

BEYOND GUILT, SHAME, AND BLAME TO COMPASSION, RESPECT AND
EMPOWERMENT: YOUNG ABORIGINAL MOTHERS AND THE FIRST NATIONS
AND INUIT FETAL ALCOHOL SYNDROME/ FETAL ALCOHOL EFFECTS
INITIATIVE

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ABSTRACT

Over the past decade, the “problem” of Fetal Alcohol Syndrome and Fetal Alcohol Effects among Aboriginal peoples has received increasing attention from the Canadian nation-state. However, few feminist, anti-racist, anti-ableist, and anti-colonial scholars have offered a critique of FAS/E “prevention” policies aimed at Aboriginal women. In this dissertation, I present my analysis of the “official knowledge” and “public pedagogies” articulated in one such policy, *The First Nations and Inuit Fetal Alcohol Syndrome/ Fetal Alcohol Effects Initiative* (herein “the Initiative”). This analysis unravels the complex and contradictory tensions in contemporary state policy formation. My findings show how the Initiative paradoxically supports the development of inclusive, grassroots approaches to FAS/E prevention in Aboriginal communities while at the same time eclipsing the voices and concerns of Aboriginal women.

Though neglected in the official policy texts and talk of the Initiative, young Aboriginal mothers’ agency and insights are central in the dialectic of ideology, discourse, and lived experience that this study documents. To facilitate this shift, I engage a productive methodological synthesis of textual analysis, institutional ethnography, and participatory research, by grounding my analysis of the texts in in-depth group interviews with six Aboriginal mothers whose lives include substance use and FAS/E.

This study offers significant implications for the development of future policy, research, and “culturally appropriate” pedagogy for and about FAS/E “prevention”. My findings do not support the outright rejection of medical models of disability, as has been favoured by many critical theorists and activists on the grounds that such models are

universally oppressive and disenfranchising. Rather, the women's insights into their own lived experiences emphasize the simultaneously enabling and disabling consequences of medicalization. Accordingly, my findings underscore the urgent need to reconsider the roles of "race", gender, class, nation and dis/ability in contemporary theories and practices of substantive citizenship and nation-building in and outside of education.

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DEDICATION

For my daughters

Mikaela Susan Haeusser, who was here from the beginning
and Clara Robin Haeusser, who we welcomed along the way

Chapter 1: Introduction

Introducing the Initiative

In 1999, the federal government of Canada expanded the Canada Prenatal Nutrition Program with funds dedicated to initiatives that address FAS/FAE. At that time, a total of \$11 million over three years was committed to fund the First Nations and Inuit Health Branch (FNIHB) and the Population and Public Health Branch of Health Canada in developing, implementing, and administering a “national strategy on community based FAS/FAE prevention, awareness, and surveillance programming” targeting First Nations and Inuit communities (www.hc-sc.gc.ca/fnihb/sppa/ppp/emerging_priorities_youth.htm). Termed *The First Nations and Inuit Fetal Alcohol Syndrome/ Fetal Alcohol Effects Initiative* (referred to herein as “the Initiative”), this policy claimed to be “based on the values, objectives, and needs identified by First Nations and Inuit communities across Canada”, that were collected in a series of “regional information-sharing and feedback discussion sessions” that were held in First Nations and Inuit communities between January 20, 2000 and February 23, 2002 (FAS/FAE Technical Working Group 1997:5). The stated goal of the Initiative is to provide policy directions and funding to “(1) prevent FAS/FAE births, and (2) increase the knowledge, skills, and quality of life of FAS/FAE affected children, mothers, fathers, and families” (FAS/FAE Technical Working Group 1997:11). In 2001, an additional \$25 million over 2 years was allocated specifically to continue the work of the Initiative.

The Initiative was implemented in correspondence with FNIHB’s mandate. As such, the Initiative was “directed towards on-reserve First Nations, First Nations North of 60°, and Inuit communities” (FAS/FAE Technical Working Group 1997:21). Funds were

made available to First Nations Bands and Tribal Councils, and national, provincial, and regional First Nations and Inuit organizations, and community-based organizations sponsored by First Nations or Inuit governments to develop their own regional and local projects that would “increase awareness” of FAS/FAE¹ and contribute to “capacity building”, to enable communities to develop and implement their own FAS/FAE “prevention” and “support” programs (FAS/FAE Technical Working Group 1997). In addition, the Initiative funded national “projects that provide leadership to the regions and have a national impact” (FAS/FAE Technical Working Group 1997:22), including a “national awareness campaign”, “needs assessment” and “curriculum template development” (ibid). According to the “Framework for the First Nations and Inuit Fetal Alcohol Syndrome/ Fetal Alcohol Effects Initiative”, projects received funding based on the extent to which they reflected the four main objectives of the Initiative (FAS/FAE Technical Working Group 1997:21). Those objectives were:

- 1) “Raising Awareness of the general population, particularly young people, about FAS/FAE and the dangers of drinking during pregnancy” (p. 11);
- 2) “Reaching Those At Risk”, specifically “pregnant women or women in their child-bearing years who consume alcohol (“women at risk”) and their partners, in order to reduce the risk of FAS/FAE” (p.12);
- 3) “Working With Those Affected”, to “identify and work with FAS/FAE affected individuals in order to lessen the educational, social, and behavioural

¹ Currently, “Fetal Alcohol Spectrum Disorder” is the term most favoured by practitioners and researchers to describe the spectrum of physical, cognitive, and behavioural characteristics attributed to prenatal exposure to alcohol (Poole 2004). However, in this dissertation, I retain the use of the earlier terms “Fetal Alcohol Syndrome (FAS)” and “Fetal Alcohol Effects (FAE)”, in keeping with the terminology employed in the texts of the Initiative. Throughout this dissertation, I use the term “FAS/FAE” to refer to the separate (but related) diagnoses FAS and FAE simultaneously. Where I use the term “FAS”, the reader should note that I refer specifically to Fetal Alcohol Syndrome. Likewise, where I use the term “FAE”, the reader should note that I refer specifically to Fetal Alcohol Effects.

impact, complications, impairments, and disabilities of FAS/FAE by supporting them” and to “reduce the risk that these individuals will have FAS/FAE children themselves” (p. 12); and

- 4) “Creating Linkages” between “related programs and initiatives” to ensure that “projects, services, and activities designed to address interconnected problems and issues are not fragmented” and “ people and organizations with similar or shared goals have the opportunity to share information and expertise in an atmosphere of cooperation, collaboration, and coordination” (p. 13).

The primary policy documents supporting the work of the Initiative were published together by Health Canada in 1997 under the title, *It Takes a Community*. The *Framework for the First Nations and Inuit Fetal Alcohol Syndrome and Fetal Alcohol Effects Initiative* outlines the guiding principles, vision, goals, objectives, and components of the Initiative, as well as the eligibility criteria for Initiative funding and the structure for its implementation. The *Framework* also provides an overview of FAS/FAE and the historical and cultural context of FAS/FAE in Aboriginal communities. *A Resource Manual for Community-based Prevention of Fetal Alcohol Syndrome and Fetal Alcohol Effects* supports the implementation of the Initiative in Aboriginal communities by offering “facts” about FAS/FAE and its “root causes” in Aboriginal communities (FAS/FAE Technical Working Group 1997:65), and strategies for developing and implementing FAS/FAE awareness and prevention programs and activities in Aboriginal Communities. *It Takes a Community* was prepared by a working group that included representatives from Health Canada, FNIHB, the Aboriginal Nurses

Association of Canada, the Assembly of First Nations, Inuit Tapirisat of Canada, the Canadian Paediatric Society, the First Nations Education Council, and Pauktuutit Inuit Women's Association, as well as a variety of Tribal Councils, urban and rural Aboriginal communities, and social service providers. In addition, 10 Aboriginal communities reviewed *A Resource Manual for Community-based Prevention of Fetal Alcohol Syndrome and Fetal Alcohol Effects* prior to its publication.

Although the funding provided by the Initiative for community-based and regional programs was limited to on-reserve First Nations, First Nations North of 60°, and Inuit communities, the public education and "awareness" activities of the Initiative aspects of the policy were not. Since its publication, Aboriginal communities and organizations across the country have used *It Takes a Community* as a guide for a variety of education and community development initiatives related to FAS/FAE. Indeed, in the introductory pages of *A Resource Manual for Community-based Prevention of Fetal Alcohol Syndrome and Fetal Alcohol Effects*, it is noted: "The publishers encourage widespread use of *It Takes a Community* to any and all groups, Aboriginal or not, who strive to prevent FAS/FAE and undertake supportive interventions for persons already affected" (FAS/FAE Technical Working Group 1997:52). Likewise, the pamphlets, posters, and fact sheets produced via the Initiative have been circulated across Canada to on and off reserve Aboriginal communities and individuals.

The Initiative and *It Takes a Community* promised an approach to FAS/FAE prevention that departed from earlier policies and programs that isolated the issue of FAS/FAE as a medical diagnosis existing outside of the historic and contemporary context of Aboriginal communities. One of the ways the Initiative promised to be unique

was in its stated commitment to approaching FAS/FAE in an “integrated” and “holistic” fashion, that supported “coordinated”, “multidisciplinary” and “community-based” programming. For example, the introduction to *It Takes a Community* states:

Each new community initiative increases awareness of FAS/FAE. More Aboriginal caregivers will care and contribute as community awareness increases and people acknowledge that FAS/FAE is a concern that requires a coordinated, multidisciplinary approach. *It Takes a Community* was written with a team and multidisciplinary approach in mind and is directed at community resource people in the fields of health, education, justice, social services, as well as Aboriginal political leadership at all levels. It can be used with other resource materials such as positive parenting programs, training for trainers programs, cultural teachings, or any community development process in the community (FAS/FAE Technical Working Group 1997:51).

As a student of the sociology of education committed to understanding the gendered, racialized, national, class-specific and dis/ability dimensions of formal and informal “public” education, I encountered these texts as provocative sites of knowledge production and circulation, and competing epistemic claims. While the Initiative appeared to offer opportunities for understanding the of the importance historic, social, political, economic, and cultural context in responding to disability issues, I was struck by what I found to be an absence in the texts of the voices, needs, concerns, and interests articulated by Aboriginal women themselves. Accordingly, over a period of nearly 2 years (between June 2002 and April 2004), I conducted an analysis of the official policy texts of the Initiative that was grounded in what I learned from a group of young Aboriginal women whose lives have included mothering, substance use, and FAS/FAE. In this dissertation, I present the results of this study. In this chapter, and those that follow, I outline the questions and methods that I used to guide this analysis and the findings of my research.

Statement of purpose

The purpose of this research was three-fold, with investigations aimed simultaneously at engaging public policy, pedagogy, and service provision as sites of lived experience and knowledge production. First, through a critical analysis of the texts of the Initiative, I considered the ways official policy discourses of the Canadian state construct and position young Aboriginal mothers and their children in relation to FAS/FAE. Young Aboriginal women negotiate multiple inter-related and mutually constitutive oppressions in their daily lives, by virtue of their gender, "race", class, age, and "dis/abilities", as well as the macro-level relationships between Aboriginal peoples and the colonial institutions and practices of the Canadian Nation-State. These complex, multi-layered, and often conflicting realities require studies in which policy and pedagogy, and women's experiences of them, are situated socially: at once personally, structurally, and institutionally.

In this research, I was particularly interested in understanding how the Initiative functions as a means for (re)producing "official knowledge" (Apple 2000). "Official knowledge" is knowledge that is taken up and circulated by and through state institutions. Out of the "vast universe of possible knowledge," hegemonic institutions position official knowledge as the only "knowledge worth knowing" and "knowledge worth teaching" (Apple 2000:5). Apple (2000) argues that official knowledge is most evident in texts that are produced by or for hegemonic institutions. As such, Apple (2000:46) explains:

Texts are really messages to and about the future. As part of a curriculum, they participate in creating what a society has recognized as legitimate and truthful. They help set the canons of truthfulness and, as such, also help recreate a major reference point for what knowledge, culture, belief, and morality really are.

Apple (2000:46-7) further notes that official knowledge is often positioned in public discourse as through its (re)production and circulation is a collective activity, shared by all members of the “society” in which it is located, as “common sense” that “everybody” should know and agrees to. This, however, is misleading, as some individuals and groups are more responsible for and invested in the success of the texts and the knowledge they contain than others (ibid).

“Public pedagogy” (Luke 1996) is an important mechanism for the circulation and (re)production of official knowledge. As Luke (1996) defines the term, “public pedagogies” are the informal teaching and learning that takes place in everyday life, in encounters between differentially located people and diverse agents including popular culture and media, literature, parents, friends, partners, and teachers. Public pedagogies involve the transmission of “common sense” (Gramsci 1992) knowledge that is often simultaneously hegemonic and contradictory, which is intended to shape ideas about identity, difference, “the way things are” or “the way things should be”. In this dissertation, I argue that public policies, and most particularly public education campaigns such as the Initiative, are also powerful sites of public pedagogy. As I will show, the circulation of official knowledge through the public pedagogy of the Initiative about the causes and consequences of FAS/FAE in Aboriginal families and communities does more than shape “common-sense” understandings of FAS/FAE in public discourse and everyday life. These pedagogies and the knowledge they transmit also have profound effects on the discursive and material resources available to Aboriginal mothers and

people living with FAS/FAE to have their knowledge and interests acted on in their communities and in state institutions.

In this dissertation, I build on the productive insights offered by Luke's (1996) concept of "public pedagogy", to highlight the effects of what I will call "private pedagogy". Unlike public pedagogies, which circulate knowledge that it is assumed "everybody" needs to know and is necessary for negotiating everyday life, "private pedagogies" originate in the learning that comes from lived experiences that it is assumed "no-one" should talk about or acknowledge publicly. Private pedagogies are those teaching/learning encounters that do not enter into public discourse, because the experiences they represent are not assumed to contain knowledge properly belonging in or to the "public". The teaching/learning encounters about the causes and consequences of FAS/FAE that emerge from the experience of using alcohol or drugs during a pregnancy, or from observations about the effects of substance use on one's children provide a potent example of "private pedagogy". Together, public and private pedagogies are organizing devices that position the inter-related domains of "public" and "private" as separable, contradictory, and shifting. As such, I argue that these pedagogies act as sites that devalue and individualize women's experiences.

These discourses and textual practices are not merely linguistic tropes that are ephemeral or inconsequential. Rather, they are powerful components informing the structural and material conditions with which young Aboriginal mothers and their children live. My research therefore also sought to uncover the material and structural effects of the discourses that circulate in a particular public policy on the lived experiences of young Aboriginal mothers, which are too often overlooked in textual

analyses. Moreover, analyses such as these demand that signifiers of social location be considered relationally, to avoid the tendency so often found in policy analysis to consider gender, “race”, class, age, and “dis/ability” as additive constituents of “identity” or “experience”. To date, these concerns have been under-appreciated and under-theorized, and have tremendous implications for advancing anti-colonial, feminist, anti-ableist, and anti-racist policy analysis and pedagogical practice.

The second purpose of this research was to develop an understanding of the ways in which competing and highly politicized conception of the needs, interests, concerns, and experiences of Aboriginal communities, and young Aboriginal mothers in particular, affects public discourses, policy, pedagogies, and social service provision in relation to FAS/FAE. In so doing, I wanted to understand how a group of young Aboriginal mothers who were accessing a program for FAS/FAE “prevention” articulate their own needs, interests, concerns, and experiences, and how these may be similar to or different from the ways they are constructed in texts of the Initiative. Examining this relationship provided opportunities to listen to and learn from young Aboriginal mothers, to develop a critique of the ideologies that underlie these policy and programming interventions. In so doing, I examined how young Aboriginal mothers affected by these policies negotiate and challenge the conventions, relevancies, and hegemony of education and social service provision related to FAS/FAE “prevention” and “support”. This analysis points to important implications as to how “public” institutions serving young Aboriginal mothers and their children might amend their pedagogies and services to be better reflective of the needs, interests, concerns, and experiences articulated by their so-called “clients” and “target populations”.

The final purpose of this research was to examine the relationship between the constructions of young Aboriginal mothers and their children articulated in the Initiative and projects of nation-building. Although Aboriginal organizations, First Nations, and Inuit communities provided “consultations” that shaped the direction of the Initiative, the responsibility for conceiving, implementing, and administering the policy rested solely with the Canadian federal government. As Taylor et al (1997) have demonstrated, social policies constructed in and through contemporary Western democratic Nation-States are fundamentally ideological texts. As such, social policies can be understood as a terrain in which the State is continually contested and renewed (Taylor et al 1997). As products achieved through the negotiation of hegemonic and counter-hegemonic ideologies and interests, policy texts are directly implicated in practices of nation-building (see also Hall 1988, Torres 1995, Luke 1997). In this dissertation, I focus this discussion around two recurring themes: a) the representation of FAS/FAE, and substance-using² Aboriginal mothers who give birth to children affected by FAS/FAE, as a “risk” and a “threat” to First Nations and the Canadian Nation-State; and b) Aboriginal women’s lived experiences of “citizenship” in the context of their daily lives, and the implications of public discourses about FAS/FAE for advancing social justice for Aboriginal women and people with disabilities on the basis of their rights and entitlements as “citizens”.

Mothers in Canada have been subject to on-going “public education” and “public health” campaigns instigated by various branches of the federal government for almost

² In this dissertation, I use the term “substance use”, rather than “substance abuse” or “substance misuse” to describe a pattern of regular alcohol and/ or drug use. “Substance use” is the term favoured by many practitioners and researchers using harm reduction approaches to supporting the well-being of people involved with alcohol or drug use, as it offers a less stigmatizing and value-laden description of people’s activities in relation to alcohol or drug consumption (c.f. Boyd 1999, CAMH 2002, Erickson 1999, Robertson and Poole 1999)

100 years, in which they have been simultaneously praised and vilified as both “guardians” and “threats” to the Nation and its institutions (Arnup 1994, Davin 1978). While many of these campaigns were undertaken for the seemingly philanthropic purpose of decreasing infant mortality and providing access to health and education services for women and children, it remains that many were also fueled by eugenic concerns for the perceived need among those in middle and upper classes to undertake measures to prevent “race suicide” by “preventing births” of people with disabilities, people living in poverty, and racialized minorities (Mitchell and Snyder 2002, 2003). Katherine Arnup (1994), Mariana Valverde (1991), Margaret Hillyard Little (1998) and many others have provided excellent feminist critique of maternal education initiatives in Canada. Scholars including Marlee Kline (1993), Jo-Anne Fiske (1992, 1993), Karen Swift (1995), and Kim Anderson (2000) have further demonstrated how Aboriginal women in Canada have been marginalized by European ideologies of motherhood in general and in child welfare legislation in particular. However, very little scholarly work combines a feminist, anti-racist, and anti-colonial critique of contemporary maternal education campaigns, such as the Initiative, aimed at Aboriginal women specifically. Moreover, young Aboriginal women’s voices and experiences have been neglected in this analysis. My research therefore contributes to the advancement of feminist, anti-ableist, and anti-colonial scholarship on motherhood and “at risk” youth. It is equally my hope that this research supports the on-going struggles of women who are “mothering on the margins”, to advance their movements for social, economic, and political justice on their own terms.

The research questions

The following questions guided this research:

1. How are young Aboriginal mothers and their children positioned discursively and materially in the texts of the Initiative? In what ways do these texts position the needs, interests, concerns and experiences of young Aboriginal mothers and their children in relation to FAS/FAE? How are the emergence of FAS/FAE as an “important public health issue” and the texts of the Initiative that respond to it informed by the historical, social, economic, political, cultural, and national contexts in which they are situated? What do these policies address explicitly and implicitly in terms of their goals and intents? What do these policies ignore or eclipse? How do the ways in which these “problems” are constructed inform the solutions proposed through policy?
2. How does the language of the Initiative construct the “risk” posed by substance-using mothers and FAS/FAE to Aboriginal communities and the Canadian Nation-State? What does FAS/FAE mean in the daily lives of young Aboriginal women whose experiences include mothering, substance use, and FAS/FAE? How are these issues mediated by the larger context in which Aboriginal women and their children live? How do young Aboriginal mothers articulate and analyze their own experiences, needs, concerns, and interests with respect to policies and programs for FAS/FAE?
3. How does the Initiative function as a form of “public pedagogy” (Luke 1996)? What does the Initiative communicate to young Aboriginal mothers and the

general public regarding the definition, presumed causes, and consequences of FAS/FAE? What is the relationship between the “official knowledge” and “public pedagogy” about FAS/FAE articulated in the texts of the Initiative and the lived experiences of young Aboriginal women whose lives have included substance use, mothering, and FAS/FAE, and their own analysis of these experiences?

In keeping with the traditions of critical feminist qualitative research, these questions remained open and were revisited and revised throughout the research process in accordance with the issues that were raised by the women who participated in the project and through my evolving understanding of the texts I was studying.

Methodology

I designed this research using qualitative, inductive methods of textual analysis of key documents supporting the work of the Initiative, that were grounded in the experiences of 6 young Aboriginal women whose lives have included mothering, substance use, and FAS/FAE. This research design employed Dorothy Smith's (1987) methods of institutional ethnography, as well as her (1990, 1992, 1999) approach to textual analysis. Throughout the research process, the focus of my critique was the official policy texts of the Initiative, and not the behaviours or practices of the women themselves. However, situating the analysis of these texts within the context of the voices, understandings, and relevancies of young Aboriginal mothers who negotiate the complexities of FAS/FAE, substance use, and mothering in their daily lives was crucial to this research. This approach enabled me to develop an analysis that uncovered the

points of contact and disjuncture between the discourses, relevancies, and priorities articulated in the documents of an official state policy and the lived experiences of members of the most salient “target population” of the policy. This understanding would have been impossible to develop using methods of textual analysis alone, and underscores one of the primary deficiencies of this methodology and the policy texts themselves³.

At the time I began this research, the first community-based projects supported by the Initiative were in the development and the initial implementation stages. Accordingly, the timeframe and resources available for this research did not make it feasible for me to base this research in interviews with women who had participated in one of the programs funded by the Initiative to directly evaluate its impact on their daily lives. As an alternative, I interviewed women who were participating in one of the FAS/FAE prevention programs identified in *It Takes a Community* as a successful program in keeping with the goals, scope, and objectives of the Initiative, and which the texts offered as a possible model for other Aboriginal communities wishing to develop their own FAS/FAE prevention programs. Although this program is located in a multicultural, urban Aboriginal community (and thus outside of the direct mandate of the Initiative), the women I interviewed did occupy other locations that were similar to the “target groups” of the Initiative. All were self-identified young Aboriginal mothers in their childbearing years. 5 of the 6 participants were designated as “status” by the Department of Indian and Northern Affairs. 5 of the 6 women are registered members of a First Nation or Band. Like many urban Aboriginal women, half of the participants regularly moved back and

³ For further discussion of methodological issues, see Chapters 3 and 8.

forth between the city and their reserve community, while others who did not regularly live in their reserve communities retained a significant connection to their Band.

In inviting women to participate in this research, I was aided significantly by the coordinator of this program, who I had come to know well through another participatory research project I had facilitated with Aboriginal women in the community on issues related to FAS/FAE. The women who I interviewed chose to participate in 2 semi-structured group interviews. During the first interview, the women were asked to reflect on their understandings of FAS/FAE, and what FAS/FAE has meant to them in their daily lives in their community. With their full consent, this interview was tape-recorded and transcribed. I then analyzed this data using a coding schedule consistent with qualitative, inductive research methods and principles of emergent research design (c.f. Luttrell 2003, Pillow 2004). At the second interview, I presented the women with a copy of the interview transcript and a summary of my preliminary analysis of the transcript in relation to the policy texts. I then asked the women questions designed to solicit their analysis and to confirm whether or not my preliminary findings resonated with their own analysis of their experiences. Their feedback was then incorporated into my final analysis, as presented in this dissertation⁴.

Limitations of this study

The primary limitations of this study are consistent with those common to qualitative research. In comparison to quantitative research, qualitative researchers generally use smaller sample sizes to encourage depth of analysis and understanding. These interviews utilized a small sample size, and were designed to focus on the

⁴ The details of my methodology are described in Chapter 3.

experiences, needs, and interests articulated by a small group of Aboriginal mothers situated within a specific geographic, temporal, social, economic, and political context. Thus, while certain resonant themes may occur, the results of my study may not be generalizable to all Aboriginal mothers across differences in age, class, geographic location, sexuality, or dis/ability, non-Aboriginal mothers, or Aboriginal peoples as a whole. Furthermore, these factors mean that this study is unlikely to be replicable in the traditional sense, and other researchers conducting research in this setting or others similar to it may or may not share the analysis brought to bear on the data I collected. However, this approach had the advantage of allowing me to probe in depth the experiences, observations, and insights of participants in a way which larger sampling schemes that privilege quantity over quality of responses do not. In addition, the fact that I am non-Aboriginal and do not share many of the social locations of the research participants may have resulted in miscommunication, misunderstanding, or lack of attention to nuances which might be obvious to someone occupying a similar location to the research participants, or to the research participants themselves. Another limitation may be found in that my efforts be as nonintrusive as possible in the participants' lives and my limited research funds for honoraria⁵ meant that I was unable to have a prolonged engagement with the participants in the research or to conduct more than two interviews with them. These conditions would have undoubtedly provided opportunities to achieve even greater depth and complexity in my findings.

In acknowledging this limitation, it is also important to note that my relationship with the women who participated in this study has not ended. I continue to do community-based research in their community for an organization serving and supporting

⁵ For further discussion of these issues, see Chapter 3.

Aboriginal mothers with issues related to substance use. Through this work I have remained connected and accountable to most of the women who participated in my research⁶. In seeing them and their children regularly, we continue our discussions about these research findings as well as new areas for doing research with and for Aboriginal mothers in the community.

The limitations of textual analysis and the methodological and theoretical orientation of this study mean that I cannot claim to offer “the one and only” interpretation of the texts under study. However, this methodological framework did enable me to reveal, at least in part, the textual strategies and material practices which organize and constitute a specific set of social relations (Smith 1990, 1999). I approach my analysis of the *First Nations and Inuit Fetal Alcohol Syndrome/ Fetal Alcohol Effect Initiative* as an example of ideologically mediated and socially constructed nation-building practices. In so doing, I am attending to the specificities of one particular policy initiative located in a particular historical, social, geographic, and political context. Therefore, my research cannot claim to speak to the nuances and intricacies of all federal government policies, nor to the other policy approaches taken by provincial and federal governments related to FAS/FAE prevention.

Defining feminist materialist, anti-colonial, and anti-ableist analysis

For the women I interviewed, their experiences as Aboriginal women and mothers who are struggling to make lives in which they and their children can thrive, in spite of poverty and disabilities, mattered most in their analyses of FAS/FAE. Therefore, “race”, gender, class, and dis/ability, and considerations of anti-oppression and empowerment

⁶ Exceptions to this are 2 women who have since left the community to live elsewhere.

that accompany them, are central features I offer in this representation of the women's understandings and lived experiences, and in my theorizing of them. Accordingly, I found the approaches offered by feminist materialist, anti-colonial, and anti-ableist analysis to be useful for situating this inquiry.

My use of feminist materialist analysis is based on the assumption that gendered, racialized, and class-specific operations and effects of language and discourse are implicated in structures and practices that marginalize and disenfranchise (Kelly 1993, Kelly 2000, Lesko 2001, Pillow 2004, Roman 1996). Similarly, my use of anti-colonial and anti-ableist analysis includes recognition of the ways in which historic and contemporary practices of nation-building support colonial and ableist practices that subsume the interests of Aboriginal peoples, racialized minorities, and people with disabilities. As such, my approach to inquiry is committed to creating knowledge that supports movements to create social change and transform the conditions of people's lives (Boyd 1999: 36, Reinhartz 1992).

Unlike postmodernism and some approaches to poststructuralism, feminist materialism avoids the reductivism inherent in distilling all aspects of lived experience or textuality to the effects of language or discourse. This reductivism eclipses people's agency in negotiating the systems of power and privilege that disenfranchise them. Moreover, this reductivism can obscure the material consequences of discursive and linguistic operations in people's everyday lives (Kelly 2000, Lesko 2001, Luttrell 2003, Pillow 2004, Roman 1996). Feminist materialist approaches address these problematic tendencies toward reductivism in two important ways. First, in attending to the social relations that structure, order, and mediate discursive texts as sites of analysis, feminist

materialists highlight the material consequences of frameworks provided by language and discourse. Specifically, feminist materialists pay attention to the ways discourses reify or reinscribe relations of power and privilege differentially across contexts and according to constituents of social location (such as gender, “race”, class, or dis/ability). Second, feminist materialist analysis attends not only to the ways discourses structure or order women’s lived experiences, but also to uncovering “the fissures or contradictions between peoples lives and representations of gender” and other constituents of social location, identity, and lived experience (Roman and Christian-Smith 1988:21). As such, my use of feminist materialism acknowledges the agency of people, both individually and collectively, in resisting, negotiating, and transforming oppressive power relations that marginalize and silence them.

Overview of the dissertation

This dissertation is organized into eight chapters. In Chapter 2, I review the empirical and theoretical literature that informed the development of this research, by providing a contextual and conceptual framework for the research questions I outlined above. In Chapter 3, I detail the methodological decisions I made in designing and enacting a methodology for a feminist, materialist, anti-colonial, and anti-ableist analysis of the texts of the Initiative grounded in the lived experiences of a group of young Aboriginal mothers and their analyses of these experiences. Chapter 4 analyses the ways in which FAS/FAE are defined and positioned ideologically, discursively, and materially in the primary policy texts of the Initiative. In Chapter 5, I turn my attention to the lived and embodied dimensions of these discursive practices. This chapter focuses on the

experiences and analysis articulated by young Aboriginal mothers themselves, highlighting their own understandings of the causes and consequences of FAS/FAE in their daily lives. In Chapter 6, I consider the function of “official knowledge” (Apple 2000) and “public pedagogy” (Luke 1996) in the education materials produced to support the work of the Initiative and in the experiences of the women who I interviewed. In so doing, I consider the means through which certain types of knowledge come to be taken up as “official” knowledge in the public pedagogy of the Initiative, as well as the points of contact, tension, and disjuncture between and among the texts of the Initiative and the women who participated in the group interviews. This discussion is extended in Chapter 7, which examines the impact of the discursive strategy Apple (2000) identified as “mentioning” on the inclusion and exclusion of “culturally appropriate” pedagogies and “traditional knowledge” in the Initiative. Chapter 8 offers a summary of my research findings, and a discussion of the implications of these findings for transforming the official knowledge and public pedagogy of FAS/FAE prevention to achieve social, political, and economic justice for Aboriginal women, children, families, and communities affected by FAS/FAE. This chapter concludes with a brief discussion of directions for future research, education, and policy-making for and about FAS/FAE that could address these concerns while at the same time supporting the well being, self-determination, and empowerment of all Aboriginal women, children, families, and communities.

Chapter II: Literature Review

In this chapter, I provide a review of the empirical and theoretical literature that has informed the development of my study by providing a contextual and conceptual framework for the research questions outlined in Chapter 1. In the first section of this chapter, I attend to the medical literature documenting the emergence of FAS/FAE as a public health issue, with specific attention to FAS/FAE in Aboriginal communities. I then provide an analysis of the empirical literature highlighting the salient historical, social, economic, and political factors that inform the material conditions under which contemporary young Aboriginal mothers give birth to and parent their children. Following this, I turn to the theoretical literature regarding nation-building and “citizenship”. This is followed by discussion of the construction of social problems and the construction of “youth at risk” and substance using mothers as sites of moral regulation and public policy making. I conclude by exploring the significant challenges disability theory presents to contemporary anti-oppression scholarship in the analysis of social problems, motherhood, citizenship, and nation-building, which provides a theoretical and empirical foundation for my study of the Initiative.

FAS/ FAE and Aboriginal communities

The first article documenting a shared cluster of “birth defects” associated with prenatal alcohol exposure in an English-language⁷ medical journal was published in The Lancet 1973. In this article, written by members of the Dysmorphology Unit at the University of Washington Medical School, the authors documented “a pattern of altered

⁷ Armstrong (2003) notes that a 1968 article published in a French medical journal (Lemoine et al 1968) is frequently acknowledged as the first published documentation of FAS. However, this article was not acknowledged by English-language medical journals until after the publication of Jones et al’s (1973) article in The Lancet.

morphogenesis and function in eight unrelated children who have in common mothers who were chronic alcoholics during pregnancy” (Jones et al 1973: 1267). This report was based on clinical case studies collected from 8 children⁸ born to women who had been alcoholics for an average of over nine years, and whose alcoholism significantly compromised their own health (i.e. causing cirrhosis and nutritional anemia). The infants in this study shared in common a cluster of physiological characteristics, including small head size, slow pre- and post-natal growth, a flattened and shortened area between the nose and lip, epicanthal folds (giving the eyes a rounded look), small jaws, joint anomalies, altered palmar crease patterns, and heart troubles, as well as developmental delays. Later that year, Jones and Smith (1973) published a second article in The Lancet, in which they coined the term “fetal alcohol syndrome”. This report was based on case studies with 3 additional children (all Native American), and catalogued similar physiological and developmental characteristics.

In contemporary medical literature, a diagnosis of fetal alcohol syndrome is generally considered appropriate if an individual presents 4 main diagnostic criteria (O’Malley and Nanson 2002, Stratton et al 1996). The first criterion is a confirmation of maternal alcohol use during pregnancy. While researchers argue that any prenatal alcohol exposure may result in the fetus developing FAS, others argue that heavy, episodic drinking (or “binging”) is the predominant risk factor (i.e. Alberta Medical Association 1999, Manwell et al 2000). The second criteria is slow or compromised physiological growth, during gestation and/or after birth, resulting in an infant with height and/or weight below the tenth percentile. The third criterion is central nervous system involvement, including a head circumference below the third percentile, developmental

⁸ These children are identified racially as “3 Native American”, “3 Black”, and “2 Caucasian”.

or cognitive disabilities, or learning disabilities. Some researchers have noted that Attention Deficit- Hyperactivity Disorder frequently accompanies a diagnosis of FAS or FAE (O'Malley and Nanson 2002). The fourth identifying characteristic of FAS is distinctive facial features, as enumerated in the original Jones and Smith (1973) article. An individual is deemed to have Fetal Alcohol Effects if there is confirmed or suspected prenatal alcohol exposure and the individual possesses some, but not all, of the three other identifying characteristics of FAS.

In addition to the physiological characteristics noted above, diagnoses of FAS or FAE are understood to have psychological and behavioural dimensions. For example, individuals with FAS and FAE are described as having “deficits in relationships”, “immature social skills”, “confusing and non-productive communication”, and “poor daily living skills” (Bert and Greene Bert 1992). People diagnosed with FAS and FAE have also been observed to be “impulsive” and to display “erratic sleeping patterns” (Black 1993). Carney and Chermak (1991) report that children with FAS and FAE achieved lower scores on the Test of Language Development than did children without FAS or FAE. Feelings of isolation, loneliness, depression, poor achievement in work and school, and difficulties in forming and maintaining relationships have also been attributed to FAS and FAE (Bert and Greene Bert 1992, Burgess and Streissguth 1992, Gessner et al 1998, Streissguth 1994, Rice 1992). Many researchers have highlighted the educational difficulties and learning disabilities experienced by children with FAS and FAE (i.e. Asetoyer 1990, Black 1993, Burgess and Streissguth 1992, Duckworth and Terry 2000, Harwood and Smilg 2002, Johnson and Judith 2000). While some educational researchers have argued that parallels exist in the learning characteristics of students with FAS /FAE

and students with other learning disabilities that enable educators to employ effective general interventions to similarly support all groups of learners (Johnson and Judith 2000, see also Brady and Sharon 1994, Forness and Kenneth 1994), others have characterized the learning differences associated with FAS/FAE as unique to the condition and therefore requiring specialized curricular and pedagogical approaches (Duckworth and Terry 2000, Findlay and Amy 1995, Harwood and Smilg 2002, Isbell and William 1993).

Most medical literature documenting the causes, characteristics, and consequences of FAS/FAE treats both the teratogenic effects of in-utero ethanol exposure and the diagnosis of FAS /FAE as forgone conclusions beyond question or debate. Indeed, the hegemony of FAS/FAE privileges understandings that pin-point alcohol exposure alone as the causative agent of disabilities and difficulties experienced by people diagnosed with FAS/FAE. As a result, research on FAS/FAE includes an over-representation of medicalized responses to FAS and a relative deficit of structural analyses of the possible social, economic, political, and historic factors that may act as (co)contributors to diagnoses of FAS/FAE or that might mediate or inform the lived experiences of individuals with disabilities related to prenatal ethanol exposure. As Armstrong (2003: 82) observes, "The focus on alcohol alone ... stresses the individualization of this problem by singling out drinking as the cause of FAS". As I demonstrate in later chapters, the individualization and medicalization of FAS/FAE as "social problems" has powerfully shaped public policy responses to FAS/FAE as well as the lived experiences of young Aboriginal mothers whose lives have been affected by the conditions.

However, since the introduction of this term to contemporary medical research and practice, researchers have maintained a heated debate as to the appropriateness of the diagnosis and the effects of maternal alcohol consumption on a developing fetus. Indeed, early responses to the original Lancet articles questioned whether there was indeed a “similar pattern” of malformations and disabilities evidenced in the original 11 documented cases of FAS (i.e. Johnson 1974). Since then, a growing body of literature has documented the social, economic, and environmental factors that contribute to the development and diagnosis of FAS.

For example, Bingol et al (1987) were among the first researchers to document that socio-economic factors contribute to the occurrence of FAS. In this study, Bingol et al concentrated their attention on women who admitted to drinking 3 or more alcoholic beverages per week during pregnancy, disaggregating the sample by socio-economic status. 71% of low-income women participating in the survey gave birth to children who were diagnosed with FAS, whereas only 4.5% of women of higher socio-economic status had children diagnosed with FAS. In their conclusions, Bingol et al identified nutritional status during pregnancy, which is directly related to poverty, as the key variable accounting for these disparate outcomes (see also George 2001). Abel and Hannigan (1995) argue that alcohol acts as a teratogen only when accompanied by other “permissive and provocative” cofactors, including malnutrition, smoking, stress, and exposure to environmental toxins during pregnancy. Gessner et al’s (1998) retrospective study of the educational records of 36 Alaskan students who met the diagnostic criteria for FAS found that 34 % of the students had documented speech impairments, 20 % had been classified as “mentally retarded”, 20 % had learning disabilities, and 6 % were

considered to have “serious emotional disturbances”. Given the low incidence of these conditions, which are frequently highlighted as “typical” characteristics of individuals with FAS, Gessner et al were unable to conclude that a “consistent pattern of educational deficit or service requirement [is] associated with FAS” and that “designating FAS as a qualifying condition for educational services does not seem warranted” (ibid: np). These researchers also suggested that factors including exposure to toxins, poverty, child abuse and neglect, and “exposure to a chaotic social environment” are implicated in the neurological and developmental outcomes generally attributed to FAS (ibid). Attending to the material conditions, including social, economic, political, environmental, and historical factors, that inform the diagnosis, incidence, and experiences of FAS/FAE are particularly crucial when examining the impact of FAS/FAE in Aboriginal communities.

Since its emergence in the medical literature, Aboriginal peoples and communities have been over-represented in diagnoses of FAS/FAE and have been identified as being particularly “at risk” for FAS/FAE, beginning with the first Lancet articles. Indeed, while most estimates of incidence of FAS/FAE place rates at about 3 for every 1000 births, it is believed that rates of FAS/FAE among Aboriginal peoples are as high as ten times this figure (Boland, Burrill, Duwyn, and Karp 1998, Ennis 2001, Square 1997).⁹ However, Tait (2002) observes that many methodological problems exist in studies arguing that Aboriginal heritage is a risk factor for FAS/FAE. Rather, she argues that

... chronic poverty and social marginalization appear to variables more important to identifying women at risk than ethnic identity. Because Aboriginal women are the poorest and most marginalized group in Canada these factors, rather than their Aboriginal culture

⁹ This assumption is based on data from the US, as no studies have yet been completed in Canada to determine rates of FAS or FAE among First Nations.

or heritage, situate them among women at risk (174).

The emphasized relationship between Indigenous peoples and FAS/FAE is not limited to medical-scientific or other disciplines of academic literature. From its first emergence in public discourse as a "social problem", special attention has been paid to the effect of FAS/FAE on Aboriginal peoples and communities. The publication of Michael Dorris's (1989) book, The Broken Cord, is widely acknowledged as the catalyst for the popularization of FAS/FAE. In this book, Dorris chronicles both the emergence of scientific understandings of Fetal Alcohol Syndrome and his struggles as the adoptive father of his Native American son, who has Fetal Alcohol Syndrome. While Dorris does note that Fetal Alcohol Syndrome is not a condition specific to Native Americans, he does argue that Aboriginal Peoples have been most affected by Fetal Alcohol Syndrome, in what he calls the "nightmare statistics" (136) of a "ballooning emergence of FAS among Indian people" (137).

However, in her analysis of Dorris' work, Stange (1994) argues that "the growing alarm over FAS- an alarm whose context includes devastating impairment of Native Americans- has meant that Native American women are often singled out for scrutiny and condemnation". Thus, although Dorris does attempt to provide his readers with a cultural context in which to consider the impact of FAS on indigenous and non-indigenous communities,

For Dorris and other writers on Native American struggles, this notion of alcoholic disease as a legacy passed on by female bearers of children has enabled an etiology of Native American distress in which woman is both the medium of infection and, through her sexuality and fertility, an infectious agent in her own right. (ibid).

In fact, despite Dorris's professed commitment to "every self-evident liberal belief", including the rejection of forced sterilization, state-sponsored genocide, and the wrongful imprisonment of Aboriginal peoples, Dorris argues for the imprisonment of alcoholic women who continue to drink during pregnancy and the sterilization of those who refuse to quit (1989:166-7). Given that Aboriginal women have been singled out both for being particularly "at risk" for an "FAS birth" and requiring specific attention for the "threat" FAS/FAE poses to the institutions of the Nation-State, it is important to consider the material conditions under which young Aboriginal mothers, who are frequently identified as most "at risk", give birth to and parent their children.

Locating young Aboriginal mothers: the social, economic, and political context of early-childbearing

Early childbearing, particularly when undertaken by young Aboriginal women using alcohol during pregnancy, remains a potent condensation symbol (Edelman 1988) for multiple social anxieties and moral panics (Cohen 1972, Kelly 2000: 43) in contemporary North America, including the shifting of social norms related to sexuality, motherhood, substance use, and gender roles. Moreover, the past four decades public discussions and policy responses to early childbearing and substance use from both ends of the political spectrum have been focused primarily on the "problems" of "dependency" among young, unmarried mothers and so-called "substance abusers" alike, and the costs and consequences posed by this "dependency" on the institutions of the Nation-State (c.f. Bode 1992, Boyd 1999, Furstenburg et al 1987, Gillham 1997, Gomez 1997, Humphries 1999, Kelly 2000, Luker 1996, Moore and Burt 1982, Moore and Manlove 1998, Sawhill 2000, Solinger 1992, Ventura et al 1999). Consequently, young Aboriginal mothers are

over-represented in the literature in pathologizing terms, and under-represented in structural analyses. This deficit became readily apparent to me in my efforts to understand both the agency of young Aboriginal mothers and their marginalization in gendered, racialized, classed, and ableist terms, and how this resistance informs public policy making, practices of nation-building, and the continuing colonization of Aboriginal peoples in Canada.

Much has been made of the correlation between early childbearing and poverty. For many commentators, early childbearing and single motherhood have come to represent the most urgent challenges faced by policy makers and educators intent on disrupting the so-called “cycle of poverty”. For these observers, the fact that many young mothers are poor and living on social assistance is understood to be an inevitable consequence of their “poor choice”¹⁰ to have children at the “wrong time” and outside of marriage. Thus, so the logic goes, efforts to reduce poverty and other related social “problems” should focus on reducing the number of births to young, single mothers (c.f. Furstenburg et al. 1987, Gillham 1997, Moore and Burt 1982, Phoenix 1991). This perception has been bolstered by recent neoliberal economic and social policies that position young single mothers as irresponsible “welfare queens” who give birth to children indiscriminately in order to collect welfare, secure social housing, or other “benefits” from the State. These beliefs are enshrined, for example, in an early 2002 announcement by the B.C. provincial government welfare policies had been reorganized to allow individuals to collect social assistance for only 3 years during a five year period

¹⁰ For an analysis on the discourse of “good choices” as related to teenage sexuality, pregnancy, and maternity, see Kelly (2000: 47-66).

(after which benefits will decrease by 11%), and that require single mothers receiving social assistance to return to paid employment once their youngest child is 3 years old.

However, it is becoming increasingly apparent in the literature that early motherhood in itself does not in fact cause poverty in later life. Rather, due to inequalities in the availability of safe, affordable, and reliable birth control backed up by accessible abortion services, coupled with an uneven distribution of educational services and employment opportunities that may increase young people's perceptions of positive future prospects apart from childbearing (Freeman and Rickles 1993) many white, middle class young women are able or choose to delay pregnancy and maternity to a degree that many working class women and women of colour are not. Thus, while there has been an over-all decrease in the number of births to young women, the decline has been sharper among more privileged groups and less so among groups marginalized by class and "race" (Luker 1996, Phoenix 1991).

This is particularly the case for young Aboriginal mothers. Aboriginal women are more than three times as likely than non-Aboriginal women to give birth between the ages of 15 and 24. Young Aboriginal women are also more likely than non-Aboriginals to be single mothers and to live below the low income cut-off line. Within Aboriginal identity categories, it has been noted that Registered ("Status") Indians¹¹ have twice as high a proportion of single mother families as non-Aboriginal Canadians in both urban

¹¹ The term "Registered Indian Status" is an administrative category used by the Government of Canada to recognize rights and entitlements afforded to persons registered under the *Indian Act*. The *Act* defines an "Indian" as "a person who, pursuant to this *Act*, is registered as an Indian or is entitled to be registered as an Indian." To be eligible to receive benefits under the *Indian Act*, individuals must be registered in the Indian Register, which is maintained by the Department of Indian Affairs and Northern Development (DIAND). Generally, persons are eligible to register if one or both of their parents are registered (for exceptions, see Cornet 2001). In Canada, Aboriginal people (which includes peoples who identify as First Nations, Metis, or Inuit) who are non-registered (or "non-status") may not have access to certain rights and entitlements (i.e. to on-reserve housing, education, non-insured health benefits, etc.) afforded to "Registered" or "Status Indians".

and rural areas. Based on findings from 1996 census data, it has been further demonstrated that in urban areas, 38% of Registered Indian families with children under the age of 15 were single mother families, compared to 29% of non-status Aboriginal and Métis families, and 18% of non-Aboriginal families (Hull 2001).

Phoenix (1991) has noted that, “ [p]overty is... the context in which the overwhelming majority of instances of motherhood under 20 occur, rather than a causative factor” (90). For young Aboriginal mothers, this context is compounded by the systemic poverty and unemployment they encounter in most reserve communities, which is a direct result of the Canadian federal government’s negligence of its fiduciary duties to First Nations and Aboriginal peoples (Royal Commission on Aboriginal Peoples 1996). This is further compounded when considered in conjunction with the continuing impact that loss of land and access to resources, along with paternalistic colonial policies aimed at the assimilation of Aboriginal peoples, the destruction of First Nations families and communities, and the disenfranchisement and marginalization of Aboriginal women within and outside of First Nations governance structures (Acoose 1995, Fiske 1993, Royal Commission on Aboriginal Peoples 1996, Silman 1987, Turpel 1993). These conditions experienced by Aboriginal peoples are not confined to reserve communities. Aboriginal peoples as a whole, and Aboriginal single mothers in particular, continue to face economic marginalization in all Canadian urban centres (Hull 2001).

While Townson (2000) notes that Canada is currently experiencing the highest rate of women’s poverty in 20 years, with 19% of all adult women living in poverty, the experiences of poverty are most acute among Aboriginal women. To illustrate, in 1995, 72% of Aboriginal single mothers identified government transfer payments (such as

social assistance) as their major source of income, compared to 49% of non-Aboriginal single mothers, with status and non-status Aboriginal single mothers living in urban areas more likely to depend on government transfer payments than those living in rural areas (Hull 2001). Feminist and anti-poverty analysts have repeatedly demonstrated government's complicity in perpetuating women's poverty (Baxter 1995, Brodie 1998, Cohen 1997, Janovicek 2000). Drawing on discourses of "individual responsibility", "cycles of poverty", and related ideologies which simultaneously pathologize individuals living in poverty and position them as lacking in personal initiative to improve their circumstances, social assistance policies of provincial governments keep welfare rates significantly below subsistence levels in an effort to discourage individuals from becoming "dependant" on welfare (Fraser and Gordon 1997). Furthermore, Aboriginal single mothers living in urban centres who are successful in securing paid employment are disproportionately concentrated in the lower occupational levels when compared to non-Aboriginal single mothers (Hull 2001). The average income of Aboriginal single mothers in 1996 was less than \$16,00 per year, compared to an average of about \$22,000 among non-Aboriginal single mothers (Hull 2001).

Moreover, it is important to note that the context in which early-childbearing occurs for young Aboriginal women is further informed by experiences that are in many ways distinct from those of non-Aboriginal youth. This context includes the legacies of provincial and federal government policies aimed at the eradication and assimilation of traditional Aboriginal family and kinship structures. To cite but one example, Swift (1995), Turpel (1993), Fiske (1992), and Anderson (2000) have observed that the over-representation of Aboriginal children in the child welfare system is a direct result of the

colonial legacy with which First Nations peoples in Canada live, including the residential schooling system. This legacy is further informed by ethnocentric and patriarchal constructs which position Aboriginal mothers as abusive, neglectful, and otherwise dangerous to their children. This in turn creates the increased likelihood that Aboriginal mothers will have their children removed from their care (see also Fournier and Crey 1997, Royal Commission on Aboriginal Peoples 1996, White and Jacobs 1992). Current figures from British Columbia note that although only 8% of all children in the province are Aboriginal, they represent over one third of children in care (www.mcf.gov.bc.ca). These factors in concert inform the development and implementation of public policy “including the Initiative” that position young Aboriginal mothers and their children, and not other mothers and children, as “social problems” requiring of specific kinds of interventions by and for the State.

The construction of social problems

In contemporary public discourse, young Aboriginal mothers and people with disabilities are frequently constructed as social problems. As a mechanism informing popular “common-sense” making about FAS/FAE, these discourses provide a rationale for simultaneously excluding young Aboriginal women, their children, and people with disabilities from advancing and articulating their own experiences, interpretations, and understandings toward improving their material conditions on their own terms. But what is it about the ways in which social problems are constructed and articulated through public discourse that fuels these “common-sense” exclusions?

In his work on the construction of social problems, Edelman (1988:12) has noted that

Problems come into discourse and therefore into existence as reinforcements of ideologies, not simply because they are there or they are important for well-being. They signify who are virtuous and useful and who are dangerous or inadequate, which actions will be rewarded and which penalized. They constitute people as subjects with particular kinds of aspirations, self-concepts, and fears, and they create beliefs about the relative importance of events and objects. They are critical in determining who will exercise authority and who will accept it.

Therefore, as Gusfield (1996) notes, employing the language of “problems talk” in a claim to represent a particular societal consensus requires the positing of a “society” which is homogenous, with shared interests and values, against which the “problem” situation can be contrasted. This feature of “problems talk” is well evidenced in the texts of the Initiative, in which the needs and interests of “FAS affected individuals”, “FAS children”, and “FAS babies” are positioned as oppositional and threatening to the needs and interests of “society as a whole”, “the Canadian people”, and “their communities”. This is rationalized primarily by emphasizing the “organic brain differences” and “special needs” of people diagnosed with FAS/FAE (FAS/FAE Technical Working Group 1997:1; for further discussion see Chapter 4). By positioning the “problems” of FAS/FAE as those of “troubled persons” through medicalizing and psychologizing discourses, attention is drawn away from the institutional and structural aspects informing the construction of FAS/FAE as an “important health and social issue”, thus effecting the depoliticization of FAS/FAE as a “social problem”.

Therefore, as Miller (1993:355) argues, “just as there are discursive practices or strategies that politicize [problems] talk, thereby putting problems *on* the agenda, so there are strategies that depoliticize talk and keep them *off*” (italics in original). For Miller (1993) and myself, these strategies are best understood as those that underscore or perpetuate the marginalization of subordinate groups. This marginalization, in turn, compromises the ability of speakers, individually and collectively, to advance their understandings and interpretations of “social problems” in public discourse and debate. In other words, they are practices which place limits on the “epistemic space” (Roman 2001) available to marginalized groups to name, speak, and be heard in articulating their lived conditions and experiences as knowledge claims. These practices also mediate and inform articulations of citizenship / membership interests via the mechanisms of the contemporary welfare state (see Chapters 4 and 5). This issue becomes particularly salient when considering the discursive and material effects of the language of FAS/FAE prevention policies on Aboriginal women and their children.

Nation-building, productive citizenship, and the construction of “youth at risk”

As a colonial state, the institutionalized practices of Canadian nation-building have been founded upon the social, political, economic, and cultural domination of Aboriginal peoples. As official “wards of the Crown”, Aboriginal peoples remain formally disenfranchised in their relations with the Canadian state through the contemporary administration of the Indian Act, which reinforces their paradoxical location as “non-citizens” and what Cairns (2000) calls “citizens plus”. Contemporary contestations over self-government and the settlement of land claims are fueled by the

continuing impact of the loss of traditional lands and access to resources, the enactment of policies aimed at the assimilation of Aboriginal peoples and communities, and the eradication of indigenous languages, spiritualities, and cultures, and traditional social, political, and kinship structures (Royal Commission on Aboriginal Peoples 1996). The on-going colonial relations between the Canadian state and Aboriginal peoples have mediated the unique position of Aboriginal women in their struggles to secure rights and entitlements as citizens in and of Canadian Nation-State.

As Fiske (1992) has highlighted, the gendered and racialized legacy of colonial nation-building has resulted in the paradoxical positioning of Aboriginal mothers as both “children of the state” and “mothers of the nation”. The mutually-constitutive relations of what Turpel (1993) has called the “patriarchy and paternalism” of the Crown also informs the disenfranchisement and marginalization of Aboriginal women within and outside of First Nations governance structures (see also Acoose 1995, Anderson 2000, Fiske 1993, Silman 1987). The formal and informal disenfranchisement of Aboriginal mothers as “non-citizens” organizes the material conditions under which the overwhelming majority of Aboriginal women in Canada live.

Feminist and post-colonial scholars provide a substantial contribution to my understanding of the discursive, ideological, and structural apparatuses of nation-building and citizenship, and the mechanisms through which marginalized groups are constructed as a “threat” to the institutions of the nation state. According to Himmani Bannerji (1997:24) “ ‘Canada’ ...cannot be taken as a given. It is obviously a construction, a set of representations, embodying certain types of political and cultural communities and their operations”. Bannerji marks the distinction between “formal” citizenship in a Nation-

State and “membership”. According to Bannerji, membership in a Nation-State is a signification of belonging, or the ability to signify, represent, or “project” “the nation”.. Drawing on the work of Althusser (1971) and Gramsci (1992), she states:

We are pasted over with labels that give us identities that are extraneous to us. And these labels [i.e. “immigrant”, “citizen”] originate in the ideology of the nation, in the Canadian state apparatus, in the media, in the education system, and in the common-sense world of common parlance (26).

Following Bannerji (1997), Young (1990) and other feminist anti-racist critics, my understanding of citizenship as an organizing constituent of social, political, and economic relations exceeds its employment in formal legal-juridical terms. Indeed, by focusing solely on the formal domains of citizenship, such as the right to own property, to vote, or to freely associate, conservative citizenship theorists have overlooked important dimensions of citizenship interests (c.f. Marshall 1950). These include those aspects of citizenship that are evidenced in the recognition of individual and collective experience, knowledge, and condition as well as efforts toward the redistribution of state resources to improve the material conditions of marginalized groups (Fraser 1997b).

Held (1989) and Abu-Laban (1998) have referred to these dimensions as “substantive citizenship”. In distinguishing between formal and substantive citizenship, Held (1989: 22) argues that although citizens must “formally enjoy ‘equality before the law’”, it is equally important that citizens also have “the material and cultural resources to choose between differing courses of action in practice”. Moreover, Held (ibid) underscores that contemporary social inequalities, including those of gender, class, race, and ethnicity, render it difficult for some individuals and groups to “allow citizenship to become a reality in practice”. Similarly, Abu-Laban (1998:70) differentiates the domain

of substantive citizenship as including “pressing issues related to the equality of rights and opportunities, treatment and life conditions, and, not least, participatory involvement that ought to come from holding formal citizenship” (1998:70).

The identification of an individual as a “citizen” signifies their membership in what Anderson (1991) has called the “imagined community” of the nation. These discourses of citizenship and nationhood are often invoked by claims-makers in their efforts to acknowledge the effects of particular policies and/or to effect the (re)distribution of state resources toward specific ends or purposes. However, the assignment of citizenship and membership interests in the imagined community of the nation depends greatly on the confluence of a number of salient factors. As Ross (1998: 189) has observed, “exploring the ways in which people construct their “imagined communities” can tell us much about how they locate themselves in relation to others and where they draw the lines between groups” (see also Faingold 2001). Accordingly, the categorization of marginalized groups as “others” is fundamental to the delimitation of membership in a nation state. Accordingly, Ng (1993) argues that the categorization of “otherness” reifies Canada as a raced, ethnicized, and gendered state, and is, as Bannerji (1997) notes, “integral to the structure of the Canadian polity itself” (25).

One of these factors underpinning the “othering” of groups marginalized by gender, race, class, and dis/ability is the historical memory of the “nation”, and the historical positioning of particular groups inside or outside the borders of the state and its “official” history (Stanley 1998; Roman and Stanley 1997). Stanley (1998) has noted that “the absence of fully historicized understandings” of the “official” history of the nation can position racisms as either inherent in the nation from time immemorial, as the result

of the recent arrival of diasporic populations, or as an unfortunate relic of the “long distant and dead past” (42). This has been further underscored by Sharma (2000), who notes that the reality that “such notions of a ‘national interest’ or ‘Canadian sovereignty’ have been built on stolen land and entrenched racist inequalities” (196). As such, she argues, “the notion of citizenship is the glue that holds the Nation-State together as a seemingly natural community authorized to exclude those rendered as Other” (Sharma 2000:196). Similarly, I argue that the denial of the colonial and eugenic legacies which have been infused into Canada’s institutional policies and practices function to naturalize and render unproblematic contemporary ableism and colonialism in policies aimed at the prevention of FAS/FAE.

Another integral factor to the “othering” of marginalized groups, and most particularly those marginalized by gender, “race”, class, and “disability” is the discourse of “productive citizenship”. As Meekosha and Jakubowicz (1996) have argued, the discursive and material practices that construct the ideologies of productive citizenship are enabled and inscribed by capitalist modes of production. According to the ideology of productive citizenship, the “ideal citizen” is seen as one who is economically self-sufficient, and for whom membership in the nation is contingent upon an ability to be seen as a “productive” and “contributing” member supporting the political economy of nation-building (see also Roman and Christian-Smith 1988). According to the discourse of productive citizenship, those who are constructed in hegemonic institutions and popular imaginations as unable, unwilling, or unsuited to participate in capitalist modes of production, including women, indigenous peoples, racialized migrant populations, and people with disabilities, are construed as “burdens” on the institutions and citizenry of the

nation (see also Meekosha and Dowse 2002, Meekosha and Dowse 1997, and Meekosha 1999). While not addressing the issue of disability, Sharma's (2000) study of the construction of migrant workers similarly demonstrates the ways in which positioning non-white (non-citizen) residents in Canada as "burdens" to "Canadian" taxpayers, intent on "abusing" the educational and social welfare institutions of "Canadians", has played an integral role in Canadian nation-building practices generally and the formation of federal policy regulating migrant workers specifically (see also Alexander and Mohanty 1997, Bannerji 1997).

As Fraser and Gordon (1997) have so astutely demonstrated, the feminization and racialization of "dependency" has served as a rhetorical foil for discourses of productive citizenship. According to Fraser and Gordon (1997), discussions of "dependency", and the "risks" and consequences thereof, are ideologically mediated constructs of "need" that emerge in the context of movements from late capitalist, welfare-state societies to late capitalist, laissez-faire societies. These ideologies rely on gendered, racialized, and culturally-specific definitions of "motherhood" and "the family". Accordingly, the definitions of "dependency" they inspire are interpreted, highly political, and subject to dispute, and allow policy-makers to position the "needs" of poor, racialized minority women and their children against those of "the public" and "the rest of society" in an attempt to secure public consent for the dismantling or implementation of specific social programs. Tracing the emergence of "welfare dependency" as a "postindustrial pathology", Fraser and Gordon (1997) argue that "properties once ascribed to social relations [i.e. slavery, labour relations in industrial capitalism, the emergence of "separate spheres" ideology in the social organization of the nuclear family, etc.] came to be

posited instead as inherent character traits of individuals or groups" (143). Thus, according to Fraser and Gordon (1997), "public" concern over the "welfare dependency", particularly of poor families headed by single mothers, functions to individualize and depoliticize issues of structural and systemic poverty in favour of explanations that are "as much moral or psychological as economic" (123). The result, Fraser (1989) writes, is that the "politics of needs interpretation" evident in the social welfare system of these societies "does not honor these women...[as it] decrees simultaneously that these women must be and yet cannot be normative mothers" as well as "independent" "citizens" (p.153).

Building on Fraser and Gordon's (1997) work, Lesko (1996) has argued that the concept of dependency is especially useful for interrogating the construction of specific groups of youths as being "at risk". In highlighting the "paradoxical relationship of dependence and independence for youth"(45), Lesko (1996) calls attention to the "doublespeak" evident in U.S. (and, I would add, Canadian) secondary school systems that simultaneously valorize independence as a primary indicator of success while creating educational environments that enforce the dependency of students by failing to allow them to exercise autonomy in decision-making, use of resources, or interactions with adults and peers. Moreover, Lesko (1996) notes, differentiations between students who are "at risk" and those who are "making it" are generally invoked to signal the likelihood that an individual student will not make a successful "transition to adulthood", which is normatively understood to mean being "at risk" for continued "dependency" on the institutions and resources of the state. However, as Fine (1993), Kelly (1993, 2000), Kelly and Gaskell (1996), Sangster (2002), Roman (1996), and other feminist materialist

scholars have also argued, designations of an individual youth or identifiable groups of youths as being “at risk” (i.e. for “dropping out”, “juvenile delinquency”, teen pregnancy, and the like) frequently overemphasize the perceived psychological or emotional vulnerability or volatility of the youth in question, absent of structural and material considerations which inform their systemic marginalization socially, economically, and politically. Thus, while these scholars do not engage with the ways in which dis/abilities are constructed and mediated in and through the conceptual category of “at risk youth”, they provide the important contribution of underscoring the means through which educational systems position some types of dependency as normative and acceptable, while rendering others problematic or pathological.

The invocation of particular groups of youths as being “at risk” for “dependency” in nation-building activities mediating the social citizenship of marginalized constituencies is very germane to my study of the Initiative. As I demonstrate, constructions of FAS/FAE frequently position Aboriginal youths, and specifically young Aboriginal mothers, in pathologizing terms as being “at risk” and potential “dependants” on the institutions on the Nation-State while failing to attend to structural considerations that perpetuate the marginalization and subordination of young Aboriginal women by gender, “race”, class, age, and (perceived) “dis/ability”. Discursive and rhetorical devices employed in the texts of the Initiative construct the Nation-State as being “at risk” as a result of the “burden” presented by Aboriginal youths with FAS/FAE on the “Canadian public”, and the material and structural consequences thereof for young Aboriginal mothers and their children.

The reproduction and circulation of discursive and material practices that inscribe physical, cognitive, and behavioural difference as “limitations, dependencies, and abnormalities” have been used to “define disabled people as excessive to traditional circuits of interaction and as the objects of institutionalized discourses” (Mitchell and Snyder 1997:3). This is particularly true of capitalist Nation-States and relations of global corporate capitalism, that privilege productivist definitions of “citizenship” that are grounded in an (assumed) ability to participate in activities producing sufficient economic value to support an individual’s material needs, those of their “dependants”, and national and transnational economies (Stone 1984, Gleeson 1999). Thus, as well as being highly gendered and racialized, discourses and practices that circulate ideologies of “productive citizenship” are disabling for a number of important reasons. First, the economic relations of industrial and global corporate capitalisms absent people with impairments, (as well as indigenous peoples) from circuits of production, as “burdens”, “drains”, and even “threats” to the institutions of the Nation-State (Meekosha and Dowse 2002, Meekosha and Dowse 1997, Meekosha 1999). As such, people with disabilities, Aboriginal peoples, and others are excluded from a significant (if not the significant) foundation for consideration as citizens. Accordingly, these groups come to be seen not only as having interests that do not contribute to the building and maintaining of the Nation-State, but as having interests that are antithetical to those of the Nation-State. Historically, these conceptions of citizenship, dependency, and nation-building have informed a variety of eugenic programs, including the forced confinement, sterilization, and extermination of people with disabilities. Similar conceptions of citizenship, dependency, and nation-building have also informed projects of colonization. Moreover,

they are enshrined in contemporary policies resulting in the segregation of people with disabilities and Aboriginal peoples in schooling and housing, employment discrimination, institutionalized poverty, lack of access to public spaces and services, social and political isolation, and harassment by public and private sector bureaucracies (Browne, Connors, and Stern 1985, French 1996, Meekosha and Dowse 2002, Morris 1996, Rizvi and Lingard 1996, Wendell 1996).

Second, productivist concepts of citizenship that provide a rationale for disenfranchising and oppressing disabled subjects as “non-citizens” obscure the fact that it is often not the existence of impairment per se, but structural, institutional, and environmental factors that create and mediate experiences of disability. As a result, medicalized conceptions of disability are (re)produced by practices used to regulate the use of public space as well as institutional and structural relations that dis/able the participation and enfranchisement of people with impairments. Thus, medicalization is directly implicated in the assignment of citizenship/ membership in local communities and the “imagined communities” of the Nation-State (Anderson 1991).

Constructing the “bad mother”: gender, “race”, ability, and the substance-using mother

Feminist and anti-racist scholarship on the social construction of mothering has highlighted the numerous ways in which women, and most particularly those further marginalized by “race”, class, “dis/ability”, and sexuality, are punished through State-sponsored disciplinary regimes for failing to conform to Western European ideologies of “good mothering”. According to these ideologies, a “good” mother is one who displays an unflinching dedication to homemaking and ensuring the welfare of her children and

husband. A “good” mother is self-sacrificing, self-disciplined, morally irreproachable, and capable of meeting the physical and emotional needs of her children, husband, and relatives without assistance (c.f. Anderson 2000, Arnup 1994, Collins 1991, Kline 1993, Oakley 1980, Rich 1977, Smith 1999).

Armstrong (2003: 17) observes that “constructions of FAS... incorporate deep cultural anxiety over changes in gender roles, particularly notions of motherhood”. These anxieties couple with hegemonic notions of “good” mothering to position mothers who use alcohol or drugs, and most particularly those who use them during pregnancy, as “unfit” or “bad” mothers, posing simultaneous threats to their children, their communities, and the institutions of the Nation-State (see also Boyd 1999, Campbell 2000, Humphries 1999, Gomez 1997, Swift 1995). Boyd (1999) correctly observes that similar concerns regarding the possible dangers posed by substance using fathers have remained marginal to non-existent in the literature, thereby further underscoring the gendered nature of these ideologically-mediated constructs. The power, influence, and authority to define and position maternal substance use as a social problem must therefore be acknowledged as emerging from a broader social context, in which epistemic power and privilege are differentially conferred on the basis of “race”, culture, nation, gender, class, sexuality, and “disability”.

The co-construction of race, gender, and dis/ability as related to maternal substance use has been previously explored in the work of Humphries (1999) and Gomez (1997) on representations of “crack babies” in the United States, and by Boyd (1999) in her work on the construction of Neonatal Abstinence Syndrome. Gomez (1997) has noted that by the late 1980s, the American “war on drugs” had become a “war on drug users”,

who were portrayed in the news media and other forms of popular culture as emerging from a “Black and Brown urban underclass” (2). Invoking a spectacle of Black “crack-addicted” mothers as dangerous to their children through the transmission of biological “defects” and medical distress, and as pariahs in their communities for their “voluntary” involvement in a subculture promoting crime, violence, vice, and poverty, Humphries (1999) posits that these images of crack mothers serve the ideological functions of providing a scapegoat for a complex array of “urban problems” while at the same time activating racial fears among the White, suburban, middle-class. Moreover, the positioning of maternal drug use as a “Black” and “urban” problem also obscures the reality that white, suburban, middle class mothers also use drugs. Humphries (1999) observes this has resulted in a popular “common-sense” (Gramsci 1992) making that has lead to an over-representation of Black women and an under-representation of white women being administered perinatal drug tests in hospitals (Humphries 1999: 48-9). Noting that women of colour and women living in poverty have historically been denied the right to mother their children, Boyd (1999) has similarly demonstrated that women whose children are diagnosed with neonatal abstinence syndrome are monitored and controlled, and if they are seen as being “non-compliant” with treatment protocols, they face an increased likelihood that their children will be apprehended by child welfare authorities.

As such, public concern regarding the “dangers” posed by substance-using women and their children may be viewed as an initiation of moral panic (Cohen 1972, Thompson 2001). Accordingly, images of maternal drug use by women of colour are frequently utilized to position “Black women’s failure to conform to the cult of true

womanhood ... as one fundamental source of Black cultural deficiency" (Collins 1991:74), which in turn provided justification for the continued intervention of the State into the lives of low-income, urban, women of colour and their families. In addition, Tsing (1990) has observed that during the same period neo-conservative forces were mobilizing a public debate to position the rights of women as being outweighed by "fetal rights". They note that this movement advanced numerous "cautionary tales" of women as dangerous to their children, as "potential aborters and child abusers", designed to "advise and inform about acceptable ways to live" (282). Kline (1993:119) has further argued that these representations of "bad" mothers, and most particularly Aboriginal mothers, have served to "limit and shape the choices women make in their lives, and construct the dominant criteria of 'good' and 'bad' mothering (c.f. Swift 1995).

For Aboriginal women, who have for generations struggled against the forced removal of their children by various agencies of the State under the auspices of assimilationist and "child protection" policies, the discourse of mothers as transmitters of physical, moral, and cultural contagion remain particularly salient. As Kline (1993) has observed, the socially, culturally, politically, and historically mediated ideology of motherhood has had a significant impact on First Nations women, in that what is often considered evidence of "bad mothering" (i.e. maternal alcohol use or drug addiction) is frequently isolated by agents of the State as individual behavioural "choices", rather than locating them within the broader contexts and lived experiences of on-going colonial and racialized oppressions of First Nations peoples. This is particularly apparent in the case of alcohol use, in that the introduction of alcohol to First Nations has been acknowledged as a tool of colonialism (Anderson 2000, York 1990). As Swift (1995) has demonstrated, the

presentation of alcoholism as a “disease” to which First Nations peoples are particularly inclined continues to pathologize individual Aboriginal mothers as “sick”, and Aboriginal families and communities as unconscious and uncritical perpetrators of “disease”.

Defining disability

While social theorists have provided us with an extensive literature deconstructing the common-sense categories of gender and race that have been incorporated the current literature of the sociology of education, similar work in the area of disability has remained marginalized. Given that “disability” in itself is a highly problematic category of analysis, and that definitions of disability vary significantly between and among educational and sociological literatures, it is important to explicate my use of the concept of “disability” as a socially constructed category of analysis and as an organizing constituent of social, political, and economics relations. Indeed, definitions of disability have significant implications for the analysis of policy responses to disability, including FAS/FAE, and for the advancement of social justice for people with disabilities. As feminist philosopher of disability Susan Wendell (1996: 23) reminds us,

[D]efining disability and identifying individuals as disabled are ... social practices that involve the unequal exercise of power and have major economic, social, and psychological consequences in some people's lives. To ignore these practices would leave us with an idealized picture of the problems of definition. To understand how the power of definition is exercised and experienced, we have to ask who does the defining in practice, for what purposes, and with what consequences for those who are deemed to meet the definition.

As I demonstrate, the ways in which FAS/FAE are defined as disabilities in the policy texts of the Initiative are implicated in practices of nation-building that allow for the

disenfranchisement and marginalization of individuals diagnosed with FAS/FAE and for young Aboriginal women deemed to be “at risk” for giving birth to a baby affected by substance use.

Disability as difference pathologized: medical models of disability

Most “common-sense” definitions of disability generally rely on the application of etiological, physiological, diagnostic, and therapeutic criteria to assess the physical, cognitive, and/or psychological traits of an individual. This is known as a “medical model of disability”. Medical models of disability are functionalist, in that they locate disability as a condition that is inherently pathological, and that can (and should) be subjected to “objective” diagnosis, treatment, and prevention (Gabel and Peters 2004). Thus, using a medical model of disability, an individual is deemed to be “disabled” if features of their body, intellect, psyche, and/or behaviour fail to conform to specific expectations as to what is considered a “normal” characteristic, function, or ability. The medical model of disability therefore requires the recognition and application of binaries. Like all binaries, these construct an ordered hierarchy of opposites, with one term assuming the positive valence and superior rank, and the other the obverse. These are applied under a medical model of disability to include normal/abnormal, function/dysfunction, presence/ absence, healthy/diseased, and so forth. This binary opposition assumes a normative and acceptable standard of physiology, cognition, and behaviour, against which “others” are to be measured. In its application, it allows for the use of words such as “disorders”, “delay”, “deficit”, “impaired”, “retarded”, or “defect” to describe disability and people with disabilities. However, most important among these oppositions is the binary of Self/

Other, as it is used to signify the position of people with disabilities as inferior Others. As disability theorists David Mitchell and Sharon Snyder (1997:1) have noted, the reproduction and circulation of discursive and material practices that inscribe physical, cognitive, and behavioural difference as “limitations, dependencies, and abnormalities” have been used by professional and academic communities to position people with disabilities as “the purest example of a “special needs” community” and to “define disabled people as excessive to traditional circuits of interaction and as the objects of institutionalized discourses” (3). In this way, disability as a site of ontological and epistemic investment and struggles for social justice remains absent(ed) from productivist notions of citizenship and enables policy responses that entrench the disenfranchisement and marginalization of people with disabilities.

Moreover, the language of medical models of disability places disability in totalizing terms as the primary identifier and descriptor of individuals with disabilities. For example, a medical model of disability may describe a child who cannot hear well as “a hearing-impaired child”, rather than “a child with a hearing impairment”, or a woman with cognitive disabilities as “a retarded woman”. As such, medical models of disability employ, and indeed privilege, a conception of disability as an individual diagnosis, achieved through scientific observation and measurement, requiring “management, repair, and maintenance of physical and cognitive incapacity” (Mitchell and Snyder 1997). Typically, it is the medical model of disability that informs most hegemonic pedagogical and policy responses to disability, as well as the provision of certain entitlements and supports (where they exist) to people with disabilities. Moreover, as is noted in the documents “It Takes a Community”, the medicalization of disabilities related

to FAS/FAE has been necessary to address a “lack of awareness of FAS/FAE”, which has lead to individuals diagnosed with FAS/FAE being “isolated from their communities” as objects of “shame, guilt, and grief” (FAS/FAE Technical Working Group 1997:1).

While medicalized conceptions of disability have been important in identifying supports related to specific impairments that have been beneficial to people with disabilities, medical models of disability remain widely criticized for two important reasons. First, in reifying the location of people with disabilities as inferior Others, medical models of disability have been employed by hegemonic institutions to justify the subjugation of people with disabilities. This has occurred historically through a variety of eugenic programs, including the forced confinement, sterilization, and extermination of people with disabilities, as well as in contemporary policies resulting in the segregation of people with disabilities in schooling and housing, employment discrimination, institutionalized poverty, lack of access to public spaces and services, social and political isolation, and harassment by public and private sector bureaucracies (Browne, Connors, and Stern 1985, French 1996, Meekosha and Dowse 2002, Morris 1996, Rizvi and Lingard 1996, Wendell 1996). Second, medical models of disability fail to recognize that it is often not the existence of impairment per se, but structural, institutional, and environmental factors that create and mediate experiences of disability. As a result, the medical model obscures the extent to which dis/abilities are (re)produced by practices used to regulate the use of public space as well as institutional and structural relations that dis/able the participation and enfranchisement of people with impairments. Thus, medical models of disability are limited in their analytical and empirical utility to explain and understand experiences and consequences of disability, and in their application to

efforts to address social, political, and economic injustices experienced by people with disabilities.

Disability as difference politicized: social models of disability

Standing in contrast to medical models of disability are what have come to be known as “social models of disability”. According to most disability theorists, disability as a definitional category, like gender, race, class, and sexuality, must not be understood as an inevitable set of conditions, behaviours, or experiences arising as a result of an individual’s biological or corporeal characteristics. Rather, disability is a social construct, constituted by and mediated through specific sets of social relations that are upheld ideologically, symbolically, discursively, and materially that marginalize and disenfranchise people with disabilities. As such, social models of disability tend to view disability as difference arising from random human variation (similar to differences in height, weight, hair colour, or eye colour) that have been politicized through a societal privileging of certain corporeal, cognitive, and behavioural characteristics over others, and by a failure of architects of “public” spaces (including “public” institutions) to account for the consequences of these differences and the presence of people with impairments (Pfeiffer 2003). Gabel and Peters (2004) observe that social models of disability are often structuralist in their focus on material conditions informing disablement and structural inequalities experienced by disabled persons. In this way, social models of disability highlight the ideological, discursive, and material practices that inform, mediate, and contribute to experiences and consequences of bodily difference and impairment. Thus, social models of disability have provided important

contributions to the advancement of struggles for human rights for people with disabilities.

However, in attending to the discursive and ideological formations that (re)produce disability as a social construct, social models of disability should not be misread as attributing causes and consequences of impairment solely to effects of discourse or ideology, that can in turn be ameliorated entirely with the appropriate paradigm shift or change of appellation. Rather, social models of disability that have been advanced through critical disability scholarship and disability activism do maintain that bodily difference has consequences for people with disabilities that are material, and must be acknowledged as having significant impact on people's daily lives (Davis 1995, Fine and Asch 1988, Mairs 1987, Mitchell and Snyder 1997). Indeed, social models of disability exceed the deficiencies of medical models not only for their political utility, but also for their empirical value in that they allow for more accurate description and analysis of both the causes and consequences of impairment as they are negotiated in the everyday lived experiences of people with disabilities.

Conclusion

In considering the ways in which "social problems" are constructed and (re)produced in and through public policy, it is clear that the social, political, economic, and ideological contexts inform the mechanisms through which particular groups come to be identified as being "at risk". However, there is a conspicuous deficit in the literature presenting a relational analysis of disability alongside gender, "race", age, and nation. A critical engagement with public policies regarding FAS/FAE and the experiences of

young Aboriginal mothers that are informed by the material and symbolic consequences of FAS/FAE demands such an analysis.

The relationship between poverty and early childbearing is not as straightforward as it originally appears. Indeed, the material conditions experienced by young Aboriginal mothers are mediated by many factors other than age, including “race”, class, geography, and Aboriginal “status”. Moreover, young Aboriginal women’s experiences with mothering as well as substance use are informed by a legacy of colonialism and paternalism in their relations with the Canadian state. This legacy has unique consequences for the positioning of young Aboriginal women and their families in public policies and in institutional practices of nation-building.

However, despite the research noted above, very little scholarship to date has examined the ways in which young Aboriginal mothers are positioned in policy directed at young mothers, Aboriginal youth, substance-using mothers, or other “targeted interventions” that serve as so-called “prevention” programs for “youth at risk”. Most importantly, there is a distinct absence of research incorporating the voices, experiences, and analysis of young Aboriginal mothers in discussions of policy initiatives directed specifically at them and their children. Consequently, the convergence of ideological, discursive, and material practices that form the “signification spiral” of policy talk related to FAS/FAE ensures that these voices go unheard.

Chapter III: Walking the Talk: Making Choices about Theory and Method

Public policy in Canada (and elsewhere) tends to frame both disability and motherhood as simultaneously individualized experiences and national concerns. When policy talk positions disability and motherhood as individualized experiences, the challenges faced by mothers and disabled people are viewed as evidence of personal “failure”. This is often because the structural conditions that mediate these struggles are ignored or misunderstood. Policies that cast disability and mothering as national concerns enables surveillance and intrusions by state institutions into the intimate and personal lives of women and disabled people. The contexts of neocolonial racialization and the organization of formal and substantive citizenship rights and interests inform Aboriginal women’s unique experiences of motherhood and disability, especially those related to maternal substance use. The contradictory and shifting relations determining when motherhood and disability are considered “private” or “public” matters hold significant and often unrecognized consequences for women. As I discussed in Chapter 2, these issues are well documented in contemporary feminist, anti-racist, anti-colonial, and disability scholarship.

However, my efforts to understand the effects of racism, ableism, sexism, and colonization on Aboriginal mothers whose lived experiences include substance use and FAS/FAE did not begin and end with academic literature. Rather, they took root in the 5 years I have spent researching with and learning from Aboriginal women, women with disabilities, and women living in poverty in Vancouver’s Downtown Eastside. During this time, Aboriginal mothers in this community have taught me that issues such as substance-use, pregnancy, and FAS/FAE cannot and should not be viewed or responded

to as individualized experiences, occurring in a vacuum outside of the place, time, or context of women's lives. I had learned from many women that their experiences of substance use during pregnancy were significantly mediated by poverty, violence, dislocation from their families, communities, and cultures of origin, child apprehension, lack of access to needed services such as medical care and welfare, as well as fear, loneliness and isolation¹². I had also learned from these women that their experiences of accessing services that attempted to isolate their substance use from these other facets of their lives and experiences were generally unhelpful, unproductive, and in many cases exacerbated the guilt and shame the women already carried with them regarding their substance use during and between pregnancies¹³. As such, in encountering the texts of the Initiative, I was struck by what I originally perceived as a disjuncture between what I was learning from the Aboriginal women I knew who had shared with me their experiences of using drugs or alcohol during a pregnancy, and the public pedagogy of the Initiative that focused its FAS/FAE prevention efforts primarily on educating Aboriginal women on the need to abstain from alcohol during pregnancy. Thus, I knew from the beginning of this research that many Aboriginal mothers have much to teach about FAS/FAE, substance use, and mothering in their communities. However, my reading of FAS/FAE prevention policies such as the Initiative was showing me that the voices and experiences of Aboriginal mothers whose lives include substance use and FAS/FAE were largely absented from or neglected in this arena of policy talk.

¹² These issues are discussed in detail in Chapters 5 and 6.

¹³ For a detailed discussion of these experiences, see Chapters 5 and 6.

In this chapter, I detail the choices I made in designing and enacting a methodology for a feminist, materialist, anti-colonial¹⁴ textual analysis grounded in Aboriginal mothers lived experiences and enabled me to investigate the disjuncture I was observing informally, between the social organization of knowledge that influences the development of public pedagogies surrounding FAS/FAE prevention, and the material conditions in which many Aboriginal women mother. In so doing, I describe how the development and trajectory of this methodology worked to both uncover and challenge some of the problematic aspects of the simultaneously “public” and “private” pedagogies¹⁵ of the Initiative. As I note in Chapter 1, these pedagogies are organizing devices that state institutions use to position the inter-related domains of “public” and “private” as separable, contradictory, and shifting sites that devalue and individualize women’s experiences. As I found in this research, these practices can hinder efforts to more fully understand Aboriginal women’s experiences of mothering, substance use, and FAS/FAE and how they are mediated and informed by relations of power and privilege. I begin with a brief discussion of the specificities of the local context in which my research was situated, and how the concerns and interests of Aboriginal women in the Downtown Eastside informed my use of textual analysis grounded in interviews as the primary research tools in this study. I then turn to the methods I used to recruit participants for the group interviews and a description of the interview participants. Following this, I draw on the transcripts from these interviews in an analysis of how the methods used in the groups challenged the privatizing of women’s experiences that were evidenced in and beyond the

¹⁴ Understandings of what constitutes feminist, materialist, and anti-colonial frameworks varies significantly among researchers and research communities. I explain my use of these frameworks in Chapter 1.

¹⁵ For a definition and discussion of “public” and “private” pedagogies, see Chapters 1 and 5.

texts of the Initiative. In so doing, I show how the sharing of analysis with the interview participants helped to address issues such as power and privilege in research encounters, (mis)representation and appropriation of Aboriginal women's voices and interpretations, and the contradictions that arose for me in developing a methodology that attends meaningfully to feminist materialist and anti-colonial critiques of building research relationships across differences in social location and experience. I then turn to the methods I used in my textual analysis of the primary documents of the Initiative, drawn from the work of Dorothy Smith. I conclude with a discussion of the implications of the methods I used for advancing the practice of feminist materialist and anti-colonial policy analysis.

In the time I have spent doing research with Aboriginal women in the Downtown Eastside, I have learned a great deal from them about what it means to conduct respectful, rigorous, and welcoming inquiries that are grounded in the specificities of this community's needs, interests, and expectations that can never be fully conveyed in a medium such as this dissertation. Accordingly, in my dissertation, I have been guided by Luttrell's (2003: 152) decision to discuss and present only "material that was meant for public viewing", which in this case primarily includes material drawn from the group interviews which women intended to be shared with this audience. Out of respect for the women's confidentiality, other conversations I had with them outside of formal interviews that informed my methods but were not intended to be shared in a public forum remain absent in this narrative, although they were equally important in guiding me as a researcher. The reader should accordingly note that where this information surfaces in my accounts of my research practice, they represent only my own

understandings, observations, and interpretations that are by definition situated and partial. These should not be read as a direct representation of the Aboriginal women and the Aboriginal community in the Downtown Eastside, or as indication that I am an authorized representative of this community in this context and on these issues. I also note that where I draw on field notes from my conversations and observations with Aboriginal women in the community, I do so with each woman's permission to present these notes to an academic audience in this manner.

Setting the context: researching with Aboriginal women in the Downtown Eastside

While there are many unique issues, concerns, and experiences that emerge from the diversity and complexity of the urban, multicultural Aboriginal community in the Downtown Eastside, this community has also shared in the neo-colonial experiences of indigenous-white research relations common to Aboriginal communities in and beyond North America. In Canada, as elsewhere, Aboriginal peoples have been the objects of intense scrutiny by researchers in all fields of inquiry. As has been noted by Linda Tuhiwai Smith (1999), these research endeavours have, and continue to be, intimately connected to experiences of colonization and imperialism. As a result, many Indigenous scholars and leaders, as well as non-Indigenous researchers allied in an anti-racist and anti-colonial framework, have argued that it is impossible to separate research activities with Indigenous peoples from the colonial and imperial context in which they emerged. Indeed, many argue that it is a replication or reproduction of colonial and imperial practices for white researchers to develop and undertake research in which Indigenous peoples and their customs, practices, and lived experiences are the sole object of inquiry

(L.T. Smith 1999, Swisher 1998). That many Aboriginal communities continue to experience white researchers as insensitive or unresponsive to their concerns regarding research activities unfortunately lends much credence to this claim. As a result, some indigenous scholars argue that there is a very limited place, if any, for whites in researching issues uniquely affecting Aboriginal peoples (Mihesuah 1993, Swisher 1998). Similarly, non-Aboriginal researchers who align themselves with the anti-colonial struggles of indigenous peoples frequently express concern as to what role their work could play both in advancing the political and social movements of Aboriginal peoples or re-inscribing the colonial legacies that continue to oppress them (Brayboy and Deyhle 2000, Cruikshank 1990, Cruikshank 1998, Culhane 2004, Deyhle 1992, Haig-Brown 1995, Haig-Brown 1998, LeCompte and McLaughlin 1994). Moreover, despite the many interventions by feminist, anti-racist, and anti-colonial scholars who have underscored the need to transform the oppressive relations inherent in standard social science research methods, Aboriginal women, and particularly those whose lived experiences include poverty, substance use, and disenfranchisement, continue to be treated as "objects of study" rather than "experts" of their lives and the conditions which mediate them (c.f. Boyd 1999, Harding 1987, McTaggart 1997, Ristock and Pennell 1996, Smith 1987, L.T. Smith 1999). Given their positioning in public discourse and policy as "social problems", it is not surprising that Aboriginal women, women living in poverty, and women whose lives include substance use (often mutually inclusive rather than exclusive categories) and who live in the Downtown Eastside also live with frequent intrusions by both academic researchers and state institutions wishing to gain access and "insight" into

intimate and personal aspects of their daily lives (c.f. Benoit, Carroll, and Chandhry 2003, Culhane 2004, England 2004).

These issues shaped my decisions regarding the design of this research from the outset in very significant ways. To begin, it was my original intention in developing this study to render the texts of the Initiative the primary site of inquiry, and not Aboriginal mothers themselves. In so doing, I sought to attend to the critiques advanced by anti-colonial scholars and activists highlighting the colonial effects of white researchers scrutinizing the customs and practices of indigenous peoples while simultaneously ignoring the ways in which neo-colonial practices of Nation-States inform, mediate, and order those practices. At the same time, I wanted to ground my analysis of these texts in Aboriginal women's experiences and analyses, as their absence has had important implications for the development of "official" public policies and public pedagogies of FAS/FAE.

Although I am trained in the discipline of critical ethnography, I rejected a primarily ethnographic methodology as inappropriate for this project. Ethnography (critical or otherwise) relies on prolonged engagement with a researcher who is given access to observe participants in areas of their people's lives that are often quite private, such as in their homes and in their personal interactions with others in their community. However, Aboriginal women in this community already experience frequent and unwelcome intrusions by agents of the State into these and other intimate aspects of their daily lives. Therefore, the methodological decisions I made were guided by the principle of remaining as minimally intrusive on the lives of Aboriginal women in the community as possible.

In the years I have spent doing research work with Aboriginal women in the community, I have learned that most Aboriginal women in the community, as well as many service providers who work with them, perceive researchers as individuals who collect information from Aboriginal people but “don’t give anything back” (fieldnotes 01/31/03, 02/10/03, 03/05/04). Unfortunately, during most informal conversations I have had with Aboriginal women in the community about research, they reported personal experiences with research/ers that confirm this perception. To illustrate, one Aboriginal woman who is a long time resident of and service provider in the Downtown Eastside explained,

I’ve been part of lots of research. They come, talk to us, do their research, write our names in the report like we supposedly contributed. Then they go away and we never hear from them again. Or we never see what they’ve written until it’s been sent out all over the country. That’s what researchers do all the time to the women here (02/13/04).

One of the expectations for conducting research in this community that evolved from these experiences is that researchers acknowledge the importance of research participants’ contributions to their work by providing honoraria to those people participating in interviews or completing surveys. For many people in the community, the immediacy of this acknowledgement ensures that participants benefit in a tangible and meaningful way from their involvement in research. From my informal conversations with Aboriginal and non-Aboriginal community members and service providers, I came to understand that academic researchers who do not offer honoraria are often viewed at the community level as suspect. Moreover, because most people living in the Downtown Eastside (including Aboriginal people) live well below the poverty line (Benoit, Carroll and Chandhry 2003), even a small honoraria makes a significant contribution to enabling

a person's participation, for example, by allowing them to pay for child care, transportation, or a meal. Culhane (2004) documents that similar understandings regarding the role of honoraria in conducting ethically responsive and responsible interview-based research were articulated by community-based researchers in the Downtown Eastside in the context of her own research. She explains, "If the research was seen as worthwhile, if they felt respected when they participated, if honoraria and food were provided, then women would be more likely to make and keep appointments for interviews" (p.11).

To provide an illustration from this research, on the day of the second group interview session, Wonder Woman¹⁶ arrived and stated, "I'm really glad this is happening today. I'm totally broke right now, and don't get money until next week. With the \$25 and bus tickets [from the honoraria], I can get some groceries and take the kids on the bus to our next appointment. Otherwise, I don't think I would have made it here" (field notes 04/16/04). I explained to Wonder Woman that I was concerned she was feeling pressured to do the interview for the honorarium, on a day when she had other issues that were more important for her to attend to. When I offered to advance her the honorarium and do the interview at a time better for her needs, she replied, "No, this is important. I want to be here. I just wouldn't have been able to be here if it weren't for the \$25" (ibid).

While the provision of honoraria alone is not seen as sufficient to satisfy community norms and expectations for conducting respectful research, it is nonetheless clearly important for many reasons. As a graduate student with minimal funding my research

¹⁶ To protect their anonymity, I refer to each participant and their children using a pseudonym. Most women chose their own pseudonyms, although some women preferred to conduct the interviews using their own names, and noted "you'll need to change the names on the transcript". In these cases, I have assigned the pseudonyms.

budget was quite small, and thus my ability to provide honoraria to participants was limited. Consequently, while I remained committed to developing a qualitative research project grounded in the experiences of analysis of Aboriginal women in the community, I knew it would not be feasible for me to develop a methodology that relied solely or even mainly on interview.

I therefore needed a research methodology and design that would enable me to accomplish three primary tasks. First, the methods needed to support developing analytical insight into the content, organization, and implications of the texts of the Initiative, with specific attention to how the texts operate as public pedagogy. This is important because these discursive and material practices educate us in the “common sense” of FAS/FAE as a “public health issue”. This in turn consolidates “public” support for directing “public” resources toward some efforts (such as education campaigns to discourage maternal alcohol consumption in order to prevent FAS/FAE), but not others (such as measures to improve the material conditions in which women who are most “at risk” for an “FAS/FAE birth” live and mother). They also provide the terms for rationalizing the exclusion of Aboriginal women and their children whose lives have been affected by substance use from public discourse and debate on the causes and consequences of FAS/FAE¹⁷. Second, the methods had to facilitate examination of how substance use and FAS/FAE inform the context and practices under which Aboriginal women are mothering. This is important because these lived experiences are too frequently left out of policy talk regarding substance use and FAS/FAE. Having a more complete understanding of how FAS/FAE and substance use are negotiated in the daily lives of Aboriginal women and communities can enable the development and

¹⁷ For an analysis of how the texts of the Initiative operate in support of these efforts, see Chapter 4.

improvement of public policies and programs that are better suited to address the needs, issues, and concerns of Aboriginal women, children, and communities¹⁸. Finally, the methods needed to provide a means for shared analysis and more democratic knowledge production, that meaningfully included those Aboriginal mothers whose lived experiences are both objectified and eclipsed in policy texts such as the Initiative. This is especially important in projects such as mine, where the researcher is situated outside the social location(s) of the research participants, and in which the community being researched has specified the importance of meaningful inclusion in the analysis and public representation of research findings. As McTaggart (1997:28-29) and other practitioners of participatory research demonstrate, using methodologies that go beyond the “mere involvement” of those whose experiences are being researched to allow for their “responsible agency in the production of knowledge” significantly reduces the “risk of co-optation and exploitation of people in the realization of the plans of others”. A methodology that supports participants to share analysis with the researcher can also ensure that the representation of the participants’ experiences are accurate and that the analysis brought to bear on them is appropriate. It would also support my efforts to respond to criticisms from the community of researchers who “don’t give anything back” and who “go away” after data collection is complete and are “never heard from again”.

A qualitative design including textual analysis, group interviews, and sharing analysis with the Aboriginal mothers who participated in this research best met these requirements. In the following sections, I detail how these methods were utilized to address both the problems and contexts of this research, as well as how they were adjusted in light of unanticipated issues that emerged from the insights of the Aboriginal

¹⁸ For discussion of these issues see Chapters 5 and 6.

women who participated in the research. Because it is impossible to overstate the significance of the contributions of the Aboriginal women who participated in the group interviews in framing my analysis of the texts of the Initiative, I begin with a description of the interview methodology and the women who participated in and transformed it. In so doing, I will highlight the ways the use of group interviews challenged the privatization of women's experiences evidenced in the texts of the Initiative by encouraging discussion of the shared or collective aspects of the participants experiences of mothering, substance use, and FAS/FAE.

Interview methodology

An integral component of my research was to highlight the voices, experiences, and concerns of young Aboriginal mothers with lived experiences of substance use and FAS/FAE who are currently accessing services supported by the Initiative, specifically those related to FAS/FAE "prevention" and "treatment". Because these women's voices and concerns have been marginalized, overshadowed, or in some respects completely ignored in the policy texts I was studying, the use of interview in this study is crucial for understanding the material and structural consequences of the discursive constructs informing this policy, as young Aboriginal mothers and their children experience them.

The methodological approach I took in this phase of the research was primarily organized around the methods of what Dorothy Smith (1987) has called "institutional ethnography". Despite its retention of the term "ethnography", institutional ethnography is unlike most conventional approaches to ethnography, in which a researcher resides with members of a given (sub)cultural group for a prolonged period of time in order to

document some aspect(s) of the group's cultural practices or component of member's lives. Institutional ethnography is a method grounded in phenomenology, whereby the everyday lived experiences of individuals are used as a starting point for an inquiry into structural or institutional practices that are mediated, informed, or constituted by the dominant, hegemonic social order, or what Smith (1987, 1990) refers to as the "ruling relations". In other words, the work of the institutional ethnographer is not to document the practices of members of a (sub)cultural group, but the ways in which people's everyday lives and practices are governed by or mediated through the social order. In this way, the methods of institutional ethnography were in keeping with my own research interests, to render the organization and impacts of the Initiative as a public policy of the Canadian state the primary object of research, rather than the practices of Aboriginal women and children themselves.

As a methodology, institutional ethnography assumes two key things. First, it assumes that individuals are subjects and knowledge producers, and "experts of their own lived experiences" (Smith 1987:153). Thus, any inquiry into institutional or organizational practices that impact upon an individual's life must begin inside the relevancies of her or his lived experiences, as she or he experiences and understands them. In this way, the methods of institutional ethnography take seriously Marx's (1976) caution that the attempt to generate theory or explanations of phenomena absent of the material conditions of actual people is to create ideology, not knowledge (see also Smith 1990, 1999). Second, this method assumes that individual's lived experiences are shaped by the social order or "ruling relations", which marginalize and subordinate individuals by gender, "race", sexuality, age, "dis/ability", class, nation, citizenship status, and other

aspects of social location. Thus, institutional ethnography by definition promotes a politically interested research agenda, in that through uncovering the discursive, material, and political practices of the ruling relations (which, for Smith (1999), are mediated by texts) the researcher seeks to challenge and transform those ideologies and practices that differentially confer power privilege between and among groups.

Participant recruitment and description of research participants

Locating and inviting women to participate in the interview component of this research proved to be one of the most challenging aspects of this project. The issues of maternal substance use and FAS/FAE remain highly stigmatized, and recruiting women to participate in research on these subjects is complicated by a number of interwoven structural and ideological factors. Women's experiences of substance use, particularly substance use during pregnancy, are often accompanied by intense feelings of guilt, shame, and trauma which can render women vulnerable if asked to disclose them to an unfamiliar researcher during an interview. Moreover, many women's experiences of disclosing substance-use have resulted in negative consequences for themselves and their families, including the apprehension of their children, increased surveillance by social service, medical, and criminal justice authorities, loss of access to support services, evictions, and loss of meaningful personal relationships (field notes 03/03/04, see also Boyd 1999). Because British Columbian law requires individuals (including researchers) to report suspected child abuse and neglect, a researcher's personal opinions of substance use and her understanding of the impact of substance use on a woman's ability to parent can also discourage mothers whose lived experiences include substance use from

volunteering to be interviewed on these topics. Given these realities of women's lives, I was not surprised that after four months of applying my university's Behavioural Research Ethics Board's preferred participant recruitment strategy of traditional third party measures (primarily through posters placed in public locations identifying the participant inclusion criteria¹⁹ and inviting interested women to contact me for further information), I was unable to recruit a single participant for this research²⁰. Given my lack of success with this recruitment method, I had to amend my strategies to include ways to build trust with potential research participants through the recruitment process so as to make participating in this project more.

While working for a community-based health program on a different research project, I had become acquainted with Mary²¹, a well-known community leader and activist in the Aboriginal community of Vancouver's Downtown Eastside. Mary's own lived experiences include substance use, poverty, and single parenting, and these experiences continue to inspire and inform her paid work, co-coordinating an FAS/NAS education and support program for a local women-serving organization. Much of our exchanges involved discussion of the impact of research on the lives of Aboriginal women in the Downtown Eastside. "It's more of the same, it's colonization all over

¹⁹ In order to be included in the project, participants needed to a) self identify as Aboriginal women (including women who were First Nations, Inuit, or Metis, irrespective of whether she was designated as "status" by the Department of Indian and Northern Affairs) and; b) have lived experiences of substance use, FAS, or FAE and; c) have given birth to at least one child (although the child did not have to reside with them) and; d) be between the ages of 15-24 years. I included the age criteria because my original research questions included analysis of "youth" as a category of lived experience and policy formation. However, over the course of my research it became apparent to me that age is less significant a factor mediating women's experiences of FAS/FAE and substance use than are other factors, such as poverty. Moreover, due to difficulties in recruiting participants for this research, I felt the need to broaden the criteria to include women who had become mothers while "youth" and who in all other ways fit the inclusion criteria, but who were now older than my specified range. Accordingly, women were included in this study who had become pregnant between the ages of 15-24 years, and who had given birth to a child in the last 5 years.

²⁰ Similar experiences are documented by Boyd (1999).

²¹ Because identifying Mary by name would make it relatively easy to identify the women who participated in the research, I refer to her using a pseudonym.

again”, were words Mary frequently used to describe the activities of university-based researchers in this community. During our work together, I spoke with Mary about my research project, and the difficulties I was having finding women who would agree to participate. I also shared with Mary my concern that while I wanted to welcome the participation of any woman who wanted to contribute her analysis and insights to the research, I was unsure how to account for the fact that given my lack of training in counseling, it would not be appropriate for me to interview women who are currently (re)experiencing trauma or are involved in high levels of daily substance use, although they may not self-select themselves out of research (nor could I necessarily prior to an interview). During the course of our working relationship, I had also been very transparent with Mary regarding my personal politics and commitment to feminist and anti-colonial research, many of which were views consistent with her own. This openness and transparency lead to developing a level of trust that was grounded in our shared understanding of the need to find meaningful ways to include Aboriginal women whose lives have included substance use and FAS/FAE in policy research and the importance of developing FAS/FAE research and policy that is responsive to Aboriginal women’s needs, interests, and concerns.

Mary offered to approach the women who were participating in her program on my behalf (to protect their confidentiality), explain the project, and provide them with my contact information if they were interested in participating.²² I provided Mary with notes outlining what the research was about, the participation criteria, and the research procedures. Mary also informed me that she would communicate to the group that this

²² Browne (2003) used similar third-party measures to invite Aboriginal women to participate in her research located at a health-care facility, also to protect their privacy.

research was “a good thing to be a part of because it would go into a book that people would read and might somewhere down the line help other women in their situation” (field notes 02/10/04), and that I was a person whom the women could trust to be respectful of and sensitive to their concerns. After receiving this initial information from Mary at a group meeting, the members of the group decided they wanted to invite me to attend a portion of one of their regular meetings to discuss the project, the terms of their participation, and my goals and intentions in conducting the research. Despite the reservations she had expressed in other conversations about the general usefulness of research for Aboriginal women in the Downtown Eastside, I was struck by the enthusiasm Mary demonstrated to the women in her group for my project. “This is your chance to tell it like it is”, she told them. “Amy will bring the policies to you, and you can take this chance to give your opinions about them. She will put it in a book, and lots of people will read it. Then people can use what they read to make changes, to make things better. This can be a really important thing to be a part of. What you know could make a difference” (field notes 02/24/04). After this meeting, I was contacted by women who were interested in participating (about 2/3 of the women who were at the group meeting on the day I attended) and we scheduled our first interview at a mutually convenient time. I asked that the women contact me outside of the group meeting to ensure that their anonymity and confidentiality would be protected. This was also to ensure that no one would feel pressured or coerced into participating because they happened to be participating in the program or because their group leader had informally endorsed my research and encouraged them to participate. I also assured the women that Mary, and all other service providers at the organization, would not be informed as to who was

participating in the research unless the participants chose to tell them on their own, and that any information that could identify them or their children would be removed from the transcripts and any publication of results.

Recruiting participants through Mary's group provided an important opportunity to gain insight into the relevancies of the Initiative in a number of ways. First, Mary's program is identified in the document *It Takes a Community: A Resource Manual for Community-based Fetal Alcohol Syndrome/ Fetal Alcohol Effect Prevention* as an exemplary program for FAS/FAE prevention for Aboriginal women, that the texts suggest could be looked to as a model by other Aboriginal communities seeking to apply for funding via the Initiative to establish their own programs. Mary's program is located in an off-reserve, urban, multicultural Aboriginal community, and was tailored specifically to meet the needs of women in that community. This location is therefore geographically quite different from the primary focus of the Initiative, which is on-reserve and Northern Aboriginal communities. As such, this site presented an interesting opportunity to situate my exploration of the ideals, intentions, and contradictions of the stated goals and scope of the Initiative as they played out in the local contexts of a specific Aboriginal community. Moreover, although the program's participants all reside in the Vancouver area, 5 of the 6 the women who participated in my research are designated by the Department of Indian and Northern Affairs as 'Status Indians', and many women frequently move back and forth between the Downtown Eastside and their on-reserve community of origin. As such, all participants in my research are connected in some way (and generally in multiple ways) to the administrative relevancies of the Initiative's programming and funding objectives (as "Status Indians" connected to on-

reserve Aboriginal communities) and have recent personal experience of living in a reserve-based Aboriginal community, despite the fact that they do not reside full time on reserve. In other words, they exemplify in many ways the “target population” the architects of the Initiative were intending to reach, while at the same time alerting us to questions about the assumed homogeneity of issues, concerns, and experiences which appear in the texts of the Initiative to be associated with belonging (or not belonging) to the specific, imposed identity category of “Status Indians”²³.

Second, this program is highly regarded by Aboriginal women in the Downtown Eastside as providing support that is respectful of and responsive to the needs and interests of Aboriginal mothers in the community who struggle with issues related to substance use and FAS/FAE. Although membership in this group is not limited to Aboriginal women, the programming and pedagogy are structured around traditional Aboriginal spirituality, parenting, and teaching practices, and Aboriginal women are the majority of the group members. One participant was recruited using snowball sampling, as a woman who agreed to participate took the initiative on her own to inform friends who fit the participation criteria of the project and invited them to come to the first group interview.

Third, I was very interested in the fact that in addition to functioning as an education and support group for the members, the women participating in this program recently began their own community education and outreach initiative, in which they give presentations and workshops to members of their community about the causes and consequences of FAS and FAE. During these sessions they share their own life

²³ This issue becomes quite salient in Chapter 7, in which I discuss the issue of “culturally appropriate” pedagogy for Aboriginal women regarding FAS/FAE.

experiences with substance use, mothering, and FAS/FAE. In this way, the participants in this program are themselves educators with unique insights into not only the experiences of substance-using Aboriginal mothers in their community but also of the educational needs, interests, and priorities of Aboriginal mothers related to FAS/FAE “prevention” and “treatment”. Moreover, their participation in the program provided women with opportunities to share, reflect on, and analyze their experiences related to substance use and FAS/FAE outside of a research context, as well as access to a support network they were actively drawing on to assist them with these and other issues in their lives.

Consequently, I was more confident that the women who agreed to participate in my research would not be significantly traumatized as a result of sharing their experiences, analyses, and interpretations in an interview. My informal discussions with women in the weeks and months after the interviews confirmed that this confidence was warranted.

At the time of the interviews, all women were in their early to late 20s, and had given birth to between 1 and 5 children. The age of the women at the birth of their first child ranged from 15 to 26. One woman is partnered, the others are single mothers. All of the women admitted to drinking alcohol and/or using drugs with teratogenic²⁴ effects during a pregnancy. Some of the women have children who have been diagnosed with disabilities related to prenatal drug or alcohol exposure, and others have children that they suspect have FAS or FAE, but who have not been formally diagnosed due to either their age²⁵ or lack of available diagnostic services. One woman, who has a spinal cord injury, has a child who has a number of impairments attributed to the anti-spasmodic

²⁴ Teratogenic agents are those substances that have been identified as causing adverse effects on the development of a fetus during gestation.

²⁵ It is difficult for clinicians to make an accurate diagnosis of Fetal Alcohol Spectrum Disorders (which include FAS and FAE) prior to a child's second birthday.

medication the woman was prescribed during her pregnancy that is a known teratogen. Some of the women have family members, partners, or other significant persons in their life who live with FAS or FAE, and some are concerned that they themselves might have FAE.

Procedures for data collection

For this research, I interviewed 6 women. Each woman was interviewed twice. When I approached the women to invite them to participate in this project, I provided them the option of being interviewed individually or in a group. All of the women opted for a group interview, as they felt this would provide them with additional support, encouragement, and an increased sense of safety and trust when being interviewed by a researcher who was previously unknown to them. (field notes 02/24/04). I therefore conducted two group interviews with each of the women, and the grouping remained the same for both interviews. Each participant in the group interviews received a small honorarium of \$25 per interview to acknowledge her contribution and compensate her for any costs she may have incurred as a result of her participation, as well as bus tickets to subsidize her travel to and from the interview. Refreshments and childcare were offered to participants on-site at the time of the interviews. With the full consent of all participants, I audio-taped and transcribed these interviews for analysis.

During the first interview, I asked the women questions that encouraged them to reflect on the experiences they have had in their lives and in their communities that informs their understandings and experiences of FAS and FAE. The interview schedule was reviewed and approved by the Behavioural Research Ethics Board of my university,

and all participants were given a verbal and written description of the kinds of questions I wanted to ask them in advance of the interview and as part of the process for obtaining informed consent to participate. However, I attempted to facilitate the interviews in a way that would encourage the participants to move in and out of the questions in the interview schedule to include topics more reflective of their interests, experiences, and needs.

The most significant area in which this occurred was in the questions I had wanted to ask the women about the issues raised in the policy texts themselves. At Mary's suggestion, I brought with me to the first interview copies of the primary policy texts of the Initiative (*Framework for The First Nations and Inuit Fetal Alcohol Syndrome/ Fetal Alcohol Effect Initiative* and *It Takes a Community: A Resource Manual for Community-based Prevention of Fetal Alcohol Syndrome/ Fetal Alcohol Effect*), as well as plain-language Executive Summaries of each document prepared by the First Nations and Inuit Health Branch. Mary and I informed the women during my introductory visit to the group that I would have these documents available for the women to review at the interview, and that I would ask them to share their reactions to the documents during the interview. However, during the first interview women appeared much more interested in discussing what impact FAS/FAE and substance use has had on their lives and experiences as Aboriginal women and as mothers, as well as the context in which these experiences emerged. When the group took a short break to accommodate washroom use and refreshment (and one participant who needed to leave early to pick up her child), I asked the women if they wanted to spend some time when we reconvened talking about the Initiative. The women uniformly rejected this proposal, stating that they found "policies like this don't have much to say about how we live our lives here" and

“they aren’t all that relevant to us” (field notes 03/05/04). Instead, the women stated that they preferred to talk more generally about their own experiences of FAS/FAE, substance use, mothering, and the kinds of information and supports they felt Aboriginal women needed to work through these challenges, arguing that “that’s more important” and “you don’t find those in any of the government papers” (field notes 05/03/04). These reflections spoke clearly to me of the gaps between women’s “private” experiences and the official “public” renderings of these experiences in policy texts and talk.

After transcribing the first interview, I developed a coding schedule using inductive methods consistent with qualitative analysis to identify convergent and divergent themes emerging from the women’s testimonies. The women expressed frustration during our first interview that their experiences with researchers in the community was that “they come, do the research, and then it’s months or years before we hear from them again” (field notes 03/05/04). As a result, I was eager to bring the results of my analysis, as well as my follow-up questions, back to the group in a timely fashion. I was concerned that asking women to wait the months it could take to produce the first draft of my dissertation to receive their feedback would provide confirmation to the women that researchers could not be trusted to be responsive to their concerns. Instead, I created a report summarizing my initial analysis and the arguments I would be making in my dissertation based on their contributions in the interview. I returned these preliminary findings to the group at our second interview, approximately 6 weeks following the first interview.

During the second interview, I provided each woman with a copy of this summary report and a transcript of the first interview. Each woman reviewed the transcript to

ensure that it represented her contributions accurately and fairly. As a group, we then reviewed the summary I provided, and I asked the women questions intended to solicit their analysis and confirm whether or not my preliminary analysis resonated with their own analysis of their experiences. I also pointed to sections of the interview transcript that I drew on to formulate my analysis and that I hoped to include in my dissertation. The excerpt below, which begins with me reading from the summary report and extends into Super Woman's elaboration and clarification of the analysis provides a typical example of how these exchanges took place.

AS: Alcohol and drug use, I learned, are intimately connected with the conditions and experiences of women's lives. They're not separate from them. For some women, alcohol and/or drug use are an acknowledged part of their family histories that they continue to struggle with. People in the interviews mentioned experiences with their family members, parents, grandparents, and their own experiences, and give examples of that. (interruption from lots of background noise from kids playing) Alcohol and drug use are also connected to experiences of living conditions that are dangerous, painful, or traumatic (i.e. experiences of violence, sex trade work, poverty, abuse etc.) that were all experiences that came up in the transcript. Substance use can also be a major part of people's social lives among their friends and in the larger community that can be difficult for women to get away from if they have no other support systems. ... So that's, like, the first part. How does that sound so far?

Super Woman: One thing that I would like to say, at least for me, is that the addiction was there before I was pregnant and, like, I knew the possible damages that could happen. I didn't know the extent, but I knew that they could happen. But I had an addiction, and therefore, um, it's like you just can't stop the addiction. And there's ways to hide the pregnancy, too. Like, if I was still using people wouldn't assume I was pregnant. And the thing about what you're saying about people's intimate people in their lives is so true. I was either using with my son's dad and drinking, or because we'd had an argument and I didn't know how to deal with those feelings, so I'd drink cause of that, too.

AS: So is that, then, where what I said about support systems comes in?

Super Woman: Yeah.

AS: Like, if you don't have the support systems, that can make it harder with these things?

Super Woman: Yeah, like if those supports were there. But I felt like if I said things to people that I would be judged, or possibly my other child would be taken away while pregnant, and just all the negative consequences that I didn't think I could trust around it.

AS: Ok, thanks. That's important. I'll make sure this goes in there.

I conducted both interviews according to the norms for sharing and discussion that had been previously established by the women based on their participation in Mary's group, and I facilitated this process under the guidance of the women in the group. In some instances, this was accomplished when an interview participant interrupted the interview process to ask that the group observe a particular procedure. For example, during the first interview, Tricksey shared an experience with a police officer, and appeared to have finished her train of thought. As the facilitator, I then indicated to another participant that she had the floor to speak. This led to the following exchange:

Super Woman: Can I say one more thing about the cops?

AS: Sure.

(unknown speaker): Yeah, with the cops it just seems to go on...

Super Woman: Yeah, there's lots to say about the cops.

Tricksey: I'm not finished.

Super Woman: Oh, I'm sorry.

AS: I'm sorry.

Tricksey: No, I'm just joking. (all laugh) No, but there is a thing that we say that we're finished, or "All My Relations", because people do tend to butt in. They don't mean to butt in, but just say it, when you're finished, for each person that talks. Because we do tend to jump in.

AS: That's a good idea. We'll do that, OK?

(all agree)

Tricksey: OK. I'm finished. (all laugh)

In this exchange Tricksey educated me, as an outsider to their pre-established group, on the protocols adopted by the group to prevent women from interrupting or talking over one another, as well as those designed to ensure a woman had adequate time to reflect while she was speaking. In agreeing to adopt Tricksey's suggestion, the group acknowledged that the process I had introduced to the group was not only different from their established norms, but that it was important create conditions that were different from those I presented that would better support women's efforts to be heard and acknowledged during the interview. By changing the terms of the interview to those that were more in keeping with the expectations of the participants, I was also able to act on an opportunity to redistribute the power I held to direct the interview process to the research participants.

The need to change the terms of the interview to reflect the needs of the participants also emerged in other contexts. During the first interview, Super Woman shared an experience of being assaulted in a public park during time she spent working in the sex trade. She began sharing this experience as follows:

Super Woman: OK. This is really confidential, so please all of you don't take this outside the room, but.... (pause)

AS: Would you like me to turn off the tape?

Super Woman: No, it's ok. I'm speaking from experience, so I'm not worried about it.

During their regular group meetings in Mary's program, the women had developed the practice of indicating to one another what material was not acceptable to share with others "outside the room". Because I was committed to ensuring that my research was ethically responsible and would not leave participants open to harm (including the harm of violating their confidentiality), I thought Super Woman was asking that the experience she was about to share not be included in the research, and I wanted to communicate to her that I was vigilant about respecting her rights in this way. However, Super Woman's statement that she was "speaking from experience" and wanted this included in the research underscored that while she did not want to be identified by other participants outside the research process as a former sex trade worker, it was important to her that her experience be included in the research. Indeed, after relating her experience to the group, Super Woman concluded:

And I know this isn't just my problem alone, because I've read reports from sex trade workers and stuff. And that's probably one of the biggest times you feel unheard, when you're in that type of situation. Whether it's for survival, or addiction, or whatever, your way of life, or whatever reasons you're in there. You know? You're not heard by police and you've been discounted. And it's really painful, because it makes you feel that you can never go to the police if you have something bad happen to you...I just wanted to say that, because I know it's a problem for a lot of women down here.

"Speaking from experience": group interviews and sharing analysis

As has been noted by many feminist social scientists, group interviews provide specific benefits in the research process, including addressing feminist and anti-racist concerns regarding researcher privilege and the sharing of power in research settings, allowing for the co-construction of meaning between and among researchers and

participants, and generating high quality, interactive data consistent with the development of emergent hypotheses (c.f. Harrison and Barlow 1995, Kitzinger 1994, Wilkinson 1998). Through their involvement in the group interviews, participants had an opportunity to share their individual experiences with others, but also to reflect on the extent to which their experiences are similar to, different from, or otherwise related to the experiences of others in the group. In this way, group interviews assisted me and the participants collectively in uncovering the ways the experiences of young Aboriginal mothers are informed and mediated by the social order, and in particular, the policies and practices of the Canadian Nation-State. Most significantly, the group interviews provided a venue through which participants could give voice to collective experiences that are often privatized in policy texts such as the Initiative as the failings or short-comings of individual mothers acting alone. Often during the interviews, women's testimonies regarding their personal experiences with substance use, relationships, or other areas of struggle would build off one another. During these times, I would try to "stay out of the way" by focusing my participation on asking questions of clarification, as well as asking the women if and how they felt the experience they had described was similar to or different from others they were hearing. As the conversations built, the enthusiasm women expressed for joining their lived experiences with those of other women was palpable. An example of this can be found in the following exchange from the second interview:

AS: [reading from summary report of findings] "When women ask for help and are turned away, it is very difficult to ask for help elsewhere, even when those supports are really needed".

Jo-Anne: Well, it's disturbing, too, because that's where they eye-ball you. Like, when I told my mom. First, she doesn't listen all the time. So when I

first told her I was in an FAS group, there was no response. Then afterwards she said “oh, it’s good you’re learning all this stuff”. And then she’s like, “Why are you doing that? Why are you in that group?”. And I said “Because it’s helping me to understand my family”. And that was that, it shut her up, because she knows. And then after that, there was this. Because learning that she kind of felt guilty, so she told me she didn’t drink with me, but she drank with everybody else. But it was double-sided, because she told my sister that she drank a little bit with all of us, but it wasn’t very much so it’s ok. No big deal. You know? So, just telling her that it helped understand things more. You know, because you get, automatically, it’s like you’re a bad person automatically.

AS: Is it like the guilt and shame from before [in the first interview], or is it something else?

Jo-Anne: Yeah. You know, like I’m trying to get help now, but it doesn’t count for anything.

AS: You mentioned something about that, too, Shannon, when we did the interview and today, too. When people would ask you “why did you go there?” or “why did you do that?” when really it’s information that’s useful for everybody to have and support that was useful.

Shannon: Definitely.

Super Woman: Yeah, me too. (long pause).

The excerpt below between Shannon, Jo-Anne, and myself provides a different example of this type of exchange. This occurred in the context of a discussion about the role of significant people in a woman’s life in mediating her decisions about substance use during a pregnancy.

Shannon: I have to agree about the people in your life. I’ve had best friends tell me to come out and drink with them, encouraging me, you know. So it’s sort of having the double standard feeling, that this isn’t a thing they probably wouldn’t do with their own kids, but when someone has a problem, they have no problem encouraging me to drink with her, because she wanted someone to go out with, or whatever.

AS: Oh. So you think that maybe if this was in her own experience that she wouldn’t drink, but with you...

Shannon: Yeah, she would probably try to not. But, well, I don't know about now, but at the time that's what I thought. That she was trying to get me to drink, but she probably wouldn't do that if she was pregnant. I don't know what she's doing now, but, yeah... And just being in stress, having arguments, breaking up with your spouse, and then just not knowing how to stop that cycle of what do you do when you have a fight and argue? Go out, usually with your friends and drink. And that was kind of the cycle of what I did before, and it's really hard to break that.

AS: Ok, thanks.

Jo-Anne: One thing I had, when I was pregnant with my son. I actually had a doctor tell me that it was ok in the first two or three months, because if you didn't know you were pregnant, that's ok. It didn't matter how much you drank. And that was really stressful for me, you know? Like, especially it actually wasn't until this pregnancy that I actually went to FAS groups. And I'm, like, ok, this is absolutely retarded. There was never... there was none...like, it's true, in the doctor's office, most of them have posters, but most of them don't even have pamphlets about FAS. Just all I knew was that you're not supposed to drink when you're pregnant and that FAS can happen. But I didn't know what it was. It wasn't until here. You know, it wasn't just, um... Because I had a guy friend do the same thing on my birthday, because I wasn't sure in this pregnancy if I wanted to drink. And it was because it was a birthday party, then there were multiple birthday parties, and everyone was like, "no, no, you don't know if you want to have the baby anyway, so just drink. It's ok." And it's just really hard. You know? Because with my son I couldn't handle alcohol, and unfortunately with this one I found out that I could. But I ended up having a couple, and after that I was just, like, forget it. You know, like, I've got to get out of here, it's not good hanging around people like that. They were ok about that. It's just hard to have people like that, who are insistent that "it's ok, it's ok"...

Shannon: It is, it is.

Jo-Anne: Or whatever, "it's only one time".

Shannon: Yeah, I had a friend who would say to me "oh, you smoked marijuana, what's the difference? I mean, it's only one drink". And I would be like, "but I don't want to drink. And there is a big difference". I mean, just because I smoked pot during that pregnancy doesn't mean I should drink, too. You know? And add a whole bunch more problems then, too. And I think that what needs to be taught is that even one drink can be the problem. It doesn't have to be the whole thing with binge drinking. I think, well I was sort of unaware of that, and I think a lot of people have that perspective that it's only once in a while, or whatever, so

it won't bother or hurt the baby. Because that's what they tried telling me, that "oh, it's not going to hurt the baby, it's only one", or whatever. I still believe that people know about it, but they don't really know about it, you know what I mean? They think that, and I was sort of like that before I took the FAS course.

AS: So is that sort of like what Jo-Anne was saying? Similar to what she's saying?

Shannon: Oh, yeah! Yeah.

Using a dialogic style in sharing my initial analysis and inviting the women to share their interpretations of their experiences proved an invaluable component of the methodology. My original analysis was changed and refined based on the women's rearticulations of their experiences through the activity of our shared analysis. The excerpt below provides a typical example of this exchange:

AS: (reading from summary report of findings) Some women are also forced to take drugs that can have negative effects on their unborn babies that doctors prescribe to them for medical conditions, and are not given safer alternatives even when they ask for them. So that's, like, the first part. How does that sound so far?...

Wonder Woman: Or what about this one? I wasn't forced to take it, but it was my only option for my pain and my spasms. Like, it was pretty much, you take this, or live with this. So it was more like it was the only option available. That would be better than, it looks like my doctor's forcing pills down my throat.

Wonder Woman's revision is significant. In describing her experience with her doctor as one in which she was "forced", I inadvertently eclipsed her own activities as a woman making a decision based on the careful weighing of information presented to her. In challenging the reductivism of my earlier analysis and recasting my interpretation of her experience, Wonder Woman underscored and insisted I acknowledge her own agency in a negotiating system that significantly constrains but did not in itself determine her activities.

The dialogic style of the group interviews and shared analysis also proved crucial in that it supported the identification of emerging issues and questions from the women.

The following exchange from the second interview provides an illustration.

Jo-Anne: Can I just say one thing here? When I met [names prominent doctor expert in the field of FAS], I remember he was saying, like, I know caffeine's bad during a pregnancy in excess. And he had met a baby who he thought was FAS, and the mother had never drank during the pregnancy but had excess in caffeine and still had the FAS effects.

AS: Hmm...

Wonder Woman: One of my friend's daughters was hospitalized for two weeks after she was born. She drank a lot of pop when she was pregnant. And I drank pop constantly with both my pregnancies, except with her. And her daughter was in withdrawal from caffeine. But she probably drank enough that it was... well, I don't know how much she drank.

Shannon: But how much would be too much? I mean, I drank lots of pop.

Super Woman: Yeah, I drank lots of pop. Tons of pop.

Wonder Woman: Yeah, because I found out, when was it? I found out four weeks ago that I was pregnant, and then I stopped all caffeine, but I still miscarried. But, because I learned with her that caffeine can contract, like it can... I stopped as soon as I knew, but I still miscarried. But how much is too much? We don't know.

Shannon: Yeah, I don't know.

Jo-Anne: I don't know either. Nobody knows.

Shannon: And then what if your kid has something wrong? Like, I did drink pop the whole time, except in the beginning when I was getting sick. But I mean, I still drank a lot.

Jo-Anne: Yeah, I did. Coca Cola, too.

AS: I did, too. And coffee and tea, and all that.

Jo-Anne: It's not a lot. There's not enough in the amount. Because they're saying, I was just looking through some paper work recently,

they were saying a little bit more. And everywhere where it's found.
Cola, chocolates, tea.

AS: And I know some prescriptions have some caffeine in them, too.

Jo-Anne: Yeah, and it's just really hard, because they say some places that one cup a day is ok, two cups a day is ok, some places say two to three a week. Like, there's not enough out here to tell...

(unknown speaker): Yeah, we don't know.

Wonder Woman: Well, one of the books I have, it says so many milligrams, which is the equivalent of 6 cups of coffee a day.

AS: Well, that's a lot!

Shannon and Super Woman: Lots! (laughing)

Jo-Anne: But with pop, like, I could drink a whole two litre a day.

Wonder Woman: Especially diet. And then there's the aspartame. Because when I was pregnant with Emily, I was going to school and this girl comes up to me and says "you can't drink diet pop, because my brother was born with liver problems from my mother having too much aspartame". And, ok, so it's either I drink diet pop or I don't drink anything, because I can't have the sugar. So pretty much told her where to do (all laugh). But then when you add the caffeine and the aspartame.

Shannon: Just a second. (to son) Are you thirsty? Do you want some juice? (to the group) Because I don't let him ever have pop! (all laugh).

As can be seen from this excerpt, the dialogic style used in the group interviews supported the participants (including, in this instance, me) in building and articulating collective experiences as mothers. This not only enabled the building of rapport between the participants with one another and with me as the researcher, but also presented a direct challenge to the privatization of mothering as work and embodied experience. As is also seen in this exchange, this method allowed the women to highlight knowledge gaps (in this case regarding caffeine and aspartame intake) that were significant to them and

important for their ability to make informed choices regarding their health and the health of their children. It also brought to the forefront issues related to FAS/FAE diagnosis that might otherwise have been overlooked. Finally, as is seen in this exchange, the use of group interviews allowed conversations to be built that enabled the women to position themselves alongside one another as mothers who take an active interest in seeking out information to protect their children's health that they incorporate consciously into their mothering practice.

The group interviews and the use of dialogic analysis created some of the conditions that supported the women in sharing concerns and articulating collective experiences. When I brought my preliminary analysis of the Initiative to the group for our second interview, this prompted more direct conversations about bridging policy and personal experiences. While respecting the women's preference from the first interview not to answer series of questions about the Initiative specifically, I brought my preliminary analysis of these texts to women with the hope that they could guide me toward an analysis that was more clearly articulated to their own lived experiences and understandings. These conversations made it clear to me that in discussing the complexities presented by substance use, pregnancy, and FAS/FAE in their own daily lives, the women were developing solutions, not just documenting problems. The excerpt below provides an example of how these exchanges often occurred:

Jo-Anne: Being singled out for FAS and FAE was hard, too. Especially when you had a doctor who even said that. You know, my son's not even two. You know? So having that stuff for three years, you know? And then all of a sudden they turn around and point the finger, but then they're saying it's ok? You know, like some doctor's still saying it's ok to drink, it's no big deal, just as

long as you didn't get smashed. You know? And then they turn around and point the finger at you, and you're like, what the hell?!

AS: And that's where I get concerned about some of these policies, where they say "you've got to tell women not to drink", like it's just that one individual women who needs to be told. Like, you're saying your doctor didn't know, or friends, or other support people, that help to influence these decisions. That give the supports, or don't give the supports. So is that right?

Shannon: I think it needs to be everybody's responsibility. I don't think it should just be put on the mothers. I think it should be the father's job. I mean, I've had his dad (interrupted by son) like, made me drink a couple of times when I was pregnant with him, because he was... I mean, to try and make us not to fight, he would try to get me to drink, when I was angry, and that kind of stuff.

Jo-Anne: Yeah, like, that's what I was saying, too. Like a lot of people think the same thing.

Shannon: Like, they don't know about it. They should know.

Jo-Anne: Yeah, they didn't know!

AS: And you guys did know.

Jo-Anne: Yeah, they think that if you don't drink that often it's ok. Like, they said in my birthday, they said the same thing. "Oh, just have a couple". And then I felt like crap afterwards, you know? And, just, it's hard, because people are saying "oh, that's ok". Like, not enough people know either.

Most of the women provided additional testimony to support the analysis I had offered them and highlighted additional issues that they felt were important for me to include that I had not originally included. Other participants preferred to make amendments to the transcripts and my preliminary findings document directly, rather than through conversation. Consequently, these changes are invisible to readers of this text, although they remain significant to the findings. All of the changes and additions the

women presented are included in this dissertation. However, all of the women stated very strongly during the second interview that my analysis and arguments were consistent with those that they would wish to advance themselves. For example, in discussing my preliminary finding that women's histories and experiences of substance use are rarely acknowledged in discussions of FAS/FAE education and policies, Jo-Anne stated:

Jo-Anne: I'm only 25, but I've been a heavy drinker for 10 years. It's not just something where I decided to start drinking yesterday, you know, and now I'm going to stop. It's not like that.

AS: And some of the policies, they're written like women never really drank before the pregnancy, it's like you get pregnant and then it's something you decide.

Jo-Anne: Yeah. Exactly.

Super Woman: Yes!

Shannon: Yes, that's it!

Throughout the course of the interviews, I came to appreciate how even limited use of group interviews, when they include a significant component of sharing analysis with participants, can be a useful methodology for addressing important concerns regarding the risk of a researcher appropriating the voices of marginalized women in ways that can perpetuate disempowering aspects of traditional research paradigms and methods. These concerns have been well documented by many feminist qualitative researchers in and outside of education (Luttrell 2003, Opie 1992, Pillow 2004, Stacey 1988). The issues of misrepresentation and appropriation of voice remained especially salient in my research because of the colonial legacies of indigenous/white research relations.

Using group interviews and sharing analysis with the women I interviewed help to ensure that I minimized the risks I was “speaking for others” (Alcoff 1992). As Alcoff (1992) explains, “speaking for others” occurs when the researcher offers interpretations and analyses that are not responsive to the interpretations and analyses advanced by members of the groups themselves. Instead, the methods I used helped to ensure I was “speaking with” the women who participated in this research by offering an analysis that is responsive to the issues raised by members of the researched group and is consistent with how members of the group would represent themselves. While acknowledging that “speaking for Others” in academic research contributes to marginalizing and disenfranchising less privileged groups, Alcoff (1992) argues that the practice of “speaking with” less privileged groups can support these groups efforts toward improving their material conditions on their own terms.

In developing and conducting this research project, I allied with scholars such as Linda Tuhiwai Smith (1999), Graham Smith (1992), and Celia Haig-Brown (1988) who suggest that non-Aboriginal researchers can and should, in Alcoff’s terms, “speak with” Aboriginal peoples by ensuring that their efforts are incorporative of and responsive to the needs, concerns, and interests of Aboriginal research participants, that the researcher and the research are accountable to Aboriginal communities and research participants, and that the outcomes of the research are beneficial and useful for Aboriginal peoples. Furthermore, I believe that it is in fact incumbent on those researchers who have been privileged by hegemonic institutions and who ally with the struggles of Aboriginal peoples to find creative ways in which they can use the privilege and influence available to them to transform those institutions to the benefit of those who have been oppressed by

them. This point is best articulated by Emma LaRocque (1993:76), who states, "The onus for change cannot rest solely on Aboriginal shoulders. White people in positions of power must share the burdens of finding answers, as they have been part of the problem."

At the conclusion of the second interview, I informed the women that I would be happy to provide them with a copy of the entire text of my dissertation, and collected contact information for them for this purpose that was stored in a location separate from any data that could identify the women as participants.

Textual analysis: criteria for document selection

Grounded in the experiences of the Aboriginal mothers who participated in the group interviews, I conducted a textual analysis of the *First Nations and Inuit Health Branch's First Nations and Inuit Fetal Alcohol Syndrome and Fetal Alcohol Effects Initiative*. I chose these texts for two reasons. First, they were fundamental to the formulation and implementation of the Initiative. Second, these texts have to date been overlooked by critical feminist, anti-ableist, anti-racist, and anti-colonial scholars. The texts I examined fell into three broad categories. First, I examined "official" policy documents specific to the Initiative including, *Framework for the First Nations and Inuit Fetal Alcohol Syndrome and Fetal Alcohol Effect Initiative*, *It Takes a Community: A Resource Manual for Community-based Prevention of Fetal Alcohol Syndrome/ Fetal Alcohol Effect*, *Terms of Reference: National First Nations and Inuit Canada Prenatal Nutrition Program FAS/FAE Steering Committee*, and *Emerging Priorities for the Health of First Nations and Inuit Children and Youth*. All of these documents were produced and published by Health Canada and the First Nations and Inuit Health Branch. Next, I reviewed "popularized" policy statements intended for public information and to

consolidate support for changes in policy. Specifically, I focused considerable attention on public education campaigns undertaken under the rubric of the Initiative designed to inform “the public” in general and young Aboriginal women specifically of the causes and consequences of FAS/FAE²⁶. These texts were read both for content and the discursive constructs and tropes explicit and implicit in the texts which rely on them for their operation and (re)production. In analyzing these documents, I generated a coding scheme based on identification and analysis of the emergent themes evidenced in the texts.

Methodological framework for textual analysis: texts, discourse, and the relations of ruling

My methodology in approaching textual analysis is drawn from sociologist of education Dorothy Smith, whose work is grounded in a Foucauldian-informed phenomenology and Marxist-feminist materialism. Smith’s (1990, 1999) method was useful to me as it is devised as a means for uncovering and understanding the role of texts and discourses in perpetuating relations of ruling. As such, Smith’s methods for approaching and analyzing texts attends not only to linguistic and discursive organization of texts, but also to the material consequences of textual organization for those whose lives are organized or mediated by them.

Following Smith, I use the term “text” to mean the “written (or otherwise inscribed) words, or other symbols” printed on paper as well as “practices of reading and writing” used by readers to decode, or make sense of, the text. Seen in this way, a text is more than simply a physical document containing words or symbols. Rather, a text is something that is achieved, a product of the interaction between a physical, inscribed

²⁶ The findings based on this analysis are included in Chapters 4 and 6.

document, the discourses invoked in it, and its readers. This process of achieving a text is referred to by Smith as a “text-reader conversation”.

The ways readers interpret a text are dependent upon the conditions of the text’s reception (Smith 1990). These conditions include the social locations of the reader and the author, the reader’s position relative to the intended or perceived “audience” of the text, the material conditions of the text’s production, the meanings assigned to the discourses invoked in the text, and the saliency of these discourses and meanings in the social, economic, and politic climate in which the text is being read. Thus, “texts are not seen as inert extra-temporal blobs of meaning, the fixity of which enables the reader to forget the actual back and forth work on the piece of paper in front of her that constitute the text as a body of meaning existing outside of time and all at once.” (Smith 1990:3). According to Smith (1999), texts are generated by ideologies, concepts, and theories that constitute the internal organization of a text, and “interpret texts as sites of reading” (157). As such,

Texts generated in different settings- for example government systems of collecting statistics, social scientific research in universities and think tanks, policy-making in government, and mass media- are coordinated conceptually, producing an internally consistent picture of the world and providing the terms of policy-talk and decisions (157).

It is this feature of texts that makes them important sites of knowledge production as well as knowledge circulation, and therefore significant points of inquiry for sociologists of education.

A “discourse” is generally understood to be an inter- and extra-textual system of organizing, consolidating, and encoding meaning, and naturalizing that meaning into “common sense” (c.f. Gramsci 1992, Fiske 1987, Foucault 1973). In this way, a discourse

may be seen as a mode (or perhaps, *the* mode) of operationalizing of what Foucault has called a “power/knowledge” regime. However, as Smith (1990, 1992, 1999) has argued, Foucault’s understanding of discourse as it relates to the inter-relations between power and knowledge is somewhat problematic. She astutely observes that by locating power as originating and residing within texts themselves, Foucault eclipses the fact that discourses are created, invoked, circulated, and maintained by “actual people”. In this way, discourses and the texts that circulate and maintain them are key constituents supporting what Smith has called “the ruling relations” that ascribe power and privilege to certain groups and institutions and disenfranchise and subordinate others. But how is it that discourses and texts are able to function as consolidators and perpetuators of these ruling relations? What are the mechanisms that inform text-reader conversations to support hegemonic institutions, epistemologies, and ontologies? It is here that Smith’s development of the concepts of *objectifying discourses* and *ideological codes* represents an important intervention that proved most useful in helping me to understand how the texts of the Initiative, and other public policy documents, function.

Objectifying discourses and ideological codes

According to Dorothy Smith (1999), the power of texts lies in their ability to constitute and mediate the social organization of authority. Textual processes of assigning authority are key, in that they “regulat[e] whose voices will count” in public discourse (Smith 1999:177). Indeed, as I demonstrate in Chapter 4, the textual practices evidenced in the policy documents of the Initiative work to underscore popularized conceptions of Aboriginal people with FAS/FAE and substance-using Aboriginal mothers as creators

and perpetrators of “social problems”. Because they are positioned as creators and perpetrators of “social problems”, it becomes a matter of “common sense” that the voices of Aboriginal mothers and Aboriginal people with FAS/FAE do not “count” in public discourse and public policy focused on preventing or ameliorating the impact of FAS/FAE in their communities and in their Nations. Attending to the terms of policy talk that allow for the “common sense” exclusion of substance-using Aboriginal mothers and people with FAS/FAE thus becomes an important and necessary consideration in understanding the mechanisms by which the subordination of Aboriginal peoples is perpetuated in and through public policy.

In my analysis of the texts of the Initiative, I concentrate on two discursive devices that are regularly evidenced in the texts: objectifying discourses and ideological codes. Together, these devices are employed in the textual processes that establish the hegemony of one discourse over another and confer authority to specific groups to define and respond to FAS/FAE as a “social problem”²⁷. Most contemporary public policy in Canada (and other Western “democratic” Nation-States) is achieved through the negotiation of many diverse and often competing voices, interests, and perspectives. However, despite these contestations, Canadian public policy generally supports a unified and hegemonic position that ignores or subsumes the epistemic struggles that informed them. This is often accomplished in policy texts by the employment of objectifying discourses. Objectifying discourses are those ways of consolidating, circulating, and naturalizing systems of meaning that pre-empt these diversities in understandings, meanings, perspectives, and experiences. In so doing, objectifying discourses work to establish the hegemony of one discourse over another, thereby subduing and superceding

²⁷ For further discussion in relation to medical and social models of disability, see Chapter 4

these differences into “methods of dispelling ambiguity” (D. Smith 1999:212). In other words, objectifying discourses are the mechanisms for instituting structures of preference that are in turn used to assign meaning in a text. Objectifying discourses are structured using the language of typification, and locate the issue under discussion in the atemporal present. In so doing, objectifying discourses function to universalize hegemonic or “objectified” knowledge (see Chapter 4). These structures reduce contested and conflicting ways of knowing or being into simple determinations of “true” and “false”. In this way, objectifying discourses refine the terms in which an issue will be debated and responded to, and determine what terms will become “inadmissible to the text-reader conversation” and in public discourse (D. Smith 1999:221).

Objectifying discourses are a type of discursive formation that universalize from divergent experiences, ontologies, and epistemologies evidenced in a specific site in order to consolidate a hegemonic rendering of an issue. Ideological codes, on the other hand, are not a type of discursive formation, but rather a device that generates and reproduces discursive formations. An ideological code is like a genetic code in that it is capable of replicating its organization within and across multiple discursive sites. An ideological code is “a constant generator of *procedures for selecting syntax, categories, and vocabulary in the writing of texts and the production of talk for interpreting sentences*, written or spoke, ordered by it” (D. Smith 1999:159, emphasis hers). Indeed, ideological codes are distinctive in that they reproduce their organization in discursive texts without being manifested in the use of specific terms. In this way, an ideological code may be understood as a simultaneously absent and omnipresent referent that structures text or talk along specific (hegemonic) lines of thought. Thus, ideological

codes provide us a mechanism for understanding how structures of preference in assigning meaning are produced and reproduced discursively and materially (see also Hall 1980). Smith (1999:175) explains:

Ideological codes don't appear directly... no-one seems to be imposing anything on anyone else; people pick up an ideological code from reading, hearing, or watching, and replicate it in their own talk and writing. They pass it along. Once ideological codes are established, they are self-producing.

Readers of texts, then, are social subjects. The way they receive a text, the meanings that they assign to a text, and the evaluations they make of the text as it relates to their lived experiences and processes of common-sense making are all socially-mediated acts, and cannot, therefore, be considered outside of the social context in which texts are produced, circulated, and read. Moreover, this diversity among readers and the conditions under which texts are received often result in many varying and contested discourses and meanings being assigned to or evidenced in a given text. This is not to say, however, that texts hold within them an infinite number of possible readings, or that no preferred readings of a text exist. These structures of preference are best understood as structures of not only discursive, but also political power. Thus, while variously positioned readers may produce differing interpretations of the meanings and discourses associated with a given text, the production of these meanings is constrained by the discursive practices of the text's production which encourage some meanings rather than others, and the relationship of these constructs and practices to those discourses and meanings which reflect and enforce the ideology of the dominant hegemony.

Bridging the gap: the contradictions of feminist materialist and anti-colonial textual analysis

As Smith (1990:4) has stated, the task of the sociologist is to uncover the ways in which texts participate in organizing, mediating, and upholding social relations that differentially confer power and privilege, as well as “penetrating them, discovering, them, opening them up from within, through the text”. Accordingly, “the text before the analyst, then, is not used as a specimen or sample, but as a means of access, a direct line to the relations it organizes” (ibid). This understanding of texts represents an important departure from objectivist²⁸ approaches to policy analysis that is particularly useful to me. Using Smith’s theoretical framework allowed me to view the policy documents of the Initiative not as existing outside of time and place, but as being infused with the effects of the colonial subordination of Aboriginal peoples by the Canadian state, the disenfranchisement of Aboriginal women, and numerous political movements in support of self-determination and self-government by and for Inuit, Métis, and First Nations in Canada, as well as struggles by the women’s movement for social, political, and economic recognition of their rights and interests (including those related to the feminization of poverty and reproductive autonomy). As I learned from the women who participated in the group interviews, this context is important for understanding both the conditions of the texts’ production and the conditions under which Aboriginal people with FAS/FAE and the women who give birth to and parent them come to be viewed and responded to as “social problems”.

While I find much utility in Smith’s approach to textual analysis, my experience of conducting this study prompts me to question Smith’s assumption that texts are in

²⁸ For a detailed critique of objectivism and its relation to positivism in research, see Harding (1991).

themselves a direct means of accessing social relations. If this were the case, the analyst could uncover the “true” meaning and implications of the text without having to engage with the actual people whose everyday lives and experiences are organized through and mediated by the texts under question. In this way, Smith contradicts a fundamental precept of her methodology- that sociological inquiry by and for women must be grounded in the relevancies of women’s lived experiences. Indeed, one of the most salient problematic features of the responses to FAS/FAE in the Initiative is that the texts do not appear to attend to the needs and interests voiced by Aboriginal women whose lives would be most directly impacted by this policy. Thus, by failing to include Aboriginal women’s articulations of their concerns in their own voices and on their own terms as part of my project, I would run the risk of reproducing precisely those relations of power, authority, and dominance that I was critiquing in my study. This underscores a key deficiency of inquiry grounded in textual analysis alone. Indeed, incorporating group interviews and sharing analysis with Aboriginal women whose mothering experiences include substance use and FAS/FAE proved to be integral and indispensable for building a method of textual analysis that reflects their own interests, priorities, and understandings while challenging the highly problematic and neo-colonial research practices of “speaking for” rather than “speaking with” Aboriginal women (Alcoff 1992). A further, and unanticipated, outcome of including group interviews as a foundation for textual analysis was that the group interviews created some of the conditions that supported the women in articulating collective experiences that challenged the privatization of mothering, substance use, and FAS/FAE found in the Initiative’s texts.

Critical policy analysts, particularly those working in feminist materialist and anti-colonial frameworks, must take this concern seriously as an important component of advancing efforts toward a decolonized, woman-centred policy analysis. Phillips (1996: 243, cited in Kelly 2000) underscores “policy design must be examined for its differential effects based on gender, class, race, age, community and other dimensions, and the effects need to be evaluated and understood from the lived experiences of those groups or communities affected”. Kelly (2000) expands this argument in noting that grounding policy critique in the lived experiences of those most affected by the policy in question is not simply a matter of theoretical or epistemic significance, but also of “rigorous and respectful research” (p.186). In reflecting on her analysis of educational policy for teen mothers, Kelly observes that her commitments to conducting rigorous and respectful research meant that she “could not simply infer their [teen mothers] needs from the policy responses that sought to meet their needs, no matter how progressive these policies seemed to me at the outset” (ibid).

These issues remained salient with me as I worked through the development and execution of my research methodology in such a way as to ensure that the concerns, needs, and interests of Aboriginal mothers whose lives had been effected by FAS/FAE remained in the forefront of my analysis while at the same time working to transform those aspects of indigenous- white research relations that have been oppressive to Aboriginal women and their children. Accordingly, in designing my research methodology I found that it was of equal importance on both empirical and political grounds that conducting interviews with young Aboriginal mothers whose lives include experiences of substance use and FAS/FAE complement my analysis of the policy texts

of the Initiative. Locating my methodology within the traditions of critical policy analysis and qualitative research proved important not only in terms of my own ethical and political commitments, but also provided a structure from which to construct an intellectually rigorous alternative to the positivist and objectivist foundations of colonial, imperial, and masculinist legacies in academic research. My commitments to democratizing as much as possible the process for conducting my research and to incorporating participatory elements into its design created some of the conditions which welcomed the six Aboriginal mothers I interviewed into the research process and a grounding from which to exercise their agency in transforming those aspects of the process that hampered their efforts to be heard and acknowledged.

Chapter IV: “It Takes A Community”: Defining Fetal Alcohol Syndrome and Fetal Alcohol Effect in/through the Policy Texts of the Initiative²⁹

This chapter will consider the ways in which Fetal Alcohol Syndrome and Fetal Alcohol Effects are defined and positioned ideologically, discursively, and materially within the texts outlining the goals and scope of the Initiative, *Framework for the First Nations and Inuit Fetal Alcohol Syndrome and Fetal Alcohol Effects Initiative* and *A Resource Manual for Community-based Prevention of Fetal Alcohol Syndrome and Fetal Alcohol Effects*. These documents were published together by Health Canada, under the title “It Takes a Community” (FAS/FAE Technical Working Group 1997). By examining the language used in these policy texts to communicate what FAS/FAE are, how FAS/FAE are caused, and the impact of FAS/FAE on the individuals, families, communities, and nations, it becomes evident that the definitions of FAS/FAE are not simply objective and value-free physiological and behavioural descriptions of corporeal, intellectual, and behavioural characteristics of individuals. Rather, the discursive and rhetorical strategies operationalized in policy talk surrounding FAS/FAE are ideologically, socially, and politically mediated, and have direct implications for projects of nation-building. These may in turn inform the provision of services to Aboriginal peoples affected by FAS/FAE.

Like most contemporary public policies in Canada, the texts of the Initiative must be understood as being achieved through the negotiation of many diverse and often competing voices, interests, and perspectives. As such, the Initiative should not be misread as unyieldingly monolithic. Indeed, in this chapter I show that the texts act as a

²⁹ A version of this chapter has been published. Salmon, A. (2004). “‘It Takes a Community’: Constructing Aboriginal Mothers and Children with FAS/FAE as Objects of Moral Panic in/through FAS/FAE Prevention”. *Journal of the Association for Research on Mothering* 6:1. 112-123.

formation and function of diverse epistemic and ontological positions that both support and challenge the hegemony of the Nation-State. However, while these tensions render it difficult to “fix” a single, unified conception or meaning of FAS/FAE, it remains that structures of preference exist within and beyond the texts of the Initiative that serve to privilege a hegemonic rendering of FAS/FAE and close off the possibility of other readings (c.f. Hall 1980).

Defining FAS/FAE through medical models of disability

Nearly all discussions of the definition, causes, and consequences of FAS and FAE in the texts of the Initiative are consistent with contemporary mainstream medical literature and are grounded in medical models of disability (Conroy 1990; LaDue, Streissguth, and Randels 1992; Warren and Foudin 2001). For example, in the introduction to “It Takes a Community”, the following explanation of FAS/FAE is offered:

FAS/FAE individuals experience neurodevelopmental disorders as a result of prenatal alcohol exposure. In other words, FAS/FAE are birth defects, resulting from a pregnant mother’s consumption of alcohol during her pregnancy... Children living with FAS (1) have a low birth weight and a slow growth rate, (2) have abnormal facial features and ears, and (3) often experience learning and behaviour problems, such as hyperactivity, poor judgment, and anti-social behaviour. Children living with FAE have some, but not all of the characteristics described above. FAE children do not have a “milder” case of FAS, and they can suffer debilitating learning and behaviour problems as severe as those experienced by FAS children... FAS/FAE are leading causes of developmental delays in children (FAS/FAE Technical Working Group 1997:3).

This passage demonstrates a number of features of medical models of disability. First, FAS/FAE is used as a primary identifier and descriptor of a person affected by the

condition. In this way, the characteristics, behaviours, and interests of “FAS/FAE individuals” are rendered distinct from those of the implied normative, non-FAS/FAE individuals. This positions FAS/FAE as the key organizing constituent of social location and experience for “FAS/FAE individuals”. Second, evaluations of an individual who has FAS/FAE are made in terms that require an assessment of their traits as compared to a presumed “norm”. Accordingly, FAS/FAE are described as “defects”, resulting in “abnormal facial features and ears”, and cause individuals to exhibit behaviours that are not simply different, but “problems” and “delays”. Although a statement of the Canadian Centre on Substance Abuse (1996) cautions that “recognizing the facial features associated with the syndrome requires considerable experience” and that “some of the features occur normally in different racial groups”, the use of occularcentric diagnostic criteria for FAS is embraced within the texts of the Initiative³⁰. Third, this description of FAS/FAE is characteristic of medical models in that it offers an etiology of FAS/FAE that exists entirely in individualized terms, without consideration of the context in which the disability occurs, and without reference to ways in which this context in its self creates and mediates experiences of disability. Thus, the cause of FAS/FAE is attributed solely to a specific type of alcohol exposure, “a pregnant mother’s consumption of

³⁰ It is difficult to observe these practices without being reminded of earlier phrenological studies, which attempted to explain the “inferior” biological and behavioural characteristics of specific racial groups on the basis of their skull measurements, in which the social categories of race and disability converge to signify the inferior Other. For example, Down’s (cited in Gould 1980) documentation of a recurring pattern of ear and skull shape that he observed of the children in his care were attributed by him to be representative of a “biological throwback” (Radford 1994) to a previous stage in the development of the “race” (see Gould 1980 and 1996). Down assumed these physical attributes to be evidence of the “emanation of a race just one step down in a supposed racial hierarchy”, from the Caucasian to the Mongolian (ibid). Down subsequently conflated racial inferiority with biological and intellectual inferiority, in labeling these children “mongolian idiots”. Later, this term fell out of favour and was replaced by the current diagnosis, Down’s Syndrome. As Lesko (2001) has demonstrated, these practices are directly implicated in practices that have entrenched racism and colonialism in education

alcohol during her pregnancy”. As a result, statements are made repeatedly throughout the texts of the Initiative that encouraging pregnant women to abstain from alcohol use will prevent FAS/FAE. As I shall argue later in this chapter, this presumption holds a number of important consideration for advancement of women’s citizenship interests and human rights *vis a vis* the institutions of the Nation-State.

In addition to the physiological characteristics noted above, individuals with FAS/FAE are also understood to exhibit distinctive behavioural criteria. These behaviours are also interpreted using a medical model of disability. As lower levels of fetal alcohol exposure may not produce the distinctive physiological characteristics, practitioners are encouraged to assess the behavior of an individual suspected to have FAS/FAE in order to help them determine a diagnosis (i.e. FAS/FAE Technical Working Group 1997:29, 1997:73, see also FAS/FAE Technical Working Group 1997, “What is Fetal Alcohol Syndrome”, n.p., “What is Fetal Alcohol Effects”, n.p.,). For example, the following excerpt lists behavioural traits that may be used as diagnostic criteria to identify FAS/FAE along with a positive history of maternal alcohol consumption during pregnancy:

FAS/FAE individuals may experience all or some of the following intellectual, physical, social, and learning difficulties, amongst others:

- attentional difficulties (distractibility);
- inability to connect cause and effect (understanding consequences);
- a lack of understanding of social cues and relationships;
- poor comprehension of social rules and expectations;
- trouble making friends and easily influenced;
- a poor sense of personal boundaries;
- poor impulse control;

- even minor changes in routine can be overwhelming;
- poor and inconsistent memory function, leading to a need to be retaught the same concepts over and over again;
- trouble remembering where things are;
- learning and retrieval of information may be spotty or intermittent;
- difficulty remembering and understanding directions (especially if lengthy or complicated);
- trouble with spatial relations and orientation;
- trouble with abstract thinking (understanding ideas and relationships between things);
- can be lethargic or hyperactive;
- demanding of lots of one-to-one attention;
- trouble telling right from wrong;
- wanting lots of physical contact;
- giving an appearance of capability without actually having the abilities that they seem to have (illusion of competency);
- difficulty separating fact from fantasy;
- temper tantrums, lying, stealing, disobedience, and defiance of authority;
- lack of fear and tendency to take risks (high pain threshold);
- application of faulty logic;
- egocentrism and inability to comprehend and/or respond appropriately to the feelings, needs, and desires of others;
- low motivation;
- low self-esteem; and
- physical difficulties, including vision, hearing, heart, and growth problems and deficits. (FAS/FAE Technical Working Group 1997:29)

These behavioural symptoms are very broad and often contradictory (i.e. “can be lethargic or hyperactive”, “egocentrism” and “low self-esteem”). Furthermore, this

understanding of FAS/FAE relies on a subjective assessment of behavioural indicators that are socially and culturally mediated. For example, a description of an individual as having “poor comprehension of social rules and expectations” assumes the establishment of “social rules and expectations” as self-evident, legitimate, and agreed upon by all constituents of the society. This also implies that adhering to these “social rules and expectations” is desirable, beneficial, and produces positive experiences for all parties. Moreover, given that no definitive biological marker exists for FAS/FAE, diagnosis depends on application of the highly subjective assessments noted above. Consequently, one can readily observe instances in which other factors could be used to explain the behaviour “anomalies” present in those diagnosed with FAS/FAE.

For example, discussion of the context of FAS/FAE in Aboriginal communities in the texts of the Initiative notes that as a result of colonial incursions of the Canadian state into First Nations and Inuit communities (including through the institution of residential schooling), Aboriginal communities experience a loss of traditional cultural values, spiritual practices, and parenting skills, as well as intergenerational cycles of addictions and physical, sexual, and emotional abuse (FAS/FAE Technical Working Group 1997:4). However, no consideration is made in the texts of the Initiative as to how these experiences could inspire behaviour that could lead to a (mis)diagnosis of FAS/FAE. Similarly, in *It Takes a Community* it is stated that “Individuals affected by FAS/FAE often experience secondary disabilities such as mental health problems, disrupted school experience, involvement with crime, substance abuse, dependant living, and employment difficulties” (FAS/FAE Technical Working Group 1997:3). As it has been repeatedly demonstrated that Aboriginal children and youth frequently find mainstream public

school curricula irrelevant, biased, and exclusive of Aboriginal peoples and their experiences, it is curious that issues such as “disrupted school experience” are never considered in the texts of the Initiative to be possible manifestations of resistance to the curriculum and institutional practices of non-Aboriginal, middle-class education, rather than evidence of a significant psychosocial disturbance (c.f. Kelly and Gaskell 1996, Willis 1977, National Indian Brotherhood 1972). Likewise, the texts fail to consider how systemic discrimination against Aboriginal peoples in Canada, the social, political, and economic marginalization of Aboriginal peoples institutionalized in the Indian Act, the impact of on-going colonial relations enforced by the Canadian State, and the structural disadvantages experienced by Aboriginal youth related to unemployment and poverty (Anderson 2000, Royal Commission on Aboriginal Peoples 1996, Turpel 1993, York 1990), might mediate experiences of “dependant living”, “involvement with crime”, “substance use”, “mental health issues” and “employment difficulties” experienced by Aboriginal people diagnosed with FAS/FAE. Indeed, rather than viewing them as effects of colonial subordination which call into question the legitimacy and beneficence of the contemporary Canadian Nation-State in its relations with Aboriginal peoples, these behaviours are pathologized as the “disabilities” of individual people diagnosed with FAS/FAE. In this way, the structural factors mediating their experiences are left intact and unquestioned. Instead, these behaviours are unproblematically attributed to a totalizing pathology, absent of historical and contemporary structural considerations. Cloaked in the “objective” and normalizing mantle of medical science, diagnostic criteria for FAS/FAE as evidenced in the Initiative may be seen to reproduce the relations of

ruling which naturalize the subordination of Aboriginal peoples and people with disabilities.

Defining FAS/FAE through social models of disability

Although the meanings that are (re)produced policy texts of the Initiative privilege definitions of FAS/FAE informed by medical models of disability, the texts do not discount social models of disability entirely. This points to significant tensions in the texts that underscore them as a product of diverse, competing, and contradictory discourses and ideologies. Indeed, the Initiative is unique among policy responses to FAS/FAE in that it does attempt to account for the context in which substance use occurs in First Nations and Inuit communities. To illustrate:

Having been stripped of political agency on the nation level because of colonial attitudes of dominance and paternalism, First Nations and Inuit families and communities find themselves with decreased levels of self-sufficiency ... For instance, as a result of their upbringing in residential schools, generations of First Nations and Inuit have been unable to develop traditional knowledge and skills, including basic parenting skills.

In the face of enduring these hardships and cultural disruption, addictions, and substance abuse have become prevalent in Aboriginal communities.... Furthermore, an intergenerational cycle of physical, psychological, sexual abuse, and loss of spiritual practices has sprung from this history of devaluation and control, providing fertile soil for addictions, alcoholism, and substance abuse.

As one woman appearing before the Royal Commission on Aboriginal Peoples put it, the "absence of self-government created a climate in which alcoholism and violence were allowed to flourish". (FAS/FAE Technical Working Group 1997: 4)

Similarly, in a section titled "First Nations and Inuit History and Culture", it is observed that:

Many First Nations and Inuit in Canada experience poverty and health problems. This poverty and poor health exist in light of the

history of First Nations and Inuit. First Nations and Inuit families, and communities find themselves with less self-sufficiency than they used to have...Addictions, substance abuse, physical, psychological, and sexual abuse, have become part of life in First Nations and Inuit communities. (FAS/FAE Technical Working Group 1997:36).

These observations that contextualize issues related to substance use and the prevalence of FAS/FAE in Aboriginal communities are important, in that they point to institutionalized policies and practices that have oppressed and disenfranchised Aboriginal peoples, and points to the structural inequalities enabled by racism and colonialism as direct influences on the health and well-being of Aboriginal communities. Acknowledging these histories in developing policy related to FAS/FAE are crucial in implicating the Canadian state directly in the continuing struggles by First Nations and Inuit communities to secure their social, political, and economic autonomy and enfranchisement. Contextualizing discussions of substance use in this way also disrupts discursive, ideological, and material practices that position Aboriginal women who use substances as objects of blame and pathology. This allows for an accounting of the ways structural and institutionalized oppressions mediate women's decisions around and experiences of substance use, reproduction, and motherhood. This was further highlighted in a report synthesizing findings from a national consultation regarding the Initiative, which stated "FAS/FAE is not just a mother who drinks. Governments and communities need to acknowledge how racism, poverty, sexual abuse and family violence are linked to addictions." (McKechnie 2000:7).

While the texts of the Initiative stress that alcohol use and incidence and prevalence of FAS/FAE in First Nations and Inuit communities must be understood as

existing within a highly salient historical, social, political, and economic context, it remains that no distinction is made as to how these contexts themselves might (re)produce characteristics or behaviours consistent with the diagnostic criteria for FAS/FAE. Nor do the texts describe how these contexts might inform the highly subjective and ideologically mediated assessments based on normative/non-normative binaries that result in a diagnosis of FAS/FAE. Consequently, many of the problematic features of the medical model of disability go uninterrupted. In reifying the definition of FAS/FAE in deterministic terms as being caused solely by maternal alcohol consumption, the marginalized position of substance-using Aboriginal mothers goes unchallenged.

Medicalization as an objectifying discourse

As I discussed in Chapter 3, objectifying discourses are mechanisms for consolidating, circulating, and naturalizing systems of meaning that are employed to preempt recognition of diversities in understandings, meanings, perspectives, and experiences in people's everyday lives (Smith 1999: 220). Recognizing the use of objectifying discourses in texts, including policy texts, is important because objectifying discourses reduce contested and conflicting ways of knowing or being into simple determinations of "true" and "false". In this way, objectifying discourses redefine the terms under which an issue will be debated and responded to, and determine what terms will become "inadmissible to the text-reader conversation" and in public discourse (Smith 1999:221).

In the policy texts of the Initiative, medicalization functions as an objectifying discourse³¹. By incorporating structures of preference into the texts of the Initiative that privilege medical models of disability and medicalization, the texts preclude recognition of social, cultural, political, and economic relations that inform and mediate experiences of FAS/FAE. In this way, medicalization (re)defines the terms on which FAS/FAE will be acknowledged and debated as an “important national health issue” for Aboriginal peoples and the Canadian Nation-State (FAS/FAE Technical Working Group 1997: 27).

Recall that objectifying discourses are structured using the language of typification, and locate the issue under discussion in the atemporal present. In so doing, objectifying discourses function to universalize hegemonic (or “objectified”) knowledge. There are many examples of this evident in the texts of the Initiative. For example, consider the following statements offered in Appendix A of “Framework for the First Nations and Inuit Fetal Alcohol Syndrome/ Fetal Alcohol Effect Initiative”, entitled “What are FAS/FAE?”:

According to the traditional diagnostic criteria, a child is FAE when there has been prenatal exposure to alcohol and some, but not all, of the above-noted diagnostic criteria. FAE is not a milder form of FAS; both are spectrum/ continuum disorders, meaning that FAS/FAE individuals present varying degrees of intellectual and physical deficits (FAS/FAE Technical Working Group 1997:28).

In this passage, the language of typification employed in the objectifying discourse of medicalization is evidenced in repeated reference to the “diagnostic criteria” for FAS/FAE. FAS/FAE are typified in this passage as medicalized “disorders” that can be accurately and unproblematically identified and assessed by utilizing specific criteria. Moreover, the criteria themselves are reified as “traditional”, signifying that the criteria

³¹ For a complete description of medical models of disability and medicalization, see Chapters 2 and 5.

are commonly acknowledged and accepted and therefore not subject to credible contestation. This strategy pre-empts consideration of the numerous controversies surrounding the identification and diagnosis of FAS, FAE, and other Alcohol-Related Birth Defects (ARBDs), and obscures the fact that the medical community itself has not achieved consensus³² as to the specific teratogenic effects of ethyl-alcohol (Armstrong 2003, see also Chapter 2). In this way, debates around FAS/FAE come to be centred on two main topics: 1) how to diagnose whether an individual has FAS/FAE or is “at risk” for giving birth to a child with FAS/FAE; and 2) what interventions are necessary (in the form of public policy as well as in the activities of healthcare and social service providers) to ameliorate the “disorders” and “deficits” inevitably accompanying the medical condition.

The use of the atemporal present as a discursive strategy used in describing FAS/FAE is also readily apparent in this passage. The texts employ language such as “a child *is* FAE”, “FAE *is* not a milder form of FAS; both *are* spectrum/ continuum disorders”, and “FAS/FAE individuals *present* varying degrees of intellectual and physical deficits” (emphasis added). These textual practices should not be misread merely as evidence of the appropriate adherence to conventions of good grammar. Rather, the use of the atemporal present in describing FAS/FAE functions to universalize a medicalized understanding of FAS/FAE, as an objectively identifiable condition that accurately describes the physical and behavioural traits of affected individuals

³² For example, while Astley et al (2000) identify prenatal ethyl alcohol exposure itself at the primary cause of FAS/FAE, Abel and Hannigan’s (1995) research demonstrates that FAS/FAE occurs only with the presence of additional “permissive and provocative cofactors”, including malnutrition, maternal stress, smoking, high parity, advanced maternal age, or exposure to environmental pollutants. In addition, Christoffel and Salafsky’s (1975) studies of FAS in dizygotic twins (in which one twin developed FAS and the other did not) suggests that the presence of a genetic anomaly is required to precipitate the teratogenic effect of alcohol on a fetus. For analysis of the emergence of FAS as a diagnosis and review of medical literature on FAS/FAE, see Armstrong 2003.

everywhere, at all times. For example, the defining characteristics of FAE that become universalized in statements such as “FAS/FAE individuals present” suggests not only that the same characteristics and traits are shared by all “FAS/FAE individuals” across time and space, but also that these characteristics are objectively appreciable to anyone who cares to look for them. In this way, the social, cultural, economic, and political specificities that mediate the specificities in diagnoses and experiences of FAS/FAE are absented from the policy texts as legitimate frames for negotiating and contesting responses to FAS/FAE in and through public policy. By emphasizing what FAE *is*, the texts simultaneously reify medicalized understandings as naturalized, inherent, and not subject to debate or dispute. In this way, medicalization functions as an objectifying discourse to subsume these contestations into simple determinations of what is “true” and what is “false”. The defining characteristics that spell out for us what FAE *is* closes off the possibility of counter-hegemonic understandings of FAE as illegitimate. Furthermore, in reifying a medicalized understanding of FAS and FAE, the texts also re-inscribe what FAS and FAE are *not*. As I will demonstrate in subsequent chapters, the terms in which FAS/FAE are responded to and debated in public policy enables some issues and experiences advanced by certain claims-makers to figure on the public agenda, and also keeps those articulated by other claims-makers off (Miller 1993). Indeed, similar critiques of the use of the atemporal present have been advanced by Said (1978), who notes that the use of the atemporal present in descriptions of “Orientals” functions in similar ways to universalize and also exoticize “Orientals” and “the Orient”, reifying them unproblematically as “Other” (see also Said 1993; c.f. Clifford and Marcus 1986, Marcus and Fisher 1986). Together, the objectifying discourse of medicalization and the

ideological codes of the “normal human body” and “normal human behaviour” enable the co-ordination of concepts that produce a false “internally consistent picture of the world and [provide] the terms of policy-talk and decisions” (Smith 1999:157).

The “normal human body” and “normal human behaviour” as ideological codes

Ideological codes are textual devices that generate and reproduce discursive formations. As described in Chapter 3, an ideological code generates procedures for selecting syntax, categories, and vocabulary to provide a frame or lens through which to interpret texts (Smith 1999:159). Ideological codes are powerful organizers of discourse and texts in that they provide structures of preference for assigning meaning to text-reader conversations without requiring the invocation of specific terms (see also Hall 1980).

In the texts of the Initiative, the “normal human body” is a simultaneously absent and omnipresent referent that functions as an ideological code. The following passage, excerpted from a fact sheet appended to the policy texts of the Initiative entitled “What is Fetal Alcohol Syndrome”, provides a typical illustration:

Features of FAS

Growth retardation- Babies grow at a slower than normal rate during pregnancy and after birth. Children are typically small and skinny, growing into short adults.

Appearance- The FAS child has distinct facial features. These could include shortened eye slits, flattened mid-face, a flattened midline ridge between nose and lip, thin upper lip, and other features. An FAS child may have some or all of these features.

- Facial features may fade as the child grows. Using facial features alone to identify FAS is not advised. This can promote a stereotypical image of the FAS affected person.

Brain and central nervous system- The most critical effect

of alcohol on the fetus is the permanent damage to the brain and central nervous system.

- This includes small brain and head circumference, brain malformations, developmental delay, intellectual impairment, behavioural disorders, learning disabilities, attention deficit disorder, and hyperactivity (FAS/FAE Technical Working Group 1997: n.p., emphasis and formatting as in original)

As is readily apparent in this passage, the “normal human body” is repeatedly invoked as an ideological code. In this way, “the normal human body” as an ideological code bears features of a “contrast structure”, in which a description of “behaviour is preceded by a statement which supplies instructions for how to see that behaviour as anomalous” (Smith 1992:33). Comparisons abound that distinguish “the FAS child” from those who are “normal”, in terms of their growth and physical development, physiology and appearance, and intellectual ability. These distinctions are not merely described as differences or uniqueness, but as “retardation”, “malformation”, “delay”, “impairment”, “disorders”, and “disabilities”. Accordingly, invoking the “normal human body” as ideological code enshrines the “otherness” of people diagnosed with FAS. Moreover, organizing talk about FAS through the ideological code of the “normal human body”, consolidates the ideological and discursive operations of the text so as to exclude non-medicalized and non-pathologized understandings of the causes and consequences of FAS from the text-reader conversation. This in turn provides the discursive frame for both policy responses to FAS as well as attempts by Aboriginal mothers and children affected by FAS to advance claims via the welfare state³³. Indeed, it is important to note that the differences are enumerated from the outset as “features of FAS”. As such, the “normal human body” as ideological code provides a structure of preference that further

³³ See Chapter 5 for further discussion of this issue.

preserves the hegemony of medicalization within the text, locating the “problem” of FAS as originating in the biology of deviant “others” rather than in social, economic, or political structures or practices.

Subduing the social: the consequences of FAS/FAE and the hegemony of the medical model

Defining FAS/FAE through a medical model as being caused entirely by a pregnant woman’s decision to consume alcohol has significant implications for the citizenship interests and human rights of women. Indeed, ideologies of motherhood that invest a pregnant woman with the sole responsibility and obligation to protect her fetus from harm, and that define harm only in medicalized terms that fail to consider the context in which women become pregnant, give birth, and parent their children, and have allowed for the on-going surveillance of women in their child-bearing years (Mitchell 2001). These ideologies have also reproduced discourses that position women’s interests as antagonistic to those of her fetus³⁴, that have in turn enabled legal interventions providing for the confinement of substance-using pregnant women and the apprehension of infants diagnosed with impairments related to maternal substance use (Armstrong 2003, Boyd 1999, Gomez 1997, Humphries 1999). While the texts of the Initiative themselves do not argue for the confinement of substance-using pregnant women, they actively participate in reproducing those discourses that do. Evidence of the medical model of disability can also be seen in many of the less dramatic interventions suggested in the texts of the Initiative to support individuals diagnosed with FAS/FAE. The following passage, outlining one of the key components of the Initiative, provides an example:

³⁴ For further discussion of this issue, see Chapter 6.

This component consists of all efforts to identify FAS/FAE individuals and subsequently support them and their families in an effort to (1) reduce the impact of FAS/FAE on their lives (i.e., reduce the chances of secondary disabilities, such as mental health problems) and (2) reduce the chance of those individuals having FAS/FAE children themselves, including but not limited to:

- * efforts aimed at early identification and diagnosis,
- * implementing appropriate teaching/learning strategies in classrooms,
- * implementing appropriate teaching/learning strategies in families,
- * interventions in the justice system designed to refer FAS/FAE affected individuals to rehabilitation resources, and multidisciplinary care for FAS/FAE affected individuals, including family support medical care, counseling, occupational therapy, speech therapy, and teaching assistance. (FAS/FAE Technical Working Group 1997: 18)

As can be seen, medical models of disability are operationalized in the above passage in numerous ways. First, FAS/FAE as a disability is seen to exist entirely within the body of the individual affected by it, and not as being mediated by or responding to social, political, or environmental factors that in failing to respond appropriately to impairment create disability. Likewise, "FAS/FAE affected individuals" are positioned as requiring distinct and non-normative interventions resulting from their identification and diagnosis, including the need for "appropriate teaching/ learning strategies", "rehabilitation resources", "multidisciplinary care", and other forms of "therapy" and "assistance". As such, the needs of "FAS/FAE affected individuals" are implicitly contrasted with those expected of the "norm". This is further underscored by appeals for the need to identify "FAS/FAE affected individuals", to reify their separation from the presumed "norm". Thus, people with disabilities are further marginalized as dependants requiring interventions to manage and contain their impairment(s). Moreover, it is significant to note that the suggested supports for individuals with FAS/FAE outlined above are entirely concerned with modifying and rehabilitating the impairments and behaviours of

those with FAS/FAE. At no point is it suggested that policies and practices of “mainstream” educational, medical, corrections, or other institutions are themselves disabling, and in need of intervention, modification, or rehabilitation, or that making these changes could also provide benefits to children who do not have FAS/FAE.

Accordingly, utilizing medical models of disability, individuals with FAS/FAE are placed discursively and materially as objectified Others, requiring interventions and supports that are substantively different from the “norm” that place extraordinary demands on “public” institutions. This not only provides a rationale for allocating continuing funds to operationalize policy responses such as the Initiative, but also provides justification for measures designed to “prevent the birth” of FAS/FAE affected individuals and to render “at risk” pregnant women as objects of on-going surveillance. Again, decisions to take up these discourses in the implementation of public policy has decidedly gendered implications that may be seen as undermining women’s struggles to achieve human rights and reproductive autonomy. Indeed, given that privileged definitions of the causes and consequences of FAS/FAE regard the disability as being caused solely by maternal alcohol assumption, it is clear that efforts to provide “support” to FAS/FAE affected individuals aimed at “reduc[ing] the chance of those individuals having FAS/FAE children themselves” involves direct interference with women’s agency and decision-making regarding reproduction.

However, the texts of the Initiative obscure these important human rights considerations in favour of economic assessments of the impact the birth of individuals with FAS/FAE have on the resources of their communities and the institutions of the Nation-State. For instance, in appealing to the “extra lifetime costs” associated with

FAS/FAE and the impact individuals with FAS/FAE have on their community, the texts argue for the need to continue funding to FAS/FAE identification and “risk reduction” programs:

As mentioned in the preface, the extra lifetime health care, education, corrections, and social services costs to society associated with an FAS/FAE individual have been estimated at US\$1.4 million ... Since it [this estimate] is over 10 years old and applies to an American context, it is almost certainly an underestimate of the extra lifetime costs associated with caring for an FAS individual in Canada.

This estimate illustrates the potential costs that FAS/FAE represents. Take the extra lifetime costs per FAS affected individual (US\$1.4 million) and multiply it by the incidence of FAS (potentially 740 FAS births a year in Canada). The total is over US\$1 billion; this represents the total cost (in monetary terms alone) of FAS to Canadian society for one birth cohort alone (group of children born in one year). This cost needs to be balanced against the continuing annual funding allocated to the Initiative (CND\$1.7 million) when making FAS/FAE funding decisions in the future.” (FAS/FAE Technical Working Group 1997:23).

This statement demonstrates the impact of definitions of FAS/FAE on considerations of citizenship/ membership interests of Aboriginal mothers and children diagnosed with FAS/FAE. To begin, the statement suggests that substance-using Aboriginal mothers who give birth to children diagnosed with FAS/FAE have interests that are antagonistic and threatening to the interests of the institutions of the Nation-State. As a result, they are positioned as legitimate “targets” of “interventions” to modify their behaviour and infringe upon their reproductive autonomy, as supported by the implementation of the Initiative. Moreover, it proposes that individuals with FAS/FAE have “extra” needs that cannot be met, nor should they be expected to be met, through the resources available to institutions of the Nation-State. Given the orientation of the contemporary Canadian welfare state toward a collectivist ethos, that presumes that the resources of the state should be made available to the whole of “Canadian society”, the needs and interests,

and indeed the existence, of persons with FAS/FAE are therefore seen as being at odds with the needs, interests, and expectations of “Canadian society”. As I shall demonstrate in Chapters 5 and 7, this underscores a number of noteworthy contradictions that arise when substantive issues around citizenship, membership, and entitlements for marginalized groups are articulated through the language and mechanisms of the welfare state.

Conclusions

In this chapter, I have demonstrated the ways in which features of medical and social models of disability are taken up and operationalized within the primary policy texts of the Initiative in articulating the definitions, causes and consequences of FAS/FAE in Aboriginal communities. As I have shown, despite their saliency in the texts of the Initiative, medical models of disability alone are inadequate for describing the characteristics, causes, and consequences of FAS/FAE. These models do not admit consideration of structural considerations that mediate experiences and diagnosis of FAS/FAE. Moreover, reifying medical models of disability in policy responses to FAS/FAE does little to secure the social, political, and economic rights and entitlements required to advance the interests of marginalized groups, including people with disabilities in general and Aboriginal women children affected by FAS/FAE specifically. While these policy texts do employ some aspects of social models of disability in attempting to situate issues related to FAS/FAE and substance use in historical and cultural terms, it remains that these texts privilege a hegemonic understanding of FAS/FAE articulated through a medical model. Indeed, although the Initiative concludes

that Aboriginal women who are the birth mothers of children with FAS/FAE should not be objects of "blame, guilt, and shame" and that "historical and cultural" factors must be considered when addressing issues of maternal alcohol use and FAS/FAE, situating FAS/FAE as being caused solely by maternal alcohol consumption reinforces this blame. This in turn has serious implications for the advancement of women's struggles for human rights and reproductive autonomy. Finally, in defining individuals with FAS/FAE as inferior Others with needs and interests that are contrary to those of "Canadian society", I have argued that definitions of FAS/FAE are implicated in the continuing marginalization and disenfranchisement of people with disabilities in general, and Aboriginal people with FAS/FAE specifically.

However, in advancing my critique of medical models of disability and medicalization, I do not intend to imply that there are no instrumental or strategic uses for medical models of disability. In the next chapter, I will consider the ways medicalization both supports and undermines Aboriginal women's abilities to articulate claims to recognition and redistribution of rights and entitlements via the Canadian welfare state (Fraser 1997b). This has important consequences for discussions of who can lay claim to citizenship and membership interests in the polity and institutions of the Canadian Nation-State (Bannerji 1997).

Chapter V: Dis/Abling States, Dis/Abling Citizenship: Young Aboriginal Mothers, FAS/FAE, and Nation-building

In Western democratic Nation-States, individuals and groups organizing to ameliorate social inequalities for marginalized groups frequently articulate their demands for change in claims to rights and entitlements people have as “citizens”. In some instances, these claims call attention to the need for Nation-States and their institutions to expand the rights and entitlements accompanying “citizenship”. In other instances, such claims highlight pre-existing rights and entitlements that are being neglected.

Feminist anti-racist scholars of nation-building practices have noted that differentially-located groups experience two distinct dimension of “citizenship” as an organizing constituent of social, political, and economic relations (Fraser 1997a, 1997b, Ng 1993, Sharma 2000, Young 1990). These scholars refer to the first dimension as “formal citizenship”. Formal citizenship are best understood as the rights or entitlements afforded to individuals as “citizens”, as described or guaranteed in formal declarations, legislation, policies, or statutes of the Nation-State. In Canada, these include the right to vote, the right to own property, the right to enter and leave the country, or the right to attend public school. While significant for protecting citizens’ human rights, this legal-judicial conception of citizenship has been criticized as inadequate for understanding the perpetuation of social inequalities for between and among groups identified as “citizens” (and “non-citizens”). This is because this dimension of citizenship is “abstracted” from the conditions of everyday lives (Ng 1993, Roman 2004, Young 1990). Conversely, “substantive citizenship” rights and interests are evident in the recognition of individual and collective experience, knowledge, and conditions. This includes the presence of

structural supports that make formal rights and entitlements present and meaningful in people's everyday lives. Substantive citizenship is also found in efforts to ensure that all groups have equal enjoyment of their formal rights and entitlements, including the redistribution of state resources to enable enfranchisement of marginalized groups through the improvement of their material conditions (Fraser 1997a, Young 1990). Bannerji (1997) refers to conditions of substantive citizenship as evidence of "membership" in the Nation-State. According to Young (1990), evidence of individuals and groups enjoying substantive citizenship is an important indicator that they are experiencing justice in their relations with state institutions.

In Chapter 4, I argued that discursive practices evident in the texts of the Initiative participate in defining individuals with FAS/FAE as inferior "Others" with needs and interests that are contrary and threatening to those of "Canadian society" and the Canadian Nation-State (c.f. Meekosha and Dowse 1997). Accordingly, I argued that medicalized conceptions of FAS/FAE may compromise the citizenship interests of women and people with disabilities in general, and Aboriginal mothers of children with FAS/FAE in particular, by undermining their efforts to achieve equality in social, political, and economic rights. But what does this mean to young Aboriginal mothers who are negotiating the realities of this FAS/FAE in their daily lives? How do they understand the social, economic, and political conditions that underlie the causes and consequences of FAS/FAE in their community? What relationship is evident between medicalization and substantive citizenship interests in these experiences?

In this chapter, I draw on the experiences shared with me by the young Aboriginal mothers I interviewed to highlight the multiple and often contradictory ways in which

disability as a constituent of social relations is defined and lived. In so doing, I reflect on how the process of “medicalization” informed the women’s experiences of substantive citizenship in their everyday lives and the lives of their children. Far from being an unyieldingly monolithic construct and process, I show how the process of medicalization in the diagnosis of and intervention for FAS/FAE is simultaneously imposed, upheld, resisted, and transformed by young Aboriginal mothers. I argue that the hegemonic discursive and material practices of medicalization are one means through which the substantive citizenship interests of Aboriginal peoples affected by FAS/FAE are both differentiated and contested, simultaneously enabling and disabling citizenship in the Canadian Nation-State. As such, medicalization comes to serve both as a site of oppression and a site for advancing claims to knowledge and social justice. The discursive and material practices of medicalization in turn place substantive limits on what Roman (2001) has called the “epistemic space” available to young Aboriginal women and people with disabilities to articulate claims to specific rights and entitlements as democratic citizens via the welfare state (Meekosha and Dowse 1997). I conclude by exploring the implications for social justice and substantive citizenship raised for marginalized groups when the languages and mechanisms for identifying knowledge claims and oppressive material conditions requires the reification of the mechanism of oppression.

Dis/abling citizenship: negotiating citizenship in the home, in the streets, and on the margins

Not surprisingly, the young Aboriginal mothers I interviewed did not use terms like “citizenship”, whether in its formal or substantive terms, to describe dimensions of

their lived experiences. Neither did they speak of “citizenship” to describe mechanisms or grounds for securing their individual and collective rights, entitlements, and interests in their daily lives. However, all of the women shared experiences that illustrate one of the most salient indicators of substantive citizenship: the ability to successfully advance claims on the institutions of the Nation-State (Young 1990). For example, Super Woman shared the following experience of advocating for her daughter at school:

I was struggling for a long time with my daughter, trying to get support for her, and we needed help. And then, in grade 1, she finally started getting some help, and we had a big meeting of occupational therapists, speech therapists, ... her teacher, her resource teacher, and even the school principal who doesn't usually attend these meetings stepped in. And they were really supportive and they listened to my concerns ... We were supported and therefore I'm keeping my daughter in the school.

Tricksey shared an instance of successfully laying claim to state resources to secure entitlements to financial support as an illustration of a time when her voice was heard.

[M]y voice was heard when I had my son and I was living in the Downtown Eastside, just a block from Crabtree [Corner, a program providing education, support, and advocacy for mothers and their children run by the YWCA]. Anyways, the social worker was not answering phone calls, because I wanted an emergency allowance, where they give you \$100 for your son, or for your baby, newborn babies. So I asked for that, and I needed that money. For a whole week I was phoning, phoning, phoning every day. So, no response. So I finally called the last call. I said if I don't hear from you within an hour, I will phone your supervisor and I will tell them how many phone calls I've been calling you, and you're not responding. And sure enough, who calls a half hour later? “Don't call my supervisor! Don't call my supervisor! What do you want? How much?” And I was like, “Yeah, I want a hundred dollar cheque!” (all laugh). So that was my voice.

With a sense of pride and accomplishment in her voice, Wonder Woman related her experience of securing entitlements not only for herself, but also for other marginalized women and children.

[M]y voice has probably been heard the biggest after the Liberal [provincial government] cut-backs, when they cut childcare subsidies for single parent families for medical reasons, if you needed a medical childcare subsidy. And I'd been fighting through my whole pregnancy, and when I was 20 weeks pregnant I went into preterm labour. They couldn't have cared less. And then, when I was 25 weeks... I was in labour again, and the doctors estimated the cost over \$600,000 for her [daughter] to be in the NICU, because she was 4 months early... Then I phoned [Jenny Kwan, local Member of the Legislative Assembly], and they said they weren't sure what they could do [to get her subsidy]. They went to Question Period, they did a bunch of stuff. And then, within a week of coming home from the hospital, I had two Ministers phoning me from the province, stating that they would pay for a nanny, they would pay for a bunch of things. I said, "No, I just want the legislation reversed". And within two days I had a phone call from my subsidy worker, saying "I don't know how in the f-ing something hell and something you managed to get this, but they've reversed the legislation... I received a letter from two Ministers, saying they apologized and they've reversed the legislation, and I've been getting my subsidy ever since. And it was all because of my little baby... And I was on bed rest the whole time. I had to lie flat on my couch, so I had to do everything from my couch. So, that's when my voice was heard.

However, in analyzing the interview data provided by the Aboriginal mothers, it became clear to me that these experiences of substantive citizenship were not universal, even when considered in the context of an individual woman's life. Their experiences of having voices that were "heard" or "counted" were accompanied just as often (if not more often) by experiences of being silenced, disenfranchised, ignored, or marginalized. Each woman in turn readily identified times in which they felt they had not been heard by individuals and institutions representing the interests of the Nation-State, or when they felt their voices did not count in interactions with these agents. Their lived experiences of substantive citizenship varied greatly between and among institutions of the Nation-State, in some cases protecting their entitlements to resources, recognition, and support, and in others ignoring these entitlements in ways that compromised their well-being. Cheryl's

experience of being pushed out of an education program offered by a community organization for Aboriginal mothers provides an example:

I had a problem with... the [Aboriginal program]. I went there and I didn't know anybody. And I took a little class. It was a TPS class. I had no problem with the teacher, but the main boss there, she has... a daughter that volunteers there. And her daughter ended up sleeping with my baby's dad. ... She told me [about it] in the Aboriginal Centre, in the kids' area, so I couldn't say anything or do anything. That's probably why she told me there. And then I was taking the TPS class, and I finished it and did all my subjects on it, and I ended up getting into an argument with the main boss. And she told me to go somewhere else... And I made complaints about it and I was never dealt with. (pause) Oh, and another thing was that, because of her daughter working, or volunteering there, I wasn't allowed to graduate with my class. I wasn't allowed to be there anymore, even though I'd finished the class.

For others, interactions with police officers who were dismissive, unresponsive, and in some cases blatantly cruel provided evidence that their voices had been silenced or marginalized. Indeed, five of the six women I interviewed reported negative experiences with police officers. For example, Jo-Anne describes an experience of being attacked by her ex-partner:

I was with my ex, and he started really using drugs and he got really abusive. And, um, one day I decided I was going to call so, I still had my cell phone. It was actually minutes prior to not having one. And, I decided I was going to call 911, and walk down to the police station there, and tell them what happened. So I called 911, and I was standing there talking to a 911 operator, and I realized I was standing in front of where the Native [police] Liaison Office used to be. And I told her, "I see him!" He was gone, but then I saw him across the street... And then he just came out of nowhere. So in the last minute I said to her 'He's right here!' You know, like, I'd told her he could be armed, but he'd been gone for ten or fifteen minutes. And, um, he came at me and smashed my phone. And she could have got somebody to come out. Nobody came out. I had to go inside the police station and get help. And I had my son in the stroller, and I was really upset, because, you know, I'm standing out front, and he's trying to attack me and smash my phone. And I was telling her, but then he smashed my phone. And she never sent anyone out. And I know that they can. She could have sent someone out, and at least got him. Because for

all I know, he's still wandering out there somewhere, you know? And he was right out front, and he still got away. They came up after I went inside. I went inside and waited 20 minutes before the police helped me. I didn't really feel I was heard then either. And the last time I saw him at my house, I waited for over 4 hours for the police to come.

(unknown speaker): I waited six once.

Jo-Anne: And it was really disgusting. The cop had the nerve to sit there and say "Oh, you don't bruise easy, hey?" cause he was looking t my face. And then, at the time, I didn't realize I had bruises all over my body. I was just waiting for them, and I just like.... And I felt then like he wasn't even going to... He was just going to go on. Like, "too bad, bye". You know? So then, it was really hard then, it didn't seem like I'd been heard.

When I asked Jo-Anne what the police should have done for her in that situation, she replied:

[I]t would have been nice if they'd sent somebody who wasn't such a jerk. You know? And if they'd gotten there sooner than 4 hours. Because after I had left and I was taken to a shelter, I realized I had a huge bruise on my stomach, under my shirt and all over my arm. And he didn't ask me that. He didn't ask me anything. He didn't even go look to where he could see that the door was kicked in, and he'd smashed stuff. And I told him, and he just brushed it off like it was nothing.

Experiences of male violence were common among the women I interviewed. Shannon shared an experience that she agreed was similar to Jo-Anne's, stating:

I had the same problem, where it took, like... They didn't care. It took an hour. I had my ex banging at my door for an hour, like yelling and screaming. I hadn't even been with him for two years. He was just stalking me again. And then, the cops, I was on the phone with her [indicates Jo-Anne] because I was scared. We were waiting on the phone for an hour. And then, when, as soon as they got there, he goes running down the stairwell. And then, instead of arresting him for harassment, they just brang him to his brother's house. What I would have liked to see is him actually getting arrested, me getting a restraining order. Even though those things don't always help. But at least I'd have it where he can't come into my building. Because for that period of time he was going into my building, falling asleep in the stair wells, waiting for me to come home. Standing across the street, waiting for me to leave the house when I was

going away. And you know, they didn't listen to any of that stuff. They just made it seem like, oh, we were still in kind of a relationship and I was just mad at him and didn't want him in. And I'm like, "No! I haven't been with him for over two years, ok? We've been separated that long." And they were just, "Oh well, we took him to his brother's house and he won't be back tonight." You know? Like, "He won't be bothering you tonight". And I was, just, like, why did it have to take an hour? What if he had actually kicked my door in? You know?

Super Woman, a former sex-trade worker who struggled with substance-use issues, observed that working in the sex trade leaves many women in the Downtown Eastside vulnerable to violence as well as disenfranchisement. This vulnerability is compounded when unresponsive law enforcement officials compromise a woman's safety. To illustrate, she described the following experience:

Before I had my kids, I was involved in the sex trade, and I was almost raped by this guy in the park. And, um... Thank god this other guy walked into the park to hear me scream. At the time I was really unaware of what was going on. This guy that I was with, I don't know why, but I let him smoke some heroin. Like, I don't know why, but he totally went insanely crazy. And I was yelling for help and stuff, 'cause then I realized that I had a knife in my purse and he had found that before I could get into it. So now he had it. And this other guy walking through the park heard me scream and he came over and he managed to scare the guy off. And then, I guess, another apartment in the area heard all the commotion and called the police. And the police came, and it was, um... Well, they saw the way I was dressed, with the high heels and the clothes. And just... at first they thought it was the guy I was with, and I was, like, "No! It's not him!". They had him up against the car and everything. And I was, "It had nothing to do with him!". So then they were searching us both for drug paraphernalia, and, um... I wasn't even known to police, and they just did all this stuff that made it seem like I was asking for it. Like, "well, you were out on the street".

Super Woman further emphasized the consequences of being "discounted" for women who experience violence in this way:

I know this isn't just my problem alone, because I've read reports from sex trade workers and stuff. And that's probably one of the biggest times you feel unheard, when you're in that type of situation. Whether it's for survival, or addiction, or whatever, your way of life, or whatever reasons you're in there. You know? You're not heard by police and you've been discounted. And it's really painful, because it makes you feel that you can never go to the police if you have something bad happen to you. So, I don't have a whole lot of trust in the police officers down here.

Indeed, in analyzing experiences and analyses the women shared with me in these interviews I was repeatedly struck by the ways in which the citizenship/membership interests of young Aboriginal women are articulated through the display of entitlements (or lack of entitlements) to safety, dignity, and autonomy.

Claiming Dis/Ability: Medicalization as a Mechanism for Securing Substantive Citizenship

The women I interviewed were well versed in the medicalized discourses of FAS and FAE. Tricksey provides a typical illustration. In response to my question "In your daily life and experiences, what has FAS or FAE meant to you?", she replied:

FAS is Fetal Alcohol Syndrome and FAE is Fetal Alcohol Effects. FAS is a full-blown syndrome, where you might see the facial characteristics, where they might have a thinner upper lip, and their eyes are beady, and then they're born, it's a low birth weight. And it's just how it is. And of course on the inside, their body, their brain, it's dysfunctional... Yeah, and FAE, they have just a normal look, but sometimes they might have the hyper... like a child that's really hyper... [O]ne of the things that FAS will have is a loss of memory. You have to tell them something constantly. Like, you have to repeat something to the FAS person over and over. And, um, they constantly lose time, and they don't know the cause and the effect when they get older.

Wonder Woman's response to this question indicated a similar medicalized understanding of the causes and consequences of FAS/FAE:

I know some adults, but I know some kids who are, well, I shouldn't say 'full-blown', I guess it's not 'full-blown', but they have almost all the characteristics of FAS. And that's what I think of when I think of FAS. The kids that are short, eyes that are small, that have learning disabilities, that don't understand the consequences, that are born with multiple birth defects. You can... that's what I see FAS is.

However, while some of the women I interviewed accepted a medicalized understanding of FAS and FAE, it is important to note that they also contested medicalized discourses that position individuals with FAS/FAE as overwhelmingly "different" from "normal" people. For example, Super Woman cautioned:

[T]he thing to remember about this is that a lot of regular kids without FAS are gonna have these characteristics. They're gonna have these traits. But the thing to remember is the difference... It's more the build-up. When you compare, when you compare each child, the FAS child will have more severe. The other kids might have tendencies to be like that, but they're not always like that. So that's one thing I like to remember. When people, like, jump. Oh, my child has this and this and this, they must be FAS. And I'm like, slow down first.

Shannon emphasized that the techniques she had learned to educate and parent one of her children who has FAS were equally useful in parenting and educating her children who do not have FAS. She stated

[I]t's helped to learn about it and have the information [about FAS and FAE] to be able to do that [parent her children]. And it helps dealing with children without FAS as well, you know? Like, just the way you would teach a child with FAS, you have to spend more time, and repeat over and over again.

Meekosha and Dowse (1997) observe that medicalization can also be necessary, if problematic, process for laying claim to necessary resources via contemporary welfare

states. In the interviews, the women repeatedly noted the importance of medicalization for supporting the well-being and enfranchisement of their children, families, and communities via the provision of appropriate supports. Super Woman's experience provides an example:

In my pregnancy with my son, I went to do an assessment with my daughter for FAS and... I was about half way through my pregnancy and I was pretty stressed out I was highly still involved with drugs and alcohol at this part of my pregnancy and... [My doctor] shifted the focus and realized what was happening, and tried to change it around to getting supports for my pregnancy with my son, which was great.

Indeed, for many women, the fact that their children had not been able to access appropriate diagnostic and support services for FAS and FAE was a substantial barrier to securing recognition and supports for their struggles as mothers. Shannon's struggle to access resources for her son, whom she believes has FAE, was shared by most of the women I interviewed:

When I was pregnant with [my son], I came to [a pregnancy outreach program] And they said I couldn't get in because I didn't live close enough to them...And out of all my kids, I think he was the one who would have really benefited from the program, because he has health problems and speech delays, and all the delays that he has had. You know, I'm getting help with him now from [the program], but when he was an infant is when I would have liked to have... it's when he really could have used that help.

For many of the women, having accurate medical information about the causes and consequences of substance use during pregnancy and about the diagnostic criteria for FAS/FAE provided grounds for exercising their substantive citizenship interests, in that the information created some of the conditions that enabled them to make autonomous decisions regarding the health and well being of themselves and their children³⁵. Super

³⁵ I describe the role of education and information-sharing about FAS/FAE and substance use during pregnancy in Chapter 6.

Woman shared her recollection of an acquaintance for whom lack of information about the effects of substance use during pregnancy led to the death of her fetus.

I knew an Aboriginal woman in Surrey who was really young. And she knew not to drink, but she continued to smoke crack. And she kept getting bigger and bigger, and then one day I asked where she was. Someone said she was at the hospital. And then she came home, and the baby was dead. It had a heart attack when she was getting high. And everyone worries that you can have a heart attack when you smoke crack. Well, your baby can, too.

While education remained an important mechanism for enfranchising young Aboriginal mothers who struggle with substance use issues, the women I interviewed repeatedly emphasized that information without structural supports provided by the welfare state and personal supports offered by networks of women in the community would be insufficient for improving their material conditions. Jo-Anne explained:

They definitely need a lot more support. Because from the women I've talked to in the groups, they drank and stuff, and they obviously needed support. Like some people said they were angry with the baby's dad taking off on them. Or just dealing with the pressures of friends who weren't being supportive, and instead of saying "you're not supposed to drink", saying "who cares? Let's go out to the club!", and you're going to burst any second... You need support systems. Like, I know it's hard trying to find new friends when you're pregnant and stuff, but that's a thing too. If you're so used to clubbing, you need something to do other than going out clubbing and drinking. There's lots of stuff that needs to be done. Like I said, I didn't know most of the stuff. There's not a lot of information out there, other than "here's a pamphlet, here's why you shouldn't drink". Because nobody sits there and tells you unless you get involved in a program.

Indeed, while all the women agreed that the education and support program they attended together was invaluable in providing them the resources and supports they required to support their well-being as women and mothers, and the well-being of their children, all the women also noted that access to appropriate programs was difficult, and there were

not enough programs to meet the needs of women in the community. Often, this occurs when mandates of service providing organizations are too narrow to accommodate the diverse needs of women in the community. For example, Shannon recommended an expansion of infant development workers to other organizations in the community, based on the consequences of her experience of being denied access to their services for her son:

I think what would have been done differently, or done at least, would have been to have infant development workers in other places, you know? Like, I'd never heard of that until the [program]. Right? I'd never seen them, or heard of that position before. If I would have been able to go somewhere else and bring him there, that would have been... I would have been able to start helping him at a younger age, rather than waiting 'til he was two and then starting speech therapy. So, those kind of things. Just having those kind of things accessible to those people who aren't in the mandate of the service program. There are a lot of people who don't know how to ask for help, and then when they do, they get turned away, so they don't want to go ask for more help. At least they should have some other places to send people, if they are turning them away. You know, for whatever reason?

AS: It seems like you were left, really, with nothing.

Shannon: Yeah, I was, you know? 'Cause I was in a really bad relationship, and I had lots of different issues at that time, that... that... It was difficult. And I didn't even want to go there in the first place, but I did, and then they said "Oh, no". It was hard. But I'm still glad I went.

The medicalization of FAS/FAE also proved supportive of Aboriginal mothers and children in indirect ways. For example, some women spoke of the ways in which applying medicalized "labels" to explain the behaviour of individuals diagnosed with FAS or FAE helped them to make sense of their experiences with their children, families,

or partners that had been confusing or painful for them. This is well illustrated by Jo-

Anne's comments regarding the value of the FAS/FAE program she attended:

I've learned more about the people around me. Like, why they're like this, why my family is messed up, or why people I've been with are messed up. That it's not just them. It's issues that are out of your control. And I think with parenting, if there's ever any issues, it's that it helps you not to think you just have a "bad kid". You know? It helps, the labels. You know, finding out the source issues.

Shannon noted that lack of access to medical diagnostic services proved a substantial impediment to service providers willingness to act on her concerns about her son's well-being. She explains:

With my child, I had a hard time with people taking it seriously. Like, "Oh no, he just wants to be in the stroller, it's his age". You know?... So that's where I've found it hard, just getting the help I needed.

For Shannon and her son, the process of medicalization was important because it assisted her efforts to have her son's challenges recognized and supported. On multiple occasions, women also spoke of how medicalization of FAS/FAE has lead to an improved understanding of the challenges faced by those who have been affected by prenatal substance exposure. In fact, without a diagnosis of FAS or FAE, the women noted that some people with FAS or FAE come to be viewed as hopeless or disposable to their families and communities. Jo-Anne explains:

I think that happens, well, it's like what happened with me growing up. Like, they're not really aware of the effects, so then, you know, they think that they have bad kids, and they treat them as bad, and then they give up on them. You know, because they're kids who can't stay out of trouble, or kids who can't learn, you know, more drop outs. It's nice to see now more understanding. They understand now that these kids aren't just bad. They're not

just stupid. They're not just lazy. Like, it's the same with grown-ups. Why can't you hold a job? Why are you such a deadbeat? You know, it helps.

In the passage above, Jo-Anne also invokes and troubles familiar stereotypes frequently used to characterize Aboriginal peoples in general (i.e. those “who can't stay out of trouble”, “can't learn”, are “lazy”, who “can't hold a job”, or are “deadbeats”).

Accordingly, the medicalization of FAS/FAE may also be seen to inform challenges to popular racisms and colonialism that provide a hegemonic rationale for the marginalization and exclusion of Aboriginal peoples, as well as racialized and productivist conceptions of citizenship³⁶.

Dis/abling states: the contestations and contradictions of medicalization for substantive citizenship and social justice

For the young Aboriginal women I interviewed, substantive citizenship was evidenced and articulated in three ways. First, the contested domains of women's citizenship interests were evidenced in their efforts to have their voices heard and acknowledged. The women spoke repeatedly of struggles to be taken seriously when voicing their experiences, concerns, or claims to resources. Education proved also to be an important site in which these women's citizenship interests were negotiated, upheld, or compromised. While some identified formal education programs and institutions (such as a public school or adult education program), they also spoke of the importance of having access to accurate, detailed, and appropriate information from health care and social service providers about FAS/FAE and substance use during pregnancy. Access to this

³⁶ For discussion of discourses of productive citizenship, and their implications for Aboriginal peoples, women, and people with disabilities, see Chapter 2.

information supported these women's substantive citizenship by creating some of the conditions enabling them to make autonomous decisions affecting their and their children's well being. Finally, the women I interviewed identified challenges they face in the fundamental domain of substantive citizenship: the structuring of discursive and material practices that position young Aboriginal mothers and their children as worthy and deserving of help when in need. For example, Jo-Anne stated that racist stereotypes of Aboriginal peoples as alcoholics in need of specialized services to prevent maternal substance use leaves many Aboriginal women feeling like "they don't deserve help" when they want or need to access supports related to substance use or FAS/FAE. She explains:

To just focus on Aboriginals, it makes you feel more ... what's the word? I don't know if stigmata is really applicable, but there's a lot all ready. Like, people talk about treaties, and people already think badly about Aboriginal people...I think, too, it limits when you say Aboriginals and people who aren't. Or people who aren't aware they are. You know? Then they don't want to go. You know, like they feel they don't deserve help. And then people who are racially biased, they'll be, "see look." There are people who complain about "oh, they get all these things. You can see why they need it. They can't not drink when they're pregnant". That what I mean about stigmata, like, the bad label.

As such, institutionalized and popular racisms, sexism, and ableisms are experienced by the Aboriginal mothers I interviewed and present barriers to accessing the services and care they want and need. As Jo-Anne notes, this results in negative consequences both for Aboriginal mothers and their children who have FAS or FAE.

The process of medicalization was one that the women I interviewed identified as important for helping them to secure both recognition of the realities of their and their children's lived experiences and access to the medical, financial, educational, and other

supports that are critical to their well-being. In receiving a diagnosis of FAS or FAE the young Aboriginal mothers found that their well-being was also enhanced by providing them an opportunity to reconsider experiences in their own families and communities that had previously been confusing or painful to them. Furthermore, discourses of medicalization may provide avenues for resisting naturalized and racialized stereotypes of Aboriginal peoples.

For example, in the current relevancies of the Canadian welfare state, people with disabilities must medicalize themselves in order to successfully advance claims for the recognition of their status as a differentiated, marginalized group and for the redistribution of resources that will enable them to improve their material conditions. Thus medicalization of impairments would seem to be a process for enabling the citizenship of people with disabilities. However, given the productivist notions of citizenship that are salient in capitalist Nation-States, medicalization also positions people with disabilities in biologically determinist terms as "burdens" on the resources of national economies and institutions. These realities were familiar to Wonder Woman, who recalled the impact these discourses have on her mothering experiences:

So now I'm seen as the disabled mom who went and had a kid that's disabled. A couple of times. Emily was revived when she was born, so I suspect, and that's what the neurologist suspects, that there's a lesion on her brain as well as a cyst, that the epilepsy, at least, comes from her traumatic birth. Lisa, um, her hips come from sitting upside down inside of me... But I've been medicalized for all my births, except for the miscarriages. I'm seen as disabled. I can walk, but I'm still seen as the mom with the disabled child. And now that she's got a seating device, and it's like, "oh, she's a burden on our government, and now her child's going to be.'

Without access to medical testing, diagnosis, and treatment Wonder Woman and her children would not have received many of the supports that have been crucial to their health and well being. However, Wonder Woman notes that being “seen as the disabled mom who went and had disabled kids” and receiving the supports they require (such as the seating device for Lisa) also positions them in popular discourses about disability as “burdens” on “our government”. The effect of this discourse is to undermine the substantive citizenship interests of people like Wonder Woman and her children, and to place significant limits on the epistemic space available to women and people with disabilities to articulate their experiences and mobilize for social, political, and economic justice (Roman 2001).

These experiences of the women I interviewed point to a need for a highly nuanced analysis of the complexities and contradictions in the relationship between medicalization and the citizenship interests of young Aboriginal mothers and individuals affected by FAS/FAE. Medicalization simultaneously enfranchises and disenfranchises people with disabilities as “deserving citizens” and “non-citizens”. The contradictions and contestations of these effects are not easily reconciled. At the same time, these tensions are significant for the mothers I interviewed, in that they shape and mediate their interactions with state institutions. These contradictions are best described in our exchange below, in which the women and I were developing an analysis of the experiences they articulated during the first interview:

AS: I was left scratching my head, because it seems like then the relationship between being medicalized...

Wonder Woman: Everything’s medicalized!

AS: Yeah, it's kind of double-edged. Because on one hand, it was seeming from the interviews that it's important to get the diagnosis, to do all those things, because that gives you access to the supports.

Shannon: But then you're labeled.

Super Woman: You're labeled. Like my daughter had an issue at school, um, and the principal told me I should go back to [a centre specializing in FAS/FAE diagnosis]. And I told him she doesn't have FAS or FAE, like, there's issues with her, yeah, but why would I go back there? She was diagnosed with not having it. But that's the first place he wanted to send me. And because she has all these reports and stuff. And now, I don't know. I'm feeling... well, I was the one that was advocating to get her all these supports. I'm the one that put her on all the waiting lists, and signed her up, and filled out all the paperwork, and asked for and advocated for myself. And now, because she's having problems, the principal is telling me it's coming from home. Like, that's where all the problems stem from. And I told him, "no, there's stuff going on at school, too". And I'll take my blame, or my responsibility part of it, but there's stuff going on at school. And he's like, "no, I don't think that's the case"...

Wonder Woman: The nurse at the hospital thinks that my house is a mess, that my kids aren't well fed, because I'm disabled. My house is spotless! I'm a neat freak! ...But I've got all the supports in place. Lisa was a preemie, and I was still in the hospital, phoning Infant Development... going "OK, we're going to need follow-up, she's preemie, she's got these problems". I was on the ball, two days after she was born, saying "can I make the first appointment?", because I knew there was a wait list. So I've gotten all the supports in place. If I needed something, I stood up.

The women I interviewed taught me that the substantive citizenship interests of young Aboriginal mothers and their children are frequently disregarded on multiple levels in their interactions with other Nation-State institutions, including those related to education, health care, social services, and policing. As Super Woman and Wonder Woman explain above, this often requires that mothers advocate on their own behalf and on their children's behalf for access to supports and services on the basis of a medicalized

“label”. Indeed, as I noted earlier in this paper, receiving access to diagnostic and other services that result in “labeling” of people with disability is not easy or guaranteed. As Super Woman and Wonder Woman note, the supports their daughters have been able to access are the direct result of their advocacy work. The importance of these mothers’ work in supporting the health and well being of their children cannot be overemphasized or underestimated.

However, these women’s experiences show us that advocacy on the basis of medicalization can have multiple, sometimes unintended, consequences for mothers and children. For Super Woman, the result of her daughter being “labeled” has required the recognition that some of her daughter’s “issues” at school may be related to prenatal alcohol and drug exposure. However, this has enabled school administrators to pathologize Super Woman’s parenting and living conditions as well as her daughter’s behaviour. In this instance, medicalization allowed school administrators to emphasize that “the problem is at home”, and consequently limit the epistemic space from which Super Woman can articulate her and her daughter’s lived experiences. The consequences of these limits are to eclipse the ways schooling practices impact children’s ability to learn and thrive at school. Similarly, Wonder Woman notes she has had to advocate to ensure that she and her daughter will receive appropriate care in and outside of hospitals, which requires a recognition by medical and social service staff that both she and her children have disabilities and need specific kinds of supports. While this advocacy has resulted in Wonder Woman and her daughters receiving the support they need, the effect of advocating using discourses of medicalization has also been to invoke stereotypes of

mothers with disabilities as unable to care for their children, including keeping a “messy house” with “kids [that] aren’t well fed”.

Similarly, Wonder Woman’s experience of medicalization in relation to her daughter’s disabilities has presented significant barriers to her ability to return to university and to her daughter’s access to childcare. She explains:

Even I...I hate being called “disabled”...There’s other issues. Like, if there were more accesses for me to go to school, or more programs and services. Not just, oh you’re disabled, let’s get you more money, it’s ... I want to get back to school. I want to finish. And even with Lisa, [one local daycare] has a 30 percent load of special needs kids in the daycare, and I went to the other 2 [local] daycares, and they refused to take special needs. So this 1 [local] daycare has to take up the load from the others. Well, she’s special needs, and I called up a few other daycares and they’re, “oh, our special needs placements are full”. I said, “well, could you put her in a regular spot?”, and [they said] “well, we can’t”.

In sharing this experience, Wonder Woman underscores the ways in which using medicalized discourses of disability obscure the social, political, and economic conditions that contribute to the marginalization of people with disabilities. Indeed, by emphasizing the lack of resources available to her in her community that would support her return to school, Wonder Woman reminds us that the impact of a disability on a person’s life is mediated considerably by the availability of structural supports that some people with disabilities require to access public institutions (in this case, post-secondary education institutions) and services (such as child-care). These conditions must also be understood in gendered terms, in that as a single mother, Wonder Woman’s ability to access post-secondary education is limited much more significantly by her lack of access to childcare than by the effects of her disability.

Moreover, Wonder Woman's experience of attempting to access childcare demonstrates the ways in which medicalization, in this circumstance indicated by the description of Lisa and other children with disabilities as "special needs", can be experienced as both enabling and disabling. In some circumstances, the process and discourse of medicalization enabled Wonder Woman and her children to access the health care and social services they needed, including access to infant development workers, specialist physicians, and assistive devices. However, medicalization also proves disabling to Wonder Woman and her children, in that designating her daughter as "special needs" rendered her ineligible for a "regular spot" in the childcare centres in her community. As such, the practice of labeling Lisa a "special needs placement" meant that childcare centres could position her as having needs and abilities that are fundamentally different from, and perhaps in conflict with, the needs of "regular" children. Moreover, the practice of limiting the number of "special needs placements" in childcare centres further reifies the differentiated subject positions of disabled and non-disabled children, to result in "special needs" children having less access to childcare centres than "regular" children. These contradictions and contestations of medicalization and citizenship prompt the question: how social justice and substantive citizenship for marginalized groups be secured when the languages and mechanisms for identifying knowledge claims and oppressive material conditions requires the reification of the mechanism of oppression?

Abstracted notions of "citizenship" appear to have questionable utility when decontextualized from the relations between marginalized peoples and institutions of Nation-States. In order to effectively lay claims to status as "citizens", individuals or groups must first be recognized as "citizens" in both the formal and substantive senses of

the term, with voices that count and interests that matter in their daily interactions with the members and institutions of their communities and nations (Young 1990). The experiences of young Aboriginal mothers whose lives have been impacted by substance use and FAS/FAE confirm that many women and children who are marginalized by gender, race, class, nation, and dis/ability still await this recognition. Abstracted notions of citizenship, as defined in and through the formal recognition of rites and entitlements, mask the means by which substantive citizenship is negotiated and contested in people's everyday lived experiences. Abstracted notions of citizenship are further entrenched by rendering citizenship in monolithic terms, as something an individual or group does or does not have in all contexts, at all times. Supporting the substantive citizenship interests of marginalized women and children requires a recognition of the ways these interests are mediated and differentiated in and through their interactions with various institutional policies and practices at the local and national levels. These findings demonstrate that efforts to support marginalized groups in their struggles to secure rights and entitlements as "citizens" cannot ignore the structurally and contextually dependant domains of formal and substantive citizenship that shape the lived experiences of marginalized women and children.

To satisfy the anti-oppressive possibilities suggested by discourses of citizenship, we must ground our understandings of citizenship in the challenges of the local, particular material conditions and the social, political, and economic relations of people's everyday lives. Securing the full substantive citizenship of those peoples who continue to be marginalized by gender, race, class, dis/ability, and other aspects of social location, identity, and experience requires a transformation of specific institutionalized practices of

Nation-States as well as national economies that mediate substantive citizenship interests and are obscured in abstracted notions of the term. At the same time, we must continually question our own assumptions and relevancies as to who counts as a citizen, for what purposes, and under what terms.

Chapter VI: The Contradictions and Contestations of “Official Knowledge”: Articulating Public Pedagogies of FAS/FAE in the Initiative and in Aboriginal Mother’s Lives

As I have demonstrated in earlier chapters, some kinds of knowledge about FAS/FAE are recognized and taken up in the texts of the Initiative and by state institutions as legitimate: as worth knowing, teaching, and acting on in the development and implementation of public policy. After Apple (2000, 2003), I have referred to this kind of knowledge as “official knowledge”. In Chapter 1, I argued that official knowledge (Apple 2000, 2003) is often circulated through “public pedagogy”, or the informal social and cultural teaching/learning experienced by differentially located people in the context of their everyday lives (Luke 1996). As I argued, public policies, and most particularly public education campaigns supported by these policies, are powerful sites of public pedagogy. As I showed in Chapters 4 and 5, the circulation of “official knowledge” through the public pedagogy of the Initiative about the causes and consequences of FAS/FAE in Aboriginal families and communities not only shapes “common-sense” understandings of FAS/FAE in public discourse. They also have profound effects on both the discursive and material resources available to Aboriginal mothers and people diagnosed with FAS/FAE to have their knowledge and interests acted on in their communities and in state institutions in ways that improve the conditions of their everyday lives.

In this chapter, I will consider the function of official knowledge and public pedagogy in two specific sites: the public education materials produced to support the work of the Initiative and the lived experiences of the Aboriginal mothers I interviewed. In so doing, I reflect on the opinions and analyses offered by the women and the texts of

the Initiative about a) what Aboriginal women want and need to know about FAS/FAE; b) effective strategies for teaching and learning about FAS/FAE with and for Aboriginal women; and c) which individuals or groups require FAS/FAE education (and what kind of education each group requires). Through my analyses, I ask the questions: Whose knowledge is taken up and taught as “official knowledge” in the public pedagogy of FAS/FAE education, and on what terms? What differences and similarities exist in the pedagogic strategies embraced by the texts of the Initiative and by the Aboriginal mothers? How do the realities of Aboriginal mothers’ lived experiences translate (or fail to translate) into the “common sense” public pedagogy of FAS/FAE as articulated in the Initiative? In answering these questions, I highlight the points of contact, tension, and disjuncture between and among the texts of the Initiative and the women who participated in the interviews. I begin by turning my attention to the Aboriginal mothers I interviewed, and their understandings of what Aboriginal mothers in their communities want and need to know about FAS/FAE.

Getting the information: what Aboriginal mothers want and need to know about FAS/FAE

As objects of public discourse and “problems talk”, Aboriginal women are frequently positioned as the passive recipients of knowledge, rather than the active producers of it. These discourses suggest that professionals, including health care providers, social service workers, and educators, are the ones who should decide what kind of information Aboriginal women should be given about FAS/FAE and alcohol use during pregnancy. However, during the interviews I conducted with Aboriginal women whose lives include substance use and FAS/FAE, the participants very clearly articulated

both their own knowledge about FAS/FAE and what they believe Aboriginal women in their community want and need to know about it.

The public education materials supporting the Initiative suggest that the most important piece of information Aboriginal women and communities need about FAS/FAE and substance use during pregnancy is simply that a woman must stop drinking alcohol when she is pregnant to protect the health of her baby. For example, the posters produced by Health Canada to support the public education efforts of the Initiative prominently feature slogans such as “Alcohol and Pregnancy Don’t Mix”, and “Pregnant? No Alcohol!”. This messaging is in marked contrast to the experiential knowledge shared by the Aboriginal mothers I interviewed. Five of the women provided examples from their own lived experiences illustrating that they were aware of the importance of abstaining from alcohol during pregnancy for the health of their fetus, even in the absence of any formal or informal education about the subject. Each provided examples demonstrating how they internalized and acted on information they had learned informally about the relationship between drinking alcohol and FAS/FAE. As Shannon explains, these understandings guided her decisions about alcohol use during her first two pregnancies, before she had a detailed understanding of FAS/FAE:

I never drank with my first two pregnancies, and I was a teenager then. And I drank before I got pregnant, I just knew not to drink. I don’t know where I learned that from. But I didn’t know why. I didn’t know any of the effects of drinking. I didn’t know any of the things that would happen. I knew FAS, but what is FAS as a syndrome? I had no idea what it was, I just knew the term FAS.

In sharing this experience, Shannon points to a need for more detailed understanding of FAS/FAE that extends beyond simplistic messages provided to women urging them to prevent FAS/FAE by abstaining from alcohol during pregnancy. Unfortunately, this

information can be difficult to secure. Super Woman relates some of the difficulties she had trying to access the information she needed when she was pregnant:

I remember not knowing and going to the library in Calgary and looking up alcohol and pregnancy, seeing what it can do. And I didn't know that much, I just knew you shouldn't drink, and I was pregnant and I'd had these three drinking times.

As I noted in Chapter 4, the absence of this information makes it difficult for Aboriginal women to make autonomous, informed decisions about their health and the health of their children.

Information about the causes and consequences of FAS/FAE is not only valuable to individual Aboriginal women negotiating decisions about alcohol use during pregnancy. In detailing the benefits of attending Mary's FAS program, Jo-Anne emphasizes the importance of providing this information to Aboriginal families and communities who struggle with the negative effects of alcohol use:

We come from a long line of alcoholics. We've been around alcohol since we were really little. So now I understand, from the programs, it helps me to understand some of the youth issues, too. Like when I was young and running around and some of the youth, they just wouldn't get it. Like, the consequences. Like, they'd have this huge record and say, "I won't go to jail, I won't get caught", and then they would, but they'd keep doing it. It just makes no sense. And it's helped me a lot, too, understanding some of my brother's characteristics. It's hard. He doesn't have the small eyes or anything, but he's extremely hyperactive. He has attention problems, he has.... It's painful, but I'm learning now, more of what to expect from him.

The women also identified a need for the interrelated factors that mediate the effects of fetal alcohol exposure. For example, the women agreed that focusing on alcohol use alone as the key to preventing FAS/FAE ignores the other equally important supports women need to assure their health and well being during pregnancy, as well as those of

their fetus. Super Woman describes how this information helped her place substance use during pregnancy within the larger context of her living conditions:

Mary taught and showed me, too, that it's kind of like a weight scale. Like, if I'm taking care of my health for the most part, and eating well, and resting, and doing what you're supposed to be doing. And I'm not saying what I did was ok, but it kind of balances it out, so the effects aren't going to be as great.

A close reading of *It Takes a Community* suggests that the Initiative supports this type of FAS/FAE education, too. While most of the document focuses primarily on alcohol use in describing the causes and consequences of FAS/FAE, texts do note:

Alcohol causes a wide range of effects on the fetus... The effect or damage could be influenced by a number of other maternal factors including general health, diet, smoking, other drugs, genetic factors, and metabolism. (FAS/FAE Technical Working Group 1997: 70).

The women also expressed significant concerns regarding the lack of detailed information available to them about the effects of substances other than alcohol on a developing fetus. Super Woman explains that this lack of information is significant for poly-substance using women in her community, and obscures the fact that poly-substance use can have considerably greater impacts on the health of developing fetuses than alcohol use alone:

There isn't a lot of information on drugs and pregnancy. There's quite a bit on FAS, and pregnancy and drinking. They say the reason behind that [developing FAS] is because a lot of times when a woman is drinking there's other drugs, and cigarettes, and maybe pills or prescriptions that they're taking, so it's hard to kind of differentiate all those things...I'm sure more information would be good. Because the effects of things other than alcohol could be just as serious.

One such area the women I interviewed identified a need for more information was regarding marijuana use during pregnancy. In the texts of the Initiative, information about the effects of marijuana on fetal development is confined to one subsection in *It Takes a Community*. It reads:

Marijuana: Risk of low birth weight. May have some learning disabilities. Marijuana is often used with other drugs such as alcohol or tobacco so the baby is influenced by a combination of effects from multi-drug use (FAS/FAE Technical Working Group 1997: 72, emphasis in original).

During the group interviews, half of the women described misinformation they had heard circulated in their community about the effects of marijuana on fetal development, and decisions women had made based on this misinformation. This is well illustrated in the following exchange:

Jo-Anne: And that smoking pot, you can't smoke pot- this is what my friend said- you can't smoke pot, but you can eat it. So she ate it all through her pregnancy.

Super Woman: Oh my god.

Jo-Anne: So somehow from smoking it, the toxins from it weren't going to get into her body. Something like, you're digesting it so it gets into your body, but I guess, the effects on the baby's body weren't... like the baby's oxygen wouldn't have been decreased and stuff... I know (small laugh)

Others noted that misinformation is not limited to marijuana, but extends to other street drugs as well. Super Woman provides the following example of misinformation about cocaine that she reports circulates commonly in her community:

They tell you, especially with cocaine, too, that you just don't go into labour high, because, like, then your baby's born addicted. But if you quit before that, you'll be ok. And that's all bull shit, too, I believe. Luckily I didn't smoke a lot before. But that's all going on, too. The thing is that, yeah, don't go into labour high, because your baby will be born addicted. But there's way more than just that, and a lot of women don't know that when they're pregnant, and those drugs and alcohol are in their system.

The circulation of misinformation, or misleading information, about the effects of street drugs on fetal development is not an activity limited to Aboriginal women's peers. Jo-Anne shared how her doctor had also mislead her about the effects of marijuana use on her unborn baby:

I know I didn't smoke pot for the first while when I was pregnant with my son. But then I did, and I justified it... And I was so panicking, but there isn't information, because the doctor's said, "Oh, it's probably ok. If you don't smoke and drink a lot, it's probably ok". So then I went, "oh sure". And I was sitting there. And what I learned from the [FAS] group is that even then, it's not when you smoke every day, or you don't have a cigarette to yourself everyday. It can come out. Even after 18 months it can come out. So if it starts to come out after 18 months that my son has effects, then I have to own that. And if there's any issues ever, that's why.

Jo-Anne went on to describe how receiving misinformation from her doctor during her pregnancy made it particularly difficult to later learn that her child was experiencing impairments attributed to her substance use. She explains:

Being singled out for FAS and FAE was hard, too. Especially when you had a doctor who even said that. You know, my son's not even two. You know? So having that stuff for three years, you know? And then all of a sudden they turn around and point the finger, but then they're saying it's ok? You know, like some doctor's still saying it's ok to drink, it's no big deal, just as long as you didn't get smashed. You know? And then they turn around and point the finger at you, and you're like, what the hell?!

In studying Jo-Anne's narratives, and those of the other women who participated in the group interviews, I was struck by the fact that although the women frequently expressed frustration with friends and services providers who gave them misleading information about the effects of substance use during pregnancy, all the women used language emphasizing that they made a decision to use alcohol or drugs and that they are ultimately responsible for, or in Jo-Anne's terms, "have to own" the effects of their substance use that they were observing (or anticipating) in their children. The women I interviewed were generally very critical of what Jo-Anne described as the "shame and blame approach" to FAS/FAE education, which singles out individual substance-using women for scrutiny and condemnation without considering the conditions in which women negotiate experiences of substance use, mothering, and FAS/FAE. However, while the women highlighted many of the social and historical dimensions that shaped their substance use, their testimonies provide little opportunity or tolerance for constructing them in deterministic terms as passive victims of circumstance or actors without agency.

Recognizing that the impairments their children experience are the results of decisions they made inspired tremendous feelings of guilt that were shared by most of the women. Super Woman's experience below demonstrates this well:

I watched this movie one time with Mary... It's about this lady who smoked pot, and she was saying that if you smoke pot, your baby could be born webbed. It messes with the bone formation. And, um, I don't care if people know this: I'm a pot smoker. Still am. I smoked a little bit when I was pregnant with my daughter, but I smoked right through, even when I was in labour, with my son. And they told me, "Don't do it when you're in labour!". But I didn't listen, right? So it fucked up his heartbeat. So he was born, and I was checking out his whole little body, and... he's... it's not severe... but if you check, you can see a little bit of webbing on his

feet. And I just feel so guilty, because here it was all these years thinking smoking pot's not that bad, you know? And it does stuff, too. It slows down their learning process, too. But that doesn't seem to be an issue with my son. It could be, but I haven't seen him slow down, he's doing quite well. But those feet. I just feel so guilty every time I look at those little toes. And it's not that bad. It's not a huge deformation where it looks weird. But to me, because I'm his mom, it really weirs me out. So for me, I'm trying to let other women know. It's probably good that I shared that, because there's people out there that think there's nothing wrong with smoking pot. And the same time I'm a hypocrite, because I've had friends who were pregnant and were asking me to smoke with them, and I feel guilty about that, too. But it's their own choice, right?

Indeed, during the interview, Shannon explained that the information she did have about the different effects of fetal alcohol and marijuana exposure created conditions that made it possible for her to make choices for herself about substance use during pregnancy. She states:

I had a friend who would say to me "oh, you smoked marijuana, what's the difference? I mean, it's only one drink". And I would be like, "But I don't want to drink. And there is a big difference". I mean, just because I smoked pot during that pregnancy doesn't mean I should drink, too. You know? And add a whole bunch more problems then, too.

As Jo-Anne explains, the guilt and shame she lives with enables her to transform her lived experience into pedagogy. She explains:

I did drink with my daughter. I was about 4 1/2 months... I took the FAS course and some of the things she [Mary] told me with my daughter is showing up. And for me, that's my lesson. I drank, I did that to her. If I didn't drink she would never have had problems. And the only thing that I don't understand for myself is... If I have another baby, I'm not going to drink. And I don't understand, to be constantly having kid after kid and drinking, and drinking every kid. And they're raising these kids that all have problems, or getting their kids taken away. I don't understand. I'm stuck on that. I have a child that is FAS, it's not severe because she's only 11 months and I'm just starting to learn what she has. And... I mean... the society out there has to, I mean, if these

women don't want to help themselves, I guess they're going to have to do something about it. You know? Like, why does this lady keep having kids if she's constantly drinking? You know? Like, yeah, it's in my family, everyone drinks. But I'm not blaming them. I did it to myself. They didn't give me the beer. I paid for it out of my own pocket. But that's the one thing that I have problems with. For myself, I know that if I have another child, I'm not going to drink again. The only thing is, I really have a problem with someone that's doing it.

During the interviews, other women shared experiences like Jo-Anne's, underscoring the multigenerational dimensions of substance use and FAS/FAE for Aboriginal families and communities. Often, these experiences acted as a type of "private pedagogy" about the causes and consequences of maternal substance use and FAS/FAE.³⁷ Tricksey stressed the complexities of intergenerational alcohol use during pregnancy, weaving her grandmother's and mother's histories of alcohol use into her description of her own decision not to drink when she returned home to her reserve during her recent pregnancy:

I know that some of my family members are FAS because my grandma admitted it that she drank with her son, the baby of the family. And, um... he... my uncle's down here, in the Downtown Eastside, and he's been in and out of jail and all that. He knows that he's FAS, because my grandma told him that she did drink during pregnancy. So, I'm like, well at least one person admitted that they were drinking during pregnancy in our whole family. Because I know my mom and dad did drink constantly, even before we were conceived. They just drank, drank, drank. They had the money, so people said "Go ahead. Go drink".

So still to this day on my reserve, there's women drinking while they are pregnant. And, um, when I went home I never drank. Well, I did have one drink, at the beginning of the pregnancy, but I didn't know I was pregnant at the time. I only had one Caesar, that's it. And I was like, "oh my god!"

³⁷ For definition and discussion of private pedagogies and their relationship to public pedagogies (Luke 1996), see Chapters 1 and 3.

Integral to all the women's testimonies was an acknowledgement of individual women's agency in a context of multigenerational substance use and their own emerging understandings of the effects of prenatal substance use. However, acknowledging this agency makes it difficult for some of the women to negotiate relationships with family members who have given birth to children affected by exposure to alcohol and/or drugs. Indeed, Jo-Anne and Tricksey shared insights that suggest that experiences of guilt associated with substance use are also multigenerational. To illustrate, Jo-Anne describes her mother's reaction upon learning that Jo-Anne was attending Mary's FAS education program:

Like, when I told my mom. First, she doesn't listen all the time. So when I first told her I was in an FAS group, there was no response. Then afterwards she said "oh, it's good you're learning all this stuff". And then she's like, "Why are you doing that? Why are you in that group?". And I said "Because it's helping me to understand my family". And that was that, it shut her up, because she knows. And then after that, there was this: Because learning that, she kind of felt guilty, so she told me she didn't drink with me, but she drank with everybody else. But it was double-sided, because she told my sister that she drank a little bit with all of us, but is wasn't very much so it's ok. No big deal. You know? So, just telling her that, it helped understand things more.

Learning about the multigenerational effects of substance use during pregnancy inspired questions from many of the women during the group interviews. In fact, some of the women who are aware that their mothers drank during pregnancy identify their most urgent information need regarding FAS/FAE as whether they might have it themselves.

This exchange about the benefits of Mary's program provides an example:

Tricksey: I see that in my family. I'm going to Mary's group, and I took the first level, and now I'm taking the second stage. It's a good program for me to take.

AS: What helps you about that program?

Tricksey: What helps me? Just so that I can know that, and I can see that it's in my family. You know, my sisters, my auntie, my grandma. And maybe, I'm like, my god, maybe I'm FAE. I don't know, until I get an.... What do you call it?

Wonder Woman: Assessment?

Tricksey: Yeah, an assessment by a doctor here... Like... for myself I would like to get assessed on my own as well. Because when I was in elementary school, I was in the modified classes (pause). So, I don't know (long pause).

Wonder Woman lives with disabilities related to a spinal cord injury and has two children with physical and developmental disabilities. She is also concerned that she may have been affected by her biological mother's alcohol use. She explains:

My mother drank when she was pregnant with me, because she didn't know she was pregnant. She was 18 weeks, and she went for an ultrasound and she found out she was pregnant with twins. They told her two boys, and the other twin died. I survived, and was a girl. So, she drank until she was 18 weeks. And I looked into it, because then the information was just starting to come out. The only thing I notice is that I'm shorter than everyone in my biological family. Um, adoption records show that everyone was 6 feet. My mom is 6 feet. I hadn't even thought. But they looked into everything else, for my kids, but... (long pause)

“It needs to be everyone’s responsibility”: the role of male partners and friends in women’s substance use

It Takes a Community recommends that community-based FAS/FAE prevention include efforts to “Seek out the spouse, family, and circle of friends closest to the woman at risk to make them allies for support of changing behaviour” (FAS/FAE Technical Working Group 1997: 87). Indeed, during the interviews women shared how their substance use was shaped by the relationships they had with friends and male partners. However, some women also underscored that their substance use was often a response to, rather than a cause of, struggles in these relations. They identified a strong need for

information and support that would provide them and their male partners with alternative strategies for dealing with conflicts in their relationships. For example, Shannon explains the “cycle” of her alcohol use as a response that helped her cope with difficult periods in her relationship with her partner:

Just being in stress, having arguments, breaking up with your spouse, and then just not knowing how to stop that cycle of what do you do when you have a fight and argue? Go out, usually with your friends and drink. And that was kind of the cycle of what I did before, and it's really hard to break that.

Jo-Anne confirmed that Shannon's experiences with alcohol use in the context of relationships with partners and friends is unfortunately not unique, emphasizing:

They definitely need a lot more support. Because from the women I've talked to in the groups, they drank and stuff, and they obviously needed support. Like some people said they were angry with the baby's dad taking off on them. Or just dealing with the pressures of friends who weren't being supportive, and instead of saying “You're not supposed to drink”, saying “Who cares? Let's go out to the club!”, and you're going to burst any second.

The women who participated in the group interviews agreed that the male partners were important mediators of Aboriginal women's experiences with substance use during pregnancy, and must participate in FAS/FAE education. For example, Shannon states:

I think it needs to be everybody's responsibility. I don't think it should just be put on the mothers. I think it should be the father's job. I mean, I've had his dad [interrupted by son] like, made me drink a couple of times when I was pregnant with him, because he was... I mean, to try and make us not to fight, he would try to get me to drink, when I was angry and that kind of stuff.

Super Woman agreed, “The thing about what you're saying about people's intimate people in their lives is so true. I was either using with my son's dad and drinking, or because we'd had an argument and I didn't know how to deal with those feelings, so I'd drink cause of that, too.” The gendered dimensions of some Aboriginal women's

substance use are not confined only to the domain of lived experiences in relationships with male partners. In significant ways, the texts of the Initiative also evidence gendered dimensions of substance use in how categories of “risk” for FAS/FAE are (re)produced.

Engendering “risk”: education, intervention, and the roles of Aboriginal women and men

It Takes A Community favours FAS/FAE prevention strategies that are grounded in education campaigns “targeted” to women of childbearing age, elementary school children, young adults, men, persons with learning disabilities, community leaders, and the community as a whole. Indeed, one of the main contradictions of FAS/FAE pedagogy articulated in the Initiative is found in defining who needs FAS/FAE education and why. At times, the texts emphasize the ways in which all members of Aboriginal communities should become involved in FAS/FAE education and prevention efforts. For example:

Following the cycle of life, it is hard to know where to begin with education and prevention strategies. Does prevention of FAS/FAE begin in the womb or before, and who needs to be targeted? The ideas that follow start with strategies for women of childbearing age. But, *prevention strategies are equally important for all target groups.* (FAS/FAE Technical Working Group 1997: 81, emphasis added)

Elsewhere, the texts state:

FAS/FAE prevention is directly affected by whether or not a woman drinks during pregnancy. But it is not the responsibility of only the mother to change the drinking practice. This is a difficult part of preventing FAS. In the past, most health and social services would have focused on the mother and worked to change the drinking mother’s behaviour. Today, more people are recognizing that the mother and baby are part of a larger circle that involves partners, families, and communities- and everyone has a responsibility in preventing drinking behaviour during pregnancy. (FAS/FAE Technical Working Group 1997: 85)

However, closer examination of the texts makes salient the ways in which gender and dis/ability mediate conceptions of who is “at risk” for FAS/FAE and inform the pedagogic strategies suggested by the texts as best able to support community-based FAS/FAE prevention. The ways the texts position specific groups within Aboriginal communities by gender and dis/ability suggest conflicting pedagogies and differential outcomes for women and men with and without disabilities.

Given the intimate connections between FAS/FAE, maternal substance use, and the biological realities of gestation and birth, it is not surprising that education and intervention efforts outlined in *It Takes A Community* focus most intently on Aboriginal women. Indeed, while the texts of the Initiative often specify that efforts should target “women at risk”, the intervention strategies they privilege invoke a tacit assumption that all Aboriginal women are, to varying degrees, “at risk”. A section titled “Intervention Strategies for Women At Risk” provides an example:

Start with women of childbearing age, at puberty

- Emphasize effective use of birth control
- Emphasize respect for your body and traditional teachings

Educate about the facts of FAS in a talking circle session or small group

- Utilize creative ways to educate women and their partners
- Train peer counseling skills

Deal with the drinking through support and treatment

- Access to treatment and child care
- Target teenage girls
- Target women who have other children with FAS/FAE
- Educate the community workers who have contact with women who are at risk
- Provide opportunities to learn about the special needs of children with FAS/FAE (FAS/FAE Technical Working Group 1997:86)

Some sections of the passage above clearly identify specific groups of women as being “at risk” and a “target” as the result of certain behaviours or life experiences, such as

“women who have other children with FAS/FAE”, and women with a need to “deal with drinking through support and treatment”. Available research identifying “risk factors” for FAS/FAE confirm that women who use alcohol regularly and have at least one child with FAS/FAE are indeed more likely to have a(nother) child with FAS/FAE than those who do not (Kvinge et al 2003). Accordingly, developing support strategies for women in these groups to reduce the risk of FAS/FAE would appear reasonable. However, other passages from this same section underscore that in fact much broader categories of women are equally “at risk” and in need of certain “interventions”. These groups include “women of childbearing age”, beginning “at puberty”, and “teenage girls”. The absence of modifiers to describe these categories (for example, women or girls who have alcohol or drug addictions) further accentuates the unspoken assumption in the texts that all women by virtue of their reproductive capacity, regardless of their individual substance use behaviours, embody a “risk” to their communities requiring specific types of intervention. Indeed, it may be true that many Aboriginal women and girls who do not use alcohol or drugs would value the opportunity to learn about the “effective use of birth control”, “respect for your body” and “traditional teachings”. However, articulating these pedagogies through a discourse of “risk” highlights the gendered dimensions of FAS/FAE education that suggest all Aboriginal women bear a significant responsibility to reduce the “risk” posed by FAS/FAE that they cannot expect to share with all Aboriginal men.

Other passages in the texts evidence similar gendered conceptions of “risk”. For example, in describing the Traditional Motherhood and Traditional Fatherhood programs at the Skookum Jim Friendship Centre in Whitehorse, Yukon, the texts state:

The target groups include:

- Aboriginal young women
- Women experiencing risk behaviour during pregnancy
- Women who do not access prenatal health care
- Aboriginal men experiencing risk behaviours
- Men in parenting roles
- Future fathers (FAS/FAE Technical Working Group 1997: 61)

In reading this passage, it is important to note that the texts place “Aboriginal young women” as a whole at the beginning of the list of target groups understood as being “at risk” for FAS/FAE. Again, the assumption is made that simply because Aboriginal women are young and female, and presumably biologically capable of reproduction, they require interventions from service providers to reduce the “risk” they present in their community. This group is followed by non-age specific categories of women explicitly related to their reproductive activities: “women experiencing risk behaviours during pregnancy” (although the “risk behaviours” are undefined in the text) and “women who do not access prenatal health care” (although the reasons women are not accessing prenatal health care are similarly unidentified). It is significant to note that although “young Aboriginal women” as a whole represent a “target group”, young Aboriginal men as a whole do not. Indeed, Aboriginal men become present in this passage as target groups only when they are explicitly involved in fathering or (undefined) “risk behaviours”, either as “Aboriginal men experiencing risk behaviours”, “men in parenting roles”, or “future fathers”. This again reinforces a gendered discourse of “risk”, in which it becomes possible to assume that *all* Aboriginal women bear a biologized responsibility for reducing the “risk” of FAS/FAE in their communities, while Aboriginal men participate in “risk” reduction only socially, through certain behaviours and as fathers.

At other times, the texts adopt seemingly gender-neutral language

when referring to “at risk” groups. The passage below provides an example:

Many people who have FAS/FAE are at greater risk of misusing and abusing alcohol. They in turn could become parents of FAS/FAE children. Individuals diagnosed as having FAS/FAE must understand what happened to them so they are better positioned to prevent their children from having the same problems. When dealing with FAS/FAE persons who are learning disabled, emphasis should be on recognizing abilities and reinforcing self-esteem (FAS/FAE Technical Working Group 1997: 83)

Although this passage does not specifically single out Aboriginal women are the subjects of intervention, the pedagogic strategy underscoring that affected persons “must understand what happened to them so that they are better positioned to prevent their children from having the same problems”, and the direct linkage made between “misusing and abusing alcohol” and “becom[ing] parents of FAS/FAE children”, signals that Aboriginal women are the intended “target”. Moreover, the reference to “dealing with FAS/FAE persons who are learning disabled” adds a significant dimension to the role of gender and dis/ability in constructions of “risk”. The gendered dimensions of “risk” are underscored in an earlier passage:

Children of alcoholic fathers have been shown to have defects in intellectual function such as learning and memory and to be more hyperactive than children of non-alcoholic biological parents. These data have raised the question of whether these effects are the result of genetic transmission or a direct effect of *parental alcohol consumption on the father's sperm* prior to conception. *There is no conclusive evidence that parental drinking before conception causes direct adverse effects on the fetus*

The social effects of the father's drinking are enormous, as women most often drink with their partners. A father's drinking *after the baby is born* could also adversely effect the nurturing environment needed to raise a child. (FAS/FAE Technical Working Group 1997:72, emphasis added).

In stressing that there are merely “questions”, and in fact that “there is no conclusive evidence”, that “parental [used to signify biological paternal] drinking before conception causes direct adverse effects on the fetus” and privileging only the social and postnatal aspects of a father’s drinking as “enormous”, these texts consolidate meanings of “risk” in relation to FAS/FAE prevention that have differential and unequal implications for Aboriginal women and men, and persons with and without disabilities.

However, it is important to note that Aboriginal men as a group are not entirely discounted in the texts of the Initiative as an important part of community-based prevention efforts. For example, a section of *It Takes a Community* titled “Strategies for Men” suggest the following as components of FAS/FAE prevention specifically for men:

Traditional teachings:

- About men’s role and responsibilities in the family and community
- Opening “Grandfathers Trails” in traditional territories and learning the stories and laws of the land
- Role of men in ensuring a healthy pregnancy. The most effective way to do this is not to drink (Women usually drink with their partners)

Facts about FAS

- A broad based knowledge of FAS and its long term implications including the possible link between their own drinking and possible alcohol effects to the child
- Strategies for daily living with persons with FAS/FAE

Support and counseling

For men who are drinking and whose partners are drinking during pregnancy (FAS/FAE Technical Working Group 1997: 83)

As can be seen in this passage, *It Takes a Community* clearly describes an important role to be played by Aboriginal men in FAS/FAE prevention, including educational activities aimed at cultural renewal, supporting their partners to have healthy pregnancies, learning

daily living strategies useful for people diagnosed with FAS/FAE, which are gender specific. However, what distinguishes the discursive positioning of Aboriginal men in this excerpt from the positioning of Aboriginal women in others above is the emphasis (or lack thereof) on risk. This passage does not explore how Aboriginal men's behaviours themselves are in need of intervention because they are "risky" in terms FAS/FAE prevention. Rather, this passage suggests that interventions for Aboriginal men are important, such as those to encourage them to refrain from drinking during a partner's pregnancy, because they will reduce the risk presented by Aboriginal *women's* behaviours.

The construction of Aboriginal mothers who use alcohol or drugs during pregnancies as "risks" to their communities, and the gendered stigmas associated with maternal substance use and/or giving birth to a child has been diagnosed with FAS/FAE, have effects that are not only discursive. These effects have material dimensions that impact young Aboriginal mother's everyday lives. Shannon and Jo-Anne spoke candidly of stigma they have experienced that is assigned to FAS/FAE education and the women who access it. These testimonies speak to a "common sense" understanding that FAS/FAE education is necessary only for substance-using women or those whose children live with FAS/FAE, and that mothers who use alcohol or drugs are "bad mothers"³⁸. Shannon described the frustration she felt when she encountered this stigma during a court experience:

I talked about being part of an FAS group with my lawyer through my court process. It was like, "Why would you do that? Why would you go to that? Why would you go to that kind of program

³⁸ For further discussion of the gendered, racialized, ableist, and class-specific discourses that construct certain groups of substance-using mothers as "bad mothers", see Chapter 2.

unless you had a child with FAS?" It was really, like, "Why wouldn't I do that? What wouldn't I want to learn about that? Why shouldn't people want to learn about FAS? Why should it only be a problem for people who have FAS?" And they were, "Well, why are you going to that?". Like, with testifying about what kind of programs I'm in, it's like, they made it seem like...they tried to turn it around into being a negative thing, when it should be a positive thing, just going and being informed. And I felt like the whole system was against it. ...I'm going because I want to be informed and I want to learn about it. And if I didn't have a child with FAS, I'd still go. You know? Like, that's obviously something that needs to be learned, not discouraged. And they were still, "why would you do that?". So that's frustrating, like why would it automatically come across as a negative thing that I wanted to understand this?

Jo-Anne also describes the importance of destigmatizing FAS/FAE education to encourage more people to access it: "Well, a lot of people think, too, it's that... I thought it, too, like I don't need to go there, I don't have FAS and I didn't drink with my son. But it's important".

"Education" and "role-modeling": strategies for sharing FAS/FAE knowledge in the context of Aboriginal women's lives

When describing teaching/learning encounters they found meaningful, the women made a distinction between "education" and "role-modeling". During the interviews, strategies were identified by the women as appropriate methods of FAS/FAE education with and for Aboriginal women in their community. As they used the terms, "education" generally described situations in which information is directly imparted to an individual through the sharing of facts. Some women voiced concern that Aboriginal women in their community did not have access to enough accurate and detailed information about the effects of substance use during pregnancy and FAS/FAE. These women argued for an

increase in the amount of information circulating to Aboriginal women in the community.

Jo-Anne, for example, urged:

There's lots of stuff that needs to be done. Like I said, I didn't know most of the stuff. There's not a lot of information out there, other than "here's a pamphlet, here's why you shouldn't drink". Because nobody sits there and tells you unless you get involved in a program. And I heard about this program from a friend.

When I asked her what she thought others in her community needed to know about

FAS/FAE, Shannon's response indicated a preference for an information sharing strategy supporting abstinence during pregnancy:

I think that what needs to be taught is that even one drink can be the problem. It doesn't have to be the whole thing with binge drinking. I think, well I was sort of unaware of that, and I think a lot of people have that perspective that it's only once in a while, or whatever, so it won't bother or hurt the baby. Because that's what they [friends] tried telling me, that "oh, it's not going to hurt the baby, it's only one", or whatever. I still believe that people know about it, but they don't really know about it, you know what I mean? They think that, and I was sort of like that before I took the FAS course.

As I noted in Chapter 5, the women I interviewed agreed that having access to information about the effects of prenatal alcohol and drug exposure on fetal and child development provides important supports to women who experience pressure from significant people in their lives to use alcohol or drugs while they are pregnant.

Moreover, the women I interviewed and the texts of the Initiative agree that people occupying a range of formal and informal positions in Aboriginal communities could provide this information to Aboriginal mothers, but that some community members are situated in ways that make their participation in FAS/FAE education particularly important.

Doctors are one such group highlighted both by the women I interviewed and the texts of the Initiative as having a significant impact on the success of FAS/FAE education efforts. *It Takes a Community* emphasizes the importance of physicians' participation in FAS/FAE education, underscoring that "Ideally, the physician should play an active role in educating the pregnant woman and creating awareness about alcohol issues in pregnancy" (FAS/FAE Technical Working Group 1997:86). Some of the women also argued that other health care providers should become more involved in FAS/FAE education for Aboriginal mothers. Wonder Woman suggested that more information about FAS/FAE and the effects of alcohol on fetal development should be provided to women in medical clinics, when a woman is first informed that she is pregnant. She explains:

I found out [about FAS/FAE] from the street nurses, because I didn't want to go to the walk in clinic, cause I was 18 with Emily, and I'd lost a pregnancy before hand. And so I went to the clinic on Main and Hastings, the one upstairs, to find out I was pregnant. And she told me nothing. Just "here's your prenatal vitamins". Nothing. You've got the perfect opportunity to tell her not to drink, because I was only 5 weeks along, not to drink, not to do this, not to do that.

Based on her experience with her physician, Jo-Anne agreed that doctors should assume a more active role in FAS/FAE education. She states:

One thing I had, when I was pregnant with my son: I actually had a doctor tell me that it was ok in the first two or three months, because if you didn't know you were pregnant, that's ok. It didn't matter how much you drank. And that was really stressful for me, you know? Like, especially it actually wasn't until this pregnancy that I actually went to FAS groups. And I'm, like, ok, this is absolutely retarded. There was never... there was none...like, it's true, in the doctor's office, most of them have posters, but most of them don't even have pamphlets about FAS. Just all I knew was that you're not supposed to drink when you're pregnant and that FAS can happen. But I didn't know what it was.

However, during the interviews participants also acknowledged that women who drink alcohol during a pregnancy often have considerable information about the effects of alcohol exposure on a fetus and the attendant risks of FAS/FAE. As such, they were concerned that prevention efforts by physicians and others that focus solely on telling women not to drink and emphasize the dangers of fetal alcohol and drug exposure obscure the realities of living with addiction. Super Woman explains:

One thing that I would like to say, at least for me, is that the addiction was there before I was pregnant and, like, I knew the possible damages that could happen. I didn't know the extent, but I knew that they could happen. But I had an addiction, and therefore, um, it's like you just can't stop the addiction.

Jo-Anne expressed a similar concern, noting "I'm only 25, but I've been a heavy drinker for 10 years. It's not just something where I decided to start drinking yesterday, you know, and now I'm going to stop. It's not like that." Accordingly, some women expressed reservations about the appropriateness of demanding that physicians and others emphasize abstinence-based FAS/FAE education as a means to support Aboriginal women struggling with addictions during a pregnancy. Super Woman shared her experiences of what she described as "full blown addiction" during her pregnancy, advocating in favour of the woman-centred, harm reduction approach to supporting Aboriginal mothers that she experienced:

When I was pregnant with my daughter, I found out and I quit everything right away. I used to think "How can women who drink and use when they're pregnant be so irresponsible?", and be such assholes about it, and do this to their babies. And then I ended up pregnant with my son, with a full blown addiction. And it wasn't that I didn't love him, you know? I had a lot of guilt, and I still carry a lot of stuff around with me.

But what I'm hearing is that some people are saying that their doctors should tell you "don't do this or this could happen",

or “don’t do this”, or whatever. I also think that they shouldn’t turn around and be the other way, either. Because sometimes I think that doctors tell you if you’ve had a drink don’t worry about it, because they don’t want to add more stress to your life. Like at [a community-based pregnancy outreach program], the doctors, they tried to do harm reduction with me, and not fully beat me up emotionally if something had happened. Because I think that if you’re being told “don’t do this” or if you did do something and they’re getting upset with you, that just makes you feel more guilty. And then the cycle keeps going.

So I think that it’s a really touchy topic, how to approach, and what to say to who. Because some women listen, but for me, it wasn’t about listening. With my son I had a lot of information. I was pregnant and doing Mary’s program, and I couldn’t even stay clean because it was bringing up so many feelings and emotions and I didn’t know how to deal with that stuff. So I’d leave with this fuel that I’d end up using drinking.

To be effective, the women I interviewed suggested that FAS/FAE pedagogies undertaken by all community members must be grounded in the realities of Aboriginal mothers’ lives and must sensitively and respectfully account for the guilt, blame, shame, and other emotional traumas with which substance-using mothers often live.

“Role-modeling” was the second pedagogic strategy embraced by the women I interviewed for providing information and support to Aboriginal mothers about substance use and FAS/FAE. To illustrate, Wonder Woman shared the benefits of role-modeling that she had experienced, which shaped her own decisions about drinking during pregnancy:

I knew, and no one ever told me, not to drink. Nobody. I never drank, but I had issues with the medication they were putting me on. Um, except her [daughter’s] dad was always, “let’s go party”, and I was always, like, “no”. Cause from when I was a little kid, I knew, cause one of our friends has lots of kids. I always knew that when she was pregnant, she wasn’t allowed to drink. So that was my role model, seeing her not drinking and knowing it was bad. I remember after she was pregnant and the baby was out, that second she had a drink because the baby was born. (all laugh). But that

was how I grew up. So they need good role models, to see that women aren't drinking.

In discussing the kinds of supports that they feel Aboriginal women in their community need to make informed choices about substance use, Super Woman and Shannon also emphasized the value of role-modeling, as seen in the following exchange:

Super Woman: I feel that education is important, but role modeling is probably the best way.

AS: And it's another support, too, it sounds like.

Shannon: Yeah, it is totally a support.

In distinguishing between "education" and "role-modeling" as pedagogic strategies, Super Woman, Shannon, and many of the other women I interviewed underscored that Aboriginal women in their community want positive, supportive opportunities to learn from each other and from their service providers about maternal substance use and FAS/FAE.

Targeting "at risk" groups: educating the educators

Throughout the interviews, the women emphasized that education about substance use and FAS/FAE should not be provided only to pregnant Aboriginal women in their community. Some mothers spoke of an urgent need to introduce FAS/FAE education well before pregnancy, beginning with children in the public school system. In the following exchange between Shannon and myself, she underscores the importance of education efforts that support children to learn about substance use in ways that extend beyond the abstinence model favoured by many drug and alcohol educators:

Shannon: I personally think that they should start teaching it in schools. That's the only way it's going to be taught. Especially to young kids. Because there's lots of teen moms, and lots of teen dads. And not only that, its a general thing that people need to learn about. At least it seems that way to me. Like, you know, about substance abuse. Not just, "oh, stay away from drugs".

AS: Like the "just say no" stuff?

Shannon: Yeah, you know what I mean. There are reasons. Like when you grow up and you have kids, they could be affected.

In light of her own experiences of peer pressure that made it difficult to abstain from alcohol during her second pregnancy, Jo-Anne agreed that educating children about FAS/FAE is critical:

I think it's also helping teaching the kids. Maybe that will help reduce the chance that friends like ours, they won't do that. You know, they'll know that, you know, that it's wrong. You shouldn't get your pregnant friend to drink. You know, especially since they knew that I used to be a really big party animal. I mean, they knew that this was the thing. So maybe that will stop the future friends from saying "oh, it's ok, go ahead". You know?

It Takes a Community supports a position similar to Shannon and Jo-Anne's, stating:

Children need to know the actual facts of FAS/FAE and how to prevent it before they begin to be sexually active and before they begin to use alcohol and drugs. An emphasis needs to be placed on how important it is not to drink if a person is at any risk of becoming pregnant. Otherwise drinking could occur before they are even pregnant.

These children may also have classmates, friends, and relatives who are living with FAS/FAE. They need to know how to support these friends and relatives and help them find a productive life path. The more they know, they more they will be able to help (FAS/FAE Technical Working Group 1997: 82)

However, children are not the only group the women identified as being in need of FAS/FAE education in the public school system. Shannon argued that mothers of

children with FAS/FAE would be better served if teachers, principals, and other support staff in schools were better educated about FAS/FAE:

There are kids who are affected at school, and school teachers, principals, those people that need to deal with you a lot, they should take workshops or something. Like, they should have a particular set course for professionals and for schools, so they could be more sensitive to the issue. Because I don't know what it will be like next year when he's [her son] in school. (snip)...And it's hard to explain that [her son has FAE] to people and have them understanding. And it's hard to explain, like, maybe I drank when I was pregnant with him, so maybe he has health issues because of that. You know what I mean?

Given the high degree of stigma associated with maternal substance use and the negative consequences for Aboriginal women and families linked to disclosure of alcohol and drug use during pregnancy³⁹, it is not surprising that Aboriginal women whose lived experiences have included substance use and FAS/FAE would identify the consequences of disclosure as a barrier to accessing support services for themselves and their children. Voicing similar concerns similar to Shannon's about the consequences of disclosure for herself and her children, Super Woman explained that she was unable to access the services she needed during her second pregnancy to support her health and the health of her children: "I felt like if I said things to people that I would be judged, or possibly my other child would be taken away while pregnant, and just all the negative consequences that I didn't think I could trust around it." Jo-Anne expressed frustration with the reactions of others when she discloses her history of substance use during pregnancy, saying "It's like you're a bad person automatically...I'm trying to get help now, but it doesn't count for anything."

³⁹ For detailed discussion of this issue in academic literature, see Chapter 2.

This reality of Aboriginal mother's lived experiences renders problematic one of the premises of *It Takes a Community*: that parents of children affected by FAS/FAE should take a leading role in providing education for schools and other institutions about FAS/FAE and the needs of their children. For example, in the section of *It Takes A Community* titled "Advice for Caregivers", the texts state:

Without the recognition of FAS/FAE as a neurological disorder, parents or caregivers of children with FAS/FAE are often subjected to unwarranted criticism of their ability to parent the child. The extraordinary energy required to parent an affected child needs to be recognized through support groups and respite care. However, this will happen only when caregivers and others who deal with the child are aware of the nature of any disabilities, and just as importantly, know of strategies that work with the child. *Ideally the parent, as the main advocate for the child, should make the effort to inform others- this way caregivers are better positioned to help the child and parents.* (FAS/FAE Technical Working Group 1997: 111, emphasis added)

The experiences of the mothers I interviewed suggest that in the absence of conditions that enable mothers to disclose their histories of substance use without fear of reprisal from service providers, including educators, it can be difficult for mothers to act as FAS/FAE educators and as their child's "main advocate". Moreover, these experiences point to the importance of educating teachers and administrators about the material conditions in which Aboriginal mothers and their children live that shape experiences and consequences of substance use. As their testimonies demonstrate, educators seeking to create welcoming environments for Aboriginal families affected by substance use and FAS/FAE must understand that the effects of substance use and FAS/FAE are mediated by experiences of poverty, inadequate housing, unequal access to health care and health education, gendered dimensions in intimate relationships, and lack of support. These experiences also highlight the importance of acknowledging Aboriginal mothers' agency

in the contexts of these experiences (including the efforts made by Aboriginal mothers to improve the conditions in which they and their families live) and the expertise of mothers who are parenting children who have been diagnosed with FAS/FAE in destigmatizing FAS/FAE. Together, this type of professional development for educators may create some of the conditions in which parents can better advocate for their children in and outside of schools.

Conclusions: becoming “official knowledge” and “public pedagogy”

Close reading of the Initiative’s public education and resource materials alongside the experiences and analyses of the Aboriginal mothers I interviewed shows us that the relationship between public and private pedagogies and what comes to count as “official knowledge” is complex and, at times, contradictory. These findings prompt many important questions, which have no clear answers or solutions: How can we account for the overlaps, disconnections, and tensions between the pedagogies articulated by the Aboriginal mothers and the pedagogies of the Initiative? How does some knowledge regarding the context, causes, and consequences of FAS/FAE get taken up as “common-sense” and “official knowledge” in certain contexts, while other knowledge does not?

It is often tempting in circumstances such as this to turn to a reductive analysis of cultural reproduction in the “common-sense” and official knowledge of public policy and public pedagogy. Reductive analysis of this type assumes that marginalized or disenfranchised groups (such as urban Aboriginal mothers living in poverty) have interests and analyses that are monolithic, and that are always in opposition to the interests and analyses of more powerful groups, including State institutions. This would have us believe that marginalized groups who take up positions similar to those of

hegemonic institutions are simply “cultural dupes”, unable to appreciate the inherently conflicting interests of marginalized and hegemonic groups. However, my reading of the testimonies offered by the 6 Aboriginal mothers who participated in this research convinces me that this is not the case. Theorizing their lived experiences demands attention to the structural factors that mediate the production, circulation, and reception of official knowledge. At the same time, it is imperative to account for Aboriginal mothers’ individual and collective agency in understanding, articulating, and negotiating the complexities of FAS/FAE in their daily lives. This requires an understanding of the specific social, political, cultural, and economic context in which official knowledge and public pedagogies in Canada are created and circulated.

In my discussion above, I noted that the opinions and analyses advanced by the Aboriginal mothers regarding their own lived experiences and the kinds of FAS/FAE education and supports women in their community are at times also evidenced in the texts of the Initiative. This is not coincidental. Indeed, FAS/FAE emerged as a policy and programming area for Health Canada and FNIHB in part because of hard-won gains made by Aboriginal peoples movements to have the State respond meaningfully to the effects of colonization in Aboriginal families and communities. These effects include FAS/FAE. These movements also demand that the State uphold its fiduciary duties to Aboriginal peoples. Among these are the duties to honour the rights and entitlements protected by treaties, to provide medical care, housing, and education, and to support Aboriginal communities in capacity-building and self-determination.

At the same time, certain aspects of the Canadian political landscape shape preferences by dominant groups and hegemonic institutions to favour some types of

policies and programs more than others. As had been irrefutably demonstrated by the Royal Commission on Aboriginal Peoples (1996), policies of the Canadian Nation-State have traditionally blamed and scape-goated Aboriginal peoples for the social problems arising from residual effects of colonialism in their communities. These policy directions continue in the contemporary Canadian context, and have disproportionately targeted Aboriginal women, and particularly those Aboriginal women who use alcohol or drugs, as a “risk” and even a “threat” to their children, communities, and to the institutions of the Nation-State⁴⁰. Approaching Aboriginal women as “risks”, rather than as sources of knowledge and strength, eclipses the contributions and insights Aboriginal women can offer to FAS/FAE education and prevention efforts in and beyond their communities. It also enables public discourse and policy responses that minimize or neglect the “risks” posed by the behaviours of male partners, friends, family, health care providers, educators, and other community members in relation to issues of substance use, pregnancy, and disability.

The effects of these practices are particularly apparent in examining the areas in which the experiential knowledge articulated by the Aboriginal mothers I interviewed departs from the issues, experiences, and analyses advanced in the texts of the Initiative. As can be seen from the interview excerpts included in this chapter (and others), those aspects of the women’s experiential knowledge that are not included within the relevancies of the Initiative tend to be those that challenge the positioning of FAS/FAE as a “social problem” in individualized, medicalized, and gender-specific terms. This reminds us that although the structural location of actors in relation to “official knowledge” cannot be considered in reductive or deterministic terms,

⁴⁰ For detailed discussion of this point, see Chapter 2.

The social institutions directly concerned with the “transmission” of this knowledge are grounded in and structured by the class, gender...and race inequalities that organize the society in which we live. The area of symbolic production is not divorced from the unequal relation of power that structure other spheres (Apple 2000:55).

The official knowledge and public pedagogies of the Initiative carry significant material consequences for Aboriginal mothers of children who have been diagnosed with FAS/FAE. Together, they place limits on if, when, how, and with whom Aboriginal mothers can articulate their experiences and have them responded to by State institutions, including educational institutions. In the next chapter, I build on these concerns to consider the roles of competing and contested ideologies of “culturally appropriate” pedagogies for FAS/FAE in Aboriginal communities, and the discursive strategies employed in the texts of the Initiative that foster the inclusion and exclusion of “traditional knowledge” in these relations.

Chapter VII: Adaptation and Decolonization: Unpacking the Role of “Culturally Appropriate” Knowledge in FAS/FAE Education

In their struggles to achieve self-determination, Aboriginal peoples have demanded that the State recognize the importance of cultural revitalization and renewal. For many Aboriginal communities, cultural revitalization and renewal efforts continue to be central in and beyond education for seeking healing, recovery, and justice in light of the legacies of assimilationist and colonial State policies (Battiste 2000). The importance of Aboriginal People’s movements in constructing the current responses of the Canadian state to FAS/FAE in Aboriginal communities should not be overlooked or underestimated. One example of this influence evident in the texts of the Initiative is in mentions made of the importance of incorporating “culturally appropriate” pedagogies and “traditional knowledge” into community-based FAS/FAE education for Aboriginal peoples. In this chapter, I draw on the Aboriginal mothers’ perceptions of the values and consequences of “culturally appropriate” pedagogies for FAS/FAE to inform a close reading of the Initiative’s texts uncovering what “counts” as “culturally appropriate” pedagogy, and on what terms. In so doing, I unpack the disjunctures and contradictions evident in the official knowledge and public pedagogy of FAS/FAE espoused in the Initiative’s texts in light of the women’s everyday experiences. Accordingly, this chapter extends discussion from the previous chapter, to emphasize the complex relations between agency, ideology, discourse, and lived experience evident in the Initiative. This chapter concludes with an analysis of the institutional and discursive practices that give saliency to the inclusion and exclusion of “culturally appropriate” and “traditional knowledge” in public policy and public pedagogy.

Adaptation: “culturally appropriate” pedagogies as acts of translation

It Takes a Community affirms that all FAS/FAE prevention efforts in Aboriginal communities should be grounded in education efforts that are “culturally appropriate”. In outlining the Initiative’s priorities for FAS/FAE prevention and underscoring the value of specific types of FAS/FAE prevention activities, the texts employ the term “culturally appropriate” in two distinct ways. In the first understanding of “culturally appropriate” approaches suggests that “traditional knowledge” or “the old way of doing things” remain significant ways of knowing and being for Aboriginal peoples in Aboriginal communities. As such, the texts argue that their use can inspire “positive” approaches to FAS/FAE prevention, and improve the chances that such initiatives will be implemented successfully. For example the introductory chapter of *It Takes A Community* notes:

Before contact with Europeans, First Nations and Inuit societies across Canada had their own customs and laws that guided people through life. While many changes have occurred since time of contact, the old way of doing things and guiding people are still an important foundation for personal and community development (FAS/FAE Technical Working Group 1997:59).

The passage above illustrates an additional tension evident in the text’s use of phrases such as “the old way of doing things” to describe the importance of traditional knowledge in FAS/FAE education and prevention. Despite the devastating impact of colonization on indigenous languages, spirituality, family forms, and governance structures, Aboriginal cultures retain vitality, growing and changing in response to the contexts in which Aboriginal peoples live. However, phrases such as “old way of doing things” fail to acknowledge the important distinction between Aboriginal cultural practices of the past and the philosophy, values, and principles that guide them⁴¹. This view eclipses the

⁴¹ I thank Jo-Ann Archibald for offering me this productive insight.

vitality of Aboriginal cultures in contemporary contexts, presenting a romanticized construction of Aboriginal cultures as static and unchanging.

The same chapter similarly states:

Knowledge of traditional practices relating to conception, pregnancy, and birth can be a good basis for developing community based prevention programs. FAS/FAE information presented in a larger socio-economic context may facilitate easier understanding of FAS/FAE issues by setting a positive tone for public education (FAS/FAE Technical Working Group 1997:58)

Elsewhere, texts describe how “old values and teachings” can provide a useful frame for service providers, which recasts the “special needs” of people diagnosed with FAS/FAE in ways that suggest challenges to contemporary (medicalized) understandings of disability.

Resource workers, coming to terms with the special needs of these community members, sometimes look upon persons with FAS/FAE as teachers who challenge communities to rethink existing perceptions and remember old values and teachings (FAS/FAE Technical Working Group 1997: 53)

It Takes a Community provides many examples of how incorporating traditional knowledge and values as “guiding principle[s] in FAS/FAE prevention will promote positive development in the community” (FAS/FAE Technical Working Group 1997: 54). The “guiding principles” for FAS/FAE prevention drawn from “traditional” and “culturally appropriate” knowledge that are included are: respect, hope, humility, compassion, patience, patience, and co-operation. Some of these principles are first introduced in the preface as “gifts from the creator”:

Children are a special gift of the creator. An individual child is not owned by the parents- but borrowed for a time to be in the physical world and live as an integral part of creation. A new child has been given many “gifts” by the creator. These are interpreted differently by Aboriginal

nations- but they are generally known as humility, respect, compassion, courage, truth, wisdom, and love. These gifts provide guidance and strength to the child. How these gifts affect a child's life will depend on the nurturing received in the child's home and community. A stable and loving home will bring out these special attributes in the child. In turn, the child will help to make the future for his or her community (FAS/FAE Technical Working Group 1997: 47).

Decolonization and revitalization: “culturally appropriate” pedagogies as acts of cultural renewal

The second approach to “culturally appropriate” pedagogies evident in the Initiative differs in important ways from the adaptation approach. The second approach focuses less on translating a generalized program into the specificities of existing cultural practices of a particular group. Instead, this approach emphasizes efforts to counter the effects of colonization in Aboriginal communities and encouraging the revitalization and renewal of traditional cultural practices and teachings. This approach to “culturally appropriate” pedagogies compels recognition of the historical, social, political, economic, and cultural dimensions of FAS/FAE in Aboriginal communities. This approach also supports views of Aboriginal cultures as generative and dynamic, which change over time in light of the social, geographic, economic, and political contexts in which the culture is practiced (c.f. Geertz 1973). This approach is well illustrated in the following excerpt from a section in *It Takes A Community* titled, “Understanding the “root causes” of FAS/FAE in Aboriginal communities” :

FAS/FAE in Aboriginal communities can find its roots in Canada's colonial past. The deterioration of Aboriginal political and social institutions; the suppression of traditional spirituality, culture and language, the apprehension of Aboriginal children and loss of traditional lands and economies is the legacy of Aboriginal peoples after European contact in the new world. The current health and

socio-economic conditions trace their beginning to these historic events.

But Aboriginal people have never ceased in their efforts to survive and flourish. Today Aboriginal nations work actively to counter the devastating impact of colonialism. They are regaining control over their lives through the development of Aboriginal community-based institutions in the areas of culture, education, health, economics, and justice, and it is these efforts which provide a foundation and give direction to successful FAS/FAE strategies.

People designing community-based FAS/FAE strategies need to consider the root causes of alcohol abuse and the community responses... Likely the important initiatives in the community involve efforts to counter the debilitating impact of colonialism- the root causes of many social ills such as loss of lands, language, culture and resources. If possible and appropriate, these factors should be integrated into the strategy. This means that an FAS/FAE strategy could have linkages to a number of on-going community initiatives such as affordable housing, education, cultural programs, or recreation (FAS/FAE Technical Working Group 1997:65-6).

This approach to "culturally appropriate" FAS/FAE education is significant, in that it affirms that the health and well-being of Aboriginal women, children, and communities are connected to the historic, social, political, cultural, and economic conditions in which they live their lives, and their ability to influence or change these conditions. Recognizing these realities enables responses to FAS/FAE that not only challenge individualized understandings of the causes and consequences of FAS/FAE, but that also creates space for actions that support social justice and decolonization for Aboriginal Peoples.

The following excerpt detailing the importance of respect is further illustrative:

Respect is a fundamental teaching of indigenous peoples around the world. It can be summarized as respect for all creation- the land, animals, plants, people, and self. Respect comes from the belief that every living thing has a spirit. All creation fits into the circle of life and as such is deserving of kindness, caring, and honesty. Using respect as a guiding principle in FAS/FAE

prevention will promote positive development in the community, among family members, individuals affected by FAS/FAE and community workers. Respect can come from:

- Understanding the traditional First Nations and Inuit teachings.
- Understanding the history of your community- what changes has it gone through? What was it like before European contact?
- Understanding your family history- what has been the impact of colonization and economic development? How has alcohol affected the family?
- Understanding the mother's story- is she an adult child of alcoholics, at risk of FAS/FAE herself? Has she suffered abuse in her life? Does she currently live under stressful conditions?
- Understanding that the individual affected with FAS/FAE is, first of all, a spiritual being.
- Understanding that a person with FAS/FAE is a person with a disability.
- Understanding that a person with FAS/FAE has talents and potential.
- Healing the resource worker- the community worker will likely have, directly or indirectly, experienced similar traumas as the at-risk group in the community. Personal growth and coming to terms with past traumas must be respected as a vital part of community prevention activities. (FAS/FAE Technical Working Group 1997: 54)

The understandings articulated above challenge some aspects of medicalized constructions of FAS/FAE, in that the texts underscore the importance of understanding the contexts that inform how some Aboriginal women, families, and communities experience alcohol use and FAS/FAE⁴².

⁴² For a detailed description of medicalization and FAS/FAE, see Chapters 4 and 5.

Contextualizing the promise of “culturally appropriate” pedagogies: lessons from Aboriginal mothers

While the utility of “culturally appropriate” FAS/FAE programming may appear promising, the Aboriginal women I interviewed received this idea with more skepticism than enthusiasm. As is seen in our exchange below, Cheryl responded to my question by sharing her conviction that “culturally appropriate” information about FAS/FAE and alcohol use in itself would be inconsistent with her own culture’s teachings about alcohol and drugs:

AS: So in this Initiative... it says that Aboriginal people, and Aboriginal women in particular, need information about FAS and FAE and alcohol use during pregnancy that is culturally appropriate. What are some of your ideas about what’s culturally appropriate?

Cheryl: I don’t really agree with that. Because well, for me, my culture, our beliefs are that alcohol is bad. Drugs is bad, you know? So if you’re going to, not practice, but if you’re going to start doing all the cultural stuff and all that, you don’t drink. You don’t do drugs. You know? It’s really spiritual. Um... I don’t know. Just that it, their beliefs are like that. I don’t really know too much about what they believe, but that’s just their beliefs. Cultural wise, if you’re going to be practicing it, you’re not going to be drinking or doing it. (Pause)

Cheryl’s observations that alcohol and drugs are considered “bad” in her culture, and that “Culture wise, if you’re going to be practicing it, you’re not going to be drinking or doing it” are noteworthy for two reasons ways. First, her understanding of what would be “culturally appropriate” in the context of her community suggests a potential incompatibility with harm-reduction approaches to FAS/FAE education, such as those described by Super Woman in Chapter 6. This is because harm reduction approaches are grounded in the assumption that women should be empowered to make their own decisions about substance use, and should be provided with information and supports that

enable her to use in a safer manner if she chooses. Many Aboriginal women and their service providers in this community favour harm-reduction approaches because they decrease the stigma and the “shame and blame” described earlier in Chapter 6 as barriers to women and families receiving care. Second, Cheryl’s comments above are significant in the ways she describes her culture as something she is disconnected from, as “their beliefs” that “I don’t really know too much about”. This is experience was shared by most of the women in the group, including women with close connections to their Bands and home reserves. For example, in response to the same question I asked Cheryl, Jo-Anne states:

I haven’t participated in any of that until just recently. So, I don’t know exactly what you mean by that. Like, I didn’t know. There isn’t a heck of a lot of information. All I knew was that you shouldn’t drink when you’re pregnant, it’s bad for the baby. So what do they mean by culturally appropriate? Like, Native culturally? Or the whole community culturally? It’s like, what does that mean? Which culture are we talking about?

As a member of an urban, multicultural Aboriginal community, Jo-Anne highlights an important issue overlooked in the texts of the Initiative: that there are many “traditional” Aboriginal cultures, values, and practices that exist simultaneously in some Aboriginal communities, and that not all aspects of a given Aboriginal culture may be shared by “the whole community”. Moreover, Jo-Anne’s experiences, and those of other women who participated in these interviews, indicate that successful FAS/FAE education efforts exist in a context of cultural diversity, and that an “at risk” Aboriginal woman or family may identify themselves as belonging to more than one cultural group. Shannon’s reaction to the issue of “culturally appropriate” FAS/FAE education strategies is similar. Her description below of the context in which a “culturally appropriate” approach to

FAS/FAE education could be useful is similar to the adaptation approach to “culturally appropriate” education described above:

Is there going to be a different pamphlet for every culture, or just one in particular? You know what I mean? Like, maybe in different places. Say, like [this city] has such a vast community of people that one particular way of teaching might be all right, and as they go along they could incorporate whatever kind of cultural things, depending on who's in the groups, or who's learning, or whatever. But, you know, if they're going to a reserve and teaching just people who are there, those people could be more comfortable if it was culturally, you know, made up for them. Because sometimes each cultures have... Like, in the one program I'm in has something to do with owls, and then the culture that they're teaching, on one reserve, had bad stigmas about owls, so they had to change that, or whatever. Things like that are important, you know? But, you know, I personally wouldn't see the difference really for me. I would probably go to it regardless of whether it's Aboriginal focused or not.

Although she agreed that she “would probably go” to an FAS/FAE education program “regardless of whether it's Aboriginal focused or not”, Shannon values the opportunity to learn about and take part in traditional Aboriginal cultural and spiritual practices, such as smudging, that have been made available to her through her participation in Mary's FAS program. However, close attention to her narrative also points to the complexities of providing FAS education in a “culturally appropriate” context. She explains:

I think that for me, personally, culturally wise, it doesn't really matter. I didn't really grow up with learning the culture. I mean, I don't really see it that way. I think it's good that with Mary's group, there is some Native culture in there. And a lot of it she taught me. She taught me smudge, she does that kind of stuff. And I like that, it was good to have that be a part of it. But I was really uncomfortable with it at first. Like, being Native, because I never grew up that way. Like, it might work for the people who grew up on a reserve, if they grew up knowing what basic culture for their area is. But if you didn't, it's really uncomfortable for you. You'd rather, it's like if you didn't grow up knowing what those things were, or whatever, that's when it is uncomfortable, if you didn't know what that was. It takes time. I think everyone's different. It's

not to say that it won't work or it will. But I find, just what I've learned from Mary, it's been really helpful. But from her, how she's gone about it is good. But it took time for me to get comfortable doing smudge and being a part of that.

Shannon's description of her initial experiences with smudging as "uncomfortable" and as something that "it took time for me to get comfortable doing" suggest that designing "culturally appropriate" FAS/FAE education programs in itself may not necessarily create conditions or experiences that are initially welcoming to all Aboriginal women. At the same time, Shannon's experiences in Mary's program also point to the importance of incorporating decolonization and cultural renewal efforts as part of FAS/FAE prevention strategies.

For Wonder Woman, contemporary and historic manifestations of racism, colonization, and ableism are significant aspects of her lived experiences that provide additional dimensions to her disconnection from her Aboriginal culture and traditions. In our exchange below, she explains the reasons and the consequences of this disconnection:

Wonder Woman: I hate to say this, but I'm white and I'm status. But I only recently learned that I was. So, up until a year ago, I was going around and living a non-Aboriginal lifestyle. And then I learned. So to me, either way, it's the same. And I only just in the last year got involved with help. Like, my daughter goes to extra preschool. We've just dove in. Because my adoption file was declared that it could be opened. And that's when I learned that I've been status since I was born.

AS: But you didn't know?

Wonder Woman: I didn't know. They removed it from my foster care record after my car accident. Because try to adopt a Native disabled child (long pause), into a home, it's nearly impossible. I hate to say it, but it's nearly impossible. And because I was so white, they decided I could be passed off as a white child. And that's why. My family would have adopted me either way, they

said. But it probably got me adopted quicker. And I didn't bounce around in foster homes.

The realities of child protection and adoption practices of the Canadian state, for Wonder Woman and many other Aboriginal women (Fournier and Crey 1997, Kline 1993) and people with disabilities (Burns and Kellington 2004), underscore the many ways interwoven legacies of ableism, racism, and colonization inform the complexities and contradictions of identity, experience, culture, and pedagogy. In light of the experiences of the women I interviewed, it becomes apparent that the relationship between identity, experience, culture, and pedagogy is not always as straightforward as one might anticipate. Indeed, the Aboriginal mothers I interviewed emphasized that not only is it important to consider the information and supports an Aboriginal mother may need to access "culturally appropriate" FAS/FAE education and programs, it is equally important to consider the socio-political context in which "culturally appropriate" FAS/FAE initiatives are conducted. As Jo-Anne explains,

Last time I smudged, I must have been, like, 10. And then I finally started to feel somewhat, like... just focus on Aboriginals, it makes you feel more... what's the word? I don't know if stigmata is really applicable, but there's a lot all ready. Like people talk about treaties, and people already think badly about Aboriginal people. And, like, it's not... it shouldn't... I think for some people it might help, but then there's a lot of us, too, who don't really give a shit, you know? I'm sorry, but they don't. You know, like, I'm Native, and some people are really ashamed of being Native. When I was growing up I hated being Native. I always wanted to be like my best friend, my little white girl friend, because she had it so easy. But she didn't have it so easy. It's not just a racial thing, it's everyone. A lot of white people have FAS. A lot of Chinese people have FAS. A lot Native people have FAS. It's everywhere. (...) I think, too, it limits when you say Aboriginals and people who aren't. Or people who aren't aware they are. You know? Then they don't want to go. You know, like they feel they don't deserve the help. And then people who are racially biased, they'll be, "See,

look.” There are people who complain about, “Oh they get all these things. You can see this is why they need it. They can’t not drink then they’re pregnant”. That’s what I mean about stigmata, like, the bad label.

As Jo-Anne observes, FAS/FAE and maternal substance use are indeed found in all communities and occur in all cultural and racialized groups. However, not all communities and racialized groups have received equal attention in public education and public policy addressing the causes and consequences of FAS/FAE. Jo-Anne’s statement that FAS/FAE is “not just a racial thing” speaks to the effects of common-sense constructions of FAS/FAE as an “Aboriginal problem” in the everyday lives of Aboriginal women, children, and communities. Indeed, Jo-Anne’s experiences of racism in her community, particularly when considered together with historic and contemporary manifestations of colonialism, raise important ethical questions about the effects of “culturally appropriate” FAS/FAE interventions targeted at Aboriginal peoples. As I demonstrated in Chapter 2, Aboriginal communities are frequently positioned in public discourse as making problematic claims on state resources, as people who, in Jo-Anne’s words, “get all these things”(including, not insignificantly, entitlements connected to treaty rights). Moreover, Aboriginal women are often represented as people who, as Jo-Anne explains, “can’t not drink when they are pregnant” and are consequently in need of certain interventions that other (non-Aboriginal) women are not. In her testimony, Jo-Anne demonstrates that the effects of these “common-sense” constructions of Aboriginal women and communities carry very real material effects. In her analysis, not only do these discourses fuel the racisms of “people who already think badly about Aboriginal people”, they consolidate feelings of shame and “hate” in relation to one’s Aboriginal

ancestry, manifested in a reluctance to identify with a community or group that has been subject to this “bad label”, or stigma. In this way, public education efforts that focus exclusively on Aboriginal peoples can be seen to reify climates and conditions that discourage Aboriginal (and non-Aboriginal) people from accessing resources related to FAS/FAE. At the same time, racializing FAS/FAE as an “Aboriginal problem” continues to result in responses to FAS/FAE prevention that do not similarly problematize white middle-class women’s alcohol use as “risky” or “dangerous”. Indeed, during the funding years for the Initiative’s public education campaign directed at Aboriginal communities, no large-scale parallel FAS/FAE education campaigns targeting a non-Aboriginal audience were implemented.

In analyzing the discursive and material effects of “culturally appropriate” FAS/FAE education campaigns for Aboriginal women and communities as evidenced in the Initiative, it is important to note that the content and emphasis of FAS/FAE information and education campaigns differs in significant ways for materials intended for different audiences. In fact, a substantial disconnect exists between the need for historically, socially, culturally, and politically situated and responsive FAS/FAE education emphasized in *It Takes a Community* and the content of the FAS/FAE fact sheets and public information campaign materials produced by the First Nations and Inuit Health Branch to support the work of the Initiative.

For example, *It Takes A Community* contains 10 “fact sheets” that are “for community caregivers who are planning public information sessions in their communities” (FAS/FAE Technical Working Group 1997:118). In the preface to this section, titled “Using the Fact Sheets”, a bold type insert positioned prominently on the

page states, “Traditional knowledge regarding conception, pregnancy, birth, and parenting can be a good basis for community education” (ibid). As I noted above, this statement and others similar to it are also found elsewhere in the manual, frequently underscoring that the incorporation of “traditional knowledge” or “culturally appropriate” content are important components of successful FAS/FAE education and prevention efforts. However, in spite of these statements, none of the 10 fact sheets contain information that could be described in culturally specific terms as “traditional knowledge”. Indeed, the organizing devices of these fact sheets more closely mirror medicalized conceptions of FAS/FAE. To illustrate, I offer the text of one of the fact sheets, titled “Pregnancy and Alcohol Use” (FAS/FAE Technical Working Group 1997: n.p.)⁴³.

Now you see her, now you don't: the disappearing/reappearing maternal body

The first section of the fact sheet reads as follows:

Fact Sheet: Pregnancy and Alcohol Use

PREGNANCY

Rapid organ development occurs in the early stages of pregnancy. Organ growth continues throughout the pregnancy but at a slower pace than the earlier stage.

(FAS/FAE Technical Working Group 1997:np).

Close reading of this text demands that the reader recognize in the first instance the significance of the title of this text: it is a “fact sheet” about pregnancy and alcohol use.

⁴³ For ease of reading, I have divided the fact sheet into distinct portions. However, the reader should note that I have presented all portions of the text, in the order they appear in the fact sheet, without omissions or reorganization.

As such, the text begins by providing the reader with what can be seen as a set of instructions for interpreting the text (Smith 1990:32). These instruct the reader that what they are about to read are indeed “facts”, rather than, for example, “stories” or “ideas” or “one person’s view of things”. Because the information is presented as “facts”, it is to be seen by the reader as offering an authoritative description of pregnancy and alcohol use, which is “true” independent of whatever interpretation authors of the texts may have wished to bring to bear on them. These instructions therefore close off the possibility that other accounts, descriptions, or interpretations of the relationship between alcohol use and pregnancy are worth knowing or carry interpretive authority greater than or equal to “facts”. In this text, the texts instruct the reader that the things worth knowing about pregnancy and alcohol use are limited to specific areas: the processes of organ development, maternal and fetal alcohol absorption, and the need for pregnant women to abstain from alcohol.

The mother as a disembodied site of gestation and metabolism

Although the activities of pregnant women and mothers are the objects of this text, women themselves are excluded from the text as readers, agents, and embodied subjects. In each section, women are simultaneously absent and present in one of three ways: as disembodied collections of body parts (stomach and intestines, liver, “enzyme systems”, etc.), as absorbers of alcohol (through which alcohol “easily passes” to a fetus), and as “drinking mothers”. No language offered by the texts suggests that women are being talked to directly. For example, the texts use third person descriptors to show that women are being talked about (the mother), but never language indicating that women

are the anticipated audience being talked to (for instance, using “you”). As they are neither readers of the text, situated actors with lived experiences affected by the described activity, or people with bodies, the textual and discursive strategies employed in the “facts” presented make women disappear. For a “public” education tool about FAS/FAE designed for members of Aboriginal communities, this is indeed curious.

Furthermore, the reader will notice that the texts define pregnancy solely as an extended period of “organ growth”, with some periods of organ growth described as “slower” than others. Indeed, it is critical to note that this description of pregnancy includes no reference to it as a process or activity that is done by an actual woman, or as involving her partner, family, or community. As such, the semiotics of this passage offer an interpretive code that presents the *mother as a disembodied site of gestation and metabolism*. The use of bio-medical discourse in this code supply the reader with a set of what Smith (1990:48-9) calls “authorization rules”, that instruct the reader on what criteria to use in determining the adequacy of the descriptions and credibility of the account offered in the text. Moreover, although *It Takes A Community* repeatedly emphasizes (elsewhere in the text) the importance of traditional knowledge and teachings about conception, pregnancy, and birth for Aboriginal women and families when providing information about substance use and FAS/FAE, this information is not included in the fact sheet, nor is reference made to its importance. Rather, the “fact” of pregnancy in this educational tool is to be understood by the reader as an exclusively biologized and medicalized process.

In the next section of the fact sheet, the texts instruct the readers on the process of “how alcohol is absorbed by the body”. It reads:

HOW ALCOHOL IS ABSORBED BY THE BODY

* Alcohol is absorbed into the blood, from the stomach and intestines and transferred to the liver. The alcohol is broken down in the liver by two enzyme systems.

* In the pregnant woman, alcohol easily crosses the placenta to the circulatory system of the fetus. The placenta does not act as a barrier. The fetus cannot rid itself of alcohol as quickly as the mother because of its small and underdeveloped liver and enzyme system. The fetus is exposed to alcohol for longer periods than the drinking mother.

Again, biologized discourses are used to describe the process of alcohol absorption as though “alcohol” is somehow acting on its own in exposing itself to the blood, stomach, intestines, and liver, entering a body’s “two enzyme systems”, and eventually “crossing the placenta”. In this way, the reader is discouraged from considering the alcohol absorption by a body as the effect of an activity performed by a person within a material context of choices, constraints, and history. This is underscored by the use of language that does not acknowledge until the last two words of the section (“drinking mother”) that the body of a woman and a fetus comes to be exposed to alcohol because a woman actually consumes it. At the same time, the frame for understanding the effects of alcohol on the body limits recognition of these impacts to those affecting the liver and “two enzyme systems”. Note that this frame works to dismiss other impacts that alcohol may have on “the body”, removing them from the realm of “facts” and things worth teaching and knowing about. More importantly, the texts insistence on using the article “the” to describe body parts (i.e.: “the blood”, “the stomach and intestines”, “the liver”, “the placenta”) absent from discussion the recognition that these are parts of a body that *belong to* a woman. Using “the” as a preceding article works to remove these body parts from the realm of something that a woman owns and controls. In this way, they are not *her* blood and *her* liver, but objects without a possessor that can be claimed or acted upon

by anyone, without interfering with personal autonomy, privacy, or ownership. This encourages the reader not only to dehumanize the actions being described (as they are not being performed by or on an actual person) but also to strip the actions of the context in which they occur and are experienced.

The mother as objectified source of fetal endangerment

In the second point in this section (beginning with “In the pregnant woman...”), a shift occurs in the semiotics that support the authorization rules for reading the text, in which the mother reappears. This introduces a new code, which I will call the *mother as objectified source of fetal endangerment*. This code is evident in descriptions of the effects of alcohol on a fetus that emphasizes the “risk” presented by the pregnant woman’s actions and the “vulnerable” position of the fetus in relation to its mother. Because the liver and “enzyme system” of the fetus is “small and underdeveloped”, the texts convey that “the fetus cannot rid itself of alcohol as quickly as the mother”. This statement suggests that because alcohol exposure is dangerous and not something the fetus can avoid on its own, the fetus requires some form of protective action from an outside source. The semiotic device also leads the reader to conclude that the mother cannot appreciate the negative consequences posed by alcohol exposure to the fetus (again, note it is not *her* fetus), as a mother rids herself of alcohol “quickly”. Moreover, the texts remind the reader that the resource provided by mother to nourish and support her fetus independently (“the placenta”) are inadequate for the task at hand, as “alcohol easily crosses the placenta” and “The placenta does not act as a barrier”. These textual strategies support authorization rules that set up the concluding section of the fact sheet

by shifting the activities and experiences of the “drinking mother” out of the realm of a woman’s personal choice-making and into the domain of activities and experiences that can be and must be acted on by others.

In the final section of this fact sheet reads:

WHAT DOES THIS MEAN FOR MOM AND BABY

- * Drinking at anytime during pregnancy could possibly affect the normal development of the baby.
- * Not drinking at all is one sure way to increase the likelihood of a healthy baby.
- * If the mother is drinking, interventions to stop drinking at any time during pregnancy will help the chances of a healthier baby.”

As in earlier sections of this fact sheet, the reader is instructed to consider that the implications of the information presented above can be confined to simple decision-making about drinking/ not drinking during pregnancy. By attending only to the risks posed by alcohol to the fetus as “facts”, the effects of other risks that may exacerbate (or even trump) the effects of alcohol are obscured. For example, these “risks” could also include maternal malnutrition or exposure to environmental toxins. These “risks” are outside an individual woman’s ability to control and require collective responses at the community and state level. This point is also highlighted by the second line of this section, which states that “not drinking at all is *one sure way* to increase the likelihood of a healthy baby” (and not, say “one of many ways”, or “one possible way”).

Throughout the text, the focus of discussion remains steadily on the risks and harms to the fetus that are associated with alcohol exposure. As such, the reader is instructed to view alcohol consumption as an act that a) does not affect the well being of a woman, and b) exists outside of the historic, social, political, economic, cultural, and familial relations in which a woman lives and negotiates choices. In this way, the reader

is encouraged to respond in a way that is mindful of and sensitive to the interests of the fetus only, and to consider those interests as separate from the interests of the mother. This is further emphasized by a shift of language in this section, from discussion of “the fetus” (which is a part of the “drinking mother”) to “the baby” (which is a person separate from the “drinking mother”).

Absenting the experiences and effects of alcohol use as “facts” that impact the well-being of the mother positions maternal alcohol use as something a woman *does to* a fetus, rather than something a woman *experiences with* a fetus. This supports a rationale for others to undertake “interventions to stop drinking at any time during pregnancy”, to “help the chances of a healthier baby”. In other words, this language works semiotically to position the mother as having interests that are antagonistic to the fetus, and as having resources that are inadequate for protecting her fetus from harm. At the same time, the fetus is positioned as having interests that require others to intervene and protect it from its mother. As such, this code operates to consolidate a “common sense” (Gramsci 1992) view of and response to FAS/FAE that positions the substance-using mother as an object for the community to act *on*, rather than a person that the community acts *with* or *for*.

It is also significant to note that the bottom of this fact sheet, and the other nine in the series, emphasizes that “FAS and FAE are easily prevented”. This statement appears in direct contradiction to earlier references in the documents, emphasizing that “*It Takes a Community* recognizes the complex causes, consequences, and potential community responses to FAS/FAE” (FAS/FAE Technical Working Group 1997:51), that “Understanding the complexity of FAS/FAE, the people it affects, its characteristics and root causes takes time” (FAS/FAE Technical Working Group 1997:55), and that “FAE/E

is a complex health condition involving many mental, emotional, physiological, and social factors. The causes of FAS/FAE are equally profound” (FAS/FAE Technical Working Group 1997:56).

Conclusions: “mentioning” as a tool for unpacking the context of “culturally appropriate” pedagogies

As can be seen from the texts of the Initiative and the testimonies of the Aboriginal women I interviewed, the issue of producing (and reproducing) “culturally appropriate” FAS/FAE education campaigns targeting Aboriginal communities suggests possibilities that are both provocative and problematic for advancing interests of social justice and decolonization. Incidences and experiences of FAS/FAE in Aboriginal communities are mediated by the contemporary legacies of state-sponsored activities designed to dismantle Aboriginal cultures, languages, spiritualities, families, and social and political institutions. Thus, efforts toward cultural revitalization provide a foundation on which to build programming aimed at improving the health and well-being of Aboriginal women, children, families, and communities, including FAS/FAE prevention. The Aboriginal women I interviewed welcomed the opportunity to participate in those aspects of Mary’s FAS program that taught them about Aboriginal cultures and traditions. However, the reality that most of the women, and many others, are disconnected in some respects from Aboriginal cultures demands recognition that providing “culturally appropriate” FAS/FAE education is not simply a matter of translating information developed in one cultural context into the specificities of another. Rather, these experiences suggest that successful efforts to provide Aboriginal women with “culturally appropriate” FAS/FAE education also requires the creation of conditions

that enable women to connect with the traditional knowledge of their cultures in ways that are welcoming and meaningful to them.

This concern also prompts important questions regarding who bears the responsibility for ensuring Aboriginal women have opportunities to access “culturally appropriate” programming, particularly in urban contexts. Aboriginal community-based organizations remain chronically under-funded in their efforts to provide even the most basic services. Local, provincial, and federal governments advocating for “culturally appropriate” programs and services must therefore share in the responsibility by funding them adequately. Efforts to provide “culturally appropriate” FAS/FAE education must also acknowledge the ways in which these activities may unintentionally fuel pre-existing stereotypical and stigmatizing representations of Aboriginal women and communities that can in turn create barriers to accessing FAS/FAE education and support.

Attempts to understand the overlaps, tensions, and disconnects between the discourses of the Initiative’s policy texts, the content of its public education materials, and the insights of Aboriginal mothers regarding their preferred approaches to FAS/FAE education demands close attention to the contexts which mediate them. Historically, Canadian policy makers have favoured the implementation of public education campaigns for mothers, as a relatively cheap and uncontroversial way to respond to public health issues, including those related to infant mortality, malnutrition, and the spread of disease (Arnup 1994). This approach to public health and welfare issues remains popular among policy makers, as they cost little in comparison to the implementation of policies that would, for example, ameliorate the gendered, racialized, and ableist effects of systemic poverty.

The impact of current neo-liberal global economic and political trends make these legacies all the more salient. These include demands for Nation-States to “restructure” social programs, to create “lean states” that enable national economies to remain “competitive” in globalized markets. These trends favour initiatives that devolve responsibilities for ensuring the health and well-being of marginalized groups from the State to community-based or private organizations, and that provide interventions to decrease individual “dependency” on or cost to the State. In practice, this results in policies that are “guided by a vision of the weak state leaving the development of society to the dynamics of private initiatives and cost-benefit analysis” (Aasen 2003: 123). These trends support policies such as the Initiative, which rely on Aboriginal communities (rather than the State) to undertake public education campaigns for the prevention of FAS/FAE on the grounds that it represents an unjustifiable “cost to communities” (FAS/FAE Technical Working Group 1997).

However, while this context is important for understanding how and why these policy directions may be favoured by the State, context alone does not explain for how or why the vision, priorities, objectives, or relevancies of the Initiative gain the support of Aboriginal women or communities. As Apple (2000:53) has argued, countries with democratic traditions of governance rarely impose curricula (or pedagogies) of dominant groups forcibly, or as Bennett (1986:19) explains, “as an alien external force onto the cultures of marginalized groups”. Rather, the process of enacting public pedagogy by or through the State is better understood as an active and contested process in which State institutions are continually engaging in the “rebuilding of hegemonic control” (ibid). To

be successful in maintaining control, dominant groups must gain at least the partial consent of the broadest possible constituency.

Apple (2000) argues that one way of maintaining dominance is through the process of “mentioning”. As he uses the term, “mentioning” is a textual and discursive strategy in which “limited and isolated elements of history and culture of less powerful groups are included in the texts... but without any substantive elaboration of the view of the world as seen from this perspective”. As such, mentioning provides a mechanism for “actually incorporating the knowledge and perspectives of the less powerful under the umbrella of the discourse of dominant groups” (53).

Mentioning as a textual and discursive strategy provides a useful tool for understanding how the texts of the Initiative operate. As I have demonstrated in this chapter and others earlier, the policy texts of the Initiative spend considerable effort emphasizing the importance of identifying the “root causes” of FAS/FAE in Aboriginal communities and grounding FAS/FAE education and prevention efforts in “culturally appropriate” pedagogies and “traditional knowledge”. By incorporating some of the discourses, epistemologies, and priorities advanced by Aboriginal Peoples’ movements, the texts acknowledge the gains of these movements and appear to embrace their concerns as worthy of “public” attention and “public” funds. At the same time, incorporating these knowledges and perspectives into official State knowledge increases the possibility that Aboriginal communities will embrace the policy and practice of the State in the area of FAS/FAE prevention.

In fact, in many ways the texts employ strategies that appear to exceed Apple’s conception of “mentioning”, in that some areas of the text do include “substantive

elaboration of the view of the world as seen from this [traditional Aboriginal] perspective". This is evident in the considerable discussion of the meaning of "respect" in traditional teachings and in the understanding of children as "gifts of the Creator" I noted earlier in this chapter. However, as can be seen from the fact sheet and pamphlet produced as part of the public education activities of the Initiative, these issues and perspectives are almost entirely removed from the "official knowledge" circulated by Health Canada and FNIHB⁴⁴. The use of mentioning in these texts enables State institutions to maintain hegemony by constraining the frames of reference in which FAS/FAE can be addressed and debated in public pedagogy and public policy.

In the final chapter of this dissertation, I consider the possibilities presented by the public pedagogies and official knowledge in the Initiative for advancing anti-oppression work in and outside of education. I examine how "mentioning" appears to have provided a "loop hole", through which Aboriginal organizations and communities were able to access funding for projects that go beyond "just say no" and "shame and blame" approaches to FAS/FAE education, to address pressing issues of social justice and inequality. These "loop holes" may also hold the possibility of creating some of the conditions that support progressive movements to have their concerns addressed through the institutions of the Canadian State. At the same time, translating these discourses and issues through the relevancies of the State places limits on the means by which Aboriginal women and

⁴⁴ However, this does not preclude the possibility of other actors, including Aboriginal organizations and communities, from making use of this strategy for more progressive or emancipatory purposes. As I will discuss in Chapter 7, the use of mentioning seems to have provided a textual or discursive "loop hole" for supporting the development of some grass-roots organizations and First Nations to support decolonization and cultural renewal in their communities.

communities can gain support to improve their health and well being and articulate concerns for social justice.

Chapter VIII: Transforming Public Pedagogies and Official Knowledge: Conclusions, Implications, and Ways Forward

In this dissertation, I have critically engaged with the discursive and material consequences of FAS/FAE, as they are articulated within and across two sites of teaching and learning: the texts of the First Nations and Inuit Fetal Alcohol Syndrome/ Fetal Alcohol Effects Initiative and the lived experiences and insights of 6 young Aboriginal mothers. This chapter emphasizes the significance of the findings my analysis generated. These findings both support and challenge the existing theoretical and empirical literature, and offer productive insights and possibilities for future directions in public policy, education, research, and social movements responding to the challenge of FAS/FAE.

There is a common assumption in many Canadian approaches to FAS/FAE prevention that experiences of drinking or using drugs can and should be viewed in isolation from women's life experiences (Greaves, Cormier, and Poole 2002, Poole 2004). There is also an assumption that the conditions of women lives have only a small impact on if and how they will use drugs or alcohol during pregnancy, or whether their children will be diagnosed with FAS/FAE (Armstrong 2003, George 2001). This assumption obscures the reality that experiences and consequences of substance use for women and their children are strongly mediated by other "social determinants of health", including poverty, malnutrition, stress, trauma, violence, and marginalization (Armstrong 2003, Murphy and Rosenbaum 1999, Poole 2004). These assumptions also suggest that women always have the resources they need to make independent, informed, decisions about substance use, and that they will be taken seriously and given help with these issues if they simply they ask for it. Together, these ideologies and assumptions culminate in

policies that blame individual women for their substance use and for the harmful effects that it can have on their babies, while at the same time dismissing the social, economic, and political contexts that give rise to substance use and FAS/FAE and require collective action by communities and state institutions (Greaves et al 2002, Humphries 1999, Gomez 1997). As has been demonstrated in other research contexts, FAS/FAE prevention policies that are predicated on these assumptions have consequences that are decidedly gendered by positioning substance-using women, their bodies, and their activities as “social problems” requiring interventions by their communities and by the State (Humphries 1999, Gomez 1997, Greaves et al 2002). At the same time, concerns about the possible dangers posed by substance-using men and fathers remain marginal (Boyd 1999). These policies also have racialized and class-specific consequences, as white middle and upper class women’s substance use is rarely constructed and responded to as a “social problem” requiring State intervention. Moreover, because white middle-class women’s substance use is less often seen as “risky”, dangerous, or threatening, the effects of their substance-use on the health and wellbeing of their children and communities are more often over-looked (Boyd 1999, Humphries 1999, Gomez 1999, Greaves et al 2002).

My findings confirm that FAS/FAE prevention policies founded on these assumptions are highly problematic. The women who participated in this research taught me that alcohol and drug use are intimately connected with the conditions and experiences of women’s lives. Some of the women acknowledged that alcohol and/or drug use are a part of their family histories that they continue to struggle with. For Super Woman, Jo-Anne, Shannon, and Tricksey, alcohol and drug use have been connected to living conditions that are dangerous, painful, and traumatic. These conditions include

male violence, sex trade work, poverty, racism isolation, and fear. Substance use can also be a major part of some people's social lives among their friends and in their communities, and it can be difficult for women to cut down on or find alternatives to alcohol or drug use if they have no other support systems. Five of the six women I interviewed stated that significant people in their lives, most particularly their male partners but also members of their families and communities, have impacted their substance use in important ways.

In their everyday lives, the women who participated in this research struggle in many ways to be heard and to have their concerns acknowledged, respected, and responded to. The reality of their experiences challenges the assumption that all women will always be helped or supported when they ask for the things they need. As I describe in Chapter 5, they have been ignored, discounted, marginalized, and belittled by police officers, lawyers, 911 operators, boyfriends and spouses, social workers, educators, service providers in community programs, and many others. It is clear from their testimonies that treating Aboriginal women in this way compromises their educations, access to much needed services, and their health and safety. Recent provincial, federal, and municipal government cutbacks also limit their access to these services. Reductions in funding to programs and services that were already funded inadequately have resulted in an insufficient number of service-providing organizations to meet the needs of substance-using Aboriginal mothers and their children in the Downtown Eastside. The women include among these lack of services supporting women to make changes in their substance use, lack of child care and educational opportunities, and very restricted access to infant diagnostic services for impairments related to substance use.

At the same time, the women also shared instances that provide evidence of enjoying substantive citizenship interests. As Young (1990) argues, recognition of substantive citizenship interests is an important indicator that a group is experiencing social justice in the context of their daily lives and in their interactions with the State (see also Bannerji 1997, Ng 1993). I learned from the Aboriginal mothers I interviewed that their lives include many times when they have had their voices heard by and their interests responded to by people in positions of power or authority. These include times when they have made complaints to social workers, doctors, transit authorities, teachers and school administrators, and government ministers that have resulted in recognition of their difficulties and improvements to their material conditions.

The realities of Aboriginal mothers' lives in the Downtown Eastside must prompt a significant re-examination of contemporary theories of citizenship to account for the structurally and contextually dependant domains of formal and substantive citizenship that shape the daily lives of marginalized women and children. Specifically, we must recognize that marginalized groups, such as Aboriginal women and children impacted by substance use, do not experience formal or substantive citizenship as monolithic, as something they enjoy all the time, in all places, and in all institutions (c.f. Young 1990). Substantive citizenship interests are contextual, mediated in and differentiated through interactions with various institutional policies and practices at the local and national levels over time. As such, the impacts of Aboriginal women's drug and alcohol use are informed by what Smith (1987) has called the "ruling relations". Acting on this knowledge demands that we rigorously question the assumption that only individual

women, and that alcohol use alone, should be singled out and blamed (or as Jo-Anne described, “eye-balled”) for FAS/FAE.

Negotiating policy analysis as a method of feminist, anti-colonial, and anti-ableist research praxis

Aboriginal mothers have much to teach about FAS/FAE, substance use, and mothering in their communities. However, my readings of the texts of the Initiative showed me that the voices and experiences of Aboriginal mothers whose lives include substance use and FAS/FAE were largely absented from or ignored in this arena of policy talk. Forging a methodological synthesis between textual analysis (Smith 1990, 1992, 1999), institutional ethnography (Smith 1987), and participatory research enabled me to uncover the relationship between the public pedagogy and “official knowledge” about FAS/FAE articulated in the Initiative and the lived experiences of Aboriginal mothers who have used alcohol or drugs during pregnancy. This approach not only supported knowledge production that points to new directions for FAS/FAE prevention and education efforts; it also met the expectations of Aboriginal women and their community for conducting respectful research.

While Smith’s productive insights proved very useful to this research, my findings also reveal a significant contradiction in her methods. Smith’s (1990:4) assertion that a discourse or text provides “a direct line to the relations it organizes” stands in sharp contrast to the lived experiences articulated by the women who participated in this research. Indeed, the simultaneously disabling and enabling contradictions of medicalization evident in their testimonies show that relations of power and privilege cannot always or easily be drawn as “direct lines”. The realities of negotiating the

complexities of FAS/FAE, substance use, and mothering show that everyday life does not often fit tidily into the narrow and prescriptive confines of ideology, discourse, or hegemonic “common sense”⁴⁵. To suggest that texts alone offer a “direct line” of access for understanding how power operates would be to remove the messy realm of everyday life from this dialectic. As such, while Smith’s concept of “text-reader conversation” (1992) is intended to critique sociological approaches to understanding knowledge production that divorce from lived experience as “ideological”, her understanding of texts as “direct lines of access” to relations of power and privilege unmitigated by the experiential realm of the everyday fails to adequately account for this contradiction. Thus, I found textual analysis alone to be an insufficient and problematic method for constructing this inquiry. Had I failed to include Aboriginal women’s articulations of their own interests, on their own terms in this research, I would have reproduced one of the most important critiques I advance about the organization of the texts of the Initiative: that the texts do not attend to the concerns of Aboriginal women whose lives are most directly impacted by this policy.

The complementary methods of textual analysis, group interviews, and shared analysis enabled me to construct an intellectually rigorous alternative to the positivist and objectivist foundations of colonial, imperial, and masculinist legacies that have been historically evident in indigenous/white neo-colonial research relations. Incorporating participatory elements into the research design helped to welcome the women into the research process. This included an acknowledgment of their agency in transforming those aspects of the research process that inadvertently hampered their efforts to have their

⁴⁵ I thank Kogila Adam-Moodley, who in highlighting this disconnect assisted me greatly in clarifying my own position on this issue.

interests, experiences, and analyses heard and acknowledged. An additional, and unanticipated, outcome of grounding my analyses of the Initiative's texts in group interviews was the creation of some of the conditions that supported the women in articulating collective experiences that challenged the privatization of mothering, substance use, and FAS/FAE evidenced in the texts. These findings affirm that efforts to advance anti-colonial, anti-ableist, women-centred policy analysis requires the substantive inclusion of those most affected by the policy under inquiry.

The contradictions of medicalization for advancing substantive citizenship interests

In considering the ways in which "social problems" are constructed, circulated, and (re)produced in and through public policy, it is clear that historical, geographical, social, political, economic, cultural, and ideological contexts inform the mechanisms through which particular groups come to be identified as "at risk". My research contributes to an emerging literature that brings a relational analysis of disability alongside gender, "race", class, and nation (c.f. Meekosha and Dowse 1997, Meekosha and Dowse 2002, Meekosha and Jakubowicz 1996, Rizvi and Lingard 1996, Roman 2001, Stange 1994). My findings show these documents to act as a formation and function of diverse epistemic and ontological positions that both support and challenge the hegemony of medical models of disability, which have to date been privileged in the Canadian Nation-State's policy responses to FAS/FAE and other disabilities. Tensions evident in the text make it difficult to argue that the documents present a "fixed", singular, or monolithic "official" conception of FAS/FAE. However, structures of preference or "codes" do exist within and beyond them which privilege medicalized

conceptions of FAS/FAE and close off the possibility of other readings and responses to FAS/FAE as a “social problem” and “serious public health issue” (c.f. Hall 1980, Smith 1999). I have identified four textual and discursive strategies that support these structures of preference.

The first strategy I identified is the use of *medicalization as an objectifying discourse*. Like other objectifying discourses, medicalization operates in these texts to reduce conflicting ways of knowing and being into simple determinations of “true” and “false” (Smith 1999:220). In this instance, medicalization works to universalize understandings of FAS/FAE as an objectively identifiable condition that accurately describes the physical and behavioural traits of affected individuals everywhere, at all times. In this way, debates about FAS/FAE evident in the texts of the Initiative come to be centred around two main topics: 1) how to determine whether an individual has FAS/FAE or is “at risk” of giving birth to a child with FAS/FAE; and 2) what interventions are necessary to ameliorate the “disorders” and “deficits” inevitably accompanying this medical condition. This strategy introduces codes for understanding the causes and consequences of FAS/FAE in Aboriginal communities that preclude the recognition of social, cultural, political, and economic relations that inform and mediate experiences of FAS/FAE.

The second strategy I identified is the use of the “*normal human body*” and “*normal human behaviour*” as ideological codes. As ideological codes, the “normal human body” and “normal human behaviour” are simultaneously absent and omnipresent referents evident throughout the texts of the Initiative (Smith 1999:160). These codes work as a type of “contrast structure” enshrining the “Otherness” of people diagnosed

with FAS/FAE (Smith 1992: 33). I have argued that invoking hegemonic conceptions of the “normal human body” and “normal human behaviour” preserve the hegemony of medicalization within the texts, by locating the “problem” of FAS/FAE as originating in the biology and behaviour of “defective” Others, and not in institutionalized social, economic, or political structures or practices. This strategy supports the policy directions of the Initiative, which are entirely concerned with modifying and rehabilitating the impairments and behaviours of Aboriginal people diagnosed with FAS/FAE and the women who give birth to them. Accordingly, the policies and practices of “mainstream” educational, medical, corrections, or other institutions that mediate and create experiences of FAS/FAE do not enter the text-reader conversation (Smith 1999) as “risks” or “targets” in needs of intervention, modification, or rehabilitation.

The third strategy I identified in the public education materials produced under the auspices of the Initiative is the use of semiotic codes that construct the *mother as a disembodied site of gestation and metabolism*. As I described in Chapter 7, this code provides the reader with a set of “authorization rules” (Smith 1990:48) that give a frame for understanding the “fact” of pregnancy as an exclusively biologized and medicalized process, associated primarily with “growth periods” of various paces and metabolic processes of individual organs and “enzyme systems”. The effect of this code is to subsume the reality that pregnancy is also a state of being experienced by women, in their bodies, living in a specific set of material conditions in which they negotiate choices, including choices about substance use. Semiotics that subsume this reality encourage an understanding of FAS/FAE that dehumanizes the activities and experiences of pregnancy and substance use and strips them of the contexts in which they occur. This obscures the

subjectivity and agency of substance-using pregnant women, makes their perspectives, interests, and concerns invisible in public discourse.

The fourth strategy can be found in the use of semiotic codes that position the *mother as objectified source of fetal endangerment*. This code is found in language that simultaneously emphasizes the “risk” presented by the actions of individual pregnant women and the “vulnerable” position of the fetus in relation to its mother. This code positions the mother’s interests as antagonistic to those of her fetus, views her as having resources inadequate for the task of protecting her fetus from harm. At the same time, the fetus is seen to have interests that require others in the community to intervene to protect them. Moreover, by privileging concerns regarding the harms to the fetus (as constructed in medicalized terms) associated with maternal alcohol use, this code encourages the reader to view maternal alcohol use as an act that a) does not affect the well being of the woman herself, and b) exists outside of the historic, social, political, economic, cultural, and familial relations in which the women lives. Accordingly, this code consolidates an “official” “common-sense” (Gramsci 1992) view of and response to FAS/FAE prevention in which the substance-using mother is an object for the community to act *on*, rather than a person with agency that the community acts *with* or *for*.

These findings highlight the complexities and nuances found in role of medicalization in public policy. My analysis of the texts of the Initiative and the women’s experiences confirms that medicalized discourses place limits on efforts to achieve social justice for Aboriginal peoples, women, and people with disabilities. At the same time, medicalization also has strategic or instrumental uses. The process of medicalization, particularly as constituted in access to and participation in services that enable diagnosis

of FAS/FAE, is very important for individuals, families, and communities who have been affected by alcohol and drug use during pregnancy. Without a diagnosis, it can be very difficult for children and their parents, as well as adults with FAS/FAE, to receive the supports and accommodations they need from health care providers, educators, law enforcement officers, employers, and other professionals. However, the Aboriginal mothers who participated in this research explained that they have a hard time accessing the services they need to receive an assessment or diagnosis when they suspect their children may have FAS or FAE. This is not only due to the lack of services available, but also because those services that are available often have narrow mandates that exclude many women and children who need to access them (i.e. doctors, infant development workers, etc.). When women ask for help and are turned away, it is very difficult to ask for help elsewhere, even when those supports are necessary.

The mothers reported that when Aboriginal people do not receive an appropriate assessment and diagnosis of FAS/FAE, they may become objects of stereotype and prejudice. For example, Jo-Anne stated that in her community, others can view Aboriginal people with undiagnosed FAS/FAE as “bad kids”, “lazy”, or “dead-beats”. In this way, the fact that the Aboriginal mothers expressed views favouring the medicalization of FAS/FAE can be seen as a way of resisting “common-sense” racism in representations of Aboriginal peoples. As I noted in Chapters 2 and 5, such representations are evident in public pedagogies and policies that construct Aboriginal peoples as people with disabilities as unable to be “productive citizens”. These concerns that position Aboriginal people with FAS/FAE as potentially “unproductive” in the absence of appropriate supports are echoed in the document *It Takes a Community*:

“...children may also have classmates, friends, and relatives who are living with FAS/FAE. They need to know how to support these friends and relatives and help them find a *productive* life path. The more they know, the more they will be able to help”
(FAS/FAE Technical Working Group 1997:82, emphasis added).

In this dissertation, I have argued that discourses of “productive citizenship” are most often expressed in very narrow terms⁴⁶. In capitalist Nation-States (such as Canada) these terms are articulated through definitions of citizenship that are grounded in an assumed ability to participate in activities that produce sufficient economic value to support an individual’s needs, the needs of his or her “dependants”, and the needs of national economies (Stone 1984, Gleeson 1999). In so doing, I contend that discourses of “productive citizenship” are disabling. These discourses absent people with disabilities (as well as Aboriginal peoples, other racialized groups, and women) from capitalist circuits of productions by representing them and their interests as “burdens”, “drains”, or even “threats” to the institutions and economies of the Nation-State (Meekosha and Dowse 2002, 1997, Meekosha 1999). Furthermore, “productive citizenship” discourses position these groups having interests that are antithetical to those of the Nation-State. Accordingly, ideologies of “productive citizenship” similarly exclude people with disabilities, Aboriginal peoples, and women from a significant foundation for consideration as “citizens”. At the same time, this discourse obscures the structural and institutional factors that create and mediate experiences of disability and differentially enable some individuals and groups to participate in communities, national economies, and institutions as “citizens”.

For the Aboriginal mothers I interviewed who were negotiating the challenges of

⁴⁶ For a detailed discussion of “productive citizenship”, see Chapter 5

FAS/FAE (and other impairments) on a daily basis, medicalization proved to be a simultaneously enfranchising and disenfranchising process. Receiving a diagnosis of FAS/FAE was clearly a benefit to the women and their children, as it enabled them to access resources and services that were necessary for supporting their well-being and the well-being of their children and families. Because the availability of these resources and services is limited in their community, most of the women were required to engage in an enormous amount of advocacy work in order to access them. At the same time, the consequences of being “labeled” through assessments and diagnosis of FAS/FAE were disenfranchising for the women and their children in other respects. For example, Super Woman noted that “labeling” her daughter has required school administrators to recognize that some of her daughter’s “issues” at school may be related to prenatal alcohol and drug exposure. School administrators used this information to pathologize the child’s behaviour as well as Super Woman’s parenting and living conditions. In this way, medicalization enabled school administrators to argue “the problem is at home”. Not only did this limit the epistemic space from which Super Woman could advocate for changes in the way her daughter was being schooled, it also eclipsed the ways schooling practices impacted her daughter’s ability to learn and thrive in school. Similarly, Wonder Woman found that advocating using discourses of medicalization has resulted in experiences of being positioned according to health care provider’s stereotypes about mothers with disabilities as unable to provide care for their children. Wonder Woman’s experience of medicalization in relation to her daughter’s disabilities has presented significant barriers to her ability to return to university and to her daughter’s access to childcare. The fact that her daughter has been labeled a “special needs placement” has been problematic for

Wonder Woman and her child, because this “label” has disqualified her from being placed in a space reserved for “normal” children. In a community with few daycare centres offering a very limited number of “special needs placements”, Wonder Woman has found that an unintended consequence of her advocacy to have her child’s needs responded to and supported through medicalization has been that her daughter has less access to daycare centres than non-disabled children.

These findings have significant implications for the development of the social model of disability, which has been the cornerstone of critical disability studies. Specifically, my findings lend complexity to the implications of medicalization for compromising or advancing the substantive citizenship interests of people with disabilities. One of the defining features of critical disability scholarship and disability rights movements has been the “wholesale resistance of the functionalism of the medical model” (Gabel and Peters 2004:20). The process of medicalization (as articulated in the medical model of disability) is in this way typically responded to as though it is entirely and always oppressive for people with disabilities. As I described in Chapter 2, disability theorists and activists have generally rejected medical models on the grounds that these models attribute all aspects of disability to the presence of pathologized, biologized, and objectified “defects”, “diseases”, or “deformities” (Barton 2001, Oliver 1990). Thus, the ideologies informing medical models support the structural, institutional, and material practices that marginalize people with disabilities and mediate the consequences of impairment or bodily difference in people’s everyday lives (Shakespeare and Watson 1997).

However, critical disability scholars of education Gabel and Peters (2004:20) have argued that within disability studies and disability rights movements, “resistance exists within and around the medical model”. They (ibid) explain:

As understood within the medical model, most of us resist our physical bodies in some way during our lifetime... Furthermore, many disabled people actively participate in their own medical decisions within the medical model and in so doing they even accept some aspects of the medical model as “true” for them (e.g., that a spinal cord injury has predictable physical effects, that losing one’s hearing has functional implications). Disability, after all, “sits at the intersection of biology and society... agency and structure” (Shakespeare and Watson 2001:19).

Accordingly, Gabel and Peters (2004) argue for an expansion of social models of disability, to recognize the important role that medicalization can have in improving the health and well-being of some people with disabilities without negating the importance of resisting those aspects and consequences of medical models that marginalize and disenfranchise people with disabilities and their struggles for social justice. As such, Gabel and Peters (2004) favour what they describe as “resistance theories of disability” as more useful for describing and improving the material conditions and lived experiences of people with disabilities.

My findings indicate that resistance theories of disability bear considerable merit. To deny the challenges presented by FAS/FAE as only or primarily effects of discourse or oppressive institutional practices does little to support the daily struggles experienced by Aboriginal mothers, children, families, and communities who regularly negotiate the physical, cognitive, and behavioural dimensions of their impairments. It is clear from the experiences of the Aboriginal mothers I interviewed that they already receive inadequate

support in their advocacy efforts to access the limited diagnostic and support services that are available in their community. However, embracing those aspects of medicalization that have instrumental value for supporting the health and well-being of those affected by FAS/FAE must not preclude critical examination and transformation of institutionalized policies, practices, and pedagogies that marginalize and disenfranchise people with disabilities and position them as “burdens”, “drains”, or “threats” to their communities and to the Nation-State.

Responding effectively, compassionately, and justly to the challenges of FAS/FAE requires an integral shift in how we think about FAS/FAE. This shift must include a movement away from entirely individualized, biologized, and pathologized notions of FAS/FAE and maternal substance use to one that enables collective action grounded in deep respect for the autonomy and humanity of mothers who are involved with substance use and people living with disabilities. It must also include a transformation of those institutional practices, including educational practices that mediate, exacerbate, and even create experiences of dis/ability.

Transforming public pedagogies and official knowledge: “culturally appropriate” pedagogies and the limits and possibilities of “mentioning”

It Takes a Community stresses that Aboriginal women, children, families, and communities need information and support services regarding FAS/FAE that are “culturally appropriate”. Four of the women who participated in this research stated that they value the opportunity to learn about and take part in traditional Aboriginal cultural and spiritual practices, such as smudges, and to learn about traditional approaches to parenting. Mary’s FAS program, which includes these teachings, was one that the women

agreed helped them to learn about the context, causes, and consequences of FAS/FAE for Aboriginal communities. However, the usefulness of these “culturally appropriate” pedagogies cannot always be assumed. Five of the six Aboriginal women I interviewed grew up disconnected from their own Aboriginal cultures and traditions. Indeed, Wonder Woman was not even aware that she was an Aboriginal woman with Status until well into adulthood. Based on their own experiences, and what they knew of the experiences of other Aboriginal women in the Downtown Eastside, the women agreed that many Aboriginal women in their community are unaware of what is “culturally appropriate” and can be uncomfortable when first experiencing “culturally appropriate” pedagogies. Moreover, Cheryl’s understanding of her culture’s beliefs about alcohol and drugs suggests that these teachings and practices can be incompatible with the harm reduction approaches to substance use and FAS/FAE that were preferred by the women who participated in this study. Also, the women were concerned that an over-emphasis on Aboriginal women or providing programs that serve only Aboriginal women may fuel pre-existing racist stereotypes and stigmas associated with alcohol use during pregnancy, that suggest Aboriginal peoples are particularly inclined to drink while pregnant or are unable to control their drinking. As such, the women repeatedly underscored that FAS/FAE and substance use are found in all communities and cultural groups, and all women need to be able to access services for them that are respectful, non-judgmental, and that respond holistically to the needs of mothers and children.

In Chapter 7, I showed that *It Takes a Community* stresses the importance of identifying the “root causes” of FAS/FAE, including historical, social, political, and economic factors that have resulted in loss of cultural traditions and institutions. I argued

that the incorporation of this perspective into this text is a testament to the successes of generations of Aboriginal People's movements to have the effects of colonization and the concerns of their communities recognized and responded to by the Canadian Nation-State. These are significant victories. Indeed, one of the major findings of this work is to emphasize these victories as they occur in personal, local, and national contexts while pointing out their material and discursive limits. At the same time, the public education materials produced under the auspices of the Initiative neglect to include any significant reference to "culturally appropriate" or "traditional" knowledge. Instead, these materials favour biological and medicalized understandings of the effects of alcohol on a developing fetus and of FAS/FAE. As such, these materials present a conception of "risk" in relation to FAS/FAE that often contradicts the "traditional knowledge" presented elsewhere in the policy texts.

After Apple (2000:53), I described this disjuncture as evidence of "mentioning", in which "limited and isolated elements of history and culture of less powerful groups are included in the texts... but without any substantive elaboration of the view of the world as seen from this perspective" (ibid). As such, the public education materials produced in support of the Initiative appear to provide little foundation from which to advance interests of women, people with disabilities, and Aboriginal peoples for self-determination, social justice, and decolonization that are in conflict with the hegemonic interests of the Canadian Nation-State.

At the same time, the use of "mentioning" as a textual strategy in developing the texts of the Initiative appears to have provided a textual or discursive "loop hole" for supporting the development of some First Nations and grass-roots organizations to

support decolonization and cultural renewal in Aboriginal communities. As such, “mentioning” seems to have had contradictory effects in the operationalization of the Initiative. For example, in the 2000-2001 fiscal year, the Alberta Treaty 8 Health Council received funding from the Initiative to deliver “awareness training” on FAS/FAE to community health centres and schools in the 23 First Nations within their territory. Among the reported outcomes of this project is that the training “provided the parents of FAS/FAE children with a sense of hope, understanding, and inspiration to continue to the challenging job of raising an FAS/FAE child without feeling isolated” (www.hc-sc.gc.ca/fnihb/fas_fae/projects_funding/fas_fae_projects.htm). Moreover, it is reported that this project “enabled communities to develop their own prevention models conducive to their cultural and traditional values” (ibid). The Taku River Tlingit First Nation received funding in 2000 from the Initiative to develop a “community mobilized social action justice plan” for FAS/FAE, which created “a support/ respite network for FAS/FAE care givers” (ibid). That same year, Pauktuutit Inuit Women’s Association received funding from the Initiative for their FAS/FAE Prevention/ Community Mobilization project. Reaching 53 Inuit communities, this project extended beyond efforts to “target” Inuit youth, to involve youth in the active production and creation of a “culturally and linguistically appropriate” radio play and video that “promoted healthy, alcohol-free pregnancies and encouraged discussion about FAS/FAE” (ibid). Youth participated in this project as producers, directors, actors, and filmmakers of a story “about a young pregnant teenager and her journey through pregnancy”, which includes a poster and viewing guide featuring artwork produced by a young woman from Labrador (ibid).

The fact that these projects (and others) were funded by the Initiative suggest that the “loopholes” provided by the use of “mentioning” (Apple 2000) may have create some of the conditions that support progressive movements to have their concerns addressed through the institutions of the Canadian State. For example, as has been noted by feminist disability scholar Barbara Hillyer (1993:190-2), efforts to transform the conditions under which mothers care for their children with disabilities are integral to the advancement of social justice for women and people with disabilities alike. Rebecca Martell (2003:212), a Cree counselor who works to support Aboriginal children, families, and communities living with FAS/FAE underscores “the importance of honouring each community’s unique cultural and community spirit in finding their own answers to FAS/FAE”. Martell (2003) notes that the traditional teachings of many First Nations challenge workers to “explore the many factors woven into the fabric of a historical heritage that brought many Native people into the twenty-first century in pain” (205), and that using traditional knowledge and cultures as a foundation for FAS/FAE prevention provide opportunities for “collective power in community development” (211). Accordingly, Apple (2003:14) reminds us:

Where something comes from... need not determine its political or educational use in any concrete situation. Context and the balance of power in the specific situation *do* count. This is one of the reasons we need to be cautious of what might be called the productivist or genetic fallacy. This assumes, often wrongly, that the politics of a commodity’s production and where something comes from totally determine its ultimate use... While we must not be romantic about this, texts can be and are subjected to oppositional readings.

Research is necessary to evaluate the development, implementation, and outcomes of the projects funded by the Initiative, to determine the extent to which these projects were

successful in achieving empowerment or social justice objectives in Aboriginal communities. At the same time, it is equally important to heed Apple's caution against romanticizing the emancipatory possibilities presented by oppositional readings of texts, including the texts of the Initiative. The experiences and analyses shared by the Aboriginal mothers I interviewed affirm that the practice of translating the discourses and issues of medicalization, "culturally appropriate" pedagogies, and "traditional knowledge" through the relevancies of the State places limits on the ability of individuals, communities, and social movements, most particularly those supporting Aboriginal women and people diagnosed with FAS/FAE, to articulate concerns for social justice⁴⁷.

Directions for future research

Critical policy analysis can best bring to light the textual, discursive, and material consequences of policy and pedagogy for marginalized groups and their struggles for social justice when analysis is rooted in the diversity and depth of people's everyday lives (for examples, see Boyd 1999, Gordon, Holland, and Lahelma 2000, Kelly 2000, Luttrell 2003, Mitchell 2001, Pillow 2004). In this research, I have concentrated on the textual and discursive strategies that (re)produce official knowledge (Apple 2000, 2003) and public pedagogies (Luke 1996) about FAS/FAE found in one specific policy. However, my analysis is also grounded in what I have learned from a small group of Aboriginal mothers whose lives have included, at various times and with various consequences, mothering, substance use, and FAS/FAE. Thus, textual analysis need not be at the expense of analysis of lived experience. The texts of the Initiative and the Aboriginal

⁴⁷ I argue this point in detail in Chapter 4.

mothers I interviewed are located in very specific times, places, and conditions. Future research in other local, national, international contexts and involving groups differentially positioned by gender, "race", class, age, citizenship, sexuality, and dis/ability will develop a more complete understanding of the ideological and pedagogical implications of FAS/FAE prevention policies and programs. Research that includes a larger number of participants and is carried out with a more prolonged engagement than I was able to achieve with the resources available to me for this project will surely add even greater depth and nuance to the analysis I have offered here.

For the women I interviewed, the realities that they are Aboriginal women and mothers who are struggling to make lives in which they and their children can thrive, in spite of poverty and disabilities, mattered most in their analyses. Therefore, "race", gender, class, and disability are central features I offer in this representation of their lived experiences, and in my theorizing of them. While these constituents of identity and social location were the most salient in this research, I have no doubt that others are also at work in informing "common-sense" understandings about which mothers and children are considered to be "at risk" for FAS/FAE and substance use. Specifically, I am aware that issues of sexuality remain unexplored and unaccounted for in this dissertation. Moreover, I had originally thought that issues of age would be predominant in understanding young Aboriginal women's experiences of motherhood and would intersect more significantly with the construction of them and their children as "at risk youth". However, age ultimately played a much more limited role in my analysis, as the women I interviewed rarely articulated understandings and experiences of "risk" in relation to mothering, substance use, and FAS/FAE in these terms. This is likely a

function of the fact that the all women who participated in this research were in their early to late 20's at the time of the interviews, and therefore may not have considered the discursive and administrative relevancies of "youth" to be a salient organizer of their current lived experiences. I look forward to future research that will present sociologists of education opportunities to attend more closely to issues of both sexuality and age in relation to mothering, substance use, and FAS/FAE.

As I noted above, understanding the full spectrum of the effects of the Initiative for Aboriginal communities, mothers, and people living with FAS/FAE requires research documenting the development, implementation, and evaluation of projects that were funded by the First Nations and Inuit Health Branch under the auspices of the Initiative. Although analysis of this process was beyond the scope possible with this research, this work presents intriguing possibilities to me for future work in this area. More research is also needed that examines other successful models of FAS/FAE education and support for Aboriginal women, children, families, and communities, beyond those opportunities presented by the Initiative.

In 2004, Health Canada unveiled its new policy framework to guide community-based prevention and capacity-building initiatives related to FAS/FAE. Titled, *Fetal Alcohol Spectrum Disorder (FASD): A Framework for Action*, and adopting the currently-favoured term "FASD" in favour of the older descriptor "FAS/FAE", this program is intended to expand the work supported by the 1997 Initiative to "build and maintain a strong system of supports and services to prevent FASD and to meet the needs of people in Canada who are affected by this life-long disability" (www.phac-aspc.gc.ca/dca-dea/publications/fasd-etcaf/framework_e.html). This new policy

framework represents an attempt to attend to needs that were, in the words of one FNIHB official, “not well met by the earlier program” (personal communication 03/05/04). These include the needs of Aboriginal peoples with status living permanently off- reserve and in urban areas. An analyses of this new policy direction, particularly the extent to which its discursive and material effects are consistent with and depart from those of the 1997 Initiative, also presents important prospects for future research.

Directions for future FAS/FAE education and policy-making

In this dissertation, I have argued for ways of thinking about FAS/FAE, including ways of teaching about FAS/FAE and substance use during pregnancy, that extend beyond an individualized “shame and blame” approach to acknowledge the conditions in which women negotiate and experience substance use, pregnancy, and mothering. This approach would allow for the development of programs, resources, and policy responses that more closely reflect the realities of Aboriginal (and non-Aboriginal) mothers lives and the lives of their children who have FAS/FAE. The mothers I interviewed taught me that such a shift is much needed, because existing programs and services often attempt to isolate substance use from other facets of Aboriginal mother’s lives. For the women who I interviewed, the result of these exclusions is that they often have encounters with service providers (including educators) that are unhelpful, unproductive, and in some cases traumatic. As a result, many Aboriginal mothers living in the Downtown Eastside who want to make changes in their substance use, access information about FAS/FAE and other consequences of prenatal exposure to alcohol or drugs, or receive support in parenting their children who have FAS/FAE are not getting the supports they want and need.

As I noted in Chapters 5 and 6, the women I interviewed agreed that all mothers (including Aboriginal mothers) need accurate information about FAS/FAE. This includes information about the defining characteristics of FAS/FAE, information about the consequences of FAS/FAE, and accurate, reliable information about the effects of alcohol and drug use during pregnancy. In order to be meaningful and useful to mothers, the women argued that public education about FAS/FAE must be more detailed than simplistic and reductive messages such as “just say no” or “don’t drink or use drugs if you are pregnant”. Focusing only on alcohol and drug use also ignores other factors that influence whether a person will develop FAS/FAE, as well as other consequences for women’s and children’s health and well being that are related to prenatal drug or alcohol exposure. In Chapter 5, the women explained that equally important are considerations such as whether a pregnant woman has access to good nutrition, pre- and post-natal care, appropriate medication, support from partners, family, and friends, and other factors that help her to care for herself and her child(ren). Having this information is important for supporting women’s substantive citizenship interests because it allows women to make independent, informed decisions that support their health and well-being as well as the health and well-being of their children. As Jo-Anne and Tricksey noted, this information also helps them to make sense of life experiences in their families, intimate relationships, and communities that have been painful, confusing, or traumatic. In the interviews, the women also suggested that access to information about the effects of alcohol on her fetus may support women in their relations with friends and intimates who may influence or pressure women into drinking during pregnancy. Given that women’s decisions about alcohol and drug use are made in the context of unequal gender relations, and that male

partners often use alcohol or drugs to maintain power or influence a woman's behaviour in these relationships (Astley et al 2000), public education and policy efforts that support women who wish to abstain from substance use during pregnancy clearly have a key role to play. In addition, the women who participated in this research called for the expansion of community-based health and social services to make sure that all women have access to this information in a way that is welcoming, non-judgmental, supportive, and consistent with harm-reduction frameworks. Also, the women noted that much more information is needed on the effects of other substances during pregnancy, including information about "street drugs", prescription drugs, and common ingredients in non-alcoholic beverages, such as caffeine.

According to Ward and Bouvier (2001:5), "Understanding the context of Aboriginal peoples' experiences... is crucial to determining the strategies that might be employed through education systems that are devoted to the 'public common good'". As educators, the policies that we create and implement, the pedagogies we develop and enact, and the interactions we have with those who live with the challenges of substance use and FAS/FAE are not of passing significance. They provide us opportunities to create conditions that welcome Aboriginal women, families, and communities to work with us in a respectful, collaborative way, that is grounded in a shared commitment to provide women, men, families, and communities with the best education possible. This means approaching people diagnosed with FAS/FAE, and the mothers who give birth to and care for them, as sources of knowledge, experience, and strength. It means greeting the person with FAS/FAE as a person first, who has a variety of needs, interests, and

challenges. It means working with a person who has FAS/FAE and her/his support network to find the best method for meeting their needs in a positive, encouraging way. It also means rethinking the source of the "risks" and "problems" of FAS/FAE as located in the policies and practices of state institutions, including schools, not just in Aboriginal families and communities. Most of all, it means working to identify and transform those institutions and practices from ones that disable and marginalize to ones that offer compassion, respect, and empowerment.

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