University of Alberta

Discourses of Fetal Alcohol Spectrum Disorder in Alberta

by

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A thesis submitted to the Faculty of Graduate Studies and Research
in partial fulfillment of the requirements for the degree of

Doctor of Philosophy

Department of Sociology

Fall 2011
Edmonton, Alberta

Abstract

Our understandings of health and illness are shaped by the social and political context in which these understandings emerge (Foucault, 1975). Accordingly, I explore the socio-political context in which Fetal Alcohol Spectrum Disorder (FASD) emerged in Alberta through investigation of three research questions: 1) how did FASD emerge and become recognized as a public health concern in Alberta? 2) how do those in charge of managing FASD in Alberta understand this disorder? and 3) what are the implications of understanding FASD as it is currently understood? The data for this qualitative study was collected through 23 semi-structured interviews, archival research, and document analysis and was analyzed using discourse analysis.

I examined the key individuals responsible for bringing FASD to public attention, the understandings those individuals have of FASD, and the effects of this history on the way that FASD is currently understood. The results demonstrate that discourses of risk, responsibility, gender, and race are invoked in FASD understandings.

Public FASD discourse represents the unborn child as being “at risk¨ for FASD and the mother as being “responsible¨ for creating this risk. FASD discourse ignores the structural context (i.e. poverty, racism, marginalization, mental health disorders, and a lack of available addiction treatment programs) in which pregnant women consume alcohol. This focus on the child “at risk” in FASD discourse renders adults with FASD invisible and without adequate services and support.

While FASD professionals are aware and critical of the ways in which discourses of risk, responsibility, gender, and race are invoked in FASD understandings, their ability to enact substantial change is limited by structural constraints.

This is the first investigation of FASD discourse in Alberta. I trace the FASD discourse and its implications, as well as argue that it is characterized by the hyper-visibility of women deemed to be at risk for giving birth to children with FASD, the invisibility of adults with FASD, and silence on race. I also illustrate how FASD professionals attempt to negotiate these understandings and shape future discourse on FASD. My findings demonstrate the significance of undertaking a historical examination of health disorders, such as FASD.

Acknowledgements

I am very thankful to all the research participants for generously sharing their experiences, expertise and insights with me. I am extremely grateful for Dr. Amy Kaler's outstanding support and continued mentorship. This dissertation would not have been completed without the incredible patience, guidance, and counsel of Dr. Kaler. I would also like to thank my committee members: Dr. Sara Dorow, Dr. Harvey Krahn and Dr. Malinda Smith for their insights and assistance throughout this process.

My undying gratitude goes to my amazing group of friends who spent countless hours reading and editing my dissertation: Dr. Shane Gannon, Dr. Sarah Wall, Mr. Tim Hartley, Dr. Tim Haney, Dr. Kristin Lozanski, Mr. Sunoop Menon, and Ms. Lisa Lozanski.

I am particularly grateful to Colleen Anderson, Milijana Setka, Beverly Matthews, Rupa Gannon, Sacha Ravelli and Lata Narayan for keeping me sane throughout this arduous process. I want to thank my parents Kala and Shiu Shankar for everything they have done and continue to do to ensure my continued success in life. I would also like to thank the rest of my family members, Dalip, Kamal, Aida, Anita, Walter, Sylvia, Jaynen and Amit, for their support.

Finally, I want to thank Isobel Kala Clark for bringing unprecedented joy and happiness into my life. Philip Clark, without you this little success and the entire big world mean nothing. I thank you for giving me love and a life worth living.

Chapter 1: Introduction

Fetal Alcohol Spectrum Disorder (FASD) is an umbrella term for a spectrum of disorders that result from in utero alcohol exposure. In Alberta, FASD came to public attention as recently as the late 1980s and early 1990s.[1] An estimated 23,000 Albertans are afflicted with FASD, and each year, an estimated 360 Alberta children are born with this disorder (Government of Alberta, 2009). The Government of Alberta considers FASD to be a "significant social and health issue" and has responded by investing in FASD programs and services and forming a Fetal Alcohol Spectrum Disorder Cross Ministry Committee (FASD-CMC), comprised of nine provincial government ministries (Government of Alberta, 2008b, p.2).[2] The FASD-CMC has developed a "unique, made-in-Alberta solution" for FASD. Since 2007, it has invested nearly $37 million in FASD programs and services, and almost $16.5 million in 2008 - 2009 alone (Government of Alberta, 2009). The province's early adoption of a FASD strategy and substantial investments in FASD prevention and treatment have facilitated the perception that Alberta is a "world leader" in FASD programming, services and research (Government of Alberta, 2008a, p. 1).[3] This perception of Alberta as a world leader in FASD

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[1] The history of Alberta's programs and policies on FASD is discussed at length in chapter 3 of this dissertation.

[2] The nine provincial government ministries are: Aboriginal Relations, Advanced Education and Technology, Children and Youth Services (co-chair), Seniors and Community Supports, Education, Health and Wellness (co-chair), Employment and Immigration, Justice and Attorney General, and Solicitor General and Public Security.

[3] In the interviews conducted for this research, several respondents considered the province of Alberta to be spearheading FASD initiatives in Canada. In addition, a Government of Alberta document (2008a) presents Alberta as a "world leader" in FASD initiatives. This sentiment is also adhered to in newspaper articles published by the Canadian Broadcasting Corporation (CBC) titled "Kids with FASD Need More Services" (CBC, 2009b) and "Alberta Experts Leading Research on FASD" (CBC, 2009a). The province of Alberta is seen as a leader in FASD initiatives because it provides substantial funding for FASD programming, services and research and was one of the first provinces to recognize and address FASD. However, there is no substantive evidence that Alberta is indeed a "world leader" in FASD research,

programming and policies implores us to investigate how FASD emerged and became accepted in Alberta as a public health concern.

In this dissertation, I answer the following three questions: (1) how did FASD emerge and become accepted as a medical disorder and public health concern in Alberta? (2) how do FASD professionals in Alberta (namely public officials, researchers, health workers, and social workers in charge of managing FASD) currently understand FASD? and (3) what are the implications of our current understandings of FASD? My ultimate goal is to understand how gender and race are invoked in FASD discourse in Alberta.

Scholars agree that health diagnoses and disorders must be understood as experience and that our knowledge of health is historically and culturally shaped and determined (Adelson, 2000; Crawford, 1980; Golden, 2005). As Adelson (2000) explains "all definitions of health are laden with ideological nuances and can never be separated from cultural norms and values, regardless of how the latter are played out in our everyday lives" (p.3). For example, the Black Death that plagued Europe in the fourteenth century was understood in three different, culturally-determined ways: one segment of the population considered the plague to be a manifestation of God's wrath, a second blamed Jews for spreading the plague, and a third thought the plague was the result of the alignment of Saturn, Jupiter and Mars. Religious beliefs, anti-Semitism and astronomy all shaped the public understanding and perception of the bubonic plague. A more recent example is the human immunodeficiency virus (HIV), which was initially named gay-related immunodeficiency disease or GRID because of the common (and misguided) perception that HIV only affected those who engaged homosexual relations.

That health diagnoses and disorders are historically and culturally shaped does not

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programming and services.

contest the reality of FASD. This analysis recognizes that FASD is a material health condition caused by alcohol consumption during pregnancy. Alcohol consumption during pregnancy can lead to brain damage in the child. However, our understanding of FASD, and its causes and solutions, is historically and culturally relative, being both a product of historical events and of particular cultural worldviews, economic conditions and social beliefs. Thus, this research explores the discursive construction of FASD. It does not contest the medical, physiological and/or biological dimensions of FASD. Instead I examine how FASD understandings emerged and developed in Alberta. My analysis sheds light on how FASD is currently understood and managed in Alberta and, perhaps more importantly, explains why it is understood and managed in this way.

There are two important reasons why I conducted this research in Alberta. First, as discussed above, Alberta is considered – and considers itself – a "world leader" in FASD programs and interventions. FASD professionals from Alberta are often hired as consultants and advisors for FASD program development in other Canadian provinces. Because of the important role that Alberta is playing in FASD programming and development in Canada, it is important to examine how FASD is understood in Alberta. It is worth noting here, and will be discussed further in chapter 3, that the province of Alberta has followed the United States of America's lead in FASD initiatives and programming. The FASD policies and programming in the United States are particularly punitive towards poor and/or racialized women and essentially hold them responsible for FASD (Roberts, 1999; Armstrong, 2003; Golden, 2005). Therefore, in this research, I also consider how those in charge of managing FASD in Alberta have adopted, resisted or otherwise negotiated this discourse from the United States.

Alberta is also an interesting research location because it has the distinction of being the only province to successfully imprison a pregnant woman for inhaling intoxicating vapours. Ms. Jeanette Reid, an Aboriginal woman, was seven months pregnant with her eighth child at the time of her arrest. Charges like these against Aboriginal women[4] have led some to criticize current FASD programs and policies in Canada. For instance, Salmon (2004) and Stange (1994) argue that in Canada, FASD has come to be understood as a disorder that primarily affects the Aboriginal population. In a similar vein, Tait (2009) argues that media, medical professionals, and researchers increasingly depict the "intergenerational effects of colonization" or the conditions that result from colonial legacies, such as "endemic poverty; racism; food, water, and housing insecurities; social and economic marginalization," as manifestations of FASD and other mental health issues (p. 208).[5] This understanding of FASD perpetuates racialized stereotypes of Aboriginals and holds Aboriginal women responsible for the social and economic marginalization of their communities (Salmon, 2004; Tait, 2009).

The term racialized refers to the association of an undesirable thing (i.e. event, place, disease) with a particular racial category or group. For example, to say that certain undesirable locations within cities have become racialized means that certain locations are perceived negatively because people of certain race are understood to be the primary inhabitants of that space. Similarly, in Canada, FASD has become racialized. FASD is represented as a health disorder that primarily affects members of Aboriginal

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[4] In 1996, Ms. G, a 22 year-old, pregnant, Aboriginal woman, was declared "mentally disordered" under Section 53 of the *Manitoba Mental Health Act* and ordered to enter treatment. This case is discussed in greater detail in chapter 2 of this dissertation

[5] Caroline Tait (2009) cites newspaper articles (from the Calgary Herald and the Globe and Mail), research (completed by David Square) and comments from medical professionals (such as Dr. Geoffrey C. Robinson) that clearly depict FASD as an Aboriginal people's issue and as a health disorder that is responsible for the current marginalization of the Aboriginal peoples in Canada.

communities. This is an inaccurate perception that is based upon negative stereotypes of Aboriginal communities. As I discuss in this dissertation (Chapter 2) there is currently no data regarding FASD prevalence rate in Canada and as such, there is no way of knowing whether FASD is more or less prevalent in Aboriginal communities. Despite this lack of evidence there continues to be a prevailing association of FASD to Aboriginal communities. It is precisely this discursive construction of FASD as an Aboriginal issue that is explored in this dissertation. To reiterate, I am not examining the epidemiology of FASD. Instead, I explore how FASD has been represented as an Aboriginal health issue.

Alberta's current status as a leader in the FASD field necessitates an examination of how its experts deal with such racialized and gendered representations of FASD. The issue of racialization within FASD programs needs particular attention given that Alberta is projected to have the second largest Aboriginal population in Canada by 2017 (Statistics Canada, 2005). Accordingly, in this dissertation, I examine the ways in which FASD experts in Alberta negotiate and work with(in) the racialized and gendered understandings of FASD.

To understand the current contours of FASD in Alberta, I undertook a historical investigation and examined when, how and why FASD emerged in Alberta as a public health concern. I adhered to a qualitative research methodology and utilized three research methods: 1) in-depth interviews; 2) archival research; and 3) document analysis research. Twenty-three in-depth, semi-structured interviews with FASD professionals and a comprehensive review of FASD literature in Alberta yielded the majority of the data. This data was then analyzed using the Foucauldian discourse analytic methodology.

Discourse analysis deconstructs the literature and conversations surrounding

FASD in order to understand "… who does the speaking, the positions and viewpoints from which they speak about it, [and] the institutions which prompt people to speak about it and which store and distribute the things that are said" (Foucault, 1990, p. 11). In other words, this methodology focuses on how particular understandings are constructed and notes what is included and what is excluded in such representations.[6] Foucauldian discourse analytic methodology encourages the examination of both the explicit and implicit values and beliefs that are embedded within discourse.

According to Foucault (1990), all discourse is comprised of both power and knowledge. Power is a set of practices and is embedded in all social relations. An examination of knowledge must answer the questions: what makes such knowledge possible? And what discourses and events does such knowledge rely and build upon? Foucault explained that "it is not possible for power to be exercised without knowledge, it is impossible for knowledge not to engender power" (Foucault, 1980, p. 52). Therefore, knowledge and power are interconnected whereby any increase in power involves an increase in knowledge and vice versa (Turner, 1997). For instance

> if sexuality [is] constituted as an area of investigation, this [is] only because relations of power [have] established it as a possible object; and conversely, if power [is] able to take it as a target, this [is] because techniques of knowledge and procedures of discourse [are] capable of investigating it (Foucault, 1990, p. 98).

My research uses this Foucauldian epistemological framework and the case study of FASD to unearth the power relations and knowledge creation strategies that are enacted in health and medical discourses.

While Foucault used discourse analysis in his own work he did not provide a clear guideline on how discourse analysis can be used as a method. However, other

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[6] Discourse analysis and Foucault's theoretical framework will be discussed in detail in chapter 3 of this dissertation.

researchers (such as Gilbert, 2003; Lupton, 1995; Turner, 1997) have conceptualized and used Foucault's theorization of discourse analysis as a methodological tool.

Lupton (1999) uses discourse analysis to examine the ways in which risk is invoked and understood in Western societies. She explains that we can only understand and perceive information through discourse because discourse regulates what we say about and/or understand as risk (Lupton, 1999). Using discourse analysis, Lupton (1999) shows how meanings and understandings of risk have changed over the years and how our awareness and understandings of risk shape our everyday life and interactions in society. Similarly, Petersen (1997) examines discourses of risk in Australian health promotion campaigns and how these discourses encourage people to "self-manage" their health. Given that discourses on FASD have a similar preoccupation with risk, the conceptualization of Foucauldian discourse analysis used by Lupton (1999) and Petersen (1997) was employed in my research.

This dissertation begins by providing a historical and national context for FASD. Chapter 2 examines the historical perspectives on alcohol consumption during pregnancy and considers how these perspectives have transformed into the views that are pervasive in Canada today. It also traces the origins of FASD in Canada and explores how the federal and provincial governments have tried to manage it.

Chapter 3 elaborates on the research methodology that was briefly discussed above. It explores, in greater depth, the Foucauldian epistemological framework and discourse analytic methodology and the application of both to this research project. The chapter also details the methods of data collection and data analysis. It concludes by outlining the methodological limitations of this study.

Chapter 4 discusses the historical development of FASD in Alberta. It examines what early FASD professionals (from both governmental and non-governmental backgrounds) set out to do and why they made the decisions they made. It also highlights the strategies that they used to bring FASD to public attention. The chapter, guided by Foucauldian theoretical framework, does not present a chronological timeline of events, but rather concentrates on mapping the ideas and individuals that initially brought FASD to public attention in Alberta.[7] The chapter reveals that FASD came to public attention in Alberta through the efforts of two social workers, who, in an attempt to secure funding and governmental support for FASD programs, strategically used images of hurt children. Because the movement for FASD started as a child welfare concern, women who give birth to children with FASD now take on particular representations within FASD discourse. The chapter concludes with a discussion of how this early history has affected the way FASD is currently understood in Alberta.

Because public knowledge of FASD is shaped, intersected by, and often located within larger discourses of health and medicine, chapter 5 presents a detailed overview of how discourses of risk and responsibility (as integral components of the contemporary health paradigm) are embedded in understandings of FASD in Alberta. The chapter reveals that FASD discourse focuses almost exclusively on at-risk children. As a result, adults with FASD are rendered invisible (and, in turn lack sufficient programs and services in Alberta). Moreover, women are targeted by prevention campaigns and are presented as potential culprits who create the risk of FASD. The chapter also highlights

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[7] This dissertation does not attempt to provide a chronology of FASD developments because it is difficult to verify and present an accurate timeline of events. There is no official record of how FASD developments took place in Alberta. In addition, the intention of this dissertation is not to complete a chronology of FASD. The intention is to examine the ideas and individuals that have shaped current FASD understandings in Alberta.

how FASD campaigns fail to consider the conditions under which pregnant women decide to consume alcohol.

In contemporary society, governance is enacted through technologies and strategies that seek to reshape the conduct of people without taking away their freedom to live as they see fit (Rose, 1999). Accordingly, chapter 6 explores how FASD experts in Alberta discursively position themselves in relation to the public perception that women who give birth to children with FASD are grossly irresponsible. The chapter highlights the complexity and/or difficulty of implementing FASD prevention measures that do not implicate or hold women responsible for FASD. The chapter reveals that while FASD experts are aware and critical of the ways in which FASD discourse implicates women, they are unable to enact substantial change due to the structural constraints (such as lack of funding and pressure to provide measurable outcomes).

The complex strategies employed by those who manage FASD in Alberta are further explored in chapter 7. The chapter looks at the strategies that FASD professionals use as they try to address FASD in Aboriginal communities and, at the same time, avoid reinforcing negative stereotypes and further racialization of FASD. The chapter shows that those in charge of managing FASD are aware and critical of racialized depictions of FASD but find themselves embedded in and limited by various negative discourses of race and FASD.

I conclude the dissertation by examining FASD knowledge production and the dissemination of discourse and best practices by FASD professionals (Gastaldo & Holmes, 1999). The final chapter (chapter 8) will examine the socio-political consequences of understanding FASD as it is currently understood in Alberta and the implications of such understandings for future FASD policies, programs and services.

This research makes make three significant contributions to the study of FASD specifically and to the field of public health more generally. First, the historical examination of FASD illustrates how Alberta's socio-political environment and the key players who bought FASD to public attention have shaped the ways in which FASD is currently understood and taken up in Alberta. It shows that the history of FASD has resulted in the constructed belief that some bodies are "at risk" and that others are "responsible" for creating this risk. By tracing the early history of FASD in Alberta, we now better understand how certain conceptions of risk, responsibility, gender, and race have become embedded within FASD discourse in Alberta.

Second, my findings expand upon the discourse of risk in public health literature, which, to date, concentrates on the ways in which individuals are encouraged to take responsibility for their own health and manage their behaviour to reduce the risk of sickness. My research shows that, within FASD discourse, women (particularly poor and/or Aboriginal women) are encouraged to take responsibility for the health of another – an innocent child – and to manage their behaviour to reduce any risk to the child's well being. In the context of FASD, alcohol consumption by a pregnant woman is seen as problematic not because it endangers the woman but because it poses a risk to the unborn child.

Third, the ways in which medical professionals and other experts understand a diagnosis or a disorder is often neglected. My research is, therefore, novel in its attempt to understand the ways in which FASD professionals understand this disorder. My findings show that those in charge of managing health and illness are not unthinking and uncritical administrators. They are aware of the limitations in FASD understandings, but are unable to enact significant changes due to structural constraints (such as funding limitations, pressure to demonstrate concrete outcomes, and a lack of political will to address structural issues like poverty and marginalization). In sum, this research exposes the attitudes toward and conversations about FASD in Alberta, and in so doing, identifies where such discourses limit or misdirect Alberta's FASD initiatives. Such conclusions lay a foundation for future research on FASD prevention and treatment in Alberta.

Chapter 2: Literature Review

Fetal Alcohol Spectrum Disorder (FASD) refers to a spectrum of disorders that result from in utero alcohol exposure. According to Golden (2005), FASD "is a way of naming the behaviour of pregnant women" that is "reflective of both pathological events and of late twentieth century ideas about fetuses and mothers" (p. 18). In Alberta, FASD programs and policies emerged as recently as the late 1980s and early 1990s.[8] However, there has long been speculation about the impact of alcohol consumption during pregnancy (Armstrong, 2003). The following historical accounts are not just early indications of FASD; they also exemplify how scientific theories and social perceptions shape broader understandings about alcohol and its impact on reproduction (Golden, 2005).

Women have been warned against drinking while trying to get pregnant for centuries. For example, in the Bible, they are instructed to "…drink not wine nor strong drink" during periods of potential conception (Judges 13:3-4 King James Version). In the eighteenth and nineteenth centuries, concerns about alcohol consumption during pregnancy became linked with the notion of heredity – in other words, people believed that alcoholic parents would produce alcoholic offspring and children with physical and mental defects (Armstrong, 2003). Both physicians and philosophers supported this belief. Physicians maintained that the mental, emotional and physical state of the parents (both father and mother) during conception determined the child's mental and physical character (Armstrong, 2003). Philosophers such as Plato argued that "children shouldn't be made in bodies saturated with drunkenness" because such bodies are "bad sower[s] of

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[8] The history of Alberta's programs and policies on FASD is discussed at length in chapter 4.

seed, and [are] likely to beget … offspring who are irregular, untrustworthy, and not at all straight in character or body" (Plato as cited in Pangle, 1980, p. 163).

Although physicians and philosophers initially discouraged both parents from consuming alcohol, over time focus began to shift almost exclusively to the mother and her alcohol consumption. The belief was that a child most resembles his or her mother and therefore inherits key traits from her. A child conceived while his or her mother is drunk is thus likely to inherit the mother's undesirable traits and be born with physical and mental defects. This belief evolved into Maternal Impressions philosophy, which maintained that a woman's imagination, moods, cravings, desires and whims affect the development of the fetus and, in turn, that when a woman's dreams, moods, cravings, desires and whims are considered inappropriate, they result in birth defects (Armstrong, 2003). This philosophy recognizes the harmful effects that alcohol can have on a fetus. However, it does not focus its attention on the cognitive and physical impact of alcohol exposure. It is, instead, preoccupied with the impact of maternal mood, attitude and emotion – which can be influenced by alcohol ingestion (Armstrong, 2003).

The English Gin Epidemic intensified concerns about parental alcohol consumption. The epidemic began in 1720 when the British government lowered taxes on gin to assist grain producers and the distilling industry (Armstrong, 2003; Golden, 2005). Lower prices meant that gin quickly replaced beer as the beverage of choice among the poor and working classes. The rapid increase in gin consumption, along with a substantial rise in social problems and public disorder, led to an increase in fetal and infant morality. In 1725, the College of Physicians petitioned for an increase to the gin tax, claiming that gin was causing children to be weak, feeble and distempered (Warner

& Rosett, 1975). The prevailing public concern about gin consumption was masterfully depicted in William Hogarth's 1751 painting "Gin Alley" (Armstrong, 2003). The painting depicts chaos, crime and general havoc all centering around the consumption of gin. It contains images of men fighting one another and falling down drunk – one man's body has even wasted away from alcohol consumption. Nearby a woman is being assaulted, while another is feeding gin to her baby. Perhaps the most striking image: a baby falling out of a drunken woman's arms. While Hogarth's painting illustrates the general breakdown of social mores and values, it remains most famous for its images of drunken mothers endangering the well being of their children.

Public concern and academic curiosity about the effects of alcohol on mothers and their children continued into the nineteenth century. In 1899, W.C. Sullivan compared children of alcoholic mothers to the children of their non-alcoholic relatives and noted that children of alcoholic mothers were twice as likely to die within the first two years of life. Sullivan also noted that an alcoholic mother was more likely to give birth to a "normal" child when she was incarcerated and unable to drink alcohol (Golden, 2005). As will be discussed later, the Manitoba government tried to adopt this approach of forced sobriety almost 100 years after Sullivan's study was published.

In 1968, French physician Paul Lemoine and his collaborators were the first to provide evidence that physical deformations of children can be attributed to alcohol consumption by their mothers. Lemoine published an article in a French medical journal describing his study, which involved 127 children born to 69 alcoholic families, and his findings. Lemoine's claims were met with scepticism by his French colleagues. However, five years later David Smith and Kenneth Lyons Jones came to a similar conclusion in the

United States. After studying a number of children with disabilities and developmental delays, they identified alcohol consumption by the mother as the common denominator. Smith and Jones went on to label these alcohol-induced disabilities and/or developmental delays as Fetal Alcohol Syndrome (FAS) (Armstrong, 2003; Chudley et al., 2005; Golden, 2005).

Like Lemoine's, Smith and Jones's claims were challenged by some medical professionals. However, they also garnered support from doctors and patients around the world who considered them to be "master detectives who had succeeded in deciphering symptoms that had long eluded [the medical community and general public]" (Golden, 2005, p. 6). Doctors and other medical professionals began sending them case studies, reports and descriptions of FAS, which led to a rapid increase in FAS literature. Professionals working in the area of mental disabilities found that a significant number of their cases involved alcoholic mothers; those working with alcoholic women reported higher rates of stillbirths, miscarriages and low-weight babies (Golden, 2005).

These initial findings were supported by a large epidemiological study called the Collaborative Perinatal Project (CPP).[9] The data from this study was used to compare the offspring of alcoholic and non-alcoholic mothers and, while it was not designed to measure impact of alcohol intake, it did provide valuable information about the long-term effects of prenatal alcohol exposure. The data revealed that 32 percent of children from

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[9] David Smith and Kenneth Lyons Jones, along with their Seattle colleagues, undertook this extensive, countrywide epidemiological study between 1958 and 1965. In the study, they compared 55,000 mother-child pairs from 14 different university-affiliated hospitals for risk factors related to cerebral palsy and other neurological disorders. During an interview with a mother, the researchers asked about present and previous drug use and about the woman's reproductive, medical and social history. They did not ask about alcohol use. Regardless of this omission, 23 women were identified as alcoholics. At a later date, the researchers compared the offspring of each of these 23 women to 2 other women of the same age, race, socioeconomic status, education and other relevant characteristics. The results showed that perinatal mortality among children from alcoholic women was 17 percent; perinatal mortality among children in the control group was only 2 percent (Golden, 2005).

alcoholic mothers were retrospectively diagnosed with FAS (no children from non-alcoholic mothers were retrospectively diagnosed) and that 44 percent had an IQ of 79 or lower (only 9 percent of children from non-alcoholic mothers fell into this IQ range) (Golden, 2005). The results of the study showed that prenatal alcohol exposure could lead to permanent disability and damage.

The lifelong effects of prenatal alcohol exposure were further confirmed when Jones, along with Streissguth and Clarren, explored the histories of children diagnosed with FAS. The researchers found that of the eleven children studied, two were dead, four had borderline intelligence and required remedial teaching, four were severely handicapped, and one could not be located for follow-up (Golden, 2005). Among these eight living children, only two resided with their biological parents while the others lived either in adoptive care or foster homes. Similarly, when Lemoine followed-up with his original patients 30 years later, he found that most were residing in institutions and had extensive mental and emotional disorders (Golden, 2005). Together, these studies presented FAS as a permanent and serious disability that leads to a lifetime of dependence.

Since its initial categorization FASD has been known as Alcohol-Related Birth Defects (ARBD), Fetal Alcohol Effects (FAE), Fetal Alcohol Syndrome (FAS) and Alcohol-Related Neurological Disorders (ARND). The latest incarnation, FASD, is an umbrella term that includes a range of effects borne by the child when the mother consumes alcohol. This term is widely accepted and subscribed to by medical professionals, educational institutions, legislators and the public.

In part due to the studies discussed above, Americans overwhelmingly believe that alcohol is dangerous to fetuses and that women should be responsible for ensuring the health of their unborn children; these are “well-known ‘facts’ in American society” (Armstrong, 2003, p. 2). The widespread acceptance of FASD as a public health concern in the United States is visible in the mandatory warning labels on alcoholic beverages. In 1989, the American government mandated that all alcoholic beverages in the United States be labeled with the following statement: “Women should not drink alcoholic beverages during pregnancy because of the risk of birth defects” (Golden, 2005). Similar warning messages can be found on alcoholic beverages in Canada, although they are not mandated by federal or provincial legislation. It could be argued that these kinds of messages have helped to reduce the incidence of drinking while pregnant in Canada over the last 20 years. For example, between 1994 and 1995, 17 to 25 percent of women reported drinking at some point during their pregnancy and 7 to 9 percent reported drinking throughout their pregnancy. Between 1998 and 1999, only 14.4 percent of women reported drinking at some point during their pregnancy and 4.9 percent reported drinking throughout their pregnancy (National Population Health Survey, 1994-95 and National Longitudinal Survey of Children and Youth, 1994-95 & 1998-1999 cited in Chudley et al., 2005).

However, the effectiveness of labels on alcohol is limited simply because many women do not have planned pregnancies and, therefore, are unaware they are pregnant when they consume alcohol. Moreover, this continued attention on alcohol consumption in FASD prevention campaigns ignores other risk factors for FASD such as higher maternal age, lower education level, lower socio-economic status, paternal drinking and drug use, reduced access to prenatal and postnatal care and services, inadequate nutrition, mental health problems, social isolation, and abuse (Astley et al., 2000; Chudley et al., 2005)

More recent studies have found FASD to be a complex and multifaceted disease, which is not just linked to alcohol consumption but also to environment and socioeconomic status. For instance, Bingol et al. (1987) found that women of different social classes produced FAS children at different rates despite consuming the same amount of alcohol. The study found nutrition to be the determining factor as upper class women ate a more balanced diet while lower income women often missed meals and relied more heavily on carbohydrates. Poverty can therefore exacerbate the impact of alcohol and "in doing so makes the behaviour more visible and thus more susceptible to public scrutiny"(Daniels, 1999, p. 91).

Despite evidence that correlates FASD with environmental and structural factors, most FASD initiatives and programs continue to focus on the prevention of alcohol consumption, and women who do not abide such warnings are subjected to legal sanctions. For instance, in 1996, Deborah Zimmerman, a resident of Wisconsin, was charged with attempted murder and reckless endangerment for giving birth to a child with the suspected diagnosis of Fetal Alcohol Effects (FAE) (Armstrong, 2003). While Zimmerman is just one of the many women charged in the United States[10] for endangering their children's health during pregnancy (through alcohol and/or drug use), she was the first to face a homicide charges for consuming alcohol during pregnancy.[11]

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[10] In the 1980s, hundreds of women were charged for illicit drug use during pregnancy. The charges ranged from child abuse to supplying drugs to a minor to assault with a deadly weapon (Armstrong, 2003). Inner city African-American women were disproportionately targeted for legal sanctions during this time period (Roberts, 1999).

[11] Zimmerman spent three years in jail as her case went through Wisconsin's judicial system. In May 1999 Wisconsin's Second District Court of Appeals ruled that Zimmerman could not be charged with attempted

A History of Fetal Alcohol Spectrum Disorder (FASD) in Canada

In the same year as Ms. Zimmerman's arrest, a Manitoba court ordered a 22 year-old, pregnant Aboriginal woman to enter treatment against her will. This woman, identified as Ms. G, was pregnant with her fourth child.[12] Her other three children were in the care of the provincial child welfare agency and two of these children were diagnosed with disabilities thought to be related to her addiction. Ms. G had attempted to access treatment repeatedly but was unsuccessful and was placed on a lengthy waiting list at her last attempt. A few weeks later, she discovered she was pregnant. Winnipeg Child and Family Services met with Ms. G and she agreed to enter treatment. However, five days later when the worker arrived to take Ms. G to the treatment facility, the worker found her intoxicated. Ms. G. stated that she would enter treatment, but "not right now" (Roy, 2005). In response, Winnipeg Child and Family Services brought forward a motion to send Ms. G to a treatment facility against her will in order to protect the fetus from harm. The Manitoba Court of Queen's Bench heard and upheld the motion three days later, declaring Ms. G to be "mentally disordered" under section 53 of the *Manitoba Mental Health Act* even though there were psychiatric reports to the contrary. Ms. G was placed in the custody of Winnipeg Child and Family Services and was forced to enter treatment in order to "protect the child to be born" (Schulman J. of the Manitoba Court of Queen's Bench quoted in Roy 2005, p. 108). The Manitoba Court of Appeal stayed the order and overturned the previous ruling, stating that, under Canadian law, the fetus does not have

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homicide because the unborn fetus is not recognized as a human being in Wisconsin (Armstrong, 2003).

[12] Another case that is frequently cited in FASD discourse is that of Jeanette Reid. On July 17, 1998, Jeanette Reid, a 33 year-old Aboriginal woman, was arrested for sniffing a lacquer-soaked rag at a bus stop in Edmonton, Alberta. Ms. Reid was seven months pregnant with her eighth child at the time of the arrest. Ms. Reid pleaded guilty to inhaling intoxicating vapors in violation of Alberta's *Public Health Act* and was sentenced to six-month prison term. As stated earlier, the case of Ms. G and Ms. Reid are frequently invoked in FASD discourse in Canada.

the status of a person and the finding of mental incompetence was not supported by evidence.[13] Canada, like the United States, has tried to use legal means to hold women responsible for the health of their unborn children. So far, however, these attempts have been unsuccessful.

In Canada, FASD has a fairly short history; most FASD prevention programs and interventions have been initiated in the past 20 years. Government-sponsored FASD initiatives began in the early 1990s with the Fifth Report of the Standing Committee on Health and Welfare, Social Affairs, Seniors and the Status of Women, titled “Foetal Alcohol Syndrome: A Preventable Tragedy” (Government of Canada, 2007a). In 1992, the Government of Canada responded to this report by developing and publishing a Joint Statement on Prevention of Fetal Alcohol Syndrome and Fetal Alcohol Effects (FAS/FAE) (Government of Canada, 2007a). Four years later, several government departments, along with health-related organizations and associations,[14] released another Joint Statement, this time acknowledging alcohol consumption during pregnancy as a “national health concern” and urging health professionals to implement prevention strategies to reduce the incidence of FAS/FAE (Government of Canada, 2007a, p. 1). In 1997, the co-signatories of this Joint Statement requested that a comprehensive approach to the prevention of alcohol-related birth disabilities be developed (Government of Canada, 2007a). Two years later, $11 million was allocated (over a 3 year period)[15] to the

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[13] Ms. G remained in the treatment facility and went on to give birth to a healthy baby. By the time the case had reached Supreme Court of Canada, Ms. G. had overcome her addiction and was raising the child on her own (Roy, 2005).

[14] The Joint Statement was produced collaboratively by Health Canada, the Canadian Pediatric Society, and 17 other national associations representing medical, nursing, and midwifery disciplines, aboriginal and multicultural organizations, and other groups active in the area of FAS/FAE (Government of Canada, 2007a).

[15] Five million dollars were allocated each fiscal year. $3.3 million was to given to Health Canada’s

development and implementation of FAS/FAE initiatives and strategies including public awareness campaigns, surveillance, and early identification and diagnosis (Government of Canada, 2007a; McKechnie, 2000). In 2000, the federal government, along with provincial and territorial governments, committed to a 5 year, $2.2 billion agreement on early childhood development ending in the 2007-2008 fiscal year. Under this agreement, the Government of Canada provided $500 million annually to the provinces and territories to enhance early childhood development programs and services. British Columbia, Alberta, Saskatchewan, Manitoba, Ontario and Yukon listed FASD as their priority issue and chose to increase supports for those affected by prenatal alcohol exposure (Government of Canada, 2007a).

Financial and political support for FASD prevention and treatment initiatives continued to grow. In 2001, the federal budget included $25 million in new funding for Fetal Alcohol Spectrum Disorder (FASD) prevention efforts on Aboriginal reserves. In the 2002 Speech from the Throne, the federal government committed to providing Aboriginal communities with the tools to address FAS and its effects. This same year, the Public Health Agency of Canada started a strategic planning process and scheduled consultations with provincial and territorial governments and other key stakeholders on FASD. These consultations informed the publication "FASD: A Framework for Action" (Government of Canada, 2007a, p. 1). This 2003 report starts with a note from then Minister of Health, the Honourable Anne McLellan, who claimed that approximately 9 out of every 1000 children born in Canada have FASD. The report goes on describe

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Population and Public Health Branch (now known as Public Health Agency of Canada) to spend on FASD initiatives across the country. $1.7 million was given to Health Canada's First Nations and Inuit Health Branch to spend on FASD initiatives in First Nations and Inuit communities (Government of Canada, 2007a).

FASD as a "preventable" and "life-long disability" that "puts a heavy social and economic burden on those with FASD, their families, their communities and our society as a whole" (Government of Canada, 2007a, p. 4).

The Government of Canada's programs and policies on FASD are located within its health portfolio, which currently supports two major FASD initiatives: 1) the Pan-Canadian FASD Initiative and 2) the First Nations and Inuit FASD programs. The Pan-Canadian FASD Initiative evolved out of the Canada Prenatal Nutrition Program (CPNP). This initiative is guided by the 2003 "FASD: Framework of Action" report and is designed to ensure that all of the collaborative partners are working towards common goals. The five common goals are:

1) Increasing awareness and understanding about the long-term implications of prenatal alcohol consumption for the children, families and communities;
2) Increasing capacity to identify the needs of those affected by FASD and of women who consume alcohol during pregnancy;
3) Creating tools to meet the needs of those affected in the community and facilitating the development and dissemination of national guidelines for FASD diagnosis and screening;
4) Expanding knowledge about the cause and impact of FASD and about effective preventive and supportive programs; and
5) Supporting action to prevent FASD and to assist those affected along with their families and communities by securing commitments from a range of stakeholders (Government of Canada, 2007b).

FASD has been recognized as a serious public health concern in Canada and particularly so in Canadian Aboriginal communities; this in spite of a critical lack of statistical information about the number of people afflicted. The Public Health Agency of Canada estimates that at least one child is born with FASD every day and that rates of FASD/FAE may be higher in some Aboriginal communities, but the Government of Canada does not actually collect statistics on FASD and therefore cannot establish accurate FASD incidence rates. The estimates put forth by the Public Health Agency of Canada are based upon several academic studies (see Chudley et al., 2005; Square, 1997; Asante & Nelms-Matzke, 1985; Habbick et al., 1996).

One study of an isolated First Nations community in British Columbia, found the FASD incidence rate to be 190 per 1000 births (Chudley et al., 2005). Another study in northeastern Manitoba, found an incidence rate of 7.2 per 1000 live births (Williams et al., 1999). The studies do not paint a consistent picture of FASD in Canadian communities, Aboriginal or not. Moreover, these studies have been criticized for their methodological flaws and limitations (Tait, 2009). Bray and Anderson (1989) argue that they

> lack methodological sophistication and therefore warrant scientific conservatism in accepting the prevalence rates prima facie … Native peoples should not be stigmatized by a condition such as FAS[D] which is difficult to prove as factual and which may have negative impact within the Native community. Caution is warranted before we conclude that FAS[D] is more prevalent in any Native peoples (p. 44).

However, as Salmon (2004), Stange (1994) and Tait (2009) point out, the lack of concrete statistical evidence has not altered the perception held by the federal and provincial governments and the general public that FASD is an Aboriginal health issue.

The absence of accurate incidence rates has been attributed to the lack of standardized criteria for diagnosing FASD and to the limited availability of medical personnel and FASD support services (Chudley et al., 2005). Without specific and widely agreed upon criteria for diagnosing FASD, diagnoses – when they were made – were inconsistent at best. Also, the diagnosis of FASD is a complicated and lengthy endeavour that requires a multi-disciplinary team of medical professionals. According to a recent study of Canadian medical professionals (i.e. paediatricians, psychiatrists, obstetricians, gynaecologists, family physicians and midwives), less than 60 percent of respondents knew that an individual with FASD has physical growth impairments, brain defects, *and* facial abnormalities (all three must be present) (Clarke et al., 2005). The need for a multi-disciplinary team makes a diagnosis difficult, particularly in rural and remote communities, which typically lack access to a variety of medical specialists. Moreover, doctors recognize that there is little value in diagnosing FASD unless the diagnosis is followed by treatment and support. As a result, medical professionals in Canada are either unable or unwilling to diagnose potential FASD cases.

In 2005, Health Canada's National Advisory Committee on FASD, in consultation with experts and practitioners on FASD diagnosis and treatment, developed the first Canadian guidelines to diagnosing FAS and its related disabilities. The complex diagnostic criteria contain multiple measures. The main measures focus on mental and/or physical defects and the amount of alcohol consumption during pregnancy. Within the FASD diagnostic criteria, the presence of facial dysmorphology is the most sensitive and specific marker of alcohol-related brain damage. The FASD facial criterion includes short palpebral fissures (i.e. a smaller opening for the eye between the eyelids), a smooth philtrum (the area between the nose and upper lip)[16], and a thin upper lip.

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[16] On most children the area between nose and lip is grooved. However, in children with FASD this area is smooth.

The inclusion of such facial features in the FASD diagnostic criteria is problematic for various reasons. First, racial groups that are genetically disposed to shorter palpebral fissures and/or thin lips are more likely to be flagged as having FASD. Second, the norms for palpebral fissures and philtrum are based on white, North American subjects. The measurements for other racial groups are not available to doctors and professionals making FASD diagnoses. Thus, members of other racial groups are being measured and diagnosed according to white, North American standards, resulting in inaccurate diagnoses (Chudley et al., 2005). Finally, children who do not exhibit physical abnormalities can still suffer the psychosocial impairments associated with FASD (Clarke et al., 2005). Thus, reliance on facial features as one of the primary criteria for diagnosis places those children not exhibiting physical abnormalities at risk of being overlooked or misdiagnosed.

Despite the problematic nature of utilizing facial features in diagnosing FASD, facial dysmorphology continues as one of three main FASD diagnostic criteria. In fact, new technology and software are being developed to aide in the measurement of facial features. For instance, the FAS Diagnostic and Prevention Network has developed FAS Facial Photographic Analysis Software and it is being marketed as an important tool for screening and diagnosing FASD in rural and remote communities.

The FASD diagnostic criteria also include body size measurements. The utilization of size – or even ratios of size – as a criterion is problematic because there is a wide discrepancy in size and shapes among “normal” individuals and communities or those not suspected of FASD. Moreover, using size as a diagnostic criterion does not account for racial and/or class variances in size and shape.

Conclusion and Discussion

There has long been public concern when pregnant women – or women who may become pregnant – consume alcohol. Initially, alcohol consumption by either parent was considered risky and was discouraged. However, these views gave way to the perception that women are solely responsible for the health of their unborn children. In other words, when a woman imagined, desired, or craved inappropriate things or when she behaved inappropriately [drank alcohol], she compromised the health of her baby; she created physical and mental disabilities in the child.

In part due to these lingering assumptions, researchers began to establish connections between the physiological and mental disorders of children and alcoholic mothers. By the late 1960s, this connection was given a name: Fetal Alcohol Syndrome (FAS). Medical literature on the subject exploded. Despite the findings by some researchers (i.e. Bingol et. al., 1987) that FASD may result from the interplay between alcohol consumption and other factors, like maternal age, nutrition, and access to health care, most Canadians – and the federal and provincial governments of Canada – continue to believe that alcohol consumption by pregnant women is the sole cause of FASD. As such, women are responsible (and can be blamed) for the prevalence of FASD. Women are also targeted by the public health campaigns that ignore the factors highlighted by Bingol et. al. (1987) and the context in which women consume alcohol.

Equally disturbing is the widespread perception – based on lacking diagnostic and statistical data – that Aboriginal communities have a higher incidence of FASD than non-Aboriginal communities, and by extension, that Aboriginal women are responsible for the poor physiological and mental health of children in their communities. FASD has been widely accepted as a medical health disorder and public health concern in Canada – particularly in Aboriginal communities. However, given the uncertainty surrounding its diagnostic criteria and prevalence rate, it remains unclear where these conclusions came from.

Chapter 3: Research Methodology

Research methodology refers to the researcher's theoretical perspectives or epistemologies[17] and his or her research methods, data collection strategies, and analysis techniques (Mayan, 2009). Accordingly, this chapter discusses my theoretical position along with the method, data collection strategies and analysis techniques that I use in this research.

In this dissertation, I trace the history of FASD in Alberta in an attempt to understand how the social and political climate facilitated the recognition of FASD as a medical disorder and a public health concern. This exploration centers on the following three questions: (1) how did FASD emerge and become accepted as a public health concern in Alberta? (2) how do FASD experts (namely public officials, researchers, health workers and social workers) currently understand of FASD? and (3) what are the implications of the current understanding FASD? The data for this qualitative research was collected through in-depth interviews, archival research and document analysis. I investigate concepts of power and knowledge within FASD understandings in Alberta through discourse analysis method.[18] Moreover, particular attention is paid to the ways in which race and gender are invoked and understood in FASD prevention campaigns and by those in charge of managing FASD in Alberta. I received ethics approval from the University of Alberta's Arts, Science and Law Research Ethics Board for this research.

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[17] Epistemology refers to the relationship between the researcher and the "known" (Denzin, 1989). Put more simply, epistemology refers to what can be accepted as evidence and knowledge.

[18] The data collection and analysis methods will be discussed in detail later on in this chapter.

Epistemology

I utilize a Foucauldian epistemological framework in this research. Michel Foucault's writings provide contemporary researchers with a theoretical framework for examining the historical process through which individuals are constituted as the subjects and objects of political, scientific, economic and legal discourses and practices (Horrocks & Jevtic, 1999; Mills, 2003). Foucault's work encourages individuals to question the "established way of thinking and behaving" and provides "a framework for thinking about questions of power which were the focus of his larger scale political interrogation" (Mills, 2003). He urges scholars to investigate the mechanisms through which we come to understand certain concepts and to consider the "conditions of their emergence and operation" (Foucault, 1985 p.73). Foucault argues that because all concepts, including gender, sexuality and health, change over time, we must continually interrogate the various motivations that invoke such concepts and reflect on how these concepts have been historically invoked and understood (Mills, 2003; Rabinow & Rose, 1994).

Foucault highlights the potential of health diagnoses to be invoked as normalizing[19] discourse and demonstrates how such discourse can be understood by tracing its history. In fact, Foucault is instrumental in exploring the ways in which particular epistemologies of disease categories are used to impose moral control and surveillance on individuals and populations (Turner, 1997). However, to understand how Foucault theorized surveillance, it is vital to situate his argument in his larger theoretical perspective.

Foucault (1977) argues that we have moved from a society based on punishment

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[19] Normalizing discourse refers to the process in which certain behaviors become ideal or the norm. Individuals would therefore use self-regulation and self-discipline to behave in the way that is considered to be normal and/or desirable in society.

to one based on discipline. In the previous form of society, the population acted out of fear of being physically punished. However, now we are in a social context where we have internalized the discourses of proper behaviour. This transition is best captured in Foucault's metaphor of the Panopticon.

The Panopticon is a physical structure that allows prison wardens to observe prisoners without being seen. Such a structure ensures that prisoners are never really sure if they are being observed or not. The knowledge that one could be under constant surveillance leads to internalized disciplinarily practices whereby people start self-regulating their behaviour (Mills, 2003). As Clarke (2006) explains, the Panopticon's effect is to make

> the prisoner think and feel that he is the object of constant surveillance, of the eye of power.... Gradually the inmate internalizes the inspector, the inspector is everywhere and nowhere, and it is, for all intents and purposes, the psychological internalization of power (p. 99).

Many prisons, schools and factories have been designed with the Panopticon in mind; many prison wardens, teachers and factory supervisors can now observe their prisoners, students or factory workers without being seen.

The metaphor of Panopticon is situated in Foucault's idea of surveillance. Surveillance refers to the gaze directed at all subjects. This gaze is a way of managing the population. There is no specific body that conducts surveillance per se; instead, particular discourses (such as medical discourse of a healthy body) do. People internalize these discourses and adjust their behaviour according to what is considered desirable in a specific discourse. For example, if it is considered healthy to be thin, then people regulate their bodies according to this discourse by dieting and exercising to obtain and/or maintain this body form.

To illustrate how epistemologies of disease categories facilitate surveillance, it is useful to examine Foucault's construction of mental illness. In his book *Madness and Civilization*, Foucault (1965) examines how discourses of madness facilitate the emergence of the field of psychiatry. The knowledge produced by the field of psychiatry is used to exert control over populations (De Maio, 2010). According to Foucault (1965), the medical treatments offered to those deemed to be mad are, in fact, indirect ways of regulating and controlling individuals. In addition to medical treatment, the figure of the doctor also embodies a framework of meaning that legitimizes governance over individuals. In the words of Clarke (2006),

> the physician, argues Foucault, plays no part in the life of confinement but becomes a central figure in the asylum. He is the gate keeper; the point of entry. He signs the certificate of admission and diagnoses the disorder (p.90).

Of course Foucault does not limit his analysis of disease to that of madness. He also examines the ways in which masturbation and hysterical women are constructed as medical disorders (see Foucault, 1990). Using these three examples

> Foucault shows us how expert discourses [or, in the case of this dissertation, medical discourses] develop systems of knowledge that sustain power relations and dominations in society (Clarke, 2006, p. 90).

Foucault perceives medical institutions as coercive in the sense that they exercise control and surveillance over individuals in everyday life and determine which individual actions are permissible and which are not (Tyler, 1997). The population does not consider these acts of control by the medical institution to be coercive, but rather accepts them as normal and legitimate. As Turner (1997) indicates,

> medicine and religion exercise a hegemonic authority because their coercive character is often disguised and masked by their normative involvement in the troubles and problems of individuals (p. xvi).

Foucault's theoretical concepts have been used extensively in the study of health and medicine. For instance, McCallum (1997) demonstrates how law and psychiatry construct certain persons as dangerous. He argues that the classification of "dangerous" is not based upon genetic or intrinsic characteristics of these individuals. Instead, the term "dangerous" constitutes a government's attempt to know, understand, and control certain individuals. In other words, certain individuals are constructed as dangerous through the discourse of law and psychiatry.

Similarly, Tyler (1997) uses Foucault's concept of governmentality to examine the various ways in which Australian boys are constructed as being "at-risk" for crime, instability, suicide, and imprisonment. This conceptualization and designation of risk is invoked to justify and promote various interventions. Tyler's genealogical examination of "at-risk" children shows that the characteristics for "competent" and "at-risk" children varies over time and is contingent upon institutional goals.

As seen above, McCallum (1997) and Tyler (1997), like many other health researchers, focus on the power of medical institutions and medical professionals to construct subjects through medical discourse. Lupton (1997) is critical of this focus on the power of medical institutions. She believes that such focus pays inordinate attention to the relative power of medical professionals and insufficient attention to the agency and power of patients. Foucault (1975) maintains that when patients assume control of their own health and well being, they are, in fact, manifesting their internalization of medical discourse and surveillance. For instance, when patients exercise and eat "healthy" in order to achieve what is considered to be a healthy body weight, they have internalized the medical discourse of a healthy body. The patients' acceptance of this discourse further reinforces the power of medical professionals. However, Lupton (1997) remains critical of Foucault's concentration on the diffusion of power because it overlooks the role that human agency plays in resisting oppressive power relations. Other scholars have also criticized Foucault for failing to consider how medical professionals and those in charge of managing disease make sense of, practice, and experience disease and medicine. In this research, I draw on Lupton's use of Foucault: I explore how FASD discourses was constructed in Alberta, how this history shapes current understandings of FASD, and I explore the ways in which FASD professionals exert individual agency to perpetuate and/or resist such discourses.

McCallum (1997) and Tyler (1997) drew upon Foucault's theorization to interrogate the ideas and histories of medical institutions and practices and thus better understand how discourses are created and sustained. They show that the Foucauldian theoretical framework can be particularly useful in mapping the history of a health disorder (such as FASD) and in developing a nuanced understanding of the processes through which health disorders are recognized. Foucault's framework encourages scholars to investigate the ways in which various perspectives of FASD became accepted as the official knowledge within Alberta. Moreover, this framework allows us to explore how children with FASD – and how the women who give birth to them – are depicted in FASD discourses.

Discourse Analysis

To understand the current FASD discourse in Alberta, I explore the ways in which it was created and made possible (Foucault, 1972). Foucault defines discourse as knowledge, representations, and/or understandings about a particular concept. This definition has been refined by more recent scholars, who consider the term “discourse” to mean a general domain of statements, a group of statements, and the regulated practices that produce particular statements (Fairclough, 2003). A general domain of statements includes all texts, statements, representations and meanings that exist about a particular subject and/or object (Mills, 2003). For instance, the discourse of alcoholism refers to all of the knowledge and/or understandings that exist about alcoholism. To elaborate, the public understanding of alcoholism has changed over the years. In the past, people generally perceived alcoholism as a personal weakness and a moral failing. However, currently alcoholism is largely understood as a disease that requires medical intervention and treatment. The discourse of alcoholism includes and refers to the changing understandings of alcoholism, which, in Canada, have been shaped by social movements and institutions (such as the 1920s temperance movement, federal and provincial governments’ regulations and taxes on alcohol, and the advertising and marketing of alcoholic beverages) (Giesbrecht et al., 2006).

Social institutions and their social, economic and political contexts play an instrumental role in the “development, maintenance and circulation of discourse” (Mills, 2004, p. 10). Discourse can also include all “things said and those concealed, the enunciations required and those forbidden” (Foucault, 1985, p. 100). Thus, discourse analysis requires the study of all that is prevalent and present along with all that is absent, silenced or excluded. Moreover, discourse analysis requires attention to not only what is being said but also who is saying it. As explained by Foucault, the examination of discourse requires investigating “who is speaking, his position of power, [and] the institutional context in which he happens to be situated” (Foucault, 1985, p. 100). Finally, discourse analysis does not deny the existence of non-discursive realms. Rather, it maintains that material reality and objects can only be experienced through discourse and the structures that discourse imposes upon our thinking (Foucault, 1985).

Power

According to Foucault (1985), discourse is comprised of both power and knowledge and contains a myriad of discursive elements that are employed using various strategies. Foucault conceptualizes power as localized, dispersed and diffused within social practices and relations (Turner, 1997). Such an understanding does not locate power solely within larger institutions and/or within the state. In fact, despite its overarching presence, the state is not considered capable of controlling individual behaviour and relationships (Gilbert, 2003). It is unable to assert such control because power is dispersed throughout society (Mills, 2003). Power is much like a capillary; it can emerge from anywhere and it exists in all social relations (Holmes, 2002). In other words, power is a set of practices and is embedded in social relations.

Power also cannot be possessed, only invoked or used strategically (Mills, 2003). This particular understanding of power does not present human beings as oppressed subjects of the state. Rather, human beings at all levels of the social structure and in all social institutions (i.e. family, school, police, and government) may encounter and access power (Lupton, 1995). In other words, power operates in all social systems and in all administrative and professional activities (Gilbert, 2003). It engages individual actors, who are both recipients of power and sites where power is enacted and resisted (Mills, 2003).

The study of power involves an examination of governmentality. The study of governmentality is concerned with the ways in which life is problematized and then managed (Gilbert, 2003). For example, an individual's ability to travel is dependent on the technology of the passport. In Canada, to acquire such a document, a citizen must follow a state-sanctioned process and, every five years, provide evidence of his or her Canadian citizenship. The Canadian state determines whether the claim to identity and citizenship is accurate and whether the applicant is then eligible for a passport. The state is thus able to manage an individual's identity by controlling the document that allows him or her to legally travel internationally.

An analysis of governmentality begins by determining what various experts set out to do, why they set out to do it, and what strategies they employ to achieve their goals (Rose, 1999). Such an analysis examines both the coercive and non-coercive strategies that the state and other institutions undertake in order to encourage individuals to engage in certain practices (Lupton, 1995). In the end, the study of governmentality seeks to understand the ways in which governments and other social institutions encourage citizens to exercise self-control and become self-managing.

Governance is successful when it convinces individuals to take responsibility for their own health, wealth and general well being and to practice self-control. The term "self-control" refers to the behaviours that result when people constrain themselves and act according to the standards of a "good" and "responsible" community member. These standards are not explicit and they are not directed by oppressive mechanisms. The behaviours or actions that correspond to these standards, however, are much more visible and are encouraged simply as a way to enhance well-being, happiness and pleasure (Lupton, 1995; Petersen, 1997). Foucault (1988) conceptualizes these behavioural practices as “technologies of the self” (p. 19).

In contemporary society, a range of interventions and programs are initiated to encourage each individual to be responsible for and in control of themselves (Rose, 1999). This enacting of self-control as a mode of governance is actively promoted by normative discourses and knowledges produced by literary works, educational systems, political bodies, and/or institutions of health. The apparatus and logic of governmentality (that is, notions of self-control and self-management) are also strongly tied to the development of the neo-liberal state which, traditionally, has relied on a discourse of individual liberty and rights and has advocated against intervention of the state (Lupton, 1995). Governmentality enables the management of people’s behaviour through non-intervention tactics such as normalizing discourses and knowledges instead of outright domination and control.

Knowledge

As explained earlier, governmentality depends on systems of knowledge.

> Knowledges are governed by certain rules that establish what can be said truthfully in any one time, the criteria of evidence, the forms of proof, and even the very object of which they can speak (Rabinow & Rose 1994, pg. xii).

Knowledges should be understood as “regimes of enunciations,” which determine who can speak, “according to what criteria of truth, from what places, authorized in what ways, through what media machines, utilizing what form of rhetoric, symbolism, persuasion, sanction or seduction” (Rose, 1999, pg. 29). In other words, the term “knowledges” refers not only to the specific knowledge in question but also to the discourses and events that make such knowledge possible. Because knowledge is socially produced, it is important to examine how and from where knowledge emerges as well as the process through which it becomes generally accepted.

Experts play an instrumental role in constructing and legitimating normalizing discourses and knowledges. The knowledge that they produce enables populations to be measured and documented, compared to each other, and categorized as normal or abnormal (Lupton, 1995). Experts identify ways in which individual behaviour can be managed so as to improve societal well-being, ensure political gains, and/ or solve social problems (Lupton, 1995). The power of an expert is based on the perception of the expert's competence, training, and ethical values (Rose, 1999).

Experts play an instrumental role for governments because they link political objectives and personal conduct. Knowledge that is created and supported by experts (especially those discourses that can be used to encourage a greater sense of personal responsibility and self-control) is often compiled and used as a technology of the government. In other words, it is used by the government to justify a practice that will shape individual conduct in the hope of achieving certain results while avoiding others.

As seen above, Foucault urges scholars to investigate power and knowledge in health discourse. He does not, however, provide a clear methodological framework. As such, I rely upon the work of the scholars discussed in this chapter (i.e. Mills, 2003; Lupton, 2005; Turner, 1997) and upon their conceptualization of Foucault's theoretical framework to guide my research tools and techniques.

Data Collection

I collected data in three different ways. I conducted interviews; I conducted archival research; and I collected policy and program documents. These methodologies were employed to ensure that I acquired a great range and a great depth of understanding of FASD discourse in Alberta. They were used simultaneously and often guided each other. For instance, my interview questions were shaped by the data that I discovered during archival research and document analysis. Similarly, the searches that I conducted in the archives and in FASD documents, programs and policies stemmed from information I learned from interview respondents.

While the Foucauldian framework provided an overarching guideline for this research (in terms of tracing the key ideas, figures and historical processes that brought FASD to public attention), the actual data was collected using various qualitative methods. I chose qualitative methods because they allowed me to examine how respondents understood FASD and made sense of FASD programs and policies. In addition, a qualitative methodology allowed me to examine the reasons behind the respondents' beliefs and perceptions. This qualitative research began in January 2006 and concluded in December 2007.

Interviews

A total of 23 semi-structured interviews were conducted with several professionals who were either currently or previously employed in the field of FASD in Alberta. These semi-structured interviews were conducted utilizing a core set of questions (see appendix C). As mentioned earlier, some interview questions were based upon the ongoing analysis of archival and policy and program research material. The interview questions were designed to examine how FASD officials operated and otherwise thought about FASD programs and policies. I used the questions to inquire about an interviewee's understanding of FASD, his or her position of employment and employment duties, and to determine where the interviewee stood in relation to the various discourses of FASD. For instance, the questions sought to draw out the interviewee's perspective on: the way FASD is currently understood, the ways in which programs and policies are enacted, and the objectives and practices of prevention campaigns.

I chose to conduct semi-structured interviews because of their flexibility. This type of interview gives respondents the opportunity to respond and to illustrate concepts in their own words. It allows respondents to provide information that they think is relevant or important and researchers to clarify and more fully explore the responses as the interviews proceed. For instance, a researcher may seek further details about information that has been disclosed in an interview and/or follow leads on topics not covered by the prepared questions. Moreover, the interviewer can change the interview questions to reflect the information gathered in previous interviews.

During the interviews, there was simultaneous collection and analysis of data. Soon after an interview was completed, it was transcribed and analyzed; subsequent interviews were informed by the information it gathered. Therefore, while the core set of questions remained the same, I constantly added new questions to further investigate and clarify information that was provided by respondents. Some respondents were even interviewed more than once in order to clarify or collect further details on the information gathered during the first interview.

With the exception of two phone interviews with respondents from Fort McMurray and Cold Lake, all of the interviews were conducted in person. One interview took place in Salmon Lake, British Columbia. The rest were located in Alberta, specifically in Lloydminster, Vermilion, Red Deer, Calgary, Lethbridge and Edmonton.

I began my research by investigating the role that the Alberta government and other FASD-focused institutions played in bringing FASD to public attention. I identified government departments and agencies that were involved in FASD and was careful to ensure that a wide variety were represented. It was critical for me to learn how the individuals in charge of managing FASD within these departments and agencies understood FASD (Mills, 2003). An analysis of these perspectives would produce a rich understanding of FASD's historical and present context. In contrast to a simplistic cause-and-effect analysis of historical events, this type of analysis could uncover the myriad of complex intersections and relationships that contribute to a given circumstance or situation. This type of analysis could also expose intricate and complex relations of power.

To maintain confidentiality and protect privacy, I will not disclose the names of the interview respondents. However, I can say that the respondents held (or had held) the following positions: police officers, medical doctors, university researchers, child welfare workers, senior government officials, addictions counsellors, community workers, and employees and program directors of nongovernmental and non-profit organizations.

I started the interview process by identifying and selecting key respondents who had particular insights into and/or experience with FASD (Morse & Field, 1995). The initial set of respondents was selected because they met one or more of the following criteria: 1) They had personal experiences within the FASD field; 2) They had worked or were working in the FASD field; and/or 3) They occupied positions of social or political significance within the FASD field.

The first respondents were selected for their role as "claim makers." Gomez

(1997) defines claim makers as individuals, organizations or other social actors who make assertions about a problem to raise public awareness and provoke a public response. Therefore, the first respondents were selected because of the role they played in getting FASD recognized as a medical, social and political concern in Alberta. Due to my previous employment experience[20] at a not-for-profit agency, I knew that two key figures were responsible for bringing FASD to the attention of the Alberta public in the 1990s. Therefore, I interviewed these two individuals to understand the historical development of FASD in Alberta. In turn, these two respondents referred me to others who had worked or were currently working in the FASD field. I obtained the contact information for the majority of these referrals through Alberta Children and Youth Services' official website.[21] The referrals were listed on this website because of their involvement in FASD programs and organizations. The remaining respondents were located using a snowball technique (i.e. interview subjects frequently offered suggestions and contact information for other people that I should interview).

An additional five respondents were contacted on the FASD Canadian Link listserv.[22] These secondary informants were recruited through a posting on the electronic mail listserv requesting the participation of anyone currently working in the FASD field in Alberta. Secondary informants are located in the same or similar settings as key informants and are interviewed to verify the information provided by key informants (Morse & Field, 1995). I placed an advertisement on this listserv to recruit front line

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[20] I worked at a not-for-profit agency in Edmonton, Alberta as a placement coordinator. This employment position will be discussed in detail further on in this chapter.

[21] The current website address is of Alberta Children and Youth Services is http://www.child.alberta.ca. The names and contact information listed on the website have changed since these interviews took place. The people interviewed for this study are no longer listed on this website.

[22] FASD Canadian Link is run by Christine Leblanc and serves people working in the FASD field. Further details are available on its website at http://lists.von.ca/mailman/listinfo/fasd_canadian_link.

workers and those who were new to the FASD field. This last group of interviews represents an attempt to gather the perspectives of individuals from the larger FASD field (i.e. to include community workers, doctors, teachers, nurses, and police officers who work with either individuals who are afflicted with or affected by FASD or women who are considered to be at risk for giving birth to children with FASD). In this research the secondary informants not only confirmed the initial findings, but also provided further depth and insight into the subject matter. They provided information that was only accessible from their particular subject positions. I stopped conducting interviews once they reached saturation. Saturation is when the researcher is able to identify patterns and themes in the data (Morse & Field, 1995). I realized saturation had been achieved when the last few interviews failed to elicit any new themes or information.

The interview respondents were initially contacted by email, phone, and/or regular mail. Those contacted through email were sent a brief description of my research project (see appendix A) along with a copy of the consent form (see appendix B). Those contacted by telephone were asked for their email address or mailing address, to which I sent a description of the research project and a copy of the consent form. All respondents consented to the interviews and indicated so by signing the consent forms or providing verbal consent during an audio recording. Some respondents were given a $25 gift certificate to Chapters as a gesture of gratitude for their participation. Others declined the $25 gift certificate because their employment positions restricted the acceptance of gifts from public.

All the interviews were recorded on digital recorders. The transcription was completed by three different typists and checked for accuracy by the researcher and another hired individual. The typists and the proof reader signed confidentiality agreements. The audio files were burned onto compact discs for transcription. All of the compact discs were returned to the researcher upon completion of the transcriptions.

Archival Research

Archival research was undertaken to explore the socio-political and historical conditions that led to the emergence of FASD as a public health concern in Alberta. In other words, it involved examining not just what is known about the topic but also how we have come to know what we know about it. More specifically, I set out to investigate how FASD as a concept has been produced and understood and how it has changed over time.

I focused my archival research on the question: how did certain perceptions and ideas about FASD diagnosis come into existence? Therefore, I examined the discourses on mothering, children, child health, pregnancy, prenatal and postnatal health, gender, race, and alcohol that were prevalent in the 1970s, 1980s, and 1990s. A review of the discourses in the 1970s and 1980s revealed very little about the understandings of FASD, but did shed light on major developments in children's and women's rights in Alberta. This discourse of children's and women's rights in Alberta is discussed in chapter 4 of this dissertation. The archives also revealed very little about mothering, prenatal health, pregnancy, and FASD in the 1990s. I found most of this information online, and it informs the substantive chapters of this dissertation.

My archival research was conducted at the Alberta Provincial Archives in Edmonton and the Glenbow Archives in Calgary. While the ultimate goal of the search was to understand the socio-political context in which FASD rose to the forefront of public consciousness, I was also interested in how gender, race, health, and alcohol had been historically conceptualized in Alberta. In other words, who was considered responsible for health of women and children? Who did health interventions target? What discourses facilitated interventions? I searched for documentation that illustrated or explained how the consumption of alcohol by women has been historically understood in Alberta. I also conducted searches for any historical events, discourses, or practices that spoke to racialized mothering and surveillance in Alberta. In order to trace discourses of health, gender, alcohol, and race, I started with a broad examination of the following organizations:

1) The Imperial Order of Daughters of the Empire
2) The Calgary Status of Women Action Committee
3) The Elizabeth Fry Society
4) The Follinsbee Centre for Mentally Handicapped Children
5) The Victorian Order of Nurses
6) The Alberta Council of Child and Family Welfare
7) The Calgary and Edmonton Birth Control Associations
8) The Samaritan Club of Calgary

These organizations were selected because their work focused on women, children, and/or alcohol use and provided insight into Alberta's historical context. The initial examination of these files provided information on how health, hygiene, and maternal responsibility have been historically conceptualized and understood in Alberta. It also led to the examination of other organizations that worked on issues related to women's health, race relations, and/or alcohol consumption.[23]

Once I had thoroughly researched the above organizations, I began searching for additional information using the following terms: temperance, alcohol, child, children health, pregnancy, baby, fetus, drunk, women + alcohol, Aboriginal, drugs, child + disability, fetal alcohol, mother(ing), blame, stigma, criminal, responsible, and risk. I selected these terms because they were prevalent in my FASD research and literature review. Despite the assistance of the staff at the archives, these search terms did not yield any relevant information.[24]

Next, guided by information from the interviews and document analysis, I proceeded to search the archives for information on the following organizations:

1) The Alberta Legislature (using the Legislative Session Papers)
2) The Alberta Department of Health, Alcohol, and Drug Abuse
3) The Alberta Alcohol and Drug Addiction Centre
4) The Action North Recovery Centre
5) The Alberta Council of Women (1991-1995)
6) The Alberta Council of Women's Affairs (1983-1989)
7) The Alberta Association of Young Children (1978-1982).

In the archives, I found membership records and meeting minutes that belonged to these organizations, but not much that pertained to FASD as it is understood or has developed

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[23] I also conducted searches on The Catholic Women's League, The Indian Association of Alberta, The Old Sun Residential School, The Calgary Indian Friendship Centre, The Calgary Indian Missions, The Women's Christian Temperance Movements of Alberta, The Metis Association of Alberta, The Hobbema Indian Agency, and The Sarcee Indian Agency. These searches did not produce information pertinent to this research project.

[24] The lack of relevant information could be due to the following: 1) The way that information is currently classified and stored in the archives made it difficult to access; 2) Information on these topics were not organized and available at the time of this research; and/or 3) Information on these topics was classified as confidential and, therefore, was not available in the public records.

in Alberta. Therefore, the majority of the materials gathered in this search were not used in the analysis.

Given the history of the eugenics movement in Alberta, I also spent a considerable amount of time identifying the events and individuals that promoted sterilization in Alberta.[25] The purpose of this research was to understand the particular discourses that were invoked and utilized to justify eugenics in Alberta. I was interested in knowing whether discourses of mothering, race, gender, and nation building were invoked and, if they were, how and in what context such arguments were made. This train of investigation proved to be to huge endeavour in itself and, instead of adding to the research, it led the focus away from the original research goal. Therefore, the significant data gathered on the eugenics movement will be utilized in future research projects.

Policy and Program Documents

Throughout this research project, I used the Internet extensively to conduct background searches on particular organizations and individuals and to download brochures, posters, and policy documents from relevant organizations. My preliminary research on FASD focused on materials that were disseminated by or discussions that were conducted on the following listservs: CHNET and FASDlistserv. Both listservs send FASD-related information, such as newspaper articles or event information, to their subscribers. They also enable subscribers to engage in discussions about various FASD topics and to express parental and professionals concerns. The exchange of information on these listservs was useful because it helped me identify some of the discourses that are

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[25] There is a history of eugenics and sterilization in Alberta. Between 1929 and 1972, the Alberta Eugenics Board sterilized 2,834 people (Grekul, Krahn & Odynak, 2004). Such sterilization was legal under the Alberta's *Sexual Sterilization Act*. The Alberta Eugenics Board targeted women, teenagers, young adults, and Aboriginals for sterilization (Grekul, Krahn & Odynak, 2004).

prevalent within the field of FASD and it improved my understanding of how Alberta's current programs and policies compare to those in other provinces in Canada and in the United States. The listservs also helped me identify the individuals and organizations deemed to be experts or leaders in the area of FASD.

My research included attendance at two provincial conferences on FASD. The first took place in Calgary and the second in Lethbridge. The first conference, titled "Promising Practice, Promising Futures,"[26] was held on March 16 and March 17, 2006 at the Calgary Hyatt Regency Hotel. The other, titled "Fetal Alcohol Spectrum Disorder: A Growing Perspective Conference," was held on May 4, 2007 at Lethbridge Community College. Both conferences were funded and organized by the Government of Alberta. These conferences aided in: 1) the detection of the various competing discourses of FASD; 2) the identification of key informants or individuals considered to be leaders in the FASD field; and 3) the recruitment of research participants. The conferences also helped me to identify which issues were considered important in the FASD field and to understand the contemporary direction of FASD initiatives.

Because this research seeks to understand the process through which FASD came to be recognized as a medical disorder in Alberta, medical organizations also had to be examined. The Alberta Medical Association and The College and Association of Registered Nurses of Alberta were investigated to understand the roles that doctors and nurses played in early FASD advocacy movements. However, neither organization's web

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[26] The following Government of Alberta departments funded this conference: Aboriginal Relations, Advanced Education and Technology, Children and Youth Services, Health and Wellness, Education, Employment and Immigration, Justice, Seniors and Community Supports, and Solicitor General and Public Security. AADAC and the Alberta Gaming and Liquor Commission also provided funds.

site contained any historical information.[27] Interestingly, during interviews with medical professionals, I discovered that medical workers were not involved in the initial FASD advocacy movements within Alberta. This finding shifted my research project from its initial focus on medical professionals to a broader examination of the public perceptions and socio-political factors that were responsible for bringing FASD to public attention in Alberta.

To this end, I spent a considerable amount of time examining promotional materials and posters on FASD, which were distributed by various governmental departments and not-for-profit organizations. It was significant that these promotional materials and posters were produced through the intersectoral collaboration of various agencies and governmental departments.[28] The concept of "intersectoral collaboration" refers to the forging of alliances between different levels of government, private bodies, non-government organizations and community groups, to create, in effect, a multi-leveled and multi-organizational network of surveillance and regulatory practices (Petersen, 1997; Turner, 1997).

Additional documents from the following organizations were also collected and analyzed:

1) The Alberta Alcohol and Drug Addiction Commission (AADAC)
2) Alberta Children and Youth Services
3) Alberta Health and Wellness
4) Catholic Social Services (CSS)
5) The Southwest Alberta Child and Family Services Authority

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[27] The Alberta Medical Association's website is http://www.albertadoctors.org/. The College and Association of Registered Nurses of Alberta website is http://www.nurses.ab.ca/.

[28] All of the posters analyzed were produced in collaboration with AADAC, Alberta Health and Wellness, and Success by Six.

6) The Lakeland Centre for Fetal Alcohol Spectrum Disorder
7) Success by Six
8) Alberta Learning
9) The Legal Aid Society of Alberta
10) The Alberta Aboriginal Committee on FASD
11) The Edmonton Journal
12) The Edmonton Sun
13) Well Community Well Families
14) The Alberta Solicitor General
15) Capital Health
16) The YWCA
17) The Bissell Centre
18) Bosco Homes

To contextualize and understand Alberta's FASD programs and services, documents from the following federal and provincial agencies were also examined:

1) Health Canada
2) The Aboriginal Healing Foundation (AHF)
3) The Canadian Parliament
4) The British Columbia Centre of Excellence for Women's Health
5) The First Nations Health Bulletin
6) The National Collaborating Centre for Aboriginal Health
7) The Yellowknife Association for Community Living
8) The Canadian Nurses Association

All of the documents examined discussed FASD in some capacity. While reviewing these documents, I paid particular attention to how FASD was being discussed, which individuals were being hailed as authorities in the field, how individuals diagnosed with FASD were represented, and what major issues or concerns about FASD were discussed. In addition, I paid careful attention to the manner in which women who gave birth to children with FASD were talked about and/or represented.

Along with various program and policy documents, I undertook an extensive search of legal and governmental discussions of FASD. The following key terms and their derivations were searched in the Alberta Hansard[29]: FASD, alcohol, drug use, pregnancy, Aboriginal, women, child, health, fetus, damage, and addiction. These search terms yielded documents that provided an extensive chronological history of the FASD-related discussions that took place in the Alberta Legislature. I included in my analysis any discussions about FASD from 1970 to present day. The year 1970 was selected because FASD was first diagnosed in North America in 1973.[30]

Data Analysis

In this research, I used discourse analysis to examine (1) the social and political process through which FASD first emerged and became recognized in Alberta as a public health concern; (2) the perceptions that those who currently manage FASD in Alberta

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[29] Hansard is the edited verbatim reports of the debates that take place in a Legislature or a Parliament and in its committees. Alberta Hansard has a yearly index that lists the subject and a speaker list for each session of the Legislative Assembly of Alberta. All legislative debates utilized in this research are available online at http://www.assembly.ab.ca/net/index.aspx?section=doc&p=han.

[30] I also searched the following electronic databases available through the University of Alberta library: 1) The Alberta Law Collection, which includes statutes and bills of Alberta, debates of the Alberta Legislature, journals of the Alberta Legislature and The Alberta Gazette; 2) The Canadian Information Resource Centre, which includes the Canadian Research Index and the Canadian Information Desk; 3) Alberta Queen's Printer, which includes acts, regulations and other government publications; 4) The Legislative Assembly of Alberta, and 5) Early Canadiana Online, which includes bills and statutes. These searches did not produce any relevant information.

have about the disorder; and (3) the implications of understanding FASD as it is currently understood. My data analysis was guided by more specific and detailed questions, which are elaborated upon below. These questions were constructed to support and help answer my three central research questions.

As Fairclough (2003) explains, discourse analysis is "concerned with continuity and change at this more abstract, more structural, level, as well as what happens in particular texts" (p. 3). Discourse analysis allowed me to determine whether FASD is framed by broader societal perceptions of gender, class, health, and race, and, if so, to explore the manner in which it is framed. I wanted to understand the ways in which FASD discourses are "at once controlled, selected, organized and redistributed by a certain number of procedures" (Foucault, 1985, p. 52). Therefore, I used discourse analysis to deconstruct and analyze not only oral narratives (provided in the interviews) but also texts (taken from posters, policy documents, and program mandates).

The responses given by the FASD professionals that I interviewed were closely scrutinized in an effort to understand if and how their understandings of FASD were framed by broader discourses of race, gender, class, and health. This was done because all knowledge is socially constructed and produced within discourses (Boutain, 1999). I closely examined how FASD professionals spoke about FASD as a health disorder, women who give birth to children with FASD, and children diagnosed with FASD. I paid particular attention to the language used to describe FASD because FASD as a health disorder gains meaning and is understood by policy makers and the general public in accordance with how FASD professionals talk about the disorder. Both official and unofficial FASD discourses were analyzed to determine how these discourses were formed, which discourses were circulated, and which statements were excluded. This research also noted which discourses were funded, promoted, and disseminated and identified the social and political positions that invoked and enforced these discourses.

As discussed earlier, an examination or deconstruction of discourse serves to reveal the underlying knowledge and various power relations upon which such discourse is premised and reliant. The data collected in this study (i.e. interview transcripts, archival material, and program and policy documents) was therefore, examined for the particular ways in which (1) power was conceptualized and invoked and (2) FASD knowledge was produced. More specifically, I reviewed the data with the following questions in mind: What is currently known and accepted about FASD? How did such knowledge and practices come to be accepted? What socio-political conditions were necessary for such knowledge to be accepted? What prior knowledge or conditions were necessary for the current understanding of FASD to be accepted? What social practices have been recruited into the present FASD understandings and interventions?

In addition to these questions, I also considered how individuals (i.e. those that I interviewed and the authors of the texts that I collected) negotiated and understood various programs, policies, and perceptions of FASD. During data analysis, I paid particular attention to the ways in which these individuals negotiated the multiple discourses of FASD, which are often contradictory or competing.

I also examined the data to see if professional manifestations of power[31] – or resistances to power – were present in FASD discourses. The interview transcripts and the archival, program, and policy documents were analyzed for the various ways in which

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[31] The manifestation of power in this context means the ways in which FASD professionals shape and define our understanding of FASD in Alberta and the impact of that these understandings ultimately have.

individuals (i.e. front line workers, program designers, policy advocates, etc.) enacted power. For example, how did they adhere to and/or resist particular definitions of FASD? Did they disseminate certain representations of FASD (i.e. representations of children afflicted with FASD, representations of mothers who give birth to babies with FASD, etc.)? Did they promote certain understandings of FASD and oppose others? (i.e. maintain that certain individuals are at risk or that certain segments of the population are most affected by FASD)? I also noted the perspectives that were missing from the FASD discourse because, when investigating power, a researcher cannot just pay attention to the public performances of power; he or she must also consider the hidden transcripts (Mills, 2003).

Limitations

After completing my bachelor's degree, I was employed by an Edmonton-based not-for-profit agency[32] as a Placement Coordinator. In the two years that I was employed there, I learned about the bureaucracies, difficulties, and tensions present in the field of children's services. I dealt with overwhelmed relatives and social workers, and with children with extensive needs. I noticed the persistent lack of adequate resources and the overwhelming shortage of qualified child welfare workers. Throughout this research, I have been mindful of my past experience and the ways in which my employment history influenced my interview questions and my analysis of the information gathered. In order to circumvent personal biases or leading questions, I had my interview questions examined by my doctorate supervisor and other colleagues. Also, being mindful of my critical stance, I took extra measures to understand FASD through the perspective of

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[32] The name of the agency is omitted to preserve the confidentiality of research participants who were recruited from this agency.

those I was interviewing. It is through self-reflection and conversations with my supervisor and other colleagues that I became curious about how these workers understood the various contradictions and competing discourses of FASD. I can confidently assert that my interviews greatly benefited from such candour and self-reflection. As a result, these interviews speak to the contradictory and difficult positions that workers are placed in and how they try (successfully or unsuccessfully) to negotiate various political and social terrains. My employment experience and self-reflections enabled me to understand the respondents' perspectives and to ask questions that elicited greater detail or more information about the topic at hand.

Finally, while Foucault approaches his work from a critical perspective, he does not believe that the discovery of hidden truths is inherently good or will lead to positive results. He cautions people to be critical of their own perspective and to assume that no one ever reaches a position where they are privy to the final truth about a subject (Mills, 2003). Accordingly, in this research I have not attempted to understand the truth about FASD but rather to trace the discourses of FASD through a particular theoretical framework. According to Foucault, our analysis is determined by our theoretical perspective and mine is no exception (Mills, 2003). Therefore, this chapter has presented a detailed account of the perspectives and questions that guided this study and its collection and analysis of data. It should be reiterated that while Foucault does not present us with a concrete methodology, he does offer a method of thinking and posing questions critically. It is this method of thinking and posing questions that I used in this research.

Chapter 4: The Making of a Medical Disorder: Tracing the History of FASD in Alberta

When members of the Alberta legislature debated Bill 45, they presented FASD as a problem that is caused by negligent mothers and that involves helpless children who eventually grow up to be a significant financial and social burden on society. This chapter helps us understand why this understanding of FASD has emerged in Alberta.

On Wednesday, November 16, 2005, the members of the Alberta Legislature met to respond to the second reading of Bill 45, the proposed *Maternal Tort Liability Act*.[33] This bill would allow children to seek compensation for the prenatal injuries that they sustained due to negligent driving by their mothers (Legislative Assembly of Alberta, 2005a). In other words, it would allow a child to sue his or her mother for damages and to receive compensation from the mother's insurance company. The bill was defeated for two reasons: first, it imposed a legal duty of care upon a pregnant woman in respect to her fetus and later on to her child; and second, in order to recognize a child's right to sue for prenatal injuries, the court would need to recognize a fetus as having legal rights and, therefore, as a person before law (Legislative Assembly of Alberta, 2005b).

Interestingly, while the proposed legislation pertained to motor vehicle accidents, parties arguing both for and against this bill frequently invoked FASD. For instance, one Member of the Legislative Assembly (MLA), Dr. B. Miller,[34] compared prenatal injury from car accidents to the "so many children who suffer from Fetal Alcohol Spectrum

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[33] Bill 45 was introduced by Member of the Legislative Assembly (MLA) Frank Oberle on November 15, 2005. Frank Oberle is a member of Alberta's Progressive Conservative Party and represents the constituency of Peace River, Alberta. He is currently serving his second term in the Alberta Legislature.

[34] Dr. B. Miller was a member of the Alberta Liberal Party and represented the constituency of Edmonton-Glenora from 2004 to 2008.

Disorder as a result, you know, of negligence of the pregnant mother" (Legislative Assembly of Alberta, 2005b, p. 1683). He went on to argue that while "we might sympathize with [the court] going after the liability of [a] woman who drinks so much and has a child with Fetal Alcohol Syndrome," he had concerns about allowing courts to penalize women for negligence of any kind during pregnancy (Legislative Assembly of Alberta, 2005b, p. 1683). MLA Bill Bonko[35] similarly invoked maternal responsibility for Fetal Alcohol Syndrome in his arguments:

> If this bill's intent is to protect the unborn and allow for the unborn to sue later on for injuries sustained while in the womb, then why not expand the bill today and allow for children whose mothers are negligent during their pregnancy; for example, mothers that drink and mothers that do drugs? We all know that Fetal Alcohol Syndrome and drug-addicted children when born, you know, cause all Albertans to pay a heavy price through health care and just overall with our ability to maintain and look after these children from birth to the end of their lives. It's unfortunate, but it does cost all Albertans through health care and education … There are two examples that cost Albertans as to the negligence of parents. Now, the question that comes to the floor is: what is the government doing to protect these children and provide these children with a voice? Why not allow them to sue as well? This goes on each and every day with no charges being laid? (Legislative Assembly of Alberta, 2005b, pp. 1685-1686).

The object of interest here is not the bill itself but rather the ways in which FASD is invoked in the debate surrounding this bill. It is revealing that both legislators are sympathetic to the idea of holding women who consume alcohol during pregnancy responsible and legally liable for giving birth to children with FASD and are critical that parallel legislation does not exist for FASD.

The debate on Bill 45 creates powerful images of negligent mothers who drink during pregnancy, of helpless children who are victims of their mother's decision to drink, and of the financial and social burdens that the province will bear to care for

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[35] Bill Bonko, a member of the Alberta Liberal Party won the 2004 provincial election in the newly created constituency of Edmonton-Decore. He went on to lose the riding in the 2008 election to a Progressive Conservative candidate.

children affected with FASD. These representations of FASD beg the following questions: (1) how has FASD emerged and become accepted in Alberta as a public health concern? (2) how do those in charge of managing FASD in Alberta understand this disorder?[36] and (3) what are the implications of understanding FASD as it is currently understood?[37]

This chapter examines the processes through which FASD became accepted as a public health concern and the social actors that were responsible for bringing FASD to public attention in Alberta. Through such analysis we learn about not only the particular history of FASD in Alberta but also the social and political context within Alberta that facilitated such rigid ideas and punitive actions toward pregnancy and women. A historical examination of the programs and policies of the Alberta government will provide an in-depth understanding of the various discourses that have shaped and moulded the current practices and programs on FASD.[38]

As discussed in chapter 1, the way in which illnesses and/or diseases are understood and experienced is related to the historical context in which they emerge and exist.[39] Therefore, this chapter explores the historical context in which FASD emerged in Alberta. The chapter's ultimate purpose is to understand how FASD became defined as a social problem in Alberta and to consider the strategies and consequences that flowed from that definition. I begin by briefly discussing the context in which FASD emerged in

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[36] The subsequent chapters in this dissertation will examine the ways in which FASD is currently taken up in Alberta as a health concern. This particular question is answered in chapters 5, 6 and 7.

[37] Chapters 5, 6 and 7 will discuss in detail some of the lingering influences of this history on the current conceptualization and understanding of FASD.

[38] As discussed in this chapter, FASD first emerged and came to public attention through the efforts of social workers employed by the Alberta government.

[39] Please note that this chapter (and dissertation) does not contest the reality of FASD. Rather, it explores the ways in which FASD is understood and the social process through which FASD came to public attention in Alberta.

the United States. It is important to understand this context because Alberta has largely modeled its FASD interventions and programs on those in the United States. An analysis of the American context is followed by a review of Alberta's social history and the ways in which it facilitated public awareness of and concern with FASD. Together, these socio-political contexts allow us to understand how societal concerns and beliefs allowed for the acceptance of FASD as a public health concern. An exploration of social and political context is followed by a description of FASD as it first emerged, the social actors[40] who advocated for its public recognition, and the government's official reaction to FASD.

To understand the various constructions of FASD, we need to pay attention to the conditions under which they became accepted as truth (Rose, 1999). In the end, this chapter will reveal the reasons why – and the conditions under which – FASD emerged and became accepted as a public health concern. It will also consider the implications of the current understandings of FASD in Alberta. This chapter is not intended to be a chronological account of FASD history; rather it will highlight some of the political tensions and social complexities that are present within FASD discourse.

Social and Political Context

American Influence

Current FASD research and policy initiatives in the United States are greatly influenced by the work of Dr. Sterling Clarren[41] and Dr. Therese Grant.[42] Both of these

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[40] The key players names and details have been removed to maintain the confidentiality of the respondents.

[41] Dr. Sterling Clarren has been conducting research on FASD since 1975. He is currently employed at University of British Columbia in the department of Developmental Neuroscience and Child Health. He previously worked at the University of Washington's Faculty of Medicine in Seattle, Washington. Dr. Clarren's work has been essential in defining and providing diagnostic criteria for FASD.

researchers have worked in collaboration with Dr. Ann Streissguth, who is also a leading scholar on the Fetal Alcohol Spectrum Disorder in the United States. In 1973, Dr. Streissguth, along with paediatricians Kenneth Jones, David Smith, and Christy Ulleland published a paper that linked Fetal Alcohol Syndrome to alcohol abuse by women during pregnancy. It was the first widely circulated paper on FASD in the United States.

Clarren and Grant's work began to command the attention of federal and state governments and the American public in the 1980s, which is characterized by some as "an era of growing interest in the fetus" (Golden, 2005, p. 55). During this period, new diagnostic and treatment tools such as amniocentesis, ultrasound, fetal genetic testing, and fetal surgery emerged, and scientific discoveries were made. Reproductive technologies that allowed infertile couples to become biological parents (i.e. in vitro fertilization) became more accessible.[43] These technologies led to the fetuses becoming "patients in their own right" (Golden, 2005, p. 56). There was an increase in the number of parents who sued physicians and other service providers for not releasing pertinent information about products that harmed the fetus during pregnancy. Manufacturers were also being sued for failing to warn consumers about the dangers that their products posed to the fetus. On the political side, Americans continued to debate legal abortion and fetal rights (Golden, 2005).

> The public's heightened interest in and visualization of the fetus meant that federal officials faced with evidence about alcohol as a teratogen had little choice but to issue a warning … Policy makers thus began with the belief that all fetuses needed protection and that all women had the right to know the possible effects of excessive alcohol consumption in pregnancy (Golden, 2005, p. 56).

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[42] Dr. Therese Grant is the director of the Fetal Alcohol and Drug Unit at the University of Washington in Seattle, Washington. The Fetal Alcohol and Drug Unit researches ways to effectively prevent and treat FASD.

[43] Due to the expense, this technology was usually only accessible by middle and upper class (often white) families.

Alberta

FASD emerged and became accepted in the United States during a time of heightened interest in fetal health and welfare. Alberta experienced similar increase in interest. For example, in the late 1970s there was a marked increase in the number of newspaper stories related to child welfare and well being. Perhaps this was in part due to the International Year of the Child in 1977, which saw a media explosion of concern over child abuse. Inquests, trials of parents, and suicides of teenagers were all widely reported and brought forth waves of indignation and demands that something be done about this hideous social disease (Cass, 1978).[44]

In 1979, the Alberta government was brought to task for the reported neglect of children in provincial care. One case in particular made headlines as an illustration of child neglect by the Alberta government (Brekke, 1979).[45] The case involved an 11-year-old deaf girl with cerebral palsy, who was a permanent ward of the Crown. The public was shocked and outraged upon discovering that this girl, despite being of normal intelligence, had only received one year of education. This case exposed the inability of the provincial government to provide adequate care for children with disabilities.

In addition, issues related to abortion and birth control continued to make news in Alberta in the late 1970s and 1980s. Women's groups and non-profit organizations struggled to provide birth control to Albertans as the funding for such programs remained in permanent flux. In 1978, the Calgary Birth Control Association made headlines for

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[44] Accessed at Glenbow Archives, Calgary, Alberta. File titled Calgary Local Council of Women Paper 1919-1980 (1965-78), M5841/282.

[45] Accessed at Glenbow Archives, Calgary, Alberta. File titled Calgary Local Council of Women Clippings 1975-1978, M6802/318.

retaliating against the City of Calgary for its "systematic attempts" to shut the Association down (Greenwood, 1978).[46] The City of Calgary had awarded the Association a $14,000 grant (considerably less than in previous years) on the condition that it could not use these funds to provide abortion referral and counselling.

In this unsupportive atmosphere, some family planning organizations drew attention to the plight of children in foster care. Frequently, newspaper articles contained horrific stories of child abuse and neglect and concluded that such incidences could have been avoided if birth control had been made available to the mothers of these children. Some advocates went as far as to promote eugenics and the sterilization of those who, for mental health or genetic reasons, were considered unfit to bear and care for children.[47] This discourse is articulated below in an excerpt from a 1978 newspaper article.

> Most violent offenders … have a history of being shuffled from one foster home to another as children, most unwanted at birth … And unborn children have rights, he emphasized. Greenland said birth control and birth termination clinics should be universally available in every part of the country to prevent unwanted or irresponsible birth … People with genetic defects should be discouraged from having children in the same way carriers of hereditary disease are discouraged from producing children, he urged ("Tests Urged for Would-Be Parents," 1978).[48]

While the article above cited Professor Cyril Greenland of McMaster University, these sentiments were pervasive in Alberta as well. For example, to give weight to the Calgary Birth Control Association's request for an increase in funding, Calgary resident Dorothy Dickson attached a letter that outlined a case where a 17-year-old boy was tried

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[46] Accessed at Glenbow Archives, Calgary, Alberta. File titled Calgary Local Council of Women Clippings 1975-1978, M6802/318.

[47] There is a history of eugenics and sterilization in Alberta. Between 1929 and 1972, the Alberta Eugenics Board sterilized 2,834 people (Grekul, Krahn & Odynak, 2004) under Alberta's *Sexual Sterilization Act*. The Alberta Eugenics Board targeted women, teenagers, young adults, and Aboriginals for sterilization (Grekul, Krahn & Odynak, 2004).

[48] Accessed at Glenbow Archives, Calgary, Alberta. File titled Calgary Local Council of Women Paper 1919-1980 (1965-78), M5841/282.

for robbery and violence. Dickson had served as a juror on this boy's court case and in her letter she outlined the boy's life history: "His mother tried to abort him but failed. He was an unwanted, neglected and battered child in the homes of both his parents and grandparents." Dickson went on to state that she wondered about such children "who never have a chance and would be better never born."[49] As seen above, Alberta in the mid-1980s found itself in the midst of competing discourses on unborn child's rights, child protection, birth control, and abortion. The discourse of child's rights and child protection was invoked quite readily in support of birth control.

By the early 1990s Alberta was in the middle of an economic recession due to plummeting oil and gas prices and had a heavy debt of more than $20 billion. Under the leadership of Premier Don Getty, the conservative government promoted the privatization of health services (Legislative Assembly of Alberta, 1992b) and implemented cuts to social programs such as the Aids to Daily Living program. This cut meant that parents of severely handicapped children had to use more of their savings to care for their children.

In 1992, under the leadership of Premier Ralph Klein, the conservative government cut again; this time more drastic spending cuts were made in the areas of education, health care, and social services. Two alcohol treatment programs in Calgary were forced into temporary closure due to a lack of funding (Legislative Assembly of Alberta, 1992b). For example, the Sunrise Residence in Calgary, "a native, co-ed alcohol and drug treatment centre" was closed for two and half months due to a lack of funding (Legislative Assembly of Alberta, 1992a, p. 1695). Alberta's official opposition opposed the severity of the budget cuts and persistently called for greater action on child poverty,

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[49] Accessed at Glenbow Archives, Calgary, Alberta. File titled Calgary Local Council of Women Paper 1919-1980 (1965-78), M5841/282.

the restoration of benefits to seniors and disabled children, increased attention to the welfare of Aboriginal children, and educational reform (Legislative Assembly of Alberta, 1991, 1992a, 1992b, 1992c, 1993).

At this time, the Ministry of Family and Social Services in Alberta was also coming under fire. It was criticized for having "an atmosphere of management by fear," for allowing "budgetary concerns [and] not client needs [to] driv[e] the system," for the increasing number of "children [alleging that they were] abused while under government care," and for the "high staff turnover in child welfare" (Legislative Assembly of Alberta, 1993, p. 958). Alberta MLA Grant Mitchell[50] also voiced concerns[51] about the lack of preventive services, "support services [such] as shelter, counselling, medical, dental, and optical care, [and] services related to Fetal Alcohol Syndrome." He noted "a shortage of appropriate placements, especially for foster homes [and] a lack of sensitivity to cultural, social or religious needs of minority groups." He lamented the fact that children had been returned to abusive parents or died in provincial care (Legislative Assembly of Alberta, 1998b, p. 132).

> The young boy … was allegedly murdered in Red Deer just recently, within the last week to 10 days … [When] a child of 17 … dies of pneumonia, [it] is at least worthy of questioning … [T]he series of reports that we did receive from the last medical officer's report … indicated that far too many of these children [have] apparently committed suicide, but no inquiry was done to see whether in fact there may have been things going on (Legislative Assembly of Alberta, 1998b, p. 133).

Overall, there were concerns that the Alberta government "tended to overlook the

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[50] Grant Mitchell was the leader of Alberta Liberal Party from 1994 to 1998 and represented the electoral district of Edmonton-McClung from 1993 to 1998.

[51] These concerns were raised to support the Mr. Mitchell's motion to make the Child and Youth Advocate Office in Alberta completely independent from the Alberta government. The Child and Youth Advocate Office was established in September 1989. It provides individual and systematic support and advocates on behalf of children and youth in provincial care.

interests of the child"[52] (Legislative Assembly of Alberta, 1993, p. 960). It was regularly accused of ignoring the daily realities that children in Alberta were facing. As stated by one MLA,

> when it comes to children, reality is fundamentally important … [to the maintenance and implementation of] positive, proper policy … governments that run from that [reality] are governments that hurt children (Legislative Assembly of Alberta, 1998b, p. 133).

In this era of budget cuts, the Alberta government was also heavily criticized for reducing welfare payments to poor families. The opposition raised concerns that "over the past four years as welfare rates have dropped, the number of child welfare cases have (sic) risen" (Legislative Assembly of Alberta, 1998c, p. 521). According to then Minister of Family and Social Services, Dr. Lyle Oberg, the increasing number of child welfare cases was not due to budget cuts and could be explained by "Fetal Alcohol Syndrome" and "110,000 [other] explanations" (Legislative Assembly of Alberta, 1998c, p. 521).

FASD was readily invoked as one of the reasons for the rising number of children in provincial care. It was believed that "FAS and FAE [could] be at the bottom of … the problems that children go through," particularly when there are "a number of issues that they have to deal with." (Legislative Assembly of Alberta, 1999e, p. 1528). Interestingly, while the Alberta government readily invoked FASD as one of the primary reasons behind the child welfare crisis, it provided only provisional acceptance and acknowledgment of FASD as a social and health concern and limited funding to FASD

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[52] MLA Alice Hanson made this statement when she expressed her support for Bill 207. Ms. Hanson represented the constituency of Edmonton-Highlands-Beverly from 1993 to 1997. She was the Native Affairs critic and Social Services critic for the official opposition (i.e. the Alberta Liberal Party). MLA Elizabeth Jones Hewes (representative of electoral district of Edmonton-Gold Bar from 1986 to 1997) introduced Bill 207 for debate in the Alberta Legislature. The bill proposed the adoption of *The Children's Rights Act*, which was a carbon copy of the *Convention on the Rights of the Child* adopted by the UN's General Assembly in 1989. This bill was defeated (16 to 44) in the second reading.

programs and services. Only after considerable advocacy did social workers and caregivers of children with FASD secure greater support from the Alberta government. The section below discusses the particular individuals and social movements that were able to bring FASD to public attention and garner greater government support.

The Emergence of Fetal Alcohol Spectrum Disorder in Alberta

Becoming Debbie and Janet[53]

FASD emerged in a social and political context rife with concerns about the welfare and well being of children in provincial care. The movement to get this disorder recognized was led by two individual social workers, who were confronted either personally or professionally with undiagnosed cases of FASD. The first of these two women, Debbie, started her career as a social worker in 1977 at a residential treatment centre in an Alberta city.[54] During this time, Debbie "recognized…what … [she] really wanted to do" (Debbie). She left her post eager to complete a social work degree and to work with people with disabilities. Later on, Debbie married and moved to another Alberta city where her interest shifted toward child protection. In this city, she began her career as a front line worker and eventually moved up the ranks so that she was the "…supervisor of the investigation unit for the whole area south[ern] [region of the city]" (Debbie).

In 1988, Debbie saw a pattern beginning to emerge in some of the children in government care. This particular group of children had "really poor outcomes, you know, multiple placements, abuse, neglect, maltreatment, all in care" (Debbie). Her colleague,

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[53] The names of these two experts have been changed to maintain confidentiality.

[54] The names of the cities have been removed to maintain confidentiality.

Janet, recalls that Debbie

> started looking at, you know, the presentation of these kids and recognized … a common denominator, which was that they had parents that used drugs and alcohol, …. most notably, the mothers did [used drugs or alcohol] … [and they] did [so] during their pregnancy.… [She] wondered if there could be a link there.

Motivated by her desire “to really figure out why these kids were so hard to take care [of],” Debbie enlisted the aid of her mother, who was a librarian in the psychology department of a Canadian university. Debbie’s mother conducted an exhaustive literature review and among the few resulting articles, Debbie discovered Dr. Sterling K. Clarren’s work on FAS/FAE. During this time Dr. Clarren, a leading researcher in the area of FASD since 1975, was based in Seattle, Washington.[55]

> The early ‘70s was when Sterling was looking at this and naming it. But that wasn’t the norm anywhere in North America probably. It was rare. You had to be so incredibly damaged and [even] then I’m not sure they had the information that Sterling was coming up with … it wasn’t really being disseminated within the medical community (Janet).

Debbie contacted Dr. Clarren and he sent her “a few more articles” (Debbie). This was the start of a collaborative relationship between Alberta and Washington, which has continued to the present day. “So, I got absolutely passionate about it and just took it on in addition to what my role was” (Debbie). Debbie reports that with time, her manager allocated her time to work on this issue and later on got her an audience with several ministers, deputy ministers and directors

> to tell them … how many of these kids were in our care, what [FAS] looked like developmentally, [and] what [it] meant for our resources, for unification, [and] for repatriation [of] Aboriginal children back to their home communities (Debbie).

The government officials and senior bureaucrats told Debbie “‘we need to train

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[55] The implications of Dr. Clarren’s work for the Alberta context will be discussed in detail later on in this chapter.

our social workers,' so [she] developed curriculum and … started [her] first training session in December of 1992 for child protection workers" (Debbie). In 1997, Alberta Children and Youth Services hired Debbie as a "specialist … in the area of Fetal Alcohol Syndrome[56]" (Debbie).

The awareness and education initiatives that stemmed from Debbie's early work meant that many more children in provincial care in Alberta were subsequently identified as having FASD:

> So, it was through this process that we figured out, I mean, the first couple of rounds in 1992, 1993, probably even 1994, we would get workers in [who] said "we have 1 or 2 on our caseload" and "I'm here because we have 1 or 2" and then by 1995, 1996 … what were hearing extensively was "most of my kids have this disability." And what I know – and we have done enough surveillance work – is that if you have kids in care, half of them have an alcohol-related disability, whether it is diagnosed or not – half of them do. So it influences your practice like crazy because all the traditional mechanisms of support aren't going to work for this population (Debbie).

It was during one of these training sessions that Debbie met Janet. During this session, Janet, a participant in the training, shared her personal experience as an adoptive mother to two children with FASD. Debbie invited Janet to assist with future training sessions by presenting the family perspective. "I … participated in all the training since then, first as a volunteer and then as a co-trainer" (Janet). Janet's background provided her with particular insights and perspectives. She explains: "I adopted those children a lot of years ago, in '73 and '74. I had zero knowledge of Fetal Alcohol Spectrum Disorder, had never heard of it" (Janet). This lack of awareness of and knowledge about FASD had a detrimental impact, particularly on the parents of FASD-afflicted children. As Janet explains:

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[56] In the1980s and early 1990s Fetal Alcohol Spectrum Disorder was referred to as Fetal Alcohol Syndrome (FAS) or Fetal Alcohol Effect (FAE).

> those two sons I raised without any support whatsoever because it didn't [exist]. We would try, on occasion, to get support through family doctors or school but when it has no name, it is [considered just] bad behaviour. Mostly what you get is it must bad parenting or poor adoption, a failed adoption.

Therefore, Janet entered Debbie's class with a certain experiential knowledge of FASD. This initial meeting led to a lengthy collaborative relationship between the two women. Janet describes the sequence of events below:

> Um, and so the next time she taught it she said "please come and tell your story" and so I did and we did that a couple of times until Children's Services said based on the evaluations, it looks like you both need to do it all the time and so they hired me. So I always did it on a contract whenever these [training sessions] came up, and they started coming up a lot actually, started interfering with my work. So then I was part of the package all the time and moved from telling my story to just being one of the trainers (Janet).

Janet and Debbie went on to rewrite Debbie's FASD manual, adding new content related to grief and loss within FASD. This new and revolutionary work on FASD was done with "a sort of child welfare perspective" (Janet).[57]

> In any child welfare case, we found there were four possibilities. There were unaffected parents caring for unaffected children so the issues were something else. You had affected parents caring for unaffected children so the parents had the issue. You had affected parents and affected children or you had unaffected parents caring for affected children so you had something. So we started a bit of a grid and asked, "what we could teach child welfare workers to do in response?" We could teach them to do a little "could this be?" [which would help them to determine] what it is and then [teach them] what to do with [it]. And so that was how this got started and this was in the child welfare context. (Janet)

Janet and Debbie's journey filled with obstacles and, as a result, they stopped teaching for a while. As Janet explains,

> we did that for quite a few years, with very little support actually, and at one point we sort of said, you guys [government officials] aren't being very supportive …

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[57] The implications of initiating FASD programs and policies from a child welfare perspective will be discussed later on in this chapter.

> Because we were getting some criticism, I think we went on strike for a bit and said "oh, we are not doing it for a little while, you guys have to figure this out" (Janet).

Since the FASD training was happening in the context of and in response to the needs of child welfare, there were no efforts being made to address the issue of FASD outside of these child welfare-training programs.

The required push for action came during a visit from Dr. Albert Chudley, a geneticist at the University of Manitoba. Prior to Dr. Chudley's visit, there had been minimal response by ministry officials to Janet and Debbie's numerous requests for government action on FASD. Janet explains,

> We had gone to Maria David Evans, [the then Deputy Minister of Family and Social Services], and everybody else and said "please pay attention to this because it is a huge big deal for child welfare" … I think part of the reason for the sort of dragging of feet [by] the Department of Child Welfare (sic) [was that] … people … were thinking that we were just exaggerating … It's like that with anything as it starts and comes into being across the horizon. …That was way back in the early days when [everyone was] making lots of noise [about other disorders] and people were going "ya, whatever, Autism is a big deal"… so they weren't particularly supportive [of FASD] (Janet).

FASD not only had to struggle to receive public recognition, it also had to compete with other medical conditions such as autism for funding and resources.[58] As alluded to by Janet, Autism has a strong parent advocate group, and the public is quite sympathetic to this disorder. Therefore, a major struggle in getting FASD recognized was and continues to be the presence of "other pressing issues that affect far more people … When you look at things like diabetes and heart disease and wait[ing] lists [for health

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[58] On April 23, 2007, The Province published an opinion piece by a paediatrician, who stated that "calls for a national strategy for Autism, while well-intentioned, reflect an overly narrow view of the issue of neuro-developmental disorders in children, and risk further marginalizing one group at the expense of another …To do the right thing for these children, we have to move away from potentially pitting one disability group's need for supports and resources against another's. We need a national strategy that does the right thing for children with complex neuro-developmental disorders of all kinds including Autism, Fetal-Alcohol Spectrum Disorders and all the others for which a clear medical label or explanation is currently unavailable."

care services], you know there are those cris[es] in the system that need addressing right away" (Tanya). Therefore, advocates for FASD needed to find a way to highlight the seriousness of this FASD as a social and health problem.

Eliciting Public Support

In the late 1980s and early 1990s, many foster and adoptive parents became caregivers of children with FASD and, having no prior knowledge of or experience with FASD, found themselves overwhelmed. As Janet explains, "it was just so hard for them [caregivers/foster parents]" (Janet). The incredible needs of these children led to the rapid exhaustion of their caregivers and placed the children at great risk for abuse and neglect. At the time, child-welfare caseworkers and the general public attributed the high number of placement breakdowns as well as the high incidence of abuse, neglect, and abandonment to "bad" foster parents or caregivers.

> I could tell you some stories in the early days from some parents that I know very well who ended up with three or four of these kids in care, and whose lives were in shambles and who went to Child Welfare and said, "help" and Child Welfare said, "you are not coping, you are not doing a good job, we are going to take all the kids away" (Janet).

As is evident above, struggling caregivers not only lacked assistance but also risked being shunned by the public and by government officials if they asked for help. In response, caregivers responded by "professionalizing" themselves. In other words, the parents began to advocate for themselves and for the children in their care.

> They started saying to Child Welfare, "you have to listen to us, we are not bad people"… [We] were eventually able to convince an amount of people that much of the placement breakdown[s] that happened [were] due to this kind of complication or [to] the fact that these are really hard-to-manage children (Janet).

In order to underscore the seriousness of this disorder, caregivers and other advocates needed to frame FASD as an urgent health concern. They did so by emphasizing particular representations of "hurt children," by generating statistical data, and by presenting FASD as a 100 percent preventable disorder.

Stories and Representations of the "Hurt Child"

> They [elected officials and the public] make more noise about affected kids [than they do about adults] and …the reason that people got [all] excited about … this issue is because we saw hurt children. If it would have started with awareness of birth mothers, we would be nowhere. But we saw hurt children and we thought, "that's bad, what can we do?" (Janet).

Informed by the above line of thinking, advocates depicted children with FASD as helpless victims, who were violent, dangerous and "very hard to care for" (Janet).[59] According to Janet, it was these stories of FASD and images of hurt children that truly mobilized the FASD movement in Alberta. The hurt child representations began to make their way into the political arena. For instance, during a legislative debate, one MLA cautioned that "some of these children getting into teens now are really in a position where they're becoming a threat to that family and a threat to the peers they deal with" (Legislative Assembly of Alberta, 1999h, p. 190). A similar image of children-at-risk was used to elicit funding and support for FASD programs.

> What we need is sustainable funding to carry those kids through the most important years they have … Those kids are the ones who are susceptible to becoming criminals. They have poor judgment, lack of control, and behavior problems …" (Legislative Assembly of Alberta, 1999c, p. 2315).

These representations of FASD children as victims and potential predators were intentionally presented to the public to underscore the seriousness of the disorder at a time when the public was either unaware or unwilling to accept that alcohol consumed

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[59] This chapter only acknowledges that advocates used representations of children as both of victims and possible predators to underscore the seriousness of this issue. Chapter 5 of this dissertation will more fully examine these representations.

during pregnancy can inflict life long damage on a fetus. The images were highly effective in eliciting public support for FASD programs and initiatives.

The Numbers

To accompany the above representations and further highlight the gravity of the situation, advocates for FASD programs generated numbers. In Alberta, reports emerged claiming that "thousands of children … suffer[ed] from fetal alcohol syndrome [and from FAS-induced] developmental disabilities" (Legislative Assembly of Alberta, 1999d, p. 631). The official opposition, guided by such estimates, began questioning the government about its lack of assistance. The opposition even incorporated these figures into the questions it posed: "given that 1,200 children in government care alone are afflicted with this syndrome, what's going to be done?" (Legislative Assembly of Alberta, 1998a, p. 1988).[60]

The utilization of these numbers also led to increased support by the ruling party. For instance, the then Minister of Family and Social Services, Dr. Oberg increased the provincial budget for various children's projects by $3.4 million. He justified this increase, stating that approximately "60 to 70 percent of the kids in the special-needs classrooms are actually suffering from fetal alcohol syndrome or fetal alcohol effect" and acknowledged that such prevalence was "obviously … one of the reasons why we, [the Ministry of Family and Social Services], have put in this critical element in our department" (Legislative Assembly of Alberta, 1999a, p. DSS6). The numbers reinforced that FASD was a "huge, huge problem" that required government action. The government was called on to "make this [FASD] more known to pregnant women" and

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[60] These numbers were generated by FASD advocates.

“to ensure that physicians know how to deal with it” (Legislative Assembly of Alberta, 1999a, p. DSS27).

The images of children with FASD together with generated numbers reinforced the idea that “fetal alcohol syndrome and fetal alcohol effect [was] much more [of a] problem [than] … originally anticipated” (Legislative Assembly of Alberta, 1999a, p. DSS24). Together, they convinced public officials not only that FASD was a public health concern but also “that a lot of … ADD [Attention Deficit Disorder] issues are … related to fetal alcohol syndrome, fetal alcohol effect” (Legislative Assembly of Alberta, 1999a, p. DSS24). Thus, these messages about the magnitude of FASD and its possible correlation to other pressing health concerns led to increased public acceptance of FASD.

A Preventable Disorder

Public support for FASD programs and policies was also aided by the presentation of FASD as a “100 percent preventable” disorder (Legislative Assembly of Alberta, 1999g, p. 1425). It was through this discourse that FASD is “a totally preventable disease yet totally incurable” (Legislative Assembly of Alberta, 2000a, p. 706) that the official opposition called on the government to implement “prevention strategies to reduce the number of children with fetal alcohol syndrome” (Legislative Assembly of Alberta, 1999g, p. 1425). Moreover, it was using this same discourse of preventable disorder that governmental officials justified various budget increases and FASD interventions. One official stated that FASD “is the most common mental disease in the world that is preventable and I think that’s something we all should remember” (Legislative Assembly of Alberta, 1999g, p. 1425). The “100 percent preventable” disorder message was akin to a FASD slogan and was disseminated as such on posters and stickers at liquor stores and restaurants.

> There are things such as car stickers. If anyone has noticed my car in the parking lot – it has a sticker that says fetal alcohol syndrome is 100 percent preventable, with a circle and a line through [a] pregnant woman (Legislative Assembly of Alberta, 1999g, p. 1426).[61]

It was the strategic and continued advocacy by Debbie, Janet, and other "professional parents" that led to the initial acceptance and support of FASD as a social and health problem. They were able to elicit public and governmental support by representing FASD-afflicted children as "hurt" or as potential criminals, by disseminating data, and by presenting FASD as a completely preventable disorder. The next section of this chapter presents an overview of the governmental response to the strategic measures employed by Debbie, Janet, and other professional parents.

"They Just Really Came on Board": The Development and Funding of FASD Programs

"What she [Debbie] saw, of course, was the child welfare population so … kids that were coming into care" (Janet). Touched by these children, Debbie began advocating on their behalf to political female figures like Iris Evans and Colleen Klein,[62] both of whom later took up the cause. "When Colleen heard us speak about it [and] Iris heard us speak about it, they just really came on board and [asked us] 'really, it's that important?'" (Janet). In time, Ms. Evans became interested in FASD and began discussing it with the Minister of Family and Social Services, Dr. Oberg. The persistence of various FASD advocates eventually resulted in a meeting between Dr. Albert Chudley and Dr. Oberg.

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[61] Dr. Oberg made this statement in response to questions about FASD prevention strategies that were being implemented in Alberta. One MLA asked whether Dr. Oberg intended on issuing warning labels about FASD on alcohol bottles. Dr. Oberg responded that he did not support such a measure; however, his ministry did circulate FASD posters and stickers, like the one on his car, to liquor stores.

[62] Colleen Klein is the wife of former Premier Ralph Klein. Ralph Klein was the premier of Alberta during this time period.

Dr. Chudley stressed the urgent nature and immensity of FASD. According to David (a senior level bureaucrat in the Ministry of Children and Youth Services),[63] Dr. Oberg became interested in FASD after meeting with Dr. Chudley and "thought there would be an opportunity for the government to take a leadership role." In 1998, the two men formed and developed an interprovincial partnership on FASD.[64] The Prairie Fetal Alcohol Syndrome Partnership[65] sought to coordinate FASD efforts across Alberta, Saskatchewan and Manitoba.

> So they declared on the heels of that partnership to look at this [FASD] and then declared that they needed to pay some particular attention to training and that's when Debbie and I got hired. Debbie got seconded and I got hired, well seconded, hired to do it. And so that is how we became Debbie and Janet (Janet).

The public's reaction to FASD slowly began to change and those in charge at the Ministry of Children and Youth Services became much more responsive to issues of FASD.

> After Lyle Oberg declared [that] this [was] something that we were going to pay attention to, Child Welfare came on board … Sharon Haron was the director at the time and she was the one that got Debbie and [me] started on the path to the road show … we spent four years on the road (Janet).

An intra-provincial partnership was formed shortly after the inter-provincial one. In 1998, the Alberta Partnership was established to better coordinate FASD programs and initiatives in the province. The partnership included government ministries and community organizations that were working with, or were affected by, FASD. In 1999,

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[63] This name has been changed to maintain confidentiality.

[64] In February 1998, Alberta, Saskatchewan, and Manitoba formed a partnership titled The Prairie Province Fetal Alcohol Syndrome Partnership. This partnership was initiated in an effort to coordinate provincial approaches to FASD. In 1999, the Yukon, the Northwest Territories and Nunavut joined this partnership. At that time, the name was changed to Prairie Northwest FAS Partnership. In 2001, the name changed again to Prairie Northern Pacific FAS Partnership to reflect the joining of British Columbia. In 2003, this organization changed its name to Canadian Northwest FASD Partnership.

[65] As explained earlier, this went on to become Canadian Northwest FASD Partnership (and now includes Manitoba, British Columbia, Yukon, Northwest Territories, Nunavut, Saskatchewan and Alberta).

an Alberta Prairie Province Conference on Fetal Alcohol Syndrome titled “Together Let’s Find a Solution,” was held from May 4 to 7 at the University of Calgary. According to Dr. Oberg, over 700 people registered for the conference (Legislative Assembly of Alberta, 1999f, p. 1270). This was the first in a series of annual conferences designed to provide education and training in the area of FASD (Badry & Debolt, 2000). In the same year, Dr. Oberg committed $2 million in funding to Fetal Alcohol Syndrome-related programs and activities (Legislative Assembly of Alberta, 1999g).

Janet, having completed her four-year secondment to the Ministry of Children and Youth Services, returned to a not-for-profit agency, where she developed four new FASD programs.[66] These programs started out as pilot projects but now they are fully operational and funded by the province. The first program was started in 1999 and is called the First Steps Program. It replicates the Parent-Child Assistance Program (PCAP), also referred to as Birth to Three, which was initially developed in Seattle, Washington by Therese Grant.[67] The program focuses exclusively on women who are at-risk of using alcohol and drugs while pregnant, and once introduced in Alberta, was quickly flooded with referrals. Over the next five years more than 300 women went through the program. A particular strength of the program was that it countered the stereotype that these women were “people that you couldn’t build relationships with” (Janet). Janet explains that these women

> were happy for the intervention. They were eager to talk about family planning and postponing pregnancy if they weren’t ready to stop using. They were eager to have assistance with their pregnancy. And many of them were eager to enter

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[66] Interestingly, all four programs focused on care-giving relationships and none of these programs were designed to address issues pertinent to adults suffering with FASD such as employment and sexuality. This continued focus on children with FASD and the resulting lack of attention given to adults afflicted with FASD is discussed in greater detail in chapter 4.

[67] Therese Grant is a pioneer scholar on issues related to high-risk mothers in United States.

treatment as well (Janet).

The second program, Coaching Families, is geared toward families and caregivers of children with FASD. This program was designed to help reduce the stress and grief of parenting a child with FASD.

> The by-product of all of that was, of course – would be – … less breakdown (sic) in placements, which was the reason that Alberta Children's Services was quite happy to fund this with FASD funding (Janet).

The initial funding for First Steps and Coaching Families came from the McDaniel Foundation.[68]

The third program, Step by Step, is designed for "moms who themselves had FASD and who were attempting to parent" (Janet). The government mandate to keep children with their birth parents means that there has to be support for "moms, who themselves had FASD [and] who are [now] attempting to parent … [These moms] were taking up huge amounts of time"; time that the First Steps mentors didn't have (Janet). The mentors working with these women quickly realized that this is a labour-intensive role and that "[they were] not very well set up in society to support women whose needs are that high" (Janet). The needs of these women greatly superseded the capacity of any community program; so Step by Step was created. The fourth and final program, works with people who suffer from FASD-related brain injuries; it seeks to integrate them more fully into the community.

These programs have served as the blueprint for various FASD programs throughout Alberta. Just as these programs were, many of Alberta's FASD programs are

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[68] The McDaniel Foundation was formed in 1997 by Joan McDaniel. The foundation provided assistance to the disadvantaged of Edmonton, Alberta. The foundation was also the primary funder of the FASD programs at this non-profit agency (name withheld) for the first few years. The foundation continued to fund the First Steps and Coaching Families programs when the Alberta government began provide funding a few years later.

currently demonstration projects. The term "demonstration project" refers to programs that are funded on a trial basis; funding is short-term and the province can decide at any point not to renew it. Demonstration projects face considerable challenges. Insecure funding compromises the ability of project managers to initiate long-term plans or expand a project's reach. Some demonstration projects have evolved into fully funded programs over the course of time, while others are dropped because they fail to produce positive and measurable results. In addition, some FASD programs do not receive support or funding from the Alberta government.

Most FASD programs started as demonstration projects and were funded by the Alberta Lottery Fund. However, the decision to maintain FASD programs through lottery funding has been criticized by the official opposition. In 1998, MLA Linda Sloan[69] asked, "why [is] the funding for this [FASD] program … being provided by lotteries?" (Legislative Assembly of Alberta, 1999a, p. DSS18). Ms. Sloan, and others who shared her view, object to this funding structure for a couple of reasons. First, they found this practice to be "exploiting one addiction to treat another" (Legislative Assembly of Alberta, 1999a, p. DSS18). Second, they argued that the Alberta Lottery Fund "is not a stable, guaranteed source of funds" and funding FASD programs with money from the Lottery Fund gives the impression that "we don't need them [FASD programs and initiatives] very much and that's why we can put them under an unstable source of funding" (Legislative Assembly of Alberta, 1999b, pp. 1092-1093). In spite of such objections, the initial FASD Initiative budget of $1 million (used to fund some of the programs mentioned above) was provided solely from lottery revenues. Presently,

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[69] MLA Linda Sloan represented the constituency of Edmonton-Riverview from 1997 to 2001. She served as the official opposition's critic for Social Services, Child Welfare and Disability Programs.

however, key FASD programs have secured funding in the annual provincial budget.

> The FASD Initiative budget has slowly grown from $1 million in 1999
>
> to [$]2.5 [million] in about 2002 … From there [it] grew to [$]4 million and then to [$]5 [million] and this year … the government has added another [$]4 million to the cross-ministry work that is going on. So, now Alberta is investing [$]9 – almost [$]10 – million dollars for services that specifically target FASD (David).

In the 2008 – 2009 budget, the Government of Alberta allocated almost $16.5 million for FASD programs and services (Government of Alberta, 2009). Surprisingly, in the last 10 years FASD programs have gone from unsecured and precarious funding to a budget of $16.5 million. As can be seen in the following statement by Janis Tarchuk, Minister of Children and Youth Services, FASD is considered a high priority in the Alberta government (Legislative Assembly of Alberta, 2008a).

> An estimated 23,000 Albertans are living with fetal alcohol spectrum disorder, a preventable, lifelong disability with no cure. A significant number of individuals in criminal justice, child protection, and disability systems have been diagnosed with FASD. But there is hope. Our government has made a commitment with a 10-year plan involving nine ministries to reduce the incidence of the disorder and improve the quality of life and productivity of those already affected. This year a new investment of $8.5 million for a total of $18 million will support this ministry's efforts to reduce the number of babies born with FASD and support those living with FASD and their caregivers. We are expanding on what we know, making it available to more Albertans and continuing to work together to help those affected to prevent future incidents. (Legislative Assembly of Alberta, 2008b, p. 735).

There are FASD programs in many areas of Alberta, notably Cold Lake, Lethbridge, Medicine Hat, Red Deer, Calgary and Edmonton. However, many areas do not have services for children and adults with FASD. Because FASD developed as a child welfare concern, adults with FASD in Alberta continue to want for adequate services and support. Most adults with FASD encounter significant barriers when they attempt to access disability benefits and services. A common challenge is that

> [t]o receive government support services, an adult with fetal alcohol syndrome, commonly known as FASD, must fall below a specific IQ level. However, this support system does not take into account adults with FASD who may be above the IQ level but lack basic functioning ability or for safety reasons, theirs and society's, require support (Legislative Assembly of Alberta, 2007, p. 1728).

Discussion and Conclusion

This chapter reveals the various individuals, socio-political events and discourses that have shaped FASD-related programs and practices in Alberta. In so doing, it introduces some of the major tensions, complexities and trains of thought that are present in current FASD discourse. I will discuss three particular trains of thought below.

The first train of thought is that FASD is a children's disorder; innocent children are most at risk of getting the disorder and children who are already affected by the disorder constitute a risk to society. A general preoccupation with child welfare provided the backdrop for the recognition of FASD in Alberta. To reiterate, FASD awareness and educational campaigns were started within the ministry responsible for child welfare and, more importantly, were undertaken in response to reports that foster placements were increasingly unsuccessful and that neglect, abuse, and even the number of deaths of children in provincial care were on the rise.

The public's increasing concern for child welfare aided in the recognition of FASD. Without it, FASD may not have gained the exposure and support that it did. However, one implication of this history is that the disorder is still understood and depicted as a childhood disorder. While children are undoubtedly affected by FASD, they eventually grow into adults and, as adults, they continue to suffer its effects. The perception that FASD is a children's disorder results in the relative invisibility of adults who suffer from FASD and who lack adequate support and services. Chapter 5 considers the ongoing invisibility of and lack of services for adults with FASD in greater depth.

Before FASD was publically acknowledged, foster parents, adoptive parents, and caregivers who struggled to care for children with FASD were considered inadequate or "bad" parents or caregivers. To appeal to the public and to prove their lack of culpability in these children's ongoing difficulties, social workers and caregivers emphasized the link between the children's poor behaviour and a newly discovered developmental disorder: FASD. To strategically elicit support for FASD programs, advocates presented FASD-afflicted children as damaged, difficult, and dangerous. These representations helped to convince the Alberta government and the general public that the province must a) recognize FASD as a medical and social problem and b) implement policies and programs to help those diagnosed. Chapter 5 explores the conceptualization of children (as being at-risk and as constituting risk to society) in more depth and considers the ways in which these conceptualizations continue to be part of FASD interventions and programs in Alberta.

The second train of thought is that birth mothers are to blame for this entirely preventable disease. The discourse of the hurt child reduced some of the stigma and blame that had been targeted towards the parents and caregivers of children with FASD. In some cases, it even generated sympathy and respect for parents and caregivers; after all, they were caring for children who were too damaged or dangerous to be elsewhere.

Although they presented themselves as the answer to these children's predicament, professional parents also took particular measures to distance themselves from their children's present condition. At every conference that I have attended, and in every article that I have read, foster or adoptive parents have prefaced their story (about what it means to parent a FASD-afflicted child) by announcing their biological distance from the child. They make statements such as "this is my adopted/foster child" or "I am the adoptive/foster mother." These statements redirect the cause (and the blame) for the child's present condition to somewhere (and someone) else. They serve to differentiate and discursively position the adoptive mother as separate from the birth mother, who drank during pregnancy and, therefore, is to blame for child's current condition. Responsibility is clearly placed on the party who was missing from the conversation – the birth mother.

The belief that birth mothers are culpable for FASD-afflicted children is also reinforced by the discourse that FASD is a 100 percent preventable disorder. FASD advocates were able to secure funding and support from the Alberta Government by presenting FASD as a preventable disorder. However, this understanding of FASD simplifies a very complex issue. It suggests that FASD is an easily solvable problem: if women simply chose not to drink alcohol during their pregnancies, FASD would not exist. This understanding does not consider the structural constraints[70] that some pregnant women face, such as addiction or poverty. It does not consider that some pregnant women cannot afford quality health care or cannot access treatment centers that work with pregnant women or pregnant mothers. Sadly, the debates surrounding Bill 45 indicate that many people still consider FASD to be the result of negligent mothers who inflict harm on their innocent children. In turn, these children are perceived to be social and economic burdens on society.

The images of sympathetic caregivers presented in opposition to negligent

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[70] These structural constraints are discussed in detail in chapter 5.

mothers, and combined with images of damaged children, likely aided in the generation of public sympathy and support for FASD programs and polices. It is interesting to note that most of the "professional parents" and social workers who helped bring FASD to public attention were women. I discuss the gendered advocacy of FASD in Alberta in chapter 6. In that chapter, I consider how women are depicted by FASD advocates and how these representations are understood and negotiated by the FASD professionals.

The third train of thought is that FASD mainly involves poor Aboriginal women. The FASD programs that Janet created (while working at the non-profit organization) target high needs women and children from the most marginalized segments of the population. In Canada, there is a disproportionate representation of Aboriginal children in state care.[71] From 2000 to 2002 approximately 30 to 40 percent of children placed in out-of-home care in Canada were of Aboriginal descent (Farris-Manning & Zandstra, 2003). This is a shocking number considering that Aboriginal children make up less than five percent of the child population of Canada (Gough et al., 2005). Given these statistics, it is no surprise that Aboriginal women and children are also disproportionately represented in FASD programs, like Janet's. Their visibility in these programs further entrenches the idea that FASD mainly involves mainly poor Aboriginal women and children. In chapter 7, I discuss in more detail the ways in which FASD has been racialized and understood as an issue affecting poor Aboriginal women. I also reveal how FASD professionals attempt to negotiate these racialized discourses.

In conclusion, the way that FASD programs came into existence, the social climate surrounding their emergence, and the social actors who brought FASD to the

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[71] This disproportionate representation is due to ongoing issues of hyper-surveillance, a lack of structural services, and the ongoing impact of residential school systems.

forefront have particular implications for how women and children are currently represented within the FASD discourse. This chapter has discussed the movements, social actors, and social context responsible for invocation of particular representations within FASD discourse. The next three chapters delve deeper into the themes highlighted above to show how images of children at-risk, representations of absent and negligent mothers, and racialized understanding(s) of FASD continue to be invoked and understood in FASD discourse.

Chapter 5: The Risk of and Responsibility for FASD

This chapter examines the FASD prevention and awareness campaigns employed by Alberta Children and Youth Services and considers how the concepts of risk and responsibility are utilized within these campaigns. I deconstruct verbal narratives (from the interviews that I conducted) and visual texts (from the posters, pamphlets, books, and other education and awareness campaign tools that I collected) to reveal the ways in which risk and responsibility are taken up by FASD professionals in Alberta. My findings suggest that there are gendered implications of utilizing the concepts of risk and responsibility within FASD prevention and awareness campaigns.

This chapter begins with a brief overview of the concepts of risk and responsibility. In the first substantive part of the chapter, I outline and discuss how "risk" is invoked within FASD discourse, and, in the second part, I highlight and discuss how "responsibility" is allocated. These two sections are followed by an in-depth discussion about the implications that these representations (i.e. that certain bodies are at "risk" and other bodies are "responsible" for creating this risk) have for FASD prevention and awareness campaigns.

This research on FASD is distinct from other studies on risk and responsibility because it recognizes and explores the separation of bodies that are considered to be at "risk" from those that are deemed to be "responsible" for creating such risk. To elaborate, most public health literature has considered how public health campaigns invoke risk to motivate individuals to change their behaviour. These campaigns allocate responsibility to the potential beneficiary. In other words, the individual who makes lifestyle changes reduces his or her own risk of ill health and sickness. In contrast, FASD discourse allocates responsibility to women of reproductive age and encourages them to adopt certain behaviours to reduce their unborn children's risk of developing FASD. In FASD prevention campaigns women are urged to plan their pregnancies, to use birth control if they are consuming alcohol, and to completely refrain from alcohol use if they are having unprotected sex. Thus, FASD prevention campaigns concentrate on the behaviour of women to reduce the risk to the child. The particular ways in which this discourse of "risk" and "responsibility" continues to be part of the official FASD discourse is discussed in detail in this chapter. The chapter concludes with a discussion of the reasons why such concepts are readily invoked and utilized in health-related discourses like FASD discourse.

Risk and Responsibility

Neo-liberal society promotes individualization, which emphasizes an individual's freedom to make choices and his or her responsibility to make the right choices. Accordingly, any risks faced by an individual are often understood as the consequences of his or her choices and, therefore, are the sole responsibility of the decision maker. This focus on the individual and "the emphasis on risk factors which are within the control of the individual contributes to the confirmation of [the] active citizen, the self who can be, and indeed ought to be, in control of his or her self" (Nettleton, 1997, p. 215).

Robert Castel presents risk as a contemporary mechanism of governance (Petersen, 1997). He argues that many contemporary neo-liberal societies have shifted their "forms of surveillance and control from those based upon the direct, face-to-face relationships between experts and subjects to those based upon the abstract calculation of risk" (as cited in Petersen, 1997, p. 189). In other words, these societies have shifted how they attempt to control behaviour. Instead of undertaking individualized interventions that alter lifestyles one person at a time, they undertake more general campaigns that target an entire society and that, ultimately, attempt to prevent the emergence of undesirable events, illnesses, abnormalities and deviants in the first place (Petersen, 1997). In these societies, each individual is considered capable of managing and preventing risk and, therefore, the successful prevention of undesirable occurrences or outcomes relies on individuals making "smart" choices and behaving "appropriately." With such a focus on prevention, many experts have identified "a mass of new risks which constitute … many new targets for preventive intervention" (Petersen, 1997, p. 193). In other words, the sheer number of "risks" that have been constructed has created almost limitless opportunities for the state to intervene in the lives of individuals on the premise that it is protecting them from various "risks." The presence, validity and threat of such risks are often disputed.

Anthony Giddens (1999), expanding on Ulrich Beck's concept of a risk society, explained that a risk society needs to be analyzed through a series of distinctions. Most importantly, there needs to be separation of risk from danger. A risk society is not necessarily more hazardous or dangerous than a non-risk society. However, it is "increasingly preoccupied with the future [and with safety and this] generates the notion of risk" (Giddens, 1999, p. 3). Risk only exists in the context of choices and decisions and therefore is closely connected to responsibility (Giddens, 1999).

> As it is used today, 'responsibility' is an interestingly ambiguous or multi-layered term. In one sense, someone who is responsible for an event can be said to be [the] author of that event. This is the original sense of 'responsible', which links it to causality or agency. Another meaning of responsibility is where we speak of someone being responsible if he or she acts in an ethical or accountable manner. Responsibility also however means obligation, or liability, and this is the most

interesting sense to counterpose with risk (Giddens, 1999, p. 8).

Discourses of risk and responsibility have become increasingly common and more frequently used within the area of health (Nettleton, 1997; Petersen, 1997). According to Skolbekken (1995), the focus on risk in health promotion serves three main functions: 1) it helps doctors and patients to predict disease and/or death; 2) it prompts preventative interventions, which, in turn, save health care dollars; and 3) it justifies the medicalization of bodies. Skolbekken (1995) argues, "risk factors which are hypothesized to be linked to disease come to be treated as 'diseases to be cured'" (as cited in Nettleton, 1997, p. 215). Petersen (1997) reiterates that

> a close examination of the recent goals of health promotion and of its related strategies shows how the processes of risk management have, in effect, served the objective of privatizing health by distributing responsibility for managing risk throughout the social body while at the same time creating new possibilities for intervention into private lives (p.194).

The concept of risk in health promotion relies on the premise that individuals are fully responsible for their own health. They are responsible to regulate what happens to their bodies (i.e. exercise, food, exposure to the sun, etc.) and to monitor the effects that these things may have. When an individual is unable to regulate and modify his or her behaviour to reach optimal health, he or she is considered a failure (Petersen, 1997). Therefore, individuals whose behaviours and actions are "deemed contrary to the pursuit of a 'risk-free' existence are likely to be seen, and to see themselves, as lacking self-control, and as therefore not fulfilling their duties as fully autonomous, responsible citizens" (Petersen, 1997, p. 198). Within the discourse of risk and responsibility, the individual is held accountable and responsible for the care of themselves and others (Petersen, 1997).

> Each individual thus acquires a personal preventive capacity vis-à-vis the event of his or her illness, a preventive capacity structured around the possibility of self-transformation and, before that, of self-knowledge. If the regulation of lifestyle, the modification of risky behavior and the transformation of unhealthy attitudes prove impossible through sheer strength or will, this constitutes, at least in part, *a failure of the self to care of itself* — a form of irrationality or simply a lack of *skillfulness* … The mastery of the self is thus a prerequisite for health; the lack of self-mastery, accordingly, is a 'disease' prior to the actual physical complaint, whose symptoms are detectable as behavioral, psychological and cognitive patterns (Greco, 1993, p. 361 as cited by Nettleton, 1997, p. 214 *italics in original*).

In contemporary health campaigns, individuals are assigned responsibility for managing their own health. If the individual "chooses" to behave in a way that is conceptualized as risky, his or her ill health is seen as self-inflicted and a failure of "self-mastery." The assignment of responsibility to the individual also eliminates the state's responsibility to aid in individual health (Kacki, 2004; Petersen, 1997; Nettleton, 1997). Therefore, discourses of risk and responsibility not only promote a shift in responsibility for health to the individual, they also reduce the state's responsibility for people's health and illness (Donahue & McGuire, 1995). This shift is greatly facilitated by the current biomedical paradigm, which emphasizes individual – rather than social or political – causes and explanations of disease (Donahue & McGuire, 1995).

> The emphasis on the disease as an object that occurs within an individual produces the tendency to locate responsibility for illness in the individual, often resulting in blaming the victim. The sick person is assumed to be responsible for having taken health risks, such as accepting a hazardous job, failing to use seat-belts, or moving to an area with polluted water. The individual is held accountable for unhealthy lifestyle choices, such as smoking, drinking, poor eating habits or lack of exercise, as well as for illness-producing emotional styles and characteristic responses to stress. Such emphasis upon the individual's responsibility for illness often results in inattention to the sick person's whole situation (Donahue & McGuire, 1995, p. 48).

The unambiguous assignment of individual responsibility in the contemporary biomedical paradigm – and thus in current health promotion campaigns – ignores the broader structural limitations or constraints that prevent people from exercising "responsibility" and minimizing their "risk." As a result, health interventions and prevention programs often attempt to change individual behaviours without adequate consideration of the broader context in which individuals make health decisions.[72]

Risk of and Responsibility for FASD

The concepts of "risk" and "responsibility" are frequently used across a broad spectrum of health promotion campaigns. Similarly, in the FASD health promotion discourse there is a very clear and succinct reliance upon the notions of "risk" and "responsibility." I will analyze both oral narratives (i.e. transcripts of my interviews) and visual texts (i.e. FASD posters, books, and media campaigns in Alberta) to trace the particular ways in which concepts of "risk" and "responsibility" are invoked in FASD education, awareness, and prevention campaigns in Alberta.[73] The academic literature suggests that the concepts of risk and responsibility are applied, in equal weight, to one individual (i.e. the individual is at risk and this same individual is responsible to manage that risk). However, my research on FASD departs from and expands upon this notion of risk and responsibility by examining the ways in which these concepts are applied to more than one individual (i.e. a child is at risk and the mother is responsible to manage the risk to the child).

Some interview respondents are concerned with the overly simplistic messages of

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[72] For example, diabetes awareness campaigns urge people to eat well and exercise without any consideration for the context in which people make decisions about food or exercise. Diabetics may know that they are supposed to eat well but may not have the funds to afford fresh and healthy foods. Similarly, their ability to exercise may be limited because they have mobility restrictions or do not feel safe leaving their house. Maybe there is a lack of parks or walking paths in their neighborhoods. Maybe the weather prevents them from going outside.

[73] Please consult chapter 3 for a detailed discussion of the theoretical framework and methodologies employed in this study.

risk and responsibility invoked in FASD posters.[74] When discussing the simplistic messages (i.e. do not drink) on these posters, one respondent explains

> right now some [of the posters] are still on our website and we can also put together a chronology [of the posters we have used] starting with born free and then moving to the baby bottles … some of them have been absolutely appalling[75] and … I've received calls from all over saying "I can't believe you guys did that" and it's like, well, we didn't want to, but [the] politicians thought that was a very good message (Tom).

Another respondent, who was in charge of FASD prevention in her local district, confides that videos about FASD have been produced with similarly simplistic messages because

> the passion in the community [was] beginning to wane a little bit, so we wanted to do something and [were] hoping… [to] stoke the fires again, the passion of the general community not our group, but of the general community (Colleen).

Most of the respondents consider these messages and representations of FASD to be problematic and potentially damaging, but continue to disseminate them to the public. According to Colleen, one reason for their continued use is that these messages are still favoured by the politicians and are seen as an effective method to elicit community support. It is ironic that the Alberta government makes substantial profits from the sale of alcohol, but abdicates responsibility for the health risks that alcohol poses to its citizens by promoting messages of personal risk and responsibility. The fact that the state's role in distributing alcohol has not been critically examined by FASD advocates illustrates just how ingrained the discourse of individualized risk and responsibility is in our society. In the following sections I discuss how FASD discourse in Alberta continues

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[74] The images and representations of FASD on the posters will be discussed later on in this chapter. These posters were created by various governmental and non-governmental agencies in Alberta to educate women about the dangers of drinking during pregnancy.

[75] This respondent considers the messages on these particular FASD posters to be appalling because they do not acknowledge the complexity of this health issue. According to the respondent, the poster's focus on individual women has the effect of invoking guilt and allocating responsibility to all women who intentionally or unintentionally consumed alcohol during pregnancy. Such messages essentially shame women and make them more hesitant to disclose alcohol use or addiction.

to rely upon individualized notions of risk and responsibility.

Defining Risk

At Risk: Children[76]

As discussed in chapter 1, FASD is a medically defined disorder that results from prenatal alcohol consumption. In other words, if a woman consumes alcohol while pregnant, her child may be born with FASD. Those in charge of managing FASD are predominantly concerned with the health of the unborn child and, in turn, focus their attention – and their educational campaigns – on reducing and/or eliminating the risk that a child may get FASD. However, in order to prevent risk to the unborn child, these campaigns must target the mother. For instance, programs such as the First Steps Program[77] work with pregnant women in order to "reduce [the number of] future births of children with FASD."

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[76] Because FASD results from prenatal alcohol consumption, FASD health campaigns continuously focus on the child as being at-risk for FASD. This research does not dispute that a child's health is at-risk. Rather, as will be demonstrated, it argues that this focus on the child being at-risk overshadows the fact that pregnant women may be at-risk. The exclusive focus on the child ignores the structural context in which women decide to consume alcohol during pregnancy.

[77] The First Steps Program is one of the programs administered and run by a non-profit agency (name withheld) in Edmonton, Alberta. The mandate of this program is to work with women who are considered at-risk for producing children with FASD. Other community-based agencies have similar programs.

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The above poster contains a logo that says “Keep the Circle Strong.” This was the slogan for the 13th National Addiction Awareness Week, which was held across Canada from November 12 to 18, 2000.

Similarly, the above poster, disseminated by the Alberta government’s FASD awareness and prevention campaign, tells mothers how to have healthy babies. The subject or content of these kinds of posters is the unborn or newborn child; however, the object or purpose of the posters is to change the behaviour or actions of the mother. Interestingly, the posters utilize images of healthy infants and not fetuses (where the impact of alcohol is initially felt) or young children (where symptoms of FASD begin to manifest). Perhaps images of young infants are used to underscore how vulnerable children are, particularly as infants when they are biologically closest to their mothers.

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[78] This poster is produced by The Alberta Partnership on Fetal Alcohol Syndrome and AADAC.

[79]

The text in the above poster reads: "There is no 'safe' amount of alcohol for a pregnant woman. There is no 'safe' time to drink during pregnancy. There is no cure for alcohol-related birth defects and brain damage, and the consequences last a lifetime. If you know someone who is pregnant, support her healthy choices."

The image of an innocent and at-risk (or vulnerable) child appears again in the above poster. In this poster, the picture of the infant's head and bottles mimics the skull and cross bones symbol, which is widely known for poison. The poster informs readers that there is no 'safe' amount or time for alcohol consumption in pregnancy, and that alcohol use by a pregnant woman results in permanent and irreversible damage to the fetus. The underlying message is that a woman who drinks alcohol during pregnancy is, in effect, poisoning her child. In this poster alcohol consumption is presented as a dangerous choice that has dire consequences for the fetus.

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[79] This poster is distributed by Alberta Children and Youth Services and AADAC.

[80]

The text in the above poster reads: "Alcohol is toxic to an unborn child. Exposure to alcohol before birth can lead to long-term, life-long disabilities."

The poster above declares, "No alcohol is best when pregnant." The poster's main concern is the baby, which has been placed in the middle of the poster and is surrounded by a circle of hands that are ready to catch him or her. The small print on the poster states "the hands in the circle symbolize friends supporting friends,[81] for a healthy baby and a healthy future." In these messages the woman's body is the site of intervention for the interest and well being of the unborn child. These prevention campaigns are directed at women who "aren't diagnosed with FASD but because of their addictions and their pregnancy, their children are at risk" (Amy).

The concern about the "risk and damages" of FASD extends beyond an

> unborn baby … to families, you know, because growing up in an environment like that just, kind of, can go in cycles and [if we] could break as many of those cycles

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[80] This poster was distributed by the then Calgary Health Region and Three Cheers for the Early Years, in partnership with The Calgary Fetal Alcohol Network and The Minnesota Department of Health.

[81] This poster calls on family and friends to help ensure that women do not drink alcohol during their pregnancies. This focus on friends demonstrates an awareness of how powerful social and interpersonal contexts can be in a woman's decision to drink during pregnancy. However, missing from this discourse is the role and responsibility of state (which will be discussed in more depth later on in this chapter). Despite the focus on family and friends, there continues to be an individualization of risk whereby the state – and structural factors that affect a woman's decision to consume alcohol – is overlooked. Overall, this is another instance where family and friends are held responsible for one another's well being without consideration of the broader structural factors that enable and/or hinder health.

> as possible (pause) [then] the less there would be out there (Anita).

As I discuss next, social workers, bureaucrats, government officials, and the general public are also concerned about the impact of FASD on society.

At Risk: Society

> The effects of Fetal Alcohol Spectrum Disorder (FASD) are not only damaging to individual children, but to society as a whole. (Government of Alberta, 2004, p. 5).

The well being and future success of a child diagnosed with FASD most often concerns the child and his or her family; however, because children born with FASD have been presented as an economic and/or physical risk to “society as a whole,” the general public is also worried about their progress, and more particularly about the burden they may pose. One MLA expresses this concern as follows:

> The societal cost is huge in [terms of] the loss of potential to the children that are involved, in the dysfunction within the family units that’s caused by this dysfunction, later in the school system, and then, unfortunately, in the criminal justice system. I am aware that the majority of people [who are] incarcerated do suffer from either fetal alcohol syndrome or fetal alcohol effect (Legislative Assembly of Alberta, 2003a, p. 947).

Another MLA states,

> we need to consider the harm done to society, families, and especially to children by … fetal alcohol syndrome and fetal alcohol effect, and consider it a great public health problem (Legislative Assembly of Alberta, 2002b, p. 46).

A criminal justice officer similarly highlights the potential burden of FASD using the following example:

> this was a kid that’s really damaged and that was it exactly. He could not tell you his date of birth and he can barely scratch out a signature, ah, so, his reading and writing skills are really low (David).

The consensus appears to be that alcohol consumption by the pregnant mother damages the fetus and renders it utterly without the skills it needs to manage and cope in society. FASD-afflicted children are seen as “a specific group of kids who likely will not do well” and who will put “increasing stress and pressure on our system” (Legislative Assembly of Alberta, 2002a, 969).

It is believed that because of FASD, these children are incapable of functioning in society. Children with FASD are more often considered to have “mental health problems, disrupted school experiences, trouble with the law, confinement, inappropriate sexual behavior, and alcohol and drug problems” (Badry, Peleech & Norman, 2005, p. 62). According to this line of thinking, FASD is more than a public health concern. It poses health risks to unborn children, but it also poses financial and criminal risks to society as a whole.

First, due to their limited skills and abilities, FASD-afflicted children are seen as vulnerable to exploitation and abuse.

> Like, I mean, first of all, I think [that] the social cost on [the] kids is [that] they, for sure, lose their potential, like, whatever they could have been, they are not going to be …We have a hard time keeping them in their families, we have a hard time educating them, we have a hard time keeping them socially connected, they end up being taken advantage of, I mean, it’s one thing after another (Julie).

As seen above, there is a perception that children with FASD have lost the potential to achieve as well as the ability to recognize when they are being exploited. As David explains below, these children are expected to be unsuccessful in their educational and/or vocational pursuits.

> Some kids are gonna be dishwashers; some kids are going to be labourers, you know, they are, ah, education-wise, ah, some of the kids I deal with are young teenagers, ah, grade 6, grade 7, that’s as high as they are gonna get, so it’s tough (David).

Because FASD is thought to limit the educational or vocational potential of children, it is seen as a terminal disorder. Children with it "don't recover, and often those with FAS become adults who are not financially or socially self-sufficient" (Legislative Assembly of Alberta, 2003b, p. 56).

Second, these children are depicted as a financial risk and/or liability to society. FASD documents and policies continuously reiterate that "FAS irreversibly reduces human potential" (Szabo, 2000, p. 28) and that a child who is diagnosed with FASD can cost taxpayers "as high as $1.5 million" (Legislative Assembly of Alberta, 2000b, p. DSS64). Children with FASD are considered a huge financial burden. The Government of Alberta has had to increase department budgets "due in part to the risk of complex cases such as children with Fetal Alcohol Syndrome" (Legislative Assembly of Alberta, 2000c, p.1901). As described by one MLA, children born with FASD are "resulting in significant human cost and cost to public services, which I find disturbing" (Legislative Assembly of Alberta, 2001, p. 512).

Third, and finally, not only are these children seen as having limited potential, but the skills they do possess are considered undesirable and dangerous. It is believed that children with FASD have "mental health problems" and lack reasoning skills, and therefore, are more likely to engage in dangerous and criminal activities. "They have limited tools [under] their belt and the tools they do have are either assault or threatening, which are primal, right? It's fight or flight" (David). These children are not only damaged, they are "primal" and lack the qualities that distinguish us as human beings. Such discourse creates a direct relationship between the physiological and cognitive effects of FASD and violence. Children with FASD are seen as being irreversibly damaged. They lack promise and possess only primal skills, and are therefore, more likely resort to violence. They

> end up [as criminals] – they are not born to be criminals, but they have their disability [and] without proper supervision [or] structure, they can – something in their impulsivity… make[s] them prone to become active in criminal activity. (David).

One MLA concurs,

> There has been some dramatic crime, some murders committed in this province by people who suffer from this condition [FASD], and they really have no conception of what they're doing (Legislative Assembly of Alberta, 2003b, p. 56).

This sentiment is shared not only amongst those working in the FASD field, but also amongst senior public officials, as indicated below.

> I don't know about you, but, I really get angry when I think about the fact that we are sacrificing kids to a life of anger and maladjustment, to potential violence, to potential criminal conduct and a life of incarceration – in and out of jails – when in fact, fetal alcohol syndrome is completely preventable (The Honourable Anne McLellan,[82] the then Minister of Justice, quoted in Szabo 2000, p. 2).

In sum, children with FASD are seen as significant financial and criminal threats to society; there is a widely shared fear that they will grow up to be a "frightening problem for this society" (Legislative Assembly of Alberta, 2003b, p. 56), that they will "lead a very at-risk existence," and that they may inflict harm upon others. Some have even gone as far to say that if children with FASD "happen to harm one of our children that have grown up in a different environment, then we'll only have ourselves to blame" (Legislative Assembly of Alberta, 2000b, p. DSS59). As seen above, within FASD discourse, children with FASD are depicted as both potential victims and potential aggressors.

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[82] Anne McLellan served four terms as a Liberal Member of Parliament (MP) for Edmonton Centre from October 25, 1993 to January 23, 2006. From December 2003 to January 2006, she served as Deputy Prime Minister of Canada and as the first Minister of Public Safety and Emergency Preparedness, a ministry created by then Prime Minister Paul Martin. This information was taken from Anne McLellan's official website http://www.annemclellan.com/bio.

Designating Responsibility

> Diagnosis of this disability [FASD] is recognized as a diagnosis for two. This is a medical diagnosis for the child and an evaluation of a birth mother at risk for producing other children with this disability (Badry, Peleech & Norman, 2005, p. 63).

FASD prevention campaigns rely upon the rhetoric of risk. However, alongside the conception of risk, there also lies the allocation of responsibility. Within FASD discourse certain bodies are either overtly or subtly deemed to be responsible for creating this risk. Consistently the responsibility for prevalence of FASD is assigned to alcohol and more importantly (and punitively) to pregnant women who consume alcohol.

[83]

The pink and blue caption in the black box states: "Your Decision: Baby's Future." The text at the bottom of the poster says: "There is no 'safe' amount of alcohol for women who are planning a pregnancy, expecting, or breast-feeding. There is no 'safe' time to drink during pregnancy. There is no cure for alcohol-related birth defects and brain damage, and the consequences last a lifetime. If you are a friend, father-to-be, or relative of a pregnant woman, please support her healthy choices. To learn more about the effects of alcohol on baby's development, please visit www.child.gov.ab.ca and click on Fetal Alcohol Spectrum Disorder. For help, call 1-866-33AADAC (332-2322)."

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[83] This poster was produced collaboratively by The College of Physicians and Surgeons of Alberta, The Alberta Medical Association, The Alberta Alcohol and Drug Abuse Commission (AADAC), and the Government of Alberta. It was accessed online from http://www.child.gov.ab.ca.

Within Alberta, a cursory examination of FASD prevention campaigns indicates that the messaging is targeted at women and, more specifically, women of reproductive age. For instance, the poster above pictures a woman with one hand on her distended pregnant stomach and another hand reaching for a glass that contains alcohol, ice, and dice. The woman's head is missing from the picture, which indicates that advertisers are interested in certain parts of her – namely her stomach and the baby within it – and not in the woman as a whole. The text states: "Pregnancy and Alcohol? Don't take the chance." As seen in the quote below, the message is clearly directed towards women because they are seen to be at-risk for producing a child with FASD when they "take the chance" and drink alcohol during pregnancy.

> You know there are a number of at-risk communities. There are women that you think of probably when you immediately go to who are at-risk women. So, women … who struggle with addiction issues [are at-risk]. There is a significant – I think we consider women 18 to 24, who are a lot of the university group, who are quite heavily involved in binge drinking – that that could be considered an at-risk population. Some of the Aboriginal communities can be considered an at-risk population, but that – for me – the most significant population that we don't think of are (sic) – it's women who are a little bit older, 24 to 35, who are well educated who make, sort of, $60,000 plus a year, who drink regularly, and who are less likely to access services because of the stigma associated with alcoholism … the literature that I'm reading is saying that this [is] a group that really is at-risk (Tanya).

While the respondent above acknowledges that certain demographic groups, such as Aboriginal communities[84] and women with addiction issues, are more likely perceived to be at-risk, she identifies all women to be at-risk. A high-ranking public official has a similar observation:

> If you are [a woman] in that category [of reproductive age], you may not even be thinking about getting pregnant but the fact is if you are drinking and having sex,

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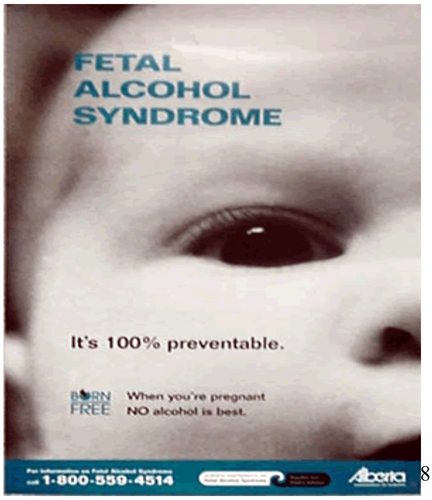
[84] The association of FASD with the Aboriginal population or the conception of FASD as an Aboriginal issue will be discussed in chapter 7.

you could have a child with FASD. It is the way it is; it is the fact (Tom).

Both Tanya and Tom are clear that any woman of reproductive age who consumes alcohol and is sexually active risks having a baby with FASD. Another FASD prevention worker clarifies: “we know that [middle class women are] the highest risk group … Aboriginal populations certainly have problems in this area but so does everybody else” (Sarah). Sarah’s comment highlights and confirms the societal perception that FASD is a particular problem in Aboriginal populations (and, by implication, for Aboriginal women); however, she extends this risk to all women.



[85]

The above poster states “Fetal Alcohol Syndrome. It’s 100% preventable. When you’re pregnant NO alcohol is best.”

“Born Free” is an early awareness campaign employed to promote the birth of children without alcohol damage. As shown above, one of its posters contains a baby’s face with the eye located in the centre of the poster. The poster proclaims “Fetal Alcohol Syndrome. It’s 100% preventable.” The “Born Free” logo (which contains a dove) is located at the bottom of the poster. Next to the slogan is another message clearly directed

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[85] This poster is distributed by the Alberta government and Alberta Partnership on Fetal Alcohol Syndrome. It was accessed online at http://www.acs.gov.ab.ca.

towards women: “When you’re pregnant; NO alcohol is best.” The subject of the poster is the baby but the message is clearly directed toward the mother. The poster is telling the mother that her child’s health is her responsibility and could be compromised if she “chooses” to drink.

[86]

The concept of risk and responsibility are highlighted once again in posters that depict the chance that women are taking by consuming alcohol during pregnancy. The poster above likens alcohol consumption by pregnant women to gambling. Notably absent from the poster are the larger social and structural factors that may drive pregnant women to drink (i.e. poverty, poor access to addiction and treatment centers, histories of violence and abuse, the ongoing impact of colonialism and marginalization) or that may worsen the impact of alcohol (i.e. poor nutrition, poor access to health care) (Armstrong, 2003; Bingol et al., 1987; Tait, 2009). The authors and distributors of this poster do not consider alcohol consumption to be an often-employed (albeit problematic) method of

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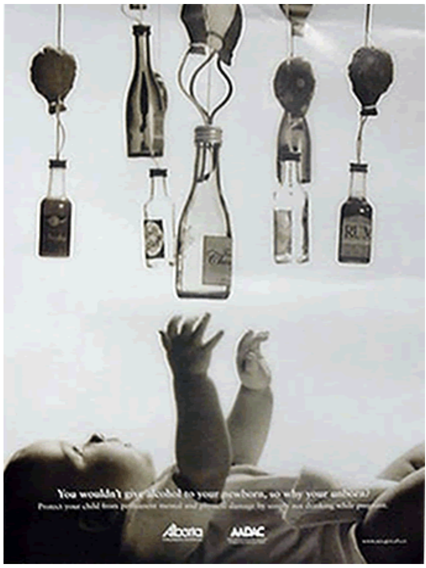
[86] This poster is produced collaboratively by The College of Physicians and Surgeons of Alberta, AADAC, The Alberta Medical Association and the Alberta government. It was accessed online at http://www.acs.gov.ab.ca.

coping with one’s circumstances; instead they present it as risky and unnecessary behaviour akin to gambling.



[87]

The above poster makes a similar assertion. It says, “You wouldn’t give alcohol to your newborn, so why your unborn? Protect your child from permanent mental and physical damage by simply not drinking while pregnant” and features a baby lying on its back, playing with a mobile of alcohol bottles. The image provokes a strong reaction. Most would be appalled if a new mother encouraged her baby to play with alcohol or alcoholic containers. Such a mother would likely be considered immature and irresponsible. The poster suggests that it is similarly reckless and irresponsible to consume alcohol during pregnancy. In addition, the message allocates responsibility to the mother to prevent her unborn child form “permanent brain and physical damage” by “simply not drinking.” Alcohol consumption is presented as a simple and straightforward choice that any responsible mother would avoid.

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[87] This poster was produced in partnership by AADAC and Alberta Children and Youth Services. It was accessed online at http://www.acs.gov.ab.ca.

[88]

This poster depicts a pregnant body, presumably at a bar, holding an alcoholic beverage. The text on the black top says, "I'm having what she's having" with an arrow pointing to the woman's head. However, the woman's head is absent from the picture, as is the rest of the body. The only two body parts seen in this poster are the hand holding the glass and a pregnant belly; the rest of the woman is invisible or, worse, irrelevant. The poster asserts that this pregnant woman is responsible for supplying alcohol to her unborn child. As symbolized by this poster, women's motivations, individual constraints, and context are erased from this discourse of risk and responsibility, and FASD is constructed as the straightforward and simple result of women supplying alcohol to their unborn child.

The message of responsibility was also heavily present in the interviews. Although aware of how the concept of responsibility may stigmatize women,[89] the respondents repeatedly utilized this stigma in their own explanations and understandings. One of the respondents, struggling with the concept of responsibility, had the following

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[88] This poster is produced in partnership by AADAC and Alberta Children and Youth Services. It was accessed online at http://www.acs.gov.ab.ca.

[89] The implications of holding women responsible for FASD will be discussed later on this chapter.

observation:

> From my view, the mom is solely responsible to produce that FASD child. No, responsible is not the right word. If mom drinks, she will have an FASD child. Responsibility is part of the bigger picture, but it is mom that has the relationship there (Helen).

Helen is aware that the concept of responsibility carries a negative connotation and tries to avoid allocating blame, but she still maintains that the "it is mom that has the relationship there." Sarah expresses similar sentiments.

> Well, I think it would play on your psyche a little bit and your own mental health if you have to accept that that I damaged my child, so already then you know they are born not going to be able to achieve everything they could have, had you not had that one drink. You didn't know you were pregnant probably when drinking occurred but one beer probably isn't worth having versus a child that has a lifelong disability (Sarah).

Sarah is adamant that while the damage inflicted by alcohol consumption during pregnancy may not be intentional, a woman still has to accept that "[she] damaged [her] child" and this damage could have been avoided if, as a responsible mother, the woman decided that the risk of having a child with "a lifelong disability" wasn't worth "one beer." Anna's comments further highlight the widespread belief that it is ultimately the mother's fault if her child suffers from FASD: "what makes it [FASD] horrific is you have caused harm unintentionally to your child when you were pregnant" (Anna). These kinds of statements exaggerate risk and assume that all women who drink are equally at-risk for producing a child with FASD. This perception exists despite studies that show that not all women who drink produce children with FASD.

As discussed above, FASD discourse relies upon the rhetoric of responsibility and focuses its attention on two parties that are deemed to be primarily responsible: 1) alcohol and 2) pregnant women who consume alcohol. In the section below I will discuss each of these in greater depth.

Alcohol as the One and Only Cause of FASD[90]

FASD prevention and education campaigns are vigilant about alcohol consumption during pregnancy and pay keen attention to the role that alcohol plays in producing FASD-afflicted children. Because FASD has been linked to alcohol intake, it is assumed to be a problem wherever there is a high level of alcohol intake. However, as will be discussed in this section, the continued attention and exclusive focus on the consumption of alcohol as the cause of FASD silences or renders invisible other factors that have been correlated with FASD.

> The simple fact is that the consumption of alcohol during pregnancy is the one and only cause [of FASD] (Szabo, 2000, p. 6).

> I think that if you want to look at the really high risk groups, the really high risk groups for FASD are no different than the high risk groups for other alcohol related harms … the drinking and driving groups, the other health issues that come with alcohol use, communities where alcohol use is very high, so you know that can include some Aboriginal populations, it also includes the university population, it also includes isolated communities so that's … anywhere where alcohol is being used at a high level you've got an increased risk for FASD. (Tom).

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[90] This section discusses FASD prevention campaigns' primary and continued focus on alcohol. This section does not attempt to dispute the claim that alcohol causes FASD, but rather critiques the exclusive focus on alcohol and the absence of socioeconomic and/or historical factors that enable or facilitate alcohol consumption by pregnant women. FASD prevention posters make it seem as if the decision to drink is very simple; however, the personal and social circumstances of some women make it a very difficult decision.

[91]

The above poster states, "Really, your baby doesn't need a cold one."

The excerpts and posters above assert that if a woman consumes alcohol during pregnancy, then she is, in fact, feeding her child alcohol. The mother's body is removed from the process and the act of alcohol consumption by the pregnant woman is seen solely as supplying alcohol to the fetus. The woman's intentions, motivations, and reasons for consuming alcohol are erased, as is the impact that the alcohol has on the woman's body.

Given the unwavering focus on the act of alcohol consumption, it is no wonder that most public service messages urge women to "just say no" to alcohol during pregnancy. The singular and narrow focus on alcohol consumption excludes attention to the structural context within which some women consume alcohol and other harmful substances. For example, drinking may seem like a rational coping mechanism to pregnant women who have grown up amidst alcohol or drug addiction, experienced social

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[91] This poster is produced by the Alberta Children and Youth Services and AADAC. It was accessed online from http://www.acs.gov.ab.ca.

isolation and abuse, or suffer from mental health problems.

The narrow focus on alcohol also ignores the findings of researchers who believe that FASD is a complex and multifaceted disease and that its causes can also be attributed a variety of structural factors (i.e. the health of an expecting mother and her baby can be negatively affected by myriad factors, including inadequate access to prenatal and postnatal care and services, poor nutrition, lower education levels, and lower socio-economic status). Bingol et al. (1987) found that when women of different social classes drank the same amount of alcohol during pregnancy, they did not all deliver children with the same degree of FAS. This study found nutrition to be the determining factor. Upper class women ate a more balanced diet while lower income women often missed meals and relied more heavily on carbohydrates. The result: the poorer women in the study produced babies that were more noticeably affected by FAS.

While the wealthier women's children did suffer some effects of FAS, the socioeconomic status of these women ensures that these effects are better managed (i.e. by highly qualified doctors, therapists, tutors, nannies, etc.) and that they are more privately managed (i.e. in the family's home, at more exclusive facilities, etc.) Thus, not only can poverty exacerbate the actual effect of alcohol on the fetus, it can also make "the [FASD-related] behavior[s] more visible and thus more susceptible to public scrutiny" (Daniels, 1999, p. 91). While the act of alcohol consumption by pregnant women is seen as an individual choice, it needs to be understood that for some women this may be a constrained choice made under less than ideal circumstances and made by women who lack resources to make alternate choices.

Unfortunately, within the discourse of choice, the structural contexts within which some addictions thrive and/or within which pregnant women decide to consume alcohol are ignored. There remains

> in Alberta… zero tolerance [for alcohol consumption by pregnant women]. There is alcohol galore but don't you dare drink and get pregnant … there is no grace; there is no allowance for understanding … what some of these women face. There is just a sheer harsh judgment (Helen).

As Helen explains, in Alberta, alcohol intake is seen as a choice and those who "choose" to drink during pregnancy are held responsible for the results.

The "just say no" campaigns also fail to recognize that for some pregnant women a "significant amount of alcohol consumption goes on before they realize they are pregnant" (Tanya). Therefore, urging pregnant women not to drink is only effective if women know that they are pregnant. Current FASD discourse continues to assert that "alcohol is a drug and a toxic substance that can harm the fetus even at relatively low levels of exposure" (Szabo, 2000, p.12). However, as Tanya points out "the jury is still out on how much damage … that [drinking in the first trimester of pregnancy] do[es]" (Tanya).

Despite the presence of structural factors that may hinder pregnant women's ability to abstain from alcohol and the fact that many women consume alcohol during the first trimester when they are unaware of their pregnancies, FASD awareness campaigns continue to tell pregnant women simply not to drink. The Alberta government's emphasis on alcohol consumption, in spite of evidence that other factors can impact the onset of FASD, needs to be questioned. Such a focus excuses political and social groups from developing programs to curb structural inequalities (Salmon, 2004; Tait, 2009). The attention on alcohol consumption is a short-term plan that works politically as there is "very little political will to fund programs to meet the needs of this population [pregnant women who drink]" (Kacki, 2004, p. 3).

The continued attention on the act of alcohol consumption allows us to ignore historical and contemporary institutions and discourses, that have created and continue to create conditions that breed destructive behaviour. The exclusive focus on the individual behaviour of women excuses us from addressing social inequities and structural constraints such as racism, colonialism, and poverty. The actions of individual women must be controlled and subjected because acknowledging other factors would clearly implicate the whole society.

Mother as Solely Responsible

The current FASD discourse not only directs inordinate attention to the act of alcohol consumption, it also holds women solely responsible for knowingly or unknowingly consuming alcohol during pregnancy. The following messages about FASD prevention and awareness campaigns are directed towards women of reproductive age.

> There is no other disability [like FASD] that directly implicates a birth mother as being solely responsible for the cause of [her] child's disease or disorder (Cindy).
>
> [W]e do… everything hard, we party hard, but, you know, God forbid that you screw up because you are going to be hung out to dry. You are the only one taking responsibility (Helen).

The intention of these messages is to change the behaviour of the woman, and, more specifically, to discourage her from consuming alcohol. However, the exclusive focus on a pregnant woman's perceived choice to consume alcohol has various social and political implications. The continued reiteration of messages urging women to "choose" not to drink during pregnancy creates "a very negative framing of a social problem" and ignores the structural factors surrounding women's use of alcohol such as "histories of traumas [and] dysfunctional family environments" (Cindy). Moreover, the messages are premised on the belief that pregnant women are intentionally consuming alcohol and this ignores the reality that

> sometimes people get pregnant and are drinking. Alcohol dis-inhibits (sic) behaviour. [So,] individuals become pregnant when they are drinking, and [they] don't stop drinking sometimes until they realize they are pregnant" (Cindy).

Prevention and awareness campaigns frame alcohol consumption as an intentional act, but alcohol consumption during pregnancy is not always intentional.

> I don't think that any mom goes into it believing – or doing it to hurt the child, but the fact is the issues around them are so overwhelming that this is one coping mechanism that works (Tom).

Cindy concurs: "It is not an intentional act, which is what I think the public response has almost attempted to frame it as" (Cindy).

The focus of FASD prevention campaigns on intention and choice further supports the widely-held belief that FASD is a preventable disability and could be prevented if pregnant women became aware and "chose" not to consume alcohol. However, the success that this approach and these messages are having is, at best, questionable.

> [There are] studies that show that alcohol use in pregnancy is 12 to 14 percent … we feel confident [that] we have a big chunk of the awareness handled, but that's not leading into action (Tom).

Therefore, although armed with the knowledge that alcohol consumption is dangerous to the fetus, a significant portion of pregnant women continues to engage in alcohol use. This indicates that while "prevention is still a huge piece" (Tom), prevention campaigns must go beyond evangelizing; they must acknowledge and address "the social determinants of health and understand why it is that people would drink during pregnancy" (Tom).

> The prevailing discourse of intention and choice leads to the
>
> perception that [FASD] is a preventable disability. I think that we are influenced by the American response to alcohol use during pregnancy, and we know that some of that response is simply to put women in jail and to frame the issue as prenatal child abuse and, in fact, when framed as prenatal child abuse, rather than alcohol exposure in utero, it puts a whole different lens on it (Cindy).

If alcohol consumption is seen as an intentional act, then alcohol consumption during pregnancy is considered "prenatal child abuse," and, the reasoning goes, women who engage in it should be subjected to legal sanctions. This discourse ignores that

> most people who have problems with drugs and alcohol and substance use and abuse have underlying issues and that's the reason they are using them, so, really, if we don't start to address some of those things in some ways, then the alcohol use is going to continue (Tom).

Current FASD discourse also creates an atmosphere in which "women are very afraid to disclose their alcohol use for fear of being judged and blamed" (Cindy). Messages that frame alcohol consumption as an intentional act and FASD as a 100 percent preventable health disorder facilitate a culture of "blame and shame"[92] whereby women are hesitant to access services due to the stigma associated with women who drink alcohol during pregnancy. As Helen explains:

> when it comes to advertising that drinking is bad for pregnancy or [to] those strong tones or [to the assertion that] FASD is 100% preventable – what that does is limit a woman going into her doctor and saying, "I'm scared. I have a problem. I'm scared that I might have affected my kid because I'm so irresponsible based on that poster back there." [The posters] create instant shame in a person … right [on the poster] there is judgment [of] a lot of people [who] are on liquors.

The overwhelming critique of FASD awareness and education campaigns is that their messages are overly simplistic and do not account for structural constraints.

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[92] The concept of "shame and blame" will be discussed at length in the chapter 6.

> [It is a] really simplistic view to [believe that pregnant women will] just stop drinking …[these campaigns] just continue to scapegoat this issue and if we have public education campaigns that aren't carefully crafted [and that continue to] … blam[e] women, we are just going to exacerbate the problem of people sort of splitting and saying this isn't an issue that affects me or impacts me (Anna).

The oversimplified messages used in campaigns invoke images of irresponsible and careless mothers with whom the majority of people do not identify. As such, it is easy for members of the public to dismiss the messages as irrelevant to their own lives. In their minds, FASD pertains exclusively to those women who intentionally choose to harm their fetus by consuming alcohol during pregnancy. Moreover, the attention of such campaigns focuses on women's behaviour instead of on the social and structural issues that facilitate alcohol consumption during pregnancy. The experts I interviewed acknowledge, "we need to be careful … [there is] so much scapegoating that happens in this issue" (Anna). They believe that new education and awareness campaigns need to highlight the complexity of FASD.

> [New campaigns should highlight FASD as] … a male issue as well as a community issue so that's what we want to focus on … It's not just the women drinking in pregnancy, it is helping the male to help support a woman to have a healthy pregnancy and what would that look like (Anna).

However, to date, the Alberta government has not supported these kinds of initiatives; it continues to encourage "mothers-to-be not to drink alcohol" (Government of Alberta, 2004, p. 6) and to ignore how ineffective these messages are, particularly in addressing women with substance abuse issues.

> The low risk group is the one that posters and coasters generally works (sic) for. They are in the position of choosing with a very large degree of comfort – okay no, if it is bad, I won't do it. But we have to recognize that anybody, any dependence or anybody whose habit it is to use will not benefit from those messages. Those messages are not helpful … there have (sic) been so much noise about labelling on bottles and how wonderful that is and I don't know how helpful [it really is]. We don't have any evidence to support that whatsoever and certainly

> when we ask our high-risk moms what made the difference, they all said having a mentor (Janet).

An interesting contradiction within FASD prevention campaigns is that while the provincial government is stringently presenting messages to pregnant women to abstain from alcohol, it continues to benefit from the sale of alcohol.

> The government profits heavily from the sales of liquor and Alberta, I think, is the highest in Canada in terms of alcohol purchases. Um, which identifies the problem that it [alcoholism] is not just an issue for women who give birth to children with FAS, but it is also an issue for society and our culture (Cindy).

Despite the profits made by the government in alcohol sales, the state refuses to accept even a share of the responsibility for various risks that alcohol poses to the health and well being of its residents. Instead, it expects individuals to be able to evaluate the potential risks of alcohol and to take responsibility for the outcomes that result from its consumption. "There is (sic) so many instances of that in our society, you know …[the] way of coming at things, um, [so] it's [responsibility] downloaded onto … individuals" (Pamela). The Alberta government's "just say no" to alcohol messages continue to download responsibility onto individual women. Its allocation of individualized responsibility, and therefore, abdication of state responsibility, is obvious in the lack of government-supported alcohol rehabilitation and treatment programs that will accept women and their children. One FASD expert that I interviewed notes the role that individualization plays in Alberta's FASD prevention campaigns:

> I go back to [the] political. It's connected to conservative thinking where everything is downloaded on to the individual … you are blaming and pointing a finger [and] you don't have to change anything yourself you know. The government does not have to actually step up to the plate and become responsible for people (Pamela).

Another notes the result of such individualization:

> Well, I think that what we have done is we've not – as a society – we have not provided the opportunities for women to engage in the treatment that they need and women who are involved perhaps with one of the systems like Child Welfare, are very afraid of the systems (Cindy).

The absence of alcohol treatment programs, coupled with the prevailing punitive attitude towards pregnant women who consume alcohol, has instilled fear in pregnant women with alcohol problems; they are increasingly reluctant to disclose addiction issues because they are afraid they will lose custody of their children. Some interview respondents attribute the emphasis on individual responsibility to be a political strategy that essentially exempts the state from any culpability. Others link it to religion, saying that individualization is based on "our Western, individualistic, [and] unfortunately, Judeo/Christian background, [where] all bad things that happen are consequences of your bad behaviour" (Janet).

Although those in charge of managing FASD are highly critical of discourse that holds alcohol and pregnant women responsible for the existence of FASD, their FASD prevention campaigns continue to perpetuate these tenets. By telling women to "just say no" FASD prevention campaigns assume that a) women know that they are pregnant when they consume alcohol; and b) women are able to control their alcohol consumption once they discover they are pregnant. By urging women to "plan their pregnancies," these campaigns also assume that planning a pregnancy is the purview of a woman.

Planning Pregnancies

> [We are] kind of considering all of those issues that come together [to] … create risk, so, you know, sexually active, drinking, possibly not using protection or birth control – those kinds of things. So, kind of, that preconception … and one of the, you know, statistics that comes out quite a bit at FASD discussions is that, you know, almost 80 percent – or higher in some cases – of pregnancies are unplanned. So, if people are becoming pregnant and continuing to drink,

> especially that first trimester – not knowing that kind of thing – so, I think we have lots of opportunities for prevention and awareness of FASD in terms of reaching different groups with different messages possibly (Jackie).

Although they recognize the problematic aspects and severe limitations of the current preventions campaigns, FASD experts continue to allocate individual responsibility and risk in various ways. Many acknowledge that the current emphasis on the individual has failed to translate awareness into the cessation of alcohol consumption. However, when asked about future campaigns, they continued to emphasize the behaviours of individual women. They argue for more robust campaigns that target all women of reproductive age and encourage women to plan their pregnancies.

> We should be … planning our pregnancies and deciding the exact month when we want to get pregnant, so [that] we have no consequences about having [a drink on] Margarita Mondays and then having a child with FASD (Anna).

FASD prevention strategists in Alberta are beginning "to also look at the preconception phase and [are] advocating for no alcohol if you are planning" (Tanya). These new efforts emphasize planned pregnancies because

> it is the social drinking – when you don't know you are pregnant – that can create this [children with FASD] … for us, our radio ads do focus on that, you know, to prevent FASD means you are planning your pregnancy and not going "oops, I'm pregnant and [I] drank for the first six weeks" (Sarah).

These new messages extend beyond pregnant women; they target all sexually active women.

> If you are in that category … you may not even be thinking about getting pregnant, but the fact is if you are drinking and having sex, you could have a child with FASD – it is the way it is, it is the fact (Tom).

In order to avoid the risk of producing FASD-afflicted children, experts believe that

> boys and girls, men and women need to be informed that they are all responsible in creating a healthy environment for conception, birth control is critical in relation to drinking behaviour (Cindy).

While Cindy includes boys and men in the discourse of planning pregnancies, very few of the FASD prevention messages (posters, advertisements, etc.) reviewed in this research targeted and/or even included the words boys or men. Overall, officials in charge of FASD urge us

> to raise [the] level of awareness [that] we have, to look to our children and to [ensure] that the women who are having our children are keeping them healthy because FASD is 100 percent preventable (Amy).

As seen in this quote, women are seen as primarily responsible for producing "our" healthy children.

In conclusion, those in charge of managing FASD in Alberta acknowledge the limitations of the early FASD prevention and awareness campaigns and continue to be critical of the widespread use of such messages. However, some of these messages remain embedded in today's FASD prevention campaigns. For example, FASD prevention campaigns that urge women to use birth control while consuming alcohol assume, first, that alcohol is the determining factor in FASD and should be avoided at all costs, and, second, that potential mothers are ultimately responsible to anticipate and ensure a healthy pregnancy. Current FASD prevention campaigns continue to utilize and rely upon the conceptual framework of individual risk and responsibility. Moreover, the present understanding – that FASD is a risk to children, is caused by irresponsible women, and can be prevented by planned pregnancies – continues to ignore adults who are afflicted with FASD.

Invisible Adults with FASD

A persistent theme within FASD discourse is the child-at-risk. As discussed earlier, FASD is seen and understood as a medical risk for children; the health of the child is the driving force behind FASD campaigns and interventions in Alberta. The child-centered nature of FASD within Alberta is in part due to its origin in the Ministry of Children and Youth Services.

> So I developed curriculum and I started my first [FASD] training session in December 1992 for child protection workers, and we also expanded then to include people who worked in income support, you know, welfare programs. But our first foray was child protection workers and all those programs (Ellen).

Because FASD programs and services originated in the Ministry of Children and Youth Services, FASD "provincial initiatives … look at [the issue] from the Children's Services point of view" (Tom). Moreover, "Children's Services' money has paid for things like … social marketing campaigns" (Tom). Province-wide FASD initiatives are funded by and represent the perspective of the Ministry of Children and Youth Services. Adults, who are not the clientele of this Ministry, are therefore left out of such initiatives. One FASD expert explains

> that's their [the Alberta government's] mandate … you know, the early years. It seems to be in the last seven years their focus is early childhood development; it isn't … adults" (Anna).

The continued focus on and framing of FASD as a child welfare concern has led to the invisibility and neglect of adults with FASD. Those in charge of managing FASD acknowledge this problem.

> So we've been fairly successful in different pockets of Alberta, providing supports to children and families, but there is a huge gap in services for adults including diagnosis and support (Tom).
>
> [Adult] access to assessment [is an ongoing issue] and that is so frustrating because it is really a health issue and it is just not being picked up at all (Anna).
>
> There are no diagnostic clinics for adults that are publically funded. There are privately funded diagnostic clinics, but not anything publically funded, so, for

> example, I spoke to one woman who said, “I think I have FAS, but I don’t know because it costs between $3,000 and $5,000 to get an assessment through a private clinic.” And so nobody is going to fund that for an adult from the public purse, so there is no venue for the individual to go and get the required medical diagnosis for the adult (Cindy).

A recurrent theme in the discourse of FASD is that it is characterized as an issue of childcare and protection. This characterization, in effect, has led to continued invisibility of adults suffering from FASD.

Discussion and Conclusion

In a contemporary neoliberal society, individuals are expected to evaluate risks and to assume responsibility for the consequences of their behaviour. As discussed in this chapter, FASD discourse heavily relies upon discourses of risk and responsibility. The discourse focuses on two at-risk groups, in particular: 1) the child, who is at-risk of contracting FASD and suffering its ill effects; and 2) society at large, which may have to spend a great deal of money to care for FASD-afflicted children (FASD discourse does not, ironically, acknowledge that potential or pregnant mothers could be at-risk for addiction or ill health). While FASD prevention campaigns target women, they are predominantly concerned with the health of child, and even then, they are mainly concerned with how the child’s health negatively affects or threatens the rest of society. For instance, there are growing and persistent concerns regarding the economic cost of FASD-afflicted children and the criminal threats that they can and do pose.

FASD discourse also clearly allocates responsibility for FASD, first to alcohol and then to potential or pregnant mothers. Alcohol is the predominant teratogen and is considered responsible for the existence of FASD. FASD discourse’s almost exclusive focus on alcohol is perpetuated by FASD campaigns that focus on the act of alcohol consumption and virtually ignore other factors that facilitate alcohol consumption, such as the widespread availability of alcohol, the acceptability of social drinking, peer pressure, and issues of addiction. Moreover, the exclusive focus on alcohol ignores how structural issues like poverty, violence, and marginalization may lead to substance abuse and addiction among women.

Embedded within the singular focus on alcohol is the belief that women who consume alcohol during pregnancy are responsible (and are to blame) when babies are delivered with FASD. Such women are not only considered selfish, careless and, at times, even malevolent, they are also responsible for introducing economic burdens and criminal threats to the rest of society.

As discussed at the beginning of this chapter, the utilization of risk and responsibility is a particular characteristic of neo-liberal rationality, which assumes that individuals can assess and mitigate their own risk and that society is made up of rational human beings who have the capacity to adequately care for themselves (Rose, 1993). As Petersen (1997) explains “neo-liberalism calls upon the individual to enter into the process of his or her own self-governance through processes of endless self-examination, self-care and self-improvement” (p. 194). As such, current FASD prevention messages are only effective insofar as they reach “low risk” women or women who, upon being made aware of the risks associated with alcohol consumption during pregnancy, can make the necessary changes in their lifestyles to reduce the risk of producing FASD-afflicted children.

These messages, however, fail to consider those individuals who, due to issues of addiction, cannot adequately care for themselves and, as such, cannot “just say no” to alcohol during pregnancy. When these messages reach such women, they instil fear and guilt. When they reach members of the general public, they reinforce the notion that mothers are responsible for their children's health and, therefore, when a child's health has been compromised, his or her mother is to blame. As Gordon (1991) explains, public health campaigns have a

> widespread tendency to establish links between personal goals and the 'public good'… and [there is] the tendency for individuals to be evaluated according to their abilities to effectively regulate themselves and others in line with prescribed norms of conduct for 'healthy living' (p. 44).

Accordingly, pregnant women who are unable to "just say no" to alcohol are blamed and judged for irreparably damaging their unborn (i.e. innocent) child through their own "lack of care" and selfishness. Instead of encouraging women to seek help in curbing alcohol consumption, these messages instil fear (i.e. of stigma, judgment and punitive measures, like the loss of custody) and, as a result, many women hide their issues with alcohol.

Individuals in charge of managing FASD in Alberta are aware of the negative implications of early FASD prevention discourse; however, its conceptions of risk and responsibility continue to dominate today's prevention campaigns. Rather than instituting structural supports (i.e. ensuring that treatment centers are able to accept women and their children) and addressing structural issues that facilitate addiction (i.e. poverty, violence, and marginalization), these campaigns continue to encourage women to make "simple" and "responsible" decisions (i.e. to avoid alcohol and to carefully plan their pregnancies).

Current FASD prevention campaigns target all sexually active women who drink alcohol – and not just those women who either are or want to be pregnant. Therefore, any woman who is consuming alcohol and not using a secure method of birth control can be labelled as irresponsible; she is, after all, risking getting pregnant and giving birth to an

FASD-afflicted child. The new FASD prevention messages hold these women responsible for the births of FASD-afflicted children and, by extension, for the economic burdens and criminal threats that these children pose. Furthermore, the persistent attention on women continues to render invisible the structural and societal factors responsible for the health and well being of all individuals. The current FASD prevention campaigns, like the early FASD messages, download the responsibility of health and societal well being onto the shoulders of individuals, and excuse the state from its obligation to help individuals obtain and maintain optimal health.

In conclusion, the continued reliance upon concepts of risk and responsibility in FASD prevention campaigns is consistent with the prevailing discourse and understanding of public health management, and not surprisingly so. As Gordon (1991) explains, "given that the 'care of the self' is bound up with the project of moderating the burden of individuals on society, it is not surprising that it is in the health promotion strategies of the so-called new public health that these developments are most apparent" (p. 44).

Chapter 6: Shame, Blame, Social Reproach and Disgust: Representations of Women within FASD Discourse

This chapter provides an in-depth examination of the issue of gendered responsibility within FASD discourse, brought to the forefront in previous chapters. In the previous chapters I examined 1) the various ways in which FASD developed and came to the public attention in Alberta[93] and 2) the continued reliance of FASD prevention and educational campaigns on discourses of individualized risk and responsibility.[94] This individualized discourse of FASD holds women responsible for putting their children, unnecessarily, at-risk.[95] Earlier chapters have also highlighted the various ways in which women are implicated and represented within FASD discourse.

In this chapter, I build on these discussions by 1) exploring gendered FASD discourses and, more specifically, exploring how FASD professionals explain the origins of such discourses; and 2) examining the ways in which FASD professionals discursively position themselves in relation to these discourses. The chapter reveals that those in charge of managing FASD are aware of and try to actively discourage a gendered understanding of FASD. However, it concludes that FASD understandings in Alberta continue to articulate gendered responsibility.

To clarify, the goal of this chapter is not to blame FASD professionals in Alberta for FASD discourses or practices, but rather to explore how gendered representations of FASD are part of broader discourses and understandings that inform these practices. As

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[93] Please see chapter 2 and chapter 4 of this dissertation.

[94] Please see chapter 5 of this dissertation.

[95] Please consult chapter 5 for a detailed discussion of the discourse of gendered risk and responsibility within FASD prevention and educational campaigns in Alberta.

social actors we are all embedded in broader discourses of gender. Accordingly, my research uses FASD as a case study to demonstrate how health policies and programs, like those that address FASD, are constructed by broader discourses and representations of gender. An individual's awareness of and resistance to these broader discourses is not enough, as institutional constraints often ensure that health practices continue to be informed by these particular understandings.

Literature Review: Representations of Gender Within Medicine

Since the 1970s there has been growing interest in how women's bodies are represented through and by medicine (Ginsburg & Rapp, 1991). The resulting research reveals a long history of political surveillance and medical control over women's bodies. Women have benefited from scientific discoveries and improvements to medical services. For example, maternal and child mortality rates have dropped significantly and the number of treatments for infertility has increased. However, these advancements have also placed greater constraints and surveillance upon women's behaviour during pregnancy, at birth, and during the perinatal period (Casper, 1998; Collins, 1994; Ginsburg & Rapp, 1991; Ginsburg & Tsing, 1991; Roberts, 1999). Some scholars argue that discourses of gender, responsibility, and reproductive health legitimate and facilitate control over women's bodies (see Casper, 1998; Deveruex, 2005).

One example of how health discourse has created moral panic and encouraged public concern with and, in the end, overt control of women's bodies is the "crack baby" crisis in the United States. During the 1980s, there emerged widespread social and political uproar over the prevalence of "crack babies" or babies who had been birthed by drug-addicted mothers. Images of pregnant black women using drugs – and thus harming their unborn children – spread rapidly throughout the media and sparked political debates. “Crack babies” were depicted as damaged, as potential burdens to society, even as “uncontrollable demons” (Roberts, 1999, p. 157). This discourse created alarm; people became concerned about the economic and physical risks these children may present to society and demanded that something be done. According to Roberts (1999) and Ortiz and Briggs (2003), the “crack baby” discourse was used to blame black mothers for the marginalized status of American blacks. It was also used to explain the higher rates of incarceration, poverty, and unemployment among African-Americans.

The tendency to blame women for the health of their children has continued in the context of other ostensible illnesses, such as schizophrenia, autism, epilepsy, and asthma. For instance, mothers are consistently implicated in the debate over Attention Deficit/Hyperactivity Disorder (ADHD) (Singh, 2004). ADHD is a common child psychiatric disorder, characterized by symptoms of hyperactivity, inattention, and impulsiveness. Boys between the ages of 6 and 11 years old are most likely to be diagnosed. The increasing rates of ADHD are often (incorrectly) attributed to poor parenting (Singh, 2004). Singh (2004) explains, “the category ‘parents’ often serves as a euphemistic cover for accusations against mothers” (p. 1194). For instance, many studies that purport to examine parent-child interactions have systematically excluded fathers and girls and focused exclusively on the “potential toxicity of mothering behaviors in relation to sons” (Singh, 2004, p. 1194).

(Re)imagining Women: Perceptions and Representations of Women

Like ADHD, FASD is also deeply embedded in various discourses of gender. This section 1) describes, in the opinion of FASD professionals, how the public perceives women who give birth to FASD-afflicted children; 2) determines how these perceptions and discourses have emerged; and 3) examines the impact that these perceptions have on current FASD understandings, programs, and policies. To clarify, this section does not provide a description of how the general public actually views women who give birth to children with FASD. Rather, it is a discussion of what the respondents (i.e. FASD professionals)[96] perceive these views to be. It is extremely important to understand these perceptions because FASD professionals discursively position themselves in relation to them. Moreover, some FASD programs, such as the First Steps program, have been developed according to the perceptions that FASD professionals think are prevalent in the general public. This section of the chapter is followed by an examination of how respondents position themselves in relation to supposed public opinion and perceptions of women who give birth to FASD-afflicted children.

Gendered Discourses of Blame, Reproach, and Disgust Within FASD Understandings

"Women conceive and bear the child" (Pamela)

Many of the FASD professionals that I interviewed struggle with the public's understanding of FASD, which, they believe, holds women responsible for the existence of the disorder. They argue that the public's simplistic understandings of FASD, which do not account for the context in which women consume alcohol and which blame and stigmatize women, inform many awareness and prevention campaigns. In fact, the respondents spent a sizeable amount of time describing what they believed current public

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[96] As explained in chapter 3, 23 respondents were interviewed for this research. The occupation of these professionals included teacher's aides, nurses, doctors, police officers, program directors, social workers, and government employees. All of the respondents worked or were working with FASD. Collectively, they specialized in FASD programming and diagnosis, worked with women at-risk for giving birth to children with FASD, and worked with adults with FASD.

opinion to be.

Many respondents claim that one of the most significant perceptions about FASD is that it is all “about women and pregnancy” (Julie). This is largely “because women conceive and bear the child and often they are the primary caregiver so we [the public] always look at it as a women’s issue” (Pamela). According to the respondents, the public believes that if “women just didn’t drink, this wouldn’t happen” (Jackie) and that “the mom is solely responsible to produce that FASD child…[so] if mom drinks, she will have a FASD child” (Helen). The respondents believe that in the public eye, the “birth mother is solely responsible for the cause of [her] child’s disease or disorder” (Cindy).

In this climate, mothers who deliver babies with FASD experience “toxic shame” because it is presumed that they intentionally “hurt their babies” (Pamela). Sarah, a community worker, explains that arguably worse than the judgments made by the broader public is the internal guilt and shame that these women experience when they realize that their children will not “be able to achieve everything they could have [achieved if they were FASD-free]” (Sarah). FASD professionals expressed a number of concerns with these public perceptions. As has already been discussed, many believe that the direct allocation of blame to mothers has resulted in shame, guilt, and a reluctance to seek help.[97] Although careful not to condone these perceptions, many respondents acknowledge that these perceptions put the responsibility for FASD squarely on the shoulders of women.

“Social reproach, disgust with ... these women” (Janet)

FASD professionals believe that the public harshly judges women who have

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[97] The respondent’s understanding of the impact of these negative discourses will be discussed in detail later in this chapter.

babies with FASD. When asked to describe the context in which FASD interventions emerged, Janet said that “there was still a lot of resentment and anger and, um, what’s the word I am looking for, social reproach, disgust with respect to these women.” This attitude is still present today. For instance, in a recent training session, one FASD expert encountered a gentleman who had the following reaction to women who delivered FASD-afflicted children:

> He couldn’t let go of why these women wouldn’t be jailed when you have 8 or 9 kids that have Fetal Alcohol [Spectrum Disorder]. How do we let her have 10 or 11 and 12? How does that happen in Canada, and why don’t we step up and jail, you know? (Janet)

Another respondent reported a similar encounter. When she was travelling, a fellow passenger learned of her occupation and told her, “these women should just be in jail” (Julie).

Some respondents reported that such blame and reproach is quite prevalent and indicative of how most people in society view women who consume alcohol during pregnancy. As Anna explains, “we [the general public] do blame the women instead of saying what type of environment was she in that allowed – or this type of thing” (Anna). Colleen explains that those who hold these women responsible “come from all over, all over. Even the people that are [drug and alcohol] users themselves condemn women that are pregnant and using” (Colleen). Children do as well. As Helen reports, “we have had situations where we have heard children on the playground [insult one another by] saying ‘your mom drank while she was pregnant with you’” (Helen). Judgment and reproach can also come from “the adult child blaming the mom because they (sic) know what caused it [FASD]” (Tina).

However, other respondents, like Helen, attribute these harsh reactions against women who consume alcohol during pregnancy to “a kind of conservative group that thinks we just need to be harsher.” She and several other respondents believe that there are also segments of the population that urge for “more understanding” (Helen). Overall, most respondents’ felt that “in the Alberta government and [in] health and wellness and doctors and everything, you still have that mix” of those who are sympathetic toward women who consume alcohol while pregnant and those who not; of those who seek rehabilitative resolutions and those that advocate for tougher sanctions (Helen).

Speculations on the Origins of Gendered Discourse

Diagnostic Criteria

Many respondents believe that current diagnostic criteria are responsible for the propagation of blame and moral judgment towards women. Currently, “[a] mom [must] admit that she drank during pregnancy … [that] is a requirement to get a full FAS diagnosis” (Tom).[98] However, this requirement is understandably problematic. As Cindy and Pamela explain,

> It labels the individual. It retrospectively labels the birth mother and creates a portrait [of her] in the broader society [which is] largely uninformed [about] the complexity of the disability” (Cindy).[99]
>
> The moms [that] I’ve had on my caseload…some of them, you know – I ask them, how much alcohol did you consume when you were pregnant? Because I need that history as well and [then] they don’t come back again because there is too

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[98] Tom is referring to the Institute of Medicine diagnostic criteria for Fetal Alcohol Syndrome and alcohol-related effects. According to this diagnostic criteria, “prenatal alcohol exposure requires confirmation of alcohol consumption by the mother during the index pregnancy based on reliable clinical observation, self-report, reports by a reliable source or medical records documenting positive blood alcohol, alcohol treatment or other social, legal or medical problems related to drinking during the pregnancy” (Chudley et.al., 2005, S11).

[99] As discussed in chapter 2, FASD is a complex disorder without clear diagnostic criteria. In addition, the link between alcohol consumption during pregnancy and FASD is somewhat murky. For instance, Bingol et al. (1987) found that women from higher socioeconomic class who consumed alcohol were less likely to have children with FASD than their counterparts from lower socioeconomic backgrounds. This study highlights the importance of structural support and services (such as nutrition and access to health care) in preventing FASD.

> much shame involved, [too much] guilt (Pamela).

Like Cindy and Pamela, many respondents blame the current diagnostic criteria, and particularly the requirement that a mother disclose her alcohol use, for further entrenching the belief that mothers who give birth to children with FASD are ultimately culpable for their children's disorders.

Posters and Coasters: FASD Prevention Campaigns

The respondents not only dispute the accuracy of the underlying messages in FASD campaigns (particularly the claim that FASD is 100 percent preventable and exists only because pregnant women elect to drink), they also believe that such messages are responsible for the public stigma against and judgment of women who consume alcohol during pregnancy. The public sees "the messag[e] that … [FASD prevention campaigns] are giving now to women [which] is don't drink when you are pregnant" and it believes that women who fail to abide by such advice needlessly places babies at-risk and should be punished accordingly (Julie).

> There was a [public] discourse … that FAS [is] preventable by simply stopping drinking, which, totally, is a reduction of the problem to a simplistic response. It doesn't take into account the lives of birth mothers (Cindy).

Nor does it account for the fact that "by the time that women … figure out they are pregnant, [many have] already drank" (Julie). FASD professionals are critical of the perceptions that the public supposedly holds.

> [FASD] is not 100 percent preventable. Anybody who is saying it is blowing smoke. Can it be prevented more than it is? Oh, for sure. But is it 100 percent [preventable]? No!" (Julie).

> I have a bit of problem with [the belief that FASD is 100 percent preventable]. If mental health [problems are] 100 percent preventable, you wouldn't have drinking or self-medicating, and if poverty is 100 percent preventable, you

> wouldn't have someone drinking because they have been beaten every day … addictions are far more complex [than the public acknowledges] (Helen).

Nonetheless, these professionals are caught up in prevention campaigns that reinforce these messages and further entrench public opinion. They admit that "the common message that goes out [is] that FASD is completely preventable" (Helen) and that the ongoing use of these kinds of messages creates unrealistic "standards so that we [the public] can still get mad at women, if it [FASD] happens … we told ya!" (Julie).

Male Researchers, Media, and Writers

Along with diagnostic criteria and prevention campaigns, some respondents blamed the prevailing attitudes of blame and judgment on male researchers. "Who are these researchers? They are mostly guys, aren't they? They are saying its all women" (Anita). Many FASD professionals also believe that the media is guilty of furthering blame on women since "there is very little that is ever represented in the media about fathers" (Cindy). However, when asked why the general public holds women solely responsible for the existence of FASD, most pointed to books like as *The Broken Cord* by Michael Dorris[100] and *Fetal Alcohol Syndrome: The Real Brain Drain* by Paul Szabo,[101] which

> frame [FASD] very clearly as a woman's problem and [are] full of blaming the woman, who [is] responsible for the whole situation … in [a] way [these books

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[100] This book describes the author's experience in adopting an Aboriginal child with FASD. It is extremely critical of women who consume alcohol during pregnancy. Dorris was heavily criticized for furthering racist depictions of the Aboriginal community and for blaming Aboriginal women for the prevalence of FASD in Aboriginal communities. Michael Dorris was an anthropologist at Dartmouth University. He died in 1997.

[101] Paul Szabo is a Liberal Member of Parliament representing the constituency of Mississauga South in Ontario, Canada. He has written several books on topics such as domestic violence, divorce, families and Fetal Alcohol Syndrome (FAS). In this book he describes the incredible economic and social costs of FAS and argues that FAS can be easily prevented if the government would inform women – through labels and public messages – not to drink during pregnancy. His analysis assumes that women drink due to lack of knowledge.

> are] disrespectful, really, of the environment from which FASD emerges (Cindy).

The respondents emphasized the simplicity of arguments that place responsibility for FASD onto individual actors – in this case, women. They argued that a more sophisticated understanding of FASD must consider the context in which pregnant women decide to drink alcohol.

Women, Morality, Mothering, and Alcohol

Women who drink while pregnant are harshly judged – according to FASD professionals – because they do not align with societal ideals of pregnant women, morality, mothering, and alcohol.

> We [the general public] relegate women who are using and pregnant because we know now that alcohol causes defects. It is really a straight road from there into hell. She [the pregnant woman who drinks] is therefore immoral or amoral (Janet).

> We [the general public] absolutely revile women who don't act like Madonnas when they are pregnant. We have nothing but revulsion for them. And we are unprepared to recognize that within the context of her life, her method of coping is very reasonable (Janet).

Beneath these expectations of pregnant women are broader expectations of woman in general. The public sees a woman and thinks either now or in future, she will be a mother and, as such, should not behave in ways that will compromise her ability to be a "good mother." The act of consuming alcohol is considered to be in sharp contradiction to the behaviour expected of a "good mother." Debbie pointed out that messages that govern mothering and alcohol are present even in religious texts like the Bible.

> [It's] in the Bible – that says women shouldn't drink. That if you are pregnant…[you] shall not partake in wine. Something like that. So we knew for a long time women are not supposed to drink, right? Women are supposed to be mothers. The good ones, you know, are not supposed to do a lot of things

(Debbie).

The general public judges and blames women who consume alcohol and drugs while pregnant because, according to religious texts or broader societal ideals, these women are irresponsible, undisciplined, selfish, a poor example, etc. The underlying assumption of these judgements is that women are aware that “drinking during pregnancy is bad” but simply don’t care (Tanya). In other words, “birth mothers are [perceived to be] uncaring [and are] unwilling to stop drinking” (Cindy). They are selfish women who pursue their own desires no matter the cost to their unborn children. The public judges these women so harshly because it believes FASD-afflicted children are the result of a lack of care, a lack of will, and a lack of responsibility. In the public eye, any woman who lacks these qualities is (or is destined to be) a bad mother.

The Perceived Impact of Gendered Discourses

Many respondents believe that they regularly encounter and navigate discourses of blame in their work. Some report that they, as professionals who work with women who drink during pregnancy, have experienced similar kinds of public reproach. According to Helen, “there is a lot of judgment working with women who have FASD kids. Lots of judgment” (Helen).

> I think … one of the biggest hurdles that we have had to overcome … is basically educating people and convincing others that this is a real issue and [that] it’s not people wanting to enable [or encourage drinking during pregnancy]. Because I think that [is the] sort of misperception that a lot of folks still have. [It] is that ‘you [are] just coddling these people. You’re just making excuses for their behaviour. You’re just creating dependency (Amy).

The above comment highlights that the public often lacks an appreciation for the complexity of FASD and, in turn, judges not just the women who it considers responsible for FASD, but also the professionals who are committed to working with these women.

Overall, the respondents were not concerned about how the public judges them or their work; they were greatly concerned, however, that these discourses place unnecessary blame on their clients and, in turn, discourage women from seeking help. It is important to examine the perceived negative consequences of FASD discourses because it is in response to these consequences that respondents attempt to develop a FASD counter narrative (the counter narrative will discussed later on in this chapter).

Barriers to Health Care and Medical Assistance

According to the FASD professionals, one of the biggest problems with negative discourses and negative representations of women who drink while pregnant is that they discourage such women from seeking much-needed medical assistance. The abundance of blame and judgment in public discourse creates “a lot of shame and guilt [in individual women]” (Anita). The guilt and shame hinder these women from talking “even to their family, even [to] their children. They don’t want to admit that it’s possible that they cause[d] someone to have FASD” (Anita). The prevalent sense of judgment hinders disclosure and is a barrier to addressing addiction issues among women. Cindy explains that, “women who drink during their pregnancies tend to hide it, so they lack prenatal care [and, therefore,] they don’t necessarily come to the attention of systems” (Cindy). Debbie confirms, “to actually get people together talking about women’s substance abuse is more difficult, right. There’s a lot of stigma” (Debbie).

Avoiding public systems – and thus public stigma – is easier for some women than others. As Anna mentioned earlier, “the highest risk group [for producing FASD-afflicted children] – according to an AADAC study – is middle class women” (Anna).

However, these women are rarely on the radar of the state because they do not need to access public services; they can access private services. On the other hand, more marginalized groups, such as Aboriginal and poor women, continue to be referred to FASD agencies at a higher rate. According to the respondents, one of the reasons that Aboriginal women are referred in higher percentages is the perception that "…FASD only happens in Aboriginal and poor populations" (Anna). Thus, "you have poor, marginalized, unsupported people … their children get seen. We find them through the child protection system and they get seen" (Julie). The lack of public recognition or acknowledgement that FASD is a health issue that affects all women, regardless of class and race, has resulted in FASD prevention campaigns that target certain women and children. The respondents expressed frustration that FASD continues to be associated with Aboriginal and poor women while middle class women who are "drinking wine with dinner" are considered "acceptable" (Tanya).

> For example, when I have done presentations to social workers and school boards in Edmonton they just laugh when I say, 'who do you think is [at] the highest risk?' Right, so there are educated people in the helping profession that simply can't fathom that is the case. That this may be an issue that affects [them] and they don't want to acknowledge it because if they look back on their own lives, they realize oh well, I certainly had a few drinks (Anna).

The respondents express concern that middle class women are a "group that really is at risk [and]… we don't focus on and acknowledge [this]" (Tanya). Overall, there is great concern with the perception that FASD is an issue that only affects Aboriginal and/or poor women. FASD professionals fear that such a perception encourages non-Aboriginal men and women to ignore FASD altogether, believing that it "isn't an issue that affects … or impacts [them]" (Tanya). Respondents also fear that doctors who accept the discourse that FASD is a problem in only Aboriginal and poor communities will not be as vigilant in screening middle class women (i.e. asking about their drinking habits) and educating them about the risk of giving birth to children with FASD. As a result, middle class women will continue to drink during pregnancy, unaware that they are placing their children at risk for FASD. Interestingly, the respondents did not express concern about the racialized and classed discourse of FASD.[102]

Individualized and Gendered Relegation of Responsibility

Many respondents feel that the public belief that only irresponsible women engage in alcohol use during pregnancy essentially exempts the state from providing services and programs to help such women. To elaborate, if the public considers alcohol consumption by pregnant women to be a choice (and gives no consideration to the larger context or to the conditions or barriers that lead to issues of addiction), then the only people responsible for FASD are the women who drink during pregnancy. This allocation of individualized blame leads to women being

> labelled and stigmatized … it creates a structural oppression is what it does, gender oppression, because it does not really include anyone but the mother and that's unfortunate (Cindy).

Some respondents claim that this continued reliance on individual responsibility is carried out intentionally. As Pamela mentions earlier, when society "points a finger" at individuals, it absolves itself and its government from blame – "the government does not actually have to step up to the plate and become responsible for the people" (Pamela). By

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[102] The racialized and classed understandings and discourses of FASD are raised in this section because it was in this component of the interviews that the respondents identified these discourses to be barriers for middle class women who wished to access medical assistance for alcohol dependence or use during pregnancy. Respondents did not consider these discourses of FASD to be problematic because of their race and class associations but rather because such understandings prevent 1) medical professionals from screening middle class women for alcohol use during pregnancy and 2) middle class women from understanding that they are at-risk of producing children with FASD if they consume alcohol during pregnancy. The respondents were asked more about the racialization of FASD later in the interview. Their responses are presented and discussed in detail in chapter 7.

diverting attention to individual choice and behaviour, society does not need to confront the root causes of such behaviour, like poverty and oppression, which are politically charged and difficult to solve. The lack of political will to assist female addicts is evident in the lack of "opportunities for women to engage in treatment" (Cindy). As Janet explains, addiction treatment programs are severely limited and have only nominal success.

> Our track record with addictions and managing and treating addictions [is] really dismal and that's not a well-known fact but it is. We don't do well at it. We are very poor at it. Maybe 20 percent of people get better" (Janet).[103]

In the absence of such programs, women are expected to take personal responsibility for the perpetuation of FASD and to endure blame and judgments from the general public. Governmental agencies, however, can turn a blind eye and remain relatively unscathed. It is no wonder – given this climate – that women continue to be "very afraid to disclose their alcohol use" (Cindy).

Creating Counter Narratives and Representations

In the preceding section, the respondents described their understandings of 1) the public perceptions of FASD (and of women who drink while pregnant) and 2) the impact of these discourses. To reiterate, the FASD discourses and impacts that were highlighted above came from the respondents and reflect their opinions. To summarize, the respondents expressed concern that the public's understandings of FASD holds women primarily responsible for FASD and facilitates punitive measures toward women who give birth to children with FASD. Furthermore, these harsh judgments hinder women from accessing services for their addictions.

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[103] The availability and quality of addiction treatment programs will be discussed at length later on in this chapter.

FASD professionals intentionally position themselves in relation to the above discourses. In response to these perceived repressive and punitive discourses, some professionals try to challenge and/or change the public perception of women dealing with addiction issues. They try with "some effort to change people's mind both in the public and in the human service sector about these women" (Janet). The movement to change the way FASD is understood stems largely from these professionals and their frustration with – what they consider to be – the ignorant public perception of women who give birth to FASD-afflicted children. They believe that a change is necessary since current FASD discourse is "really about shaming and blaming …[and] frame[s] it [FASD] just simply as a woman's issue when, in fact, it is a societal issue" (Cindy). Janet explains that there is really no choice; such changes are needed because

> we c[a]n't view them [read: women who deliver FASD-afflicted children] as social outcasts or social lepers as sometimes was said … [we] need to integrate them into the community and really embrace them (Janet).

The respondents describe their past and present efforts to highlight the complexities behind alcohol and drug consumption during pregnancy. To combat the negative understandings of women who give birth to FASD-afflicted children, the respondents began engaging in the following counter narrative: all women want healthy babies but, because of structural barriers, some women are unable to do so. It should be emphasized that FASD professionals began this counter narrative out of genuine concern for and commitment to women who are deemed to be at risk for giving birth to children with FASD. They were trying to create an atmosphere of compassion and understanding for women who are struggling with addictions. They were trying to counteract the perception that FASD is an issue that involves "bad women" who drink recklessly during pregnancy by highlighting the complexity of their clients' lives and the structural barriers that their clients encounter on a daily basis. The foregrounding of structural barriers, generational issues, and the history of poverty are rather novel and valiant attempts by FASD professionals to better understand a health disorder in its historical, socioeconomic, and political context. However, intentions aside, the counter narrative is problematic.

All Women Want Healthy Children

As discussed in chapter 4, FASD initiatives in Alberta were initiated due to concerns about the children in provincial care. Janet describes the initial thought process: "we started wrapping our heads around the children, those poor affected children and said oh my God this is terrible we need to do something for the child." Early FASD programs and services in Alberta

> paid no attention to birth mothers for years. We looked at the child, the child's needs, we looked fifteen years down the road … [then] one day [we] woke up and said 'where's (sic) the moms?'" (Janet).

The child was the primary subject of FASD interventions[104] until FASD professionals "started saying 'we have to pay attention to [women]. We can't separate out the mom and make her the enemy of the babe'" (Janet).

In recent years FASD professionals have tried to present women who are at-risk of delivering or who have delivered FASD-afflicted children in a more compassionate light. To elicit compassion from the public, the respondents began disseminating

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[104] This conceptualization of children at-risk and women (mothers) as being responsible for creating that risk is discussed at length in chapter 5 of this dissertation. To reiterate, FASD prevention campaigns have focused on the health of the child and measures have been taken to prevent children being born with FASD. Therefore, in such prevention campaigns women are invoked as 1) being responsible for creating this risk and 2) someone to be managed in order to reduce the risk of FASD in the unborn child.

information that all women (including those engaged in alcohol consumption during pregnancy) want to have healthy children. As Colleen explains, women who consume alcohol and drugs during their pregnancies "do want healthy babies and they've probably made tremendous efforts" to have healthy babies (Colleen). Most respondents agreed, saying that they had not

> met a mom yet that has ever wanted to hurt her child or who would knowingly want to do that or that hasn't loved her child in whatever capacity she could (Pamela).

Even FASD programs[105] such as First Steps

> come at it from the philosophy that women do want to have a healthy baby and we know that all women [want healthy babies], you know, no one sets out to have an unhealthy pregnancy (Jackie).

These programs recognize that a woman's addiction and pregnancy place her unborn child at risk. They aim to

> support them [pregnant women who are addicted to drugs or alcohol], you know, through all the prenatal care and following that, you know, support them to stay involve[d] with other service providers that will continue to help them address those issues, then that just builds success for both mom and baby (Amy).

When working with so-called "high risk" women, FASD workers focus on harm reduction by

> linking [them] to health services, linking [them] to addiction treatment services, and meeting [their] basic needs, absolutely. Making sure [they have] a roof over [their] head[s], making sure [they have] food, making sure [that they] and [their] children are safe. So, address the basic needs with these women and creat[e] a support system for [them] so that [they are] re-linked again (sic) with the community (Janet).

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[105] The respondents are referring to programs like the First Steps program offered by a non-profit agency (name withheld) in Edmonton, Alberta. This program offers mentorship to women deemed to be at a high risk of giving birth to children with FASD. In this program, a social/community worker is matched with women deemed to be at high risk for giving birth to children with FASD. The worker assists the women by helping them access services such as health care, addiction and recovery counseling, birth control, food, clothing, childcare, and shelter. The intention of this program is to educate and assist women so that they can restrain from alcohol during pregnancy.

According to Janet, with the assistance of these programs "nearly all of [the women] ended up with a place to live. And some of them had a subsequent child, but [it was] unaffected [by] drugs and alcohol."

A particular goal of FASD professionals has been to recognize the structural barriers experienced by these women. The respondents report working hard to reinforce the message that a woman does not become pregnant with the intention to hurt her child. Rather, her circumstances are often so overwhelming that they push her to drink; drinking is the "one coping mechanism that works" (Tom). Jackie elaborates: "when we talk to women, they do want to have healthy babies but there is (sic) so many factors that get in the way of that and so many barriers" (Jackie). Amy and Debbie also make a point of highlighting the difficult circumstances that their clients find themselves in.

> Typically [the women we work with have] histories of, you know, a great deal of difficulty with unemployment, relationships, a lot of women have had past child [welfare] involvement and are no longer caring for their kids, parenting issues that they just really struggled with (Amy).
>
> Most [of my clients] … who are substance abusers have been sexually abused, have mental health problems, have had some sort of abuse within relationships, [and] have partners that drink. They don't have any support to stop drinking and no motivation to stop drinking either. If you are in a violent relationship and you're pregnant and you're poor why would you stop drinking? (Debbie).

The respondents believe that the general public is unaware of the structural barriers that these women confront and the conditions in which they consume alcohol. Therefore, they attempt to emphasize that addiction (in FASD programming and in the education of social workers) is "not a deliberate choice" (Janet) or "an intentional act" (Cindy). The message is consistent: "the[se women] are not choosing to have that next drink. It was, you know, 'grab that blanket of numbness around me [because] I can't cope'" (Janet). FASD professionals are trying to inform the public that alcohol consumption during pregnancy isn't a deliberate and malicious choice, as it is currently perceived to be. They want the public to know that "women are drinking for a lot of reasons so we need to acknowledge those reasons and … support [them] in addressing those things" (Jackie).

Thus, FASD professionals are vigilant and eager to communicate the structural factors behind the emergence of FASD. They have developed programs such as First Steps to help women to successfully navigate structural barriers and secure housing, food, clothing, and health care. However, the respondents have had little success in presenting FASD as a societal and structural issue rather than an individualized concern pertaining to women.

Birth Control and Pregnancy Planning

Despite their desire to present and understand FASD as a structural issue, FASD professionals continue to develop prevention campaigns and interventions that focus on the choices of (and thus allocate responsibility to) individual women. For example, there is a widespread focus on birth control and family planning, which implicitly suggests that women could prevent FASD if they planned their pregnancies. FASD professionals focus on the behaviours of individual women in part because funding agencies require them to identify and report on concrete outcomes, and individual behavioural change – unlike structural change – is relatively easy to measure. Birth control is only one of the many services that these professionals provide; however, in the eyes of funding agencies, the increased use of birth control is a primary marker of success.

When asked to describe the mandate of FASD programs for women (such as First

Steps), Julie responded

> one of the first things [that these programs] do is to make sure that they [addicted women] are [not] pregnant again. So [the programs] really have an emphasis on, you know, family planning that is reliable for [these women] (Julie).

Janet further describes the importance FASD programs place on birth control.

> So we just made sure that that was one of the first conversations we had even prior to the birth of baby … when we got involved, we started saying to them, 'so let's take you to the doctor and have you have a discussion about family planning. Are you interested in, you know, not being pregnant again for a little while?' And they all pretty much agree that that was what their focus was. And very few of them had babies [when they were] participating in the program. And it was certainly because we didn't want them to. It was because for the first time, really – I don't think there were any women who were actively using a reliable form of family planning when we entered their lives (Janet).

FASD professionals introduce birth control knowing that they "could be possibly criticized for [doing so]…but [feeling that they] had to take that matter up with these women" (Janet). Because funding is so closely linked to birth control and family planning outcomes, FASD professionals recognize that "you don't have any of these programs if you are not willing to touch the matter of family planning" (Janet). In addition, they believe that it is in the interests of their clients to learn about the options and then make decisions for themselves.

> [Our goal is] not [to] counsel them ourselves but [to] give them ample opportunity to … access … health providers who could, with compassion, address this with them and help them make choices that would stop the cycle (Janet).

The entire endeavour is considered "a respectful approach to [the] management of [FASD]" (Julie) because the information and options are provided in the context of a supportive relationship. "If any one of us tried to do this without relationship, it would come across punitive and awful" (Julie). The manner in which they approach the topic of birth control is important, as is the language they use. As Julie explains,

> it is all about language use. I think if we [say] these people [are] on ‘birth control’ (makes a gesture indicating that people get upset) … if you say ‘family planning’ people go, okay. No one would say no.

Overall, the respondents reported that many women are eager for information on birth control and family planning. “We end up sometimes with women who are [so] focused on their addiction and their use patterns that they are not thinking of [their] reproductive paths. They haven’t had time to consider it” (Julie). Most of these women “simply thought being pregnant was something that was just going to keep happening. And in some ways [they] were just very ignorant [about] family planning methods” (Janet). As a result, many women were receptive to these programs and to birth control. They were hopeful that it could help to prevent the unwanted pregnancies that often occurred when they were using.

These programs attracted

> a very high percentage of women whose thought processes were limited enough that it limited their ability to become drug- and alcohol-free and to really make life for their children and themselves (Janet).

Many of these women lack access to health care and birth control. Therefore, when approached with the option “many, many of them, many of them decided on permanent measures [to prevent pregnancy]” (Janet). Janet goes to explain, “many of them had four or five children, you know, all affected. Those were decisions that were probably in everybody’s best interest” (Janet).

These FASD programs, and their focus on birth control, do not just target women who are deemed to be at-risk for producing children with FASD. As discussed at length in chapter 4, the current FASD prevention campaigns urge all women to plan their pregnancies, so that they know to avoid alcohol immediately prior to conception and during the first trimester.

This focus on birth control and pregnancy planning is, in part, a response to funding agencies and the demands for concrete outcome and demonstrable results. According to Janet, FASD programs are "under an enormous amount of pressure to demonstrate the huge outcomes [which is] really hard to do." Noteworthy results take time to develop but "all governments are interested in short-term funding … There is always this demand for proof that this is a good use of funds" (Janet). If the proper indicators of success are not in place, then funding will be withdrawn. "Family planning [became] one of the indicators [of success] … Were [our programs able to convince women to use] a reliable method of family planning?" (Janet). The use of birth control proves the effectiveness of the programs to funders because

> for every woman who yet again did not have another affected child, we were saving the government a lot of money. And we were able to say that much (Janet).

In conclusion, FASD professionals have tried to alter public opinion by presenting a counter narrative of women who give birth to FASD-afflicted children. They restructured their programs to address structural barriers experienced by these women and assist them in accessing clothing, shelter, food, and health care. However, the demands of funding agencies require that these programs continue to focus on individual behaviour and the choices of women. While women certainly benefit from this individualized approach (i.e. some welcome and even seek out assistance with birth control), such an approach continues to hold women responsible for the prevention of FASD.

Discussion and Conclusion

This chapter began with a discussion of how – according to FASD professionals –

the Alberta public perceives FASD and the women who produce FASD-afflicted children. It is imperative to examine these discourses because FASD professionals discursively position themselves in relation to these perceived discourses of FASD. According to respondents, the public believes that women who drink during pregnancy intentionally place their unborn children in danger. Overall, the FASD professionals are frustrated with this discourse because it focuses on the individual woman and holds her responsible for FASD.

To address these negative discourses, FASD professionals began to present a counter narrative, which highlights the larger, more structural reasons why these women engage in alcohol consumption. This counter narrative has informed FASD prevention programs like First Steps, which help women at-risk to navigate structural barriers and access necessities such as clothing, shelter, food, and health care. Despite the intention of these programs (to resist individualizing discourses that hold women accountable for FASD), they continue to focus on the behaviours of individual women. Pressure from funding agencies has compelled these programs to target women's sexual behaviour and choices and to encourage birth control and planned pregnancies.

By heralding birth control and planned pregnancies, these programs depict unplanned pregnancies "as a failure of responsibility and a possible source of danger" (Ruhl, 2002, p. 651). The message is that "every potential parent, and especially every potential mother, [should have an] acute realization [that his or her] primary and individual responsibility [is to] bring children into the world" (Sanger, 1922, p. 23). Introducing birth control and encouraging women to plan their pregnancies are not necessarily undesirable interventions. On the contrary, according to the interview accounts, these interventions are highly sought after and desired. However, the concern is that these messages of birth control and/or planned pregnancy within FASD discourse invoke the notion of a “willed pregnancy” (Ruhl, 2002). As explained by Ruhl (2002), “the willed pregnancy demands that individual women internalize a paradigm of responsibility that assumes forethought and planning in reproductive matters” (p. 645). Therefore, all women are expected to “control their reproductive functions, indeed, that is what constitutes responsibility where reproduction is concerned (Ruhl, 2002, p. 644). Therefore, despite their best efforts, FASD professionals continue to perpetuate the discourse that women are the sole causes of FASD and therefore must take steps to prevent it.

The ongoing focus on women and reproduction within FASD discourse is consistent with the discourse of individualized responsibility that is prevalent within our contemporary health system. This discourse requires people “especially in the area of sexual etiquette, to become self-regulating and self-forming” (Turner, 1997, p. xix). As discussed in chapter 4, modern medicine holds individuals responsible for their own health; it expects them to minimize risk to their well being. In the case of FASD, women are held responsible not only for the risk they present to themselves, but also for the risk they present to their children. While FASD professionals recognize and resist this gendered discourse of responsibility, they are unable to transcend it; in fact, pressure from funding institutions compels them to adhere to it.

The experience of FASD professionals is consistent with Foucault’s (1990) theorization of discourse[106] where individual actors can recognize and resist discourse,

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[106] Please consult chapter 3 for a detailed discussion of Foucault’s theorization of discourse.

but are limited in their ability to step outside of such understandings. FASD professionals, like all of us, are bound and limited by the larger understanding of gendered responsibility, which currently is that women should be responsible for the health and well being of their children.

FASD professionals believe that current FASD discourse holds women responsible for harming their unborn children. This is the reigning "truth" – in their eyes – about women and FASD. Because they are "experts," FASD professionals are authorized to speak "truths" regarding FASD and have attempted to create a new "truth," one that does not hold women responsible for FASD. However, broad acceptance of this new "truth" requires support of other institutions. Despite their attempts to present this new "truth," their statements are "only be judged to be 'true' if they accord with, and fit in with, all of the other statements which are authorized within our society" and are supported by "whole range of practices and institutions" (Mills, 2003, p. 58). In other words, FASD professionals are unable to fully disseminate their "truth" because they lack the support of other institutions. In fact, the pressure from funding agencies leads them to support and further the very "truth" that they oppose.

In conclusion, this chapter demonstrates that local understandings of health concepts like FASD simultaneously rely upon and refute gendered discourses. The various understandings of FASD in Alberta are firmly embedded in constructions of gendered responsibility and self-control, whereby women are expected to control their fertility. Those in charge of managing FASD regularly encounter and try to resist the discourses of gender and responsibility, but they continue to propagate these particular constructions through their focus on birth control and/or pregnancy planning.

Chapter 7: Somewhere in Between: Navigating the Racialization and Gendering of FASD

In this chapter, I discuss how FASD professionals in Alberta negotiate and navigate the racialized understandings of FASD. My research reveals that FASD experts struggle with and try to refute racialized representations, but find themselves firmly embedded in a racialized discourse. Their ability to enact change is limited both by the pervasiveness of this discourse and by broader structural and discursive constraints.

Literature Review

Medical discourse, through its foundation in natural science, has been able to construct oppressive theories of the body politic and legitimate "domination based on differences seen as natural, given, inescapable, and therefore moral" (Haraway 1991, p. 8). For instance, in the early nineteenth century, a medical discourse of disease attributed the presence and spread of smallpox and the bubonic plague in San Francisco to Chinese immigrants. Such racialized understandings justified control and surveillance of Chinese bodies and living spaces (Shah, 2001). By imposing an identity on Chinese immigrants (i.e. that they were either sick or carriers of disease), white Americans could justify the policing of foreigners; in the minds of many, such interventions were necessary to curb disease and ensure public health (Shah, 2001).

A similar rhetoric has been used more recently by legal and political agencies that want to bring sanctions against women who have harmed – or who are considered to be at risk of harming – their unborn children. For example, in the 1980s, individuals who were concerned about the so-called "crack baby" epidemic in the United States drew upon discourses that projected poor, black mothers as uncaring and irresponsible and their children as irreparably damaged to gain public support for more punitive measures. As a result, women using drugs were forced, under threat of imprisonment, to accept unsafe contraception (such as Norplant) and to enter drug treatment. Ironically, later studies found that these “crack babies” did not suffer any long-term effects or disabilities from their mother’s drug use.

In Canada, at the turn of the twentieth century, high rates of tuberculosis and infant mortality among Aboriginal communities were similarly blamed on poor mothering (Cull, 2006). Such explanations ignored the impact of colonization and instead blamed Aboriginal[107] communities and, in particular, Aboriginal women for sickness and disease among Aboriginal communities. According to Salmon (2004) and Stange (1994), the current racialized and gendered understandings of FASD are an extension of this history, which blames Aboriginal women for health problems in Aboriginal communities.

The Racialization and Gendering of FASD

The Public Health Agency of Canada estimates that, in Canada, at least one child is born every day with FASD. As discussed in chapter 2, there are no definite prevalence rates for FASD in Canada. While multiple studies (see Asante & Nelms-Matzke, 1985; Chudley et al., 2005; Habbick et al., 1996; Square, 1997) have indicated that there are higher rates of FASD in some Aboriginal communities, the conclusions have been criticized for their methodological flaws and for projecting the circumstances of a few isolated Aboriginal communities onto a large and very diverse Aboriginal population. As

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[107] This chapter utilizes the term Aboriginal to refer to all First Nations and Inuit communities.

a result, there is certainly no consensus on whether Aboriginal communities are at a greater risk for FASD; although, that remains the general perception (Asante & Nelms-Matzke, 1985; Chudley et al., 2005; Habbick et al., 1996; Square, 1997). This perception has prompted a number of community groups to ask the government to develop FASD programs that are tailored to Aboriginal groups. For instance, the Report of the Royal Commission on Aboriginal Peoples identified alcohol consumption during pregnancy as the leading cause of infant health problems in Aboriginal communities (Government of Canada, 1996). The report claimed that FAS and FAE are “matters of extreme concern” due to the “alarmingly high prevalence” of FASD among Aboriginal communities (Government of Canada, 1996, p. 129).

The federal government initially denied the need to design FASD programs and initiatives specifically for an Aboriginal population. In 1996, the Minister of Health insisted that the existing FASD programs and services were both suitable for and readily accessible by the Aboriginal communities. Furthermore, the Minister argued that “no group in Canadian society is at greater risk of FAS or FAE than any other and that programs targeted to Aboriginal people would have the effect of stigmatizing them” (Government of Canada, 1996, p. 134).

The Canadian government has since changed its stance and is presently developing FASD programs that target Aboriginal communities. In 1999, the Government of Canada provided $11 million for a national strategy on FASD, which, in turn, provided funding to First Nations and Inuit communities to develop and implement community-based FASD programs in their respective communities (Salmon, 2004). The 2001 federal budget also allocated $25 million to FASD prevention programs on

Aboriginal reserves (Greaves, Poole & Cormier 2002).

These new governmental initiatives were widely criticized for perpetuating racist ideologies of Aboriginal people (Salmon 2004; Stange 1994). The specialized programs create the perception that FASD is an Aboriginal problem, that "an epidemic of FAS[D] [is] affecting upwards of 10 [percent] to 50 [percent] of the population in some Aboriginal communities and that, as a result, whole communities [are] paralyzed and dysfunctional" (Tait, 2009, p. 196). Some argue that specialized programs present Aboriginals as "multifactorigenetically defective and socio-economically invalid" (Herr, 2005, p. 151).[108] The government has also been criticized for targeting Aboriginal women who live on reserves (Salmon, 2004; Tait, 2009). This selective focus constructs Aboriginal women as malignant mothers who are responsible for producing children with FASD (Anderson, 2000; Salmon, 2004; Stange, 1994; Tait, 2009). In much the same way that Chinese immigrants were considered sickly disease carriers, Aboriginal people – and particularly Aboriginal women – are considered undisciplined or irresponsible and thus prone to producing FASD-afflicted children.

Salmon (2004) argues that constructing FASD as an Aboriginal problem places Aboriginal people outside of the nation-state and the nation building projects in Canadian society.

> [Such discursive strategies propagate] moral panic, in which an identifiable, usually marginalized, group or behavior come (sic) to stand as a signifier of generalized social crisis and is represented by hegemonic institutions as threatening or

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[108] To be clear, there are concrete implications for recognizing and for not recognizing FASD as a health concern in Aboriginal communities. On the one hand, recognition of this "increased risk" allows for the dissemination of funds that are needed by these communities. However, as argued by Salmon (2004), these linkages also facilitate and perpetuate racist ideologies of Aboriginal people. This is a complex issue that requires a nuanced understanding and examination of FASD. The object of this chapter is not to debate the merits and determinants of these discourses. Instead, this chapter will examine how those managing FASD in Alberta understand and deal with the racialized understandings of FASD.

> antagonistic to the morals, values, or interests of 'society as whole' (Salmon, 2004, p. 112)

FASD discourse is often invoked as an example of a health discourse that reinforces racialized and gendered stereotypes (Salmon, 2004; Tait, 2009), and those who are critical of the racialization of FASD discourse often hold the Canadian government responsible for its pervasiveness (Anderson, 2000; Salmon, 2004; Tait, 2009). They believe that by producing and disseminating racist ideologies through health discourse, the state is able to deflect responsibility for the continued marginalization of Aboriginal communities in Canada (Anderson, 2000; Salmon, 2004; Stange, 1994). In other words, the Canadian state uses these discourses to blame Aboriginal women for the continued socioeconomic and political marginalization of Aboriginal communities.

However, holding the state solely accountable does not explain how racialized and gendered discourses are disseminated and how they come to shape health policies and practices. Such a broad conceptualization of the state presents a hierarchical depiction of power in which the state is an overarching and all-powerful entity that is able to control individual subjects. Therefore, the individual's role in the propagation of discourses is rendered invisible. In my analysis, I pay attention to the ways in which individuals, particularly those in charge of managing FASD in Alberta, both participate in and challenge racialized and gendered discourses.

This chapter examines the ways in which policy makers, front-line workers, bureaucrats, and medical professionals deal with racialized and gendered discourses of FASD. More specifically, it examines how FASD professionals negotiate the perception that FASD is an Aboriginal problem while continuing to work with the Aboriginal communities on FASD programs.

The chapter is organized into two major sections: the first section examines how participants respond to racialized FASD discourses, and the second section examines how they explain the origins and continued presence of such racialized understandings. Overall, this chapter demonstrates how FASD professionals in Alberta negotiate the fine line of providing FASD services and programs without furthering the racialized and gendered understandings of FASD.

The findings show that the respondents are very critical of the racialized and gendered understandings that inform FASD policies and practices. However, their ability to change current practice is limited by broader racialized and gendered discourses that govern societal norms and social relations. The chapter concludes with a discussion of how larger discursive spaces and practices both facilitate and hinder the efforts of FASD experts as they attempt to manage FASD without adhering to racialized and gendered health discourses.

By investigating the perceptions and narratives of the respondents, we will better understand how FASD professionals deal with the current racialization and gendering of FASD. Because the individuals who were interviewed are not a homogenous segment of society, there is, understandably, no singular understanding or perception that is shared by all respondents. The respondents not only support and contradict one other's narratives but, at times, also contradict themselves. Such contradictions are presented here to demonstrate how respondents struggle with and are conflicted by competing discourses of FASD.

Understanding and Explaining the Racialization and Gendering of FASD: Thoughts from FASD Professionals

Linking FASD to Aboriginal Communities

When asked about the racialization and gendering of FASD, the respondents reported that there is a widespread public assumption that women who give birth to children with FASD are Aboriginal (Anna). Aboriginal women are substantially more likely to be screened for and suspected of alcohol use during pregnancy. One respondent estimates that "Aboriginal women get asked [about their alcohol use during pregnancy] ten times more than white women" (Julie). Another concurs.

> I think that a lot of professionals are more likely to get a referral from a hospital from a mother who has just had a baby if she's Aboriginal than if she's Caucasian … they will consider the issue more in Aboriginal women than Caucasian women particularly if the Caucasian woman has a husband or has a job…[and] is a professional (Samantha).

According to respondents, this biased screening process is the result of widespread societal beliefs "that if you are Native and your kids [have] behaviour problems, [it is the result of] FAS[D]" (Bill).

Allocating Responsibility

Although respondents are aware of racialized FASD discourses, they are ambivalent about the prevalence and acceptance of such ideas within their profession. They admit that "people think that FASD only happens in Aboriginal and poor populations" (Cindy), but blame these perceptions on a select group of "community people" (David). These racialized and gendered perceptions of FASD are designated to "others" who are not "working directly in the field" (Anna). Tanya, for example, blames the media. She argues that "it is not just an Aboriginal problem, and I think that a lot of people [think that it is] because … the last three or four cases of people who I've heard about in the media that have FASD … have been all Aboriginal" (Tanya). To reiterate, the respondents maintain that racist and gendered understandings of FASD are adhered to and perpetuated by "others" like the media, and not by those in the FASD field.

Tracing Time

When discussing the racialization of FASD, respondents frequently resort to past tense. For example, they claim, "there was a notion that it was an Aboriginal problem" (Cindy) or "many people felt it was more an Aboriginal issue" (Samantha). Using the past tense suggests that the racialization of FASD is a relic of the past. It suggests that while FASD may have been associated with Aboriginal communities in the past, the contemporary understanding of FASD recognizes that "Aboriginal populations certainly have problems in this area but so does everybody else" (Anna).

Othering the Racialization and Gendering of FASD

As illustrated in the preceding section, the respondents acknowledge the racialized and gendered understandings of FASD and blame such representations on "others" who are ignorant about FASD and who do not work in the field. Moreover, they describe racialized representations as a thing of the past and believe that they are indicative of out-dated ideologies that are no longer adhered to by those in the field.

During the course of the interviews, these respondents, while refuting the association of FASD with Aboriginal communities, went on to provide extensive explanations of why "others" understand FASD an Aboriginal problem. Accordingly, the following section examines the various explanations offered by the respondents for the racialization and gendering of FASD. Most importantly, this section demonstrates the complex ways in which FASD professionals in Alberta work with and against racialized and gendered understandings of FASD.

Aboriginal Origin

The respondents attribute the racialization of FASD to "the fact it started off as an Aboriginal issue [and therefore, it is] in the forefront [of the mind for] the … common person" (Sarah). In other words, "it's not an Aboriginal problem, [but when it first emerged in] the [19]90s and [19]80s, it was identified as an Aboriginal problem," and that belief continues to linger (Sarah).

> I think that Aboriginal people were the first group of people to acknowledge the problem …They were the first ones to recognize [FASD] and, unfortunately, because of that, they have this problem (Samantha).

Overall, respondents explain that FASD "started [as] an Aboriginal problem" and that the early emergence and identification of FASD in Aboriginal communities is responsible for the continued racialization of FASD (David).

Aboriginal Children and the State

Several respondents went on to explain that "[FASD] was made to seem like it was an Aboriginal problem because all the pictures were of Aboriginal children" (Anna). As discussed earlier, FASD became accepted as a public health concern in Alberta through the advocacy of child welfare workers.[109] In Alberta, a disproportionate number of children in care were (and continue to be) of Aboriginal descent. For instance, a recent

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[109] Child welfare workers (two in particular) became concerned that certain children in provincial care were encountering greater difficulties in adjusting to child welfare placements. This initial observation led to the discovery that many of these children's problems were due to FASD. Please consult chapter 4 for further details.

report indicates that while Aboriginal children consist of only 8 percent of the child population in Alberta, they makeup 58 percent of children in care (Government of Alberta, 2008). Therefore, the respondents believe that the racialization of FASD is due to the disproportionate number of Aboriginal children in state care. They argue that these children are more likely to be tested for health disorders and disabilities, and, therefore, are more likely to be diagnosed with FASD. For example, as Tanya notes, "the kids [with FASD] that are easy to identify are the kids that are in care, and the kids that are involved in the criminal justice system" (Tanya). Tom concurs.

> [The] kids that are getting diagnosed right now with FASD are not the kids that are in [the] care of their biological parents. They are kids in foster care, the kids in judicial system, the kids that are disenfranchised from their own families (Tom).

These kids – the majority of whom are Aboriginal – have become the face of FASD.

Poverty

According to respondents, FASD is perceived to be an Aboriginal issue simply because more Aboriginal children are diagnosed with FASD. The respondents attribute the greater number of FASD diagnoses in Aboriginal communities to issues of poverty. They believe that Aboriginal children are more likely to be diagnosed with FASD because of their socioeconomic class[110] and note that middle class and/or upper class children who likely have FASD are often diagnosed with less stigmatizing disorders, like ADHD.

FASD-afflicted children who are born into higher socioeconomic status families

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[110] There is an underlying assumption within these narratives that Aboriginal children diagnosed with FASD are poor. The statements discussed in this section imply that Aboriginal people tend to be poor, while Caucasians are more likely to be affluent. While there is a higher incidence of poverty and unemployment among some Aboriginal groups within Canada, the perception that all Aboriginal groups are poor is inaccurate and reinforces racialized stereotypes that Aboriginal groups are poor and disenfranchised.

tend to remain in the care of "their own parents who are investing significant, possibly financial…[and] emotional … resources into managing and supporting that child so [that] the child does well" (Tanya). Therefore, the association of FASD with First Nations people "is not about First Nations [people], it is actually more likely to be about poor people in some ways [because] rich people drink too and have many affected children, we just call it something else" (Janet). According to the respondents,

> lots of women have raised their kids with FASD, but they have … called [FASD] other things [such as] ADHD, operational defiance, [and] conduct disorder, particularly if the women are Caucasian (Samantha).

A child of higher socioeconomic status is also more likely to have " [a] diagnosis from mental health [professionals] and physicians … [which is] less stigmatizing" (Anna). Therefore, "poor kids with FASD get an FASD diagnosis and the rich kids get ADHD diagnosis, and I think that's really common" (David). The socioeconomic status of the child's parents leads to an "Aboriginal child [being diagnosed with] FASD [and] more likely … a white kid [being diagnosed with] ADHD" (Sarah). Respondents firmly believe that the racialization of FASD is due to the fact that the medical system (and society at large) treats "people who are poor and downtrodden … differently [than those with a] good education or [with] wealth" (Bill). In their eyes, economic discrepancies are to blame for the higher rates of FASD in Aboriginal communities.

Alcoholism

Respondents only indirectly point to alcohol abuse and substance addiction as a possible reason for the higher prevalence of FASD in some Aboriginal communities. They are aware of the prevailing stereotypes regarding alcoholism and Aboriginal communities and are careful not to perpetuate them. They deny that Aboriginal communities have a higher incidence of FASD and, at the same time, try to explain why those communities might engage in greater and more frequent alcohol use. These statements, although contradictory, appear to be carefully crafted by FASD professionals, who want to avoid stereotyping Aboriginal women and communities.

Respondents are adamant: FASD is considered an Aboriginal problem because more Aboriginal children are diagnosed, and more Aboriginal children are diagnosed because they are overrepresented in state care and/or come from poor families. Respondents do not directly attribute the connection between FASD and Aboriginal people to the arguably common belief that there are high levels of drug and alcohol abuse in Aboriginal communities. Instead, they say that FASD "is about women and pregnancy and if the Aboriginal communities have women [who] are drinking then it's an issue" (Julie). They are careful to stress that the risk of FASD is not specific to Aboriginal communities and that "you've got an increased risk for FASD" in any community "where alcohol is being used at a high level" (Tom).

However, during the course of the interviews, it became clear that many respondents believe drug and alcohol use – and not state care or poverty – to be the main reason why FASD is more prevalent in Aboriginal communities. Some respondents stated that: "alcoholism is a problem in a lot of Native communities" (Kiran), and that

> having a substance issue is extremely difficult to get out and it's a vicious cycle … So, I think that's why we encounter a lot of individuals who are affected who are Aboriginal, on reserve (Ashley).

Another respondent offers the following explanation: "addiction rates are higher on reserve, that is why it is a concern for me, but I don't believe it is an Aboriginal problem" (Helen).

The respondents are careful to point out some of the broader structural reasons for a higher incidence of alcohol and/or substance use in some Aboriginal communities. Kiran explains that

> [Aboriginal people have] many reasons [for] drink[ing] … a lot of them have an addiction to alcohol …When they become pregnant they will try to give it up … [but] there's just no supports available [on reserves] like in [the] larger centers (Kiran).

Overall, respondents speak with great caution about Aboriginal people and FASD, as is exemplified by Janet's response:

> I'm always extremely cautious, I am not sure that they have higher rates [of FASD]. However, it gets complicated in First Nations communities because there is a high level of shame with drug and alcohol use, very high.

Like Janet, the majority of respondents are hesitant to speak about FASD and linkages to Aboriginal communities because they are afraid to perpetuate stereotypes and negative ideals about Aboriginal women and Aboriginal communities. They discuss the racialization and gendering of FASD with careful deliberations and repeatedly sympathize with women who drink during pregnancy, saying that these women "are not engaging in any form of child abuse, but [rather] … are self medicating to deal with their lives" (Cindy).

The Ongoing Impact of the Residential School System

The respondents frequently invoke the residential school system in an effort to explain the poverty and substance abuse (particularly alcoholism) that is prevalent in some Aboriginal communities. Pamela notes that Aboriginal people continue to suffer – materially and emotionally – from the residential school system because

> it wasn't that long ago. There were still residential schools open in the 1980s. I think the last one closed down in 1981 … so we're gonna feel those effects for a

> long time (Pamela).

Others establish the link more directly, arguing that the issues that many Aboriginal communities have with poverty, alcoholism and FASD

> go back to residential schooling where individuals were taken [away from their natural parents] and [now] they have no parent[ing] skills. How many generations is that going to affect? (Ashley).

Many respondents believe that residential schools "disrupted parenting over many generation[s]" and are responsible for misshaping "Aboriginal culture" (Anna). They argue that residential schools are responsible for the societal ills that affect Aboriginal groups.

> [The residential school system has led to a situation] where parents don't know how to parent their kids. Parents are confusing parenting with friendship. Parents are abusive. Parents are stuck in the cycle of substance abuse. They are neglectful to their children. Child Welfare is overwhelmed – they can't attend to those kids, [and] they can only attend to the ones that are life threatening. That is scary (Helen).

As seen above, FASD professionals blame the residential school system for Aboriginal poverty and alcoholism (which, in this context, they would acknowledge as a problem). They also blame residential schools for the overburdened and often ineffective social welfare system.

Respondents are adamant that FASD is not an "Aboriginal problem," yet they offer up residential schools as a reason why "we see it [FASD] so high among them [Aboriginal children]" (Debbie). The respondents claim that the racialization and gendering of FASD, and the many other inequalities experienced by Aboriginal communities, result from "*The Indian Act* and the history of colonization in our – in this country" (Pamela). Debbie explains the psychological impact that she believes residential schools have had.

> [FASD has] … such a high incidence in the Aboriginal community because if you think of any community who has had more sexual abuse, violent relationships, abusive relationships, horrible upbringings … if I was or had been a young girl who had been taken away from my family put into [a] residential school and then, at the age 18, put out on the streets [then] I [would] probably drink too and what [do] I care that I was producing children who might be damaged? They were just gonna take them away from me anyway. What would I care? And so, of course, we see it [FASD] so high among them because of how they've been – this past generation – how they've been treated (Debbie).

One respondent, noting that "the Aboriginal context is very different from the non-Aboriginal context," even went so far as to say that "perhaps the government agenda of colonialization (sic) and assimilation is in fact carried out in this response [to FASD]" (Cindy).

In conclusion, in their attempts to disassociate FASD and Aboriginal communities, the respondents invoke a representation of Aboriginal communities as being "damaged" from residential school systems. Sadly, such understandings reinforce the very stereotype that FASD professionals are fighting in the first place: that Aboriginal communities are dysfunctional and rife with social ills.

Aboriginal Communities Need to Move Beyond Colonialism

The respondents blame the present day marginalization of some Aboriginal communities on historical events (such as residential schools and colonialism). However, they also believe that such events should be relegated to the past. They feel that this is the only way to manage FASD in the present. Helen recalls her interactions with Aboriginal leaders.

> I say "you [Aboriginal leaders] are absolutely right, it is colonialization (sic) that did this. Do you want to stay there? Or do you want to move past it? And do you want [the Alberta government] to help you do that? (Helen).

Like other respondents, Helen believes that invoking the past to manage present day issues like FASD is counterproductive and hinders present day efforts. Thus, while FASD and other contemporary issues are "difficult … to discuss … [there should be] no blame or pointing the finger at all … There are present day concerns, and we have to deal with that" (Ashley).

The respondents report that their efforts to work with Aboriginal groups have been largely unsuccessful because "Aboriginals like to keep to themselves" (Tina) or "[Aboriginal communities] prefer [to work with other] Aboriginal people to deal with [FASD]" (Ashley). The efforts by FASD professionals are further compromised by the prevailing "stigma piece, which make[s] it harder [to work] in First Nation communities" (Janet). Janet goes on to explain that, "whereas in Western society, we are quite comfortable with [FASD] diagnosis… [in Aboriginal communities] there is a [perception that FASD] diagnosis [is] just labelling" (Janet). In other words, Aboriginal communities see little point in diagnosing FASD since it will just label certain individuals and subject them to social stigma.

In addition, the respondents claim that their efforts to address FASD in Aboriginal communities are compromised by misunderstandings of FASD and mistrust of non-Aboriginals. For instance, "there are still older people in First Nations communities who believe that FASD is caused by those needles that they give to people when babies are born in the hospital" (Janet). Another respondent reports that some Aboriginal groups believe that "the cure for FASD is castor oil" (Janet). Most respondents maintain that it is easier to work with "Caucasian women … [because they are] more comfortable with traditional therapy … whereas Aboriginal people are more isolated, more transient, [and] unable to put their trust in traditional treatment" (Samantha).

According to the respondents, Aboriginal communities misunderstand FASD and distrust modern/Western medicine because they are "backward" and/or "non-modern." Helen explains, "I kind of view them, like, 20 years behind where we currently are." Janet similarly acknowledges, "there is a clash in some ways and [a lack of] integration between Western information and old knowledge" (Janet). According to the respondents, the "backwardness" and/or archaic beliefs of Aboriginal communities is the result of

> huge political interference that runs in there and that goes back to treaties and the medicine clause chest. A lot of communities will not engage with Alberta Health and Wellness because [health] is [a] fiduciary responsibility of the feds [the Canadian Government] … so although [we] want to work together, communities don't want us working together (Helen).

Finally, FASD professionals claim that FASD in Aboriginal communities remains largely unaddressed because of corruption on reserves.

> There is a lot of money being targeted at First Nation communities, but historically, what happens, is the money is dropped off in the community and then we walk away. We don't build capacity; we don't show them how to do it and how to be accountable within the community … you can't really blame the community for building the corruption that they have; I mean, we have taught them well (Helen).

As seen above, FASD professionals in Alberta claim that Aboriginal groups need to move beyond past injustices and past beliefs in order to effectively deal with present day health concerns such as FASD. They believe that Aboriginal communities are unable to deal with FASD because they mistrust government and non-Aboriginals, misunderstand FASD, and mismanage government funds. Again, all of these perceptions align with stereotypes that Aboriginal people are damaged and incapable.

Aboriginal Lead

The respondents provide several reasons for the lack of FASD services and programs in Aboriginal communities; at the same time, however, they note the wonderful progress that Aboriginal communities are making to reduce the incidence of FASD. "The Aboriginal communities recognize that this is an issue for some of their people and are working quite hard to try and address it" (Tanya). Respondents report that, "the Aboriginal community [is] actually doing a way better job [to reduce the incidence of] Fetal Alcohol Syndrome" because "these poor folks…[are] committed to the work that they do" (Debbie).

The success of Aboriginal communities is attributed, in part, to the involvement of men in the caring of their children.

> On a reserve, the men are still around and are actually invested with children. It is a huge strength. They might be in an abusive relationship, but the dad is still there invested in the relationship (Helen).
>
> [On a reserve] you can have this young man [with] FASD peer into your house and you bring him in, you feed him, and you say now go on to Aunt Mary. Would that happen in [any other community]? ... So [Aboriginal communities] are doing way better jobs (sic). [Moreover, Aboriginal groups have] spiritualism, … healing circles, [and] all kinds of things happening there we don't have (Debbie).

The perception that Aboriginal communities are more family-, community- and spiritually-oriented has led those in the field to

> praise the Aboriginal community for their leadership and their forward thinking and their actions that [make them] leaders in this field, and we try to encourage them [to] keep that going (Samantha).

This perception of Aboriginal communities strongly contrasts with perceptions previously expressed by FASD professionals.

Racism

Some respondents blame structural racism for perpetuating the belief that FASD is an Aboriginal issue and for compromising FASD initiatives in Aboriginal communities. One respondent argues that

> non-Aboriginal kids [with FASD] … have access to better supports and [they do not experience the] sort of racism that is built into [the] systems that Aboriginal children experience (Tanya).

Another acknowledges that efforts to initiate programming and assistance for Aboriginal groups are compromised by the underlying “inherent racism that sort of permeates all levels of whatever we do” (Tanya).

Respondents are not sure how to provide support to Aboriginal people without perpetuating negative stereotypes. Several report that they are fearful of perpetuating stereotypes, like “[Aboriginal people are] drunk all the time” (Bill). FASD professionals struggle to answer the questions: “how we can support them [without] identify[ing] them specifically? … How can we support Aboriginal women?” (Jackie). The problem FASD professionals face is that “in order to get a required program for a specific population – this labeling and stigma appears to be attached to it” (Cindy). Therefore, those in charge of managing FASD find themselves in a precarious position where any attempts to help Aboriginal communities (i.e. through targeted FASD programs) would “in fact … support [the] dominant societal discourse that … identifies [FASD as an] Aboriginal problem” (Cindy).

According to respondents, their efforts are further complicated by the fact that some Aboriginal communities have “chronic unemployment … [and a] lack of education … [and therefore] are working [and focusing] on [their] basic needs [and not on FASD]” (Anita). When programs are initiated, they are directed and controlled by the government – particularly the Canadian government, which assumes responsibility for Aboriginal affairs – and not by Aboriginal communities. “We still very much control how Aboriginal people use and develop their [FASD programs]” (Cindy). Therefore, “there are some systematic racism issues that we face that we need to work to address" (Tanya).

Discussion

In this chapter, I examined the ways in which FASD professionals understand the racialization and gendering of FASD discourse. These discourses are important to investigate as they constitute the "practices that systematically form the objects [about] which they speak" (Foucault, 1972, p. 49). In this following section, I analyze the perceptions of FASD professionals (highlighted above) to determine how they perpetuate and challenge the racialization of FASD discourse in Alberta. I examine the beliefs that: 1) others – past and present – are responsible for the racialized and gendered understanding of FASD; 2) higher FASD prevalence rate in Aboriginal communities is due to colonialism and the residential school system; and 3) Aboriginal groups are simultaneously leading and lagging behind in FASD initiatives and programming.

Others Are Responsible

The respondents in this study attributed the current racialization and gendering of FASD to "others" outside of the FASD field (i.e. laypersons). In so doing, they exempted themselves as potential creators or perpetuators of racialized or gendered representations. This distancing demonstrates that while respondents are aware of the societal repercussions of such representations, they do not believe that they – or that those in charge of managing health disorders more generally – play a role and (un)intentionally perpetuate racialized and gendered discourses.

Furthermore, by relegating responsibility for the racialization and gendering of FASD discourse to ignorant "others," the respondents overlook the possibility that such discourses are actually hegemonic understandings disguised as legitimate scientific knowledge (Mohanty, 2000). In other words, FASD professionals fail to recognize that health discourses are often established upon colonialist discourses of degeneracy (McClintock, 2000) and that, over the course of history, many medical disorders have been constructed and invoked by authorities to justify the marginalization and exclusion of certain populations. This history should be taken up and understood by those in charge of the prevention and management of health disorders like FASD. FASD professionals who fail to situate and understand the racialization and gendering of FASD in this historical context assume that science and medicine are objective truths when, in fact, they are "important and authoritative sites [in the] production of knowledge, [and that the] definitions of life created in these domains are propagated and subsequently represented in other worlds as 'truth' or reality" (Casper, 1998, p. 17).

In conclusion, the respondents exclude themselves (and by proxy, all those in charge of managing health disorders like FASD) from the creation and dissemination of racialized and gendered health discourses. They distance themselves by representing such discourses as past relics that are solely adhered to by uninformed "others." However, such understandings fail to acknowledge the broader discursive space that facilitates and propagates the racialized and gendered understandings of health disorders like FASD.

The Legacies of Colonialism

Many respondents find themselves trapped between their desire to help (and thus provide specialized FASD programs for) Aboriginal communities and their fear of further perpetuating the idea that FASD is an Aboriginal issue. The respondents in this study negotiate this precarious position by invoking the legacies of colonialism. They explain that the current prevalence of FASD in some Aboriginal communities is the result of colonialism and the residential school system, not failings on the part of Aboriginal culture, women, and/or communities. Respondents attribute the higher FASD prevalence rates in some Aboriginal communities to the effects of residential schools, whereby "generations of Aboriginal children were denied access to their families, communities, language, culture, and customs" and were subjected to neglect and abuse (Cull, 2006, p. 144).

This particular stance demonstrates the unwillingness of FASD professionals to propagate ideas that might facilitate or justify the "inappropriate and unjust scrutiny of Aboriginal mothers" (Cull, 2006, p. 141). It contradicts the work of scholars who present policy makers and those in charge of managing medical disorders as being ignorant of the historical context in which diseases among particular groups emerge. The experts' responses reveal that they do, in fact, attempt to address the racialization and gendering of FASD discourse, but find themselves in a predicament – how can they provide services without perpetuating racialist and gendered stereotypes?

Lagging While Leading

FASD experts portray the effects of colonialism and residential schools in a manner that serves to further entrench the ideas that Aboriginal communities are damaged and are lagging behind the rest of Canadian society. According to respondents, colonialism is responsible for the many ills in Aboriginal communities. It has left Aboriginal groups "20 years behind where we currently are" (Helen); it has resulted in a "clash" between antiquated, Aboriginal knowledge and modern, Western knowledge (Janet); it has encouraged corruption in Aboriginal bands.

Such representations – whether attributable to colonialism or not – place Aboriginal communities in "primitive states of evolutionary progress" and justify "direct imperial intervention and conquest" (McClintock, 1995, p. 188). They fuel the discourse that Aboriginals ought to be "sav[ed] them from themselves, from their own nature" and

> furnish the grounds of the Other's modification and modernization, establishing what will launch the other from the long dark night of its prehistory into civilized times (Goldberg, 2000, p. 155).

In other words, representations of Aboriginal communities as lagging behind or corrupt are used by health authorities to justify interventions in Aboriginal communities, and, in the end, health authorities – not Aboriginal people – dictate the terms of these interventions.

While Aboriginal communities are depicted as lagging behind, entrenched in "old knowledge" and inundated with corruption, they are also credited with leading FASD initiatives. Such leadership is attributed to the perceived spiritualism of Aboriginal people and to the entrenchment of and dedication to familial and communal relationships in Aboriginal communities. Interestingly, these are the same traits that have historically cemented Aboriginal communities as "backwards" or "non-modern." In this study, respondents lauded the supposed spiritualism and communality of Aboriginal people, arguing that they enabled Aboriginal communities to take a leadership role in preventing and addressing FASD. However, the danger of utilizing this discourse of leadership is that it exempts the Canadian state from its responsibilities (i.e. to provide the necessary resources for programs in these communities).

In conclusion, the discourses of lagging behind and leading both rely upon images of Aboriginal communities as being closer to nature, more spiritual, and more familyoriented, all of which firmly entrench these groups as "backwards" in the collective imagination. The state benefits from both discourses, albeit in different ways – it can choose to impose its will or it can walk away and leave the problem in the capable hands of the Aboriginal communities.

Conclusion

Historically, individuals in charge of managing health disorders like FASD (see (Anderson, 2000; Salmon, 2004; Stange, 1994) have been represented as agents of the state. In other words, they are responsible to carry out state mandates that further marginalize and stigmatize disenfranchised segments of the population. It is easy to hold these authorities responsible for the perpetuation of racist and gendered perceptions and ideologies. However, this chapter presents an account of how racial inequalities are enabled by discursive practices that are larger than the thoughts and acts of individual experts. Therefore, to understand racial and gender inequality, we must consider the complex context in which they exist. The findings of this study call for a more nuanced understanding of how racialized and gendered discourses are invoked and negotiated by those in charge of managing health disorders.

In this chapter, I have shown that FASD professionals are not uncritical propagators of racialized and gendered practices. They are extremely aware and critical of racialized depictions and stereotypes of Aboriginal groups. However, these respondents are also firmly entrenched in, and thus are limited by, broader racialized and gendered discourses that govern societal norms and relations. On a daily basis, they negotiate these discourses and (often unwillingly) enact practices that are rooted in these racialized and gendered ideals.

The experiences of these FASD experts indicate that “life is more complicated than those of us who study it have usually granted” (Gordon, 1997, p. 7). Moreover, we are reminded

> that even those who live in the most dire circumstances possess a complex and oftentimes contradictory humanity and subjectivity that is never adequately glimpsed by viewing them as victims or, on the other hand, as superhuman agents (Gordon, 1997, p. 4).

A more complex understanding of racial and gender inequality makes it harder to identify the cause(s) of such societal ills (and, in turn, a remedial course of action); however, it more accurately describes how racialized and gendered ideas become entrenched as facts.

In conclusion, this study demonstrates how those in charge of managing health disorders struggle with and make sense of the various discourses – often contradictory and competing – in which they are embedded. As seen in this chapter, health discourses do not evolve from pure or objective science; they are situated within, and are therefore shaped by, larger socio-political and economic discursive spaces. As a result, our current understandings of health and disease are heavily influenced by the larger discursive constructions of race and gender.

Chapter 8: Conclusion

Summary

Margaret Fee (2006) states that health disorders like FASD "acquire symbolic meanings often overlooked, dismissed or taken for granted in medical, scientific and public health discourses. And these meanings have a history" (p. 2993). This is precisely why I explored the history of FASD and its impact on present day FASD understandings in this dissertation.

I investigated the discourses of FASD in Alberta using a Foucauldian theoretical framework, which was conceptualized and used by other scholars (such as Mills, 2003; Turner, 1997; Lupton, 2005). Foucault's theorizing encourages a critical interrogation of ideas, concepts and histories of medical institutions and practices in order to demonstrate how normalizing discourses are created and sustained (Mills, 2003). This framework allowed me to complete an in-depth examination of the historical processes through which FASD has been constituted as a health disorder within Alberta. As described in chapter 3, I identified FASD discourses using three different qualitative methods: interviews, archival research, and policy and document analysis. A total of 23 semi-structured interviews were conducted with those in charge of managing FASD in Alberta. The semi-structured interview guide was informed by the archival research and document analysis, and vice versa.

Drawing on the information provided by respondents and by archival, policy, and program documents, I was able to trace the process through which FASD emerged and became accepted in Alberta. In chapter 2, I described FASD's path to public recognition and in chapter 4, I discussed the context of this path, highlighting where our current understandings of FASD come from and what impact this history has on contemporary FASD understandings and discourses.

My research reveals that FASD came to public attention in Alberta through the efforts of two social workers employed by the Ministry of Children and Youth Services. These two social workers worked with children in state care and they noticed that some children were particularly hard to care for and, as a result, had a myriad of broken foster care placements. They went looking for answers and found FASD. Therefore, in Alberta, FASD emerged and came to public attention as an issue of child health and welfare.

Initially, the FASD experts intentionally presented images of "hurt children" in an effort to elicit public attention and governmental support. This early history may have facilitated the present day understandings that FASD is an issue pertaining to young children. This understanding has also led to the current invisibility of adults suffering from FASD.[111]

In addition, as discussed in chapter 5, these representations of "hurt children" facilitated an understanding that children were at-risk for FASD and that women who consumed alcohol during their pregnancies were responsible for creating this risk. These representations of women as responsible for FASD have led FASD prevention campaigns to focus their attention almost exclusively on women and their behaviour during pregnancy.[112] These campaigns currently urge women to prevent FASD by "just saying no" to alcohol when they are pregnant and by planning their pregnancies.

As discussed in chapters 5 and 6, these messages grossly oversimplify this

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[111] I will discuss the continued invisibility adults with FASD in FASD understandings later on in this chapter.

[112] The hyper-visibility of women of reproductive age within FASD discourse will be discussed later on in this chapter.

complex issue and do not take into account the context in which women drink. These chapters also illustrate that those in charge of managing FASD are aware of the limitations of these preventive messages, but find it difficult to refute and/or change these messages due to pressure from funding agencies. Nonetheless, this chapter reveals that these experts continue to negotiate and navigate around gendered discourses of FASD.

A similar finding emerges in chapter 7. This chapter discusses the ways in which those in charge of managing FASD negotiate and navigate racialization of FASD. The chapter demonstrates that FASD professionals are aware of racialized and gendered understandings within FASD and try to refute and change the public perception that FASD is an Aboriginal issue. However, despite their attempts, they find themselves thoroughly embedded in, and at times even propagating, these racialized understandings.[113]

Research Contributions

In this dissertation, I traced the history of FASD in Alberta and in doing so showed that currently adults (both men and women) with FASD are invisible and women as mothers and/or potential mothers are hyper-visible in FASD discourse and programming (see chapters 4, 5 and 6). I have also highlighted the prevailing silence on and discomfort with issues of race and FASD (see chapter 7). Together chapters 4 through 7 reveal the complex subject position that FASD professionals occupy. My research shows that despite their awareness of and resistance to gendered and racialized discourses of FASD, these experts struggle to enact substantive changes because of larger structural and political constraints.

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[113] I will discuss how FASD professionals understand and respond to the racialization of FASD later on in this chapter.

History of FASD

This research is the first investigation of FASD history in Alberta. Like other health diagnoses and disorders, FASD is shaped by the social and political context in which it emerged. Its history, therefore, has particular implications for the way that FASD is presently understood in Alberta. This research traced the evolution of some of the most pressing FASD-related issues (i.e. the invisibility of adults with FASD, the allocation of responsibility for FASD to women of reproductive age, and the racialization of FASD) and highlights how these issues are remnants of the historical and socio-political discourses that brought FASD to public attention.

Invisible Adults with FASD

The needs and experiences of adults with FASD have received very little attention in FASD research. However, my research illustrates some of the reasons why adults are rendered invisible in current FASD programs and services. FASD prevention campaigns consistently depict the child as being at-risk and FASD experts have admitted that they intentionally invoked images of hurt children to elicit public support. As a result, FASD is presently understood as a health concern pertaining to young children. This understanding has dire implications for adults suffering with FASD. The continued focus and framing of FASD as a concern for young children has led to the invisibility and neglect of adults with FASD. As discussed in chapter 4, funding and services for adults with FASD are severely limited. This issue deserves greater attention from researchers and from those who design and manage FASD initiatives.

Women are Hyper-visible as Mothers and/or Potential Mothers

My research also shows that, in contrast to FASD-afflicted adults, who are notably absent from FASD discourse, women of reproductive age are hyper-visible. As discussed in chapter 4, there is a distinct discourse of "risk" and "responsibility" within FASD understandings. This discourse depicts the child as at-risk and the woman of reproductive age as responsible for creating and managing that risk. Despite the attempts by FASD experts to challenge this discourse of gendered responsibility, FASD prevention campaigns continue to focus on the individual behaviours of women (i.e. many urge women to plan their pregnancies) and thus, continue to hold women of reproductive age as responsible for the prevention of FASD.[114]

Ironically, while women as mothers and/or potential mothers are hyper-visible in terms of responsibility, they are largely invisible in terms of assistance. FASD programs and services remain centered on the needs of the child and, therefore, as discussed in chapters 5 and 6, the particular needs of the woman is not addressed. The singular focus on women of reproductive age as responsible for FASD ignores the structural context in which women consume alcohol and/or make reproductive choices. Moreover, this discourse of personal responsibility releases the government from its responsibilities (i.e. to provide resources and services to aid these women).

This research shows how FASD, like many other health disorders, holds women responsible for the health and welfare of their children. I did not, however, interview

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[114] The Alberta Legislature is currently debating the induction of mandatory warning labels on alcohol bottles. On March 7, 2011 Calgary-East MLA Moe Amery introduced a motion to include warnings of FASD on all alcohol products (Schneider, 2011). Some brewers already put such warning labels on their products. This is another example of how FASD prevention campaigns continue to focus on the individual behavior of women without consideration for the broader social context in which pregnant women decide to consume alcohol.

women who are targeted by the current FASD prevention campaigns. Therefore, further research is needed to explore the experiences of women of reproductive age who are targeted by FASD prevention campaigns and/or who give birth to children with FASD.

Silent (In)Articulations of Race

According to Salmon (2004), Aboriginal women are held responsible for the existence of FASD in Canada. This understanding has led to an increase in the surveillance and monitoring of Aboriginal women (Salmon, 2004; Tait, 2009). As discussed in chapter 7, respondents are extremely critical of racialized discourses of FASD. However, their discomfort and fear of propagating racialized understandings of FASD make them hesitant to discuss and address the incidence of FASD within Aboriginal communities. This hesitance (and silence) results in a lack of services for communities that need assistance. When FASD professionals do talk about Aboriginal people and FASD, they tell narratives that further entrench racialized representations and understandings of FASD. Therefore, FASD professionals challenge racialized discourses and also find themselves firmly embedded within them. They are, as Foucault explains, not entirely powerful or powerless. There are some aspects of the racialized FASD discourse that they are able to address and change, and there are other aspects that continue to challenge them.

FASD Experts

A particular strength of my dissertation is that it demonstrates the complex subject position that FASD experts occupy. To date, research on public health has paid very little attention to the ways in which experts make sense of medical disorders. My research does precisely this; it explores the ways in which FASD experts in Alberta understand and negotiate racialized and gendered understandings of FASD, and it highlights the difficulties that they encounter when they attempt to manage FASD without furthering racialized and gendered stereotypes. My research shows that these individuals are neither "good" nor "bad" and that their experiences are filled with contradictions and complexities. To manage FASD in Alberta, they encounter and negotiate various competing interests on a daily basis. These professionals are not all powerful nor are they devoid of power. Rather, they both exercise power and succumb to the power of others; they are sites where power is both enacted and resisted.

FASD experts are embedded in and are working within larger power structures. Their ability to enact and/or refute certain understandings of health disorders is determined by larger societal discourses and structural barriers. These individuals are not unthinking propagators of racism and/or sexism. They are aware and critical of the current racialization and gendering of FASD and regularly attempt to counteract such notions. However, because they are embedded in larger racialized and gendered discourses, it is often difficult for them to do so.

The perspectives of those in charge of managing health disorders have been missing in the literature on public health. To understand the complexity of managing health disorders (like FASD), these experiences must be considered.

Future Research

FASD is like ‘‘any important disease whose causality is murky, and for which treatment is ineffectual" – it is "awash in significance’’(Sontag, 1978, p. 58 quoted in Fee, 2006, p. 2993). This research demonstrates that, in Alberta, FASD discourse (and particularly the invisibility of FASD-afflicted adults, the hyper-visibility of women, and the silence on race) is a product of, and continues to be shaped by, its history.

In light of my research findings, further research is needed on how the rest of Canada understands FASD. As discussed in chapter 1, because Alberta is considered a leader in FASD initiatives and programming, FASD experts from Alberta are advising other provinces on FASD programs and policies. Therefore, we need to investigate whether other provinces also have issues concerning the invisibility of FASD-afflicted adults, the hyper-visibility of women, and the racialization of FASD, and, if they do, we need to determine how they are dealing with these issues. The responses of other provinces may provide solutions that can be used in Alberta. In addition, such an examination may reveal how the unique socio-political history of each province affects how FASD has been taken up and understood there.

Further research is also needed on FASD-afflicted adults, who have been rendered invisible in FASD discourse, and who, in turn, suffer from a shortage of programs and services. There is currently a gap in the public health literature on the experiences of adults with FASD and their caregivers. Research in this area is necessary if we want to more fully understand the impact of FASD discourse and improve care for adults who suffer from FASD.

Finally, as discussed in this dissertation, health understandings are not neutral or apolitical; they are part and parcel of the power relations and the gendered and racialized discourses that surround them. Future research on health disorders and diagnoses should thus consider how history and social context influence the public perception of disease and, in turn, inform public health initiatives.

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Appendix A

Irene Shankar, PhD Candidate
Department of Sociology
University of Alberta
5-21 HM Tory Building
Edmonton, Alberta T6G 2H4
ishankar@ualberta.ca

March 13, 2007

Dear _____________,

I am a doctorate candidate in the department of Sociology at the University of Alberta. I am contacting you today to request your participation in my research on History of Fetal Alcohol Spectrum Disorder (FASD) in Alberta. Your participation is requested due to your extensive expertise and experience in the area of FASD.

As you are aware, various governmental and non-governmental agencies have identified the issue of FASD as a top priority. In 2001, the federal government budgeted $25 million in new funding for FASD prevention efforts on Aboriginal reserves. Similar efforts are underway in Alberta. On September 15, 2004, Alberta Children's Services, in partnership with Alberta Alcohol and Drug Addiction Commission, and Alberta Learning launched an extensive FASD education and awareness campaign.

The growing attention and resources this issue is receiving from both the federal and provincial government necessitates an investigation of the various experiences and forces that have shaped the present understanding of FASD. At present, no such research exists in Canada. My research addresses this gap by examining the history of FASD in Alberta. This study follows the evolution of Fetal Alcohol Spectrum Disorder (FASD) in Alberta from its emergence in the 1970s through to the present day. This is a two-phase study. The first phase involves analysis of the programs and policies created by federal and provincial government on FASD. The second phase entails interviews with medical professionals and experts in the area of FASD to understand how FASD is presently understood and managed in Alberta.

Accordingly, I am contacting you today to request an interview. I would appreciate a chance to interview you regarding this subject matter. As an expert in the area of FASD, your insights and knowledge of this subject matter is of great importance to this study. The interview will take approximately an hour to complete.

The interview will take place at your convenience and at a location of your choice. I have enclosed a consent form, which contains further details regarding the interview. This study has received ethics approval from the University of Alberta. This study will be supervised by Dr. Amy Kaler, Assistant Professor, Dr. Sara Dorow, Assistant Professor, and Dr. Harvey Krahn, Chair, in the department of Sociology at the University of Alberta.

I will be conducting all the interviews. I have completed qualitative research for my master's degree on immigrant grandmothers. In addition, last year, I traveled to Uganda to work as a research associate on a community-based ARV research project. I am currently completing a two year CIHR Strategic Training Initiative in Health Research Fellowship where I am receiving extensive training in qualitative health research.

Thank you again for your assistance in this matter.

Sincerely,

Irene Shankar, PhD Candidate
Canadian Institute of Health Research Strategic Training Fellow
Department of Sociology
University of Alberta

Appendix B

Consent Form

Research Title:	History of Fetal Alcohol Spectrum Disorder.
Researcher:	Irene Shankar, PhD Candidate Department of Sociology, University of Alberta
Supervisor:	Dr. Amy Kaler (780) 492-7579

This consent form, a copy of which you have been provided with, is to ensure informed consent from you. This form contains information as to the nature of this research and your rights as a research participant and the responsibility of the researcher. Please feel free to ask for elaboration or clarification on any of the information included in this document.

Your participation is being requested in this study. This study is undertaken to examine the historical development of Fetal Alcohol Spectrum Disorder (FASD) in Alberta. You will be interviewed regarding your understanding, experience and perception of FASD in Alberta.

If you agree to partake in this study, your involvement will encompass the following:

I, Irene Shankar, will interview you.

The interview will be arranged at your convenience and in a setting of your choice.

The maximum length of the interview will be one and a half hours. The researcher may ask to meet again if further questions arise. You are free to refuse the researcher's request.

The interview will be conducted using both semi-structured and informal interview formats.

In order to ensure accuracy and proper representation, this interview will be audio taped. Only my supervisor and I will have access to interview transcripts and field notes. No one besides a transcriber (who will sign an Oath of Confidentiality) and myself will listen to the audio recording of the interview, and audio recordings will be destroyed after one year.

In order to ensure confidentiality, the tapes and resulting transcription of the interviews will not contain your name. The tapes and transcriptions will only be identified by a number. This consent form and any other documents containing your name and your personal details will be kept in a locked cabinet in my office at the University of Alberta and accessed only by the researcher. The notes from the interview, audio tape and/or consent form will be also kept in a locked cabinet.

While you will not directly benefit from this study, it is hoped that this study will serve to increase knowledge of Fetal Alcohol Spectrum Disorder in Alberta.

The results of this research will be used in teaching, presentations, publications and in my doctorate thesis. Your name and/or any other identifying information will not be listed in my thesis or any other publications.

Your signature on this form indicates that you have understood the information listed on this form, what your involvement in this study entails and agreed to participate in this study as an informant. You have the right to withdraw from this study or decline answering any question at any time during this interview. Your signature does not waive your legal rights nor release the investigator or involved institutions from their legal and professional responsibilities. A copy of this consent form will be given to you to keep.

If you have further questions or concerns please contact me at ishankar@ualberta.ca. You are also welcome to contact my supervisor, Dr. Amy Kaler, at 492-7579 if you have any outstanding concerns or questions that I have not addressed.

____
Participant Signature

____ ________________________
Participant Name Date

Appendix C

Interview guideline

What is your position? What do you do? How long have you been here? How did you get this position? How did you become involved in this FASD initiative/program/policy? Did you stay involved? Are you currently involved? If yes, in what capacity? What are the challenges that you face in this role/position? Chronology of your involvement.

When did you first hear about FASD? When did you first encounter FASD yourself? What did you hear? Where was FASD located in the society? Who was being affected? Why was this seen as concern? What was being done at that time? What was eventually done?

Who were the key players in FASD program/policy in the beginning? Who are the key players now?

What did you see as being the need at that time? What is the need now? What has changed?

As seen by the huge funds that are being given to FASD initiatives, the Alberta government is quite involved - why is the Alberta government concerned about this? Was this always the case? When did they become involved and why? What was happening in Alberta at that time?

What do you think are effective strategies for preventing FASD? Are there any strategies that have been implemented that you thought were great/not so good?

If you had 10 million dollars what would you do with FASD prevention? Is this the same or different from what is being done?

Where do you think the Alberta government is headed with its policies on FASD – what is the next step?

What is the social cost of FASD on children? On Albertans? On Alberta as a province?

Why does FASD keep happening? What's driving FASD? All reports cite it as a completely preventable disease, so, in your opinion, what are the social factors that are driving it?

The reports from AADAC and the Alberta government list FASD as especially problematic for Aboriginal communities. Can you think of any strategies that are especially successful/important/relevant for Aboriginal communities? What is happening in the Alberta government to counter this?