strengthen the relationship between the Program and assessment centre staff.**

    - This Program is an exemplary example of reconciliation in action. The Program is a partnership between two different organizations with two different models of operation (e.g., Western medical model and Indigenous cultural model) that have come together with a common objective to support Indigenous youth living with FASD to live their healthiest and best lives. Reconciliation is a process and does not occur overnight; the same is true for the partnership between the two agencies hosting the Program. As such, the need for continuous relationship building cannot be overlooked.

11. **Consider expanding the Program's advisory committee to include representation from both host organizations** to increase communication within the partnership. Consider:

    - Including both executive directors in the advisory committee meetings.

    - Including parents/caregivers and youth representation on the advisory committee.

12. **Consider formalizing a documentation/record keeping process of the advisory committee meetings that can be submitted to the executive directors of each partnering host organization/agency.** Consider record keeping and submitting the following documents to the executives as a means to facilitate fulsome communication and awareness of program progress:

    - Agendas,
    - Meeting minutes that detail in-depth updates, discussion points, recommendations that emerged, decisions made, action items, tabled items,
    - Supporting documents (e.g., reports, proposals).

Forward Movement

13. **Collect feedback and input from youth and families**. Compile youth and family feedback suggestions on what the Program could do more of, and what the Program might consider changing.

    - Seeking formal feedback from youth and family will not only provide the Program with important information about what youth want, need, like, and do not like about the program, but this process will also empower them as their voices will being heard.

14. **Consider developing community friendly resources.** Awareness and education on FASD assessments and diagnoses was one of the major cross-cutting themes throughout the assessment of needs. Consider the development of:

    - Community friendly resources (e.g., handbook, factsheets) on:
        i. What to expect during the assessment,
        ii. Implications of a diagnosis of FASD,
        iii. Strategies for youth, families, caregivers in leveraging the strengths and gifts that youth living with FASD possess, in addition to strategies for working with the associated challenges of living with FASD.
    - FASD and Program-specific resources (e.g., factsheets about FASD, factsheets about the Program) that can be distributed to the offices of youth probation services, the Justice Institute of BC, MCFD, First Nations courts.

15. **Continue to raise awareness publicly on FASD and the role of the Program.** A theme that was frequently mentioned in the needs assessment was around the need for public awareness and understanding of FASD. Consider:

    - Connecting with high profile Indigenous leaders who advocate for Indigenous issues and system-level changes, such as Justice Murray Sinclair, the Honourable Jody Wilson-Raybould, and BC's Representative for Children and Youth (Mary Ellen Turpel-Lafond was the Representative at the time of this study but a new Representative is to be appointed in early 2017).

    - Creating a section on the Program's website, as well as the two host organizations' websites where the public can sign up for a mailing list. Furthermore, consider sharing up-to-date information on FASD with the public (e.g., seasonal e-blasts).

16. **Develop and build Project partnerships in the community.** Consider:

    - Reaching out to Indigenous organizations and programs to enhance their capacity to work effectively with those living with FASD (e.g., Cwenegitel Aboriginal Society; Urban Native Youth Association). A frequently mentioned theme throughout the needs assessment was the need for professional awareness and understanding of FASD and the related associated challenges, particularly among substance counsellors.

    - As evidenced by the needs assessment, the needs of Indigenous youth living with FASD are many and lifelong. The Program could develop service and support partnerships with other Indigenous service providers to work collaboratively with in supporting Indigenous youth living with FASD for long-term sustainable support (e.g., Friendship Centres; key workers; health navigators; L'uma youth mentor program; Aboriginal Front Door Society).

5.4. Next Steps and Future Directions

Since Streissguth and colleagues' seminal work in the 1970s, the deficits and challenges that those living with FASD face have been well documented (Andrew, 2010; Davis et al., 2011; Nash et al., 2006; Nicholson, 2008; Streissguth, 1979; Streissguth, 2007). The culture of the system with which many youth living with FASD come in contact is a system that focuses primarily on correcting the deficits, challenges, and what is wrong with a person. Indigenous youth living with FASD have gifts and strengths in addition to

their challenges associated with their brain injury. There is very little research and information on the strengths and gifts of those living with FASD, but some publications highlight their artistry, creativity, hands-on skills, being goal-oriented, and relationships with others (Chatterley-Gonzalez, 2010; Duquette, Stodel, Fullarton, & Hagglund, 2007). In moving forward, a paradigm shift is needed, as a strengths-based approach could be highly beneficial in practice. Taking a strength-based approach does not deny the challenges or deficits a person may present, but rather, a strengths-based approach would leverage and empower the existing gifts and strengths of youth living with FASD. This is very much an area in need of further exploration, to demonstrate how to leverage the strengths and gifts of youth living with FASD for positive outcomes.

Within BC specifically, an evaluation of the cross-ministry provincial plan *Fetal Alcohol Spectrum Disorder: Building on Strengths. A Provincial Plan for British Columbia 2008-2018* would be a worthwhile next step, to assess the provinces progress towards their four initiatives, challenges, and provincial next steps. Evaluating the progress of the provincial plan parallels the TRC Call to Action 34iv, that governments (e.g., provinces) better address the needs of offenders living with FASD by appropriately evaluating and measuring effectiveness of initiatives. Furthermore, if the province's aim is to see individuals living with FASD experience their best and healthiest life and preventing future prenatal alcohol exposure, more resources and long-term government buy-in needs to occur, both at the federal, and provincial/territorial level. While there are resources that exist, they are inundated with waitlists, or are inaccessible for many Indigenous people who live in remote, rural, or on-reserve communities.

With respect to Indigenous communities, grassroots initiatives focusing on preventing FASD, and supporting those living with FASD from a cultural lens would be favorable, followed by an evaluation of the impacts of embedding cultural activities in the programs. To my knowledge, this Program is the only project doing this work from an Indigenous lens, and should more programs work from an Indigenous lens and produce favourable outcomes, a case for this approach as a best practice could be established. Furthermore, the role of cultural activities in programs, and strengthening cultural connections has found some support in protecting against or mitigating adverse outcomes (Harris & McFarland, 2000; McIvor, Napoleon, & Dickie, 2009; Rogers, McLachlan,

Viljoen, & Roesch, 2014), however, there needs to be more research on the role of culture as it specifically relates to FASD. Perhaps, future research could focus on the relationship between cultural connectedness and the various secondary disabilities. For instance, research could explore if and how cultural connectedness mitigates secondary disabilities and operates as a protective mechanism for adverse outcomes. The stigma and shame associated with FASD is also a concern that needs to be addressed at three levels: self-shame, structural-stigma, societal-stigma. In moving forward, the responsibility and shame needs to be shifted away from youth living with FASD and their mothers and toward the community, the structures in place that disadvantage women and marginalized populations, and society at large. Perhaps public awareness campaigns need broader messaging, focusing not only on the dangers of consuming alcohol while pregnant, but also demonstrating positive stories of successful lives when an individual receives the complex multi-system supports.

Finally, in a country filled with funding for new and innovative pilot projects, there is also a stark need for multi-year funding for projects that have demonstrated desired outcomes and effectiveness, so that they can be sustainable. Tait (2008) explains that much of the funding for prevention and treatment programs are government funded, giving the government significant power in decisions around which projects are funded and how. When it comes to pilot projects, the uncertainty with respect to funding at the end of their current installment can greatly impact not only the program staff, but also the clients who access the program. Tait further explains that pilot projects are a source of hope for many, an opportunity for change in their life. Yet, when the funding is cut or not renewed, those feelings of hope are crushed. Ultimately, the problem which the program intends to solve, persists, but only after getting building up the individual and community's hopes first. Indigenous people have endured generations of harms at the hands of the government, and providing services to build them up to heal, only to rip those services and supports away ultimately tears them down again. It generates a cycle of trauma and mistrust.

5.5. Structural Analysis

This section of the dissertation document extends beyond the scope of the evaluation of the Program itself, but rather, this section is a reflection of the author's

experiences conducting research and evaluation with Indigenous people and communities throughout her graduate studies.

Critical Reflexivity

Critical reflexivity is the practice of reflecting on how researchers impact the processes and outcomes, and in turn, how the processes impact the research. Being reflexive is common in qualitative work as it provides context and lessons learned, particularly as an outsider (Ziabakhsh, 2015).

Locating myself within this project

I will start by locating myself within this project. I am an anishinaabe kwe (Native woman) band member of Aamjiwnaang First Nation on my mother's side and Caucasian on my father's side. I am two generations removed from attending residential school, as my grandfather attended the Mount Elgin Industrial Institute residential school in Muncey, Ontario (southwest of London, Ontario). While being two generations removed, I am not removed from the many impacts that residential school has had on many Indigenous people throughout North America. For several reasons, linked to the legacy of colonization, I was raised assimilated, growing up off reserve and in mainstream society. This is the lens in which I operate, as a First Nation woman, who grew up assimilated, yet affected by the impacts of colonization, reconnecting with her roots.

I entered the psychology and law program at Simon Fraser University because I wanted to make a difference in the statistics for Indigenous people. Indigenous people are disproportionately represented in the justice system; despite Canada's crime rate being at its lowest in 45 years, incarceration rates are at their highest, particularly among Indigenous people. For Indigenous women, incarceration rates over the last decade are up 112%. While the rates of incarceration for Indigenous people vary between the provinces and territories, federally, Indigenous people account for 22.8% of those incarcerated in federal prisons, despite the fact that Indigenous people only represent 4% of the Canadian population (Macdonald, 2016).

I learned along the way that the problem is much larger than the statistics. There are multiple systems that are working against Indigenous people, ranging from the education system, the justice system, to the governments providing the funding. For example, First Nations students educated on reserves in Canada are underfunded, receiving up to 25% less than other Canadian children per student (Drummond & Rosenbluth, 2013; Sniderman, 2012). The disproportionate representation of Indigenous people in prisons is not due to a spike in crime, but rather to factors related to colonization and government policies, such as mandatory minimum sentences (Cook & Roesch, 2012; Macdonald, 2016). The implementation of the Safe Streets and Communities Act (former Bill C-10) mandatory minimum sentencing provisions contradicts section 718.2(e) of the Criminal Code of Canada (Office of the Provincial Health Officer, 2013). This is a sentencing provision that recognizes the intergenerational effects of historical colonization and allows judges to use their discretion in sentencing based on the systemic factors that may have brought the offender before the courts, and sanctions appropriate for the circumstances (*R. v. Gladue*, 1999). Furthermore, under the former conservative government, Indigenous organizations and communities were also faced with significant funding cuts with the 2012 federal budget, despite Indigenous youth being the fastest growing demographic (NCCAH, 2012; NationTalk, 2012). Impacts of the funding cuts to Indigenous health programming included the closure of the National Aboriginal Health Organization, which operated for 12 years, and cuts to the Native Women's Association of Canada. These are merely a few of the systems that are working against Indigenous people in Canada.

It is with this in mind, knowing that there are both historical and contemporary systems working against Indigenous people, the following structural analysis is framed.

Structural Analysis of the Barriers Between Indigenous Researchers and their Own Communities

Maori scholar Linda Tuhiwai Smith (1999) has remarked that "'research' is probably one of the dirtiest words in the indigenous world's vocabulary" (p. 1). Historically, research has been on Indigenous people versus with Indigenous people, as a means of further oppression and colonialism (Castellano, 2004; First Nations Centre, 2007). There

is a legacy of mistrust when it comes to research in Indigenous communities and populations, as historically, researchers would “parachute in” to a community, treating Indigenous people as sources of data, rather than collaborators (Davis & Reid, 1999; First Nations Centre, 2007). Oftentimes, research would occur without consultation with the community, and power imbalances were evident between researchers and Indigenous communities; findings from research mainly benefited the researcher, with the benefits for the communities being unclear (Davis & Reid, 1999; First Nations Centre, 2007; Norton & Manson, 1996; van der Woerd & Cox, 2006). As such, it is not surprising that many Indigenous people are distrustful of research and hence reluctant to be involved in research studies (First Nations Centre, 2007). Despite this history of harmful research practices, there has been a shift in varying degrees in the acceptance and involvement of Indigenous people in research. While some Indigenous people continue to participate in research that remains rooted in colonial methodologies, discounting Indigenous approaches, others are strongly opposed, agreeing to only participate in research by and for Indigenous people (Ball, 2005). Furthermore, some Indigenous people are actively taking it upon themselves to conduct Indigenous-led Indigenous-focused research (Ball, 2005).

As an Indigenous person who has been involved in conducting Indigenous-led and Indigenous-focused research, I have observed surprising barriers between Indigenous researchers and their own communities. Three interrelated themes emerged throughout my graduate studies: resistance, lateral violence, and current colonial structures, all of which are entrenched in historical and contemporary colonial efforts in Canada.

Resistance and Lateral Violence

As stated above, there has been a legacy of harmful research in Indigenous communities, which has led to mistrust and reluctance. This mistrust and reluctance also extends to evaluation, as power imbalances can lead to apprehensions of being evaluated for fear of losing funding (Castellano, 2004). As such, one cannot underscore enough the importance of collaborative and participatory research and evaluation. This is something ingrained in my approach as a researcher; with all projects, I have formed advisory committees, and worked in partnership with stakeholders, seeking continuous feedback

to ensure the project is relevant, and that the design of the project and data collection tools are in line with the views of the community representatives and/or program. It was therefore surprising to experience resistance from within the Indigenous community, despite buy-in for the need to give voice to and empower Indigenous youth, privileging their voices equally alongside the voices of those in power. From within the Indigenous community, resistance was expressed in terms of protecting Indigenous youth, as there were perceived vulnerabilities, such as Indigenous youth living with FASD have significant levels of trauma, and seeking their feedback would re-traumatize youth. Additionally, it was noted that the cognitive abilities of youth are limited, and that they will struggle to articulate their experiences, and given trauma and distrust, some family members will refuse involvement.

While in agreement that youth living with FASD have cognitive limitations, and that distrust and trauma can be a barrier to working with Indigenous youth and families, the importance of empowering Indigenous people to determine their own involvement in research, and restore their power in making their own decisions cannot be disregarded (Ball, 2005). Yet, Indigenous youth and families were not given the opportunity to self-determine whether or not they wanted to be involved in the research, undermining their right to decide.

This section started by locating myself as an Indigenous person within this project, as someone who was raised assimilated, and consequently is in the process of reconnecting with her roots. It has become apparent that the systems in which Indigenous-focused research and evaluation operate are not always receptive to Indigenous or Western ways of knowing. As someone who values the concept of two-eyed seeing, seeing the strengths in both ways of knowing, it has been my experience that this approach is not necessarily valued by everyone. Coined by Mi'kmaw Elder Albert Marshall, two-eyed seeing is a dual lens, embracing what both Western and Indigenous knowledges and worldviews contribute (Marshall, 2016; Martin, 2012). By its very definition, in two-eyed seeing, each lens has value, not placing one lens above the other; rather, both lenses should be valued for the strengths that they contribute to a balanced way of viewing things, whether that be research or the world. Oftentimes, when a researcher incorporates Indigenous knowledge, it is seen as less valid and less empirical,

lacking scientific rigour (Martin, 2012; Smith, 2012). It was with great surprise when I encountered the opposite, when the dual lens of two-eyed seeing was not embraced, and incorporating Western approaches was seen as not operating from an Indigenous lens, which ultimately felt as though my Indigeneity was in question.

When an Indigenous person questions another Indigenous person's lens and Indigeneity, to me, this is a form of lateral violence, as it discounts and invalidates one's lived experiences. Lateral violence is unique for Indigenous people, as it is intricately connected and rooted in colonialism. The behaviour is a symptom of trauma, and can be conscious or unconscious. The Native Women's Association of Canada (2011) explains that "lateral violence differs in that Aboriginal people are now abusing their own people in similar ways that they have been abused. It is a cycle of abuse … Aboriginal people now become the oppressor … [it] is a learned behaviour as a result of colonialism and patriarchal methods of governing and developing a society" (p. 1). Lateral violence is a form of internal within-group racism, it can look like bullying, insults or verbal attacks; in Indigenous communities, it can also be in the form of being told that you are not Indigenous enough, you are too white, and too mainstream (Bear Paw Media, 2006).

For me, this 'identity politic' of questioning another's Indigenous lens, and consequently their Indigeneity, parallels the Indian Act which passes judgement on who is and who is not Indigenous. It is important to note that the level of cultural connection is incredibly variable among Indigenous people, all due to colonization (Ball, 2005); some Indigenous people were raised with teachings, and are very knowledgeable, while others, such as myself, were not raised with teachings, and are still in the process of learning. Some are proud, and some are ashamed of their identity as an Indigenous person. It is individual. Furthermore, there are multiple structural factors that contribute to current colonialism and lateral violence, including: policies, governing bodies, and individual, family and community context and history (Clark, 2012).

As such, the importance of two-eyed seeing cannot be underscored enough. One Elder commented, "As Elders, we also know that today First Nations peoples all have to be able to walk in two worlds: that of their Native community and that of the newcomers, of the white people, whose ways are the ways of mainstream society. We cannot

overemphasize how important this ability is for the recovery and health of our communities and our community members" (Marshall, Marshall, & Bartlett, 2015; p.17). Furthermore, in line with two-eyed seeing, not placing one above the other, Indigenous methodologies also value cultural systems, but also do not reduce the value of other systems (Ruwhiu & Cathro, 2014). If anything, we as Indigenous people should be working to lift each other up, empowering each other to succeed, and take a cultural promotion approach and celebrate strengths, and diverse experiences.

One can only speculate about the causes of resistance and questioning another's Indigeneity, but I am led to believe it is rooted in the many systems and structures that have created mistrust and lateral violence within communities; that is, these reactions are rooted in the historical and continued colonization of Indigenous people. Colonization and forced assimilation of Indigenous people has had lasting effects, that have not only permeated the very fabric of Indigenous life, but our reactions are also rooted in the structural impacts of colonialism.

Current Colonial Structures and Resistance

We are not yet removed from colonialism; in fact, there are many colonial structures that continue to control and assert power over Indigenous people. There continues to be structural inequalities, both policy and government-driven. The federal government continues to keep communities in state of dependency and underdevelopment, and the power that bands hold remain under the authority of the federal government, as the band system and chief and council are federally constructed and imposed systems (Alfred, 2009; RCAP, 1996).

Throughout my graduate studies, I have also encountered these current colonial structures, as they have served as barriers to Indigenous-led research with Indigenous communities. Most frequently, these encounters have occurred during the processes of gaining agency and ethics approvals. Many of these structures are well-meaning, working to protect the youth in their care or attempting to operate in a culturally competent manner, yet they still operate from a place that is not accommodating to or is resistant to Indigenous research. First, with respect to agency-level barriers to Indigenous-led, Indigenous-focused research, barriers were expressed in terms of protecting youth from a legal

standpoint, as the agency has the duty to protect the rights and confidentiality of the youth. While I agree that it is of utmost importance for agencies to protect the youth within their care from harm, where their privacy and rights be preserved, I do take issue with a non-Indigenous agency deciding the methodology of a project that does not align with the wishes of the Indigenous organization and advisory committee. Despite their willingness and support for the research focus, it is still their system in which projects get approved as they remain to operate under the authority of their agency, with reviewers who are non-Indigenous. Prescribing methods to Indigenous led research is counter to Indigenous methodologies, where projects are self-determined within the Indigenous communities (Smith, 1999).

Furthermore, in terms of current colonial structures, one could argue that academia in itself contributes to the further assimilation of Indigenous students, removing them from their ways of being as Indigenous people. Archibald (2008) speaks about insider outsider relations in her research, placing her as an outsider within the Indigenous community. She explains that the tools used to record her observations and reflect resulted in tension and unease as the mere fact that she was there in a research capacity was incongruent with the way in which she would normally participate. As part of her work, she had to become an outsider, taking notes and writing for others. Smith (2012) also speaks about this relationship between Indigenous communities and academia, noting there is ambivalence in Indigenous communities towards academia, and Indigenous people educated within Western education systems. This insider-outsider relationship for Indigenous researchers ties back to where I began, with the resistance experienced within the Indigenous community. Perhaps the insider-outsider relationship was a contributing factor to the resistance experienced; I am both an Indigenous person (insider) and someone who is gathering feedback and information about the project (outsider).

Conclusion

Given the complex historical and contemporary policies that continue to perpetuate inequalities among Indigenous populations, the need for Indigenous focused research to be conducted by Indigenous people is critical. Despite the growth in Indigenous researchers, much of the research that focuses on Indigenous populations continues to

be completed by non-Indigenous researchers (Ball, 2005). Furthermore, while I am in absolute agreement that the rights of youth are to be protected, a paradigm shift is needed in which there are Indigenous ethics sub-committees, with community representative and Indigenous scholars, when Indigenous-focused research projects arise.

The barriers and challenges that Indigenous researchers face in working with their communities undoubtedly extend far beyond the internal resistance, lateral violence, and current colonial structures that I have brought up in this section. I have been fortunate enough to be in an academic program that has afforded me the flexibility to do work that is meaningful to me as an Indigenous person, while not prescribing a specific lens or approach.

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Appendix A.

Program Logic Model

Inputs	Activities	Target Groups	Outcomes		
			Short term	Intermediate	Long term
Space Advisory committee Staff ✓ Program staff ✓ Agency staff ✓ Organization staff Indigenous youth Financial resources	Attend training on FASD Community engagement Resource / tool development ✓ Wrap cards with information about the Project ✓ Business cards ✓ Website Community knowledge gatherings 1-1 support / outreach / specialized case management ✓ Support through assessments ✓ Advocacy support	Justice involved Indigenous youth Parents and guardians Indigenous communities Indigenous organizations Agency partners	Increased awareness and understanding within youth, families, & communities of how FASD diagnoses, co-existing substance use, & other life harms contribute to justice involvement among Aboriginal youth ✓ Awareness social stigma ✓ Awareness of barriers ✓ Awareness of traditional teachings, values, process ✓ Other justice sectors increased awareness FASD connection to justice involvement ✓ Awareness of services	Increased resources for youth, families, & community ✓ Youth and families connected to community services Increased capacity / support for youth, families and communities living with FASD, co-existing substance use, life harms, & justice involvement ✓ Increased asset & family sustainability ✓ Increased communication / contact between parents and youth ✓ Increased self esteem ✓ Coping skills improved ✓ Capacity – youth and family recognize factors for healing ✓ Capacity – increase self-advocacy skills, confidence to access services, & navigate supports	Reduced number of Aboriginal children with FASD being removed from their immediate &/or extended family and community. ✓ Youth currently in care of their families remain in their care ✓ Reduction of Aboriginal children with FASD entering care Family and community reunification ✓ Youth return home ✓ Youth reconnect with their cultural communities ✓ Youth & family connection to birth community and culture ✓ Families of youth in care are assisted in reunification or in developing permanency plans with the best interest of the child Children & youth experience positive outcomes ✓ Children in care transition successfully to adulthood

Inputs	Activities	Target Groups	Outcomes		
			Short term	Intermediate	Long term
	✓ Basic needs support ✓ Cultural engagement Assist in family reunification or family staying together			✓ Capacity – youth and families identify assets and support needs to transition towards reintegration Maintain partnerships between project partners & establish relationships with other service agencies, communities, & leaders	✓ Children in care are engaged & successful at school ✓ Children and youth are free from abuse, neglect & exploitation Reduction in justice involvement & breaches

Appendix B.

Needs Assessment Questions

This purpose of this needs assessment is to learn about the support needs of Aboriginal youth and families living with FASD. Questions will focus on their top needs in different areas (e.g., school needs, needs in the assessment process, etc.), what services are available and what services are missing, but needed in your community. The survey is open to those who can speak about the needs of Aboriginal youth and families living with FASD.

Your feedback is very valuable, and the information you share will be used to inform an evaluation of a current project working to support Aboriginal youth and families living with FASD. Because we are hoping that this survey will contribute to a comprehensive assessment of needs, the questions are mostly qualitative and we expect it will take you 45 minutes to complete. For your participation, your email will be entered into a draw for one of three $50 gift cards. Please know that all of your responses will be confidential. Thank you in advance for your valuable feedback! Do you agree to participate? (Yes, No)

We cover a number of different areas of support and services that Aboriginal youth and families living with FASD might need, including: Culture; Education and employment; Alcohol and drugs; Criminal justice system; Assessments and diagnoses; Children and family services (e.g., MCFD); and Health (e.g., physical, emotional, spiritual, mental). We understand that you might not be able to talk about all of these different areas, and that your time is valuable. If you have nothing to say about an area, please feel free to move to the next topic.

1. Please describe the top 5 things that Aboriginal youth living with FASD need to live their best life.
2. What are the needs of Aboriginal youth and young adults living with FASD when it comes to:
    a) Culture? (please explain what and why)
    b) School or employment? (please explain what and why)
    c) Alcohol and drug treatment and support? (please explain what and why)
    d) Reducing, stopping, and prevention of future offending? (please explain what and why)

e) Their FASD assessment and diagnosis: What do they need (a) before, (b) during, and (c) after their assessment/diagnosis? (please explain what and why)

3. What are the top needs of Aboriginal families with a loved one living with FASD when it comes to:
    a) Culture? (please explain what and why)
    b) Supporting their children in school, with their education, or employment? (please explain what and why).
    c) Supporting their children who might be misusing or abusing alcohol and drugs? (please explain what and why).
    d) Their child's involvement in the justice system. What supports and programs do they' need so they can (a) support their children who become involved in the justice system; and (b) prevent future justice involvement? (please explain what and why).
    e) Keeping the family unit together or reuniting families? (please explain what and why)
    f) Supporting their child before, during and after the assessment/diagnosis process? (please explain what and why).
    g) Supporting and raising their children? (please explain what and why)
    h) Thinking about the following areas below, what services and supports are available, helpful, in need or not helpful?
        - Services and supports that include culture
        - Employment services and school supports
        - Alcohol and drug programs and supports
        - Criminal justice system related supports and programs
        - Assessments and diagnosis supports and/or clinics
        - Services and supports that keep families together or bring families together
        - Housing supports and services
        - Holistic health services and programs (e.g., physical, emotional, spiritual, mental)
        - Services and supports specific to parents and caregivers of youth living with FASD
4. Thinking about the above list, please describe what services, supports and programs are available in your region?
5. Of the services, supports and programs you identified, what ones are *helpful* or *not helpful*?
6. Are there any services, supports, and programs for Aboriginal youth living with FASD that are missing in your region, but are needed?
7. Thinking about the Aboriginal youth and young adults that you work with, what are some of the strengths, positive qualities, and skills you have witnessed?
8. If you are a parent or caregiver to a youth living with FASD, what are some of the strengths and positive qualities you have seen in him or her?
9. Are you (check which applies): Indigenous or Non-Indigenous
10. Are you:
    - ☐ A parent or loved one caring for an Aboriginal youth or young adult living with FASD
    - ☐ Working in an organization or service that provides services or support to Aboriginal youth or young adults living with FASD

i. Is this an Indigenous organization, service, agency? (Yes, No)

- ☐ Both a parent or loved one and working in an organization that provides services and support

11. What region are you located in?
    - ☐ Northern
    - ☐ Vancouver Island
    - ☐ Vancouver
    - ☐ Fraser
    - ☐ Interior
12. What employment sector do you work in?
    - ☐ Medical
    - ☐ Social services
    - ☐ Health
    - ☐ Non-profit
    - ☐ Government
    - ☐ Other:

Thank you for your valuable feedback! To thank you for your time and feedback, you will be entered into a draw for one of three $50 gift cards. Please provide your preferred contact information. After the draw, we will delete the contact information you have provided so that the results are confidential. This information is for the purpose of a prize draw only.

Email or phone contact: _____

Appendix C.

Staff and Management Evaluation Questions

1. What is your role in the program?
2. What do you think are some of the strengths of youth in the program?
3. Thinking about the youth in the program, what are the top service and support needs for youth?
4. As someone who is working with and supporting Indigenous youth and families living with FASD, what do you need to best support youth and families within this program?
5. Are the right youth in the program? (e.g., are there any youth who aren't in the program but should be?)
6. Are there any barriers for accessing the program?
7. What is working well in the program?
8. What aspects of the program do not work well?
9. Is the holistic design of the program effective in achieving the objectives?
10. What suggestions do you have to improve the program's design and delivery?
11. Is the program relevant to youth and family needs? Why or why not?
12. Thinking about youth in this program, do you think they would have done the assessment/diagnosis if the program wasn't here? (why or why not?)
13. Do you think non indigenous youth would benefit from this program?
14. Thinking about the original design of the project, what adaptations have you made to the project? Why did you make that adaptation?
15. Are you satisfied with the program? Why (not)?
16. In your opinion, what have been the most valuable outcomes for youth because of the program?
17. Were there any outcomes that surprised you (e.g., you didn't anticipate/expect)?
18. Have youth in the program gained new knowledge and skills since being in the program?
19. Because of the program, would you say that …?

	No	Yes	Already There	DK
Youth have increased awareness/understanding of how FASD and substance use can contribute to justice involvement?				
There has been a positive change in attitudes and perceptions of FASD for youth and families in the program?				
Youth have increased confidence in accessing services and supports you need?				
Youth have increased self-esteem?				
Youth have increased coping skills (dealing with stressful things)?				
Youth are more connected to Indigenous culture and community? (e.g., traditional teachings)				
Youth know what they need for healing?				

20. What is the number one lesson that you've learned through being involved in the program?
21. How has the partnership between [the two organizations] contributed to the success of the project?
22. Thinking beyond the program, would you say that there have been changes in stigma around FASD in Indigenous communities?
23. Is there need for this program to continue in the future? If so, what needs to happen to make it a sustainable program?
24. What needs to happen in the area of FASD for Indigenous communities moving forward?

Appendix D.

Advisory Committee Evaluation Questions

1. Can you tell me how you became involved in [the Program] advisory committee?
2. In your opinion, can you share with me some of the strengths and positive qualities of Aboriginal youth living with FASD?
3. Are you aware of any resources, services or supports exist in your community to support Aboriginal youth living with FASD?
4. What are the some of the service and support needs for Aboriginal youth and families living with FASD?
5. What services and programs for Aboriginal youth living with FASD are missing in your community, but are needed?
6. In your opinion, is [the Program] relevant to youth and family needs? (is the project meeting a need?)
7. In your opinion, is [the Program] achieving the objectives to support Aboriginal youth and families living with FASD?