

UNDERSTANDING THE COMPLEX NEEDS OF
ABORIGINAL CHILDREN AND YOUTH WITH FASD IN
BC

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Abstract

FASD is a public health priority in health planning in BC. This study aims to uncover what policies best enable the Aboriginal child and youth population to receive timely assessments and diagnoses, and wrap around programs and services from childhood onto adulthood in a culturally safe manner. Twenty-seven key informants and parents participated in qualitative interviews and three Elders participated in one focus group. The results revealed five main challenges with respect to status quo policy on FASD; inconsistent assessments and diagnoses, challenges within the education system, inadequate adult services, unequal distribution of resources among foster, adoptive, and birth parents, and continuing healing among Aboriginal communities from intergenerational trauma. The results of this study along with literature review informed the development of policy recommendations for addressing these key issues. The project recommends adult assessments and diagnoses, FASD education campaigns on and off reserves, and adult day programs.

Keywords: FASD; Assessment and Diagnoses; Aboriginal children and youth; Intervention; Cultural Safety; Policy Analysis

Executive Summary

Beginning in 2003, the BC government explicitly recognized Fetal Alcohol Spectrum Disorders (FASD) as a priority within the public health agenda with the release of the first provincial strategic plan. With a prevalence rate of 9 per 1000 live births, FASD affects 300,000 individuals in Canada, with many more undiagnosed. International longitudinal studies consistently find negative life trajectories among those affected by FASD because their condition leaves them exceptionally vulnerable to substance abuse, involvement with the criminal justice system, mental health problems, and homelessness.

Moreover, these studies have called for mandatory early diagnosis, intensive psychosocial care, appropriate schooling, occupational counselling, and supportive care into adulthood. FASD is an international health concern as it does not discriminate between ethno-cultural groups. Research has successfully identified FASD risk factors, namely, lower education levels, custody changes, lower socioeconomic status, reduced access to prenatal and postnatal care, inadequate nutrition and a poor developmental environment.

In addition to racism, sexism, poverty and issues related to rural urban divides, these risk factors disproportionately affect certain Aboriginal subpopulations in BC as evidenced by the Provincial Health Officer's 2007 Aboriginal health report. Taken together these social obstacles have lead to unhealthy pregnancies, low birth weight babies, and sub-optimal child development. Furthermore, certain Aboriginal communities encounter unique obstacles associated with on and off reserve divides, FASD related stigma and discrimination, and intergenerational trauma due to their experience with colonization. Non-aboriginal populations affected by FASD do not tend to experience these factors.

Preliminary research demonstrated that FASD intervention provisions in the form of diagnostic services and FASD specific programs and services remain ad hoc, widely dispersed, uneven, and generally not evaluated for their effectiveness in supporting more vulnerable populations. Therefore, the aim of this study is to understand the needs of the Aboriginal child and youth population in order to uncover what policies best enable this population to receive continuity of care in a culturally safe manner. This goal was undertaken under a theoretical

framework that was composed of postcolonial theory, theory of intersectionality, and cultural safety.

Qualitative research methods were employed to gain an in depth understanding of the day-to-day experiences of families. Twenty-seven semi-structured interviews were conducted with parents and key informants, and an Aboriginal Elders focus group. Parents and caregivers were made up of birth, adoptive and/or foster parents of Aboriginal children and youth (n=13). Two of the Elders were grandparents and another was adoptive parent (n=3). Key Informants included FASD researchers, key workers, educators, assessment in-take workers, youth workers, ministry representatives, advocates and medical professionals, many of whom were parents as well (n=14).

The interviews revealed vast amounts of data, yet the themes that best captured the areas where policy could be improved were identified. First, the provision of FASD assessments and diagnoses in BC is inadequate as long waitlists persist and no publicly funded diagnostic services exist past the age of 19 years old, leaving many undiagnosed and ineligible for adults supports such as Persons with Disability allowance. Those families in rural on reserve communities have the worst access because specialists only make a handful of yearly visits into those communities. Second, challenges with the education system proved stressful for parents as they had to constantly advocate for accommodations even though the Ministry of Education has undertaken several FASD initiatives.

Third, all parents noticed an abrupt cut off in programs and services such as day programs and supportive housing at 19 years old, which especially left Aboriginal youth in the care system particularly vulnerable (make up 50% of those in continuing custody). This means that the FASD affected youth exit the care system at 19 and their foster parents or the government is no longer obligated to support them. Fourth, the study found unequal distribution of resources like FASD parenting education and monthly allowances among foster, adoptive, and birth parents, ironically leave birth parents, the least supported, when they required the most support for family unity. This flaw in policy design will require a certain level of political action in restructuring ministerial responsibilities

Finally, the study found that not all Aboriginal communities are uniformly affected by intergenerational trauma. Certain communities sought to empower themselves by developing and sustaining local FASD knowledge and initiatives and resisted intrusive diagnostic measures. The Elders focus group revealed that fundamental teachings on parenting and family strength have been lost in certain areas and need to be recovered. Moreover, the experiences of the birth

mothers demonstrated that they faced considerable challenges due to discriminatory attitudes, poverty, and surveillance under child-care workers, despite their sobriety.

Five policy options were developed, including the status quo. The options were based on information from participants and successful pilot programs in BC that were best reflective of cultural safety principles. They were: status quo, adult diagnostic services, interdependent living, Aboriginal FASD day programs, Aboriginal run FASD education campaigns, and respite care for adoptive and birth families. The analysis of the options was made according to the following criteria: equity, effectiveness, cultural safety, efficiency, and stakeholder acceptability. After careful analysis of the options merits as well as unintended consequences, four recommendations were made.

The first option includes the implementation of adult diagnostic clinics modelled after the success of the one in Victoria. The second option is to expand Aboriginal adult day treatment programs, which present safe daily environments for youth and holistic care in recovery from substance abuse. The third option is to support and expand FASD education campaigns on and off reserves that are designed and delivered by Aboriginal stakeholders throughout the province. Lastly, respite care services should be expanded to meet the needs of birth and adoptive families. All four options complemented by status quo provisions provide the next feasible policy measures that government may adopt in order to continue closing serious gaps in the continuum of FASD interventions.

The theoretical framework of the study allowed the analysis to account for the challenges associated with each option, while exposing the underlying power imbalances that inform Aboriginal experiences with FASD. Aboriginal authorities have long stressed that policy reform must be made within the context of community institutions, which play a critical role in empowerment of Aboriginal identity and wellbeing. Therefore, the recommendations may be most beneficial when coupled with the institutional ability of Aboriginal authorities to oversee the health of their nations at the community or regional level. In doing so, the aims of cultural safety may be fully attained.

Dedication

I dedicate this study to gifted children and youth everywhere. Your resilience, talent, and enduring souls are an inspiration. I also dedicate the study to their loving parents and caregivers who work tirelessly so that their children may prosper and reach their full potential.

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Glossary

Aboriginal	The term <i>Aboriginal</i> encompasses the First Nations, Inuu, and Métis peoples of Canada as set out by the Constitution Act of 1982.
CLBC	Community Living British Columbia
Cultural Safety	An Aboriginal informed concept and approach in healthcare and health policy that seeks to address systemic power imbalances, institutional discrimination, and colonization.
FNIHB	First Nations Inuit Health Branch
FASD	Fetal Alcohol Spectrum Disorders
MCFD	Ministry of Children and Family Development of British Columbia
MHSD	Ministry of Housing and Social Development of British Columbia
PWD	Persons with Disabilities monthly allowance in British Columbia
PHAC	Public Health Agency of Canada
VIHA	Vancouver Island Health Authority

1: Introduction

It is not your fault, it is society's fault.

Fetal Alcohol Spectrum Disorders (FASD) are among the leading causes of brain damage and developmental delays in Canadian children today (FASD: A Framework for Action, PHAC, 2005). FASD is a devastating birth condition that has lifelong implications to individuals, their families and society at large. Prenatal exposure to alcohol causes irreversible structural changes in the brain that manifest in the form of permanent physical and cognitive delays, such as deficits in memory, learning, motor and language skills etc. (Hopkins et al., 2008). The Canadian FASD prevalence rate of 9 per 1000 live births means that more than 3,000 babies are born in Canada each year with FASD, and more than 300, 000 people are currently living with this lifelong condition (Why Is It Important to Address FASD?, PHAC, 2007).

FASD crosses ethno-cultural and socioeconomic lines, yet some common risk factors have been identified. Social determinants of health, particularly those related to maternal and child health have been closely linked to FASD risk factors. Such health determinants include income, social support networks, health services, education and literacy, healthy child development and gender among others (Canada Northwest FASD Research Network, 2007). Furthermore, social determinants of health are informed by systemic and historical factors that shape experiences of discrimination, poverty, and social isolation, which weigh heavily on Aboriginal maternal health outcomes (Fiske and Browne, 2008).

The FASD literature is saturated with misguided studies that simplistically link FASD with Aboriginal populations, as if FASD were an inherent trait or even a genetic feature of Aboriginal populations. The majority of the studies do not delve deeper into an analysis of how the social structures in society have created the discriminatory contexts that allow certain Aboriginal groups to *be* and *remain* at risk of FASD. Most studies offer a shallow and ahistorical analysis that only contributes to harmful stereotypes that link FASD with Aboriginal ethnicity (British Columbia Centre of Excellence in Women's Health, 2002).

By contrast, Aboriginal authors on this issue stress the socio-historical factors that have had a profound impact on Aboriginal health inequities alongside discussions that interrogate

essentialist assumptions that relegate FASD as solely an ‘Aboriginal problem’ These socio-historical factors include the introduction of the whisky trade by Europeans into Aboriginal communities, Aboriginal children’s experiences of sexual and physical abuse in residential schools, and the mass adoption of Aboriginal children in the 1960s and 1970s (Mitten, 2009; Lavell-Harvard and Corbiere Lavell, 2006; Tait, 2003; Fournier and Crey, 1997).

The health of subsequent generations, particularly of Aboriginal women, remains affected by such intergenerational experiences (Tait, 2003). The latest Provincial Health Officer’s report (2007) demonstrates that, in comparison to the non-Aboriginal female population, Aboriginal women face poor physical and mental health, inadequate nutrition due to poverty and issues related to on and off reserve divides. Collectively, these conditions lead to unhealthy pregnancies, low birth weights, and sub-optimal child development (Pathways to Health and Healing: 2nd Report on the Health and Well-being of Aboriginal People in British Columbia, Office of the Provincial Health Officer, 2007).

With respect to FASD and policy, the BC government and the Public Health Agency of Canada (PHAC) have formally acknowledged FASD as a serious, costly and urgent public health concern. Even though FASD was formally discovered some thirty years ago, governments have only recently responded to this issue. The first BC plan was released in 2003, followed by a second one in 2008. Both plans focus on prevention and FASD education, delivery of diagnostic services, and support for pregnant and parenting mothers (FASD: Building on Strengths A Provincial Plan for BC 2008-2018, MCFD, 2008). The PHAC has primarily worked on FASD prevention and health promotion initiatives like awareness campaigns, building FASD research capacity, and the development of national diagnostic standards (FASD: A Framework for Action, PHAC, 2005).

Even though BC is ahead of other provinces in terms of implementing measures for FASD prevention and diagnoses, its commitment to intervention policy, is weak and does not account for the lifelong impact of this condition. Intervention initiatives remain ad hoc, widely dispersed, uneven and are mainly directed for those under 19 years of age, at which point they are abruptly cut off. As a result, the need to build further research strength in intervention policy has been identified (Canadian Northwest FASD Research Network, 2006).

Moreover, policy initiatives fail to explicitly address how issues of poverty, social isolation, racism, and sexism contribute to FASD and their disproportionate impact on Aboriginal subpopulations. Most plans make prescriptive recommendations for personal health practice and lifestyle changes, while assuming that access barriers are simply geographic in nature. By

contrast, barriers such as stigmatization and surveillance of Aboriginal mothers and their children, as well as fears of child apprehension, rarely receive much attention (Fiske and Browne, 2008).

To effectively achieve a multidimensional approach to FASD, the PHAC has identified three core areas that policy must address (See Figure 1 below). However, it is important to add that policy must simultaneously remain cognizant of the social determinants of health and contexts related to history, poverty, and homelessness among others.

Figure 1 Policy Approaches to FASD

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are needed to see this picture.

Source: FASD: A Framework for Action, PHAC, © 2005.

This study aims to undertake such an approach in order to find policies that best enable the Aboriginal subpopulation to receive continuity of care through culturally safe programs and services. In doing so, the study also commits itself to the further disruption and interrogation of racialized stereotypes of FASD. Nevertheless, the policy recommendations made by this study, however well intentioned, still have the potential of further embedding FASD stigma and

stereotyped beliefs. This is especially problematic in relation to system wide requirements that demand diagnostic labelling for all conditions before access to services is received. Such systemic challenges are beyond the scope of the study; however, by virtue of adopting the goal of cultural safety, the study seeks to highlight systemic inequities and offer possible solutions wherever possible.

1.1 Defining the Policy Problem

The policy problem that this study addresses is that *in BC the delivery of programs and services for the FASD population remains inadequate and time bound*. All communities in BC can be affected by FASD, yet research demonstrates that those communities facing poverty, racism, gender discrimination and social isolation feel the negative impact of this condition most acutely (Mitten, 2009; Chudley et al, 2005; Astley et al, 2000). Aboriginal communities are faced with such discriminatory contexts, which simultaneously contribute to *why* certain communities remain significantly affected by FASD risk factors such as: lower education, multiple foster placements, lower socioeconomic status, reduced access to prenatal and postnatal care, inadequate nutrition and a poor developmental environment (e.g., stress, abuse) (Chudley et al., 2005; Pathways to Health and Healing, 2007).

Aboriginal communities also encounter unique obstacles associated with on and off reserve divides, FASD related stigma and stereotyping, and intergenerational trauma, which are not commonly experienced by non-Aboriginal populations (Pathways to Health and Healing, (2007). This study, therefore, narrows the scope of the research to focus on the experiences of the Aboriginal subpopulation in BC, particularly Aboriginal children and youth. The research question then pursued by the study is to understand: *how effective are existing FASD programs and services for Aboriginal children and youth with FASD in BC?*

Aboriginal approaches to FASD can often differ from mainstream approaches, especially those heavily focused on biomedical interventions (Martin Hill, 2003). Alternative Aboriginal approaches include such initiatives like community justice programs, Elders circles, and FASD cultural awareness camps, which incorporate customs, teachings and ceremonies in order to promote healing. Experiences of trauma and abuse as remnants of colonization, have not affected all Aboriginal communities uniformly, thus some communities are healthy and thriving, while others struggle for community healing. The link between residential schools, substance abuse and the intergenerational effects of trauma may require different FASD interventions in Aboriginal communities than in non-Aboriginal communities affected by the same condition (Tait, 2003).

Even though the research question primarily focuses on experiences within the Aboriginal subpopulation, some of the research findings and policy recommendations lend themselves to an overall improvement of FASD service provision in the province. The following subsections briefly outline areas of concern in relation to existing FASD programs and services.

1.1.1 Assessments and Diagnoses

Acquiring the FASD label is imperative in order to access supports in the school environment, financial aid for families, and adult support services. However, access to diagnostic services is not uniform in BC due to variable eligibility criteria within each health authority. In rural areas, particularly around remote reserves, access to specialists like developmental paediatricians is limited, especially in the winter months when weather makes travel to these communities impossible. Moreover, the number of assessments and diagnoses provided through health authorities do not meet family demands as current waitlists range between two to three years, which results in delays for early intervention.

The fact that publicly funded diagnostic services are only available for those under 19 years of age creates a sense of urgency among families to place their children on wait lists as soon as possible. Without a formal FASD diagnosis, future access to programs and services is greatly limited. The diagnosis also acts as a legitimate claim for services because the majority of FASD affected individuals have no physical characteristics, which has often led to the dismissal of their needs. Furthermore, the absence of publicly funded assessments and diagnoses for adults means that not only are undiagnosed adults unable to access Persons With Disability (PWD) allowances and Community Living BC (CLBC) supports, they are also left dealing with a condition that remains unidentified.

1.1.2 Education

Education is the one sector that BC has successfully implemented initiatives such as FASD school programs. The Ministry of Education also formally recognized FASD as a special needs category in 2007. Nevertheless, parents find that school accommodations are not readily feasible as each school varies in their commitment to and understanding of this condition. Families that are well financed, educated, and resourced in terms of time and family support, successfully acquire services through constant advocacy.

By contrast, Aboriginal families do not always have access to the same resources. FASD school programs and services on reserve are rare and largely depend on resources of the band and its relationship with local child development centres and FASD educators. In particular, for children and youth who have been socially disadvantaged, fractured education entails dismal chances of continuing education, finding future employment, and consequently, poor quality of life outcomes (Ryan and Ferguson, 2006).

1.1.3 Adult Supports

Failed transitions into adulthood often occur because FASD affected youth are presumed to be self-supporting adults by the time they reach 19 years of age. Once youths with FASD age out of programs and services at 19 years old, they are faced with barriers in accessing adult supports such as those provided by CLBC. The majority do not meet CLBC criteria even though youth have serious deficits in adaptive and executive functioning, which impair their ability to do daily tasks such as handle money, pay rent, and sustain employment (Streissguth and O'Malley, 2000). Individuals lucky enough to receive an FASD diagnosis before 19, are eligible for PWD allowances. Yet, most live alone, unsupervised, and without access to adult special needs services.

The only option for FASD affected youth without a diagnosis at 19 is welfare or, if the option is available, to remain at home with their families who have to bear all financial responsibility. Aboriginal children and youth with FASD in the child welfare system are especially affected by the lack of FASD adult supports. They currently make up 50% of the children and youth in continuing custody (2007/08-2009/10 Service Plan, MCFD, 2007) and the majority of children in care remain in care of foster families until 19 years of age (2008/09 Annual Service Plan Report, MCFD, 2009). This means that neither the ministry nor foster families are obligated to support the youth, financially and otherwise.

1.1.4 Criminal Justice System

The aforementioned problems often culminate in involvement in criminal activity as FASD affected youth are disproportionately represented in the juvenile justice system (Fast and Conry, 2004). Studies indicated that they are more prone to maladaptive behaviour that leads to criminal offences (Fast and Conry, 2004; Streissguth et al., 1997). This behaviour is associated with FASD related neurological deficits, which increase susceptibility to criminal behaviour and

victimization in the community due to impulsive natures, poor judgement, aggression and inability to read social cues (Jones, 2004). The presence of FASD comorbidity with mental health issues and substance abuse disorders further elevates their risk in becoming involved with criminal activities (Fast and Conry, 2004; Streissguth et al., 1997). Once in the criminal justice system, individuals with FASD have difficulties in giving statements, participating in their own defense, and are known to be more prone to wrongful convictions (Mitten, 2009; Fast and Conry, 2004).

1.2 The Cost of FASD to Society

The shortfalls of FASD intervention initiatives in BC is symptomatic of ineffective policy that adopts a short sighted view of this condition and fails to provide continuity of care that accounts for lifelong impacts. By doing so, the costs to government and private costs to families accumulate over the lifespan. FASD cost of illness models may be used to validate beliefs that certain illnesses are a strain public resources or to argue that government inaction inadvertently exacerbates costs. Current PHAC research on FASD costing seeks to emphasize the latter point by affirming FASD related costs in various spheres such as social services, education and employment, the criminal justice system, mental health and addictions (National Roundtable on the Development of a Canadian Model for Calculating the Economic Impact of FASD, Public Health Agency of Canada, 2007).

The initial research for the model is also including costs that were previously unaccounted for, such as costs associated with the child welfare system, lost productivity in school due to lack of interventions, prison sentences, legal expenses, emergency room visits, cost of specialists etc. In addition, intangible and private costs to families like psychological stress and strains on caregivers' time and energy are included. The initial report calls for a parallel costing study for Aboriginal communities that would be designed by Aboriginal stakeholders.

1.3 Research Goal and Objectives

While the policy problem is wide, complex and involves the interplay of policy across systems, the goal of the research is *to uncover what policies best enable the Aboriginal child and youth population to receive continuity of care through programs and services in a culturally safe manner.*

The research objectives of the study are to:

- 1) *Determine where policy gaps exist in the provision of FASD programs and services for the Aboriginal FASD population in BC.*
- 2) *Understand how socio-historical factors and broader social determinants of health inform how Aboriginal communities experience FASD and how they approach community healing initiatives.*
- 3) *Identify successful FASD programs and services in order to develop recommendations that will inform policy changes to better improve the health and quality of life for the Aboriginal FASD population in BC.*

1.4 Theoretical Considerations

This project draws on two important theoretical frameworks – postcolonial theory and intersectionality, both of which orient themselves around the goal of social justice. Postcolonial theory allows for an interrogation of the colonial past and its role in creating the health inequities today, including its role in keeping certain Aboriginal communities vulnerable to FASD. It also places the perspectives and lived experiences of Aboriginal peoples, in the context of health needs, front and centre (Browne et al., 2005). This is critical because contemporary dialogue around Aboriginal health touches on colonial relations, but does so in such a manner that neutralizes Aboriginal health inequities as ‘treatable conditions’. In the case of FASD, claims are made that it is ‘easily preventable’ and attributable to personal health practices, issues of low self-esteem and alcohol abuse (Tait, 2003).

Mainstream health and social services then aim to ‘improve the lives’ of Aboriginal people without addressing the underlying social imbalance between them and broader society (Browne et al., 2005). Postcolonial analysis exposes these systemic power differentials while providing an intellectual space within which to interrogate racialized¹ stereotypes of FASD. These stereotypes shape epidemiology research and the views of health care professionals and policymakers’, and popular understandings of the condition.

Postcolonial theory also best captures the intergenerational effects of alcohol abuse and colonialism in Canada and in other jurisdictions. For example, in South Africa the introduction of alcohol by colonialists caused severe intergenerational FASD, which closely parallels the whisky

¹ Racialization is a process of attributing social, economic, and cultural differences to race and where attitudes and institutionalized policies and practices marginalize individuals and collectives on the basis of presumed biological, physical, or genetic differences (Fiske and Browne, 2008).

trade and its role in the colonization of North America (Mitten, 2009). By revealing the intergenerational effects of alcoholism, postcolonial theory allows for an analysis of power dynamics between social structures and dominant groups. This analysis may inform how health inequities are produced and sustained (Browne et al., 2005).

In addition to postcolonial analysis, the complex and diverse experiences among Aboriginal children and youth faced with FASD require an intersectional analysis. Intersectionality is defined as a theory of knowledge that reveals the interplay and axes of intersection between multiple oppressions that combine to create distinct experiences of discrimination (Hankivsky, 2005). Intersectionality provides a nuanced analysis of how forces such as sexism, racism, classism, ableism, and other forms of oppression come to interact within the backdrop of colonial and neo-colonial relations. Moreover, intersectionality adopts a view of health that is shaped by interrelationships of power in order to demonstrate how “the health of some is tied to the sickness of others...” (Weber and Fore, 2007).

Intersectional analysis can demonstrate, how, for example, a single Aboriginal birth mother living in poverty will experience and negotiate FASD related stigma and discrimination differently than the experiences of a Caucasian female adult affected by FASD while living on the streets. Policy makers assume uniform experiences among the targeted population they seek to serve and intersectional analysis highlights how this can sometimes create challenges not originally intended. Intersectionality in conjunction with discussions on broader social determinants of health provides a more informed perspective on what has come to be seen as simplistically a problem of ‘life style choice’ (Fiske and Browne, 2008).

This study is organized into five distinct sections. First, the literature review is presented, second, status quo policy is briefly summarized, third, the qualitative methods of research design are discussed, fourth, the research results are provided and discussed, and the final section includes a description and analysis of policy options and concludes with policy recommendations.

2: Literature Review

In order to understand the challenges posed by Fetal Alcohol Spectrum Disorders (FASD), it is necessary to first, examine the condition itself and how it relates to the Aboriginal community by reviewing the intergenerational links between FASD, residential schools, and colonialism. Second, it is instructive to review what culturally safe health care entails according to Indigenous scholarship.

2.1 What is FASD?

The first recognition of the anomalies in children whose mothers consumed alcohol during pregnancy was made in France in 1968, followed by similar findings by American researchers, Kenneth Jones and David Smith in 1973, who described the condition formally as Fetal Alcohol Syndrome (FAS) (O'Malley and Nanson, 2002). The severity of FASD, its biological markers and its impact on development and learning are not uniform and vary significantly (Sphor and Steinhausen, 2008). However, longitudinal studies of FASD found consistent findings that revealed negative life trajectories for individuals who were inadequately supported (Streissguth et al., 1996; Baer et al., 2003; Sphor and Steinhausen, 2008).

In concert with environmental and social factors, life outcomes included unemployment, truncated educations, and required assistance with daily living and supervision throughout adulthood (Streissguth et al., 1996; Baer et al., 2003; Sphor and Steinhausen, 2008). FASD comorbidity with mental illness is often cited as one of the central factors that contribute to poor quality of life. Animal research demonstrated that prenatal alcohol exposure causes permanent neurobiological changes in the brain that compromise the brain's ability to regulate emotions, which contributes to heightened vulnerability to substance abuse and depression (Weinberg, 2009; Steissguth et al., 2003).

The longitudinal studies explained that protective factors could mitigate the negative outcomes associated with the condition. The protective factors included living in stable and supportive home environments, diagnosis before the age of six years, the absence of personal experiences of violence, acceptance of therapeutic help, appropriate schooling, occupational

counselling, and supportive care in adulthood (Streissguth et al., 1996; Baer et al., 2003; Sphor and Steinhausen, 2008). These types of protective factors are difficult to realize, especially for certain Aboriginal populations whose experiences have been significantly marked by violence and community instability.

2.1.1 Diagnosis in Canada

Practices surrounding the diagnosis of FASD in Canada are varied. FASD assessments involve the gathering of all the relevant information required to make a diagnosis, such as maternal health records, social worker reports, physical examinations, and second party information among other sources. The diagnosis is dependant on an assessment of whether or not one is affected by any of the spectrum of FAS disorders; full FAS, partial FAS, and Alcohol Related Neurodevelopmental Disorder (ARND).

Because FASD shares identical features with a host of other syndromes, making a definitive diagnosis is exceptionally complex and time consuming. In order to achieve more accurate diagnoses, a subcommittee of the Public Health Agency of Canada's National Advisory Committee on FASD recommends the use of multidisciplinary assessment teams. These teams ideally should consist of a case manager, a developmental paediatrician, a psychologist, an occupational therapist and speech-language pathologist. They may be local or regional, and with the advent of telehealth services, virtual teams may mitigate some access barriers associated with rural areas. Among their numerous recommendations, they stress the importance of regular (re)testing by various clinicians blinded to previous diagnoses at various intervals in the individual's life (Chudley et al., 2005).

2.1.2 Diagnosis within the Aboriginal Population

A report by Wright and colleagues reviewed findings from interviews with Aboriginal child welfare agency representatives, Aboriginal stakeholders and parents cross nationally and found consistent themes that contributed to incomplete and inaccurate diagnoses. Three areas emerged as problematic, namely, lack of early diagnosis and intervention services, lack of follow through with assessments and lack of access to professionals with FASD specialities (Wright et al., 2005).

Wright and colleagues found that once multidisciplinary teams make a diagnosis, the recommendations of the teams were seldomly followed through on due to backlogs (Wright et al.,

2005). They highlight that the gaps are most severe in remote communities, where the waiting lists to see specialists can range between six months to a full school year. Access to health professionals required travelling long distances into urban centres and research participants noted funding disputes and weak collaborations among services on and off reserve, between bands, social workers and schools (Wright et al., 2005).

Several of the child welfare agency employees in the study noticed that children in government custody seemed to access services more readily than those in the care of birth families due to differences in funding allocations to birth, adoptive, and foster families. This concern was echoed by the Royal Commission on Aboriginal Peoples, which stated that “family caregivers in Aboriginal communities are often forced, by lack of private means or public programs suitable for their children as they grow up, to place their children in provincial care facilities” (Royal Commission on Aboriginal Peoples, 1996b, p. 133 cited in Tait, 2003, p. 211).

2.2 Epidemiology Review

The epidemiological literature highlights how FASD varies in human populations and what identifying factors influence the incidence and prevalence rates within a population. *Incidence* refers to the number of new cases of the condition and *prevalence* refers to the frequency of the condition in a population at a given time (Abel, 1998). Epidemiological studies examining population-based prevalence rates may either produce high or low estimates depending on research methodology (Abel, 1998). Not controlling for variables such as reduced access to prenatal and postnatal care services, lower education levels, lower socioeconomic status, inadequate nutrition, and poor developmental environments may obscure results when examining which pregnancies are more likely to be at risk for FASD (Chudley et al., 2005).

In Canada, epidemiological research on FASD has mainly focused on Aboriginal women and their children, or on geographical areas with high Aboriginal populations (Tait, 2003). This hyper analysis on Aboriginal communities perpetuates beliefs that FASD is somehow inherent and an essential condition of *being* Aboriginal. This view is further by the ‘drunken Indian’ stereotype. Therefore, racialized stereotypes contribute to predetermined findings in the minds of researchers before analysis even begins. Their analysis is consequently devoid of any meaningful discussions of how discriminatory social structures and environmental conditions contribute to FASD prevalence and why certain Aboriginal communities remain at risk.

For example, one study focused on an Aboriginal community in BC, which was knowingly confronted with significant intergenerational trauma and substance abuse. This study subsequently published epidemic prevalence rates attributed to the general Aboriginal population (Robinson and Conry et al., 1984). Another study done in BC and the Yukon explicitly suggested ‘racial susceptibility’ as a contributing factor in FASD prevalence among Aboriginal groups (Smith et al., 1981).

In comparison, there is much less research on prevalence rates in non-Aboriginal populations. Moreover, a lot of research, including the two studies above, is fraught with serious methodological weaknesses. Methodological problems included double counting of affected children belonging to the same birth mother and confirming maternal alcohol consumption by interviews, despite inconsistent stories of consumption patterns (Tait, 2003). Furthermore, these findings made no comparison to FASD prevalence studies in non-Aboriginal groups using the same research method and FASD criteria. Therefore, direct comparisons of prevalence rates between Aboriginal and non-Aboriginal populations were made in the absence of comparable FASD research in the non-Aboriginal population (Tait, 2003).

Studies informed by racialized stereotypes disregard discussions that factor in broader social determinants of health and risk factors that contribute to drinking during pregnancy, namely poverty, social isolation, and experiences of violence. In a 5-year follow up study of birth mothers of children with FASD, Astley and colleagues reported that the women came from diverse racial, educational and economic backgrounds, but they shared universal circumstances, notably, that the mothers faced untreated or under-treated mental health concerns, were socially isolated, and victims of childhood sexual abuse (Astley et al, 2000). These findings reiterate that FASD has no link to biological, physical, or genetic differences and emphasizes the existence of common FASD risk factors.

Studies on FASD in relation to the Aboriginal population must illuminate how colonization has shaped and sustained the presence of FASD risk factors in *some* Aboriginal communities. The socio-historical context of Aboriginal communities significantly contributes to current Aboriginal health inequities, especially among women and children. This issue will be explored in detail in the following section.

2.3 FASD, Aboriginal Women and the Intergenerational Links to Residential Schools

The devastating effects of residential schooling on the Aboriginal people of Canada continue to leave their mark on the contemporary health and social welfare of this population. The forced removal of Aboriginal children from their homes initiated a formal assault on Aboriginal culture, tradition, and identity, and consequently led to generational suffering from broken homes, abuse, and internalized racism (Fournier and Crey, 1997). Experiences of intergenerational trauma and substance abuse have left certain Aboriginal communities weak and susceptible to FASD.

2.3.1 Residential Schools

Residential schools disrupted the traditional roles of child-rearing and social structure in Aboriginal communities, which contributed to the disintegration of nations. Interviews with residential school survivors reveal that one of the coping mechanisms of parents whose children were taken away, was the increased consumption of alcohol in dealing with feelings of guilt and worthlessness under the control of the church and state (Lavell-Harvard and Corbiere Lavell, 2006; Tait, 2003; Fournier and Crey, 1997). In the last years of the residential school system, the schools' function morphed into one of a welfare institution where schools began to serve as housing for children removed from their families because of 'neglect' (Tait, 2003).

The excuses used by Indian agents and social services were to cloak the true purpose behind child apprehension, which simply continued the assault on Aboriginal culture and identity (Fournier and Crey, 1997). Fournier and Crey (1997) argue that, by the end of the 1940s, four to five generations returned from residential schools poorly educated, angry and sexually and physically abused with no experience in parenting. Caroline Tait, a Métis medical anthropologist explains that the evolution of the residential school system into a welfare institution set the stage for the "large scale apprehension of Aboriginal children under welfare reforms in subsequent decades" (Tait, 2003: 73). This led to the massive increase in Aboriginal children taken into custody in the era that has been dubbed the "Sixties Scoop".

Throughout this time, child welfare services developed a damaging and lasting image of Aboriginal mothers as deviant and neglectful parents. The intergenerational effects of the residential school system left Aboriginal women facing considerable racist and sexist stereotyping. These effects will be further explored in the next section.

2.3.2 Aboriginal Mothers, Substance Abuse, and Stereotypes

Alcohol dependency contributed significantly to the destabilization in Aboriginal communities and facilitated the removal of Aboriginal children from their families (Mitten, 2009; Lavell-Harvard and Corbiere Lavell, 2006; Tait, 2003; Fournier and Crey, 1997). Furthermore, the literature on the links between alcohol dependency and child sexual and physical abuse demonstrated that abusive experiences and factors like family dysfunction, childhood neglect, and parental substance abuse contributed to alcoholism in adult women (Tait, 2003; Langleland and Hartgers, 1998).

The literature is saturated with accounts of Aboriginal alcohol consumption, yet the same level of research is not conducted for the general population. The First Nations Regional Longitudinal Health Survey for 2002/03 by the Assembly of First Nations provides a nuanced picture of alcohol consumption because it contextualizes the findings in the experience of sexual and physical abuse (First Nations Regional Longitudinal Health Survey (RHS), 2002-2003). The survey, interestingly, finds lower frequency of use among the Aboriginal population than the general population, but finds a higher rate of problematic heavy or binge drinking among the Aboriginal groups, which is correlated to experiences of trauma (RHS, 2002/03).

Stereotypes of the ‘drunken Indian’ largely prevail in popular imagination, which perpetuate negative perceptions of Aboriginal mothers with substance abuse problems as ‘dangerous’ and undeserving of support or empathy. These stereotypes obstruct efforts of mothers seeking help and support for their addictions and for their children. Negative perceptions of Aboriginal mothers result in significant access barriers to education and gainful employment, resulting in the majority of mothers, mostly single moms, working in part-time, seasonal and low paying jobs (Cull, 2006).

In Amy Salmon’s study (2007) on young urban Aboriginal mothers and their children, she demonstrated how racist and sexist stereotypes placed FASD shame and blame onto the mothers. Salmon contended that the notion of ‘good’ motherhood is historically, culturally, and politically mediated and that the dominant Western ideals of proper parenting paint anything else as dysfunctional. She explained that negative stereotypes are devoid of any broader contextualization of the lived experiences of the Aboriginal mothers who face discrimination, be it racism, sexism, classism, and/or ableism. Salmon argued that public discourse and public policy on FASD simplistically focuses on ‘just say no’ campaigns. She emphasized the need to develop FASD policy approaches through the valuable contribution of Aboriginal mothers where the

conditions under which they negotiate and experience, substance abuse, pregnancy and mothering, can be acknowledged and understood.

In contrast to the colonial and present day concepts of Aboriginal mothering, Aboriginal cultures have a rich history of strong motherhood and matrilineal traditions (Mzinegiizhigo-kw Bédard, 2006). Strong European patriarchal traditions wiped out most of these values and instilled paternalism, which still strongly exists in Aboriginal communities today. Through the increased recognition of Aboriginal health and healing practices and Aboriginal operated community health services, Aboriginal women are helping each other to renew and strengthen parenting and promote healthy living.

2.4 Aboriginal Healing

The current section seeks to provide a better understanding of the centrality of Aboriginal healing to Aboriginal wellbeing and to demonstrate the importance of its inclusion into the care plans of Aboriginal individuals, especially children and youth.

2.4.1 Concepts of Health and Healing

Aboriginal conceptions of health and healing differ widely from Western ideals, which focus on the individual's symptomatology, physical wellbeing, and are heavily weighted against medication for treatment. First Nations, Métis, and Inuit concepts of health share much diversity and commonalities in their belief systems. The shared and central tenets of wellbeing converge on mental, emotional, spiritual, and physical health, and on the importance of spirituality, family, gatherings, and ceremonies (Martin-Hill, 2003).

Many Western concepts of health run contrary to these tenets. One such concept is disability. Disability theorists state that in Western settings being disabled carries negative connotations and permanent labels that are tied to ideas of the productive citizen. The ideal citizen is economically self sufficient and contributes to society through her/his labour, while individuals who cannot work to contribute to society are constructed as burdens and drains on the nation's resources (Salmon, 2007).

Aboriginal conceptions of disability regard individuals with disabilities as gifts from the Creator where the individual is accepted and, in the context of FASD, laying blame and shame to mothers is unacceptable (Wright et. al., 2005; Fournier and Crey, 1997). In a study by Wright and colleagues, one Aboriginal mother gave her account of 'special needs':

Let's put it this way: special needs is a white term. That's your term. Special needs, if I remember correctly, are taking care of our own way, our own herbal medicines whether they worked fully or not. As I've understood it, any child that was born into a First Nations family you just always accept them no matter what, how they come at you. That's just their way and they'll develop into their own person.

In contemporary times, Aboriginal concepts of health and healing are being revived at the community level, in health authorities and health ministries as the importance of their restoration is increasingly recognized.

2.4.2 Culturally Safe Healthcare

BC's six health authorities have for the most part incorporated the concept of 'cultural competency' in their Aboriginal health strategic plans, and it means something different in each region. There is much confusion, debate, and overlap over terms such as cultural competency, sensitivity, awareness, and appropriateness. Commonly programs calling for such 'culturally aware' practices represent patronizing ideas including the belief that social distance and perceived cultural divides exist because of cultural differences, not structural inequities, between mainstream and Aboriginal groups. These beliefs represent an example of Othering² that simplistically blames barriers in healthcare provision on the 'other's' culture; therefore these barriers may be overcome by attaining some of the 'other's cultural knowledge' (Fiske and Browne, 2008).

By contrast, the concept of cultural safety seeks to go beyond artificial notions of cultural sensitivity in order to analyse how power imbalances, institutional discrimination, and the nature of colonial relationships as they apply to healthcare encounters at the structural, institutional and interpersonal level (NAHO, 2006). The term cultural safety was developed in the 1980s in New Zealand in response to the Indigenous Maori people's discontent with nursing care. This led to a new theory of culturally safe healthcare that championed Maori self-determination and de-colonization (NAHO, Fact Sheet: Cultural Safety, 2006). Cultural safety has also been adopted in Aboriginal health circles in Canada because it is explicitly cognizant of post-colonial realities and champions Indigenous approaches to wellbeing, thus it is the preferred concept in this study.

² Othering is a way of defining and securing one's own positive identity through the stigmatization of an 'other'. Whatever the markers of social differentiation that shape the meaning of 'us' and 'them', whether they are racial, geographic, ethnic, economic or ideological, there is always the danger that they will become the basis for self-affirmation that depends upon the denigration of the other group. (University of Texas, 2010).

On the micro level, culturally safe healthcare establishes trust between healthcare provider and patient while validating the individual's lived experiences and history on an interpersonal level. On the macro level it includes, the inclusion of Aboriginal people in high-level decision-making processes in healthcare settings and policy development (NAHO, 2006). Culturally safe healthcare and policy making demand that the healthcare practitioner and policy maker need to be aware of and reflect on their subject positions in the context of colonial, economic, and political processes that have undermined generations of Aboriginal peoples (Fiske and Browne, 2008). If practitioners and policy makers do not take it upon themselves to self-reflect and thereby leave out Aboriginal stakeholders from meaningful governance and control Aboriginal health services, structural health inequities will continue to persist.

Goals of cultural safety for Aboriginal children and youth in care entail reconnecting them to their particular nation and its traditions and customs in order to instill a positive sense of identity and belonging to a community. This goal is quite challenging if the home nation is not identified or if the child is of mixed ancestry and information on biological relatives is unknown. In some cases, the child may not want to recognize or associate with the Aboriginal community for various reasons. At a FASD conference at Douglas College in October 2009, one Aboriginal educator from an FASD school program in BC noted at a workshop how some Aboriginal students equated FASD with *being* Aboriginal. However, they began to disconnect their condition from their ethnicity as they became open in learning about Aboriginal heritage through activities such as healing circles with local Elders.

As the results of this study will show, children, youth and birth mothers who have positive connections to their heritage find most strength in their teachings and beliefs for wellbeing and healing. The application of cultural safety in this study reveals many important insights among them the experiences of birth mothers and child welfare agencies and community readiness for diagnostic services. These and other findings stress the inclusion of Aboriginal experiences and approaches in design and implementation of intervention initiatives.

3: Background: Status Quo Policy in BC

The purpose of the current section is to review the programs and services that the participants in this study accessed. Discrepancies between the original intent of the policy and how it translates into reality will become apparent.

3.1 Diagnostic Services, Key Workers, and Educational Supports

Multidisciplinary assessment teams exist within each of BC's health authorities. In order to access assessments, referrals to the teams must be made through a pediatrician, psychologist or child psychiatrist. The maze like process of diagnostic services, referrals, school supports have recently become better coordinated through the aid of the key worker program. The purpose of the key worker program is to reduce the stress levels for families and help them navigate through channels of service delivery and eligibility requirements. A recent evaluation of the key worker program revealed high satisfaction among families and the suggestion that the program be extended for youths over 19 years of age (Hume et al., 2008).

The need to build better relationships between key workers, parents, and school administrators has also been recognized. Yet, this collaboration is promoted in districts where FASD educational supports are more developed, rather than in areas where such supports are fractured and inadequate. In BC, four FASD specific school programs exist in Vancouver, Surrey, Port Alberni and Prince George. These programs hold long waiting lists and limited space for between 10 to 20 students, which means that the majority of students with FASD receive their education in the regular school system (Crawford, 2008).

The Ministry of Education designates FASD as a special need under the category of 'Chronic Health Impairment' (Ministry of Education, Manual of Policies, Procedures, and Guidelines, Appendix H). This allows school districts to apply for up to \$16 000 in additional special needs funding through the Ministry in order to meet the needs of the student. The Ministry of Education has also invested in FASD training for teachers through the Provincial Outreach for Students with FASD (POPFASD) program. Overall, the Ministry of Education has taken significant steps towards ensuring meaningful education for children and youth with FASD, but as the results of the research will reveal, there is much room for improvement.

3.2 Community Living BC

CLBC is the crown agency under the Ministry of Housing and Social Development (MHSD) that provides support services such as housing and day programs for adults with developmental conditions. In order to qualify for CLBC services, families must provide CLBC with diagnostic assessments that meet “Diagnostic Criteria for Mental Retardation” as set out by the fourth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM IV) (Eligibility for CLBC Supports and Services, CLBC, 2009). This designation means that the individual’s IQ must be below 70. The majority of individuals with FASD cannot qualify because their IQ is above 70, yet they still require substantial support and supervision.

For years, this CLBC policy caused a huge gap in services for adults with FASD. In 2006, CLBC was sued by a family that was rejected CLBC services because their son, Neil Fahlman, failed to meet the IQ under 70 criterion. Fahlman’s adoptive mother sued and won in the Supreme Court of BC. Justice E.G Chamberlist ruled that CLBC had overstepped its authority because the IQ criteria was not in the *Community Living Authority Act*, but should have been because eligibility for community living services must be legislated. The court found that CLBC was confusing policy with legislation. The judge stated that CLBC failed to pay attention to the merits of Fahlman’s case, which demonstrated Fahlman could not live independently and required supervision as an adult (Justice Chamberlist, 2006).

In response, the MHSD on October 31, 2009 announced regulatory changes with respect to improved eligibility criteria to serve individuals with an FASD diagnosis and who have an adaptive functioning³ score that is three standard deviations below the mean. The amendment took effect on January 31, 2010. Since the court case, CLBC has quietly amended the *Community Living Authority Act* to include the IQ under 70 criterion as part of the definition of a “developmental disability” in addition to the definition of “impaired adaptive functioning” according to the DSM IV (Community Living Eligibility Criteria Remains the Same, MHSD, 2009).

CLBC will receive \$23.2 million dollars over the next three years to serve this new group and they estimate that 170 adults will be using CLBC services by the end of the 2010/11 fiscal year (Improvements to CLBC’s Eligibility Criteria, 2009). Given the prevalence rate of FASD at 9 per 1000 live births, CLBC’s plan to serve 170 people affected by FASD and a host of other

³ Adaptive functioning means the relative ability of someone to communicate, employ daily living skills, socialize and use motor skills, and it is generally correlated with the expected skills at a given age (Flanagan and Kaufman, 2004).

developmental conditions, notably autism, is negligible and superficial. As this study's interviews will demonstrate, many key informants are critical of CLBC's eligibility criteria and feel that CLBC will be overwhelmed by requests and that they are raising false hopes among families.

4: Methodology

4.1 Qualitative Research Design

The complexity and context of the research question, *how effective are existing FASD programs and services for Aboriginal children and youth with FASD in BC?*, is best investigated within qualitative research design. The research needs to perform in depth analysis of life experiences, history and interaction between communities, schools, and government. Qualitative methods complement the research in question as it is highly context driven and seeks to do more than replicate the status quo (Bishop, 2007). Qualitative research that is informed by critical theories, as is the case in this study, strives to expose oppressive experiences and power differentials beginning first between researcher and the researched in an exercise of reflexivity (Kincheloe and McLaren, 2002).

4.1.1 Reflexivity

Reflexivity in qualitative research requires the researcher to engage in self-criticism and highlight her/his subjectivity, specifically the ideological frames of reference that she/he uses to make sense of the world (Kincheloe and McLaren, 2002). There are dangers associated with writing about different groups, especially historically disadvantaged groups, where the postcolonial theoretical lens can inadvertently, however well intentioned, come to solidify dominant structures and “reassert liberal values through a type of covert ethnocentrism” (Kincheloe and McLaren, 2002, p. 117).

In writing about FASD and Aboriginal children and youth, I am potentially reinforcing beliefs that FASD is only attributable to Aboriginal communities, thus adding to the stigma and racist stereotypes associated with the condition. The question that I first need to answer is my motivation for undertaking this research. Over the summer of 2009, I was puzzled and concerned by statistics shown in the Pathways for Health and Healing report from the Provincial Health Officer (2007), which indicated a high usage of psychostimulants among Aboriginal children compared to their non-Aboriginal counterparts. After reading some academic papers and speaking

with Aboriginal health providers, it became apparent that medications are used to treat ADHD as well as FASD.

Further readings and conversations with healthcare providers indicated risk factors for prenatal alcohol exposure include lower education levels, custody changes, lower socioeconomic status, reduced access to prenatal and postnatal care and services, inadequate nutrition and a poor developmental environment all of which disproportionately impact Aboriginal communities. Given these findings, I decided to narrow the scope of the research question on the Aboriginal subpopulation. Moreover, other research that examines the effectiveness of current FASD intervention measures rarely account for how poverty, racism, gender discrimination and social isolation inform communities' experiences with FASD, which is what this research has strived to do.

Reflexivity also requires the researcher to state positioning of class, gender, ethnicity, sex, etc., and how it influences the interpretation of data (Mauthner and Doucet, 2003). My relative position to this research and how it influenced my interpretation of data is informed by my childhood in Canada. In 1992, I was living in Athens with my mother and brother at which point a Christian Missionary church in Ontario sponsored us as refugees, originally from Iran. The church sought to support and convert us to Christianity and into a culture supposedly superior than my own.

This experience has made me empathetic to communities whose histories and present have been marked by forced conversion and racism, and it has influenced me to investigate subject matters in research related to social justice. Furthermore, my exposure to Indigenous literature motivated me to interpret and analyze the data through a filter of empowerment and agency that purposefully focuses on the resiliency and strength of Aboriginal children, youth, and their parents/caregivers. Throughout the study, I have taken measures to counteract the possibility that I may be perpetuating harmful stereotypes by exposing the factors that contribute to these misguided beliefs in the public imagination. Furthermore, by adopting the goal of social justice, the research commits itself to knowledge transfer so that the research findings are disseminated to policy arenas, health authorities, health care professionals, child and family services, foster and adoptive families etc.

My academic discipline and institutional setting in policy studies has also influenced my data analysis (Mauthner and Doucet, 2003). I used policy analysis criteria such as efficiency, effectiveness and equity, but also added the criterion of cultural safety given the centrality of this

concept to the research and the theoretical lens of the study. Therefore, I adapted tools of policy analysis to best meet the goal of the study.

4.2 Data Collection

The research involved 27 semi structured interviews and one focus group consisting of three First Nations Elders. I made a conscious effort to recruit as many Aboriginal birth families as possible, however given the highly stigmatized nature of the subject matter that was not always possible. Key informants in the study included individuals who work as FASD researchers, key workers, educators, assessment in take workers, youth workers, ministry representatives, advocates and medical professionals (n=14). Several key informants were also parents or caregivers. Interviews with parents and caregivers included birth mothers, foster, and adoptive parents of Aboriginal children, youth and adults located all across BC (n=13). A benefit for the research was that the majority of parents cared for multiple Aboriginal children, which provided extensive insight into their children's lives at various stages in life. The focus group with the Elders (n=3) consisted of two grandparents of an Aboriginal youth and the adoptive father of an Aboriginal adult. All the interviews were recorded and transcribed.⁴

Participant involvement was solicited through advertisements on FASD related websites, email list serves, and through the help of key workers who forwarded the informed consent forms to the appropriate families on their caseloads. I acquired key workers' public contact information through the MCFD website. Interviews were conducted in person and over the phone depending on the participant's location. For the interview schedules please see Appendix A. Parents, caregivers, and Elders received \$20 as an honorarium for their time. The SFU Research Ethics Board approved the research protocol and informed consent was obtained prior to each interview.

4.3 Data Analysis

The research employs methods of thematic analysis where by induction themes are extracted from the data. Background literature review also informed the clustering of themes. The data was compared and contrasted among all participants' contributions, and triangulation was done wherever possible by comparing findings to other data sources like evaluation reports and ministry websites. The findings were further validated through informal research avenues that included my involvement in a two day FASD conference in October 2009, which had multiple

⁴ Except for one participant who preferred their comments to remain off record.

workshops and presentations by key informants and panels of parents/caregivers. I had the opportunity to participate in a parent support group, a FASD adult day program in Vancouver, an Elders Circle on FASD, and a FASD school program. These informal opportunities allowed me to confirm findings from the interviews and to receive a well-rounded account of families' experiences with FASD.

4.4 Limitations

The research's first limitation is that it addresses a wide and complex policy problem that crosses multiple systems such as infant health, special needs education, diagnostic services, adult supports etc.; therefore the scope of the research and sample size does not allow for full saturation of findings. The sample size of 30 participants allows for the research to grasp the most pressing shortfalls of existing policy, but further investigation would be needed to uncover dynamics at a more micro level, for example focusing on policy responses *only* within the school system.

Interviewing concluded when the central themes were identified in order to inform meaningful recommendations to policy and practice. Another limitation is the study's non-random sample and sample size that does not allow for generalizability of the results. Yet, the goal of the research was not to generalize results, but to capture the daily struggles and successes among families dealing with FASD, which provides nuanced and candid insight into their lives.

5: Results

There were five central themes that emerged from the interviews: first, the inconsistency of diagnostic services for those under 19 years of age, second, challenges with the education system, third, inadequate adult programs and services, fourth, unequal funding between foster, adoptive, and birth families, and lastly, the importance of the continuing healing of Aboriginal communities from intergenerational trauma. Two sub-themes emerged: involvement with the criminal justice system that is discussed within all themes, and the prevalence of mental health concerns, which is intrinsically tied to the theme of intergenerational trauma. Involvement with the juvenile justice system and the development of mental health problems as a corollary of FASD, reaffirms other research findings on FASD comorbidity and negative life trajectories.

5.1 Inconsistent Assessments and Diagnoses

Assessments and diagnosis of FASD were viewed as paramount by all parents because a diagnosis is the prerequisite to school supports, special education programs and adult disability support, such as PWD allowances. However, access to assessments revealed to be variable across the province for three central reasons: first, lengthily waitlists, second, the rural urban divide, and third, differential funding between health authorities.

The average time parents waited for a diagnosis was two to three years, which undermines the purpose of early intervention. Other parents only received early diagnoses and secondary assessments as their child's condition evolved. Moreover, some areas repositioned children and youth on the list according to whose needs were most pressing. Secondary assessments normally occurred out of another avenue such as the criminal justice system or through mental health, but the rule is one assessment per person.

Key informants explained that, ideally, children should be assessed during preschool years, then again during elementary and middle school, and through transitional years nearing the end of high school. Several parents were in a rush to get their child on waiting lists before their child turned 19 years old. Parents anxiously sought reassessments because access to certain adult services would prove to be difficult if their child's assessments were not current. One parent

expressed this worry and highlighted the lengths that other parents go to in order to secure diagnoses.

When he turns 19 and I am advocating for him to get services, you honestly think they are going to take an assessment from when he was 10? They are going to say 'why have you only got him one assessment?', what am I supposed to say that 'we live in a rural community and we can get one, in one life time'?

I have talked to some foster parents that have very disruptive children and they have been able to secure assessments and services, but I mean...having to take your child off meds for 3 weeks prior to the assessments so that they present as badly as possible so that you can access services...parents should not have to do that, it is a shame.

Before multidisciplinary assessment teams were expanded to each health authority in BC, the rural and urban divide used to be a major access barrier to diagnostic services. However, access to specialists by communities in the north, on the island, and especially on remote reserves remained to be problematic because specialists only made a couple yearly visits to the community. None of the participants noted the use of telehealth services by assessment teams in order to access hard to reach areas. One in take worker for an assessment team in the north explained that they fell behind a year in assessments because their psychologist had to take a medical leave and no replacement could be found. This particular psychologist was funded to make three trips a year into the community for a week at a time, which meant a lot of planning and coordinating to get as many children seen as possible.

Participants noted that families still had to drive for hours to reach certain assessment teams in the north, interior, and on the island. Yet depending on the band and health authority, reimbursement for travel and lodging costs were possible in certain areas. Assessments and diagnoses are rarely done on reserves and the federal health nurse is not authorized to make referrals to assessment teams. One Aboriginal health director stressed the urgency to shorten the waitlists and offered her idea of what could be done to improve assessment rates among Aboriginal children and youth on reserves:

We hope to develop a plan, we call it a blitz, in the near future where we go in as a team and do these assessments and park ourselves there for a week until we are all caught up. This should never be an obstacle in getting an assessment, the obstacle of money, they need to adopt Jordan's Principle⁵ into all of this work...

⁵ Jordan's principle is a child first principle to resolving jurisdictional disputes within and between federal and provincial/territorial governments. It applies to all government services available to children, youth and their families (2008/09 Annual Service Plan Report, MCFD, 2009).

Our children stay on the list forever and ever and by the time it comes up they have long missed their opportunities for intervention.

The relationship between reserves and child development centres, key workers, child welfare agencies and assessment teams played an important role in facilitating access to diagnoses. These relationships varied, but the issue of trust was said to be crucial because there is some fear of child apprehension among Aboriginal mothers. Communities that had established trust through years of work together had smoother processes in assessments, and a common understanding that birth family union was a priority for all.

One northern child development centre had exceptionally positive relationships with the surrounding reserve communities. The child development workers visited the communities regularly in order to share FASD education and general information on child development. The intake worker from this team mentioned that they had a First Nations community member guide them on how to approach communities in a less intrusive and culturally safe manner.

In addition to waitlists and the rural urban divide, the factor of differential funding to health authorities also accounted for variability in accessing assessments. The Provincial Health Services Authority allocates money to Interior, Northern, Vancouver Island, Vancouver Coastal and Fraser health authorities for the assessment of complex developmental behavioural conditions (CDBC), and the administrators of the multidisciplinary teams decide what portion of the assessments will be earmarked for FASD and other CDBC conditions. Differences in funding allocations thus caused a lot of the variability in access. Since the population counts of Vancouver Coastal and Fraser Health authorities are higher, they received more money, thus more assessments.

In order to control costs, assessments were aimed at those children and youth with the most pressing needs, therefore the eligibility criteria for the province requires that the child or youth have functioning scores in the bottom 5th percentile. This criteria was cited as a barrier in qualifying for assessments because one's interpretation of what counts as the bottom 5th percentile may differ from another's opinion. Key informants and parents felt this requirement made qualifying for assessments, to a certain extent, arbitrary and highly dependent on confirmation of maternal alcohol exposure. One assessment intake worker explained the eligibility procedures and her critiques of the process:

The referral form has 4 areas in which the child needs to have 3 hits in the 4 areas in order to technically meet criteria. So the first three areas are developmental and learning, mental health and behaviour, and adaptive skills.

If the child is an FASD referral and you've got some confirmation that there was prenatal exposure to alcohol or I can do some digging myself and if I find substantial indication the child was exposed, they get a hit for bio marker and then they need to have two hits in the three areas that I just mentioned. In those areas, they need to be, technically, functioning in the lower 5th percentile in any two of those areas and if that is the case, then they meet criteria.

It sounds sort of black and white but it isn't because who decides what is the lower 5th percentile? We get doctors sending things saying, 'check off yes, the child is functioning in the lower 5th percentile', but you speak with the teacher and they will say 'oh he is doing great' and then you speak with the parent and they say something else, so is that valid?

Every region is different and we here at (the assessment team) err on the side of seeing kids rather than not, which means we have a longer than average wait list, um, but we don't want to miss kids, and I know some regions do it differently, like if there is no full confirmation of exposure they don't take them and others won't see the kids until they are seven. We see kids as early as 4...

Even though participants understood the importance of diagnoses, they also stated that it would be highly unlikely and unaffordable to provide diagnoses to everyone. Nevertheless, many felt that a system for adult diagnoses is missing in the province. Some raised moral and ethical considerations in the right for someone to understand their permanent condition and felt that the fact that adults cannot receive publicly funded diagnoses is unjust. One developmental paediatrician who performs FASD assessments stated:

We have a population of people who have brain injury, if those people had brain injury due to a motor vehicle accident we would respond appropriately, but often we respond, as a society, inappropriately and I think that is a sad reflection on society's moral ambivalence towards FASD because at the end of the day the lips have opened and...you pick up the glass and you drink.

Other than a pilot program in Victoria that conducted adult female assessments up until March 2010, adult FASD diagnostic services are not publicly provided in BC.

5.2 Challenges with the Education System

In 2007, families had a major triumph when the Ministry of Education officially designated FASD as a special needs category under 'Chronic Health Impairment', thus making them eligible for funding up to \$16 000 per school year. As evidenced by the interviews, it is actually rare that a diagnosed child or youth qualifies for the full amount. If they do qualify for

the full amount, they are entitled to two and a half to three hours of individualized support per day and that is usually in the form of an Education Assistant.

One key worker in the north explained the grey area surrounding qualification for Chronic Health:

The school reps will say your child qualified for 2 hours and I say how come they qualify for 2 hours when they meet criteria for 2.5 and they will say we still need to pay for the EA's half hour lunch break...it goes into the natty gritty of the contract. So yes, it definitely depends on the school, how the ministry sees that money, how the principal feels and where the child's needs are.

The above scenario is by far the ideal. Out of all the caregiver interviews only three acquired one on one time with an Education Assistant. One school representative tried to explain the misunderstandings about 'Chronic Health' funds:

The question the Ministry of Education asks is 'how does the condition impact learning and behaviour?', but if there is no evidence it is impacting learning and behaviour, then why would you give the kid that can walk a wheelchair, so I think the parents get confused...every school district is different...

Five parents resorted to home schooling or placing their children in private schools out of frustration with the public system. They felt that other arrangements provided their child with 24/7 supervision and help to improve their academic performance. Some parents recognized the disconnection between the school's perception of their child's academic progression and scores on school based psycho-educational tests. One parent revealed the difference between school expectations and the scores received on school based assessments:

The teacher who worked with him sometimes at the learning centre said he could do more than my son actually could, he was confident that he would complete school. When his psycho educational assessment was done, we found he was at the grade 2 level and his writing was at the grade 5 level and he is 15 years old, so I don't know what happened. He fell through the cracks, he really did.

Parents believed that the school staff did not understand the severity of FASD's impact on learning. Key informants explained that the invisibility of this condition leads to the child or youth to be labelled as behaviourally disruptive rather than understanding that the difficult behaviour is linked to cognitive deficits associated with FASD. In trying to control behavioural symptoms, several parents received ultimatums from schools regarding the medication of their children and being able to continue at the schools. Key informants explained that medication should be used as a last resort rather than the first line of action.

Even with a full diagnosis, parents described that educators were still under the impression that their child could try ‘harder’ and seldom did they accept the possibility that the child simply ‘can’t’. One mother expressed her frustrations with the expectations placed on her daughter:

My daughter has birth records from Sunny Hill that show her prenatal exposure to cocaine, heroine, methadone, and alcohol...but her report card will say things like ‘when she starts to pay more attention and becomes more responsible, then she will likely improve’ and I am saying that is not acceptable...we need to be doing the environmental supports...and that resulted her in having a desk out in the hallway. That was a little frustrating.

The importance of environmental supports was raised several times by the participants. The FASD literature is rife with recommendations for classroom adjustments to limit sensory stimulus to the bare minimum. However, FASD educators explained that unless you are in a FASD specific program, the needs of the entire classroom usually prevail. One parent explained the irony of her son receiving a Dogwood diploma in prison rather than in school due to the prison’s environment:

There was a teacher for 3 people and it was absolutely quiet, it was a dull setting, no bright colours and he could concentrate and just whipped through the work.

Some FASD educators believed that the kind of close attention and environmental supports required were best provided within FASD school programs, while others believed that mainstream schools could better adapt to meet needs.

5.2.1 FASD school programs and Mainstream schools

None of the caregivers interviewed had their children or youth enrolled in any of the FASD specific education programs in BC. Most key informants believed that the main goal should not be in segregating the children, but in appropriate integration into regular classrooms. Some said a hybrid model is better where children are integrated back into the classroom for certain activities or if their needs outgrow the program. One educator and youth worker in a FASD school program explained:

Teacher: We had a student here last here for 2 and half months and then transitioned over a period of time into the regular high school. She still has her ups and downs.

The educators in this program explained that because of the dysmaturity associated with FASD, many of their students remain developmentally young and would not fit in a high school environment. Regular high schools were said to be too challenging and marked by constant bullying and exclusion.

Teacher: I think the major strength of our program is that kids are safe. They are in a smaller contained area, which just limits the amount of info that is going into them so they can have clear thoughts...and there is the understanding that everyone is going through the same thing, so there is that camaraderie.

The school administrators of this program had done previous research on successful FASD school models before initiating the program. Its current success has been documented in a recent best practice report for BC (Crawford, 2008). During the time I spent at this program, I saw how well the daily schedule fit with the abilities of the students. The feedback from the parents to the administrators has been extremely positive and they have advocated expanding the program in order to include new components such as an employment skills program.

The majority of the students are First Nations so the program includes regular Aboriginal cultural lessons where a member of the local Aboriginal community leads field trips and teaches the students about cultural activities and traditions. The educators of the program explained that most of the students were in foster and group homes and were vulnerable to substance abuse and mental health issues. Yet, the small class size and the presence of a child youth worker allowed for closer supervision and support of the students than in regular classrooms. One particular student, who was aging out of the program, had written a letter to the district principal in order to allow him to remain in the program. His letter outlined his fears of being bullied and rejected again in the regular school system and how he felt he had grown as a person and academically in the program.

The participants that advocated for pull out programs believed that mainstream schools introduce FASD affected children and youth to negative peer groups, exacerbate behavioural problems and expose them to violence, drugs and alcohol. One parent recounted how her 17 year-old daughter was at one point being recruited for the sex trade before she, her husband and community workers stepped in to protect her. The vulnerability of the Aboriginal children and youth was a recurrent theme in the interviews, which for some parents made pull out school programs worthwhile.

The general idea discussed is that every child is at a different ability level and will require different accommodations, so no size fits all approach is likely to work. However, all participants

agreed that extra precaution should be taken at schools and at home to keep the Aboriginal children and youth safe, especially those living in unstable circumstances due to multiple placements in foster homes. The continuity of supervision and supports was also seen as a necessity through to the adult years.

5.3 Inadequate Adult Services

One of the significant sources of anxiety and fear for parents/caregivers was the dismal prospects of acquiring adult support services, whether it be supportive housing, income assistance, mental health and/or employment services. Services like the key worker program, child and youth mental health services, educational supports, foster payments and adoptive assistance payments are cut off at the 19th year.

Out of all the families who had children 19 years and over, only one female was fully supported under CLBC, but the majority continued to rely heavily on their families. The others included one who is living in a FASD interdependent housing pilot on the island, another is living alone in the second home of their family, while one lives in room and board. Another adult remains with their biological grandparents, three adults are on and off the streets or couch surfing and one remains with their Aboriginal adoptive family. Another one lives with their biological mother, one lives with their adoptive mother, while another lives with their partner, and two have passed way.

Depending on the resources of the family, some parents continued to financially support their children while others provided partial monetary support because they feared that the money might be used for drugs and alcohol. Instead of direct financial support, parents and relatives were involved in daily tasks like transportation to doctors' appointments, grocery shopping, money management, etc. The majority of the parents/caregivers interviewed were not the biological parents of the children, and many believed the child welfare system abandoned their child's needs at 19. As one mother explained:

I would be in the hospital myself if my key worker was not there and the thought of that support dropping off at 19 is terrifying... We still do not have any respite. That is a criminal act. That is going to cost the system a whole lot because of my health, my husband's health.

An intake worker from one of the assessment teams echoed similar concerns about the 19th year cut off and shared her ideas of what a better transition into adulthood would entail:

How can you start transitioning at 16 when they are still kids for Pete's sake, but if you started at 19 to 24, you gradually set them up with housing, employment, skills to be self-sufficient. I think it is very short sighted to close files at 19 and expect these kids not to come back and cost the system more money in the long run.

Several key informants spoke of Germany's protocol which allows flexibility for those with special needs and mental health challenges to remain in the care system until their mid twenties. The prominent FASD advocate and physician in Germany, Dr. Hans-Ludwig Sphor has called for mandatory early diagnosis, installation of fostering or adoption, intensive psychosocial care, appropriate schooling, occupational counselling, and supportive care in adulthood (Sphor and Steinhausen 2008). Research demonstrates that the implementation of such measures can successfully mitigate the worst outcomes associated with this condition such as the development of serious mental illness and premature death (Streissguth et al., 1996; Baer et al., 2003; Sphor and Steinhausen, 2008).

Not all participants agreed that additional supportive measures or prolonged transitioning into adulthood were required. A representative from the MHSD in BC highlighted the need to improve transition planning for youth with special needs where it would start around 14 years of age. The representative stated that a cross ministry transition protocol has been signed by six ministries to improve access to existing resources and services and improve the transition for youths. The representative indicated that programs and services should not become entitlements, but tools to help FASD youths be independent and valued members of society.

Many participants acknowledged the reality that independence may never be realized, but rather *interdependence* is a more accurate expectation. One parent who had adopted and fostered several Aboriginal children and youth argued that expectations of independence were unreasonable:

...unsupported independence is a prescription for failure and disaster. My 38 year old daughter, every time she tried to live on her own she failed, she moved back in 5 years ago and stayed here ever since, she was 92 pounds, she was so ill, she is doing well now. If somebody else is taking care of the nuts and bolts, the pieces that hold her together, she functions well, remove it and she falls apart in a week.

Existing adult services such as day programs were seldom accessed because of ineligibility or long waitlists. Aboriginal youth without a diagnosis were sometimes able to acquire income assistance, but because it was insufficient, they received supplementary help from their families. There are special needs employment programs and a couple families made use of

them, but the difficulty of sustaining employment was a reoccurring problem. This was especially problematic when the adult hid their condition from their employer or when the employer did not know about FASD. One parent recounts her son's difficulties in securing employment:

He is now 20 and on his own, and he is couch surfing in town, driving a car without a license, he thinks he is doing well, but he is not. He lasts only a couple of days at jobs, somebody will tell him to do something and he will tell them to f-off.

5.3.1 Ineligibility for CLBC

Families explained that they were ineligible for CLBC supports because CLBC's definition of a developmental disability remains to be an IQ score below 70. The majority of those with FASD have higher IQs, but this is not indicative of their functioning abilities. One FASD researcher, who is also an adoptive parent, explains the problem with placing too much emphasis on an IQ score:

I have two daughters that are mentally handicapped, one's IQ is 54 and the other is 44. Now, they qualify for everything, but let me tell you they are my two most functional kids. Their adaptive functioning is way higher than their IQ.

Now, the ones that are here in the home, there is not a hope, their IQs are over 70, major problems with everything 'cause their adaptive functioning is way lower. Usually IQ and adaptive functioning for people with disability are normally on par with each other, but this is the one condition with the huge gap.

Key informants believed that CLBC eligibility criteria are excessively restrictive and a means to serve only those most severely affected because the government cannot afford to support everyone. Key informants felt that the new and supposedly improved requirements for FASD would exclude the majority of applicants because they require adaptive functioning scores to be three standard deviations below the mean.

Upon speaking with a CLBC representative, the provisions to be provided by CLBC as of January 31, 2010 will be based on individual needs, which means that there are no preset guarantees of what will be offered to the estimated 170 adults who will access services. In January 2010, CLBC held a focus group with parents of FASD affected youth to determine what supports were most needed. Currently, CLBC is seeking bidders on contracts to provide personalized behaviour supports. CLBC claims that personalized supports may include social, financial, employment, respite and supportive housing.

5.3.2 Absence of Supportive Housing

Many Aboriginal youths upon turning 19 ended up in precarious living situations with minimal supervision. All the parents interviewed stated that their homes were open anytime and many youths and adults were often in and out of their parents' home while simultaneously dealing with mental health issues and substance abuse problems. The two parents in the study whose children had passed away explained that the deaths were preventable if they had been properly supervised. The first death was caused by a car accident, and the other was a suicide. The mother of the adult in the car accident explained that it was caused by a seizure while driving because her son forgot to take his medications:

He came for a visit shortly before his death and I asked him do you want me to refill your prescription and he said he didn't need it anymore. When they did a blood test, there was no trace of the meds in his blood stream. The bottle was empty in his apartment and had not been filled for months. He did not understand that the reason why he had not had any seizures for 2 years is because he was taking his meds.

The adoptive mother of the adult who died because of suicide explains that, at least one of the positive things that came out of the suicide was that, for the first in Canada, FASD was put in the Coroner's records as a secondary cause of suicide. His mother explained:

...when life got dull, he faked a suicide attempt and it was a real problem... So one day he set up for one of his attempts when his cousin was coming over. She was late and the damn thing worked. The Coroner said it was the closest thing to an accident a suicide could ever be.

You know what would have saved him? Some kind of community housing situation...that would have worked perfect for him, he would have had someone to go to when he was strung out, someone to make sure he got to his job everyday in good order, somebody to make sure that he did not have more responsibility that he could handle.

Parent and key informants explained that FASD assessments regularly recommend youths to remain in supervised housing situations throughout adulthood, yet this recommendation was not always feasible. Moreover, aging foster, adoptive, and birth parents could not provide continuous support, yet they still wanted the peace of mind that their children were safe. One senior adoptive mother states why she paid out of pocket for the diagnosis of her 38-year-old daughter:

I did it for me, so I could relax because I am getting older and how much can you carry on doing. They need to get those kids into some kind of help because you can't go on forever...

Parents did not have expectations that their children would acquire higher education and well paying jobs, but what mattered the most was that they achieved happy, safe, and healthy lifestyles. Some adoptive parents were fearful for their children's futures and that they would end up in the same position as their birth parents, who had either passed away or were homeless while struggling with addictions.

5.4 Unequal Funding between Foster, Adoptive, and Birth Families

Key informants and parents felt that the allotment of money between foster, adoptive, and birth parents was unjustified where the majority of supports existed for foster families. One single birth mother on reserve explained how she struggled to keep the little respite care that she managed to advocate for while challenging discriminatory attitudes of MCFD representatives:

...if I got this respite two times a week for a couple of hours, it gives me time to go to parenting groups and go to my own personal counsellor and relax...I have been waiting patiently...and they are already wanting to cut it off...I think I deserve this help, with this new social worker and the supervisor (MCFD), the way they speak to me, they rather apprehend him than give me help...

Another birth mother also noted the disproportionate supports provided for the foster system versus birth families:

Why do we spend so much money to train foster parents, why do we pay foster parents to raise these incredibly difficult children, why do we not provide more funding to the parents so that they can be a full time caregiver to their children?

One key worker noted similar issues with funding provided to children in the home of relatives and the need to support grandparent caregivers:

...the (Aboriginal) grandparent was getting \$350 for the kid and basically no supports, low income, the grandparent was fragile and finally she said I can't do this anymore because the child was making some bad choices. So we go from \$350 a month to a hotel room with 24/7 group care, eating all meals out and the \$350 they were giving the grandparent was spend in half a day in foster care...

Some adoptive families also felt unsupported as they noted the high costs for such things like medication and orthodontic work for their children, which insurance from employment did not cover. Mixed adoptive and foster families strategically kept some of their children under the

foster system because they could not afford to adopt them. In terms of respite care, technically only foster parents are eligible, so the one birth mother who managed to secure the respite care was rare.

Currently, there is one pilot for respite care Queen Alexandra Centre in Victoria for those families who do not qualify. Parent burnout due to constant advocacy for their children to receive supports was a common theme in all parent interviews. The mental and emotional health of birth mothers was exceptionally strained given their simultaneous duties of sustaining their families while tending to personal struggles related to intergenerational trauma. As will be revealed in the next section, the intergenerational effects of FASD have affected Aboriginal communities, birth families, and their children in diverse ways where their progression along the road of recovery is not uniform.

5.5 Healing from Intergenerational Trauma

The link between colonization and FASD was made several times by participants. Aboriginal key informants, birth parents and the Elders spoke of the challenges associated with healing in the face of severe intergenerational trauma, and its subsequent impact on mental health. Yet, they stressed the importance of and strength received from their belief systems and culture in order to remain, and help others stay in good health.

5.5.1 Community Healing and the Legacy of Colonization

Several participants spoke of FASD in the context of colonization and compared the Aboriginal experience with other subpopulations who were colonially oppressed or subjected to torture. In doing so, they stressed several times that FASD is not exclusive to Aboriginal communities. One FASD researcher explained:

They (researchers) are looking at Italy, North America, South Africa, they are looking at all these places and the rates are staggering and they are not primarily First Nations.

It is about colonization, wherever it has occurred, you can look at the colonization in the US and which groups are marginalized, you can look at the Irish... it isn't about the colour of your skin as much as it is about colonization.

The detrimental effects of removing children from communities was said to have the most profound and negative impact on Aboriginal communities, especially on the mental,

emotional, and spiritual health of mothers. One Aboriginal parent shares the story of a grandmother:

She was four or five when she was put on a plane from a remote BC community to go to residential school and looking out the window of the plane... her mother collapsed on the dock. She was the last child in that family that was not affected by FAS because the only way mom could cope...because the joy and the spirit had been taken out of the village, the only way that mom could cope was by drinking, there was no counselling offered, these people cared about their kids, it was just so thoughtless.

The same parent explained the importance of having the community work to implement FASD structures that work for them. These structures are meant to be culturally safe rather than intrusive measures implemented from the outside:

...if the community has gotten to the place where they have got enough strength, enough cohesiveness and a sense of themselves, and say yes we have FAS, and we are going to address it, then you have a dynamo in terms of actually making progress because they are vested in their 7 generations...

Right now in...they are being funded to gain local knowledge because to get anywhere they got to drive two hours to...and then fly somewhere, even though they live in BC. They did not want outside consultation, they wanted local knowledge, the first people they spoke to in terms of learning about FAS locally just said, 'okay well just send them to us and we will diagnose them', but the community did not want to do that because the community is not ready.

Aboriginal participants explained that once a community is brought to the point where they can name and deal with their struggles, integrating local knowledge of health into the culture can allow for the knowledge to breed and sustain itself. The Elders acknowledged that there has been a profound loss of teaching in their communities; teachings among children and parents to take care of each other and exist as a cohesive unit. They believed that education on reserves for parents and professionals was necessary in order to revive teachings:

Elder 1: There are a lot of teachings in all those things that happened in a potlatch, so much teaching that a lot of people today do not even understand a lot of it...There has to be something done about...even coaching and parenting skills because people are so out of touch, even our own people on reserve feel that way.

Elder 2: People like us, people who want to learn about FAS, we go out there and talk about it and especially prevention with the moms. On reserves, they should have kids assessed right away, the families need to face it. I think a lot it is that they need to quit the provincial and federal noise about, 'you don't know how to parent because you were in residential school', nobody taught them anything, just reading, writing, go to school, go to church, take a bath, scrub the floor...

The importance of education on reserve communities and the need to invest in strengthening extended family networks was repeated several times by other participants. Moreover, several individuals found empowerment through Aboriginal teachings and belief systems in order to overcome personal struggles.

5.5.2 Individual Healing Journeys

Not all FASD affected children, youth, and adults were exposed to their Aboriginal roots. Some adoptive and foster parents did not take measures to reconnect their children for a variety of reasons such as lack of familiarity with their children's nation, fear that their child would be taken by the birth family, or because they did not see it as a priority. Other parents purposefully sought out Aboriginal communities to reintroduce their children to their particular First Nations culture.

Some instances of reunion with birth families were positive where the child reconnected with siblings and relatives, while other experiences were not so beneficial. A couple of instances of romantic attraction between newly reunited siblings were reported, which presented certain challenges for adoptive and birth families. In other instances, adopted Aboriginal children and youth were left in emotionally difficult situations where they simultaneously resisted and sought reconnection with their birth families.

During the Elders Circle focus group, one grandmother explained how when her grandson reconnected with his birth mother, he was told by his mother that he was not wanted. In response another Elder explained the importance that this youth understand how his mother had also experienced trauma in her life, which had consequently affected her mental health:

He needs to be told that it was not his mom's fault, it is nobody's fault. You have to understand your mother, part of her was affected by it, the post traumatic stress disorder, so that is a huge piece to understand that it is all connected to the problem that we have today...

This particular youth has recovered from alcoholism through the help of his grandparents and Alcoholics Anonymous (AA). He also regularly attended the Aboriginal FASD adult day program in Vancouver, and on one of my visits to the program, he received a certificate for successful completion of the treatment program. Another youth who was adopted into a non-Aboriginal home also recovered from depression and alcoholism through the support of his family and AA.

One birth mother's healing journey captured the tragedy that is inherent in intergenerational trauma and the healing that needs to occur for both mother and the FASD affected child:

...so he came home when he was 4, he had not been home that long and basically what happened was that he was getting sexually abused at the day care, so that was really hard to deal with and being native, I was affected by residential schools because it takes its time to get it out of the family...

So I did my best to deal with him, he would get severely angry, kicking and scratching, and what I would do is hold on to him and after a while he would just cry and cry and of course I would cry with him and he would then start putting words to his anger. So the other hard part was that it was triggering that type of abuse in my life that I persevered, so it was like a double whammy to try and deal with his issues while I was dealing with my own sexual abuse (begins to cry)...But we made it through... they saw him for a few months (therapy), the outbursts were very minimal, and they said, 'now it is time for you, you need to also go through some therapy for yourself'...

Despite the sadness of some of the participants' stories, it was encouraging to see the resilience of the birth mothers. One birth mother explained how she drew strength from her culture to support her son:

...so before we had diagnoses, what did we have? We had culture and our Elders' teachings and our Elders teach us that we do not have to give a name, but we need to treat it, so we need to find a way to stop the behaviour and it is not through yelling nor punishment and that is where we had our headstart.

As evidenced by the aforementioned discussions, mental health challenges such as post-traumatic stress disorder and depression in relation to and a consequence of intergenerational trauma became a reoccurring theme. Such challenges necessitated the provision of services like psychosocial therapy and family counselling alongside the presence of Aboriginal healing and health practices.

5.5.3 Mental Health Services

The majority of parents and key informants evaluated access to child, youth, and adult mental health services as fractured and inadequate throughout the province. Many felt that recommendations calling for intensive therapy were rarely met given the fact that mental health services were severely backlogged. The fractured nature of mental health services was demonstrated by the varied experiences of participants where some received psychologist services

through INAC while other Aboriginal children and youth could not because they did not have Indian Status.

Other parents were denied access because FASD was not a category covered under an agency's mandate while other agencies would not accept clients until they had a full FASD assessment and diagnosis. Some key workers felt their relationship with mental health services was fine while others believed mental health services needed to be further versed on the condition. They explained that existing mental health services are designed for normally developing children and youth, which can make therapy inappropriate for those who have been prenatally exposed to alcohol.

Participants believed that it was unnecessary for multidisciplinary assessment teams to re-refer to child, youth, and adult mental health services. One developmental paediatrician explained that work was performed in silos resulting in ineffective service delivery:

So we see children with mental health problems and often we identify parents with mental health problems. So paediatrics and mental health services are not allowed to communicate with adult mental health services...So there is no capacity in the system of a joined service, looking at the family, looking at the child as a member of the family...

Key informants believed that the negative mental health problems associated with FASD could be mitigated, to a certain extent, given the inclusion of environmental controls to minimize exposure to negative peer groups and harmful activities like substance abuse. One parent stated:

The little one was so satisfied with himself because he has never had the belittling at school, he never had an abusive teacher and he has never been subjected to the peer criticism and teasing...

The extent that families could shelter their children from harmful influences in life was exceptionally challenging given the fact that the Aboriginal children and youth in the study had been severely affected by traumatic childhoods and multiple foster placements. The mainstream medical community rarely related Aboriginal mental health issues to intergenerational substance abuse and trauma. Aboriginal participants believed that mainstream health services treated mental health concerns as an isolated phenomenon adding to their ineffectiveness. An FASD educator and birth parent shared the story of one adult male who was diagnosed with schizophrenia because he heard constant voices telling him that he was stupid and not good enough. The educator felt that he was wrongly diagnosed and that those voices were simply embedded in his memory from an abusive childhood and constant ridicule at school.

6: Discussion

Vast complexity and diversity exists in the lives of Aboriginal children and youth affected by FASD, thus no single approach can claim to address all their needs. Despite the fact that Canada, and in particular BC, is a leader in the design and delivery of FASD programs and diagnosis, the results of this study demonstrated that serious shortcomings persist in regards to existing policies and services. In particular, fractured continuity of care intensified the challenges and systemic barriers faced by the Aboriginal child and youth population, as they grew older.

In BC, the social determinants of health for Aboriginal children and youth with FASD remained exceptionally poor. The results revealed that they continued to live in precarious and unstable living conditions, while they had disrupted education and hindered access to health services. As they aged, their social support networks between family and relatives weakened, and were often replaced by unhealthy social relationships. Moreover, FASD informed their socially disadvantaged position, as they continued to be susceptible to addictions, poverty, the development of mental illness and criminal involvement. In addition, the underlying socio-historical context of their lives has resulted in traumatic childhoods, multiple foster placements and fractured connections to their families, culture and identity.

Despite tireless efforts and advocacy on the part of the parents in this study, their children remained vulnerable and in need of sustained support. Parents' socio economic status, educational background and extended family support networks had an important role to play in the extent to which they were able to advocate for and continue to support their children. Family income levels often determined if a parent could home school their children, purchase childcare services or provide membership in extra circular activities. These provisions were not always feasible for lower income birth families that were typically single mothers.

The single birth mothers in this study had experienced systemic discrimination while they tried to support their children and continue on personal healing journeys. FASD stigma followed them with the label of 'alcoholic', despite their sobriety. Stereotypes of the unfit Aboriginal mother and excessive surveillance of Aboriginal communities continue to exist as one of the many remnants of colonization and the relationship between the Canadian child welfare system and Aboriginal families. Under the gaze of child welfare workers, Aboriginal mothers remained

hesitant to access services out of fears of child apprehension and being further discredited as ‘bad’ mothers.

Mental illness, as a corollary of FASD and the intergenerational effect of residential schools, has left devastating effects of depression, suicidality, and other comorbid mental health problems. These severely undercut the quality of life and outcomes for Aboriginal children and youth, especially in the presence of weak mental health services in the province. Aboriginal participants emphasized that individual and community recovery from intergenerational trauma required courage and community readiness in being able to identify FASD and to respond accordingly. They stressed the importance of community cohesiveness and renewal of traditional teachings through Aboriginal led initiatives in order to protect future generations.

In response to the results and challenges identified in this study, advocates, health professionals, parents, and other stakeholders within the FASD community in BC have undertaken several measures to address the needs identified in this study. In BC, there are a variety of FASD pilot programs that strive to respond to the different facets and challenges associated with this condition.⁶ They serve as a strong foundation from which to inform policy options.

⁶ The 2007 Victoria Foundation FASD Action Funds funded the pilot programs in order to improve outcomes for children and youth with FASD (Victoria Foundation FASD Action Funds, 2007).

7: Policy Options

The policy problem that *in BC the delivery of programs and services for the FASD population remains inadequate and time bound*, means there is a multitude of possible policy options. The options developed in this study are intended to address some of the pressing concerns raised by the participants and to develop options that best entrust Aboriginal stakeholders as leaders in FASD policy reform. The Aboriginal Health Association of BC has long argued that, “among the barriers of improving health, Aboriginal British Columbians consistently have identified a lack of access to services, the lack of meaningful participation or control in how services are delivered, and the absence of working relationships with health service providers” (Aboriginal Health Association of BC, 2003). Policy is a form of power from which Aboriginal communities have historically been excluded. It may act as a tool to further sideline Aboriginal communities or it may be used as an enabling tool to promote meaningful Aboriginal governance and control of their health services (Fiske and Browne, 2008).

Therefore, the development of the options and their subsequent analysis applies the paradigm of cultural safety in order to ensure that options do not reinforce unequal social, political, and economic relationships between Aboriginal and non-Aboriginal communities. In this section, there will be five policy options suggested, including the status quo. The options are based on the information gleaned from the study’s participants and successful pilot programs in BC that were best reflective of culturally safe policy reform.

7.1 Policy 1: Status Quo

Status quo policy entails continuing with the current system of FASD intervention initiatives as outlined in chapter 3. To briefly recap, currently in BC, each health authority region provides different levels of assessments and diagnoses up to age 19, with support provided to parents in the form of the key worker program. The Ministry of Education captures FASD as a special needs under the ‘Chronic Health’ category, while CLBC provides supports to those with FASD with an IQ under 70. Beginning in February 2010, CLBC introduced new eligibility criteria for an estimated 170 adults with FASD and other developmental conditions.

7.2 Policy 2: Adult Assessments and Diagnoses

Adult assessments for women at risk of being affected by FASD were provided by a pilot clinic in Victoria up until March 2010 when it concluded. The clinic diagnosed over seventeen women, and these clinical diagnoses facilitated acquiring PWD allowances and other supports for the women and their children. The clinic worked under a multidisciplinary team model that collaborated with social workers and psychiatry. Initially, adult FASD clinics may target, like the pilot did, high-risk mothers dealing with substance abuse and mental health concerns before expanding to include others. All referrals were done in complete agreement and out of the free will of the women. Team members of the pilot hoped that it would become a sustainable service under the Vancouver Island Health Authority (VIHA).

7.3 Policy 3: Interdependent Living

White Crow Village Camp Society is a successful FASD support group that currently provides family stability support, employment, education in schools, addictions recovery support and an interdependent living pilot program. FASD affected volunteers largely support the society's activities, and the idea for the interdependent living pilot was informed by their experiences. One member explained:

We found that in between camps our staff were couch surfing or on the street, they'd be involved with substance misuse, even if they had the most supportive families who would take them in, they would still pretty much be couch surfing... never having a stable place.

This model of supportive housing is proving to be integral to the health of its residents and the establishment of positive support networks:

We have 6 people right now...Our objectives in this is to learn household management, to have extended or chosen family around that can give you good advice... One of the things that we want in terms of outcomes is to build equity so we are near the end of the process of forming a corporation, which owns the house and people have shares in it. So what you pay for rent goes to their share and at any point they want to move out they can take out their equity or they can take over more of it... instead of paying rent their whole lives...

If it is a family where adults have FAS, if you build a community of other people like them, then you don't require a whole lot of government intervention, you require the structure that keeps people on track...it doesn't require a paid person all the time.

A similar housing model is provided for adults through CLBC and Community Living Victoria, it is known as Supported Apartment Living. The model allows adults to rent their own apartment within one larger apartment complex that has a common use area for group social activities. Support workers are based within the same complex and provide daily assistance with such things like money management, grocery shopping, meal planning, personal safety, interpersonal skills and development of group or individual leisure activities (Community Living Victoria, 2009).

CLBC currently delegates housing services to various agencies that, depending on their size and resources, either own some properties or rent them from private owners to provide diverse housing models. The White Crow pilot has the advantage of owning their property in order to form a corporation. This is a favourable and sustainable option for CLBC, the agencies and the residents. BC Housing may also support in this model by offering rental subsidies for adults whose PWD payments are lower than average and special agreements with banks may be explored in supporting mortgage loans.

7.4 Policy 4: Aboriginal FASD Adult Day Program and FASD Education On and Off Reserves

This policy option is broken up into two sub options, which aim to place the design and delivery of Aboriginal specific programs into Aboriginal hands. The first sub option is modelled after the FASD Adult Day treatment program through Hey Way Noqu Healing Circle for Addictions Society in Vancouver. This is not a pilot program, yet its sustainability is uncertain as its funding is not secured through the First Nations and Inuit Health Branch (FNIHB). The program strives to provide a holistic approach to assist urban Aboriginals and their families through their healing journeys from substance abuse in a culturally relevant setting. Currently, the program is only offered to those with Indian Status, but ideally, the option would be open to anyone who self-identifies as Aboriginal.

The program seeks to revive the traditional teachings that the Elders focus group emphasized by regularly incorporating Elders into the program. I had the opportunity to spend a couple sessions with this program and to speak with the educator who runs the group. The educator explained that the day program provides a daytime setting for clients to get together, feel accepted and safe, while receiving support for substance abuse.

Our day treatment program is very oral, people in our group have been able to acknowledge that they don't read, don't understand letters, they know how to spell their name to sign in, so most of what we do is oral and we have lots of breaks...It is based on what they need, sometimes it is just one person who needs to walk around the room, go on the treadmill or use the ab machine, so we have it set up where we have our circle, our smudging circles, one table is for painting, one for eating and it is really neat to see how they support each other.

The second sub policy option builds on the ideas of healing in the day program and expands it to the community level. Several Aboriginal run pilot programs are funded through the Victoria Foundation that seek to promote FASD education on and off reserves. Each pilot seeks to meet the same goal of community healing, yet does so in different ways; for example, there is an Elders group through the Vancouver Native Health Society that is undergoing training and orientation in order to interact with children and families affected by FASD. Another program, funded a particular Aboriginal Child and Family Services Society was also funded to provide community based housing for families and FASD strategies rooted in their cultural traditions.

7.5 Policy 5: Respite Care for Birth and Adoptive Families

Recently, under VIHA, the Queen Alexandra Centre in Victoria received an extension to June 2010 in order to continue work on a respite care pilot program for families who cannot qualify otherwise. The pilot program functions under the existing Community Respite Service for Families program, which has been met with resounding success and appreciation. The pilot program allows parents to interview and choose their own trained respite worker and set their own schedule (Bearings Newsletter, 2007). Families explained that the respite care allowed them to renew and recentre themselves, while parents attended to personal needs, as their children were safely cared for (Bearings Newsletter, 2007).

8: Analysis of Policy Options

In this chapter, first, the criteria and measures by which the policy options will be analyzed are outlined and, second, each option will be evaluated according to the criteria and measures. By analyzing the options, the study will meet its final objective to *develop culturally safe recommendations that will inform policy and practice changes to better improve the health and quality of life for the Aboriginal FASD population in BC.*

8.1 Criteria and Measures

Social policy that seeks to address a social and health problem, such as FASD, which is complicated by divisive moral, ethical, and/or racial and gender issues presents as an exceptionally challenging task for policy analysis. The analysis is not a neutral exercise, as each analyst will champion certain values and make trade offs between different policy outcomes at the expense of another. This will accordingly lead to different policy recommendations and possibly unintended consequences. The complexity of FASD policy crosses over the work of many ministries. Therefore, it is bound to produce disagreements about the allocation of FASD resources and the extent to which stakeholders are included and excluded from discussions. By adopting the theoretical framework of the study, and in particular cultural safety, the proceeding analysis sets Aboriginal input as a prerequisite for all the options, not to merely guide recommendations, but to genuinely transform subsequent policy and practice.

Moreover, the analysis needs to remain cognizant of how the socio-historical context has contributed to and sustains poor standards in Aboriginal health and, consequently, FASD related risk factors. Even though policy measures, alone, are not fully capable of addressing underlying structural inequities and discrimination, they should still strive to create fundamental standards of health that can mitigate the negative outcomes associated with this condition. Successful analysis also needs to conceptualize FASD as a lifelong condition, where the short to long-term benefits and costs of a decision on the public purse and on the wellbeing of the population are made. In doing so, further discussion and debate will need to occur around whether the labelling of FASD as a prerequisite to services and programs is in fact a progressive way to proceed in terms of meeting the needs of this population.

8.1.1 Equity

Equity concerns the social allocation of benefits and burdens. Each policy option will entail a change in benefits and burdens among the Aboriginal child and youth population. Given the lifelong nature of FASD, effects on intergenerational equity reveal how a policy option may shift benefits and burdens to younger, older, and subsequent generations. Current inequities exist in the distribution of and eligibility for programs and services depending on various variables like geographical location, on and off reserve, socio economic backgrounds, legal Indian Status, age, or whether living in foster, adoptive or birth parent care etc. Equitable policy options seek to redress these inequities. This criterion is measured on a scale of high, medium, or low. A high rating means the option comprehensively addresses equity gaps over the status quo. A medium equity score entails the option either maintains or slightly improves current equity levels. A low score signifies an option that does not improve equity and introduces new sources of inequity.

8.1.2 Effectiveness

Effectiveness of options reveals to what extent does the option address the policy problem identified in the research and meet the goal of the study. Since the goal of culturally safe policy options was explicitly set out in the study, special attention to this criterion is paid under effectiveness. Each option selected, aside from status quo, was meant to address the goal of the study, but they do so to varying degrees and that is what effectiveness will reveal. A high score of effectiveness demonstrates an option that significantly addresses and closes an identified gap with respect to the status quo option. A medium score slightly improves on or maintains the identified gaps in that status quo and a low score does not improve the gaps identified and introduces new gaps in programs and services.

8.1.3 Cultural Safety

As outlined in the literature review, contemporary discussions on health in Aboriginal communities that strive to address systemic power imbalances sourced in poverty and discrimination champion the goal of culturally safe options. This study's goal was to uncover culturally safe options that promote intergenerational healing and that involve full Aboriginal participation in the design, delivery, and evaluation of initiatives. To reiterate, cultural safety on the micro level, includes establishing trust between healthcare provider and patient while validating the individual's lived experiences and history. On the macro level, it calls for the

inclusion of Aboriginal people in high level decision making processes in setting health care agendas settings and policy development for Aboriginal populations (NAHO, 2006).

A high score of cultural safety means an option that explicitly focuses on aims of community healing and that is driven and designed by the Aboriginal community. A medium score means the option peripherally contributes to goals of healing from intergenerational trauma and community empowerment, while on an artificial level may include the Aboriginal stakeholders. A low cultural safety score entails a deepening of structural power imbalances between the Aboriginal and non-Aboriginal community and where aims for community and individual healing are hindered.

8.1.4 Efficiency

Efficiency is one of many economic feasibility criteria that seek to quantify the costs associated with an option and the overall economic impact it has on the public purse. This criterion, in comparison with equity analysis, produces the most tension when allocating resources for social and health services. As the discussion on the cost of FASD to society explained, the costs associated with doing nothing or offering piece meal supports may lead to unintended and an exacerbation of costs for families and public resources.

Efficiency evaluations of FASD policy would ideally appreciate the life long impact of the condition and account for all costs and *savings* associated with a policy option, rather than its immediate impact on public funds. An option with high efficiency entails more savings to the system in the long run than the initial investment. A medium efficient option means equal or slightly more costs compared to savings in the long run, leaving no major net impact on improving efficiency. A low efficiency score signifies significantly more costs to the system over the long run than in savings.

8.1.5 Stakeholder Acceptability

The criterion of stakeholder acceptability strives to determine to what extent stakeholders such as the government, administrators and community members will embrace the option. For Aboriginal FASD related policy the common government stakeholders are MCFD, CLBC, Ministry of Education, INAC, FNIHB, and MHSD. Government stakeholders' understanding of FASD and their concerns over spending and other policy priorities significantly impacts their acceptability of options. Other administrative stakeholders include school districts, the First

Nations Education Steering Committee of BC, Aboriginal health departments under health authorities, (Aboriginal) child and family development agencies, and multidisciplinary assessment and teams.

Stakeholders also include families, on and off reserve communities and Aboriginal individuals affected by FASD. An option with high stakeholder acceptability means that there is strong support for the option based on current trends and priorities in FASD policy work and participant interviews. Medium stakeholder acceptability entails mixed support for the option where the option meets the priorities of some stakeholders, while not meeting the priorities of others, therefore producing neutral support for the option. An option with low stakeholder acceptability signifies strong opposition to the option among the majority of stakeholders, most notably among the stakeholder that facilitate an option's implementation, which is commonly the government and its partner agencies.

8.2 Analysis of the Policy Options

This section analyses each of the five policy options against the criteria set out in the previous section. Table 8.1 below summarizes the results and the scoring of each option to reveal the relative utility of each. High scores received three points, medium scores received 2 points, and low scores received 1 point. There was weighting used in the analysis, where double points were allotted for cultural safety given the centrality of this concept to the study.

Table 8.1 Evaluation Matrix

Policy Options	Status Quo	Adult Assessments and Diagnoses	Interdependent Living	Aboriginal Adult FASD Day Program	Education On and Off Reserves	Respite Care
Equity	Low 1	Medium 2	Med-High 2.5	High 3	High 3	High 3
Effectiveness	Low-Med 1.5	High 3	High 3	High 3	High 3	High 3
Cultural Safety	Low-Med 3	High 4	Medium 4	High 6	High 6	High 6
Efficiency	Low 1	Med-High 2.5	High 3	Medium 2	High 3	High 3
Stakeholder Acceptability	Med-High 2.5	High 3	Low 1	Medium 2	High 3	High 3
Total	9.5	14.5	13.5	16	18	18

The analysis of policy options was informed by literature review on successful policy initiatives, available data on costs, current policy and funding directions in BC as demonstrated in the 2008-2018 FASD 10 Year Strategic Plan, responses from research participants, and informal discussions with key stakeholders. The analysis finds that the policy options with the most merit and realistic feasibility are implementing adult diagnostic services, providing Aboriginal adult day programs and intensive FASD education campaigns on and off reserve, and respite care for birth families and adoptive parents.

8.2.1 Analysis of Status Quo

Equity

The reason status quo policy is inequitable is that all provisions, in one way or another, have time limits and unreasonable eligibility criteria, thus making them excessively restrictive. Instead of making use of policy opportunities to mitigate the exacerbation of FASD along the life course, current intervention measures remain only partially committed to the Aboriginal child and

youth population. The weak infrastructure of supports for youth before and after 19 years of age meant that considerable amount of burden was placed on youth, especially Aboriginal youth exiting government custody. The near absence of a FASD adult support structure in BC, left Aboriginal youth and adults only more prone to further victimization, as mental health and substance abuse problems were left under treated.

It appears that status quo policy is informed by an assumption that Aboriginal children and youth will somehow be supported through other avenues namely their foster, adoptive, or birth parents. Aboriginal youth remained unsupervised and ended up on the streets or in and out of their families' homes, while living with the remnants of traumatic and unstable childhoods. Moreover, status quo provisions assume that all families are capable and *willing* to support their child throughout adulthood. Yet, foster parents had no obligation to continue support, and aging adoptive parents and, particularly, birth mothers, were left unsupported in the difficult task of caring for their loved one while also taking care of themselves.

Furthermore, upcoming provisions through CLBC will superficially provide for only a lucky handful of adults in competition with other developmental conditions, which create a new source of inequity. Thus, the overall equity score given to status quo policy is low.

Effectiveness

Status quo policy does not dramatically help solve the policy problem, nor does it contribute to the goal of the study by presenting as an option that lends itself to continuity of care. Disjointed and uneven service delivery entailed wasted time and resources. The ineffectiveness of status quo provisions for the Aboriginal population were also linked with the inadequacy of other healthcare provisions in BC, namely the mental health system (Pathways to Health and Healing, 2007).

Nevertheless, it is important to acknowledge that the first FASD strategic plan in 2003 took important steps towards the goal of effective service provision, especially in regards to the expansion of diagnostic services outside the lower mainland. BC's FASD plans remain more focused on prevention policy, yet the prevention of FASD is not as simple as these plans assume it to be, especially when 50% of pregnancies are unplanned (National Post, Feb. 18, 2009). Intervention initiatives need further commitment and improvement across the lifespan of the individual, thus the status quo option receives a low to medium score for effectiveness.

Cultural Safety

At the surface level, it appears that status quo policy is aware of cultural safety principles and has taken measures to counter racialized stereotypes and include Aboriginal stakeholders in design and implementation of initiatives. Interviews revealed that with several status quo policies like FASD specific school programs, POPFASD and the key worker program, considerable effort and conscious decisions have been made to counter negative stereotypes. Moreover, cultural safety is set out as an explicit goal in the 2008-2018 provincial FASD Strategic plan. MCFD also scores itself on the percentage of Aboriginal children and youth in care that are placed within Aboriginal homes.

In addition, 156 delegation agreements have been made between MCFD and Aboriginal groups on and off reserves, which allow for the development of Aboriginal Child and Family Service agencies (excluding adoption) (Delegated Child and Family Service Agencies, MCFD, 2009). Delegation to these agencies ostensibly supports goals of sustaining continuities of Aboriginal heritage and supports Aboriginal involvement in addressing FASD through design and delivery of programs.

However, critics argue that simply delegating authority or the construction of various Aboriginal health departments within health authorities does not entail an equal transfer of power. Jo-Anne Fiske and Annette Browne (2008) write that, “The word *transfer* itself denotes equality, a giving over of something on an equal basis, but, in reality, this is a health care delegation policy whereby policy and fiscal powers are retained in a federal bureaucracy while increased responsibilities to meet policy goals of that bureaucracy are assumed at local levels” (Fiske and Browne, 2008, p. 31). Moreover, health transfer policies may in fact reinforce inequality between Aboriginal and non-Aboriginal authorities because the state bureaucracy sets the terms of the engagement such as accountability frameworks and outcomes measures, which inadvertently question the competency of Aboriginal authorities (Fiske and Browne, 2008).

The signing of the 2007 Tripartite First Nations Health Plan seeks to establish a new governance structure over the next ten years that aims to improve control of health services by First Nations at the community and regional level (Pathways to Health and Healing, 2007). It is not yet apparent if this step will have the capacity to genuinely empower Aboriginal communities to set and respond to their own health agendas. If such a system is realized, it may create an optimum environment for Aboriginal health promotion without further stereotyping of Aboriginal communities as solely a place of abuse and illness.

The research results demonstrated that gaps in FASD knowledge and capacity on and off reserves continued, while stereotyping and discrimination were common; therefore much progress

will be required in the future. Given the mixed results, the status quo policy receives a score of low to medium for cultural safety.

Efficiency

What makes status quo policy inefficient is that it does not accurately factor the prevalence of FASD and its life long impact. If one accepts the prevalence of 9 per 1000 live births and BC has a population of 4 419 974 (Quarterly Demographic Estimates, Statistics Canada, 2009), then it can be estimated that approximately 39 779 individuals are affected with more being born each year. This means that current measures are incapable of providing for this population and opportunities to curtail FASD related costs are missed early in life. Therefore, Aboriginal children and youth continue to fall between the ‘cracks’ of the system.

One member of the PHAC roundtable on FASD costing in Canada explained:

You can reactively provide very high cost services or you can proactively provide much cheaper ones, you'll have to double fund any system for a period of time, but after a point in time, your costs should fall significantly, but if you keep doing what you are doing, your costs will keep going up and you won't fix anything...

As evidenced by the interviews, there were costs associated with the criminal justice system and potential years of life lost due to premature deaths, but also costs related to compromised health of families because of chronic stress. Status quo policy thus receives an overall low score for efficiency.

Stakeholder Acceptability

Predictably, government stakeholders representing MCFD, MHSD, CLBC, and the Ministry of Education felt current measures matched what was economically feasible. Parents were adamantly opposed to current policy measures because of their dissatisfaction with time bound provisions and their ineligibility for numerous services. The mixed response gives status quo policy a medium to high score for stakeholder acceptability.

8.2.2 Analysis of Adult Assessments and Diagnoses

Equity

In BC, as in other jurisdictions, access to special needs supports is based on medical diagnoses, FASD being no different. ‘Labelling’ Aboriginal individuals with FASD can result in lifelong stigma and further perpetuation of racialized stereotypes, and discrimination against

FASD affected families. Depending on the context, an FASD diagnosis may serve as a double bind where it simultaneously opens doors to services, while it creates further burdens on Aboriginal communities. The ‘labelling’ of FASD invites undue scrutiny, further surveillance, and moral judgments of Aboriginal individuals. Nevertheless, a medical diagnosis is the basis on which much of health care allocations are made.

Critics have challenged the heavy emphasis placed on medical diagnoses and instead have called for services to be based on generalized disabilities or measured levels of function (Tait, 2000). However, this is a difficult goal to realize when the design and delivery of such services such as PWD and CLBC supports is largely based on medical diagnoses. This is why study participants advocated for the expansion of diagnostic services because they believed adult diagnostic services would close what has been a long-standing gap in FASD intervention in BC. Therefore, the option offers much benefit and burden, giving it a score of medium for equity.

Effectiveness

Even though early diagnoses would make for more effective intervention, providing adult diagnoses still contributes to continuity of care, thus it is still a valuable endeavour. Moreover, the stress and anxiety of families is relieved knowing they can access several assessments throughout their child’s life. Providing assessments at various stages of development are a frequent recommendation of multidisciplinary assessment teams (Chudley et al, 2005), therefore this option matches with the medical literature and with what parents identified in the study. The effectiveness of adult diagnostic clinics thus earns a score of high.

Cultural Safety

In contrast to some of the discriminatory experiences of Aboriginal mothers accessing FASD supports for themselves and their children, the environment of the adult clinic was positive, non-judgemental and removed fears of child apprehension. Women were not pressed for information they were unwilling to provide, and mothers did not put themselves at risk of being implicitly labelled and further discredited as ‘bad’ mothers by seeking out services. Moreover, women were helped to understand the medical jargon of the diagnostic reports and in dealing with the difficult emotions raised by the diagnosis.

Nevertheless, such an accommodating environment is difficult to guarantee depending on the attitudes of the health professionals involved in the clinic and their commitment to cultural safety principles. The disclosing of sensitive information by, particularly, Aboriginal mothers, may in fact create further suspicion, scepticism, and disapproval at their role as mothers (Fiske

and Browne, 2008). On the other hand, this double bind is further complicated by the fact that Aboriginal participants in the study emphasized the need for the community and individual to first acknowledge the problem in order to respond accordingly. Adhering to cultural safety principles in this situation means that acknowledgment may or may not come in the form of a diagnosis, but if it does, it must happen on the accord of the individual and community.

Furthermore, the clinic model may be further informed by culturally safe measures by partnering with Aboriginal organizations supporting at risk Aboriginal mothers, such as the pregnancy outreach program, Sheway, in Vancouver. Overall, the option receives a medium rating for cultural safety because despite the merits of expanding diagnostic services, it can simultaneously support and impede efforts of healing and community empowerment.

Efficiency

The adult pilot clinic found that FASD comorbidity with substance abuse and mental health problems were well developed in the diagnosed adults because their condition was left unidentified for too long. Therefore, it appears that adult diagnoses performed later in life are not as cost saving as those performed earlier. Yet diagnosis may still prevent further exacerbation of the condition and related costs, if it remains undiagnosed throughout the rest of adult life and old age. Moreover, by focusing on at risk mothers, the clinic was able to screen the mothers' children, which presented a unique opportunity for intergenerational screening. The possibility for early intervention for children helps to break the cycle and create further savings in the future. Given the efficiency results of the option, it is medium to highly efficient.

Stakeholder Acceptability

The current provincial 2008-2018 FASD Strategic Plan has identified accessibility to assessments and diagnoses to children, youths, and *adults* as a priority; therefore it is safe to assume that it has been identified as a possible option in the near future. In addition, all participants were in favour of expanding diagnostic services, therefore the option receives high stakeholder acceptability.

8.2.3 Analysis of Interdependent Living

Equity

While the White Crow model of interdependent housing provided residents with the benefits of a safe and supervised home environment, it also gave residents an investment

opportunity in housing, which for many of them was not otherwise possible. Interdependent living also protects Aboriginal youths, exiting the foster care system with little to no family, support, from ending up in volatile and dangerous living conditions. Even though the model reserves priority for individuals with FASD, it need not be completely exclusive and may include other high-risk adults who require assisted living situations; therefore, this option is medium to highly equitable.

Effectiveness

Interdependent living effectively sets the foundation for safer and healthier lives for a highly vulnerable group, while promoting healthy socialization. It completes the continuum of care between child to adulthood, and it is a proactive and powerful mitigating force against FASD comorbidity and negative life trajectories. This option offers the flexibility of providing as much or as little support required, therefore this option receives an overall score of high.

Cultural Safety

One member of the interdependent living pilot explained that their home was a positive, safe, non-judgmental and non-patronizing family environment. Many of White Crow Society's founders and staff were First Nations and had purposefully built a culture of acceptance based on Aboriginal principles and beliefs on health. Depending on how and who administers the housing project, culturally safe tenets may or may not be met. Preferably the administration of the model would be given to societies such as White Crow and others that are appreciative of cultural safety principles.

The White Crow model also offered a proximity to relatives on and off reserves as well as community members like Elders who provided guidance and teachings. Moreover, admission into the housing model need not be explicitly based on a FASD diagnosis. Instead, the program may discreetly recruit residents based on demonstrated need; therefore there is no need to publicize diagnoses. Either way, interdependent housing models will need to proactively work for an inclusive and culturally safe environment with the inclusion of Aboriginal input. Overall, this option receives a score of medium.

Efficiency

The residents in the White Crow pilot and the adults in supported apartment living models under CLBC paid for their rent primarily through *existing* PWD allowances, which averaged to be \$888 (MHSD BC Employment and Assistance Rates, MHSD, 2007). If one has received an FASD diagnosis and successfully applied for PWD, then they only need to secure a

housing placement that affords the benefits of these models. There are several agencies and non-profit societies that already offer housing for adults with developmental disabilities, so the main cost factor lies in CLBC committing funds to these agencies to expand and secure spots for adults with FASD.

White Crow's corporation model may not always be feasible because each housing agency is resourced differently, and it is uncertain if they or CLBC would elect to implement the model. Whether this option is provided in the form of the White Crow model or CLBC supportive living arrangements, long-term efficiency gains to systems can be made from keeping Aboriginal youth and adults off the streets and into supervised settings. This option thus receives a rating of high.

Stakeholder Acceptability

All the parents in the study favoured interdependent housing. However, current FASD policy and spending trends do not show an explicit support for allocating housing spots for FASD, other than CLBC's changed criteria as of February 2010. Given current funding constraints, as well as competition with multiple homelessness initiatives, it is unlikely that further funds will be earmarked for FASD housing in the near future. Therefore, the option receives a low score for stakeholder acceptability.

8.2.4 Analysis of Aboriginal Adult FASD Day Program & Education On and Off Reserves

Equity

Both options adopt an approach to FASD that is conscious of how intergenerational trauma has come to inform Aboriginal health, while they champion and seek to find strength in Aboriginal teachings and belief systems. The options are meant to be exclusive for Aboriginal individuals in order to empower Aboriginal stakeholders to explicitly address persisting Aboriginal health inequities, so the fact that they are not inclusive of the broader population outweighs the exclusivity of the options.

Some of the Aboriginal youth in this study were having challenges in finding a sense of belonging and identity, therefore the day program may serve as a site where they can develop a sense of community, and simultaneously, address their addictions. This is a key step in gaining control over their lives and achieving healthier outcomes. Moreover, their families have the peace

of mind in knowing that they are in a safe space; therefore this option receives a high score for equity.

Remnants of the colonial legacy have caused the weakening of community cohesiveness and family care giving in certain areas. This has led to the prioritization of reviving traditional parenting education among Aboriginal stakeholders. The provision of Aboriginal run FASD education campaigns promotes community readiness to heal from and respond to FASD through the creation of local knowledge, thus it receives a high score for equity.

Effectiveness / Cultural Safety

Similar to the option of adult diagnostic services, Aboriginal FASD exclusive options may potentially exacerbate the burden of racialization and stigma. Even though, the adult day program effectively contributes to the lack of adult FASD services and offers many benefits, the dilemma of labeling persists. However, the Aboriginal run day program in Vancouver is operated under a First Nations healing society where participant recruitment is done discreetly by word of mouth and where entrance into the program is not based on medical diagnosis, but on the individual's need for addictions and emotional support. Therefore, the option receives a high score for cultural safety and effectiveness.

The proliferation of FASD education throughout BC will even gaps in knowledge and FASD capacity, especially for on reserve communities where FASD resources remain weak. However, caution must be taken that Aboriginal communities are not stereotyped as sites of impaired conduct when applying for funds to undertake FASD education (Fiske and Browne, 2008). Criticism has been made that funding competitions for Aboriginal directed programs create a false idea that the community is in 'control' of their own programming, yet they are put in circumstances not of their own making when competing for funds (Fiske and Browne, 2008).

Therefore, control over setting health agendas and budgets should be placed within communities. This may be in the form of health transfers to Aboriginal authorities at the community or regional level, or within some other arrangement. Overall, this option receives high scores for cultural safety and effectiveness because it serves as a foundation for community healing and the protection of subsequent generations.

Efficiency

Out of all the pilot projects funded by the Victoria foundation, the education campaigns were the least expensive to implement with an average cost of \$150 000 over the span of three years to cover training, materials, transportation etc. (Victoria Foundation FASD Action Funds,

2007). FASD education does not necessarily require renting space or full time staff rather it requires a small investment to empower Aboriginal communities to develop powerful tools against intergenerational FASD. Because education campaigns would also cover reserves, federal funding support may be solicited. Education campaigns thus receive a high score for efficiency.

Upon requesting information about the cost of the adult day program under Hey Way Noqu Healing Circle for Addictions Society in Vancouver, an estimate was hard to confirm. However, what is known is that the program runs in three-week intervals and requires about \$1500 for materials including costs of food for lunches, gas for outing events and bus tickets for participants. These costs do not include the Society's overhead costs, which cover wages for the one full time employee, office supplies, rental space etc.

The program strives to keep at risk youths emotionally and spiritually supported to stay off the street and drugs, which can result FASD related cost savings. However, the day treatment program is more reactive in nature and without other related supports such as safe living arrangements and supervision upon leaving the program in the afternoons, the full cost savings may not be realized; therefore it receives a rating of medium.

Stakeholder Acceptability

It is not yet apparent if FNIHB will continue to support the day program or if CLBC would award contracts to Aboriginal specific agencies to run day programs. Given this information, clear commitment to Aboriginal operated day programs is uncertain, even though it was a favourable option among families. This option, thus, earns a medium score.

In regards to Aboriginal run FASD education campaigns, all participants were in agreement for rigorous education. MCFD and the PHAC have made education and awareness campaigns a central objective, which entails strong support for this option; therefore it receives high stakeholder acceptability.

8.2.5 Analysis of Respite Care for Birth and Adoptive Families

Equity

Respite care strengthens family unity and stability while providing parents personal time and preventing family disintegration due to overwhelming stress and burnout. Respite care promotes a supportive and stable home environment, which is paramount for Aboriginal children and youth whose living conditions were often marked by instability and custody changes. The trying experiences of the single Aboriginal birth mothers in the study demonstrated the necessity

for respite care, since they were afforded little monetary allowance in comparison to foster and adoptive parents. Moreover, the option brings birth and adoptive parents in parity with other families who readily receive respite services for other developmental conditions. This option, thus, receives a high score for equity.

Effectiveness

The expansion of respite care services successfully addresses the policy problem and helps meet the goal of this study by empowering parents to receive the gift of time in order to strengthen their roles as caregivers. Therefore, this option receives a high score for effectiveness.

Cultural Safety

The experiences of birth mothers in this study demonstrated that respite care services allow for the personal time needed to continue their healing journeys. One birth mother who lived on a reserve explained that the respite care afforded her the time to go see her therapist and visit her spiritual healer who was a two-hour bus ride away. She explained that she did not have an extended network of family members who were trained or willing to take care of her son, and that she was on the verge of burn out under constant surveillance of MCFD representatives. The respite care she received gave her the peace of mind that her son was safely being cared for by a trained professional.

In terms of an option that is led and designed by Aboriginal communities, a community respite care program could be developed. The study's Aboriginal key informants and the Elders emphasized that social networks of supports need to be encouraged. This option lends itself to the strengthening of parenting skills and community cohesiveness. This approach also affords the option to birth mothers to place their children with Aboriginal caregivers, if that is what they prefer. Overall, the expansion of respite care services receives a high score for cultural safety.

Efficiency

The community FASD respite program pilot under VIHA functions within an existing respite program that covers other developmental conditions. This has been helpful in that the program has less overhead costs, as would be the case if there were no existing program. The total grant received for the FASD respite program was \$249 750 over the span of 3 years (Victoria Foundation FASD Action Funds, 2007). The pilot currently pays trained respite care workers \$16 an hour and provides up to 30 hours of respite care to families free of charge. There are two coordinators that job share and together work an equivalent of 1.2 FTE (Full Time Equivalent,

full time being 1.0). The program pays for minimal administration costs and pays \$5 000 per training session, in which 15-20 workers are trained.

The fact that sustainable respite care programs exist in all health authorities covering seniors and other individuals affected by a variety of health conditions, begs the question, why respite for FASD could not become integrated into those pre-existing programs? The coordinators, the administrative support, and the training resources are in place, which encourages the sustainability of this option. Moreover, parental stress and burnout resulted in indirect costs, for example, loss of productivity at work, marriage counselling, physician and psychologist visits. Over the long run, these costs cumulatively develop and surpass those of sustaining respite care. Therefore costs of respite provision will not only be recovered, but further savings will be realized, making it highly efficient.

Stakeholder Acceptability

MCFD is aiming to provide respite care services in the near future as stated in their FASD plan (FASD: Building on Strengths A Provincial Plan for BC 2008-2018, MCFD, 2008). There were no participants who were opposed to expanding respite services, giving respite care high stakeholder acceptability.

9: Policy Recommendations

The analysis of the policy options revealed that discussion on FASD, Aboriginal communities and policy cannot escape politically charged arguments. Policy is, in and of itself, a powerful institution and tool that can empower and silence certain groups in society. By carefully analyzing the options, both the merits and unintended consequences of each option were reviewed. The analysis produced four recommendations that best aligned with the principles of cultural safety and with what is currently feasible. They were: adult assessments and diagnoses, Aboriginal adult day programs, FASD education on and off reserves, and respite services.

Neutral policy analysis that avoids making references to colonial legacies and discriminatory forces such as racism and sexism further cements structural health inequities. Health policy often places blame on lifestyle choices for health outcomes, which implicitly shifts problems back onto Aboriginal individuals and away from social, political, historical, and economic structures in which health conditions occur (Fiske and Browne, 2008). The analysis of the options demonstrated that even the most well-intentioned policy such as diagnostic services may further instill racialized beliefs.

However, the theoretical framework of the study allowed the analysis to account for the challenges associated with each option, while exposing the underlying power imbalances that inform Aboriginal experiences with FASD. Aboriginal authorities have long stressed that policy reform must be made within the context of community institutions, which play a critical role in empowerment of Aboriginal identity and wellbeing (Aboriginal Health Association of BC, 2003). Therefore, the recommendations may be most beneficial when coupled with the institutional ability of Aboriginal authorities to oversee the health of their nations at the community or regional level. In doing so, the aims of cultural safety may be fully attained and system barriers such as mandatory diagnostic labeling may be alleviated.

Overall, the recommendations seek to provide as much flexibility as possible in order to be amenable to the distinct experiences of Aboriginal children and youth as they age. The options do not necessarily require more money, rather they seek to promote Aboriginal ownership and design of the initiatives. Moreover, the recommendations, particularly adult diagnoses and respite care, afford much needed support for the general FASD population in BC.

The study uncovered one serious shortfall within the status quo that policy recommendations alone cannot address. The results showed an unequal division between allocations to foster, adoptive and birth parents, with foster parents receiving an average of \$2 000 a month and FASD parenting education. Ironically, reunited Aboriginal birth families received minimal supports. MCFD is not mandated to and cannot reallocate these monies to birth families because that would qualify as income assistance with respect to MHSD mandate. Therefore, this problem will need to be amended at the political level where a certain amount of restructuring of ministerial responsibilities is required.

Overall, BC has set a good standard with respect to FASD policy measures that the rest of the country can emulate, but as the study results demonstrated significant problems remain and need to be addressed vigilantly. BC and the federal government, through the PHAC, should continue investing in research, pilot projects and education because FASD is a dynamic condition in which frequent discoveries in the medical world far outpace governments' and the public's understanding of this condition.

10: Conclusion

The goal of this study was to *uncover what policies best enable the Aboriginal child and youth population to receive continuity of care through programs and services in a culturally safe manner*. The research sought to understand how the socio-historical factors and broader social determinants of health informed Aboriginal communities' experiences with FASD, and how they approach community healing initiatives. In doing so, the study was able to develop successful recommendations to better improve the health and quality of life for the Aboriginal FASD population in BC.

The literature review offered a better understanding of FASD as a life long neurodevelopmental condition. The review also exposed how faulty epidemiological studies on FASD contributed to discriminatory perceptions, especially against Aboriginal mothers. Moreover, a review of the intergenerational impacts of the residential school experience, especially the forced removal of Aboriginal children, demonstrated why some Aboriginal mothers are at higher risk of substance misuse. The theoretical framework of the study revealed how the legacy of colonization produced and sustained oppressive power imbalances rooted mainly in poverty, racism and sexism.

Moreover, this framework outlined how the intersection of these and other forces have informed diverse Aboriginal experiences with FASD. Interviews showed how Aboriginal individuals and communities negotiated and resisted discrimination as they were vested in the wellbeing of subsequent generations. The discussions on cultural safety explained that Aboriginal communities gained strength from their belief systems and teachings of health and healing, while recovering from intergenerational trauma.

The qualitative interviews with key informants and parents provided in depth insights into the lives of families affected by FASD. There were five major themes that emerged; first, the inconsistency of diagnostic services, second, the challenges within the education system, third, inadequate adult services, fourth, unequal funding between foster, adoptive, and birth families, and fifth, the continuing healing of Aboriginal communities. After carefully considering the data, the literature, BC pilot programs and current provisions in the status quo, four options were developed that responded to the most pressing concerns raised by the participants. These were:

adult assessment and diagnoses, interdependent living, Aboriginal adult FASD day programs, Aboriginal run FASD education campaigns, and the expansion of respite services.

The four options recommended proved to be most useful as incremental measures in responding to a complex policy problem. The first option included the implementation of adult diagnostic clinics modeled after the success of the one in Victoria. The second option was to expand Aboriginal adult day treatment programs, which present safe daily environments for youth and holistic care in recovery from substance abuse. The third option was to support and expand FASD education campaigns on and off reserves that are designed and delivered by Aboriginal stakeholders. Lastly, the expansion of respite care services for birth and adoptive families was recommended. All four options, complemented by status quo provisions, provide the next feasible and culturally safe policy measures that government may adopt in order to continue closing serious gaps in the continuum of FASD interventions.

Future research endeavors may focus on how to better link FASD policy and models of care between pediatrics, mental health services, and multidisciplinary assessment teams. Service fragmentation continues in BC and mental health provisions, in particular, were not always appropriate for FASD. Moreover, research may focus on how to raise the level of capacity among reserve communities in dealing with neurodevelopmental conditions to match that of off reserve communities.

Society at large is involved in one way or another in the problem use of alcohol, thus all need to be involved in the solution. Governments, especially, must be dedicated to address FASD and other alcohol related concerns, as they obtain revenues from and regulate the liquor industry. Their commitment to FASD in the future will have an important role so that Aboriginal families and subsequent generations attain a sound quality of life that is finally comparable to the general Canadian population.

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12: Appendices

12.1 Appendix A: Interview Schedules

Parent Interview Schedule

Explain purpose of study and confidentiality measures.

1. Can you please tell me a little about the composition of your family?
2. Can you please explain how your child was first diagnosed with FASD? How were your experiences with the multidisciplinary team?
3. How have the experiences with the school system been like thus far?
4. How is her/his relationship with peers? Surrounding community?
5. What types of treatments, programs, and/or services does your child use or has used in the past? Are they or were they helpful?
6. Have you ever used Aboriginal focused supports? If yes, did you find them helpful?
7. What do you think may be missing from the programs/services for yourself and your child?
8. As the guardian of your child, what have been some challenges in raising your child?
9. What would you currently improve in terms of programs and services for your child?
10. Do you have any major concerns for your child's future and wellbeing?
11. Is there any other information you would like to share?

Key Informant Schedule

Explain purpose of study and confidentiality measures.

1. Can you please explain how you first become involved in FASD related work? What are your current responsibilities?
2. What have been the successes and challenges in your role as X?
3. What has your experience demonstrated thus far in terms of successful FASD initiatives that best meet the needs of Aboriginal children and youth, and their families, that may differ from the non-Aboriginal community?
4. What do you think the strongest and weakest points of BC's current FASD policy initiatives are? What policy recommendations would you make for change that would better meet the needs of the Aboriginal population?

5. Are there any differences between the needs of Aboriginal children/youth in the care system versus those in permanent homes?
6. Is there any other information you would like to share?

Elder's Focus Group Schedule

Explain purpose of study and confidentiality measures.

1. How did you first become aware that your loved one was affected by FASD?
2. As a caregiver, what have been the challenges and successes in raising your loved one?
3. What kind of community or extended support networks have you accessed? What were your experiences with them?
4. What do you believe Aboriginal communities and individuals need in order to overcome FASD and prevent FASD?
5. What role, if any, do Aboriginal health and healing practices play in your communities?
6. If you could recommend any policy directions to better meet the needs of Aboriginal communities affected by FASD, what would they be?
7. Is there any other information you would like to share?