

The Social Organization of Mothers' Work: Managing the Risk and the  
Responsibility for  
Fetal Alcohol Spectrum Disorder

by

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BScN, University of British Columbia, 1978  
MSc (Community Health), University of Northern British Columbia, 2001

A Dissertation Submitted in Partial Fulfillment of the  
Requirements for the Degree of

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### Abstract

This institutional ethnography relies on observations, interviews, and textual analyses to explore the experiences of mothers and children who attend a women-centered agency in Vancouver, Canada where a hot lunch, child care in the emergency daycare, and participation in group activities are vital forms of support. Mothers who come to the centre have many concerns related to their need for safe housing, a sustainable income, adequate food, child care, and support. And like mothers anywhere, they have concerns about their children. While many of the children, the majority of them First Nations, have never had a diagnostic assessment for fetal alcohol syndrome (FAS) or for the relatively new *umbrella* category, ‘fetal alcohol spectrum disorder’ (FASD), a number of the mothers were concerned or even *knew* that their children had FAS. This thesis asks – how does it happen that mothers have come to know their children in this way? The study critically examines how FASD knowledge and practices actually work in the setting and what they accomplish. My analysis traces how ruling practices for constructing and managing ‘problem’ mothers and children coordinate work activities for identifying children deemed to be ‘at risk’ for FASD. In their efforts to help their children and improve their opportunities for a better life, mothers become willing participants in group activities where they learn how to attach the relevancies of the FASD discourse to their children’s bodies or behaviours. They also gain instruction which helps them to confess their responsibility for children’s problems. While maternal alcohol use as the cause of FASD is contested in literature and in some work sites it is, in this setting, taken as a fact. This study discovers how institutional work processes involving government, medicine, and education actually shape and re-write women’s and children’s experiences into forms of knowledge that make mothers and children institutionally actionable. It is only by exposing the relations of power organizing mothers’ work that it may be possible to re-direct attention to mothers’ and children’s embodied concerns and relieve mothers of the overwhelming responsibility for which they are held and hold themselves to be accountable.

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## **Dedication**

To my mother, Julia Marie (Jamison) Schellenberg (1916-1992) who, even when I was a young child, nurtured my love of learning

and

To my children, Sean, Russ, and Elise – my Malcolm/Walmsley clan – who have been and always will be my best teachers.

## Chapter One

### Beginning an inquiry in the everyday world

*We are to look therefore for the actual socially organized practices and relations expressed in that concept of knowledge. In particular we will be concerned with the practices accomplishing the disappearance of subjects and hence, as we shall discover, with the properties of objectified knowledge that accomplish its distinctive organization and over-riding power (Smith, 1990a:66).*

#### 1.0 Introduction

Mothers' work is challenging, an unpaid labour of care, concern, and responsibility. Children's young bodies must be scrubbed, dressed, fed, soothed, played with, and managed daily and often nightly seven days per week. When children are tired, anxious, hungry, or fearful the demands on mothers, particularly, mothers who may be parenting on their own can often be overwhelming. For mothers living on low incomes, or seeking employment without the security of safe housing, nutritious sources of food, respite, or child care, any safe haven offering non-judgmental support is a life-line, even a life-saver.

When I began my institutional ethnographic inquiry in Crabtree Corner, a busy, multi-services agency which offers help to 'vulnerable' mothers and children, I entered a supportive, caring environment, which some women in the centre call "a lifeline" and "safe haven". Many of the women who have made their way from small towns and Aboriginal<sup>1</sup> reserves to the city have, like other poor women, struggled to manage. Women arrive at Crabtree with many concerns – the concerns of mothers seeking a job, food, and shelter for their families. A nourishing breakfast or hot lunch, activities in the Fetal Alcohol Syndrome (FAS) Prevention group, respite in the emergency day care – all of these and more provide a work interface for mothers and children with the caring front-line personnel who provide vital services and support. I began to think of

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<sup>1</sup> Aboriginal is an inclusive term that may be applied to Canada's Indigenous population, which includes all First Nations, Métis and Inuit people regardless of where they reside (Canada, Royal Commission on Aboriginal Peoples, 1996). The term Aboriginal is not exclusive to Canada's Indigenous population. Throughout my paper, I use the terms 'Aboriginal' and 'First Nations' inter-changeably to reflect the various ways that women in my study self-identified.

all the women, those who were paid staff and those who came for help as ‘women at work’. I could see by their level of activity and engagement, just how much emotional, physical, and mental effort they put into their day. And it was in these everyday routine moments, as I listened to women and observed their work activities, that I discovered FAS to be a prominent feature particularly in mothers’ talk.

Fetal alcohol syndrome, commonly called FAS, is a diagnosis that medical experts may apply to children or adults<sup>2</sup> who show physical and/or neuro-developmental characteristics that are associated with – many would say caused by – women drinking alcohol during pregnancy. ‘Crabtree’ is not, however, a diagnostic centre, nor even a ‘health’ care site. Yet in informal discussions with women in the setting, I heard that “FAS is a huge issue in the building”. Similarly, when I began to talk with mothers, a number of them told me they *knew* their children had “FAS”. I could hear that this was a real concern for mothers. Yet, many of these children had never had a diagnostic assessment<sup>3</sup> for FAS or for the relatively new *umbrella* category, ‘fetal alcohol spectrum disorder’ (FASD<sup>4</sup>).

The problematic or puzzle organizing my inquiry emerged at just this knowledge disjuncture between mothers’ experiential, embodied knowledge and concerns about their children – concerns such as their sleep, food, and a safe place to play – and this generalizing and objectifying form in which mothers also expressed concerns about them. Here was a condition, a

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<sup>2</sup> In this paper, I am addressing the topic of FAS in reference to children and their biological mothers. FAS is considered to be a life-long disability and FAS experts suggest that there are many adults with FAS who have not been diagnosed. There is an increasing policy discourse in Canada on the need to improve diagnostic and treatment services for adults, in particular, for those who have had encounters with the criminal justice system. It is my understanding that advocates for this population believe many of these adults to be male, Aboriginal, and living in prisons.

<sup>3</sup> Tait (2008) observes that in her own fieldwork experience, she perceived that First Nations people are most commonly labelled FAS in the absence of a medical assessment. My inquiry examines how this actually happens in my fieldwork site.

<sup>4</sup> Women in the setting more often used the term ‘fetal alcohol syndrome’ (FAS) rather than FASD. I will write FASD as FAS/D as a reminder that the root of the newly constructed ‘umbrella’ category is FAS.

disorder, mothers apprehended as already present in their children, ‘something’ *known*, an entity or object they called “*FAS*”. How did it happen that mothers had come to talk about and know their children in this way?

The line of inquiry that institutional ethnographers take in collecting and analyzing data is aimed at the discovery of how social and ruling relations work in the everyday world. Dorothy Smith (1987, 1990a, 1990b, 1999; 2001; 2005) who developed this research method, uses the term social relations to identify the actual practices or work activities through which our lives are socially organized or ‘ruled’ (Campbell & Gregor, 2002). Ruling happens largely through language, texts, and information exchange, in objectifying forms of knowledge and practices that are useful to (and used by) people in systems for administering, managing, and governing people’s lives (Smith, 1990a).

Through listening to what people have to say about themselves or their children, in the terms relevant to a text-mediated conversation or ‘discourse’ such as *FAS*, we can begin to discover something about how the exercise of power works in people’s daily lives, shaping how we talk and organizing the social relations of a setting where a situation arises or carries on in other activities or actions. Social organization is present *in* people’s descriptive language and in their own implicit knowledge (1990b). And I also discovered social organization in mother’s work.

As women gain instruction in Crabtree’s *FAS/D* Prevention group, they learn how to attach the relevancies of the *FAS/D* discourse to themselves and to their children. Women learn, for example, that the ‘acting out behaviours’ of their young children, which may well be perceived as ‘normal’ variances in many other settings, are signs that their children are ‘at risk’ for *FAS/D*. They also learn that because they drank alcohol during pregnancy, they are



responsible for their children's troubles, and they learn how to confess their responsibility. This way of knowing attributes a range of 'variances' in children's faces, bodies, or brains to maternal alcohol use. While the cause of FAS/D is contested in the literature and in some work sites<sup>5</sup> it is, in this setting, taken as a fact.

The work of ruling – which objectifies and subordinates women's and children's subjectivities to the relevancies of the FAS/D discourse – is not overtly or formally imposed on the mothers in Crabtree. In modern day modes of governing, people are encouraged and, in Crabtree's setting, also 'instructed' in how to take responsibility for identifying and managing their own risks and those of their children. I am showing that the FAS/D Prevention project in Crabtree organizes a particular kind of responsibility – one which assists mothers to responsabilize themselves according to the terms of the FAS/D discourse. The mothers also learn that they can help their children by having them diagnosed – through practices that will also establish their accountability for their children. This authoritative account may help to prevent any future children with similar kinds of 'risks'.

I will argue and show that the production of the diagnostic text and, thereby, its 'capacity' to authorize further courses of action depends on establishing an 'objective' representation of the mother and child and not on ensuring its reliability or accuracy (Jackson, 1995). The production of objectivity will ensure that practices involved in identifying FAS/D and

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<sup>5</sup> Dr. Mary Hepburn (1993; 2002), a medical specialist and researcher in Scotland, who started the Reproductive Services for women in Glasgow, is known internationally for her work with women and children. Dr. Hepburn wrote to me stating:

We see plenty of effects – especially low birth weight that could be due to alcohol but could also be due to socio-economic deprivation – but very few that fulfill the FAS criteria. But what is the benefit of labelling the child in any case? We prefer to assess individual needs and respond appropriately (personal communication, March 13, 2003).

Similarly, a British Columbia (BC) specialist at the Fir Square Unit (BC Women's Hospital), Dr. Ron Abrahams, who works with pregnant women who use substances (alcohol and drugs), also questioned the diagnosis, asking me: "Why aren't we calling it 'poverty' instead?" These comments reference the multi-factorial, rather than the medicalized and mono-causal FAS/D discourse.

producing the account of the child and mother are obscured. My analysis makes practices that account for maternal responsibility visible. I am arguing that the FAS/D prevention work that begins in this setting and moves mothers and children on a trajectory toward the actual diagnostic account, is a particular kind of health care practice that establishes a different form of accountability for mothers than if their children were only ‘acting out’ or having difficulty with learning activities in school.

Tracing moments in women’s talk and work activities in the setting has assisted me to discover ‘piece by piece’ how a complex of objectifying discourses and work processes coordinates women’s talk and work in this setting. This discursive work aligns particular concerns mothers have for their children with governing interests that project a reduced role for the state – a ‘safety net’ with many holes in it. The embodied concerns mothers have when they arrive at the centre disappear from view, at least insofar as being addressed or acted upon.

My analyses demonstrate how the *help* offered to poor mothers and their children also offers ‘back door’ access to a ‘compassionate’ system of monitoring, diagnosis, and surveillance. An FAS/D institutional complex which, I show includes institutional work processes involving the state, medicine, and education coordinates and permeates this grassroots, ‘women-centred’ agency and the everyday work and talk that take place in it. My inquiry exposes a thread, as it were, in this complex web of interconnecting FAS/D discourses and work activities to show how ruling over-rides people’s best efforts to offer vulnerable women and children a safe haven.

## **2.0 Institutional Ethnography: A place to stand and a method of looking**

In an institutional ethnographic inquiry, people’s everyday activities and experiences constitute the problematic of an investigation (Campbell & Gregor, 2002). The aim of research is to begin in a standpoint in the everyday world in order to make visible the social organization

of it (Smith, 1987). George Smith (1990) observes that “the epistemological character of the problematic, the fact that it arises in the everyday world as a problem about knowing” from a particular standpoint, sets the basic framework for an institutional ethnography inquiry (632). We are to be concerned with the disappearance of subjects and with the harm that can result when people’s own knowledge, even their knowledge of themselves, is irretrievably altered (Smith, 1990a).

My investigation is directed at what people actually do to participate in and accomplish ruling in these objectifying forms of knowledge. Dorothy Smith (1987) uses the notion of ruling as a way to help us understand how power, exercised in a local setting, such as a school, a clinic, or an agency, accomplishes interests that arise from elsewhere in ‘extra-local’ ‘institutional’ sites. ‘Institution’ does not mean a ‘centre of power’ or even an organization. ‘Institution’ refers to a complex or “cluster of text-mediated relations” and work processes that occur in multiple sites (Smith, 1987:160). Texts and textually-mediated forms of knowing, such as a discourse about people as FAS, are central and indeed, indispensable to coordinating widespread ‘conversations’ across many institutional settings about those who are standardized as FAS objects. The FAS/D discourses I discover are, in effect, discourses that are *of* the institution and they are shown to be accomplished in mothers’ work.

Working with these theoretical underpinnings of my methodology, I have learned to think of my primary informants – the mothers at work in my ethnographic setting – as embodied knowers situated in the local particularities of their everyday lives. As ‘embodied’ knowers they are the experts in their own lives, and it is their standpoint that I am taking. This standpoint situates the subject and my interest in the lives of the women and children and not in texts and categories concerned with FAS and FAS/D, which make women and their children objects.

My experience as a nurse and policy consultant for children with ‘special needs’, has been showing me that children who bear the label FAS or FAS/D are, along with their mothers marginalized<sup>6</sup> – their experiences devalued and subordinated to a discursive way of knowing about them.

The key to developing knowledge that begins from a standpoint in women’s and children’s experience is not to develop more knowledge about children with FAS/D or their ‘responsible’ mothers or to enter debates about whether FAS is a ‘real’ diagnosis. My interest is to offer a social analysis on behalf of people whom these ruling forms of knowledge subjugate (Campbell & Gregor, 2002). Smith (1987) insists that by “giving voice to women’s experience, opening up to women’s gaze the forms and relations organizing women’s lives”, we also enlarge women’s own capacities to organize in the struggle against oppression (225).

The social relations embedded in mothers’ talk and work activities have provided an actual method of looking to discover how mothers and their children are ruled and also how the mothers enact and participate in their (our) own ruling. Institutional ethnography has, thereby, provided the research approach and methods for investigating social relations and for discovering how power is enacted in the routine and knowledgeable activities that are part of women’s work in this setting.

### **3.0 An insider’s knowledge: *Self* in the social relations under investigation**

My interest in conducting research with the women and children in my study developed from my own work experiences. Ruling is in my own work as a nurse. As a nurse and former public policy consultant for children with special needs, and later, as a policy consultant

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<sup>6</sup> Nurses are often interested in an approach to inquiry called ‘research from the margins’. The ‘margin’ is considered as the context in which those who suffer injustice, inequality, and exploitation live their lives, not only in terms of unequal distribution of resources, but also in terms of knowledge production (Kirby & McKenna, 1989).

concerned with FAS prevention, I am an ‘insider’ in the social relations of objectified knowledge concerning women and children. And as a researcher conducting a critical inquiry into the social relations of FAS and how they work in women’s and children’s lives, my exploration of the social relations also brings into view my own practices and concerns as a mother, woman, nurse, policy maker, and service provider.

Although I had previously conducted insider research (Schellenberg, 2000; 2003), I approached this present inquiry with a sense of uneasiness. Working as an FAS policy consultant, I had become troubled and puzzled by the diagnosis of FAS and how FAS organizes women’s and children’s lives. As a researcher “exploring social organization”, I must employ a ‘reflexive critique’ which requires that I also recognize my own ruling practices (Smith, 1990a: 204). Smith’s (1990a) work insists that when we do ruling work, our own practices articulate with relations that can overpower our embodied knowledge and also our well-intentioned work.

Working in the FAS policy field was a lesson in how power and knowledge intersect. I discovered that this intersection – expressed in the practices by which people rule – subdued questions, debates, and thoughtful exchanges about how possibly to better serve the needs and interests of the women and children on whose behalf I hoped to develop policy. Fetal alcohol syndrome is located in a field of contested medical knowledge and practices. And in the FAS prevention policy field, which is a priority of the British Columbian government, the voices of those with medical expertise in FAS tend to dominate.

The FAS field also has a well-organized network of advocacy groups and organizations throughout the province, many of whom have developed from the lobbying efforts of adoptive and foster parents. While listening to the concerns of these parents and groups, I found that there

was no place for the biological or ‘birth’<sup>7</sup> mothers of children with FAS or ‘FAS/D’ to offer their perspectives, which might otherwise (I hoped) provide for more equitable and just public policy and resource allocations.

The FAS diagnosis, which implicates certain mothers as responsible for harming their children constructs differences between groups of mothers and sets birth mothers apart – excluded and, until more recently<sup>8</sup>, silenced. However, to say that the voices of mothers were ‘silent’ does not take into account the “problem of silences” and the social relations that organize women’s experiences and their subjugation (DeVault, 1999: 183).

When I began to develop the proposal for my inquiry, I wanted to hear from mothers whose voices were, at the time, excluded from informing policy. I began my ethnographic study in a setting where there were many mothers, including family caregivers such as aunts, grandmothers, and so on. Listening to mothers experiences opened a ‘conversation’ about one of the problems of silences – that there are “things that cannot be easily said or heard” (1999: 183).

Smith (1987) also writes of women’s silence – of being silenced. When she wrote of the terrible historical silencing of women she was also revealing how women, in many times and places, have not even had the words to speak about their experiences because the knowledge they gained about their lives was in texts written by men who produced abstract knowledge about them.

The sense of disquiet I originally had in my work stimulated the early puzzles that began this inquiry. Beginning in those puzzles and contestations, I later discovered an entry point to my investigation, through which I have begun to explicate the ruling relations organizing women’s

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<sup>7</sup> The term ‘birth’ mother is commonly applied to mothers who have given birth to children who are thought to have been affected by the mother’s alcohol consumption during pregnancy (Badry, 2007-2008). I suggest it is also an ‘utterance’ in FAS/D discourse, which constructs a way of knowing about certain biological mothers.

<sup>8</sup> The current government administration in BC has gradually developed a way to engage the voices and work of birth mothers to support ruling interests, as I show in this inquiry.

and children's lives and, in some ways, also my own (see also DeVault & McCoy, 2002). I have been learning that for those of us who are engaged in what we hope is 'helping' academic or human services work, there is no 'neutral place to stand' (Campbell & Gregor, 2002) – not as a researcher, not as a worker, not as a nurse.

#### **4.0 Problematizing a mother's concerns and how a mother knows**

Beginning in the everyday world – the material context in which women and children exist in their bodies as knowing, thinking, feeling, active, working beings – offers a site from which to explore how forms of ruling work in the everyday world to organize people's experiences (Campbell & Gregor, 2002; Smith, 1999). Smith (1987; 1999) theorizes the 'everyday world as problematic' to identify how the researcher takes up an inquiry from a standpoint in the world in contrast to a "standpoint in text-mediated discourse or organization" (4). The problematic, which often begins with everyday issues, problems, or concerns, arises in the disjuncture or line of fault between the institutional 'regime' and the everyday settings where people live or work and go about their lives (George Smith, 1990a).

Smith (1987) insists that by making the everyday world our problematic, we can begin to see the organizing features of our knowledge and experiences, which have previously remained hidden, mysterious, or taken for granted. My exploration begins in talk, where it is possible to learn from those concerned more than they realize they knew about their own participation in an institutional process (Smith, 2005).

When I began my field work at Crabtree Corner, I took opportunities whenever possible to spend time with women and children where they were, involved in various activities, including 'work' and play. Following on Smith's (1987) assertion, that "we need to learn to treat one another as the authoritative speakers of our experience and concerns", I listened to what

women had to tell me about their lives. Gradually, puzzles and questions began to emerge and some of these have shaped my inquiry. I introduce one interview segment in this chapter, where a mother, Emily<sup>9</sup> relates her concerns, which also reveal disjunctures between different ways of knowing.

#### 4.1 Emily and her concerns

Emily has been telling me about her life and, in particular, her difficulties in trying to find suitable employment. She is living in inadequate housing, and her child has nowhere safe to play. She would like to work but has no one she can trust to care for her children. Emily tells me that she is worried about her child, Alix. She explains that Alix, who is three, is a beautiful child but she cannot talk well, and Emily wants to have her assessed. Alix can say, “Mom” and other isolated words, but she cannot put sentences together. I learn that Emily is not currently seeking an assessment for speech or hearing, as I had initially expected. As Emily talks about the assessment she is seeking for Alix at ‘Sunny Hill<sup>10</sup>’, she turns to talking of her concerns about another child. What Emily has to say suggests how her concerns about Alix may have developed:

Emily: And the older one, my son, had FAS.

Researcher: How did you become aware of that?

E: Because he wasn’t able to concentrate very well. He was always so short tempered from a little boy. I don’t know what was going [on] up there but I just knew, his eyes –

R. What about his eyes?

Emily. Their eyes, the way they looked, I don’t know. One ear was out, just the way, I don’t know, just he seemed to have some characteristics I could relate to.

R. You thought from what you could see –

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<sup>9</sup> All names used are pseudonyms, to protect people’s confidentiality.

<sup>10</sup> Sunny Hill Health Centre for Children, often called “Sunny Hill”.



E. Yeah.

R. – that there was something you thought was FAS? Did someone else tell you –

E. No. Cause back then –

R. How old is he?

E. He's 18.

R. So it's what you're feeling yourself?

E. Yeah. Cause nobody ever diagnosed back then, it was much more acceptable [to drink]. Nobody ever diagnosed. Nobody ever put those 2 and 2 together and said, Hey. This was...(unfinished sentence).

R. So where did you learn about it? Because you say you looked at him and thought from the way he looked?

E. I don't know. He just looked different like. A little bit off like (laughs).

R. What made you think that was FAS?

E. Because I drank a lot.

During this interview, I sensed that Emily has imported her understanding of her older child, her history of alcohol use, and her knowledge about FAS as a way to explain the problems in speech that her child, Alix, has been having. My interest is not in disputing Emily's knowledge that her older child looked or acted *different* or that Alix has difficulties with her speech that should be addressed. I recognize the importance of the understandings that women bring to their own lives and their concerns about their children. I am problematizing, however, how Emily has come to know her children in *this* way. She saw in the body and behaviours of one child the signs of FAS and her responsibility for it, yet her child was never diagnosed. In Alix, she sees a lovely child who has difficulty with speech. I can tell by how she talks that she is deeply worried that Alix

too, has FAS. How does Emily know and what is shaping Emily's concerns and the courses of action she feels she must take?

#### 4.2 Identifying disjunctures in ways of knowing

Reflecting on Emily's account, I identified a disjuncture which suggests two different ways of knowing are applied. On the one hand, Emily expresses her embodied concerns, including her worries about housing, the need for safe playgrounds and child care, and her concern that Alix is not putting her words together yet in sentences. On the other, Emily expresses a fear and a certainty about the cause of her children's problems even though neither of her children has been diagnosed. Emily is certain her older child has FAS and now, Emily is deeply worried that Alix has FAS because Emily knows she drank. As I listen to Emily, I hear how her fears and concerns about Emily seem to over-ride her other concerns.

#### 4.3 Problematizing mothers' concerns and how mothers know

In the approach I take in this inquiry, knowledge disjunctures are not suppressed but are treated as lines of fault in 'taken-for-granted' terrain, and thus point to problematics to be explored. The puzzles I have been discovering in women's talk are problems in knowledge and in how we/people know.

A common approach to understanding people's everyday lives or 'talk' is a reliance on the beliefs, explanations, or typologies that focus on individuals rather than on the institutional field that shapes and organizes their language and their experiences (McCoy, 2006:114). In contrast, institutional ethnography's social ontology relies on the discovery of an 'actual' material world of people's activities and experiences that connects with and is coordinated by institutional or ruling relations (Smith, 2005).

Dorothy Smith would argue that the talk or ‘discourse’ people use in medical, governing, and administrative practices is not just any language, it is an ideological construction of how people understand their/others lives and what people need. Ideology directs the researcher to look for and at the production of these forms of socially organized knowledge – the labels, concepts, categories, and other forms of discourse that offer an authoritative way of knowing what people need (Smith, 1987). My analytic work has been helping me to attend to how women’s use of language signals how institutional relations are at work in their/our lives.

As I reflected on the nature of Emily’s concerns and heard the traces of a responsabilizing discourse on alcohol use and FAS in her talk, I recognized that the knowledge and concerns this mother voiced were not merely a property of individual consciousness related to her consumption of alcohol during her pregnancy. Here, in how she talked, was a problematic – a methodological starting point for my inquiry in which I ask: how are the local experiential ways of knowing their children that mothers ordinarily rely on transformed into objectifying ways of knowing that are authoritative, medical, or psychological?

As a feminist and institutional ethnographer, my commitment is to begin with a standpoint in women’s and children’s everyday lives in order to problematize how seemingly arbitrary everyday activities, talk, texts, and forms of ‘help’ direct attention to the ‘institutional’ and ruling relations that organize how things happen as they do (Smith, 2005). And, in my discovery of words and phrases and women’s work activities in the centre, which make apparent and even primary certain relevancies in women’s knowledge and experiences – I am also asking: how does the organization of women’s talk and work in this setting shape, re-organize, help, or manage women’s needs and concerns?

The account I describe provides the empirical ground for my investigation into the social organization of women's knowledge and concerns. My title, 'The social organization of mothers' work', is an inquiry into how things happen to organize and shape women's knowledge, their talk, and concerns. I make my discoveries through my examination of mothers' actual work.

My focus of inquiry has been with mothers, but their children are very much a part of their lives and, as I have been showing, their concerns. I too have concerns about the children and how they are made known, and I address this concern in the following section.

#### 4.4 My concerns about the children

I observed children in my fieldwork setting and I learned about them from their mothers. While the experiences of children are not central to my inquiry, their objectification, like that of their mothers, is central to my concerns and has motivated my inquiry. In this section, I briefly introduce Beth, who talks about knowing herself as FAS when she was a child. What Beth has to show in her talk, suggests that FAS is not an easy name for a child to wear.

During an interview with Beth, a young, articulate mother of two children, she expressed concern that one of her children might have FAS. Beth said that she had been drinking alcohol for two months before she realized she was pregnant. Beth said she didn't know what she would do if her child had FAS and added: "I'm FAS myself and I know how hard it was for my parents and foster parents." I asked Beth what it was like for her to be told she had FAS and she replied:

It was just another word that they used for me, like 'trouble maker', you know, [be]cause being a child in care, you just learn to not pay attention to what the social workers are telling the foster parents like, "Oh, she has ADD" or "ADHD"; it was just another [whispers], "Oh, you know, she has FAS".

Beth, a foster child from the age of two years and the younger version of the bright, perceptive woman I was speaking with, seems to disappear – perhaps felt herself disappearing – in the categories that social workers used to describe her. Here, in her description of FAS as “just another word they used for me”, Beth directs attention to the discursive application of a diagnostic category as a practice of naming *something*. What *FAS* and *FAS/D* name, how these practices of categorizing and naming are put together, and what they accomplish, are questions which shape this inquiry.

Despite the central place that medical diagnoses and other forms of classification hold in our lives, the practices by which they are produced, circulated, and coordinated remain largely invisible and taken-for-granted. Yet the social and moral order they create, and their impact on our lives, is indisputable (Bowker & Star, 1999: 3). For Beth, and for the many other children and parents to whom *FAS/D* categories are applied the impact may be oppressive and irreversible.

I provide additional experiential accounts of mothers and children in the following chapters, and I also return to Emily and Alix in Chapter Six to explore the social organization of their experiences. Here, I provide a brief overview of each of the chapters to show how they develop my inquiry.

## **5.0 Overview of the chapters**

This chapter has introduced the focus of my inquiry, the puzzles that provide an empirical ground for my investigation, and the primary questions that I am exploring. I have also introduced the knowledge field, ‘fetal alcohol syndrome’, the latest revision of it, ‘fetal alcohol spectrum disorder’ (*FAS/D*) and some of the debates I encountered as an ‘insider’ working in the field.

Chapters Two and Three provide my reviews of literature, and the development of the conceptual framing of my inquiry. Chapter Two focuses on the evolution of the medical diagnosis of FAS and my exploration of its social organization. In Chapter Three, I examine discourses which shape and intersect with knowledges about women, children, and FAS. I also discover and show how biomedical knowledge and practices are, like FAS, contested.

Chapter Four introduces institutional ethnography and the theoretical underpinnings of my inquiry. I describe my reliance on ethnographic methods, which provide the empirical ground for my exploration and discovery of the social organization of mothers' work.

In Chapter Five, I describe my entrée into Crabtree, providing a full description for the reader to gain a sense of what the place looks and feels like for those attending. My exploration introduces the social relations of this setting and something about the lives of the women who go there for help.

Chapter Six is the first of two analytic chapters, which examine and explicate mothers' work in Crabtree. This chapter begins in women's concerns about their children and marks mothers' work engagement with discourses and practices that identify and produce children's risks and mothers' risk management work.

In Chapter Seven, my work traces how women's engagement in FAS/D prevention discourses begin in different work activities in the building. I follow women's work and their concerns to their activities in the FAS/D Prevention group where they learn to objectify their children and to responsabilize themselves.

In Chapter Eight, my examination of mother's work derives from my analysis of a text, a child's diagnostic report, which expresses a mother's and child's work engagement with the formalized processes for assessing and diagnosing children as FAS/D. I analyze the text-

mediated practices for establishing a mother's accountability for her child's FAS/D and I also discover that after Sunny Hill, mothers are encouraged to take responsibility for other mothers and children who are also constructed as 'risks'.

My concluding chapter examines how the objectifying forms of knowledge and text-mediated work processes and accountabilities that organize women's work in Crabtree can be explicated as actual practices for governing women and children. I show how front-line workers and professionals, while applying their best efforts to help women, enact relations of power in their caring encounters and thereby, despite their intentions, may actually compromise women's safety and subvert their concerns and subjectivities to discourses that work on behalf of ruling interests rather than for mothers and their children.

## Chapter Two

### A disordered birth: The origin and expansion of FAS

*We must not see any person as an abstraction. Instead we must see in every person a universe with its own secrets, with its own treasures, with its own sources of anguish, and with some measure of triumph (Elie Wiesel, 1992: ix)*

#### 1.0 Introduction

Whether we live with a medical diagnosis, support a friend or family member who has a diagnosis or is seeking one, or make use of diagnoses in our work, a diagnosis is a form of knowledge and a way of knowing that we take-for-granted. For example, Gardner's (2000) qualitative study advising nurses on issues of concern to foster parents caring for children with FAS, begins in an FAS discourse on the 'realities' of life with an FAS child. Beginning in this objectifying discourse implies that the writer – and others who take up her work – assumes that the diagnosis is knowledge that can be relied upon to guide professional care for and support of women, children, and families.

My research problematizes the specialized, objectifying forms of knowledge which displace experiential, embodied ways of knowing (Campbell & Gregor, 2002). To a nurse, schooled first in the biological, nursing, and community health sciences and in a profession that is seldom reflective or critical of its own knowledge and practices (Schellenberg, 2000; Holmes & Gastaldo, 2002), the critical literature in this and the following chapter is valuable to my own critical inquiry related to the medical diagnosis of fetal alcohol syndrome and FAS/D.

In this first of my two literature chapters, I examine the authorized literature on the knowledge field, fetal alcohol syndrome. Tracing the history and re-visioning of FAS to its latest expansion as fetal alcohol spectrum disorder has assisted my identification of its social organization including key controversies and claims. I draw considerably from the work of



Ernest Abel (1995, 1998; Armstrong & Abel, 2000), who articulates authoritative knowledge gained from his own expertise as an FAS researcher and at the same time, provides analyses critical of the knowledge claims and practices in his own field. In Chapter Three I look to social sciences fields which provide critique of FAS-related discourses, the biomedical knowledge field, and diagnostic practices.

At times, I use the term ‘illness’ to encompass disease, disability, or variances people experience in regard to that which is described as ‘health’ – a presumed ideal and holistic state of emotional, physical, and mental well-being (Kramer, 1990). However, rather than define each of these terms, which are themselves contested, I am problematizing how concepts and other authoritative forms of knowledge concerning peoples’ embodied experiences have come to comprise the basis of how we/people know ourselves and others.

## **2.0 Entering a contested field: Claims and controversies**

What is fetal alcohol syndrome and how did it come into being? Did medical experts discover fetal alcohol syndrome in infants in 1973, as many authoritative texts claim<sup>1</sup>? Is the syndrome a moralizing discourse on women and substance use and did American dysmorphologists and others, concerned with the decline in ‘morality’, create the diagnosis of FAS as a means of addressing the ‘social problem’ of substance use among women (Armstrong, 2003; Etorre, 1992)? The ‘moral’ element concerns a “normative judgment that some conduct is intrinsically bad, wrong” or involves some form of harm that must be managed through regulatory practices (Lupton, 1999:6-7). My reading of biomedical and critical literatures reveals disparate views. I first turn to authoritative accounts about the history of FAS to explore the

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<sup>1</sup> Researchers in the United States typically cite Jones and Smith (1973) as the first to ‘discover’ FAS, rather than Lemoine et al, (1968), who identified a pattern of anomalies in alcoholic mothers. Abel (1984) observes that the work of Lemoine, in contrast to that of Jones and Smith five years later, had little impact because it was published in French and readers at the time received it with scepticism.

origin of the FAS diagnosis, subsequent diagnostic revisions, and changing claims and controversies.

## 2.1 Early claims

When Jones and Smith (1973) published their account of their discovery of ‘fetal alcohol syndrome’, they claimed that the ancient Greeks had written on associations between alcohol use and birth defects. Biblical passages, plays written by early Roman and Greek writers, and even the works of Plato and Bacon are frequently cited as examples of ancient knowledge suggestive of the adverse effects of alcohol on a pregnancy (Abel, 1984).

However, other writers have examined and refuted such claims. For example, Abel observes that the historical admonitions to refrain from ‘drink’ tended to be directed more often toward the father than the mother, often in regard to alcohol’s effect on the libido and fertility. Similarly, the so-called ‘gin epidemics’ in England during the early 18<sup>th</sup> century, with various textual depictions of drunken women and weak or ‘feeble’ children, which have been regarded retrospectively as “sightings of FAS”, are also contentious (Golden, 2005: 20). Golden, who examines these claims, observes that some people blamed gin – and women’s consumption of it – for high infant mortality rates. Cheap gin, which had flooded the market, was the choice drink for poor and working classes, among them, impoverished mothers. However, subsequent studies indicated that infant mortality rates had actually been high prior to this period, for many other factors, not the least of which was poverty (2005).

Shibley and Pennington (1998) dismiss claims of historical associations between maternal alcohol consumption and anomalies in children, despite their prevalence in the FAS literature. They insist they are misrepresentations of history, which derive either from “scientists wishing to bolster their claims for the legitimacy of FAS research” or from sloppy scientific

practice (1998: 429). Possibly, the long history of stigmatizing and blaming women who consumed alcohol or other substances, one which persists to the present day, also contributes to the persistence of these historical mis/representations.

## 2.2 Historical representations of women and alcohol use

A survey of historical analyses concerned with women and alcohol use offers some of the characterizations made of women who consumed alcohol in the United Kingdom (UK) and North America. Valverde's (1998) discussion has been most helpful. In the late Victorian era, 'degeneration theory', a branch of evolutionary science, prevailed in the UK, with offshoots elsewhere in North America. People concerned with the field of degeneration, viewed alcohol as a 'racial poison' which threatened the evolution of the human race. In this paradigm, whether or not a condition was biological or moral was of little concern because the two were seen to be inter-related. "Bodily features were moralized and moral vices were blamed for causing physical degeneration" (1998:51). The mentally handicapped and single mothers, and their presumed moral vices, were among the degenerates most often blamed. However, because many writers held the view that physical and moral conduct could be inherited, they also targeted drinking men along with degenerate women (1998). However, in Britain, inebriated citizens incarcerated under legislation enacted at the time were for the most part women, many of whom were also poor urban mothers, charged with child neglect (1998).

Valverde (1998) observes that there were heated debates over whether alcohol consumption by pregnant women could harm the offspring, but interest in documenting what is now called 'fetal alcohol syndrome' was, at that time, short-lived. Most degeneration theorists were more concerned with heredity than with the conditions of pregnancy, women's choices, or their environments (1998). Valverde claims that apart from the "discursive slippage between

‘female inebriates’ and ‘the feeble-minded’”, which subsumed one large group – working class mothers – under the label of mentally deficient, fetal alcohol debates disappeared from view, for the most part, until the 1970s (57).

Even into the 1970s, most physicians discounted any major concerns about maternal alcohol consumption during pregnancy, and some routinely recommended a little alcohol as a ‘relaxant’ to pregnant and nursing mothers (Armstrong, 2003). My own physician recommended a bottle of stout daily before dinner, to help the ‘let down’ reflex when I sat to nurse my first child. However, other issues, such as the rampant use of DDT, particularly in the United States (US), and publicized effects of environmental pollution<sup>2</sup> made people increasingly aware of threats to human and fetal health (2003).

Several other significant events contributed to a developing awareness of the vulnerability of the fetus and, thereby, provided an important backdrop to the ‘discovery’ of fetal alcohol syndrome (2003). One of the most notable events concerned the harmful effects of a teratogenic agent, which was also a prescription drug. In the 1960s and early 1970s, Thalidomide, marketed as a safe sleeping pill, primarily in European countries and, to a lesser extent, Canada, was found to cause profound structural deformities in the offspring of women who had used the drug, and thereby, inadvertently, exposed them to the drug during a critical period of fetal development (Golden, 2005).

The essence of the principle of ‘critical periods’ in fetal development, which is key to the study of birth defects, is “that an agent can only cause malformation if encountered when cell groups and tissues are forming into organs” (Abel, 1998: 5). Teratogens vary widely in their effects, however, every teratogenic substance has a ‘threshold’, below which there is no

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<sup>2</sup> This awareness was largely influenced by Rachel Carson’s (1972) astounding book, *Silent Spring*, which also facilitated the ban of DDT in the US in the same year.

observable effect, in other words, the presence of alcohol in the maternal system, “does not mean it will have an effect” (9).

Teratology, the study of birth defects, is a complex field, which generally recognizes that most birth defects are multi-causal in origin (Population and Public Health Branch [PPHB], 2002). However, Armstrong (2003) observes that the field of teratology has been distorted in regard to the diagnosis of FAS:

In focusing almost exclusively on the factor of alcohol, [the debate] necessarily turns one element in a complex pattern of ‘causes’ into a single major factor (82).

The assumption of a single causative agent, alcohol, is an organizing feature of the original paradigm for the diagnosis of FAS (Abel, 1998). A paradigm is widely understood to be a conceptual frame or ‘world view’. I think of the FAS diagnosis as a ‘knowledge frame’ because it frames the conduct of birth mothers as responsible for variances in the bodies or biology of their children.

### 2.3 The ‘discovery’: naming the frame

In 1968 a French pediatrician, Dr. Paul Lemoine, and his colleagues published the first study on anomalies he had observed in children born to 127 mothers described as alcoholics (Plant, 2000). Five years later, American dysmorphologists, Jones and Smith (1973) from the University of Washington’s School of Medicine in Seattle, named this pattern of malformations ‘fetal alcohol syndrome’. Dysmorphologists are specialists trained to look for and identify birth defects (Abel, 1998). The empirical basis for the diagnosis of FAS put forward by Jones and Smith (1973) relied on data they obtained from eight case reports<sup>3</sup> and a “noncontrolled, retrospective cohort study” (Armstrong, 2003:79). The grounding assumption, which formed the

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<sup>3</sup> They based their findings on eight detailed case reports and later three chart reviews for a total of eleven children (six Native American, three black, and two white), who had in common a pattern of morphological anomalies (Armstrong, 2003).

etiological basis of the diagnosis, was that the eight unrelated children had a similar “pattern of anomalies” attributable to their mothers’ alcohol-abuse during pregnancy (Abel, 1998:7). While the diagnosis of FAS “did not depend on a history of maternal alcoholism during pregnancy”, it is strengthened by it, whenever it can be confirmed (1998:21).

The associated patterns of ‘malformation’ that Jones and Smith identified were grouped in three categories:

1. Pre-or postnatal growth deficiencies, such as:

- Low birth weight
- Head circumference below the 10<sup>th</sup> percentile, not improving with age

2. Distinctive facial features (with at least two of the following):

- short eye slits (Palpebral fissure length [PFL])
- thin upper lip
- poorly developed ‘philtrum’ (groove above the upper lip)
- flattened facial bone structure or head circumference below 3<sup>rd</sup> percentile

3. Central nervous system damage/dysfunction exemplified by:

- neurological abnormality
- developmental delay *or*
- cognitive impairment (Abel, 1998; Plant, 2000).

According to the criteria, a clinical diagnosis of FAS depends on the presence of one characteristic in the first and third items and two, in the case of facial features (1998). The basic premise is that fetal alcohol syndrome “is characterized by a pattern of anomalies rather than any single anomaly” (Abel, 1998: 26).

Abel (1998) takes issue with the application of the name, fetal alcohol syndrome, which the experts applied to the pattern of anomalies. He argues that the term is a misrepresentation “because it was not alcohol per se but its abuse” – the consumption of toxic amounts of alcohol – that leads to the pattern of anomalies (7). Abel insists that, while maternal alcohol abuse may produce facial features associated with FAS, “consumption of less than five drinks per occasion has not been reliably linked” to their production (84). Furthermore, he challenges claims made, for example, by Day & Richardson (1994), who estimated the threshold for producing FAS facial features to be an average one drink per day in the first two months of pregnancy. Abel insists that, if this were the situation, it would be the “faces of the ‘abstinent’ mothers’ children” that would be unusual because “more than 50% of all pregnant women in the industrialized world drink during pregnancy” (85). Drinking during the first two months is particularly common as many women go about their lives unaware they are pregnant.

Competing and widely divergent claims about the threshold of fetal alcohol exposure, below which fetal alcohol syndrome or other alcohol-related effects are unlikely to occur, continue to proliferate in FAS and addictions research. Controversies have led to further diagnostic terms, names, and claims, as I will show.

Armstrong (2003) insists that the diagnosis of fetal alcohol syndrome was shaped not only by the “reality of alcohol-related teratogenesis but also by how and what doctors chose to see in the syndrome” (80). I would clarify that the diagnosis was shaped by what experts perceived in children’s bodies and by how they chose to name them.

#### 2.4 Finding a ‘gestalt’ in the face of a child

Experts define syndromes as “a group of symptoms and signs of disordered function related to one another by means of some anatomic, physiologic, or biochemical peculiarity”,

which have no definite biological markers that can be used to confirm a diagnosis (Armstrong, 1998: 2025; Armstrong, 2003). None of the individual anomalies in the above frame are diagnostic for FAS and each may occur in other syndromes in association with causes other than alcohol exposure (1998). Physical manifestations such as musculo-skeletal anomalies, heart and kidney defects, have also been identified and classified in the context of prenatal alcohol exposure, however, these were not included in this paradigm for the diagnosis (Abel, 1998; O'Malley, 2007).

Abel points out that the above diagnostic criteria (pattern of malformations) are more inclusive than exclusive, and thereby increase the likelihood of over-diagnosis. For example, “a child could qualify for a diagnosis of FAS” if s/he had a birth weight below the 10<sup>th</sup> percentile for gestational age, had two of the facial features, regardless of how mild or indistinct they were, and had some kind of nervous system dysfunction such as hyperactivity (1998:21). Abel's analyses point to the wide variations built into the knowledge frame that forms the basis of diagnosing and naming children FAS.

The observer who is looking for the features representative of the syndrome in a child is to look for a facial ‘gestalt’ (Abel, 1998). A ‘gestalt’ is a ‘clinical impression’, the premise of which is that “the whole is greater than the sum of its individual parts” (1998:26). The work of diagnosing fetal alcohol syndrome is, thereby, even more uncertain in terms of clinician's judgment than that involved in diagnosing a condition such as Down's syndrome, which includes not only facial characteristics but also chromosomal abnormalities (Armstrong, 2003).



## 2.5 ‘Reading’ FAS in children’s faces

Experts attribute the significance of the facial appearance (also called facial phenotype), or what is known as the ‘FAS face’, to “correlations<sup>4</sup> between [these] midline facial anomalies and underlying brain damage/dysfunction” (Astley & Clarren cited in Astley, 2004: 27). The face of child who is to be known as FAS is, therefore, thought to be inscribed with the signs of ‘brain damage’.

The signs in the face, which are required for the application of the diagnosis, are a distinctive set of ‘sentinel’ facial features [see Figure I below]. The adjective *sentinel* refers to physical findings that experts have concluded are required for the FAS diagnosis (Astley, 2004: 20). The diagnosticians are to look for: 1) short eye slits (palpebral fissure<sup>5</sup>), 2) smooth philtrum<sup>6</sup>, and 3) thin upper lip (Plant, 2000; Streissguth, 1999). Here in this organization of ‘sentinel’ features, is a hierarchy of knowledge, which establishes that the child has FAS. The sentinel features are not required for diagnosticians to make determinations about children who will be known as FAS/D.

Streissguth (1999), a prominent US-based researcher on FAS, observes that among the range of anomalies identified under the diagnostic label of fetal alcohol syndrome, “the face of FAS continues to be the undisputed hallmark for identification of affected children” (305). Following on my experiences as a nurse and researcher, I have been problematizing how children are frequently known as FAS by their faces (see Chapter One).

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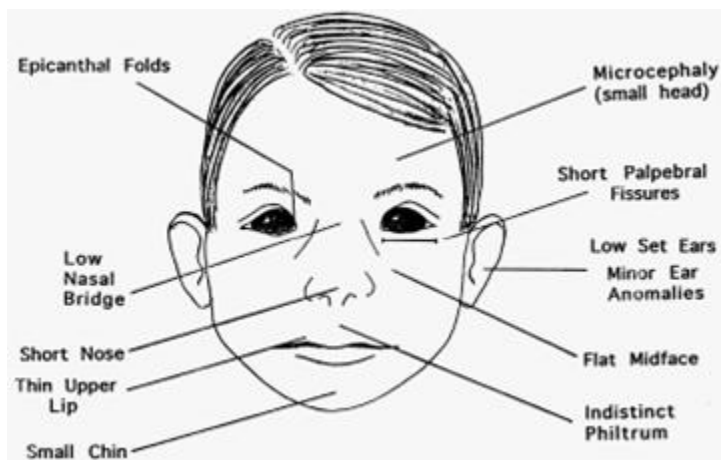
<sup>4</sup> That is, the correlation is based on the determination that “the face and the brain arise from the same embryological structures” (Abel, 1998: 72).

<sup>5</sup> Individuals with ‘short’ palpebral fissures (distance between the inner and outer canthus) appear to have wide-spaced eyes (Moore, Ward, Jamison, Morris, Bader, & Hall, 2002).

<sup>6</sup> The philtrum is the notched area or concavity between the upper lip and lower aspect of the nose that has varying degrees of smoothness or notching in different people.

**Figure I**

**Sentinel and other facial features that may be found in FAS**



(Stade, Clark, & D'Agostino, 2004: 21).

Finding FAS in children's faces may be likened to an act of reading. Similar to McCoy's (1995) description of photos or other images as documentary systems, the child's face may be read as a document that establishes a new 'textual reality' (Smith, 1990a). In finding FAS in a child's face, the identity of the child, transformed to an FAS object, will transcend any knowledge of the particularities of the individual – her features, characteristics, behaviours, or experiences.

This focus on the 'FAS face' raises a critical question about this visual method of identifying children presumed-damaged by their mothers' drinking. How does the characterization and measurement of certain features, such as the distance between the eyes' epicanthal folds (or PFL), assist doctors and others to better understand and help children? O'Malley's (2000) observation suggests that it does not help. O'Malley, who is a prominent FAS expert, observes that twenty-five years of animal and human research demonstrates that the

major management problem for children, adolescents, and adults with this syndrome is not facial dysmorphology or growth delay but a range of central nervous system dysfunctions that *do not correlate* [my emphasis] with facial dysmorphology. So here, it appears, is a debate on the importance of the face and whether facial anomalies correlate with brain damage, or whether they do not.

#### 2.6 Measuring and standardizing FAS faces: “Here’s looking at you, kid.”

Experts within the FAS field, acknowledge that there are weaknesses in making determinations of FAS on the basis of facial attributes. One concern is that faces are not static and, hence, any reading of it may be called into question. Aase (1994) observes that facial characteristics change with age, and the problems in making a reliable diagnosis are compounded depending on the age of the child. For example, growth of the face during adolescence obscures the appearance of individuals who earlier showed FAS-like facial characteristics (1994). Even experienced dysmorphologists are likely to have difficulties finding FAS in the face as children age (Abel, 1998). As an interesting note, Abel claims that, for this reason, the Institute of Medicine [IOM] (Stratton, Howe, & Battaglia, 1996) in the US created a new diagnostic category, ‘alcohol-related neurodevelopmental disorders’ (ARND) “for behavioural problems in which there is a history of alcohol exposure” but no characteristic facial features (72). Of note, Roberts and Nanson (2000) claim that the IOM revised the original diagnosis because of problems in obtaining a maternal history of alcohol use, but that is another controversy for later. The point I draw attention to is that the diagnosis of ARND, which focuses on a diversity of behavioural problems and is now included in the FAS spectrum (FAS/D), may be rendered without reading signs in children’s faces.

Another concern among diagnosticians is that features in the face that are attributed to FAS, are not necessarily discrete abnormalities and may conform to normal variations in an individual's racial group or family (Aase, 1994). For example, Abel (1995) refers to the importance of ethnicity as a confounder, when he insists that the "most critical determinant for the presence of FAS continues to be the country in which the study is conducted" (439). In a survey conducted in the 1990s, the incidence of FAS in the US was found to be significantly higher<sup>7</sup> than for other countries (Abel, 1995). Incidence refers to the number of new cases annually. Abel attributes these differences to a "tendency on the part of diagnosticians to base their diagnosis of FAS on some ethnic facial feature" which is actually a normal variant within a particular ethnic group (439). Most descriptions of children and adolescents with FAS in US studies are those of Native American children, many of whom are also adopted children (Abel, 1998).

Conclusions about diagnoses of Native American<sup>8</sup> children are often based on false assumptions, for example, that the cultural patterns of listening, learning, and behaving, which are unique to Native or other minority cultures, are indicators of FAS (1998). Similarly, on the basis of facial features and other characteristics, assumptions are made that an individual's ability to control or manage their aberrant behaviour must also be impaired (1998). Despite a lack of evidence to support the claims – children or, in particular, adolescents with FAS, are commonly depicted as "mentally incompetent, overly aggressive, and prone to criminal behaviour" (1998: 112).

Abel (1998) advises that people take caution in making inferences about someone's 'character' on the basis of a diagnosis. He recalls the history of the so-called sciences of 'facial

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<sup>7</sup> In the US the incidence was 1.95 per 1,000 compared to 0.08 per 1,000 for other countries, a difference of 24% (1995: 439).

<sup>8</sup> Abel (1998) uses the term Native Americans rather than First Nations.

anthropometry’, which became established in the 17<sup>th</sup> century, and that of the more recent ‘phrenology’, which correlated facial and skull measurements and other anomalies with character traits. I recall, as a child, reading a book based on these ‘sciences’, which depicted pictures of men, whose protruding ears identified them as having criminal tendencies. Studies that were based on these theories and measurement practices also provided the ground for the so-called science of eugenics and sordid practices of population control (Abel, 1998). Practices included forced sterilization of women deemed to be ‘retarded’.

In a recent documentary aired on public radio, (*The Current*, Canadian Broadcasting Company, November 14, 2011), a spokesperson for Alberta’s ‘Collective Memory Project’, observed that eugenics – the concept of excluding people on the basis of moral judgments – has not disappeared. The spokesperson noted that, although residential schools, which segregated and oppressed Aboriginal people based on notions of race<sup>9</sup> have been closed, and Alberta abolished their eugenics laws in the 1970s, oppressive judgments and practices continue to exclude people, in particular, people with disabilities or other negatively perceived differences. The speaker also queried whether practices of identification and exclusion, similar to those which generated the eugenics laws<sup>10</sup>, are still at work in Canada today. This discussion stimulated my recall of a research project underway in Canada concerned with improving techniques for identifying FAS in children’s faces.

In a research forum on FASD, one prominent speaker (Clarren, 2008, April 22) described a massive ‘FAS’ project aimed at standardizing techniques for measuring and classifying children’s faces. Sterling Clarren, formerly from Seattle’s FAS Diagnostic and Assessment unit,

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<sup>9</sup> Race is a highly contested term, whose meaning has changed over time. For the most part, biological claims about ‘race’ have been discounted, but the topic of ‘ethnicity’, which Berbier (2008) claims has subsumed the category, race, is also now contested. There is some agreement however, that ‘race’ is about power and dis/advantage (2008).

<sup>10</sup> See also McLaren (1990) on the history of eugenics in Canada.

was co-author (Astley & Clarren, 1997) of the first *Guide* to constructing the 4-digit code for FAS/D and a recognized expert in FAS identification. The project, led by Clarren, involved a team of researchers taking photographs of 2,000 children in Vancouver schools as part of a broader-scale study also underway in Manitoba, with the goal of providing a comprehensive “Canadian standard” for assessing FAS/D across racial phenotypes. He pointed to the massive scope of the project and its complexity. As Clarren stated, “We don’t know if there are important racial differences and we don’t know when the slit [distance between the eyes or PFL] is outside the normal range, that is, what is too small?” (see Clarren, 2006, project ongoing). I offer an anecdote from this event to show how the production of knowledge, which forms ideological functions, seems to make sense and can be so readily taken for granted as such.

During the presentation, people in the room were attentive and appeared fascinated by the discussion. We were to understand that here was high-cost, apparently leading edge research in developing standardized measures for identifying FAS in children’s faces – a standardized ‘Canadian FAS face’ – a face that would be similar to other Canadian FAS faces, but different from Canadian faces that lacked the identifying and measureable signs. After the presentation, the Ministry of Children and Family Development official stood to thank Dr. Clarren for his talk. She expressed her own fascination and, judging by the applause, that of many in the room, when she said, “Dr. Clarren, you have certainly given new meaning to that expression, “Here’s looking at you kid.”<sup>11</sup>

In their *FASD: Canadian Guidelines for Diagnosis*, Chudley, Conry, Cook, Loock, Rosales, and LeBlanc (2005) acknowledge concerns about the kind of measurement challenges Clarren addressed. The writers advise that there are a number of opinions about which PFL

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<sup>11</sup> Levine (2006) observes that differences in children call for approaches whereby a society learns to value differences, rather than medicalizing children’s differences.

norms are appropriate, and observe that all are flawed in some respect. Yet in an interesting contradiction, Chudley et al. attempt to negate uncertainty about the accuracy of measurement practices or the meaning the measures convey when they insist that “the FAS facial phenotype, including partial expressions of the phenotype, serves as a *sensitive* [my emphasis] marker of brain damage/dysfunction” (27).

Technologies are expanding the scope of FAS identification practices. Increasingly, telemedicine, a technology whereby medical experts use the real-time televised image of a child’s face to diagnose FAS, is a developing field in Canada, particularly in northern regions. LaBerge (2000) suggests that the processes through which an FAS expert analyses a child’s televised face, ties children to the social relations of race through a ritual imbued with meaning:

The face is composed of signs to be read with eyes and granted significance through the indices of normative development, the matrices of anthropometrics. We have established a system of knowledge based upon a technical operation which shifts our understanding of people. How a person behaves and how a person looks is implicated within a new calculus (42).

LaBerge (2000) insists that the identification process is a technique of “othering on the basis of phenotype” (41). Children with FAS “are perceived to appear similar (though not the same) at the same time as they are perceived to appear different from people without FAS” (2000: 43).

This means of visually identifying and objectifying children does not enlarge our understanding of their problems or experiences with learning, memory, and social interactions. The difficulties children have can better be understood through other means such as educational assessments, supportive learning environments, and drawing on experiential knowledge from parents, teachers, and children themselves in order to assist them (see Schellenberg, 2003).

Despite these controversies, the trend toward ‘improving’ determinations for measuring ‘abnormalities’ in children’s face, and improving the expertise of diagnosticians is a vigorous and widespread undertaking in Canada and the United States (US).

### 2.7 Diagnosing *abnormality* and maternal responsibility

A significant problem related to the diagnosis of FAS is that it relies on determinations of abnormality (Abel, 1998). Such determinations rely on “a set of presupposed standard conditions with regard to when, how, and on whom measurements are taken” (Mishler, 1981:4). In biology and medicine, the concept of normal, and deviations there-from, are better expressed as variability, a term which underlines that “variation is constantly at work” in the population (1981:5) and, I would add, in people’s bodies and experiences. However, diagnoses for the most part still rely on finding ‘abnormalities’ (Welch, Schwarz, & Woloshin, 2011).

Determinations of normality may rely on erroneous assumptions or interpretations of findings to which statistical significance is attributed. Abel (1998) provides an example of a study dealing with the effects of prenatal exposure, which examined differences between experimental and control groups. The researchers observed a statistically significant finding, that is, the infants of mothers who drank moderate amounts of alcohol during pregnancy were less easily aroused than those of non drinking mothers. The criterion for ‘low arousal’ included such behaviours as ‘easy to console’, frequently self-quieting’ and seldom upset. The authors attributed this low arousal state to “a harmful effect associated with drinking” (27). Abel observes that this type of negative attribution related to signs such as ‘easy to console’, which might otherwise be interpreted as ‘good’ babies, may reflect a researcher’s biases and assumptions, rather than a biologically significant finding.



According to Abel (1998), biases are apparent in a number of descriptive studies in the US of children and young adults with FAS. Many of the studies are based on Native Americans, yet seldom are cultural biases recognized or acknowledged. However, such studies are generally “culturally and socio-economically biased” because measures of normality are determined by comparisons with the dominant culture and with the normative measures and standards derived from them (1998: 136). Abel points out, as an example, that when Native American children avoid eye contact, they are not exhibiting behavioural ‘anomalies’ but rather cultural differences. Similarly, adopted First Nations children thought by their Caucasian parents to be ‘unresponsive’ or passive may be reflecting their cultural heritage and not the signs of behavioural problems due to FAS (1998). This does not suggest that children do not exhibit signs of distress, but rather, it is the assumption of ‘abnormality’ or pathology that must be queried. Distress may well be appropriate to the situation for children who may have encountered a number of foster placements before arriving in an adoptive home, a situation which, unfortunately, at least in Canada, is common-place (Walmsley, 2005).

Biological definitions of abnormality also tend to rely on forcing variables into constructed categories, which also make biases inevitable (Abel, 1998). In other words, experts construct and indeed, alter parameters which guide professionals and others in determining who is ‘normal’ and who is not (Nadesan, 2005; Rose, 1999). For example, when the criterion for determining mental retardation in the US relied on a test score that was one standard deviation or more below the average, the resulting estimate of the numbers of mentally retarded Americans was so staggering, that is, 35 million people, that experts later changed the criterion to two standard deviations below the average, thereby reducing the number to 2 million (Abel, 1998). Measures of intelligence, constructed as a quotient (IQ) are widely contested.

Working with similar processes “involving choices about what to include and what to exclude” in their characterization of children, the Seattle team named the problem FAS and established criteria for how to recognize it – or, as I suggest, find it (Armstrong, 2003: 80). Such processes of exclusion and inclusion were apparently also at work in the depiction Jones and Smith made when they identified the mothers of their cohort of ‘FAS’ children.

For example, there were several factors common to all the women in the original case studies conducted by Jones and Smith: - all were very heavy drinkers, poor, and part of the U.S. welfare system, which means that the degree of social deprivation was high (Plant, 2000). Approximately half of the mothers had experienced significant health issues, among them delirium tremens, cirrhosis, and nutritional deficits such as anemia (Armstrong, 2003). Jones and Smith chose, however, to include only certain relevancies, that is, that all the mothers drank alcohol excessively (Plant, 2000). They excluded that there were multiple health, social, economic, and environmental issues affecting this cohort of mothers, or at least, they did not account for these factors in the etiology or naming of the syndrome. The grounding assumption, which formed the etiological basis of the diagnosis, was that this small cohort of children had a similar “pattern of anomalies” attributable to their mothers’ alcohol-abuse during pregnancy (Abel, 1998:7), hence, maternal responsibility.

Shevory (1993) problematizes assumptions, which make attributions of blame based on a reductionist view of cause and effect:

The cause of the occurrence of a given phenomenon is construed as the ‘event’ which most immediately preceded it, although that event is caused by something as well. The entire phenomenal world is ultimately joined together by a complex set of causal relations (100 -101).

These observations help to underline how causal claims are a contested domain. Individual actions can “always be fit into a ‘chain of causation’” and concomitant claims of individual responsibility (Shevory, 1993: 102).

### **3.0 Contesting the cause of FAS**

There is a common assertion found in the research literature (for example, Streissguth, 1999; Astley, Bailey, Talbot, & Clarren, 2000; Astley & Clarren, 2001) that FAS is *caused by* maternal alcohol consumption. The diagnosis of fetal alcohol syndrome assumes there is a direct causal relationship between maternal alcohol consumption and damaged babies. Although the relationship between exposure to alcohol and fetal harm is not clearly understood (PPHB, 2002), the connection between maternal alcohol consumption and abnormalities in children has been specified. And for the most part, this specificity has not been questioned. Streissguth (1999), a prominent FAS researcher, insists that all FAS diagnostic systems require the knowledge that “the mother had significant alcohol problems at the time of pregnancy” (305), although my literature review will reveal how this claim is now outdated.

While the diagnosis of fetal alcohol syndrome is based in the assumption that maternal alcohol consumption causes FAS, many unanswered questions remain. For example, research findings show that, even among women who are chronically heavy drinkers, only some women will have a baby with FAS (Armstrong, 1998; Roberts & Nanson, 2000). Research has demonstrated that there is no clear correlation between the amount and timing of alcohol consumption and the effects of alcohol use in pregnancy (Armstrong & Abel, 2000; Roberts & Nanson, 2000). Newborns “can have blood alcohol levels high enough to have an acute affect on their central nervous system function and not have FAS” (Stratton et al, 1996:19). Contrary to popular claims “FAS is not a drunk baby” (19).

The authoritative U.S. Institute of Medicine (Stratton et al, 1996) acknowledges uncertainty about the cause of FAS, by observing that “[w]hile alcohol is the necessary teratogen, it *alone* [my emphasis] may not be sufficient to produce FAS in humans or birth defects in animals” (20). This view has almost consistently been disregarded in the historical descriptions, research, and policy documents concerning FAS and FAS prevention.

### 3.1 Generalizing claims

In order for a diagnosis to become well-established and utilized in the clinical field, findings similar to those in the original study must be replicated. In the scientific community, replication of findings validates the original research claims or, I would add, makes them more authoritative (Abel, 1998; Armstrong, 2003). ‘Reliability’ is based on assumptions that the people making the diagnoses hold the same acumen or clinical judgment and also that there is consistency in identification of the syndrome over time (1998). In other words, it relies on the assumption that the practice of making a diagnosis is or can be ‘objective’, which is a topic and practice my research problematizes.

Abel (1998) observes that, despite the production of hundreds of case reports, clinical research studies, and epidemiological reports, experts have not tested or demonstrated “the reliability of the various diagnostic paradigms for FAS” (25). Not only are diagnostic paradigms unreliable, but clinicians judgments vary widely also. In other words, diagnostic errors and variations, which include over- and under-diagnoses, are to be expected (1998). Similarly, there is a lack of consistency in the subject, the child, who is also the ‘object’ of the investigation. In one small study, seven of eight children diagnosed in infancy as FAS, were re-tested at age four, at which time, the diagnosis – and, hence, their status as FAS objects – was thought to be unwarranted (1998).

The complexity of teratogenic effects is often overlooked or not acknowledged in the FAS literature. While researchers may argue that there are multiple factors related to the mother's health status and other variables that serve as confounders in studies involving human subjects, these factors are generally not included in the depictions of cause or researchers generalizing claims. For example, while Streissguth (2006) agrees that it is very difficult to separate out the effects of alcohol exposure from other factors in women, such as diet and smoking, she also insists that laboratory studies in animal populations, for example, wherein pregnant laboratory mice are subjected to varying degrees of alcohol exposures, help researchers to understand the effect of alcohol exposure in humans.

Since the 1970s there have been literally thousands of papers examining the effects of alcohol exposure in animals, describing mechanisms for prevention, treatment, and screening, and elaborating diagnostic criteria. Abel (1984) examines errors and inconsistencies in animal and human studies and questions the reliability of research that generalizes exposures on animals in laboratory-controlled environments to human populations and the conditions of people's lives. Nearly all animal studies begin with pregnant animals and do not model conditions that exist prior to pregnancy in women (Abel, 1998). As Abel's analyses demonstrate, "in studying alcohol's effects in animals, we are invariably dealing with levels of alcohol exposure considered abusive if encountered in people" (11). Abel observes that if the "blood alcohol threshold at which brain damage is produced in rats" were to be translated in terms of human consumption, the level qualifying for alcohol abuse for someone weighing 130 lbs would be the equivalent of a daily binge of nine drinks over a five-hour period (12). He adds that most of the animal studies are maintained over a number of days and are therefore, comparable to chronic bingeing over the full period of gestation. However, Streissguth (1997), a psychologist who has written extensively

on FAS, counters these claims. She insists that by the 1990s, animal studies were actually using doses equivalent to the levels of consumption by women, however, she overlooks how laboratory conditions and results differ from those for actual women.

Claims arising from such studies are ongoing, and continue to raise concerns about research reliability. Practices, wherein a researcher generalizes from one sample or population to another or wider population or, in this case, to an entirely different species – would usually be considered inconclusive or, at the most, correlational (Patton, 1990).

### 3.2 Multi-factorial claims

Research in the field of teratology and fetal development, emphasizes the multi-factorial nature of most birth defects (PPHB, 2002). For example, the high rate of congenital heart defects in Aboriginal children, four times higher than in other Canadian populations, led researchers (Arbour, Gilpin, Millor-Roy, Pekeles, Egeland, Hodgins, & Eydoux, 2004) to examine relationships between genetic, nutrient, and environmental factors associated with congenital birth defects in Inuit children. Studies of complex relationships and interactions which contribute to variations in children are ongoing (see also Burstyn and Fenton, 2006; Murray 2006).

There is a growing body of research to suggest that there are other factors, such as nutrition, maternal health, paternal alcohol use, and genetic susceptibility, which, like alcohol, may be associated with FAS (Plant, 1985; Plant, 2000; Cicero, 1994; Armstrong & Abel, 2000; Moyers & Bailey, 2001). For example, research shows that orofacial clefts are strongly associated with maternal alcohol consumption and that poor folate status is also associated with high alcohol consumption (Moyers & Bailey, 2001), thereby suggesting that the deficiency of nutrients such as folate may also be implicated in FAS. Researchers also suggest that differences in birth defect risk associated with folate intake or metabolism are likely interrelated with

multiple components including nutrients, genes, and enzymes (Moyers & Bailey, 2001).

Another area of investigation is the connection between the hormonal systems of mother and fetus and normal fetal development, as well as the environment (Medlin, 2004.) Researchers are investigating how the effects of maternal alcohol consumption on fetal hormone systems may contribute to effects observed in children with FAS (1998). These studies, many of which are continuing, examine the complexity of fetal development and abnormalities. What is interesting with regard to FAS is how medical experts appear to disregard these complexities in their depiction of cause.

There is also research implicating the contribution of the father in fetal alcohol effects on offspring – effects that are separate from those which document the adverse effects of living with a father who is an alcoholic (Abel, 1998). However, Abel also points out that the impact of growing up in an environment where children may be neglected or otherwise harmed through parental alcohol abuse can be as devastating as the contribution from pre-conception or in utero abuse by either parent. Cicero (1994) asserts that paternal alcohol consumption may affect the fetus through a direct effect on the father's sperm or reproductive organs (37). Risks associated with paternal alcohol consumption have received little attention, which, Cicero (1994) observes is surprising in light of studies suggesting behavioural and intellectual impairments in the male offspring of alcoholic fathers.

A host of other factors that may contribute to neurodevelopmental problems, low birth weight, and even FAS-like phenotypes in children remain largely unexplored. Aase (1994) observes that an important consideration in establishing the diagnosis is “the normal variation of features in the patient's racial group or family”, common in many Native American groups (8). Aase (1994) also acknowledges that it is impossible to prove that the abnormalities of mental

deficit, growth delay, and maladaptive behaviour in any one child are the result of prenatal alcohol exposure since “none of the abnormalities found in FAS is specific to that diagnosis” (10).

There are still other variables that have been overlooked in developing the FAS diagnosis and the construction of cause. It is generally acknowledged that exposure to substances in the environment, such as lead contained in paints, pottery glazes, gasoline, and other sources could impair children’s cognitive function, neurobehavioral development, and growth. Toxic exposures to substances such as lead, mercury, and pesticides have been linked to a variety of learning problems in children (Olfman, 2006). Researchers have located another source of lead toxicity – in candies that have likely been contaminated from lead-exposed soil residues and other environmental sources (Medlin, 2004). While the children primarily affected were Mexican or Latinos living in the US, the study points to the little researched fields of environmental toxins and of chemicals in food that may impair children’s growth and development. It also raises questions about the effects of environmental and living conditions for poor parents and children, many of whom are Aboriginal peoples in Canada, and why so little government action has been taken to address these issues.

### 3.3 FAS is not “an equal opportunity birth defect”

Drawing on his years of research on FAS, Abel (1995) insists: “FAS has never been an equal opportunity birth defect” (437); “its inseparable handmaidens are poverty and smoking” (Armstrong & Abel, 2000: 279). Three main factors have been found to be associated with FAS: 1) socio-economic status, 2) past obstetric history, and 3) multiple drug use (Plant, 2000; Abel (1995). The third factor, multiple drug use, includes the association between heavy drinking and smoking, as well as over-the-counter preparations, which are also factors that contribute to poor



fetal health (Plant, 2000). Even in the presence of these factors, FAS occurs selectively for reasons not well understood (Abel, 1998).

Contrary to popular messages that FAS is a threat to all pregnancies, it occurs predominantly among poverty stricken women (Abel, 1998; Armstrong & Abel, 2000). Analyses show that the large socio-economic differences in reported cases of FAS are not due to differences in the number of alcoholic women among the poor compared to the middle classes as is often suggested. Middle class women in the US actually consume more alcohol than the poor. What women in poverty have in common is that they experience or are characterized by factors such as smoking and poor diet (2000).

Relatively recent research into the cognitive development and emotional health of children supports the significance that Plant (2000), Armstrong and Abel (2000) attribute to socio-economic status on fetal/child health and development. For example, in a prospective, pre-birth cohort study of 8556 pregnant women, which followed mothers and their children for 14 years after birth, researchers (Najman, Aird, Bor, O’Callaghan, Williams, & Shuttlewood, 2004) found a correlation between family income and measures of cognitive development, emotional health, and smoking. The researchers concluded that children from socio-economically deprived families, including the present and previous generations, begin their lives with a reduced health status and are economically and socially-disadvantaged over the long term.

Armstrong (2003) argues that the single-minded focus on cause has obscured the “social context in which prenatal exposure to alcohol occurred”, thereby, blinding doctors to recognizing or including other factors (2003:2028). If alcohol consumption is the cause of FAS, then surely every woman is at risk for having an affected child (Armstrong, 1998). Yet this has not been shown as the case (Armstrong & Abel, 2000). FAS is relatively uncommon, less than 5%, even

among the offspring of women who are confirmed to have been heavy drinkers during their pregnancies (Abel, 1998; Golden, 1999).

Day and Richardson (1994) suggest that the long history of fetal alcohol research may make alcohol exposure appear more significant than other drug exposure, since more is known about it. Women who drink during pregnancy, and particularly those who continue to drink throughout pregnancy, are more likely to use other substances and have less prenatal care, poorer maternal health, and lower socioeconomic status (Day, 1995). Each of these factors is in itself a risk factor for poor pregnancy outcome and must be considered in understanding concerns regarding women's and children's health (1995). These areas of research raise important considerations for understanding FAS. They also offer dissent to the authorized approach to knowing what causes it and how women are implicated.

#### **4.0 Expanding the diagnosis and the claims**

In the years following the Seattle-based study, intensive efforts by a growing number of researchers contributed new 'findings', concerning the problem of maternal drinking during pregnancy that the dysmorphologists first 'discovered'. The problem of alcohol consumption and FAS had never been properly quantified nor have quantification claims been settled. Some of the revisions to the original diagnostic frame have broadened the scope of the problem the syndrome represented, the range of effects, and the extent of responsibility attributed to it.

##### **4.1 Quantification claims**

In drug policy discourses, quantification accounts are intended to produce the 'facts', but instead, they are often used to assess moral and symbolic values concerned with levels of risk, responsibility, and blame (Campbell, 2000). The use of numbers, epidemiology, and statistics holds a central place in research studies and government policies for constructing claims

concerning the scope of harm and responsibility related to maternal alcohol consumption, FAS and FAS/D. While such claims may be impressive, they are best examined – not as truth – but as people’s claims.

The claims about how much alcohol is harmful to a fetus are widely divergent. On the one hand, prominent FAS researcher Ernest Abel (1998) asserts that “no cases of this syndrome have ever been found outside the context of alcohol abuse” (8). He argues for renaming the syndrome “alcohol-abuse-related birth defects” or “fetal alcohol abuse syndrome”, to avoid the confusing relationships cited in literature between low to moderate levels of drinking during pregnancy and the high patterns of consumption associated with birth anomalies (13). On the other hand, diagnostic guidelines published in the *Canadian Medical Association Journal* (Chudley et al, 2005) recommend complete abstinence for pregnant women in order to avoid any possibility of alcohol-related harm. A Canadian research survey cites inconclusive evidence on the amount of alcohol women can safely ingest during pregnancy, although those amounts vary between countries and jurisdictions (Dell & Roberts, 2006). In the United States, the medical research community frames the issue of fetal harm and risk in terms of low thresholds of alcohol consumption for women, a frame which appears to generate greater national panic and, apparently also higher research budgets to combat a perceived national health problem (Armstrong & Abel, 2000).

The debate on how much alcohol use is harmful to a fetus is further confused by problematic and discrepant definitions. Language is not neutral and even the act of definition is one of power (Perry & Reist, 2006). Terms such as ‘addict’ or ‘abuse’, ‘addiction’ and ‘binge’ drinking convey stereotypes and moral judgments and tend to stigmatize certain groups of people and their behaviours (2006). Armstrong (1998) takes issue with the inclusion of ‘abuse’, which

Abel applies to the syndrome. She insists that it “doubles the moral censure by implying that not only does the woman abuse alcohol, she also abuses her unborn child” (2035).

Research, policy, and medical papers often fail to define the notions of ‘heavy’, ‘excessive’, or binge drinking and the definitions, when applied, are often contested (Abel, 1998). For example, the Canadian Addiction Survey, which evaluated the level of alcohol use among Canadians<sup>12</sup>, defined ‘heavy’<sup>13</sup> or ‘binge’ drinking for women as 4 or more drinks on a single occasion (Dell & Roberts, 2003). In contrast to the Canadian survey, Abel’s (1998) “operational definition of alcohol abuse”, drawn from analyses of extensive case study literature, involves consumption in the order of 14 drinks a day<sup>14</sup> (16).

While significant associations between low levels of drinking and some behavioural problems have been cited in research, the studies tend to conflate alcoholic and bingeing mothers and their children with mothers who drink at ‘moderate’ or low levels (Abel, 1998). One argument, often cited in FAS literature, to support the view that low levels of alcohol damage the fetus, are the observable changes in ‘fetal breathing movements’ following one or two drinks. However, Abel (1998) insists that these reactions to low levels of alcohol merely “prove that the fetus is alive, not that it is suffering damage” (18). The problem of alcohol and attempts to quantify the damage continue to generate diverse claims and moralizing discourses (see Chapter Three).

Maternal alcohol use/abuse was not written into the original criteria for diagnosing FAS and after the initial conception of FAS, the amount of alcohol consumed by a pregnant woman did not figure prominently (Abel, 1998). Plant’s (2000) work suggests that there was an implicit

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<sup>12</sup> In Canada, a “standard drink refers to an amount of alcohol that is contained in 12 ounces of a 5% beer (or cooler or cider), a 5 ounce glass of 12% wine or 1.5 ounces of 40% spirits” (Stockwell, Vallance, Martin, et al, 2010).

<sup>13</sup> The term ‘excessive’ is also used here.

<sup>14</sup> Read Abel (1998) for a further elaboration of ‘excessive’ drinking.

assumption that the diagnosis was already based on the aspect of an ‘identifiable’ drinking problem. However, Abel (1998) observes that alcohol consumption was not specifically included in the diagnosis because it was problematic. The concern at the time was that diagnosis must be ‘objective’ and therefore, information concerning a woman’s alcohol consumption, which might bias the diagnostician, was not to be included. There was, and is a general consensus among multi-service care providers that women are likely to under-report or misrepresent their alcohol use and, thereby, avoid the social and legal repercussions that have long been associated with women who drink (Field, 2000).

#### 4.2 Expanding the FAS problem and the damage associated with it

In Armstrong’s (1998) view, the evolution of the FAS diagnosis is linked to the development of a ‘social problem’. A social problem is one that exists in terms by which it is conceived and defined in society, including that of medicine (Armstrong, 2003). In this view, drinking during pregnancy was a social phenomenon, which came to the attention of doctors who identified it as a problem<sup>15</sup> worthy of their attention and their moral fervour (Armstrong, 1998). Armstrong observes that medical experts, acting as ‘moral entrepreneurs’, have held a key role in mobilizing diverse institutions and multiple actors to expand the domain of the social problem represented by the syndrome, and thereby, in bringing to the minds of the American public the ‘reality’ of fetal alcohol syndrome. Moral entrepreneurs or ‘crusaders’ tend to be elites who are working to “impress their moral vision on the rest of society” (1998: 2026).

In constructing a new diagnosis and by implication a social problem, doctors speak with unique authority: in our society, it is still primarily doctors who are granted the authority to identify a new disease (2026).

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<sup>15</sup> Armstrong (2003) does not locate this particular ‘social’ problem in the historical and gendered assumptions concerning women and substance use, as a number of feminist writers do, for example, Susan Boyd (1999) (see Chapter Three).

Yet how was this controversial problem of maternal alcohol consumption and the damage attributed to it, advanced in the medical field? Armstrong developed her analysis of the expansion of the diagnosis and the social problem FAS represented by examining texts.

Texts, like doctors, speak with unique authority and their range is extensive. The dissemination of knowledge in texts which, Smith (2005) insists, include images, print, and electronic forms, has held a central place in creating a knowledgeable membership among clinicians and researchers in a variety of medical specialties and research circles (Armstrong, 2003). Armstrong has traced the vast increase in publications on the problem of alcohol and pregnancy in the years between 1969 and 2000. During the 1970s, for example, the numbers of research publications averaged less than 40 annually, but by the 1990s, publications averaged a rather surprising 100 annually – surprising for a relatively recent diagnosis affecting a small number of children. She also details the expansion of diagnostic claims she discovered in them.

Many of the claims concerning FAS were based on individual or small case studies and their often obscure findings (Abel, 1998). For example, the discovery of “tortuosity of the retinal vessels” in 17 documented case studies, was presented at a meeting of specialists in Ophthalmology, as a “new finding” that might assist in diagnosing cases of FAS that might, otherwise, be uncertain (2003: 86). ‘Evidence’, in the form of a twisted vessel in the eye, however small a finding, added to the scope of the problem that maternal alcohol consumption posed to a fetus.

In 1978, the scope of damage to the fetus further expanded when Dr. Clarren coined the term Fetal Alcohol Effects (FAE) (Plant, 2000). FAE was intended to denote individual anomalies in children rather than the earlier ‘pattern’ of effects (Armstrong, 2003). The term introduced a myriad of new symptoms, including so-called behavioural disorders such as

‘hyperactivity’, which could now also exemplify FAS. FAE was first termed ‘possible fetal alcohol effects’ (PFAE), but experts dropped the ‘possible’, which they felt cast doubt on the diagnosis, and also undermined efforts for those seeking to access support for people who bore the designation<sup>16</sup> (2003).

In Golden’s (2005) view, the revisions might also be concomitant with societal changes in the US, which brought ‘drinking’ women ‘out of the closet’ and cast more visibility on FAS. The inclusion of ‘fetal alcohol effects’ in the diagnosis, enlarged the cause of FAS from “alcoholics to alcohol use” and, thereby, also expanded the scope of risks that could be associated with alcohol consumption in the minds of the American public (Armstrong, 2003: 89).

Some FAS experts agreed that FAE mistakenly implied that relatively small amounts of alcohol can cause individual anomalies or an attenuated form of FAS, expressed primarily as cognitive or behavioural deficits (Aase, 1994; Abel, 1998; Astley and Clarren, 2000). Eventually, in response to growing debates largely within the field itself, FAS/D experts criticized the use of the term FAE, because they were unable to confirm that maternal alcohol use causes behavioural difficulties and/or learning disorders in children (Aase, Jones, & Clarren, 1995; Astley, 2004). Some experts have gone so far as to insist that it is problematic to attribute a child’s “aberrant conduct to in-utero alcohol exposure” (Aase et al, 1995: 429).

However, the claims and attributions persist. And included in claims of behavioural characteristics of preschool children with FAS and now, FAS/D, are:

- Hyperactivity ‘never sits still or listens’
- Impulsiveness
- Constant demands for attention

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<sup>16</sup> Some diagnoses, particularly, those regarded as disabling, may offer access to funds associated with the ‘disability’ label (Stone, 2008), see later this chapter.

- Frequent temper tantrums over minor issues
- Troubles with routine
- Difficulty forming friendships with other children (Abel, 1998: 121)

More extensive lists of how FAS/D children exhibit problems in learning and behaviours are now available in books and on popular FAS/D websites, some of which identify these variances in children as ‘soft signs’ of FAS/D brain damage (see for example, Kellerman, 2003-2004). These claims concerned with brain damage are very much a part of more recent diagnostic revisions and so-called improvements to it.

#### 4.3 Changing names: managing controversy?

In 1996, a committee of experts convened in an effort to quell ongoing debates and controversies regarding the diagnosis of FAS. Convened under the auspices of the prestigious Institute of Medicine (Stratton et al, 1996), the committee addressed debates, including those regarding the ‘confirmation’ of alcohol use and contested claims concerned with etiology.

The Institute of Medicine revisions proposed five diagnostic categories for FAS and other alcohol-related effects, which were intended to establish a more accurate set of diagnostic criteria (Plant, 2000; Roberts & Nanson, 2000). The core features, which the diagnosis of FAS had originally relied upon, previously identified, remained unchanged. Additional features thought to be associated with FAS, such as hearing loss, which had not previously identified, were added (Abel, 1998; Golden, 2005). One of the distinctive changes arose from the need to address controversies on the issue of maternal alcohol consumption and whether there would be a requirement for confirming it (Roberts & Nanson, 2000). The IOM created two categories for the diagnosis of FAS, one which required a confirmed history of maternal alcohol exposure, and one which did not (2000).



‘Confirmation’ of alcohol consumption – or ‘exposure’ – has been problematic for people in the FAS knowledge field (Astley, 2004). The work of confirming a mother’s consumption of alcohol during pregnancy depends on finding evidence on the birth mother’s history of alcohol use, which is often difficult for professionals to obtain. Many children who come to the attention of diagnosticians, and indeed, researchers, are foster children who are supervised by the state as ‘children in care’, and their mothers’ histories are often uncertain, unavailable, or difficult to extract from mothers (Abel, 1998; Field, 2000; Roberts & Nanson, 2000). For mothers already under surveillance by state or child welfare authorities, professional attempts to extract their compliance in disclosing their histories of alcohol use is likely to engender resistance (Boyd, 1999; Kroll & Taylor, 2003). The provision of a new FAS category, which the IOM clearly articulated as: ‘FAS without confirmed maternal exposure’, could potentially help to quell the controversy (Roberts & Nanson, 2000). Would the revised FAS, with no requirement for a confirmed maternal history, also enable medical doctors to diagnose many more children?

The IOM committee also addressed another controversy – the one pertaining to FAE. They retained the name, Partial FAS, which would require a confirmed history of alcohol use, but would not require all of the anomalies in the diagnosis, and they eliminated the controversial term FAE (Roberts & Nanson). However, Armstrong’s (2003) criticisms suggest that the revisions opened the experts to further controversies. She observed that the diagnostic category, Partial FAS – like FAE – created a “complex hierarchy of degrees of FAS” where defects seem only “partial” or alcohol seems only “partially” the cause (Armstrong, 2003: 247, fn 75). The implication here is that little had really changed except the name.

The IOM introduced a further two diagnostic categories in their revisions: Alcohol-related birth defects (ARBD) and Alcohol-related neurodevelopmental disorder (ARND). Here

again, while these changes still put maternal alcohol consumption in the FAS diagnostic frame, they also watered down maternal ‘alcoholism’ or variations thereof to alcohol exposure and also weakened the requirement for confirmation in the ARBD category (Armstrong, 2003; Plant, 2000).

Astley and Clarren (2000) subsequently responded with their criticisms of the IOM revisions. They took issue with the categories ARBD and ARND, stating that like FAE, “they inappropriately imply a causal link between exposure and outcome” in an individual (402). They observed that “there is likely to be full agreement on a diagnosis of FAS only when the anomalies in growth face, and brain are all very extreme and the alcohol exposure is conclusive and substantial” (400), a comment which appears to set the stage for ongoing controversy. They dismiss a causal relationship between alcohol use/exposure in regard to cognitive or behavioural problems in children stating that:

[w]ith the likely exception of the full facial phenotype, no other physical anomalies or cognitive/behavioural disabilities observed in an individual with prenatal alcohol exposure are necessarily specific to (caused only by) their prenatal alcohol exposure (403).

Juxtaposed against all the names and revisions that tie defects in children’s brains, bodies, and behaviours to their mothers’ alcohol consumption, these are astounding claims. These debates likely set the stage for the ‘*umbrella*’ term called ‘fetal alcohol spectrum disorder’, and the remarkable ‘truth’ claims the authors<sup>17</sup> ascribe to their production of it.

#### 4.4 The ‘spectrum’ disorder: claims of truth and ‘objectivity’

‘Fetal alcohol spectrum disorder’ (FASD) incorporates a range or ‘spectrum’ of clinical conditions associated with prenatal alcohol exposure (O’Malley, 2007; Roberts & Nanson,

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<sup>17</sup> See Astley and Clarren (1997) who introduced this revision, now part of popular FAS discourse.

2000). According to the Institute of Medicine's FAS classification system, which has been widely circulated by the National Institute of Health in the US, the FAS/D classification system is a "much less restrictive and controversial one" than FAS or other categories formerly utilized (Mattheis, 2007: 181). Indeed, the author of this system's most recently published text, *The Diagnostic Guide for FASD: The 4-Digit Code*<sup>18</sup>, 3<sup>rd</sup> Edition (Astley, 2004) or what I call the 'Guide' for short, makes claims to establishing 'truths' that counter the biases, misclassifications, and failures that were written into previous diagnostic systems for classifying children as FAS or other derivations, such as FAE (see 1-3).

This *Guide* is not the sole<sup>19</sup> classification system for FAS/D, but it is thought to be the most widely used and, at least in parts of Canada, the most authoritative. The authors who produced the *Fetal Alcohol Spectrum Disorder: Canadian Guidelines for Diagnosis* (Chudley et al, 2005) have adopted and recommended<sup>20</sup> the *Guide* (Astley, 2004) for diagnostic work in Canada.

In this latest and expanded revision of the diagnosis of fetal alcohol syndrome, experts have constructed a 4-digit code – or numerical sequence – in order to offer an objective, accurate, quantitative system of diagnosis and measurement (2004:5). Banished is the 'gestalt' – the clinician's impression or judgment, to be replaced by precise numerical facts. The 4-digit code is "based on levels of certainty, in the judgment of the clinician, that the individual's cognitive and behavioural problems reflect brain damage" (Chudley et al, 2005:S10). The construction of a numerical code based on 'levels of un/certainty' puts the clinician's judgment back in the picture, contradicting Astley's claim of accuracy and objectivity.

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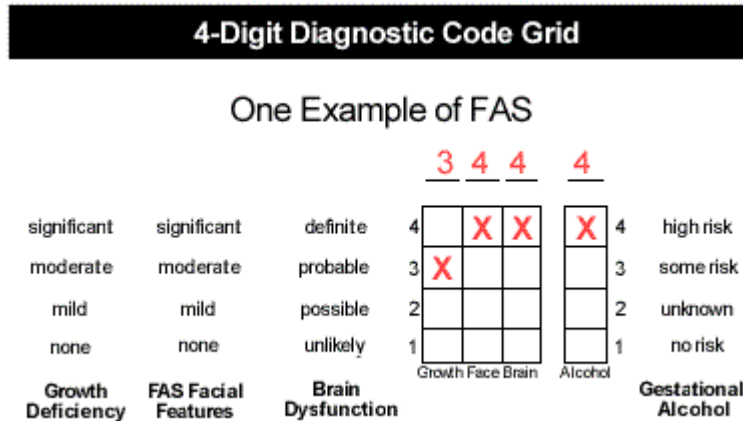
<sup>18</sup> In my analysis, I also make references to previous versions of the 4-Digit Code (Astley & Clarren, 1997; 2000) as well as to the 2005 Canadian guidelines of the 4-Digit Code, which closely follows the American versions.

<sup>19</sup> See also Astley (2006) for her comparison of the 'Guide' with the Hoymes Diagnostic Guidelines for FASD.

<sup>20</sup> The Canadian Guidelines are most similar to this 2004 version of the Guide (Astley, 2006).

The purpose of the numbers 1 to 4 is to “convey the magnitude of expression” (or *variability*) in each of the four diagnostic domains [see Figure II], “yielding 256 possible 4-digit diagnostic codes and corresponding clinical names” (Astley & Clarren, 2000: 50), tabulated in about six pages of diagnostic text.

**Figure II**



Astley, Susan & Clarren, Sterling (1997). *Diagnostic Guide for FAS and related conditions*. Seattle: University of Washington.

The magnitude of expression or ‘variability’ in the child’s growth, face, and brain is ranked independently on a four-point scale with 1 reflecting complete absence of the FAS feature and 4 reflecting a strong 'classic' presence of the FAS feature (Astley & Clarren, 2000). The position of the fourth digit (shown on Figure II as gestational alcohol) measures the level of risk that the child was prenatally exposed to alcohol consumed by her/his mother (Astley, 2004). Once the 4-digit code sequence is calculated, the diagnostic category which matches that code sequence is applied to the child. All of the 22 diagnostic categories and 256 codes sequences can go under the FAS/D umbrella, along with all the children who are thus made known. A small sample of the codes, categories, and diagnostic names featured under the FAS/D umbrella is shown below in Figure III. I draw to my readers’ attention that regardless of the ‘levels of

certainty/uncertainty' (Figure II above) in the coded information, which represents particular aspects of children's and mother's experiences, the FAS/D umbrella can still be applied to the child.

### Figure III

#### 4-Digit Diagnostic Codes Sorted Numerically (10 of 256 FAS/D codes/categories)

##### **Code Category Diagnostic Name**

1142	L	Static encephalopathy (alcohol exposure unknown)
1143	F	Static encephalopathy (alcohol exposed)
1144	F	Static encephalopathy (alcohol exposed)
1211	V	No sentinel physical findings or CNS abnormalities detected (no exposure)
1212	P	No sentinel physical findings or CNS abnormalities detected (exposure unknown)
1213	J	No sentinel physical findings or CNS abnormalities detected (alcohol exposed)
1214	J	No sentinel physical findings or CNS abnormalities detected (alcohol exposed)
1221	T	Neurobehavioral disorder (no alcohol exposure)
1222	N	Neurobehavioral disorder (alcohol exposure unknown)
1223	H	Neurobehavioral disorder (alcohol exposed)

(Astley, 2004: 53; see also pp 54-58 for remainder)

The terms, 'disorder' and 'spectrum' reflect changes to the original diagnostic category, fetal alcohol syndrome. In the authoritative text, the World Health Organization's (WHO) (1992) *ICD-10 Classification of Mental and Behavioural Disorders*, the term 'disorder' is used to "imply the existence of a clinically recognizable set of symptoms or behaviour associated in most cases with distress and with interference with personal functions" (1992: 5). The text adds that, while not an exact term, disorder avoids the problems and controversies associated with 'disease' and 'illness' (1992). For Armstrong (1983) disorder is a contested term, which in his view, applies to moral discourses, FAS among them (see Chapter Three).

The term 'spectrum' is defined on a popular FAS advocacy website (see Kellerman, 2003-2004), where the author helps readers to understand the vast scope and complexity of this FAS-related disorder. She explains how FAS/D resembles a rainbow, composed of colours we can see and colours that are invisible without special instrumentation:

FASD is a spectrum because there are many types or 'looks' of FAS, from full FAS with the 'FAS look' and all the symptoms that will get the person an FAS diagnosis from a doctor, to partial FAS where the person may have some of the looks but not enough to get a diagnosis, to the invisible types of FAS that are not seen as FAS and are not called FAS, but they are still FAS because these persons have all the same problems as the other types. FASD cover the whole spectrum of Fetal Alcohol disorders because it includes all types, whether they are visible (recognized as FASD) or not (2003-2004: 1).

The claim that FAS/D covers variances in people's faces that range "from normal to clearly abnormal" is matched with similar sweeping claims about maternal alcohol consumption.

FAS/D experts have incorporated FAS<sup>21</sup> in all its revisions, including the discredited *FAE*, into the spectrum. Readers may recall that experts had discounted 'FAE' because it inappropriately implied a "confirmed causal link" between alcohol and children's disorders (Astley & Clarren, 2000: 403b). According to Astley and Clarren's definition of the spectrum disorder, a mother's consumption of alcohol is neither normal nor abnormal but, ranges along a spectrum, a "continua from normal to clearly abnormal" (400). The claim that damage to the brain from alcohol-exposure may not even be detected on brain scans, but is nevertheless, large enough to cause significant impairments, may well support prevalent claims that 'even one drink' can cause FAS/D (Kellerman, 2000-2008). These are serious claims, particularly, in light

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<sup>21</sup> Diagnostic Categories E to I were previously referred to "as fetal alcohol effects (FAE)", ARBD, and ARND (2000: 403b).

of the view that people who are now designated as fetal alcohol spectrum-disorder/ed are characterized as having a ‘life-long’ and ‘irreversible’ disability associated with cognitive, learning, or behavioural impairments.

The claim that FAS or FAS/D cause irreversible disabilities and, specifically brain damage is relatively recent and I discuss the latter in more detail in the next chapter. Before concluding this chapter, I identify how FAS/D and FAS are treated in the authoritative medical texts which are used to manage eligibilities when people claim they have a disability. I suggest that, while disability is not (yet) a new revision in the expansion of the FAS diagnostic category, it is a new discourse, a way of generating action.

### **5.0 Managing claims for help**

FAS/D advocacy groups have, until recently, tended to avoid the term ‘disability’ and have distanced their knowledge field from related categories of disability. I noted a similar phenomenon when I worked with policies related to children with ‘special needs’, where I observed the funding allotments for FAS prevention were greater than for other special needs categories. Prince (2002) has described this ‘silo’ arrangement elsewhere in the context of governance regimes to highlight a method by which provider groups and governments manage competing interests.

However, I learned during the course of my field work for this inquiry that FAS/D advocates now have a new alignment to the ‘disability’ field. That more doctors are now authorizing FAS/D as a disability provides adults thus designated access to government disability funding. For those working in the field or living with FAS/D, *disability* has acquired a beneficial meaning.

Disability is also a contested term, one that Stone (2008) problematizes (see also Prince, 2008). Stone insists that disability is not an intrinsic or embodied characteristic, but one that is “created through practices that deny the ubiquity of impairment, that is, cognitive and physical difference[s]” in people (202). Stone who herself has osteoarthritis, insists that “impairment is not inherently disabling”, and says that she resists the illness label and the medical interventions usually attached to it (202). Unless a person’s embodied experience coincides with the authoritative approach to understanding a ‘disability’, the label is an oppressive way of knowing that is imposed on and frames people with particular impairments or experiences (2008). Stone’s work highlights debates regarding particular framings of people’s experiences, and shows how designations of illness or disability, which are often tied to certain claims, can either be sought or resisted, helpful or harmful.

#### 5.1 Authorizing or restricting access for FAS/D claimants

Need is a fundamental claim, yet there are multiple ways of defining and experiencing it (Stone, 1988). To claim need is to insist that one should be given resources or help because they are essential (Stone, 1988). Since ways of determining and defining need result in different claims, claimants will often turn to an expert or authority. The authority established in texts is particularly useful in administrative systems for managing objective responses to competing claims (Smith, 2005). However, the authoritative texts which manage access to benefits for many kinds of medical claimants have not yet validated claims for help from people with FAS/D.

Bureaucratic systems often rely on authoritative biomedical texts to determine people’s eligibility for benefits. In North America, the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) (American Psychiatric Association [APA], 1994) is the primary text for legitimating psychiatric and behavioural disorders (First, 2000). In the US system of private



health care administration, paediatricians and neurologists may not be reimbursed if the disorder or condition they are treating is not in the DSM-IV (O'Malley, 2000:2). Canada's publicly-funded system is currently not as restrictive, although insurance companies may resist benefit claims made on the basis of diagnostic categories that are not authorized in DSM-IV. That relatively few US psychiatrists are currently involved in diagnosing and treating people for FAS/D may be due to the lack of acceptance of FAS in the validating text (O'Malley, 2000). One of the indeterminacies about FAS or FAS/D is how to define it and where does it fit?

O'Malley (2000) insists that FAS/D should be recognized by the authoritative DSM-IV because it is "really a chronic neuro-psychiatric condition" (2). He claims that people with FAS/D "have a prevalence of psychiatric/mental health disorders through the life-span of 90-94%" (O'Malley, 2007:11). Prevalence refers to the number of cases existing in a population at a given point in time (Abel, 1998). At present, medical authorities have not authorized FAS or FAS/D for inclusion in DSM-IV. An intensive lobbying effort by FAS advocacy groups has been underway for some time to ensure the inclusion of FAS in the DSM-V, scheduled for publication in 2013 (O'Malley, 2000). This effort, if successful, would likely make FAS and FAS/D more authoritative and, hence, less controversial.

When a diagnostic category is not authorized in the DSM-IV, doctors may make use of other categories to authorize the diagnosis, and thereby, substantiate claims for re-imburement, for example, from insurance companies (O'Malley, 2007). For example, the DSM-IV diagnostic category for Mood Disorder, code 293.83, allows the physician access to an authorized fundable category by attaching a "general medical condition", such as "prenatal alcohol exposure with evidence of FAS" to the mental disorder (2007:6; APA, 1994). In this way, the co-morbid presentation – pairing FAS or FAS/D with an authorized psychiatric disorder – may provide the

sought-after entitlement (2007). O'Malley claims that co-morbidity – the presence of a 'dual diagnosis', is now the rule rather than exception for people with FAS/D.

Fetal alcohol syndrome is acknowledged in the *International Classification of Diseases (ICD-10)* (WHO, 1992), which is the official international system for all medical diagnoses. It appears in a section which includes codes for congenital malformations due to exogenous (external rather than endogenous or arising within) causes under the code *Q86.0* (Version 10-chapter XVII). The WHO has not yet authorized fetal alcohol spectrum disorder as an entity. The *ICD-10* is the authoritative text for legitimating diseases in the UK and European countries and experts claim it authorizes not only diagnoses but also guides treatments. What is the authorized treatment for FAS?

### 5.2 FAS: A guide to intervention or help?

Experts claim that the diagnosis of FAS and related disorders is intended, not as a label, but rather as a "blueprint for early intervention" (Chudley et al, 2005). However, the medical approaches to treatment that usually accompany a diagnosis have eluded medical experts in dealing with fetal alcohol syndrome. The educational, psychological, and other assessments that often accompany the diagnosis assist parents in managing challenging behaviours, structuring learning opportunities, and modifying environments in ways that help children in their lives at home and in school (Streissguth, 1999) and there is an extensive body of literature on these management approaches. Parents – or as my research suggests *some* parents – would also like the diagnosis in order to know what they are dealing with so that they can try and access appropriate supports and resources (Schellenberg, 2003); this topic emerges in my analytic chapters.

Governments may mobilize around specific diagnostic categories and their 'sufferers', sometimes, as a way to deflect their responsibilities for addressing social problems or inequities

for individuals (Kinsman, 1996; Petersen & Lupton, 1996). Government responses to people's requests for help may also include forms of intervention that regulate, marginalize, exclude, or monetarily compensate those to whom the category is applied (Moss & Teghtsoonian, 2008). Some diagnostic categories may also include interventionist measures, such as debilitating or mood-altering treatments. The name or discourse by which a problem is characterized may also determine the kind of social, medical, or even legal interventions. I turn to some of those discourses in the next chapter.

## **6.0 Summary**

Since the syndrome was named in 1973, it has been a contested knowledge field marked by debates about when it was first conceived or identified, whether it is a condition that affects a small number of children, an estimated 1/1000 live births, or whether it is a growing epidemic in North America and increasingly throughout the world. Debates are ongoing among FAS experts themselves and Ernest Abel's writings, in particular, have contributed to a cogent analysis of the ambiguities, claims, and counter-claims which make a surprising portion of the FAS literature weak examples of scientific scholarship.

One of the most persistent debates revolves around etiology and the efforts of many researchers to quantify just how much alcohol a woman can drink before she poses a risk of FAS/D to the developing fetus. The names FAS and FAS/D, which directly implicate mothers as causing harm to their children, and the persistent causal claims mean that, to a large degree, etiology is taken for granted among health care professionals, the media, and general public. Nevertheless, there is a small but growing body of research which is challenging the mono-causal claim. And an examination reveals that even within the FAS field, etiology is contested. There are also persistent questions about how this diagnosis helps children, for example, with

improving health outcomes, or whether it is the educational assessments and everyday strategies for parents and families that offer the most valuable help.

The latest revision and expansion to the ‘spectrum’ of disorders appears to be a concerted effort if not to resolve the debate, then to obscure it. A detailed examination of the claims reveals that they are couched in uncertainties. The numbers and codes – all 256 of them – that fall under the FAS/D umbrella seem to construct an objective and to a large degree undisputed case.

As an institutional ethnographer, I worry about the numerical product and its relation to any actuality. A body of literature in the social organization of knowledge reminds me of the prevalence of ideologically constructed knowledge. How the descriptors of FAS are tied to the phenomenon is a topic for inquiry in the social organization of knowledge. Yet, even if the connection is tenuous between actual people, mothers and children, *and* the numbers representing an expression of the syndrome, the numbers and codes carry weight.

In the second of my literature review chapters, I move from the authoritative claims related to the diagnosis, to explore how FAS is characterized in institutional sites not confined to ‘health’. And I examine literatures critical of this form of classifying and categorizing people’s experiences as a ‘diagnosis’ and of the actions or interventions that may be generated.

## Chapter Three

### Medical knowledge, discourses, and practices as contested terrain

*Discourse offers a language that is both enabling and restricting. It interprets situations, defines objects, locates our own subjectivities in relation to them, and subordinates us to its moral logic* (Griffith & Smith, 2005: 42).

#### 1.0 Chapter Introduction

During the course of my research, I frequently turned to social sciences literature to determine how various readings might illuminate, support, or contradict what I was learning and hearing about fetal alcohol syndrome. My perusal of the relatively limited critical FAS literature and of a more extensive contiguous critical literature, have offered valuable questions and perspectives that have assisted my inquiry into the FAS field of knowledge and practices.

I develop this chapter in two parts: Part I explores discourses and practices arising in various institutional sites (media, government, medicine), which intersect with the FAS knowledge field. How women or their experiences are characterized is shown to generate specific forms of action. Part II draws from writers who critically examine biomedical knowledge and practices which increasingly shape people's lives. They also focus attention on how biomedical knowledge is made authoritative and question assumptions people rely on when they produce or apply medical diagnoses.

Many of the studies I examine throughout the chapter share an interest in contesting the ways in which people's experiences are captured in unexplicated forms of language related to health, illness, or medical diagnoses. I also examine contested diagnoses which, like FAS, tend to be those which researchers, physicians, or others who work within conventional paradigms frame as controversial, "difficult", psychosomatic, or even non-existent" (Moss & Teghsoonian, 2008:7). Contestation opens spaces for critical analyses of the exercise of power in people's lives

and for challenges to conventional understandings of illness and disability (Conrad & Stults, 2008; Moss & Teghtsoonian, 2008; Smith, 1990a). To contest medical knowledge and discourses allows for debates on alternate forms of knowledge that have been discredited or obscured, and also gives voice to those who may know the world or people's experiences differently (Smith, 1990a).

## **Part I: FAS as a discursive organizer of women's and children's lives**

In the public policy context, discourses often shape which accounts and concerns are considered credible, and what policy options are more 'realistic' (Campbell, 2000). For example, when drug 'problems' are held up as an example of growing moral disorder, they are also used to deflect responsibility from governments for addressing the root causes of problem-substance use, not the least of which is poverty (Boyd, 1999). Discourses provide or 'mediate' a way of knowing in ways that displace or subvert local and experiential knowledges with knowledge that is useful for administration and control (Smith, 1987).

The critical literature on FAS articulates a number of discourses, which shape how we are to understand women, and children, and FAS. In this section, I explore three discourses – harm, rights, and risk – which are prominent in the FAS/D knowledge field and people's practices. My discussion will also expose other discourses which intersect with FAS/D.

### **1.0 Harm**

The way that harm is defined generates the actions – or inactions – that are to follow (Campbell, 2000). For example, "if the source of harm is located in individual behaviour, the larger social patterns and structures in which the behaviour is situated do not come under scrutiny" (2000: 42). The moral panic ignited by FAS in the United States (US), for example, served the purpose of "diverting attention from social inequality and displacing blame for poor

pregnancy outcomes to individual mothers rather than on social circumstances” (Armstrong & Abel, 2000: 280). An extensive area of research has developed around not only how much alcohol women can drink (and also smoke), but also how their behaviour constitutes a risk to be managed and controlled.

The harms associated with drinking play an increasing role in an ongoing debate on the risks posed to the fetus, as evidenced in literature (Blume, 1987; Knupfer, 1991; Olsen & Tuntiseranee, 1995). In the past three or so decades since FAS was first described, health authorities and practitioners in some western countries, such as the US, Australia, and the UK have generally considered that there is no safe consumption of alcohol during pregnancy (Stockley, 1998). Recently, however, people are beginning to reconsider their policies and recommendations<sup>1</sup>, as research conducted internationally describes a threshold above which FAS is observed to occur (Stockley, 1998). No one is advocating alcohol consumption during pregnancy. For the most part, however, women’s drinking is constructed in terms of fetal risk and harm, with little attention to other factors or to the harm that occurs to women and children through this construction.

Keane (1996) observes that the starting point to FAS begins, not with the discovery of FAS in a small cohort of children and their mothers, but in the “relationship between the pregnant woman, and the vulnerability of the fetus to the negative effects of maternal behaviour” (266). A popular slogan that reflects a discourse on the vulnerable fetus held captive in a ‘toxic womb’ is: “When a mother drinks, the fetus drinks, too” (Keane: 266). FAS or FAS/D are moralizing discourses because they implicate mothers as responsible for harming their

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<sup>1</sup> The National Health Service (2012, March) in the UK, for example, advises women to avoid consuming alcohol during the first three months of pregnancy in order to avoid the risk of miscarriage and to refrain from drinking any more than one to two units of alcohol once or twice weekly during pregnancy to avoid serious effects on children’s development.

fetuses/children (Badry, 2007-2008). While it is beyond the scope of this paper to examine the growing discourse that also constructs as reprehensible women who smoke during pregnancy, there is a significant body of literature that extends discourses on FAS and women's *toxic* wombs to '*smoke-filled* wombs' and fetal rights (Oakley, 1989; Oaks, 2001).

In my tracing of some of the discourses found in media, advocacy, or policy texts, it has become apparent that FAS/D discourses are still evolving. At the present time, however, a relatively new way of talking about children has entered the FAS/D knowledge field over the past few years and it is a compelling one, because it fixes attention on mothers' responsibility for damage, not only to children's bodies, but also to their brains.

### 1.1 "FAS/D kids are brain damaged."

Although central nervous system dysfunction/damage has been a feature of the FAS diagnosis since its early beginning, a widespread discourse on FAS/D children as 'brain-damaged' is relatively new, and one I had not been introduced to in my work in the FAS policy field. This discourse first came to my attention when, as a graduate student and FAS researcher, I obtained permission to attend an FAS/D research forum in Victoria in April 2008. There, I learned that, even among FAS/D experts, characterizations of FAS/D may be hotly contested. Some experts, admittedly few in this forum, insisted like O'Malley (2007) that FAS/D is primarily a 'mental disorder' and should be treated as such, while others insisted that FAS/D is a 'neurodevelopmental disability' marked by 'brain damage'. Tensions between the two groups were visible and finally, one expert clearly stated, as though it were a fact, that FAS/D children are 'brain damaged'.

I was troubled by this generalizing claim and voiced my opinion that "to call FAS/D children 'brain damaged' is a pretty sweeping claim". One individual with a leadership role in



the Ministry of Children and Family Development (MCFD) and who happened to be sitting at my table, reacted angrily. Banging her hand on the table, she exclaimed: “FAS/D kids are brain damaged”! During the conversation that ensued, she explained that the ministry had contracted with FAS/D expert, Diane Malbin from the US to provide training sessions for various levels of ministry staff. It was while she was attending a session that she learned FAS/D children are brain damaged. She said that arrangements could be made so that I could also attend one of the MCFD training sessions.

Surprising in this incident, was the degree of fervour accompanying this ‘brain damage’ discourse, as well as my discovery that this otherwise cash-strapped ministry could afford consultation fees to train not only line workers, but also those in leadership positions, and apparently, even their invited guests. Also surprising is that, apparently, Malbin’s conceptual frame, and those who have developed expertise in it are not to be challenged.

Diane Malbin (2004), a social worker, parent of FAS/D children, and founder of FAS/D-related parent support group projects, has developed a conceptual model that claims FAS/D is a ‘brain-based physical disability’, which has behavioural symptoms. The discourse is widely disseminated in texts, including web-sites popular with adoptive or foster parents and others concerned about children who are or may be FAS/D.

Malbin’s (2004) contention is that the symptoms – expressed as behaviours – associated with FAS/D are both primary and secondary. Primary behaviours relate to changes in “brain structure and function”, although none are exclusive to FAS/D (55). Primary behaviours include difficulties with memory, learning from past experiences, problems in executive function such as planning, organizing, setting goals, or understanding abstract concepts such as time and money (2004). ‘Secondary behaviours’ such as aggression, fighting, clowning inappropriately, and

getting in trouble with the law, develop over time as defensive responses to a poor ‘fit’ between the individual and her environment and again, none are exclusive to FAS/D (2004). Malbin’s view is that standardized techniques for managing behaviours do not work with FAS/D children, who need individualized approaches and modifications in their environment that allow for their own abilities and strengths. This individualized approach is unlikely to have detractors, since it is also one that teachers, for example, insist is needed for *all* children in their classes, not only those termed ‘special’ needs (Schellenberg, 2003).

Malbin’s claims about ‘secondary behaviours’ are consistent with those who claim that the greatest challenge associated with FAS/D is the “development of subsequent ‘secondary disabilities’ such as trouble with the law, unemployment, mental health problems, and disrupted school experience” (MCFD, 2008: 7; O’Malley, 2007). These claims are generally accompanied by other claims concerned with the million dollars<sup>2</sup> or so cost of supporting a child/adult with these sequelae during the course of a life-time (MCFD, 2003).

Could anyone render a more distressing claim about the lost potential of a child, or the responsibility of his mother, than one which consigns a child to a life with brain damage, with little hope of improvement?

Our times have produced a terrible confusion about drugs, mood, illness, and behaviour.

The licit and the illicit, big medical science...have combined to create a ...view of the human which traps the full range of human possibility into categories of mental disorder or criminality, with little in between (Appignanesi, 2002: 473).

In another quotation I found to be relevant to the FAS/D brain-behaviour discourse, Appignanesi (2002) calls into question the claim connecting brain chemistry to behaviour, which

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<sup>2</sup> See also Salmon’s (2004) critique of these claims.

in her view, is the dominant language at the recent turn of the century. She also insists that it is a considerable leap to assume that emotions such as, for example, sadness are caused by chemical imbalances in the brain:

To assume that sadness, even in its malignant form, is caused by a chemical imbalance may not be an altogether useful hypothesis or a particularly true one. I feel sad when my dog dies. This causes a change in my brain. The emotion isn't caused by the brain (3-4)

Yet, increasingly, in the FAS/D field, people take as truth that behaviours, whether sad, bad, or mad ones, as Appignanesi's book characterizes the human condition, are caused by alcohol-damaged brains.

### 1.2 Image as 'proof'

I have had the experience, common to many who attend FAS workshops, to view convincing 'evidence' of alcohol's damaging effects on the brain (see also LaBerge, 2000). Tait's (2003) description of the experience is engaging. Tait describes her experience when, as a member of an audience of service providers, government officials, and community representatives, Canadian FAS expert Dr. Christine Loock used visual images to demonstrate 'proof' that alcohol damages the brain. I have seen Loock's presentation in another venue, and found it very convincing. As Tait describes, Dr. Loock presented slides of two autopsied infant brains, where the larger 'normal' brain "full of detail conspicuously overshadowed the smaller smooth mass beside it" (333). Tait describes how the crowd stared at the pathology that was clear in the image of the smaller brain, as Loock announced: "This is FAS" (334). Tait explains that Loock later told the audience that FAS brains can actually be similar in appearance to 'normal' brains and that the pathology resides primarily, not in structure, but in the way the brain functions. However, as Tait observes, the powerful image on the screen has already "taught the

audience what FAS *is*” and provided the proof of how the FAS brain looks inferior to the ‘normal’ (334).

Tait’s observation that the placing of the brain images on the screen conveys a reality the viewer takes as ‘truth’ resonates with McCoy’s (1995) analysis of the photograph as a form of textual reality. McCoy observes that the practices of using and viewing photographs, or I would add, other visual images, can be analyzed as practices that ‘activate’ the image within a particular discourse. What people do with such images, and how we as viewers make sense of them, also justifies particular courses of action (1995).

The images, said to be of FAS brains, juxtaposed against ‘normal’ ones, organize a powerful discourse concerning the risks associated with the ‘secondary disabilities’ of FAS/D. The underlying assumption is that “functional brain abnormalities produce certain behaviours which, when undiagnosed would be viewed as inappropriate”, deviant, or even criminal (2003: 334). Currently, there is a widespread debate about the high numbers of people with undiagnosed FAS/D in criminal justice settings and what to do about helping them. How people develop, apply, interpret, and ultimately act on images and tests of brains and their ‘functions’ continue to be open for interpretation, examination, and debate, as longstanding and well-known controversies concerning the ‘objectivity’ and reliability of another brain discourse – IQ measurements – have demonstrated (Armstrong, 1993; Dumit, 2000).

Dumit (2000), a medical anthropologist who has conducted ethnographic fieldwork in brain imaging laboratories, argues that these and other techniques for visually demonstrating the ‘disordered’ and ‘damaged’ brain are contested and controversial. He suggests that the origins and meanings of ‘socio-medical’ diseases are not to be found in their ‘biology’, but rather in the ways that an event, which happens locally, is decided elsewhere, for example, in disability

hearings or doctors' offices and in diagnostic practices. At the same time, Dumit acknowledges that imaging techniques are persuasive and appealing, offering to sufferers and their detractors "the promise of *showing* [author's emphasis] that the disorder really is in their brain and not in their heads" (219). While even this distinction is contested, empirical attempts to find and demonstrate 'proof' of such differences are ongoing. Meanwhile, people who are developing expertise in the text-mediated brain discourse are ready to pass on these truths to others, including myself.

Emerging research, popularized in a book by Doidge (2007) is demonstrating the enormous and previously unrealized capacity of the brain to repair itself, even in people who have suffered severe brain damage from strokes or other neurological deficits. Research on the 'plasticity' of the brain challenges claims that FAS/D is an 'irreversible' brain disability, and will likely force revisions of the brain-damage discourse, and thereby, possibly provide hope for the many children and mothers who have undoubtedly been damaged by the discourse.

## **2.0 Rights**

There is a developing discourse, most dominant in the US in the context of a powerful anti-abortion lobby, which frames an adversarial relationship between a mother and her developing fetus. In the 1980s, the "convergence between the war on drugs [another discourse] and the growing legal and cultural recognition of fetal rights", created the "paradigmatic example of the figurative divorce between maternal rights and fetal rights" (Campbell, 2000:188).

In Campbell's (2000) discussion on the evolution of this rights discourse in the US, she observes that issues of individual responsibility and choice, emphasizing women's 'moral accountability', were at the centre of the debates. Conservative 'right to life' proponents profiled their concerns about 'drug-addicted' women, in order to shift the focus to parental

responsibilities – current, prospective, and back to the point of conception. The dominant claim was that women’s participation in high-risk behaviours should justify suppression of individual choice (2000). In other words, there should be legal justification for denying reproductive rights to “women who make the ‘right’ choices and women who do not” (282). One prominent fetal rights lawyer and professor, argued that there should be “court-appointed fetal guardians who could sue mothers” for conduct which posed danger to their unborn, and revoke their parental rights (182-183).

It is noteworthy that the issue of fetal rights has escalated in a direction whereby at least 300 women in the US have now been prosecuted for drug or alcohol use during pregnancy (Flavin & Paltrow, 2010). In Canada, at least one highly publicized court case on maternal substance use during a young woman’s pregnancy projected a punitive and polarized view of her (Rutman, Callahan, Lundquist, Jackson, & Field, 2000). With Canada’s proximity to the US, and a tendency on the part of the Federal government to import US policy trends, it is likely that further court cases will follow<sup>3</sup>.

Examples of enforcement projects include a bill proposed in 1992 in Washington State that would require a woman “who gave birth to a child with fetal alcohol syndrome to have the contraceptive Norplant involuntarily inserted in her”, and thereby, prevent future births (Paltrow & Tracy, 2000, fn. 10). While this particular law was not enacted, there is a growing legal capacity in the US that allows for the arrest and prosecution of pregnant women who use alcohol or illicit drugs (Flavin & Paltrow, 2010). For example, the State of Texas has recently mandated

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<sup>3</sup> Currently in Canada, a private member’s bill, Motion 312, put forward by Conservative MP Stephen Woodworth, proposes changes to the Criminal Code which would extend legal personhood to fetuses. But if that were to happen, it would ironically impact women’s rights and may possibly even criminalize their decision-making during pregnancy (personal communication, Susan Boyd, June 12, 2012).

a new method of controlling women's bodies and 'choices' by requiring that in the 24 hours before a woman seeks termination of a pregnancy she must submit to a fetal ultrasound, view the sonographic image of her fetus, and listen to the fetal heartbeat (Smith, January 26, 2012).

While no state laws specifically criminalize drug use during pregnancy or mandate the enforced sterilization of pregnant women, some states terminate parental rights or authorize civil detention for substance-using women (Paltrow & Tracy, 2000: 1-2). In several states, fetal alcohol syndrome or evidence of maternal alcohol use falls under the legal definition of neglect, which may precipitate child welfare interventions (2000: 2).

New technologies for screening and identifying substance-using pregnant women have created new ammunition for people lobbying for stiffer controls on women's alcohol and drug use. Researchers in the US and Canada are actively engaged in developing biomarkers to "help with the identification and treatment of women at risk for an alcohol exposed pregnancy who may not otherwise provide this information" (Centres for Disease Control (CDC), 2004:1). Possible biomarkers include testing of meconium from the newborn infant or testing maternal blood (2004). These developing technologies and tests can ostensibly 'confirm' neglect, potentially placing more women at greater risk for prosecution.

McNeil and Litt (1997) question the "efficacy of developing these screening technologies when there is so much uncertainty about the effects of exposure itself" (35). Furthermore, overlooked is that "poverty, maternal distress, and other social disadvantages" likely have even greater adverse outcomes for child health than in utero exposure to substances such as alcohol and drugs (1997:35; Flavin & Paltrow, 2010). Despite these controversial and even punitive trends, biomarker technology is progressing rapidly. Research into biomarker technology is also currently underway in Canada. For example, the Motherisk lab in the Hospital for Sick Children

in Toronto was in the process, earlier in this decade, of developing a method of hair analysis for alcohol detection (Motherisk, 2001)<sup>4</sup>.

These and other examples of intrusions into the lives – and bodies – of women, and infringements on their individual rights are often couched in the language of ‘compassion’, ‘prevention’, and support. Campbell (2000) cites a Harvard law professor who claims:

Simply stated, I think we have to say to ourselves that it is not punishment, rather it is prevention, to insist that a drug-addicted woman who has given birth to a drug-exposed infant submit to the kind of round-the-clock supportive treatment programs that are necessary to lead a drug-free life and thereafter to be able to give birth to healthy children. It can’t be seen as cruel to subject a woman who needs that kind of support and that kind of reinforcement to a caring and supportive living environment where she can in fact learn to resist the temptation of drugs (183).

These claims, which re-define coercive measures as compassionate forms of rehabilitation and support – along with the inevitable promise of punitive sanctions – exemplify the “ideological contraction of the state’s responsibility for social provision” to those who are most in need of support (Campbell, 2000: 183). Prevention activities and interventions are typically carried out on the basis of characteristics applied to people that specialists in fields such as ‘public health’ constitute as ‘risks’ or risk factors (Boyd, 1999; Campbell, 2000; Petersen & Lupton, 1996).

### **3.0 Risk**

‘Risk’ is an organizing discourse in many institutional sites and texts concerned with medical, public health, and schooling practices (Armstrong, 1983; Castel, 1991). In everyday

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<sup>4</sup> Motherisk also publishes an on-line journal, *The New Journal of FAS International*, billed as “the first scientific peer review journal for FASD” (p.1).



use, risk is a signal for danger or peril that may occur in the future (Petersen & Lupton, 1996). Rose (1996) argues that professional and helping interventions are ‘administered’ through governing and bureaucratic regimes in ways that reconstruct the interests of clients. People participate in managing themselves, however, when they will not or cannot, the job of professionals is to assess, intervene, and reduce whatever risk they may create to the security of others (Rose, 1996). Poor mothers, mothers parenting on their own, mothers who drink as well as the children they conceive and bear, constitute just such risks.

Poor mothers, who often are also parenting on their own, comprise the majority of mothers in the Canadian child welfare protection system (Brown, 2006). Social workers – and in my experience, public health nurses also – construct mothers as risks, in part, because they *are* poor and managing children on their own (2006). In public health and social work practices, mothers who drink – or at least certain groups of mothers including the young, single, and poverty-stricken – are considered ‘high risk’ for neglect and abuse (Swift, 1995).

In Brown’s (2006) study of mothers who were engaged in the child protection system, concern for their children motivated the mothers to try to reduce their level of risk and advocate for their families. However, Brown observed that women’s efforts to reduce their risks and care for their children often involved them in their unacknowledged work of protecting their children “from risks inherent in the child protection system itself” (368). The system, Brown observed, operated from a standpoint in institutional considerations and interests, which takes precedence over those of mothers and children.

Categorizations of ‘risk’ are projections of ‘otherness’ that target certain groups and designate people, not only as the enemy to social order (Kinsman, 1996), but also, in the case of women who drink, as enemies to their own offspring. Such discourses mobilize hatred and

discrimination, while also constructing new 'objects' for regulation (1996). At the same time, some groups of 'high risk' or affected individuals may even call for more regulation and governance in the form of social care and support however, the responses to these demands are often lacking (1996).

McNeil and Litt (1992) insist that the emergence of FAS in medical literature is "clearly about the identification of groups of women as mothers 'at risk'" and 'high risk' (1992: 131; Astley, Bailey, Talbot, & Clarren, 2000). Similarly, Griffin's (cited in McNeil & Litt, 1992) analysis of young women designated 'at risk' in social work literature has shown that certain groups of women, such as, working class, lesbian, and black (in the US), are more likely to be labelled in this way than others and are, therefore, made suspect. However, categories of 'risk' and 'risk groups' obscure that moral assumptions are implicit in this conceptualization (Petersen & Lupton, 1996).

Perhaps nowhere else than among Aboriginal women and children, have risk discourses and practices been more harmful. In the 'neutral' language of epidemiology and statistics, Canadian Aboriginal peoples are identified, among the world's populations, as being the population most 'at risk' for FAS and other birth defects attributed to women's drinking during pregnancy (Tait, 2003). Obscured are the practices that support and perpetuate the construction of risk and other features of the so-called 'Indian problem' (2003). Included in these practices are the historical development of the residential school system, child welfare practices that extracted Aboriginal children from their homes and communities, medical and other forms of "government surveillance and interventions that target Aboriginal people" (2003:155). Increasingly, FAS/D children and youth are characterized as 'at risk' because it is thought that, as adults, they will pose serious risks to society. The disproportionate numbers of Aboriginal men, also thought to be

undiagnosed FAS, who are incarcerated in prisons (Malbin, 2004) seems to justify these assumptions of risk.

From her critical perspectives in research and policy work with women and substance use, Boyd (1999) problematizes ‘risk’, observing that risk categories are artificial and risk claims are unreliable. The notion of risk, as applied to women, can best be located in an ideology of mothering and Western societies’ expectations of women as caring and virtuous. Sites for regulating and controlling women are “gender-specific, centering on familial ideology<sup>5</sup> and biological reproduction as the loci of social regulation” (1999:5).

Boyd’s (1999) research on mothers who use illicit drugs exposes how expert approaches to dealing with mothers of infants diagnosed with neonatal abstinence syndrome fail to support mothers. Boyd’s work shows how an ideology of mothering as ‘natural’ organised nurses’ understandings of substance-using women as incapable of mothering, even when the nurses’ own knowledge of the women demonstrated that this was not the case. Once an infant or child is thought to be in need of protection, which is often the case with mothers who drink alcohol and/or use illicit drugs, professionals tend to deem a woman’s capacity to mother as inadequate, and ignore her experiential knowledge of caring for her children (1999; Brown, 2006).

Society’s view of women as drinkers has been and remains one of condemnation (Plant, 1985). Although the literature has established that women, in general, have lower levels of alcohol use or problematic substance use than men, women who use alcohol or drugs often face censure and a well-entrenched ‘double-standard’ (Rutman, Callahan, Lundquist, Jackson, & Field, 2000; Boyd, 2007). While addiction is generally considered to be a ‘disease’, it is still

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<sup>5</sup> Weust (1993) says that the ideology of familism is the dominating principle of social organisation in Western societies. She adds that the ideology of the nuclear family fosters relationships of domination and subordination, patterns of domestic labour, altruistic caregiving of children and the elderly, and patterns of dependency, all of which serve women poorly (409).

framed as ‘deviant’ and pathological behaviour, and women who drink are constructed as more deviant than men (Badry, 2007-2008; Campbell, 2000; Field, 2000). In her examination of literature from the 1960s and 1970s concerned with substance use and women, Field (2000) identified two prevalent themes – sexual promiscuity and FAS – both of which characterized women in terms of moral censure rather than examining women’s patterns of alcohol use in regard to relevant social issues or the context of their lives.

Others have contextualized women’s excessive drinking in terms of a host of factors, including physical and sexual abuse as children, histories of violence, exposure to alcoholism as children, poverty, and other vulnerabilities (Badry, 2007-2008; Tait, 2003). However, for mothers who drink, these same issues or experiences are also used in health and social services literature to characterize women as ‘risks’ and their children as ‘at risk’.

Risk categories have deleterious consequences for not only women but also for their children, to whom the labels of ‘risk’ or ‘high risk’ are applied (Boyd, 1999: 33):

The label of ‘high risk’ for women who use drugs during pregnancy has not led to more resources or support for mothers. Rather, it has served to reinforce unequal power relations between medical professionals and mothers...As well, labelling infants ‘high risk’ has led to the isolation and separation of infants from their mothers through lengthy confinement in hospital, social service apprehension in Canada, and criminal charges and incarceration of mothers in the United States [and I would add, more recently, Canada] (34).

For women who drink, punishment is often swift in the form of child apprehension and once women are seen as deviant, or ‘bad mothers’, they are then ‘targeted’ for surveillance (Swift, 1995). Surveillance may take the form of ongoing monitoring and risk assessments,

interviews with others in the mother's life to corroborate evidence, and practices such as regular drug monitoring (Brown, 2006; Swift, 1995). A number of mainly feminist writers (Boyd, 2004; Campbell, 2000; Golden, 1999; Keane, 1996; Klee, 2002; McNeil & Litt, 1997; Oakley, 1984; Swift, 1990; 1995) draw on critical theoretical approaches to critique discursive practices that regulate and control women and characterize them as 'bad' mothers.

Embedded within the concept of fetal alcohol syndrome and/or FAS/D, are "deeply held moral convictions about the nature of risk and responsibility for disease" (Armstrong, 2003: 8). Throughout North America, concerns about maternal alcohol consumption and FAS/D have produced unprecedented societal responses including stigmatization and even criminalization of women who are thought to have damaged their children through drinking behaviour, which is perceived as irresponsible (2003; Badry, 2007-2008). Pregnant women who drink alcohol now commonly face harassment and open reproach from intimates and even strangers (Armstrong, 2003). At a public meeting concerned with FAS education and prevention, I personally witnessed a social worker, who was also a foster parent of a child diagnosed with FAS, exhort members of the audience to approach any pregnant woman holding a drink, or frequenting a bar or pub, and warn her of the risk of harm she poses to her offspring unless she stops drinking.

Badry (2007-2008) insists that the prevailing discourse, which "suggests women need merely to refrain from alcohol use during pregnancy", makes FAS a moralized disability (88). Notions of risk and danger inherent in this popular form of public health prevention messaging attest to the role of medicine and the state as sites for 'social control'<sup>6</sup> (Armstrong, 2003; Boyd, 1999). Social control refers to "the organized ways in which society responds to behaviour and [to] people it regards as deviant, problematic, worrying, threatening, troublesome, or undesirable

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<sup>6</sup> See Part II of this chapter for further discussion on this topic.

in some way or another” (Cohen, 1985:1 cited in Boyd, 1999: 5). Mechanisms of control, some of which I identified in describing surveillance practices, as well as women’s own efforts at managing their risks, “may be direct and explicit” as well as indirect and implicit (1999: 5). The construction of categories of risk, while ostensibly intended to serve the public good and prevent possible future dangers, is useful for managing, directing, or demanding moral behaviour (1999).

### 3.1 Historical constructions of risk

Castel (1991) traces the emergence of risk to the efforts of eighteenth century French psychiatrists to develop ‘prophylactic’ or preventive strategies for managing the dangers that unconfined mental patients could pose to others. These preventive strategies involved objectifying subjects as ‘risks’ and producing numerically calculable risks based on the frequency of mental illness in a population. At the time, the authorities designated as the primary threat the disadvantaged people who lived in conditions of malnutrition and poor housing and whose behaviours included alcohol abuse and sexual promiscuity (1991). These practices of calculating and objectifying people as risks comprise a major part of the science of ‘epidemiology’ (Petersen & Lupton, 1996). They are also part of a government strategy for making claims about who is ‘at risk’, and thereby produce differences among people that constitute them as objects to be managed. Health promotion and prevention practices take place in relations of power, wherein governments and health promoters often target as ‘at risk’ the very populations or groups that are already marginalized.

The eugenics policies of the early twentieth century, authorized by the American Psychiatric Association, employed preventive measures that targeted specific groups in an effort to ensure “preservation of the race” (1996: 285). As Castel observes, sterilizing certain groups that posed a risk to the integrity of the race would suppress future risks posed by offspring and

have more lasting effects than confinement. In almost every state in the US, special laws imposed sterilization on a wide range of individuals deemed to be ‘deficient’. Although these interventions were later halted, Castel argues that psychiatry, along with social work and other human service professions, continues to play a role in identifying and regulating populations ‘at risk’.

Castel (1991) also provides a history of practices in indentifying and managing mothers and children ‘at risk’ in France. This history was of particular interest to me, because it was only a few years earlier in France that a French physician (Lemoine, 1968) identified a small population of ‘alcoholic’ mothers with children who had ‘abnormalities’, later designated as fetal alcohol syndrome, and I wondered whether Lemoine’s work may have been a precursor to the following developments.

Castel recounts that in 1976, France installed a system<sup>7</sup> for detecting childhood abnormalities that involved conducting three examinations of all infants under age two. The purpose of the examinations was to detect “all possible abnormalities of child and mother”, including physical, psychological, and social, and to collate ‘factors of risk’, such as the marital status (or not) and nationality of the mother (287). Castel observes that the presence a number of unspecified factors would trigger an alert, after which an authority such as a social worker, would visit the dwelling to “confirm or disconfirm the *real* [writer’s emphasis] presence of a danger” based on the deduction of possible risks (287-288).

Here, as Castel insists, is a preventive policy that involves a “new mode of surveillance: that of systematic predetection” of illness, abnormality, or undesirable behaviour that must be

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<sup>7</sup> The GAMIN system was apparently dispensed with in 1981 due to concerns over breaches in the security of the system (Castel, 1991). However, Castel observes that systematic tests are carried out in the US on groups (non-specified) that pose special risks.

regulated (288). Whereas early prevention practices involved the presence of a subject and the gaze of the observer, such as the doctor and patient in the ‘clinic’ (Foucault, 1973), the new practices of surveillance can dispense with the presence of subjects in their concern with the anticipation of all possible factors – undesirable abnormalities, events, or behaviours likely to produce risks (Castel, 1991).

Discourses on risk and prevention are, therefore, intrinsically linked. Prevention policies, which identify and constitute subjects and groups as risks, also produce new objects for surveillance and, thereby, establish infinite “possibilities for intervention” (Lupton, 1999:93). In FAS/D prevention policies, the threat that maternal alcohol consumption poses to children now organizes every woman of childbearing age as a risk that needs to be managed.

In the language of FAS/D risk management, services are ‘targeted’ toward women as a measure of ‘primary prevention’ (Astley, Bailey, Talbot, & Clarren, 2000). Primary prevention refers to “avoiding the birth of children likely to be damaged by prenatal alcohol exposure” (Astley et al: 499). ‘Prevention’, it would appear, is the new risk management measure aimed at regulating and controlling women’s reproduction. Those promoting such risk management measures also assert that “surveillance be done accurately enough to monitor the success of prevention efforts” (Astley et al: 500). Surveillance too often takes the form of coercive child welfare strategies that “extract the mother’s compliance” (Campbell, 2000: 181).

Boyd (1999) asserts that the construction of high risk or “deviant pregnant women distracts society from addressing such issues as racial and class bias, ‘foetal protection’ policies, the poor maternal health and infant mortality rates”, notably, in the United States, and the lack of services and resources that address the conditions of women’s lives (24). Even where public resources may be available to some groups of women, those who are constructed as irresponsible



are also seen to be less ‘worthy’ of support<sup>8</sup>. Other researchers (see Loney, Green, & Nanson, 1994; Armstrong & Abel, 2000; Plant, 2000; Greaves, Varcoe, Poole, Morrow, Johnson, Pederson, & Irwin, 2002) also support this concern about the social and economic conditions of women’s lives and how they are often overlooked.

### 3.2 Preventing and managing risks

In keeping with current neoliberal approaches to reducing state responsibility for its citizens by redistributing it to individuals, Lupton (1999) observes that discourses and practices of ‘prevention’ and ‘risk’ are governmental strategies for governing “at a distance” wherein a variety of actors, institutions, knowledges, and practices come into play to monitor and regulate individuals and populations (87). For example, the BC government’s public policy prevention discourse, which generates actions to target every woman who uses alcohol as a ‘risk’ to her present or future fetus (MCFD, 2003; 2008), combines state action with the participation of liquor outlets, media network, private funders, and a host of non-profit groups concerned with monitoring women and eliminating fetal harm.

That many actors are now involved in risk reduction and management practices prepares the ground for competing interests as well as new sites of social action and control (Petersen & Lupton, 1996). Doctors may carve out new territory for their interests by making claims about particular health ‘risks’ and categorizing new objects for intervention (Conrad & Potter, 2000). With recent trends in the medical profession to extend medical authority over ‘health’ itself, doctors are producing a mass of new targets<sup>9</sup> for ‘preventive’ action (Castel, 1991; Clarke, Shim, Mamo, Fosket & Fishman, 2003). For example, women who are designated ‘high risk’ for breast

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<sup>8</sup> See Bach and Rioux (1996) for a more in-depth discussion of the notion of the ‘worthy’ poor.

<sup>9</sup> For example, women who are designated ‘high risk’ for breast cancer in the US are frequently offered toxic chemicals (chemotherapeutics) to “‘treat’ the *risk* of cancer” (2003: 173).

cancer in the US are frequently offered toxic chemicals (chemotherapeutics) to “‘treat’ the *risk* of cancer” (2003: 173). Yet in an interesting contradiction, even as doctors and other professionals extend their domain of observation, intervention, and surveillance (Armstrong, 1995), people are encouraged to practice ‘self-care’ and to manage their own health risks (see also Anderson, 1990).

These knowledge debates on FAS/D diagnoses, discourses on women and children, and constructions of maternal risk and responsibility, do not call into question that women and children (and men, who remain largely invisible in FAS discourses) are grappling in their everyday lives with problems and issues of often serious proportion. These debates do direct attention, however, if we are thoughtful about them, to further queries into the particular ways in which the problems and experiences of women and children are discursively framed and how women are captured and held accountable within those frames.

In keeping with the tenets of neoliberalism that focus on individual rather than state responsibility and control, individuals are expected to take more responsibility in managing their health, but do not gain resources or support in order to do this (Petersen & Lupton, 1996). For those who may appear to fail, for example, poor women with children, they are made preferential targets for intervention activities and forms of authoritative action (Rose, 1996).

## **Part II: What is a medical diagnosis?**

In this section, I shift from my examination of FAS and related discourses and their effects in women’s and children’s lives to explore social sciences literature which consider the dominance of biomedical knowledge and practices in shaping how people gain knowledge of themselves and one another. In the past two decades, researchers working predominantly in the

social sciences<sup>10</sup> (for example, Brown, 1995; Caplan, 1995; Kirk & Kutchins, 1997; Lupton, 1999; Moss & Teghtsoonian, 2008; Rose, 1996; and Smith, 1990a) have published a significant body of work, which is critical of the widespread acceptance of medical knowledge/knowers as authoritative, and illuminates how experts and technological forms of expertise advance a particular world view that frames peoples experiences of health and illness. I use the term ‘experts’ to signify people who are knowledgeable in the authoritative discourses and practices associated with their field. I identify five topics emerging from my reading of this literature, which offer ways to consider the question: what is a diagnosis?

### **1.0 A system of naming**

Medical diagnoses are central to biomedicine, a system for classifying diseases disorders, and problems in daily living (Kihlstrom, 2002). The questions the physician asks, the tests she conducts, the observations he makes are conducted with a specific intent: to determine the cause of problems, symptoms, or what I call ‘variances’ in people’s health, and to designate the appropriate diagnostic category that provides the justification for specific interventions to cure or mitigate the problem (2002). As a foundation for medical intervention, the diagnosis offers certainty and “order on the inherently disorderly human experience of illness, disease, and disability” (Armstrong: 2003: 8).

Biomedicine has been linked to twentieth century western capitalism and its forms of professional dominance and authority (Singer & Baer, 1995). As the biomedical focus on science and biology became dominant in twentieth century North America, allopathic medical practitioners legitimized themselves through claiming to be ‘scientific’ (1995). Within this paradigm, attention to discrete causes of disease is central, a focus which also deflects attention

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<sup>10</sup> Although much of the literature arises in the fields of medical sociology and anthropology, it also includes the work of scholars in fields as diverse as education, history, philosophy, nursing, and critical policy.

from the social conditions that contribute to health or illness (1995). Social scientists, though interested in the construction of medical knowledge have, for the most part, failed to critique biomedicine's foundational assumptions<sup>11</sup> (Mishler, 1981). These assumptions include: 1) a belief in a specific etiology or a model of cause and effect, 2) a view of medicine and, I would add, of medical experts, as 'objective' and neutral, 3) a concept of a universal taxonomy or classification of disease, and 4) the concept of illness as a deviation from biological 'norms' (Mishler, 1981). Here I draw from literature which challenges the first two assumptions. The remaining assumptions are explored throughout these pages.

### 1.1 The search for etiology

The search for cause or etiology has been a fundamental pursuit of clinical medicine (Armstrong, 1983). Until the 1930s, biomedicine was dominated by a search for a single cause, a notion likely arising from the germ theory of the nineteenth century (1983). However by the 1950s, multiples causes, including those concerned with the social environment, were attributed even to infectious diseases. In the case of tuberculosis, for example, experts observed that although the tubercle bacillus is always present in people with the disease, the presence of the bacillus does not in itself necessarily produce disease (1983). Similar observations have been made in the field of FAS/D. These show that even in women who have consumed significant levels of alcohol during pregnancy, only a small number will bear children who can be characterized as FAS (Abel, 1998). Yet despite this finding, the widely held view that alcohol consumption is *the* cause of a 'spectrum' of cognitive, behavioural, developmental, and physical problems in children remains dominant in medical and public policy discourse and practices.

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<sup>11</sup> The other two assumptions pertain to biomedicine's reliance on a universal disease classification scheme and the concept of disease as a deviation from specified biological norms. The construction of 'norms' is discussed later in this chapter.

The work of producing a diagnosis is often tied to a particular perception of cause (Brown, 1995). For example, in their examination of ‘postnatal depression’, Lloyd and Hawe (2003) observe that how professionals frame the problem reflects the assumptions, and practices of their particular discipline, which are often tied to a view of the etiology. In other words, professionals who make use of a biomedical knowledge frame will more likely diagnose the postnatal experience of depression as “innate vulnerability” to major depression, in keeping with psychiatry’s diagnostic criteria, assumptions of cause, and approach to intervention (2003: 1792). Here, the problem of depression is ‘in’ the individual and interventions are directed at treating the individual to either cure or control the experiences s/he is having.

By contrast, an alternate frame of this postnatal experience, such as one concerned with the social under-valuing of motherhood, and the financial and social exclusions that many mothers face, would consider multiple determinants within the socio-economic realm, and likely call for public policy responses concerned with education, child care, and other forms of support (2003). Yet another frame, for example, that of Chinese medicine, would work from a philosophy concerned with harmony and balance and would consider approaches to restoring energy balance through acupuncture, dietary means, and other supportive measures (Duff, 1993). While each of these approaches may be helpful to an individual, those who produce or make use of the biomedical frame are most likely to assert they know the ‘truth’ about postnatal depression and they will, therefore, likely claim that other knowers are biased (Lloyd & Hawe, 2003).

### 1.2 The ‘neutral’ knower

In recent years, researchers – many of whom subscribe to feminist epistemologies, have criticized the assumption that knowledge can be unbiased, ‘objective’ – independent of knowers and they have challenged dominant notions concerning ‘objectivity’ (DeVault & McCoy, 2002;

Harding, 1986; Hubbard, 1989; Poovey, 1998; Smith, 1987; 1990a). Code (1995) characterizes the notion of objectivity, prevalent in both positivist and some social sciences traditions, as one that relies on the “myth of the neutral man”, a detached knower who can represent any-and-everyone’s interests factually and objectively (15).

In Poovey’s (1998) insightful analysis of the social construction of the modern fact, she examines the historical development of a fact as a form of knowledge that is stripped of its ‘knowers’<sup>12</sup>. Poovey traces the history of positivism and the search for scientific impartiality or objectivity<sup>13</sup> in the context of tensions among two dominant groups who assert the value of different methods of investigation and reasoning by either the deductive or inductive streams of reasoning. Poovey suggests that this debate about methods for producing scientific knowledge has not been resolved but, in any case, those who claim that ‘good’ science depends on deducing a scientific formulation or conclusion from a set of ‘facts’ overlook that a ‘knower’ determines which view is to be seen (Poovey, 1998). She argues that the importance of statistics in the modern world, and the conviction that many now hold concerning the value-free nature of numerical representations, signify vestiges of this history of the modern fact and the ongoing pursuit of an ‘objective’ science. However, the issue as Jordan (1997) sees it is not that the claims concerning an ‘objective’ knowledge are correct, but rather that this form of knowledge is the one that counts.

In the fields of epidemiology and public health, there is an increasing reliance on numbers and statistics, which appear to provide objective evidence to support certain claims

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<sup>12</sup> See also Latour and Woolgar (1979) for a somewhat parallel argument concerning the construction of facts in a scientific laboratory, however, rather than in historical debates and enterprises concerning an objective science.

<sup>13</sup> Dorothy Smith (1990a) offers two analyses of ‘objectivity’ – one that takes up this notion of objectivity in which the ‘knower’ or producer of knowledge is written out of scientific accounts. Smith (2005) also offers a critique of the “social relations of objectivity” and of knowledge practices which objectify or make people into objects of study.

about segments of the population – claims concerned with denoting people as ‘risks’ and establishing who poses risks and at what levels (Petersen & Lupton, 1996). Currently, epidemiologists rely on systems for numerically calculating the frequency of childhood disorders and birth defects (Population and Public Health Branch [PPHB], 2002), and for mapping differences in child development across certain jurisdictions<sup>14</sup> (see Hertzman & Irwin, 2007). These and a host of other statistical activities are intended to prevent adverse outcomes in children and to manage the risks of mental health problems, obesity, heart disease, criminality, and those that ‘vulnerable’ children pose to society (2007). While organized under such neutral terms as ‘population health’, prevention, and ‘early childhood development’, these forms of knowledge are also useful for “political arguments and administrative decisions” that help to manage and regulate certain sectors of the population (Rose, 1999: 6; see also Petersen & Lupton, 1966). Indeed, it may be the manner in which the neutrality of this language conveys authority, which makes these discourses so useful for rational arguments. In addition, public decision makers<sup>15</sup> frequently rely on numbers in order to make claims of impartiality and fairness for decisions about resource allocations that might otherwise draw criticism (Porter, 1995).

Health experts have increasingly aligned themselves with biomedicine’s reliance on socially constructed ‘objective’ categories, often in relation to a particular cause (Petersen & Lupton, 1996). The technical work of slotting people into classification schemes such as illness, mortality, and ‘risks’ obscures that people’s experiences so very often do not conform to standardized, predictable ways of knowing them or what causes them to go awry (1996).

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<sup>14</sup> See also Maggi, Irwin, Siddiqi et al (2005).

<sup>15</sup> The current Conservative government in Canada recently drew widespread criticism from opposition parties, scientists, and statisticians for instructing Statistics Canada to redesign the methods of data collection for the country’s census. Critics argued that the elimination of the mandatory ‘long form census’ would negatively impact the scope of social programs and services by eliminating knowledge about vulnerable sectors of the population which are most in need of them.

Categories provide a standardized, “objective representation of events”, which then stands as the authoritative and ‘true’ record of a person’s condition or experience (Timmermans & Berg, 2003:46). The work of naming the category “stakes the claim of expertise”, and also ensures the right of intervention (Armstrong, 1993: 131). In the next section I will explore the ways in which a medical diagnosis operates as the work of experts. I will also explore the ways that relations of power organize their expertise.

## **2.0 The work of ‘experts’**

Jordan (1997) insists that to call a body of knowledge or knowers ‘authoritative’ draws attention to the status of a particular group. Knowledge that is seen to be scientific, objective, and fact-based is accorded higher status than knowledge and knowing that derives from people’s experiences or what people have to say about them (Code, 1995; Smith, 1987, 1990a).

Experiential knowledge, which is assumed to be subjective, is often discounted as biased.

However, Shevory (1993) argues that the scientific generation of theory and “facts” *is* itself a subjective endeavour wherein the social, economic, cultural, and gender status of experts – the ‘knowers’ – is relevant to knowledge production and to shaping whose views are counted and whose are not (103).

In her examination of the historical development of medical knowledge in North America and ways in which medical authority is constituted, Jordan (1997) observes that even in situations where equally legitimate knowledge systems exist, one system frequently gains ascendance and legitimacy through social processes that foster and reflect power relationships. In her analysis of a medically-orchestrated birth scene, for example, Jordan vividly depicts the organization of medical power and authority in a room wherein the hierarchical organization seems “literally unthinkable in any other way” (55). The power of authoritative knowledge



resides in its performance as seemingly “natural, reasonable, and consensually constructed”, while also carrying the risk of powerful sanctions against those who oppose it (Jordan, 1997: 57). Seldom are sanctions needed, however, because people – including patients, other care providers, policy makers, and so on – not only accede to authoritative knowledge and knowers, but are also active in producing and reproducing it (1997).

Drawing on the work of Bourdieu (1977), Jordan (1997) argues that the elevation of one system of knowledge also entails the devaluation of another, such as in the case of allopathic medicine, where doctors are seen to be in charge of “the facts” versus alternate forms of healing practices such as midwifery, which aim for empowerment of women (57). Similarly, forms of knowledge that are not typically supported by western medical experts, such as First Nations healing practices, traditional Chinese medicine (TCM), homeopathy, and Ayurvedic medicine, are generally framed as ‘unscientific’ and their therapies as ‘alternate’ and hence, less authoritative (Moss and Teghtsoonian, 2008).

Singer and Baer (1995) observe that the status that is accorded to biomedical experts has provided for their “monopolistic medical control over an ever growing list of conditions, experiences, and roles in contemporary life” (32). Even where efforts have been made by the prestigious World Health Organization (2000), to shift researchers and policy-makers from a biomedical focus on disease to holistic understandings of ‘health’ and illness which incorporate social life, medical experts remain largely in control of framing and naming diseases as variances in people’s experiences and concerns (see also Kelly & Charlton, 1995; Lupton, 1997).

In western societies, where biomedical knowledge is characterized as authoritative, scientific, and factually or ‘evidence’- based, diagnostic categories and practices are the dominant way to deal with a wide range of problems thought to be located in the body and/or

mind (Schneider & Conrad, 1981). This being the case, it is not surprising that researchers and, I would add, practitioners have difficulty producing or finding alternate ways of understanding people's variances in experiences, particularly in those cases where the problem involves a physical or physiological dimension (1981). That there are social and structural causes affecting health status, including poverty, environmental and workplace hazards, gender, social support and community networks that are integral to people's health and well-being, are also often dropped or obscured by the biomedical frame (Brown, 1995).

### **3.0 Reality versus social construction of a 'problem'**

There is a prevalent view among many social scientists that disease and illness and, therefore, I suggest, the medical diagnosis, are at least as much social construction as physical reality (Brown, 1995; Singer & Baer, 1995). Social constructionists<sup>16</sup> examine how a phenomenon or 'problem' is identified and acted upon, and who the relevant actors and institutions are (Brown, 1995). In this non positivist epistemology, medical knowledge and diagnoses are not derived from observations of empirical evidence in people's bodies or brains, but are produced through a belief system shaped by social and political processes (Lupton, 1997). Inquiry may focus on processes by which a diagnosis evolves, the 'reality' of a phenomenon, and whether social problems are real or the creation of problem-finders (Brown, 1995; Miller & Holstein, 2008).

Golden (1999), for example, presumes that a diagnosis or 'condition' is socially constructed if it has "no existence outside the one created" for it, and reflects cultural norms and values (9). For Schneider and Conrad (1981) however, when a physician makes a diagnosis, s/he

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<sup>16</sup> There are many and competing definitions of social construction. A prominent view is that "social problems" are concerned with social definition – "the hidden world of everyday interaction and definition making" (Brown, 1995:35).

both ‘makes’ the problem and produces a solution to the problem (Schneider & Conrad, 1981). Debates concerning the ‘reality’ of a condition are generally heightened in cases where the condition or diagnosis is a contested or controversial one (Brown, 1995; Moss & Teghtsoonian, 2008).

In her book, *The Making of Fetal Alcohol Syndrome*, Golden (1999) asserts that she does not subscribe to the view that FAS is entirely socially constructed, nor does she hold the view that FAS is a ‘fact’. The former view, she insists, denies “the historical continuities involved in the search to name and understand the subjective experience of disease, difference, or frailty”, while the latter view rejects the “ways in which subjective and culturally rooted experiences shape the interpretation or meaning of a disease or syndrome” (8). In other words, Golden observes that FAS is real because, in some ways, there is a widespread agreement concerning its reality.

When agreement over contested illnesses is achieved, it is often because diverse institutions and actors have engaged in ‘claims-making’ processes (Best, 1987). The work of the claims-maker is to convince others that there is a problem X, a solution Y, and a policy Z that will bring a particular solution (Best, 1987). Once a problem has been identified and medically defined, claims-makers – often consisting of both medical and lay parties – are likely to extend the domain and boundaries of the problem, including the symptoms thought to be associated with the diagnosis (Armstrong, 2003; Best, 1987). Success depends, at least in part, on the interests and resources available to those who are mobilizing the efforts (Best, 1987).

However, claims-making is not always directed at solidifying or settling contested claims. There are, according to Brown (1995) historical discontinuities in both the construction and deconstruction of social problems (see also Clarke et al, 2003). For example, the current

authoritative view, which convinces people that mental illness is a “purely biological phenomenon without social etiology or social exacerbation”, actually marks a re-emergence of biomedical influence (Brown, 1995: 46). In the 1960s and 70s, for example, critical views on medicine and particularly, on mental illness<sup>17</sup>, stimulated a flourishing activism among patients’ rights groups and innovative professionals, who were opposed to strictly biomedical approaches and interventions (1995). However, in the current climate of cuts to programs that support parents, schools, and communities, many families are stressed and distressed and, therefore, along with the powerful influence of the pharmaceutical and research industries, more people are accepting the dominant positivist approach to treat those thought to be mentally ill with pharmaceutical agents (Brown, 1995; Burston, 2006).

Definitions and categories pertaining to health, disease, or health ‘problems’ are subject to debates, negotiations, and revisions, often by groups of experts staking out their claims to authorize their objectified version of people’s experiences (Petersen & Lupton, 1996; Smith, 1990a). Diagnostic categories are also a product of socio-historic forces and changing power relations and, as such, are subject to change (Conrad, 1992). Some medically authorized frames, such as homosexuality, have actually been abolished. For example, in response to intense lobbying by gay rights activists, decision-makers voted to remove homosexuality from the DSM–III in 1973, and, thereby, no longer authorize it as an illness or as pathological behaviour in need of medical or social control (1992).

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<sup>17</sup> For example, see Ivan Illich (1977).

#### 4.0 Practices in ‘social control’

Studies pertaining to ‘medicalization’<sup>18</sup>, a field of research within social constructionism<sup>19</sup>, draw attention to the authority of medical experts to define, categorize, and treat as disorders or illnesses a growing number of behaviours and experiences in people’s lives by redefining the limits of normality in the body or in people’s behaviours (Conrad and Stults, 2008; Clarke et al, 2003; Williams & Calnan, 1996). In the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-IV) (American Psychiatric Association [APA], 1994), experts now categorize and authorize a vast array of human experiences as the objects, not only of medical scrutiny, but also of interventionist approaches for managing them (Lane, 2007). For Conrad and Schneider (cited in Conrad, 1992), that medical doctors have the authority to define and name “certain behaviours, persons, and things” constitutes the greatest form of social control (216). And for writers such as Zola (1977) medicalizing practices establish that medicine is itself “a major institution of social control” (41).

Early critics of medicalization focused on the organization of illnesses and psychiatric categories within the expanding realm of psychiatrists as institutional practices of ‘social control’ (Conrad & Schneider, 1981; Conrad, 1992). Much of the early criticism was directed at Parson’s (1951) conceptualization of “illness as deviance” and medical authority as means of legitimizing and controlling behaviours understood as ‘deviant’ (Conrad, 1992: 215; Lupton, 1997). Deviant behaviour is defined as “behaviour that is negatively defined or condemned in society” (Conrad & Scheider, 1981: 3). A person who fails to conform to established social ‘norms’ may be

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<sup>18</sup> Medicalization is also considered to be analogous to diagnostic ‘expansion’, wherein medical categories become broader and more inclusive in the scope of diagnosable and treatable problems (Conrad & Potter, 2000). However, in the views of Conrad and Schneider (1981), medicalization includes *all* problems or experiences that people categorize in a biomedical frame.

<sup>19</sup> Institutional ethnography has been formulated as a broader project than social constructionism. It includes not only what the notion of construction makes visible, but it also offers a wider analytic light on the ontological focus on coordination (McCoy, 2008).

subjected to a label of deviance and to medical efforts to manage and control it (Appignanesi, 2002).

In her analysis of the social organization of the life and death of a person with AIDS – that of her brother, Jay – Herringer (1998) examines the production of professional and scientific knowledge to show how norms and rules developed in medical and scientific discourses subjugate and objectify people known as ‘homosexual’. She argues that professionals who employ ideological concepts such as ‘deviance’ and ‘normality’, shape how people are known differently from others and, indeed, how they come to know themselves as new and ‘diseased’ identities.

While the term ‘deviance’ appears to have fallen from common use, western society’s decreasing tolerance of *difference* is often aligned with professional practices for identifying and pathologizing a broad range of experiences that are now examined, scrutinized, treated, and managed as problems (Clarke et al, 2003). In her comparative research on the experiences of mothers dealing with the contested diagnosis, Attention Deficit Hyperactivity Disorder (ADHD) in their children, Malacrida (2003) insists that there is now a ‘psychiatrization of difference’ (Castel, 1982) – a decreased tolerance of and increased surveillance over behaviours that were “once accepted as part of the continuum of human possibility” (18). We continue to participate in the social relations of deviance when we mark people as ‘different’ and then speak of them pejoratively (Brock, 2003).

Lane’s (2007) analysis of how experts have transformed the awkwardness and fears associated with ‘shyness’ into a disease category known as ‘social anxiety disorder’, demonstrates how experiences common to many children or adults are now textually rendered as different and ‘pathological’. Lane details the textual work through which experts came to

produce and authorize this disorder in the DSM-IV (1994). Lane also identifies the interests of drug companies and how their sponsorship of influential psychiatrists involved in the construction of the disease category combined to hype an “ordinary, if difficult emotional state like shyness” as something different – “a defect of brain chemistry that had to be treated by drugs” (2007: 6).

While a diagnosis and drug therapy for shyness, even extreme shyness, sounds implausible, one could not have imagined a decade ago, that medicating children with psychoactive drugs would now be a common practice. Over 10 million children in the US and a rising number in Canada are now being treated with anti-depressant medications (Olfman, 2006). Another estimated 4 to 5 million children are prescribed Ritalin in the United States (Diller, 2006). In Canada, an estimated quarter of a million people, the majority of whom are children, are taking Ritalin, or what one doctor calls the “sit down and shut up drug” (Malacrida, 2003: 64), a view that suggests it is a technique for child management rather than treatment.

According to the DSM-IV, children who demonstrate six of eleven behaviours in either of two categories for hyperactivity or inattention have ADHD or what is thought to be a “biologically based genetically predetermined brain disorder mediated by a ‘chemical imbalance’” (Diller, 2006). While there are biologic and genetic contributions to variances in behaviour, the brain-based contribution and, hence, treatment, is often touted to the exclusion of these and any other factors (2006). The consequences for children diagnosed with ADHD, many of whom are being treated with stimulant drugs that have unknown and/or deleterious effects on their long-term well-being and development, are disturbing (2006). While the short-term benefits of calming children – benefits that are apparently equal for any adults or children who use the drug – the long term effects for children are unknown (2006). Diller’s observation, that many

children who are being treated with this drug are treated only during school days offers support to his assumption that the lack of classroom help in school settings is a major contributor to children's challenging behaviours. Diller also observes, however, that American doctors and the public at large may prefer to treat problems of children's behaviour "as reflections of biological and biochemical factors rather than as reactions to an unsupportive, demanding environment" and children's emotional responses to those environments (2006: 147).

However, Armstrong (1983) offers another reading: In his analysis of the expansion of diagnostic names in consecutive revisions of the DSM, Armstrong questions whether the naming of new categories of "school learning problems, adolescent rebellion disorders" and so on are not so much diseases as moral judgments and moral discourses (132). He queries whether these expanding 'behavioural' diagnoses and the concomitant use of medications actually operate as new mechanisms of social control – in practices that take place in sites such as medical clinics and schools (1993). Conrad (1992) observes that one prominent form of social control is surveillance – 'the medical gaze' – which offers the knowledge through which certain people, behaviours, or bodily experiences can legitimately be acted upon.

Drawing from Foucault's views, Potts (2008) observes that women's bodies have been and continue to be a "site of struggle for definition and control" (258). Among bodily experiences that have been transformed into medical categories and objects of medical scrutiny are those associated with women's sexuality (e.g. Potts, 2008), menstrual discomfort (e.g. Ussher, 2008), and childbirth (e.g. Duden, 1993; Oakley, 1984). Similarly, a number of mainly feminist analyses (Armstrong, 2003; Boyd, 2004; Campbell, 2000; Golden, 1999; Keane, 1996; Klee, 2002; McNeil & Litt, 1997; Oakley, 1984; Smith, 1990a,b; Swift, 1995) have critically



examined the medicalization of women's reproduction and mothering and the authority of medical experts to shape women's experiences and/or subjectivity.

In Armstrong's (1993) view, the shift from experiential knowledge to authoritative biomedical knowledge and knowers has taken place on dangerous ground, and signals how knowledge practices exercised in relations of power can serve the interests of the state. For example, medical diagnoses that frame the cause of people's problems in terms of an individual's behaviours, may direct courses of action to various professional, pharmaceutical, or other management sites and release the state from a requirement to act on behalf of the people affected (Kinsman, 1996; Petersen & Lupton, 1996; Smith, 1990a).

### **5. 0 A form of governing**

In Rose's (1999) view, analyses of authoritative knowledge and expert practices for categorizing and medicalizing people's lives convey a false notion of how the medical profession exercises power. Contemporary analyses provide a framework for understanding the extension of medical authority over people's daily experiences, including their subjectivities (Brock, 2003; Clark et al, 2003; Petersen & Lupton, 1996; Rose, 1999; Turner, 1997). These analyses draw, primarily, on Foucault's (1991) writings on 'governmentality', the "approach to social regulation and control" that has, in his view, "dominated political power in western countries since the eighteenth century" (Brock, 2003: 86).

In the development of the modern state, Foucault saw mechanisms of regulation and control that operated, not as top-down state mechanisms, but at the micro level through specific disciplinary practices, such as those of the medical profession in their examination of individuals in their clinics (Turner, 1997). Disciplinary practices function as social and institutional forms of regulation, which provide guidelines that enable people to understand their own bodies and

actions and thereby, to regulate themselves (Lupton, 1997). According to Foucault, the central strategies of disciplinary power are “observation, examination, measurement, and the comparison of individuals against an established norm” which, thereby, bring people into a field of visibility (1997: 99).

Among Foucault’s contributions to critical understandings of health and illness, is his focus on “disease categories as elements of the moral control of individuals and populations” (Turner, 1997:ix). Projects involving moral control – or ‘moral regulation’ are forms of social action “in which some people act to problematise the conduct, values, or culture of others and seek to impose regulation upon them” (Hunt: 1999:1). Moral regulation takes place in and is generated from a variety of social positions not restricted to government activities and sites (Hunt, 1999).

For example, Rose (1999) traces the discursive production of the ‘normal child’ to 19<sup>th</sup> and early twentieth century philanthropic social campaigns and ‘hygiene’ movements in England and France that “elaborated a set of doctrines concerning the [proper] conditions for rearing healthy children” (128). These activities were largely directed at “reconstructing the working-class family” and regulating issues of moral conduct, such as drunkenness, promiscuity, and masturbation, in medical terms (128). Notions of normality about children developed, in particular, around the moral conduct of the ‘troublesome’ ‘recalcitrant’ and ‘feeble-minded’ child. Early attempts to individuate differences among children involved observations and measurements of the body as a means of identifying moral pathologies.

Normalizing discourses and practices are now a central feature of the work of those involved in the modern day human sciences or ‘psy’ sciences, notably, psychiatry and psychology (Rose, 1999). Among the contributions of the ‘psy’ sciences are systems for

abstracting characteristics from a population of children to construct ‘normality’ and the ‘individualized’ and ‘pathologized’ subject that is different from the ‘norm’ (1999). The intelligence test, developed in the early years of universal schooling in England and France, concerned the ‘feeble-minded’ ‘unsocializable’ child, and the social threat he/she – and the adult to be – posed. The object of the test and a later system of psychometric measurements, was intended, in Rose’s view to make individual differences and – I would add – threats visible. Standardized tests have now become “an indispensable part of any modern program” that requires making the individual and her/his differences “knowable, calculable, and administrable” (1999:140); practices which are central features of schools and their functionaries. Standardizing practices must also, conversely, reinforce the authority of those who can apply these authoritative tests and measures.

Rose (1999) extends his analyses of regulatory practices to those in the human science’s who produce normalizing and standardizing practices and discourses that construct the ‘normal’ and ‘abnormal’ child in terms of her/his behavioural development. A developmental norm is “a standard based upon the average abilities or performances of children on a certain age on a particular task or activity” (142). Discourses on children who ‘fail’ to meet the developmental ‘norm’ for their age make particular claims of truth that demand our attention (pp. 142-4).

Gesell’s (1950) pioneering work in child development involved assessments of children who were having learning problems in school. His measures of normal/abnormal development relied on observations and documentary evidence that quantified and standardized children’s accomplishments or deficiencies according to discrete measure of time. Rose insists that his and similar measures of ‘normal’ development continue to instruct the diagnostic and assessment

practices of professionals as well as the fears, anxieties, and hopes of parents – particularly mothers, who are instructed, and I would add, measured and judged against such norms.

In his detailed analysis of the practices of psychologists, Rose (1999) argues that institutions such as schools and clinics, that require “co-ordination of large numbers of persons”, have made children favoured targets for assessment techniques – methods of observing, examining, measuring, sorting, and registering human differences (136). Rose observes that psychologists make claims to having expertise in measuring children’s behaviours and aptitudes, managing their individual variations conceptually, and categorizing them. These ‘disciplinary’ methods are practices of power which take the “unpredictable complexities of human” experience, rank them against a discursive norm, and thereby ‘make’ ‘normal’ or abnormal individuals (pp.135-137; Brock, 2003). The subject, reproduced as a ‘normal/abnormal’ object conceived in variabilities plotted as points on a curved line, is treated as a fact (Rose, 1999; Smith, 1990a). Despite some opposition to the practices of producing ‘norms’ and ‘normalizing judgements’, every institution concerned with disciplining, training, and regulating individuals, relies on practices of ‘normalizing’ that simultaneously homogenize and objectify people, while also constructing some of them as different (Foucault, 1977).

## **6.0 Chapter Summary**

Two primary questions have guided my work in these literature chapters: *What is FAS?* and, *What form of knowledge is a medical diagnosis?* In exploring these questions, as distinct from trying to ‘answer’ them, I have examined the authoritative FAS literature to reveal the early history of the diagnosis, the knowledge claims, and trends in the development of its ‘science’ to the present day. I have also reviewed the growing body of work by critical researchers who have examined the claims, discourses, and some of the social institutions which have shaped the

diagnosis in its present form. Among these varied bodies of work, three central themes emerge: contestations, ab/normalizing practices, and institutionalized practices for managing and controlling people's lives.

Despite major advances in biomedical science, increasing levels of expertise among medical practitioners and researchers, and the expansion of medicine into allied fields of public health and epidemiology, medical diagnoses and practices remain contested. Many of the revisions I traced in the FAS field emerged as efforts to make the diagnosis and diagnostic practices more authoritative, and thereby, to dispel controversy. Contestations and controversies are not confined to the medical diagnosis of FAS and its series of revisions to the current FAS/D umbrella. They include a growing number of medical diagnoses which apply to variances in people's bodies, brains, and behaviours. At various times in history, similar practices have constructed groups of people as 'normal', 'abnormal', and even 'deviant' or criminal. The boundaries for experiences, previously thought to be 'normal', are shrinking and it is around these changing boundaries that many of the debates over what counts as 'real', imagined, or socially constructed, are most strident.

The literature makes apparent how the diagnosis and medical practices import and obscure moralizing assumptions and judgments that have marginalized and continue to marginalize certain groups of people. During the course of histories I traced, with the aid of Castel, Rose, and others, it became evident that among the most marginalized are people who are poor, thought to be cognitively deficient, women, and peoples of certain racialized designations or bodily characteristics. In Canada, Aboriginal people have been abused, mistreated, and continue to be marginalized, in part, because of their perceived differences. Tait's (2003) eminent research traces the impact of colonial practices on the lives of Aboriginal people still

today. Rose (1999) reveals how discourses and practices for constructing people as ‘risks’ may be perceived as a new, more benign form of marginalization but their effects can be malignant.

While programs for dealing with people’s troubles may issue from the state or involve legislation, often they are formulated in or arise from a professional group, workers, parents, social movements, or community action groups (Petersen & Lupton, 1996). In other words, there is not a single or ruling authority seeking to establish control over people’s lives. There appears to be, as Li (2007) suggests, a series of disparate assemblages comprising a medical ‘regime’ or complex, of which medical authority and expertise are but a part (Lupton, 1999). In contrast to the notion that the medical profession is ‘medicalizing’ people’s lives, my contention, drawn from this body of literature, is that a complex of discourses and work practices come into play which, while intended to help women and children, are also aimed at maintaining social order (1999).

While some of these practices are helpful, and even sought after, they warrant further inquiry into how objectifying forms of knowledge continue, in our present day, as practices that may also be oppressive. Relying on punitive approaches undermines efforts to develop effective responses to problematic aspects of substance use during pregnancy (Flavin & Paltrow, 2010). Similarly, constructing children, for example, as ‘irreversibly brain-damaged’ does not allow for alternate knowledges which support and build on people’s strengths while also valuing their differences. My inquiry problematizes objectifying knowledge and how it actually works in people’s lives. My contribution to the literature is aimed at offering an alternate knowledge about the lives of women and children who are placed under the FAS/D umbrella. In the next chapter, I introduce key elements of the methodological approach which guides my inquiry.

## Chapter Four

### Institutional Ethnography: An alternative Sociology

*Writing the social is always from where [we] people are (Smith, 1999: 8).*

#### 1.0 Introduction

Scholarly research is guided by certain theoretical perspectives and the assumptions implicit in them. Within the theorized approach or methodology, are philosophical principles that direct the research in two major areas: 1) ontology, which addresses the question, “What is the nature of reality?”, and 2) epistemology, a theory of knowledge which asks, “What is the relationship between the inquirer and what is known?” (Denzin & Lincoln, 1994: 13; Smith, 2005). I use the term methodology to refer to “a theory and analysis of how research should proceed”, while method provides the techniques for gathering data (Harding, 1987:2). Theory and method are therefore inextricably intertwined.

Institutional ethnographers assume that the social is real and can be interrogated (Smith, 1987). Smith’s (1990a) ontological and epistemological commitments have been to develop a paradigm that “opens up inquiry into just how people’s activities are socially organized to suppress their presence as actual subjects” (46). My theorized approach to discovering and explicating the social organization of everyday experience relies on an ethnographic method that begins in women’s everyday work. The project is to map connections between their everyday world and the institutional processes (Campbell & Gregor, 2002).

Maps are always ‘indexically’ related to actual territories. Analogously, institutional ethnography’s project of mapping institutions always refers back to an actuality that those who are in it know (the way that the phrase YOU ARE HERE works on a map”. (Smith, 2005:226).

Institutional ethnography's interest in discovery broadly situates the inquiry in the qualitative domain. Although Smith does not describe her work as a qualitative method, institutional ethnographic projects can often be found or referenced in qualitative research texts (see for example, May, 2002). In general, qualitative methodologies, like institutional ethnography, invite a process of discovery, emphasize the value of people's experiences, and locate their experiences in context (Driscoll & McFarland, 1989). However, as I will show, institutional ethnographers treat 'experience' differently than other qualitative researchers.

Institutional ethnography employs a distinctive language – specific terms that signify its methodological features. As a stylistic device, I use single inverted commas to initially designate a particular or methodological term. In this chapter, I identify the theoretical underpinnings, which are the pivotal analytic tools relevant to this inquiry, and I describe my methods of data collection and issues pertinent to my field work. I begin with an overview of institutional ethnography in keeping with Dorothy Smith's formulation of it as an 'alternative' sociology.

## **2.0 An alternative sociology**

Institutional ethnography is a feminist, materialist research approach, an 'alternative sociology', a term which Smith uses to signal her departure from mainstream<sup>1</sup> sociology. Established sociology, the discipline in which Smith had been teaching at the time she was also raising her young family, was a male-dominated field, and also dominated by ways of thinking and writing about people and the world that carry relations of ruling (Campbell, 2003). Smith's analytic work began to demonstrate that the conceptual work in sociology was male-oriented, and depended for its achievement on a stable domestic world untrammelled by responsibilities that men – unlike women – could take for granted (2003). What Smith (2005) saw as an

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<sup>1</sup> Smith (2005) employs the term, mainstream sociology in reference to general and defining sociological practices that accede to the dominance of concepts and theory.



overriding interest in concepts and theories was, for sociologists, a stated aim (53). Established sociology, Smith (1987) argues, has “objectified a consciousness of society and social relations that ‘knows’ them from the standpoint of their ruling and from the standpoint of men who do that ruling” (2). In practices of ruling, the forms of consciousness created are “properties of organization or discourse”, rather than those of individual subjects (1987: 3). Smith learned from Marx not to treat this conceptual world as given but, rather, to interrogate the ideological practices that subordinate local knowing and knowers (2003).

Smith (1987) employs the term ‘disjuncture’ to identify the preponderant trend in sociology (and other forms of social and scientific endeavour) to construct abstract or discursive accounts of people’s experiences which categorize or represent the material realities of everyday life. The textual representation (account) is not articulated to the actual experience, where the ‘actual’ refers to the world outside the text, the everyday world in which we live (2005).

Smith (1987) identified a disjuncture in her own life and consciousness – a ‘bifurcated consciousness’ – as she moved between her ‘embodied’ knowledge in her work of raising a family and her conceptual world as a woman academic. She recognized in her work as mother and homemaker that, in established sociology, she too was part of a textually organized world of ruling where women were objectified – made ‘objects’ of study. In the objectifying features of sociological work, Smith saw problems for women in particular, who have not been adequately represented by the authoritative knowledge that claimed to be speaking about them (Campbell & Gregor, 2002). In addition, the embodied ways of knowing Smith engaged in during her everyday activities as a wife and mother – feeding the family, caring for children and so on – were not recognized as a legitimate way of knowing in the academy (Campbell, 2003).

Active in the North American women's movement of the 1960s and 70s, Smith (1987), like other feminists writing at the time, identified women's exclusion "from the intellectual, cultural, and political world" (1). Among Smith's unique contributions is her critique of the hegemony of established sociological discourse and of women's exclusion from authorized knowledge and ways of knowing (Campbell & Gregor, 2002). In her 1987 book, *The everyday world as problematic*, Smith produced a vivid and captivating account of the historical silencing of women where, in texts and in the contexts of socially organized gendered relations, women are objectified and their work, knowledge, and contributions are devalued. Smith's feminist analysis of the subordination of women's knowledge and work contributed to her distinctive formulation of 'the social organization of knowledge'<sup>2</sup> (Rankin, 2004). Her analysis recognized how ideological procedures cancel the subjectivity of the knower, and thereby, move knowing to an abstract world, separate from the world that people live and experience (Campbell, 2003).

Smith's (1990a; 1990b) feminist sociology is not intended, however, to take up gender as a concept, but rather "to take up gender from within, exploring the particular local historical sites of women's experience" (159). Smith's proposal for a method of research that generates an alternative sociology relies on her ontological commitment to investigating social life in terms of how women's experiences are actually organized (1987). Drawing on institutional ethnography's roots in ethnomethodology, the researcher reflects critically on what people know and do from an embodied place – in their everyday experience (Campbell & Gregor, 2002).

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<sup>2</sup> 'Social organization of knowledge' is not unique to this methodology. McCoy (2008) observes that "nearly all of institutional ethnography's orienting concepts are drawn from existing sociological vocabularies but used in distinctive ways" (713, fn4).

Smith's (1987) mode of inquiry has expanded awareness of the 'gendered subtext' of the relations of ruling as well as of other forms of exclusion on the basis of race<sup>3</sup>, class, and other categories through which inequalities are organized. For Smith, categories such as class "do not appear as external determinants but rather as social relations" that organize and coordinate our experiences (36). In her book *Institutional ethnography: A sociology for people*, Smith (2005) observes that her original conceptualization of her method as a sociology for women has to work for both men and women as a sociology in which people are not objects. Smith has insisted on a method of research that "would produce knowledge *for* women" and other people, rather than knowledge *of* them (DeVault, 1999: 47). Analysis must, therefore, be grounded in a material, socially organized world (1999).

Smith (1987; 1990a; 2004) credits her readings of Marx and Engels as profoundly influential in the development of her materialist method. Marx and Engels held that consciousness is derived from and cannot be separated from the "real-life activity of actual people" (2004: 448). Their premise was that inquiry begins in people's activities under material conditions, not with abstractions or categories (2004). Institutional ethnography's ontology is a social that can be analyzed "as the ongoing concerting of actual practices of actual individuals" (Smith, 1987:125).

George Smith (1990) observes that the basic premises of this materialist, alternative method, contributed to an 'ontological shift', which moves from theorizing to investigating the everyday world as actual practices. Smith's scholarly goal has been to innovate a way of knowing – a standpoint – that, while not taking the everyday world at face value, offers

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<sup>3</sup> Race is a contested term. Eighty-five per cent of distinctive genetic variations are actually accounted for by differences between individuals, rather than between groups of people that used to be called 'races' (Brady, 1995). For institutional ethnographers, the concept 'race' or 'racial' are not properties of individuals or groups but are features of social and ruling relations.

explication of how it works, thus maintaining a central interest in the experiencing subject (Campbell & Gregor, 2002).

### 2.1 'Women's standpoint' and experience

Women's standpoint offers both a methodological position and a theorized view of experience as a place to begin an inquiry (Campbell & Manicom, 1995). Experience provides a real-life context in which the researcher can discover ruling in the bureaucratic, governing, administrative, and professional practices that organize people's lives (1995). Smith's conceptualization of women's standpoint, problematic (Chapter One), and experience are methodological devices for beginning with the subject and her experiences in order to discover the social and ruling relations that organize them. Smith (1990a) insists that by "taking up a standpoint in our immediate knowledge of the world", in experience, the researcher makes observable and problematic the social organization of that world (23).

Theorizing links between knowledge/knowing and experience has been a central concern for those working on feminist methodologies (DeVault, 1999: 38). For Smith, it has resulted in praise for her as one of the key standpoint theorists contributing to feminist epistemologies (Harding, 1991). But there has been criticism as well. For example, both Scott (1991) and Hekman (2004) challenge the concept of experience as a basis for inquiry and question the reliability of experience as a kind of 'truth' when, as Scott insists, experience is itself discursively organized. However, Smith (2005) refutes the critique and points out that institutional ethnographers do not use people's experiences to make authoritative statements about them, posit 'truth', attribute meanings, describe their "lived experience", or offer people's points of view. Smith argues that, while truth "may be an illusion it is nonetheless possible – and urgent – to investigate and describe the relations that put our lives in place" (Campbell &

Manicom, 1995: 5). Beginning in the everyday “is not to claim the character of ‘experience’ as ‘real’, but rather to trace how everyday life is oriented to relevancies beyond the particular setting” (1995: 8).

In challenging postmodernists/poststructuralists who criticize her work, Smith (1990a) insists that they fail to notice institutional ethnography’s interest in experience as a site from which to discover social organization. Institutional ethnographers give voice to experience as a rich source of understanding people’s lives and the diversities of people’s experiences (2005). Women’s standpoint is not that “women know better” by virtue of their experiences, but that a point of entry to investigation “is superior to the starting points derived from abstract theorizing” (DeVault, 1999: 39). Beginning in a standpoint in experience rather than in theory or discourse, replaces the traditional authority found in texts and, thereby, provides knowledge of the everyday world that can be trusted (Campbell & Manicom, 1995).

My commitment to a method of inquiry grounded in women’s standpoint and women’s experiences is crucial to my own interest in activist research – taking the side of people who are marginalized or oppressed. Mueller (1995) observes that the standpoint of women is central to problematizing experiences of oppression arising in the everyday world:

[standpoint] positions the researcher at precisely that moment at which people’s ordinary, everyday lives are touched by the discourses and disciplines of domination which powerfully shape (but do not determine) them... This beginning place is particularly significant for ‘it is from the perspective of the most oppressed – i.e., women who suffer on account of class, race, and nationality – that we can most clearly grasp the nature of the links of the chain of oppression and explore the kinds of actions that we must now take’ (Sen & Grown, 1987: 20 cited in Mueller, 1995: 96-97).

Taking the standpoint of women and children who are made known as FAS objects insists on an inquiry that examines and explicates the ordinary, taken for granted practices that subdue women and children as subjects with diversities in their experiences. Inquiry must begin in their lives, and for that, I turned to an exploration of women's and children's work.

## 2.2 Work

Institutional ethnographers expand the usual notion of work – something people are paid for – to “include anything that people do that takes time, effort, and intent” (Smith, 2005: 225). Smith's (2005) ‘generous notion of work’ focuses the inquiry on what women do and also on the social and gendered relations that organize women's work and people's devaluing<sup>4</sup> of it. By following women's engagement in different forms of ‘helping’ work in the setting, I also detail the extensive and multi-faceted nature of the work women must do to manage and feed their children. I show how even a woman's effort of ‘waiting in line’ is, and must be recognized, as work. I also note that children's play activities, accomplished with much effort and intent, are children's work.

Smith (1987) observes, however, that our concern as inquirers is not so much “to mark a distinction between what is work and what is not work, but rather to deploy a concept that will return” our focus to what people do under definite conditions and situations (166). The actualities of women's and children's work express the social relations in which their work is embedded. Much of my study is focused on the social organization of women's work (the interplay of social relations). Through observing children's daily activities, I also discover social organization in what children do in this setting.

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<sup>4</sup> Marilyn Waring (1988) has written eloquently on the restrictive nature of institutional accounting practices, such as those employed by the World Bank in their estimates of ‘gross national product’ (GNP) and ‘gross domestic product’ (GDP), which fail to recognize the massive economic value of women's low wage and unpaid work.

Institutional ethnographers will often employ the term ‘work processes’, which underlines the research interest in two levels of data 1) work as practical activities that are anchored in material conditions and real time and 2) the trans-local relations (or ruling relations) that coordinate the everyday activities (McCoy, 2006). The term work processes is a reminder that everyday work – what informants actually do – includes the concerting of those activities (the organization of everyday life).

To begin an inquiry in women’s work and in women’s standpoint also “begins where women are socially located and explores how their worlds come into being for them” (Mueller, 1995: 96). In my inquiry, objectifying forms of knowledge and practices coordinate mothers’ and children’s work in the setting and as I show, subsequent sequences involving professional work processes for constructing the objective account of them. As I examine women’s participation in activities in the centre, I am also examining the social organization of their work and the social relations embedded in their work. My method of inquiry assumes a “socially organized world where anyone’s experience is intimately connected to their work of bringing into being the world as they live it” (Campbell, 2003: 18).

### 2.3 Social relations

Although my inquiry begins in people’s experiences – my aim is to make visible as social relations the extra-local coordination of people’s activities and experiences (Campbell & Gregor, 2002). Social relations must be understood and recognized as material and observable – actual actions carried out in real time (2002). The term ‘extra-local’ also emphasizes that social relations are interconnected activities involving the actions of many people in different times and locations, actions which continue after those directly involved have done their part (2002).

Historical processes are embedded in social relations (1990a; 2005). Smith (2005) shows, for example, that historical forms of subordination, such as those practiced in European imperialist institutions, relied on determinations about physical traits which have also “translated historically into the racism of postcolonial society”:

We participate in the ongoing historical commitments of the social relations organizing racism in our everyday lives, and how we know each other arises from and builds upon a past that is coming into being in the present and projects into the future (62).

Smith’s (2005) insistence on recognizing the social relations of ‘racism’ (in this example) as actual practices grounds inquiry in the material world. The actions are both here and now, but they are not confined to this time or place (Smith, 2005). The social relations organizing racism in a particular place or time involve different moments of interdependent and interconnected courses of action to methodically accomplish the social phenomenon. It is the here and now of the setting that the researcher must interrogate.

Drawing on these formulations of social relations directed my examination and discovery of the social organization of women’s and children’s work. When I entered the setting as an observer, I heard talk and saw activities that offered clues to the social relations. Something was happening to organize the particular forms of talk and FASD prevention activities within it. My reflexive<sup>5</sup> approach to my data allowed me to query: how are these experiences shaped by social relations that are in but also extend beyond these immediate experiences? For example, when I observed women’s work with a consent form routinely used in the setting I asked questions about it. Further questions and observations enabled me to identify how this text activated sequences of action tied to institutional practices concerned with children’s health ‘risks’. The

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<sup>5</sup> Reflection and reflexivity are often intertwined, in my experience. For more on reflexivity, see Chapter One and later in this chapter.



social relations and practices already present *in* the setting made particular courses of action involving women and their children possible and actual. Social relations can be mapped to reveal the ways that “many individuals and many individual courses of action” play a vital part beyond any individual’s full awareness (Smith, 1990b: 124).

My work has been showing that while routine interactions, such as women’s work with a text appear to just happen, people actively constitute social relations “as they act competently and knowledgeably to concert and coordinate their own actions” with such things as organizational rules and expectations (Campbell & Gregor, 2002: 31). The concept of social relations enables the researcher to “explore how action and experience” are tied into institutional forms which coordinate them (Griffith and Smith, 2005: 17). I am directing attention to the relations of ruling<sup>6</sup>.

#### 2.4 Ruling relations: bringing the ‘institution’ into view

‘Ruling’ refers to the “socially-organized exercise of power that shapes people’s actions and their lives” (Campbell & Gregor, 2002: 32). In their formative work, “Knowledge, Experience, and Ruling Relations”, Campbell and Manicom (1995) bring together a number of institutional ethnographic projects to show how ‘experience’, ‘the social organization of knowledge’, and ruling are inextricably bound. Inquiry is “concerned with how lived experience is governed and administered – socially organized – and how that organization is achieved and mediated, particularly through texts” (17). The authors and their collective works offer insights into how ‘ruling regimes’ of administration and control rely on specialized knowledge and objectifying knowledge practices to accomplish ruling.

Smith’s (1990b) concept of ruling originated with Marx, and relies on a materialist

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<sup>6</sup> At times, I use the terms social and ruling relations interchangeably because, as Campbell and Manicom (1995) observe, for the most part, “social relations are typically relations of ruling” (: xii).

ontology that depends on “the actual practices of actual individuals”<sup>7</sup> (6). ‘Ruling relations’ direct the researcher’s attention to the ‘actual’ – the world outside the text – to the socially organized practices, which produce and coordinate knowledge in objectifying and standardizing forms (Smith, 1990a; 2005). These knowledge practices can be shown to be ‘ideological’ because they “confine us to the conceptual level” and suppress the “presence and workings of the underlying relations they express” (1990a: 37).

Ruling practices are vested in texts and carry ruling relations (Smith, 2001). I draw from my ethnographic work to demonstrate how people, conducting professionally accountable work, both participate in and enact ruling (Campbell & Manicom, 1995). I turn to Schellenberg’s (2003) research into the social organization of access to services for ‘children with special needs’ in British Columbia (BC) schools, a study that is also relevant to textual practices I discover in my present analyses. The study focuses on the social organization of teachers’ work as they conform to government mandated requirements for determining eligibility to funding for children with ‘special needs’. The project demonstrates how objectifying forms of knowledge are produced in the “socially organized practices and relations” (Smith, 1990a: 66), which are expressed in that concept of knowledge, in this example, that of *special needs*.

I first discovered traces of ruling knowledge in the language a teacher used when she talked about the children in her class. As one of my informants talked about the children, she first drew on her experiential knowledge to explain that all the children in her class needed extra help. “All of them have special needs”, she explained. For example, some children arrived at school hungry, others appeared too tired to attend to their lessons, this one was in distress, these

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<sup>7</sup> Campbell and Gregor (2002) observe that Smith (1990b) names practices of domination and subordination (ruling) in regard to contemporary times, not to Marx’s. Ruling practices coordinate us all, including today, “with the interests of capital in ways that are quite different from Marxist analyses of class oppression” in nineteenth century capitalism (2002: 39). Current practices of ruling are more in line with capitalist business practices of management and governance (2002).

two couldn't sit still, and others struggled with their school work. In contrast, when she began to describe which children received extra help, she identified some of the children as "1701s". This disjuncture between a teacher's experiential knowledge of the children and her objectified way of talking about them in this mystifying way as *1701s*, offered a topic for investigation.

My analysis in that earlier work details the extensive work processes teachers undertake preparatory to 'writing up' children into a Ministry of Education (2007) form, *Form 1701*. *Writing up* includes all the ruling work that teachers must do to access public funds to help these children. Darville (1995) suggests we can understand writing up as the textual work of entering [children] into an organizational process that accomplishes ruling interests, as opposed to "writing down" or relating back to experience (254).

The work processes I discovered relied on teachers 'fitting' children into certain categories of 'need' listed on a text called *Form 1701*. The Ministry of Education (2006) allows eligibility to funding for only certain categories (and by default, certain children) such as "autism" or "moderate to profound intellectual disability", whereas other categories, such as "fetal alcohol syndrome" were not allowed<sup>8</sup>.

The government's accountability processes ensure that teachers' work of accessing funds is orderly, standardized, and objective, based on rigorous tests and measures. The children who finally gain access to special needs funding are children that teachers must make known in this standardizing way as *1701s*. Being known as *1701s* is an administrative term that articulates children and teachers to ruling practices, including those of rationing resources. Administration offers tools that are useful to objective decision-making, particularly, when it comes to scarce

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<sup>8</sup> That there was, at the time, no category for children with FAS was a point of contention and advocacy, particularly, for many adoptive parents. My present inquiry reveals how institutional work processes for dealing with FAS/D categories have been adjusted (see Chapter Nine).

resources, however, these same tools also over-ride people's experiences and impose limits on people's best efforts to help (Darville, 1995).

The Ministry's (2007) practice of creating its own hierarchy of knowledge, organized through the categories that make certain children known as 'special need', will ensure that teachers' experiential knowledge of children is discounted. Teachers' knowledge is subjugated to the administrative requirements for knowledge in objective, standardized forms, which *Form 1701* requires. This study on ruling requirements, whereby teachers must 'fit' children into categories, is pertinent to institutional work processes I make evident in my present inquiry.

While it may not be their intention, as people go about their professional, textual work, they rely on specialized knowledge and administrative practices which accomplish ruling. As Smith (1990a) reveals, proper and accountable work relies on text-mediated practices:

I refer to that total complex of activities...by which our kind of society is ruled, managed, and administered. It includes what the business world calls *management*, it includes the professions, it includes government and the activities of those who are selecting, training and indoctrinating those who will be its governors. (Smith, 1990a: 14).

Ruling also involves the complex of discourses, including those that are scientific, technical, cultural, educational, or professional, that "interpenetrate and coordinate the multiple sites of ruling" (Smith, 1990b: 6). Discourses, too, are text-mediated practices – a topic I return to – and as such, they are central to institutional and organizational work.

Smith (1987, 2001; 2005) also develops her discussions on ruling relations through her use of the terms 'institution'/institutional. As Smith (2001; 2005) conceives it, 'institution' does not refer to a particular organization, since both "organizations and institutions exist only in actual people's doings" and people actually produce them in the course of their everyday (2001:

163). *Institution* directs the researcher's attention to "clusters of text-mediated relations organized around specific ruling functions" such as those found in education, health care, law, and so on" (DeVault & McCoy, 2002: 753; Smith, 2005). While health care, for example, may be delivered in an organization or setting such as a school, clinic, home, pharmacy, or agency – health care as an 'institutional complex' brings into view a nexus of coordinated and intersecting text-mediated work activities in and across multiple institutional sites (DeVault & McCoy, 2002). This notion of an 'institutional complex' has been particularly useful in regard to my discovery of the diverse interests and practices associated with FASD operating not only in health care but also, as I will show, in other institutional sites.

### 2.5 Texts and textually-mediated knowledge

Texts and textually-mediated forms of knowing are central and indeed, indispensable to institutional and ruling work (DeVault & McCoy, 2002). The usefulness of examining texts derives from what they reveal about how different forms of knowledge hold a place in shaping our lives. Texts appear to be simply collections of information intended to inform, instruct, or guide direction toward a specified outcome, however, texts are not inert (Smith, 1987; 1990b; 2005). Smith<sup>9</sup> coined the term, "text-mediated social organization" to express the notion that people's engagement with texts also concert and coordinates their actions (Campbell & Gregor, 2002: 29). The relations of ruling are investigated as those forms of extra-local (as well as trans-local) textual coordination "in which power is generated and held in contemporary societies" (Smith, 1999: 79).

Texts are present and active "at that key juncture between the local settings of people's everyday worlds and the ruling relations" (Smith, 2005, p. 101). Smith's (1990b) interest in texts

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<sup>9</sup> A field of ethnomethodology developed by Garfinkel has informed Smith's view of the text as organizing and coordinating courses of action (1990b; 2005).

as “constituents of social relations” references their distinctive coordinating features in the social relations of which they are a part (11).

These investigations of texts do not constitute them as a realm of meaning separated from the world they are written and read in. Rather, texts are taken up as constituents of ongoing social relations into which our own practices of reading enter us (11).

Here, Smith’s (2005) concept of a ‘text-reader’ conversation recognizes that reading a text is an actual interchange between a reader and a text, one which takes place in a local setting and involves a particular person (Smith, 2005). One side of the conversation is established by the text; as the reader becomes compliant to the text’s intended use, the text organizes what can be responded to as the reader ‘converses’ with it (Campbell & Gregor, 2002; Smith, 2005). The reader activates the text, and thereby, becomes the text’s agent (2005). The ‘text-reader’ conversation makes it possible for us to see how “the text, activated by a reader”, participates in the sequence of actions that constitutes a ruling relation (2005).

A study conducted by Campbell (2001) uses observations from an assessment interview to reveal how a nurse’s own practice of working with a text activates a ruling relation. ‘Activation’ refers to “the human involvement in the capacity of texts to coordinate action and get things done in specific ways” (Campbell & Gregor, 2002: 33). The study shows how the nurse, as a long term care case manager, employs the Health Authority’s assessment form to determine client needs and the appropriate level of services and public subsidy for the client. The analysis explicates how the form structures or mediates the interaction between the nurse and the client, inserting the Health Authority’s interests in determining ‘needs’ over other interests (2002) such as the client’s desire to talk about his difficulties. Determinations of need are not neutral (Stone, 1988) and as the study demonstrates, the text draws both the nurse and the

client into a work process that constitutes ruling relations (Campbell & Gregor, 2002). The nurse, through her reading of and working with the text, participates in the social relations of ruling while at the same time she too is ruled, as evidenced by the imposition of the text on her nursing work. Institutional ethnographers can discover how texts and textual work processes mediate ways of knowing. As Campbell et al.'s (1999) study shows, the client is known by the assessment form and by what the form – and those who activate it – organize as authorized and official knowledge about him. The text coordinates 'this' way of knowing the client and his needs, ensuring that how he is known is replicated the same at this site and others (Smith, 2005).

It is the materiality of the text and its replicability in identical forms across many different sites on a large-scale, which are also fundamental to social and ruling relations (Smith, 1999). The socially organized forms of knowledge produced in one institutional site, are 'packaged' in texts, which then transmit and replicate these forms in multiple far-flung sites (1999). I provide an example of a prominent diagnostic text that reveals how this form of packaging and replicating works.

Until a few years ago, the electronic version of *The Diagnostic Guide for FASD: The 4-Digit Code* (Astley, 2004) (or 'Guide') had to be purchased. The University of Washington FAS/D Diagnostic Centre's web-site, which produced it, offered a sample web-site of the text, and advised that the full text could be purchased for approximately eighty dollars from the university. However, for some time now the complete 122-page text has been available on the web-site accessible to anyone. The *Guide* now coordinates work practices in multiple and trans-local sites.

In her analyses of texts, Smith (2001) refers to the notion of 'intertextuality', or how one text cannot be isolated from a complex of other texts in organizational settings. One

organizational text “is embedded and implicated in and refers to the multiple texts that co-ordinate people’s” knowledge practices in a variety of organizations and settings at different times with the work of others similarly co-ordinated (Smith, 2001: 187). For example, the *Guide* has been incorporated into the development of the *Fetal alcohol spectrum disorder: Canadian guidelines for diagnosis* (Chudley, Conroy, Loock, et al, 2005) and directs diagnostic work in many FAS diagnostic sites British Columbia. Drawing on the notion of intertextual coordination of peoples’ work practices enabled me to discover through my reading of another text (see Chapter Eight) how the *Guide* also coordinates diagnostic work involving women and children in my research setting.

The “social relations based on texts transform the local particularities of people, place, and time into standardized, generalized” and trans-local forms of coordinating (Smith, 2005: 101). As I examined diagnostic texts, and listened to text-mediated discourses on FAS, I understood how these transformations are useful to the professional and administrative forms of work that must be accomplished. They create a ‘textual reality’, an objective version of ‘what is’ that is independent of particular subjectivities or knowers (Smith, 1990a).

The ‘objective’ forms of knowledge that professionals and other human service workers have of clients or of children and their problems<sup>10</sup>, must conform to the standards, discourses, and accountabilities expected of people working in bureaucratic and other human services organizations (2005). The textual reality of demographics, such as a birth, for example, strips birth from women’s experiences. The individual is entered in records as a statistic or a ‘case’ depending on the context (1990a). The records or histories “provide material that is entered into professional and academic discourses” usually as a representation of “the object of their knowledge” (1990a: 89). The objectifying practices which construct children as FAS objects

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<sup>10</sup> Here even the use of the term ‘problem’ orients the reader (and writer) to a organizational discourse.



produce objective accounts of children – and their mothers – which isolate them from their experiences in order to render an ‘objective’ account of their problems and the cause of them.

To further understand texts, and Smith’s critique of how ruling is accomplished, I turn to Smith’s (1987; 1990a; 1990b; 2004; 2005) formulations of those objectifying forms of knowledge and practices she calls ideology and discourse.

## 2.6 Knowledge for ruling: Ideology and discourse as practices

Ruling relies on specialized knowledge and on generating forms of knowledge that are useful to ruling practices (Campbell & Manicom, 1995). In section 2.4, I introduced Smith’s (1987; 1990a) assertion that objectifying or ‘ideological’ practices put in place the forms of knowledge useful to systems for governing, management, and control. In knowledge that is useful for ruling, the “presence of the subject and the subject’s interest in knowing [must] be cancelled from the ‘body of knowledge’ as a condition of its objective” and authoritative status (Smith, 1990a: 34). When text-mediated “knowledge production leaves behind what people know and becomes authoritative”, the objective knowledge frame which is put in place also forms the basis of people’s subordination (Campbell & Manicom, 1995: 9). Ruling forms of knowledge silence experiential accounts and thereby, alter irretrievably and subordinate in the process, “the experience of the subject about whom the professional was initially concerned” (Campbell & Manicom, 1995: 10; original emphasis).

The important point, therefore, is not the “critique of objectification itself, but the relation” it promotes and assumes between people’s textual work and ruling processes (DeVault, 1999: 47). This relation, which detaches the knower from what is known, supports an ideology, a ruling conceptual structure (Smith, 1990a).

### 2.6.1 Ideology

The term ideology is commonly used to describe systems of beliefs, values, or biases pertaining to special interests or perspectives (Smith, 1987). For institutional ethnographers, however, ideology is a “practice in thinking about society” (Smith, 1990a: 35). Ideology gives primacy to objectifying forms of knowledge and directs attention to those socially organized practices which displace the everyday world and how we [as knowers] know it:

When concepts are detached from the relation in which they make the world of living people observable, they become a means of operating selectively upon it and sorting it out in ways that preserve the ideal representation... [I]deological practices are pervasive features of the organization of the juncture between the relations of ruling and the actualities of people’s lives they organize and govern (Smith, 1990a:42-43).

Smith’s critique of ideology is fundamental to her epistemological commitment – expressed in ‘women’s standpoint’ – which insists that there is always a relationship between knowledge, knowers, and what is known (1990a).

Ideological practices subordinate people’s experiences to the authority of the text (Campbell & Gregor, 2002). This ‘objective’ version makes the account appear more convincing, and therefore, useful for administration or “organizational decision-making” (2002: 38). While accounts may appear objective, “they are not necessarily disinterested”, nor are text-based decisions necessarily fair (38). The “social organization of ideological accounts” are done from a standpoint outside local settings, and “with an objective structure of relevancies located” in texts (George Smith, 1990: 633).

Smith’s (1990a; 1990b) work details the ideological practices that structure the organization and interpretation of an objective account of a person who is thought to be mentally

ill. I draw here on Smith's analyses of the conceptual organization of 'mental illness' and the production of the account of a young woman, K, as 'mentally ill'. Smith (1990b) argues that the forms of social action, the authority of actors, and sites of activity are all concerned with establishing order and coherence, where others, in her example, friends and members of the community, have not been able to find it in the individual's behaviour. Those who seek to establish the objective explanation of K's behaviour will depend on the interpretive schema to direct them:

The conceptual schema of mental illness operates, as I have suggested, like a set of instructions for how to go about dealing with doubtful instances or weaknesses in the story as a story of someone becoming mentally ill. Finding some items as anomalous depends on the reader/hearer bringing together one part of the account to interpret another...This is the reader/hearer's work but it is work that is instructed by the mental illness schema (1990b: 46-47).

Smith (1990b) is showing that the social organization of the objective account, which includes following the proper procedures for interpreting it, is crucial in constructing the 'fact' of the illness (43-49). There are proper procedures for categorizing events or information (about the young woman) which will then establish them as facts. "Indeterminacy will be part of the problem in constructing the account" and may be an "essential preliminary phase" to arriving at and attaching the label 'mentally ill' (44). Uncertainties must be eliminated; scientific certainty can only be guaranteed by detaching the knower from what is known and thereby ensuring objectivity (1987). Once the category, 'mentally ill' is attached, the writer can claim that he/she has recorded the 'facts' of the matter (DeMontigny, 1995; Smith, 1990a). A reader, then reading the account, brings the text and what it intends 'to life', and makes sense of it (1990a: 153).

Drawing on Gramsci's (1971, cited in Ng, 1995) notion of "common sense" in reference to what he saw as "the uncritical and largely unconscious way of perceiving and understanding the world" in any given epoch (47, fn 4), Ng argues that an ideological frame renders as common sense the thinking and knowledge that it contains. The frame then constitutes a particular reality the relevant members are known by it (Campbell & Gregor, 2002). These studies make apparent how ideologies are practices of ruling wherein the practices themselves are 'invisible' or even 'common sense'. Also made invisible is the question about whose interests are being met and whose are subjugated by this ruling practice.

I learned from Smith's work how to begin to read the diagnostic text of a child and to analyze the practices which operate through the selection of particular relevancies, which are then used to establish the factual account of the child and also facts about his mother. I have also learned how to think about the diagnosis of FAS as an 'ideological frame', a form of knowledge which I and others take for granted due to the invisibility and "*accomplished* character of ideological thinking and processes" (1990a: 36).

In my thesis I refer to the diagnosis of FAS as a 'knowledge frame' to mark the methods of reasoning and practices that effect their concealment (1990a). Smith's (1990b) work has grounded my approach to discovering how women at work in the setting are drawn into 'ideological' practices for finding FAS in their children and also making sense of why their children *have* it. Through examining the actual text of a child's FAS diagnosis, I have drawn from Smith's work to discover how the interpretive frame guides people's practices in producing their objective account of the child.

Objective accounts represent a 'standpoint of certainty' which privilege the "organizational sources of power" that authorize this version (DeMontigny, 1995: 213). Once

established, there is no ‘escape hatch’ out of them (Smith, 1990a). Professional practices generate official knowledge on the basis of which ruling power is exercised, and of course, the generation of such texts is also an exercise of power (1995). A remarkable finding in my analysis is how women participate in this work, and in their own ruling.

Smith (1990b) insists, however, that inquiry must not be confined to texts and their production. The researcher must investigate the socially organized practices involving language and sequences of talk that are integral to recognizing the role of texts in generating courses of action (1990b). A standpoint in ruling, in contrast to a standpoint in experience, also relies on discourses that “interpenetrate the multiple sites of power” (Smith, 1987: 3).

### 2.6.2 Discourse

Discourse is of central interest to institutional ethnographers, whose aim is to discover and explicate the objectifying forms of knowledge which organize and coordinate people’s activities in their everyday world. As with other terms that Smith employs, such as ‘standpoint’, discourse has distinctive meanings that contrast with common usage or other theoretical formulations. Smith (1987) employs the term ‘discourse’, which she has borrowed from Foucault, by likening it to a widespread textual conversation in which particular words or “utterances are abstracted from particular participants” to represent some actuality we may grasp as real 1987: (61).

Like Foucault, Smith (1990a) “is interested in how knowledge and power intersect and in how their intersection can be grasped conceptually” (Campbell, 2001: 233). However, Foucault’s (1984) conceptualization of the intersection of knowledge and power is, for institutional ethnographers, “a field of relations that includes the use of texts” as well as the activities of people “who produce them and use them and take up the conceptual frames they circulate”

(DeVault & McCoy, 2002: 752, n.2). Institutional ethnographers are always interested in discourses as organizers and coordinators of experience (Smith, 2005).

The point of analysis, therefore, is not to search language or utterances or texts for people's beliefs, intentions, or perspectives but to look at how language organizes social relations that lay the basis for action and decision making on behalf of those who rule:

Language organizes relations and courses of action which can elude people's individual intentions. The way to take up texts and utterances, then, is to look at how they actively draw people into relations and organize what can be thought, said, and done in getting on with the practical tasks in a setting, and lay the ground for what can be said and done next (Turner, 1995: 216).

People participate in discourse and 'activate' the texts, which are features of "discursive organization that relate people purposively to each other, and to events, organizations, and resources" (Campbell & Gregor, 2002: 41). The text-mediated work activities involved in the social organization of a discourse develop a "world in common for those who participate" in it, constituting objects of the discourse that will exist independent of people's experiences in a particular setting (Griffith & Smith, 2005: 34).

Smith's (1990a) examination of professional and bureaucratic work processes concerned with offering psychiatric services reveals how "psychiatric discourses coordinate and standardize" professional practices as well as establishing similar accounts of the people (objects) they work upon (125):

What actually happens, what people actually do and experience, the real situations they function in, how they get to agencies – none of these things is neatly shaped up. There is a process of practical interchange between an inexhaustible, messy, different, and

indefinite real world and the bureaucratic and professional system that controls and acts upon it. Professionals are trained to produce out of this an order, which they believe they discover in it...The application of psychiatric methods of making accounts get worked out in the actual situations that arise in the community [and the] conditions and troubles characteristic of them...An interface of routine operating develops, which transposes these recurrent and characteristic local uses into the psychiatric and administrative terms that make them actionable (1990a:126).

The processes of inscribing people's troubles (and the everyday world in which they arise) into systems set up to control them are shown here to be intrinsic to professional and bureaucratic work (1990a). These practices – including the discourses, categories, and conditions of work – accomplish the work that makes the agency 'accountable' (1987; 1990a). Professional discourse contributes not only a "language and authorized practices for conducting the work of the institution", but it also frames the way the work is thought about – as proper, accountable work (Campbell & Gregor, 2002: 71; De Montigny, 1995). The discourses are 'institutional discourses' – systematically developed to provide the concepts and categories "under which what people do becomes institutionally actionable" (Smith, 2005:113).

People, who occupy positions in the ruling structure, come to view the world in distinctive ways by virtue of their participation in it (Campbell & Gregor, 2002). However, participation in ruling is not confined to those engaged in professional work. People in various fields will learn "insider discourses to demonstrate their belonging and competence" (2002: 71). Listening to how women in my study took up the terms and concepts of FASD, revealed how the social relations of the setting supported practices through which women could develop their own expertise and, thereby, make themselves knowledgeable in how to identify an FASD child.

Discourse is also relevant to social institutions such as education and the family and to their respective socially organized fields of knowledge and activities (Smith & Griffith, 2005). Drawing on her interest in the family and school relations, for example, Griffith (1995) examines how a ‘mothering discourse’ organizes the work mothers do in relation to the child’s education. She also discovers how one discourse is conceptually linked to and coordinated with others in a pattern of institutional activities useful to ruling.

Griffith’s (1995) inquiry begins with data she obtains from interviews with mothers about their everyday work of developing relations with their children’s schools. Through their talk, Griffith’s discovers intersections between multiple and overlapping layers of discourses that have been organized extra-locally and historically. Griffith’s finds that the “everyday work of mothering” school-aged children is embedded in discourses on child development – a “set of claims about children’s maturation” and its bases in biological processes (110). This conceptual ground is also tied to an academic discourse on developmental psychology and parenting discourses that give mothers advice on parenting in popular magazines. Griffith’s argues that these discourses organize “a particular version of child rearing” and at the same time, “a particular version of mothering” in which children and mothers are objects rather than individuals with differences and, as such, they can be entered into school practices. (113). This discursively organized knowledge about mothers and children is an “ideological process made possible by the articulation” of these discourses (1995: 111). The discourses and the schooling practices that rely on them combine to regulate mothers and their mothering work.

Griffith’s analysis introduces another feature of discourse as “an enacted feature of social organization” (Campbell & Gregor, 2002: 41), in revealing how the social relations of class coordinate women’s time and work in particular ways (see also Smith, 2005). Griffith’s observes



that some mothers, particularly working-class women, “organize their mothering outside of the normative work organization” (120) the school expects. Schools rely on mothering work, as Manicom’s (1995) study also shows<sup>11</sup>. For mothers who do not or cannot participate in the “discursive organization of family-school relations”, their perceived failure impacts their children’s schooling and leaves intact social inequities, which, Griffith’s argues, are inter-generationally reproduced (120).

Smith’s (1990a; 1990b) conceptualizations of discourse include and combine her analyses of language, texts, and ideology to disclose the how people’s/our actual practices for thinking about ourselves and society transpose everyday experiences into “standardized and conceptual forms” that accomplish ruling (214-5). Discourses (and our own work in activating them) provide or ‘mediate’ a way of knowing about children with special needs, high risk mothers, people on income assistance, and so on, in ways that displace or subvert their/our local and experiential knowledge with knowledge that is useful for administration and control. The discourses people use in medical, governing, and administrative practices are an ideological construction of what people need (Campbell & Gregor, 2002).

In my initial discussion of discourse, I drew attention to connections between Smith’s work and that of Foucault’s. During the course of my analyses I have discovered, and will briefly describe some useful intersections between Smith’s conceptualizations of ruling and Foucault’s work on governmentality.

### **3.0 Ruling in neoliberal times**

When Smith (1990a) writes of ruling or governing –both terms may be used – she insists that the forms in which ruling generally takes place in modern industrialized societies do not rely

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<sup>11</sup> Smith (cited in DeVault & McCoy, 2002) says that institutional ethnographic studies can fit together because they share the same ontology and “capacity to disclose features of ruling” (754)

on systems of domination or overt mechanisms of control. Ruling is accomplished in routine, taken for granted work activities involving texts, language, and the objectifying forms of knowledge that are central to the technologies and practices that get things done in and across institutional settings (Campbell & Gregor, 2002). Ruling is not centred in institutions, the state, or other systems – corporate, financial, technological – typically seen to be centres of power. It is dispersed, multi-sited, and intent on engaging the interests of communities and groups at the individual level of responsibility for themselves and their families (Li, 2007; Smith, 2005). It is in people’s practices and in what people do in their/our everyday socially organized lives. It is in the work of professionals, researchers, and front-line workers, including my own work. Even when we are acting on behalf of others who are marginalized, or advocating for others, we often bring our own interests in line with those of ruling (Walker, 1995).

This theorized approach to how ruling works in everyday practice shares certain similarities with those of researchers who draw on the work of Foucault, in particular, his work on governmentality or how he conceptualized the exercise of power. Governmentality does not speak directly to modes of governing or governance but rather to the range of techniques and practices which contribute to managing society as well as managing the ‘self’ (Holmes & Gastaldo, 2002). Foucault’s work critically examines the forms of knowledge and practices concerned with human action and those concerned with institutional arrangements for sustaining or managing human conduct (Chambon, 1999). His interest in practices (including medical) along with his interest in the ‘self’ (subjectivities) and power uncover the ‘micro-practices’ or subtle forms of disciplining that occur in everyday social encounters (1999). These ‘strategies of power’, which rely on selecting certain knowledge about subjects, makes specific aspects of people’s lives visible and, thereby, also known and governable (Foucault, 1977). For Foucault,

the “exercise of discipline presupposes a mechanism that coerces by means of observation”, that make those on “whom the techniques are applied clearly visible” (189).

Foucault (1977) asserts that through the disciplinary practices of “power-knowledge relations”, prominent in medicine, psychology and other human sciences, humans are subjugated – turned into “objects of knowledge” (175). In this ‘regime of disciplinary power’, people learn to bring others as well as themselves and their own conduct in line with ‘proper conduct’ (Brock, 2003; Chambon, 1999; Foucault, 1977).

Foucault (1977) observes that schools (historically, school buildings also) are among the disciplinary institutions (along with hospitals, clinics) in which people rely on specific practices to accomplish a progressive objectification and subtle “partitioning of human behaviour” (191). Since the eighteenth century, the forms of discipline employed in schools rely on subtle ways of punishing those who do not conform to the ‘norm’ – an apparatus of ‘functional surveillance’, which “distributes individuals in this permanent and continuous field” under a normalizing ‘gaze’ (192-196). Even the “slightest departure from correct behaviour” –those who do not conform – is punishable because the “rule of the average prevails” (194-195). Children who were indifferent and questioning, those who transgressed the norms of time, activity, attention, and cleanliness, and those who were visible by being late, absent, inattentive, impolite, or indecent did not gain membership in the “homogeneous social body” (196). Normalization imposes both homogeneity and standardization, and thereby makes it possible to measure gaps and render disciplinary measures on those with all the shades of individual differences (196-197).

Foucault’s analyses of practices involving subtle forms of surveillance, discipline, and punishment in relation to children’s deviations from the ‘normalizing gaze’ and judgment has been helpful to my reflections on current practices in and across institutional fields concerned

with education, medicine, and government. My analyses show this 'FAS/D institutional complex' to be reliant on processes for identifying and monitoring children as objects of 'risk' and holding their (also) deviant mothers accountable.

Recently, a number of scholars who conduct research in the areas of 'health and illness' have applied Foucault's work to their critical examination of medical, nursing, and other health practices which also make particular aspects of people's lives visible and objectified. In Chapter Three, I discussed some of these works (Rose, 1999) which examine discursive practices that construct people as objects of 'risk'.

A number of scholars have developed useful analyses of governmentality as contemporary neo-liberal projects of governance. Among these projects are those which, in various ways, are concerned with persuading enterprising subjects to regulate their own 'responsible' practices and manage their own health risks, thereby shifting the focus from the responsibilities of the state to those of individuals (Petersen & Lupton, 1996 cited in Angus, 2008). In these analyses as well as my own, discourses on both responsibility and 'irresponsibility' are prominent.

Purkis's (1993) work, which problematizes how a discourse on 'health promotion' shapes community nurses' work with parents, has also been instructive to my own work of examining how personnel who instruct women in the FAS/D 'prevention'<sup>12</sup> discourses also discipline them. Purkis's work examines nurse-parent encounters in a community health clinic where practitioners instruct their clients in their proper conduct as parents and she details the subtle methods, maneuver, and techniques the nurse employs to 'discipline' the parent to adjust her own knowledge of the child to the expert's (the nurse) discursive representation of him. These practices are shown to objectify the child and constitute the nurse and her account of the child as

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<sup>12</sup> Prevention and 'health promotion' can be interrogated as related fields of discursive activities.

the ‘authority’. Purkis’s project of inquiry is aimed at explicating how things happen the way they do – in the practices that govern the encounter.

Campbell and Teghtsoonian (2010) point to an interest of governmentality scholars (see also Tanya Li, 2007a; 2007b) which resonates with theirs – the intersections between governance practices and resistance in “particular empirical sites” (5). Drawing from O’Malley’s (1996) exploration of “neoliberal governance practices directed toward Australian Aboriginal people”, the authors observe that “active involvement in practices of governing – whether collaborative or resistive – builds and contributes to, even as it reconstructs, the governing discourses and practices” (5). Their discussion on resistance has stimulated my own reflections on how women in my study who have resisted or challenged the FAS discourse have, nevertheless, also been drawn in as willing collaborators in expanding and coordinating the discourse and the responsabilizing practices. I concur with Campbell and Teghtsoonian, who acknowledge the benefits of a more detailed exploration of these contiguous fields, and their shared interest in “ethnographically grounded empirical research” (2010: 6, fn7).

To summarize, I have outlined the theoretical perspectives and underpinnings that frame my inquiry. These have provided a way for me to begin an inquiry in women’s standpoint and to explore the everyday world of women and children, where I too, am part of the social relations that I am exploring. My brief introduction to Foucault’s work, and those of Foucauldian scholars, has enriched my understanding of how knowledge, as practice, is useful for governing in local settings as well as in and across institutional fields.

In institutional ethnography method and theory are always combined (DeVault & McCoy, 2002). The theoretical perspectives I have identified are intrinsic to my way of ‘doing’ the research – ethnographically – situating the inquiry in a specific place and time with

specifically located persons to accomplish a discovery of how things work in that setting (Said, 1981, cited in Kirby and McKenna, 1989). The ethnographic methods of data collection, which begin in women's experiences, make this inquiry possible and actual.

#### **4.0 A materialist, empirical method**

The research goal in the collection and analysis of data is to explicate the organization and coordination of people's experiences. Institutional ethnography's empirical approach to discovering and seeing 'social organization' involves finding the actual determinations of the everyday and 'mapping' them (Campbell & Gregor, 2002). Smith's (1987) analogy of a map has been instructive. Mapping is based on the assumption, for example, that "people and events are actually *tied* together in ways that make sense of power, knowledge, capitalism, patriarchy, race, the economy, the state, policy, culture, and so on" (Campbell & Gregor, 2002: 17). When we speak about culture or race or patriarchy, for example, we can discover how they work as practices which can be traced, like points on a map to institutional and ruling functions.

Discovering the social organization of everyday life means that data of two kinds or levels may be collected (Campbell & Gregor, 2002). The entry level of data begins in people's experiences in the research setting with individuals that interact there. As the problematic and social relations in the local setting emerge and become more clear, a second level and more focused stage of data collection is directed to finding linkages to institutional activities, which will help to explicate the earlier accounts (2002). Fieldwork is driven by the researcher's faithful attention to the work processes required to connect individual experience with the parts of an institutional complex the researcher brings into view (DeVault & McCoy, 2002).

Institutional ethnographers use multiple methods of data collection, including interviewing, field observations, archival work, and textual analyses, all of which enable the

researcher to investigate institutional and social relations as actual practices as they occur in specific local sites (Smith, 1987). Here is an overview of how my ethnographic exploration proceeded.

#### 4.1 Selection of research setting and informants

In order to begin in women's and children's everyday experiences, I selected my field study site, Crabtree, an agency located in Vancouver British Columbia, because it offered access to participant observation with women and children at 'work', in the generous sense articulated by Smith (2005). I wanted to talk with women who may have concerns about their children's health or who might have been told their children may have special needs or FAS. I did not set out to interview poor women, but the inner city location made it likely that the social relations of race and class would intersect in a centre aimed at serving 'vulnerable' women seeking basic services.

This opportunity for fieldwork in this site arose from my earlier introduction to the agency, which I gained through own work as a policy consultant. I had visited the setting to learn about the agency's plans for developing an expanded centre which would include women's housing. I remembered touring the agency, observing and discussing with personnel the various programs and activities and their goals for gaining funding from both the private and public sectors. I recalled some activities related to FAS prevention but had no further details. This work-related connection facilitated my later request to discuss access for conducting fieldwork with the women 'clients' as my primary informants.

#### 4.2 Considerations in selecting research informants

Institutional ethnographers do not think of research informants as a 'sample', nor is the research process strengthened by attending to the numbers of informants. I do provide this

information (Section 4.4) for those who have an interest in the scope of my project in this regard. The research goal is not to develop generalizing descriptions about a group or population, but to explore from a standpoint in experience (DeVault & McCoy, 2002). The perspectives of informants who are active in different social locations or forms of work illuminate the diversity of experience (2002).

I elected to use the term ‘informants’ rather than ‘participants’, which would erroneously imply that power relations in research are equalized. In conducting research with and about women, Finch (1990) suggests that, if one takes the view that participatory and equal power relations can be established, then one overlooks that women in patriarchal societies are already relatively powerless (see also Campbell, Copeland, & Tate, 1998). Analyses by Campbell et al. of their efforts to conduct participatory research with people who have disabilities, revealed that the power relations inherent in this form of research have not been resolved. Drawing from both my previous and current research with women, I recognized unequal power relations between my socially-located self and the women who participated in my research.

I undertook efforts to minimize any possible harm to my informants. In order to protect confidentiality, I have protected information that might allow for identification, for example, I used pseudonyms, and applied generalizing categories, such as ‘professionals’ or ‘front-line workers’ to avoid identification of those who might otherwise be known by their work designations and areas of responsibility. Where I change some identifying features, I still maintain the integrity of my informants’ accounts. Standard qualitative procedures for gaining informed consent from informants, protecting confidentiality, and complying with The University of Victoria’s ethical guidelines for research with human subjects have been approved and applied (Certificate of Approval: Protocol No. 06-420).



### 4.3 Research informants

My primary informants (entry level data) were women who attended the centre – women who are experts in their own lives. My aim was to develop an understanding of their everyday lives. My approach to recruitment began with informal discussions with personnel about my research project. With the agency's subsequent approval I placed some posters that identified my research interest and contact information, in accessible and visible locations. In order to protect women's confidentiality, I avoided methods of nomination, such as asking key individuals to make recommendations (Morse, 1991). Informal recruitment followed quickly – by 'word of mouth' as potential informants spoke to me directly or by telephone contact. I obtained formal consent from all of my informants (Appendices A and B).

To select and interview other informants (second level data) with practical knowledge of organizations, policies, and professional practices relevant to the broader field of 'fetal alcohol syndrome' diagnosis and prevention, I established connections with professionals and with others whom key informants nominated. The network process expanded to include individual interviews and telephone contacts with professionals, including those involved with diagnostic teams, policy makers, and decision-makers from various work sites throughout the province of British Columbia. People involved in these institutional forms of work provided important analytic linkages connecting the everyday world of my primary informants with ruling practices.

### 4.4 Data gathering

I conducted my field work investigation over a three week period (Monday to Friday during the centre's regular hours of 1830 to 1630 apart from the earlier closing time on Wednesdays) in February 2007<sup>13</sup>. After reviewing and reflecting on my initial data and field notes, I returned to the centre approximately three weeks after my field work ended for an

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<sup>13</sup> See also Appendix C for further details on interviews and locations.

additional two days in order to review pertinent texts and clarify with personnel my understanding of aspects of my data.

Because my method of inquiry is committed to beginning in an actual material world, I relied on multiple field methods involving a modified form of participant observation, individual and focus group interviews, and textual analyses. My approach to participant observation was flexible, and allowed for different levels of involvement as a participant and observer (Kirby & McKenna, 1989). Although I was not working in the setting, as one would in the more traditional participant observation approach (Campbell & Gregor, 2002), I participated in group activities, including helping with children in the daycare setting doing what people would normally do. These activities allowed for frequent, direct, informal contact with and observations of informants. While I did not interview children, I observed their activities and also professionals observing them. These observations offered vital clues to my seeing social relations as ‘actual practices’ involving children.

My level of participation in some group activities was dependent on negotiating access to a group with agreement from members prior to my arrival. In some instances, I attended groups only to observe. In the early stages of my field work, direct observation with limited interaction allowed me to familiarize myself with the setting, look and listen attentively, and record my observations. Gathering these rich sources of data also required periods of time for reflection and journaling.

I conducted a number of individual interviews both formally and informally (during activities or serendipitous encounters) including a focus group discussion (Appendix C). ‘Talk’ about the activities in the setting offered valuable clues to its social organization (Campbell & Gregor, 2002). Questions with my primary informants were open-ended and directed to learning

about women's and children's everyday lives at home and in the activities at the centre. As I learned more through both observations and interviews about women's work in the setting, some questions became more focused, building on information previously obtained – an approach in keeping with my method (DeVault & McCoy, 2002). Interviews were taped and later transcribed to facilitate review and analysis.

Texts provided vital sources of data in helping me to understand the setting and the social relations of it. Texts and textual work activities were examined for how they activate ruling relations (DeVault & McCoy, 2002). Texts became apparent during observations of work activities, while others were referenced in people's talk. Some informants provided copies of specific policy directives and other texts relevant to developing my understanding of the setting and how it is located in the institutional complex of ruling functions.

I also include as data previous work experiences, primarily as an FAS consultant. These experiences include my observation of an FAS diagnosis and the attendant practices, FAS research conferences I attended, and texts obtained through my consulting work. In addition, data collected during Schellenberg's (2003) research project<sup>14</sup>, approved according to the ethical guidelines of the University of Northern British Columbia (UNBC) and UNBC's Substance Abuse Task Force, led to analyses of texts and text-mediated work related to children categorized as 'special needs', relevant to my present inquiry.

The observations and interviews, as well as field notes and journals, collected during this inquiry have yielded a great deal of data. The work of sorting through and analyzing my data has required my returning to the problematic and the experiential ground that focuses my inquiry.

Much of this effort of focusing, sorting, and analyzing is in the work of writing.

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<sup>14</sup> The research project was funded by Health Canada through UNBC's Centre of Excellence for Children and Adolescents with Special Needs under Contract No. RC02-341. Under the contract, I retained copyright and the approval to apply the research findings to future work, including this thesis.

#### 4.5 Data analysis

While institutional ethnography is broadly located within the field of qualitative research, the approach to data analysis and the aims are distinctly different (DeVault, 1999). For example, institutional ethnographers do not generally use coding, thematic analysis, or other approaches common in qualitative research where the goal is to develop theory, interpret meanings, or provide rich descriptions of everyday life (Denzin & Lincoln, 1994). For institutional ethnographers, writing (and rewriting) *is* the analysis although it involves a specifically focused approach to writing.

Analysis, in an institutional ethnographic inquiry, begins with two essential processes: 1) learning how to begin in experience (the ‘everyday’ world), as distinct from in theory or concepts and 2) looking at what there is in the experiences (observations and accounts of everyday experience) to find social relations and social organization in them (George Smith, 1990). The analytic process is “directed to explication that builds back into the analytic account what the researcher discovers about the workings” of translocal ruling practices (Campbell & Gregor, 2002: 90).

For institutional ethnographers, engagement in the analytic process must be fully ‘reflexive’ – involving a commitment to critically addressing our own participation, whether as academics, researchers, and/or practitioners, in the conceptual practices of ruling (Smith, 1990a). Smith (1990a) also identifies a partial reflexivity involving, 1) “explicating the theorizing, categorizing, and conceptual practices” of a setting, and 2) recognizing one’s own values and social location as a researcher (147).

Reflexive processes have guided the multiple and overlapping layers of writing and interrogating my data. Questions I considered as I reflected upon my data were: How can people,

including myself as a nurse, talk, work, or know things in this way? What texts or text-mediated discourses are framing the issues, concepts, or work processes (McCoy, 2002). What is going on here, in this activity for example, that offers clues to its social organization? My inquiry has required that I learn to look in two directions analytically – to the ground of everyday work activities and to text-based forms of knowledge and their conceptual ordering of women’s and children’s everyday lives. Drawing on varying degrees of reflection and reflexivity has helped me to achieve explication of my data.

### **5.0 Generating a trustworthy account**

Researchers working in the qualitative research domain have proposed various criteria to demonstrate the standard of reliability or rigour required for scholarly work (Morse & Field, 1996). Among the criteria that have been identified for maintaining rigour in qualitative research are: truth value/credibility, auditability/consistency, confirmability (1996; Sandelowski, 1986) and reliability (Kirby & McKenna, 1989). Sandelowski (1986), for example, describes a study as credible when other people can recognize the experience when confronted with it after having only read about it.

Smith (2005), however, insists that institutional ethnographers demonstrate rigour through the production of an “accurate and faithful” account (42). Smith (2005) describes this requisite for scholarly institutional ethnographic work:

If it [the research] is to serve those whose standpoint it undertakes as its starting point, it must produce accurate and faithful representations of how things actually work (42).

The materialism in institutional ethnography’s research approach relies on the ontological assumption that an actual world exists and can be interrogated to determine “what actually happens” (Campbell & Gregor, 2002: 78) and how things are “actually put together” (Smith,

1987: 147). Here, Smith (2005) makes use of the term *actual* to direct the researcher “to the world to be explored by the ethnographer” (223). The project of ethnography “lays stress on being faithful to the actualities of social organization and relations” (Smith, 1987: 147). Ethnography signals a commitment to “empirical exploration of the way things happen through people’s describable activities” (McCoy, 2008: 706).

My ethnographic work has enabled me to begin in the actualities of the everyday – the lives and struggles of women I introduce in the next chapter – and also to go forward, as if on a map, to discover and trace how the experiences of those in the setting connect or hook into extended ruling relations (Smith, 2005). The processes of discovering and making those connections evident, which I detail in the following four chapters, establish the faithful account of ‘how things happen’ for people whose experiences the FASD institutional complex coordinates.

In qualitative research projects, the emphasis is on discovery and understanding, rather than on prediction and generalization, therefore, generalizability is not considered to be a requirement for scholarly research (Patton, 1990). However, I refer to it because of its significance to an institutional ethnographic inquiry. The institutional ethnographer’s analysis of the data is aimed “at how the individual experience can be generalized” (2002: 89). Generalizability is integral to the social ontology and the researcher’s interest in discovering how social and ruling relations “exist in and across many local settings, organizing experiences informants talked about” (Campbell & Gregor, 2002: 89). By attending to the actual, the institutional ethnographer’s project of discovering and explicating how ruling relations work establishes its generalizability.

Smith (2005) observes that ethnography has often been treated as limited in its implications because any statements the researcher might make about its significance are restricted to the particular ethnographic setting. However, Smith (2005) offers a strong rebuttal to this criticism:

Institutional ethnography addresses explicitly the character of institutions in contemporary society: that they are themselves forms of social organization that generalize and universalize across multiple local settings. While they may and do articulate differently in the particularities of local settings, their generalized and generalizing character is going to appear in any ethnography – indeed, it has to be there and should be there explicitly, even in an investigation that begins in the experience of one individual (42).

One of the significant aspects of my research is, I would argue, its generalizability. Institutions depend on texts, which coordinate people's experiences in generalizing and standardizing forms. Local experiences (actualities) have to be converted into textual realities to become institutionally actionable (Smith, 2005). While the women and children made 'actionable' in Crabtree are mainly poor and First Nations, the objectifying forms of knowledge that accomplish their representation as FAS objects will generalize how they are known as FAS across multiple sites. Objectifying people's knowledge and experience and displacing their subjectivities is the institutional work that is intended. An inquiry that begins in the actual can render a faithful analysis of the local practices that are the work of ruling.

## **6.0 Summary**

Institutional ethnography has provided the conceptual ground for my analyses of the everyday activities women and children are engaged in at Crabtree and how their work has come

to be shaped in particular ways that tie women and children to ruling. I have drawn on the tools pivotal to my analysis of the ‘social organization of women’s work’ in the FASD institutional complex, primarily, those of standpoint, experience, social and ruling relations – which also bring the institution into view – and those text-mediated forms of knowledge, discourse and ideology and the ideological practices that accomplish the disappearance of subjects, informants in my study. My ethnographic methods enabled me to explore disjunctures between embodied knowledge/knowers and the objectifying forms I discovered in women’s talk.

In the following three<sup>15</sup> chapters, I enter and explore the research setting where I conduct my fieldwork. Beginning in the everyday world, and attending to mothers’ talk and work with different texts, I enter the social relations of the setting where there is so much concern about FAS and I identify how that concern has arisen and become established. Through my analytic work have begun to explicate intersections between institutional sites in the FASD complex to reveal how extra-local coordination of the everyday is accomplished in this setting. The work of mapping an institutional complex cannot be completed in its totality (DeVault & McCoy, 2002). I identify strands that allow me to trace how ruling works in the everyday world of Crabtree.

The social [ruling] relations that organise our world and of which we are a part are not always apparent in people’s experiences (Smith, 1987). They are, however, part of the features of the everyday world as we live them in our work as mothers, front-line workers, health providers, policy makers, teachers, and so on. That is why the actual experiences of people in their everyday world offer a methodological ‘starting point’ for discovering ruling relations (Smith, 1987). It is to that starting point I now turn.

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<sup>15</sup> In Chapter Eight, my fourth analytic chapter, I show how local experiences are transformed into textual reality.



## Chapter Five

### *Help at the “back door”*: Beginning in women’s work

*People do not organize or “produce social relations, but enter into them”* (Travers, 1996: 543).

#### 1.0 Introduction

In this chapter, I begin my exploration of the ‘women-centred’ agency called ‘Crabtree Corner’, where I conducted my ethnographic research. I introduce material features in and around the building, the types of programs and services offered, excerpts of conversations with personnel and women who come to the agency, and my observations of routine activities and work practices. My exploration allows me to listen to the concerns of women who come to Crabtree, examine aspects of their daily lives and unpaid work, including their efforts to supplement their limited incomes with the breakfasts or hot lunches Crabtree provides. I also learned how Crabtree personnel assist the women to access food bank offerings, a space in the emergency daycare, and support in finding a safe place to live and work, or someone to talk with about their concerns. Reporting my observations introduces for analysis a work interface between the women who go to Crabtree and the women/personnel who offer various forms of help. Women’s concerns and their efforts to address them occur in a work interface between embodied subjects and the physical and social “spaces of everyday life” where things get done (McCoy, 2006: 111).

Beginning from my first days at Crabtree, personnel were extremely helpful by introducing me to various programs and activities and telling me about the women and children that attend the centre. In one introduction I received, I heard that many of the women are “single parents, on social assistance, and have social workers in their lives”. I also heard that “FAS is a huge issue in the building”. These terms and concepts, I came to see, connote a particular standpoint, a way of knowing women and children in professional and administrative terms and

categories that my research problematizes (see Chapter One). The reference to FAS as a “huge issue” alerted me to querying how this diagnostic category, FAS, might possibly relate to women’s concerns or to work activities in this setting. I was curious to discover how a medical diagnosis that, according to experts’ calculations, affects approximately one in one thousand<sup>1</sup> children in the Canadian population, could be such a “huge issue” among the women and children who come for help in this particular setting. One of my goals, in my exploration of this work site and women’s work engagement in it, is to discover clues to the social relations of this setting and to the particular organization of help for the women and children who enter Crabtree’s door.

## **2.0 Crabtree Corner**

The busy Family Resource Centre called Crabtree Corner is a multi-services agency that provides programs and supports for ‘vulnerable’ women and children from its location in a densely populated area of one of Vancouver, one of Canada’s largest cities. On the surface, Crabtree Corner does not appear to have an ‘institutional’ presence, suggestive of extra-local processes of administration, governing, or control (DeVault & McCoy, 2002). Crabtree personnel describe the agency as ‘grassroots’; one informant observes that the programs and services offered come from “what women say they need”. The term grassroots<sup>2</sup> suggests organized activities that arise from the efforts of people within a community rather than from the standpoint of those engaged in traditional power structures or institutional practices. Women who make use of the services highlight the non-judgmental and caring approach of personnel and their commitment to helping women. A number of women I interviewed describe the centre as a

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<sup>1</sup> The figures vary widely (see Roberts & Nanson, 2000) and later discussion.

<sup>2</sup> See Walker, 1995, and how a grassroots movement concerned with violence against women is appropriated and absorbed into ruling state practices. See also George Smith’s (1995) analysis of how the political work of a ‘grassroots’ AIDS activist group is most effective when the effort is directed at explicating the social organization of the particular ‘ruling regime’.

“lifeline” and “safety net”. Crabtree’s location in an area of a city fraught with visible signs of people’s troubled lives outside its door appears to make it an even more vital resource for the women and children who seek help within.

### 2.1 History and service model

The YWCA Vancouver (2007a, b; 2008), which opened Crabtree in 1983, identifies the agency as one of a number of core service and advocacy operations, consistent with its mission and vision for achieving women’s equality. The YWCA in Vancouver has a 100 year or so history of offering support and services to vulnerable women. In the past decade, the Crabtree operation has been expanding and a growing number of women and children are attending both the ‘drop in’ and scheduled services offered.

Funding for Crabtree, both public and private donors, flows through the YWCA. The bulk of the YWCA’s funding comes from private and corporate donors, including those allocated from the United Way<sup>3</sup>. Crabtree is the recipient of not for profit funds as well as BC provincial allocations from the Ministry of Children and Family Development (MCFD), the city of Vancouver, and the Coastal Health Authority. Federal funds from the Public Health Agency of Canada also flow through the YWCA to Crabtree. The YWCA has a policy that only one-third of their funding comes from government. In 2003 after a massive funding drive, Crabtree underwent a major expansion when it moved from its cramped quarters at a nearby location to its present site in the YWCA-owned building, where it is co-located with Sheway.

Sheway is a government-funded ‘outreach program’ that offers health, social, and treatment services to women who are pregnant or parenting children under the age of eighteen months and who also are experiencing issues with ‘addictions’. A Sheway informant indicated

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<sup>3</sup> The United Way is a prominent and well known charitable organization in many Canadian communities; it relies on public and private donors in its mission to address social issues.

that if women have only ‘occasional’ drug use, they may not be eligible for the program. Sheway services rely mainly on the work of professional staff or consultants, including doctors, nurses, social workers, and addiction counsellors.

Sheway’s reliance on professionals prompted one informant to suggest that the Sheway program is based on “expertise”, which in her/his view, contrasts with Crabtree’s ‘grassroots’ approach. These observations indicate possible tensions between ‘expert-based’ and ‘grassroots’ approaches and suggest that different, and possibly more authoritative ways of knowing, are being applied in Sheway than in Crabtree’s adjacent site. The authoritative forms of knowledge that experts generally rely on may, as my informant seems to suggest, over-ride the experiences or ‘voices’ of women, who might otherwise contribute to policies, program planning, and service delivery.

Crabtree operates primarily on a ‘peer support’ or mentorship staffing model that likely contributes to its description as a grassroots organization. Among the centre’s employees are administrative staff (manager and coordinators) and ‘mentors’ – usually former ‘clients’ who, after attending programs at Crabtree, have been mentored into paid employment at the centre where they now advocate for and support others. Crabtree’s staffing model also incorporates ‘volunteers’, particularly in the lunch program, where women who assist in the kitchen may also learn valuable skills. I rarely heard personnel refer to the women as ‘clients’. For the most part, the women who come to Crabtree are identified as women, mothers, grandmothers, or other caregivers and they, along with the children, comprise the community that regular attendees often describe as a ‘family’.

Crabtree’s model of service delivery also incorporates opportunities for health professionals to apply their expertise in the setting. According to one professional informant, the

opportunity for this form of involvement began over twenty years ago when a branch of the federal government of that time allocated money to the local Health Department for a pilot FAS/NAS<sup>4</sup> prevention program, in order to “see if there were any children at risk” in Crabtree Corner. My informant explained that the emergency daycare at Crabtree provided a site where health professionals could carry out observations that allowed them to “easily recognize early significant developmental concerns”.

My informant explained that those involved in that early initiative in Crabtree “put a name in [their] minds” to their work with mothers and children and this is how s/he described it:

Door Number One is the parent and their car and their home and their ability to fill out the forms. Door Number Two is a kid who has a social worker, and Door Number Three is the back door, how to facilitate families who are socially disenfranchised either by education, income, or many things, into the system, so this [Crabtree] is door number three, or [a] developmental outreach program....

Here, my informant contrasts Crabtree’s services, described as ‘back door’ services for disenfranchised<sup>5</sup> women and children – to those available to women and children who conform to a more normatively organized ‘conception of the family’ (Griffith, 2006), suggested to be “the parent with a car and their home”, and skills in organizational literacy, such as filling out forms. Culhane (2009) observes that what Aboriginal and non-Aboriginal women share in this particular inner city location<sup>6</sup> is ‘material poverty’. As I proceed with my exploration of Crabtree, I am endeavouring to learn about the women and children who use the services at this time and what

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<sup>4</sup> NAS refers to ‘neonatal abstinence syndrome’, a medical diagnosis that may be applied to children prenatally exposed to illicit drugs. Susan Boyd’s (1999) research examines and disputes the ‘truth’ claims concerning NAS and fetal harm and exposes discursive medical/nursing practices that have helped to produce and coordinate the claims, which include the negative labelling and targeting of mothers.

<sup>5</sup> Historically, poor people were deprived of certain legal rights, such as the right to vote, because they failed to meet the requirement for property ownership (Merriam-Webster, 2012). The operative word, I suggest, is ‘poverty’.

<sup>6</sup> See also Robertson and Culhane (2005).

is available for them. I am also querying how the historical work activities my informant identified may be shaping those of today.

## 2.2 The setting

Crabtree Corner is situated on a major transportation route for public transit and other vehicle traffic moving between the east and west sectors of the city. Many of the buildings adjacent to Crabtree and along this busy street are commercial sites, which are also part of the city's early history. Over the past two decades or more, the Downtown Eastside has evolved into a densely populated area, commonly known as one of Canada's poorest urban neighbourhoods. At the time of my field work, signs of impoverishment are visible on the street and surrounding buildings. A number of the shops and store fronts have safety bars across their windows and doors. Some of the buildings, among them old hotels that offer long-term rental units, have broken or boarded windows. Crabtree's location in the five-storey cement structure stands in stark contrast to the deterioration apparent in its surroundings. On streets behind the hotels, storefronts, bars, and drop-in centres interspersed along the street is a large residential area mixed with commercial zones, including the nearby 'Chinatown'.

On several occasions, while walking along the street not far from Crabtree, I observed discarded tourniquets, needles, syringes, and other signs of human activities involving illicit drug use. Garbage, broken bottles, condoms, and syringes litter areas near where people live. At first I was frightened walking on the street and hesitated going out alone, even though it was daylight. My own fears and reactions to the setting pointed to my social location and experiences, those of a Caucasian child growing up in a predominantly white, working class rural area and later, as an adult, living in middle income rural or urban neighbourhoods – settings which made this environment seem strange and disturbing to me. I also recognized my privilege as a white

woman researcher, walking on the street according to my own choices and preferences. I did not have to live or work or care for children in the area, nor did I have to be outside, walking or working at night. When I returned from my walks in the area where Crabtree is located, I could understand a little about what I was hearing from women, who were telling me that Crabtree is a ‘safe’ place for them.

### 2.3 Features in the building

The main entrance door to Crabtree is always locked. When opened, the door provides an entrance into a wide foyer – a clean, brightly lit, sparsely furnished area with large windows and a glass door that look out to the street. A few chairs are positioned at one side of the foyer. On one wall, hangs a large framed colour poster that features a bright open umbrella, under which is a smiling, black-haired woman and two happy-faced children. At the base of the photo is the caption: ‘*YWCA Crabtree Corner*’.

A large reception desk is positioned to one side of the foyer. The staff person sitting at this desk can see the main entrance, several other doors, and the entrance to the elevator that goes to the upper floors. The door at the far end of the foyer, opposite the main entrance, opens to Sheway’s ground floor reception area, where women can meet one another and staff and obtain a free lunch. Sheway also has a reception, clinic area, and offices that comprise part of the third floor, which is accessible by the elevator.

Along one end of the reception desk, is another locked door that provides access to the area behind the front desk, some of the staff offices along a hallway, the kitchen where meals are prepared, and its adjacent eating area. Other than Crabtree personnel, people seeking access to the kitchen and eating areas must gain admission to these areas with the assistance of personnel, usually the staff person positioned at the reception desk.

Also in the foyer, is the door to the ‘donations room’, where people often drop off bags of clothing, toys, or small household items. Occasionally, delivery personnel entered the door with a big load of donations. On one occasion, a local film company called the centre to offer a donation of new plush toys. During the hours when the donations room is open, usually three or four days per week after 2 p.m., there is sometimes a flurry of activity as women go in the room to find items of clothing for themselves or their children.

Adjacent to and near the main entrance, is a separate entrance, also visible from the front reception desk. This private entrance has a locked door, accessible to the women who live in one of the 12 self-contained subsidized units, located on the 4<sup>th</sup> and 5<sup>th</sup> floors, which comprise Crabtree’s housing. Only personnel or the women who live upstairs can access the housing floors without permission. A video camera located at the front desk makes visible activity in the hallways of the housing area. Anyone who wishes to gain access to the second or third floors asks for admission from, or gets the attention of the front desk staff person, who presses a button to ‘key’ the elevator for use.

Crabtree’s daycare, daycare staff offices, and outdoor play area are located on the second floor. On the third floor, Sheway and Crabtree share space for some of their respective offices and regular programs. Along a hall toward the back of the building on the third floor, Crabtree has a small library with a computer and work space, an open meeting area, another office, and two meeting rooms, one of which has basic kitchen equipment where the women attending the group programs can meet and/or have lunch.

Adjacent to the open meeting area near the group meeting rooms, a richly coloured wool blanket with a rainbow that arcs along the top, hangs on the wall. One woman told me that the wall hanging is representative of different First Nations tribes – among them Cree, Carrier,



Mohawk, Gitskan, and Flores Island. This blanket is a visual reminder that First Nations traditions are relevant to at least some of the women and children who come to Crabtree.

### **3.0 The women and children who come to Crabtree**

When I began my field work at Crabtree, I often sat in a location behind the large front reception desk near the main entrance, where I had an opportunity to see the main door and talk with staff or chat with women and children who came into the building. This observational ‘post’ allowed me to observe, hear and, in the way that allows, enter the everyday world of children and the women who come to Crabtree Corner. The observational note that follows suggests, superficially, that Crabtree is similar to many settings in cities and towns across the province, where mothers bring their children to attend daycare or engage in various scheduled or ‘drop in’ activities.

This segment of observational data is a moment in the lives women and children as they arrive at the centre. It is February. A cold wind is blowing outside. The children entering the building with their caregivers are bundled in warm hats, coats, and mitts against the chill morning air. Some of the infants are still asleep in their strollers. Other small faces, partially obscured, peer out sleepily from under their quilts. Older children with rosy cheeks clutch their caregivers’ hands and, as if in unison, stamp their boots. Women and staff members greet one another by their first names and exchange an apparent familiarity with one another’s lives. One woman gives an update on her morning sickness and another – the progress of recovery for a sick child at home with her grandmother. I was struck by the congeniality and warmth evident among and between the women and staff. When one of the women who regularly comes to the centre, later talked about Crabtree, she explained to me: “We’re like a big family”.

As I became familiar with this setting, I also learned about the kinds of concerns many of the women faced in their daily lives and how much effort they put into trying to improve the conditions of their lives and those of their children. What I learned caused me to puzzle about the unique features of Crabtree and women's activities in this setting. I also queried how the professional's routine description of the women who attend Crabtree constructs them as different from mothers who go to 'Door Number Three' when they need help.

### 3.1 "Like a big family"

Over a period of time, I became familiar with many of the people who enter Crabtree's door. Gradually I discovered that my initial impressions and the informal greetings and exchanges I had been observing and hearing, which seemed reminiscent of a small 'family-like' community, obscured the diversity of women who come to Crabtree, the scope of their needs and concerns, and the various and complex circumstances in their lives, some of which I try to reveal in these pages.

For the most part, those who enter are women – women alone, in groups or with children, young women, and older women depending on the activity occurring at the time of day. Among the women who have children in their care are biological or 'birth' mothers. Some women are family members such as aunts or grandmothers who have stepped in to care for children when their own mothers were unable to do so. The term 'mothers', as I now apply it, is a general descriptor for all these women and for their 'mothering work'. In exchanges I heard between the children and their caregivers the women are, for the most part, known by some variation of 'mom'. Over the course of my field work, I saw many 'moms' with children ranging in age from infancy to elementary school-age. Often in the morning, the foyer was filled with the sounds of children laughing, playing, crying, and also greeting staff and other women and children.

On occasion, fathers or male partners accompanied women or children to Crabtree. One day, for example, I saw a woman and two children arrive at the centre with a man, whom I later learned was her partner. They entered the kitchen area to have breakfast, but the young man left a short time later to take one of the children to school. Occasionally one man, who is the primary caregiver for his child, arrived with his child to attend the daycare so that he could take the bus on the weekly trip to the Food Bank.

Women from diverse ethnic groups attend the centre. Among the women I interviewed individually, over ninety-five percent either self-identified as Aboriginal or made reference to features of Aboriginal life, such as growing up “on reserve”. In the focus group I conducted, all participants with one exception, either identified themselves as “First Nations”, “Aboriginal”, or “Metis”, or they referred to their experiences living on reserves or in residential schools. The exception was one woman who laughingly told me, “I’m still old-school Indian”.

Chinese women regularly arrive at Crabtree’s door, primarily for the hot lunch program the centre offers. Crabtree personnel tell me they are seeing a growing number of Chinese women from nearby Chinatown, and an increasing number of women from other countries who have moved to this area. I also periodically saw women of white Caucasian appearance enter the door, some on their way through the foyer to the reception room in Sheway. I recall one pale, blond-haired young woman, whom I will call Shelley, who looked to be somewhat out of place when she stopped at the reception desk. She said she and her children had been staying in women’s shelters and she was looking for help with legal concerns. She returned to the centre over a period of several days and, on one occasion, we had a conversation (see Chapter Seven).

The majority of women who arrive at Crabtree live in the Downtown Eastside. Some of the women who make use of Crabtree’s services live in the building’s subsidized housing.

During the course of my interviews, I talked with women who have stayed or are staying in women's shelters, at least until they reach the thirty day limitation common to most women's shelters, when they must move elsewhere, sometimes to yet another shelter. When I talked to Shelley, for example, she and her children had just moved to their third shelter. The lack of safe, affordable housing is only one of many other concerns women have about their well being and that of their children.

### 3.2 Introducing women's concerns

As I began to converse with women in and around Crabtree, I could hear in the ordinary ways they talk about their activities and concerns, their experiences as embodied knowers. For example, I heard in how some talked about their efforts to find a safe place to live, the exhausting physical, mental, and emotional work that standardizing discourses about 'the homeless' obscure. Cammy, who is pregnant, has been renting a room in a downtown eastside hotel with money obtained through social assistance, but she tells me that the room in the hotel "freaks her out". Cammy says that the hotel has bed bug infestations, and the landlord has given each tenant a plastic cover for the bed which, she tells me, just helps to "incubate them." Cammy says she is afraid of being alone in the hotel, so she spends her nights sleeping at a women's shelter where there are other women around to help her feel safe.

Like Cammy, a number of the women I talked with rent rooms or units with kitchens for themselves and their children in nearby hotels or apartments, while they wait for permanent housing. Leslie, who lives in a nearby low-rental apartment building, is desperate to move. She explains, "I'm worried to let my son out because of the junkies and needles and condoms. There are no play areas downstairs for him." She acknowledges that she expects a lengthy wait: "I'm probably 14,200 on the wait list." Some women I talked with live in subsidized housing in areas

within Greater Vancouver, including one young woman who takes a forty-five minute bus ride Monday to Friday for the support she finds at Crabtree.

Emily (see also Chapter One), like many of the women I interviewed, is desperate to find not only affordable housing, but also paid employment and reliable childcare. Emily has been using Crabtree's emergency daycare, which allows her some time to search for work and regular childcare. In the following interview segment, Emily reveals how the lack of consistent, safe, affordable childcare<sup>7</sup> threatens to keep her living on welfare or working in low paying jobs:

I want to work and I'm worried about daycare. Because I work at night usually. When you start in a restaurant you usually do 4 to 12 and no daycare is open 4 to 12. And then who am I going to get 4 to 12? I've got [name]. She used to babysit when I worked part-time but her husband was accused of some child abuse, molesting a child, and I don't know. I don't trust him. Who can I trust? Like there's nobody to watch my child.

Emily is under pressure to find paid work, even when it means placing her child in vulnerable care situations. Policies<sup>8</sup> introduced after the current Liberal<sup>9</sup> government assumed office in 2001 allow Ministry workers to terminate a parent's social assistance when a child is three years old. Emily explains that she has been getting letters from the Ministry that warn her, "Well, you have to be working by such and such...".

As I listened to Cammy's, Leslie's, and Emily's accounts, which I understood analytically, to be their 'embodied experiences', I could also hear how outside events and activities, concerned with housing, finances, and access to publicly funded services, are

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<sup>7</sup> British Columbia has no provincially funded daycare program. Similarly, consecutive federal governments have reneged on promises to fund a nationally subsidized program of child care.

<sup>8</sup> In April 2002, the Ministry of Housing and Social Development (MHSD) (2008) introduced two year time limits for employable people receiving income assistance. Exceptions would apply, among others, to pregnant women or single parents with children under three. See also Klein & Pulkingham, (2008) *Living on Welfare in BC*.

<sup>9</sup> BC's Liberal government is generally conceded to be a coalition of right wing parties, which differs markedly from Canada's Federal Liberal party.

impinging on and organizing their everyday experiences, and those of others in the setting. In talking of their concerns, women express features of their everyday lives, as well as bringing into view the social relations that are organizing them (Campbell & Gregor, 2002).

Women also expressed concerns about their children – concerns that include difficulties with sleeping, troubling and troublesome behaviours, challenges that their children were facing in school. Ashley is worried about her daughter. She tells me, “I just pray that she’s normal and that she doesn’t have a hard time in school.” Ashley said her baby was born with low weight and she is worried that her child may have been affected by the drugs she had been using when she was pregnant. Emily is also worried about her child, who is having difficulties with her speech, and she is hoping to have her child assessed to determine whether or not she has FAS. Jennifer blames herself because she used alcohol during her pregnancy and now her child is having difficulties in school and calls himself “stupid”. These types of concerns, in contrast to those related to housing and childcare, appear to be of an individual nature involving children’s growth, development, and possibly even self worth, as well as their mothers’ feelings of responsibility for them.

In the following excerpt, when Jennifer identified another concern expressed by so many of the women – the fear of being judged, she offers to me another view of women’s experiences and concerns:

Instead of being pushed aside, they need to be heard. Quit judging these women. Quit putting them in...quit categorizing them, low income, poor native women, uneducated, this and that. They are all educated. I mean, they struggle in life because they don’t have the education, the time to go to school, or find a job. They’re raising their children and if

they're done raising their children, they're raising their grandchildren, their nieces, their nephews, and a lot of it is not by choice what they do, it's just handed to them.

Jennifer challenges the notion of 'choice' and the attributions of blame and individual responsibility in which this notion is grounded. I understood her to be challenging the stereotypical assumptions that poor women and poor, First Nations women choose to live their lives on welfare. Jennifer observes that some of the women, who have raised their own children and are now raising grandchildren or other family members, are doing so out of necessity rather than choice.

However, Jennifer's views also reflect a tension – a contradiction – between her concern over the judgments that are being rendered about women, and the judgment Jennifer applies to herself for her child's difficulties in school. Jennifer's views of her own concerns and those of other women suggest a complex field of social relations may be organizing their experiences and even their knowledge of themselves and their responsibilities. Jennifer's comments also raised questions for me about Crabtree's 'back door' or at least, why so many poor First Nations women enter it for help.

### 3.3 Routes to Crabtree's door

For women who walk, live, or work in the area, the entrance to Crabtree is often made visible by a line that begins to form before the door is opened at 2 p.m. for the free lunch the centre offers. Women arrive at Crabtree or the adjacent Sheway through both formal and 'informal' routes. Alice, at home, isolated, and trying to care for her children, one of whom had severe health problems, learned about Crabtree from a friend. Similarly, when Anne was homeless and pregnant, someone she met who was familiar with the help Sheway offers to pregnant women with addictions brought her to the centre. Emily first came to Crabtree when

someone in the Aboriginal Centre in a nearby neighbourhood suggested she could get food and clothing to help during her pregnancy. Leslie came when she was working on the streets. She said she had known about Crabtree for a long time, and her first visit was when she ‘dropped in’ to have a hot lunch.

Some women are directed to Crabtree’s door at the suggestion of social workers, community nurses, or school personnel. Cammy first came to Crabtree in compliance with her social worker’s ‘supervision order’. Acting under child welfare legislation, a child protection social worker can mandate certain requirements through which Ministry workers can maintain surveillance on a mother who is deemed to pose a risk to her fetus or offspring. As an expectant mother, Cammy has been attending Crabtree daily in order to comply with her social worker’s requirement that she maintain ‘community visibility’. To maintain ‘visibility’, Cammy visits Crabtree and Sheway daily, where she uses the phone or computer, has a hot lunch, and meets with other women or staff. Cammy says if she does not make an appearance daily, her social worker “gets upset”. This reaction suggests that, not only is Cammy’s life highly regulated, but also, that Crabtree personnel have an informal place in the child welfare system’s surveillance of mothers. However, when Beth was pregnant she was subject to more rigorous and formalized practices. In addition to complying with her social worker’s demand for community ‘visibility’, Beth also had to submit to the state’s surveillance of samples of her urine, which are tested for the presence of drugs. What I was learning from women is that representatives of the state have also found a route to Crabtree’s back door or, at least, an indirect presence through informal arrangements for regulating and managing mothers. Yet, in contrast to the more rigorous state surveillance practices some women have experienced, Crabtree is a ‘safe haven’ or, at least, a safer one for them.



### 3.4 The work of personnel: “Safety is a major issue”

My post behind the reception desk helped me to orient to the location of different services in the building and to how women gained physical access to them. During my first full day at Crabtree, I noticed that the main entrance door to the building is always locked. In order for anyone to enter from the street into the foyer and the other areas in the building, the person trying to enter must get the attention of a staff person at the reception desk, who pushes a button to temporarily release the lock. A member of Crabtree staff is always present at the desk to monitor the door and control access to the centre when it is ‘open’, a practice that seemed, at first glance, to contrast with the description of Crabtree as a “family”. When I asked one of the staff members why the main door is locked, I learned that “[a]n incredible number of women [here] have abusive relationships, and safety is a major issue for them”.

Many of the women I interviewed described their experiences of violence and abuse at the hands of men. Maintaining safety for women in this setting generally means keeping men out. I heard about one incident when this safety practice failed, with distressing results. The incident, a serious physical fight, occurred sometime after someone gave approval to a man to drop-off his child at Crabtree’s daycare without informing the appropriate personnel. Everyone in the building including the man’s former partner, whom he had subjected to abuse, was taken by surprise when the man and woman suddenly encountered each another one morning. This incident stimulated the development of safety policies that would help personnel to more effectively manage the approvals process concerning access to the building.

From my vantage point as an observer, I began to notice that safety was a major issue for women and I saw how safety concerns coordinate the everyday work of managing the door at Crabtree. In order to manage the door effectively, personnel must be knowledgeable in whom to

admit. Some days, for example, there was a progression of people, primarily men, bringing deliveries and donations to Crabtree, and these individuals were readily admitted to the building. I did not see any men turned away from the door. Men on the street may also be knowledgeable – in terms of which agencies and meal programs will admit them or not.

Safety concerns can also be an issue between women. On one occasion while I was sitting near the front desk, I heard loud voices coming from the donations room, which was open that day. Two women had selected the same item of clothing and were arguing over who would get it. A staff member quickly intervened and took the women outside. On another occasion, I saw a woman denied entrance to the building. Personnel later explained that this woman had previously been involved in conflicts with other women and is, therefore, now excluded from the building.

Through my observations and discussions, I began to understand how much effort personnel and women put into trying to manage safety. For women who attend Crabtree, concerns about male violence extend well beyond Crabtree's door, to where women live, work, or even find a meal. For example, when one woman explained that she would not go to any drop in centre or soup kitchen where men were present, she made it clear how important it was for her to attend a place that excluded men. I could hear in her descriptions just how much physical and emotional work she had to put into finding a place to eat where men were not present.

One morning when I arrived at Crabtree, I noticed a fax sheet on the reception desk that alerted me to other dangers women face and their local efforts to protect themselves and one another. One of the local agencies had received a report of a sexual assault the previous evening and had sent warnings to agencies in the area that serve women. These types of warnings often

originate when women report their experiences to staff members in one of the local agencies or, on those occasions when police issue bulletins to alert them.

Staff routinely posted safety warnings on a bulletin board that women can see as they pass by them on their way to the kitchen. One day, while on my way to get a coffee from the kitchen, I noticed a woman had stopped at the bulletin board to read and on my return, I stopped to see what was there. Here I have copied one of the “weekly updates” I read titled, *BAD DATE REPORT FOR DECEMBER 7, 2006*, which included the following safety warning. While less descriptive than some of the warnings, here is what I read:

ATTACKED AND ROBBED: White male, 30-35 years old, 6’4”, 240-260lbs. Shaved black hair, brown eyes, “Biker” type. Tattoo on left arm, block style lettering, large letters down forearm to wrist, also tattoo on left shoulder. Drives a 1989 or 1990 Olds, 2-door hardtop, he says he is a dealer/grower from Mission. Picked up girl behind Mar-Mac store at 148<sup>th</sup> and 108<sup>th</sup>. Took girl at 100<sup>th</sup> and 104<sup>th</sup>. Asked for a hand-job but couldn’t cum. Wanted money back. As soon as the girl handed it back to him, he grabbed her hand and attacked her. He is very violent; he also had a knife and gun in the back seat.

This text and similar ones that were appearing on bulletin boards and counter-tops, warn women about individual men and the risks women face from having encounters with them. The presence of such texts, which I have not previously encountered in other health, educational, or daycare settings where I have worked or participated, reveals some of the safety concerns that are a routine part of women’s daily lives and work in this environment.

### 3.5 Text-mediated knowledge: a standardizing way of knowing

My observations in Crabtree have been introducing me to various texts that offer clues to the work activities and experiences of women in the setting. In my next segment of data, I

discover how a text that people make use of to talk about a mother's experiences, also coordinates a way of knowing about the women and children who come to Crabtree, or at least, about some of them.

One day while I was observing activities from my post in the reception area, I noticed a group of people gathered around the poster I introduced earlier, which hangs in the foyer and features a First Nations woman and her children protected by the brightly coloured umbrella. The Chief Executive Officer (CEO) of the YWCA was escorting a group of about twelve officials involved with the United Way Campaign on a tour of Crabtree. Members of the group listened intently as the CEO talked about the poster and the story of the people in it. As I observed this activity, one staff member explained: "That sign is a good place to start the tour because it shows how far someone can come with support". Here is an abbreviated version of the story and my analysis of how it works in the setting.

Amy [a pseudonym], featured in the poster, has two children one of whom has been diagnosed as FAS. Amy grew up in a family where she experienced excessive alcohol use and abuse. She began to live on the street by age 13, and became addicted to drugs and alcohol. During her teen years, Amy gave birth to several children. One child was adopted and two other children were apprehended by child welfare authorities. Eventually Amy entered a treatment program for women and through her efforts, and the help she received, she is now – in the terms related to me – "clean and sober". Amy also began to attend Crabtree, initially on a 'drop in' basis for a hot meal, and later as a participant in the weekly FASD prevention group. Over a period of time, Amy also regained custody of her two children, mentored as a volunteer/facilitator in the group, and found paid employment helping other women and children. Amy is a former recipient of the 'Courage to Come Back' award, an annual award sponsored by

Coast Mental Health and she has told her story of recovery publicly in texts and through her attendance at conferences.

As I listened to this story of one young woman's challenges and her determination to make a better life for herself and her children, I was moved on hearing what she has accomplished. I could understand, therefore, how the images on this text, and the story behind it, might engage the 'readers' of the text – potential funders and fundraisers – in supporting Crabtree's programs. For visitors and potential funders to this setting, 'reading' the images on the poster and hearing the story of one woman's courage and determination, may well evoke a response that the text (or those who produced and displayed it) intends.

The poster also signals a unique accomplishment of texts – their coordination of standardized and standardizing way of knowing about women in this setting, their drug/alcohol use, their children, and the 'problem' of FAS. As I continue my exploration and discovery of work practices in the setting, including those involving texts, I am also querying what forms of knowledge/knowing the local *work* coordinates. In the next two sections, I overview the scheduled services/programs and identify organizational work efforts intended to help the women and children who arrive at Crabtree's door.

#### **4.0 Crabtree's services: organizational work**

My descriptions of Crabtree's programs and services introduce features of the organization and the work of the personnel. They also allow me to provide further glimpses into women's efforts to access the services and how 'help' is organized for them. Crabtree Corner provides both regularly scheduled programs and 'drop in' services Monday to Friday from 8:30 a.m. to 4:30 p.m., apart from Wednesday afternoons, when there is an early closure that allows for staff meetings. The calendar I have titled "YWCA Crabtree Corner February 2007" identifies

regularly scheduled weekly programs and services the agency offers. In what follows, I provide brief descriptions of services, which also point to some of the extra-local sources of funding:

- Drop-in lunch 2 p.m. to 3:15 p.m. open to women (and their children); Wednesday lunch is ‘soup and bannock’ from 10:30 a.m. to 1:15p.m., which allows for Wednesdays early closure<sup>10</sup>
- Emergency daycare (see below)
- FASD Intergenerational Group (Mondays 10 a.m. to 1p.m. including lunch), an FASD prevention, education, referral, and support group for caregivers, mainly grandmothers caring for their grandchildren, developed with funds from the provincial government
- First stage FASD Prevention Group (Tuesdays 10 a.m. to 1 p.m. including lunch) for mothers/pregnant women/women with children in their care to provide education, referral, and support; core funding from health authority and the provincial government
- Cooking group (Tuesdays 10 a.m. to 1 p.m.)
- Food Bank Group Tuesday morning (a staff person drives a van for the weekly trip to Unitarian church’s food bank in the south side of the city)
- CAPC<sup>11</sup> (Community Action Program for Children) Parent Action Group (Thursdays 10 a.m. to 1 p.m). CAPC is a Public Health Agency of Canada

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<sup>10</sup> Noted on the calendar for the third Wednesday of the month is an entry that reads: “CLOSED CHEQUE ISSUE”. “Cheque issue” refers to the day of the month when the Ministry of Social Services and Housing issues social assistance cheques. A staff member explained that the reason for the closure is that when the women receive their monthly ‘welfare’ cheques, they are anxious to shop for food and other items that they have been without. On the third Wednesday, the daycare is open until 2:30 p.m. Here in the calendar, although I did not read it ‘correctly’ at first, is another example of text-mediated knowledge about the women at Crabtree, which also standardizes how one is to know them.

(PHAC) initiative to promote healthy child development, parenting, and life skills education.

- Single Mothers Support Group (Fridays 2 p.m. including lunch)
- Saturday Family Activity Program (11:30 to 4 p.m.) for families who reserve a space in this program, which provides lunch and family activities and trips (e.g. to recreational and educational sites in the city)
- Legal Advocate (available Tuesdays 9 a.m. to 4 p.m.) and other referrals  
The referral to a legal advocate is one of the many referral services Crabtree staff offer. Staff referrals may connect women and their children with programs, services, and workers in Crabtree or at other sites that may assist them in their search for housing, child care, medical and other forms of professional support, and advocacy. Members of Crabtree staff also offer assistance and advocacy, and make their support available to women and children where they request it – in the hospital, a courtroom, a clinic, school, or at home.
- Violence Prevention Program, involving one-to-one support and referral for women dealing with violence in relationships, support during court proceedings, and individual/family support and home visiting.
- The Key Worker and Parent Support Services, which I discuss more fully in Chapter Eight, is a provincial MCFD government-sponsored program intended to assist families who have a child who has, or may have FASD.

The scheduled programs and services are, from all accounts, well attended. For example, an entry in my field notes indicates that 150 lunch bags were handed out on Friday February 13,

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<sup>11</sup> CAPC was created in 1993 following Canada's attendance at the United Nations World Summit for children in 1990 and an agreement to invest in Canada's vulnerable children, see <http://www.phac-aspc.gc.ca/hp-ps/dca-dea/prog-ini/capc-pacc/about-apropos-eng.php>

2007 – the day of the week when the kitchen offers a cold lunch. The van that transports people to the Food Bank each week is generally full to capacity. On the week I attended there were eight others in the van and room for a few more. There were nine women at the Single Mothers group meeting I attended including two new members and two women who had been going to the group for over a year. Women who attend any of the weekly groups are entitled to receive a ten dollar grocery voucher each time they attend.

Many of the services and forms of help available are clearly intended for poor women and children. The meals, donations of food, trips to the Food Bank, and food vouchers offer vital sources of nourishment and/or support. Similarly, the emergency daycare, advocacy, and referral services act as ‘stop gap’ measures that assist women to cope with urgent and emergent needs. Crabtree personnel also put a great deal of effort into advocating for women who are trying to access services outside the agency or negotiating with personnel in work sites, such as those related to child welfare supervision, public housing, and other bureaucratic and administrative functions. For example, one informant showed me the new twenty-two page form that mothers must complete if they are applying for a child care subsidy. According to my informant, the complexity of this textual work often leaves mothers going without the subsidy.

Regularly scheduled programs at Crabtree offer an opportunity to build relationships and engage women in regular contact with personnel. I will be exploring features of the work of the FASD program in Chapter Seven to learn more about how this program may be addressing women’s concerns. Access to some programs can be limited, for example, one woman told me she had to wait several months to attend the CAPC group. In the meantime, she attended the FASD Prevention group instead because, at the time, it was accessible.



## **5.0 Women's access to services**

Some services, such as the YWCA housing and the daycare are in high demand and may require women to wait in order to access them. In addition, some services and programs are not equally accessible to all the women and children who come to Crabtree. I draw from observational and interview data concerning some of Crabtree's services, to provide examples of how access is organized and managed. This section also reveals some of the tremendous effort women must make to access the services that are available and how I have come to see that 'accessing services' is as surely work for the women involved as is the provision of services by personnel.

### 5.1 Breakfast

Shortly after the centre opens in the morning, women begin to enter through the normally locked front door that a staff member opens for them. I notice that women stop at the front desk to talk to staff, often either prior to entering the kitchen or after their breakfast. Most of the women who come at this time of day are known to the staff and therefore, a staff member readily opens the locked door leading to the 'kitchen' area where people enter for breakfast. Through the early part of the morning, there is a general buzz in the area as women and children gather at the front desk, greeting one another and staff, all of which seems to contribute to the 'family-like' atmosphere. Crabtree Corner offers a free breakfast – coffee, tea, juice, toast, cereal, hot cereal, and so on. Women often come with their children for breakfast, before taking their children to school or daycare, or sometimes both. Each day that a person enters the kitchen for breakfast or lunch, she is required to sign a sheet to indicate her presence and that of her children. This text collates statistics on the number of meals Crabtree serves, information that can be useful in the YWCA's efforts to elicit financial support for Crabtree.

Admission to breakfast is limited to women whose children are attending daycare, to women volunteering their services, such as meal preparation, and to women who are involved in one of Crabtree's regular programs. These restrictions contrast with the hot lunch program later in the day, which is open to any woman or child who shows up (apart from those who may have been specifically excluded, as noted earlier in this chapter).

## 5.2 The 'drop in' lunch

The lunch program is a 'drop in' service available to any women or children, including those who come in off the street to have something to eat. Often on Fridays, the kitchen staff and volunteers prepare a bag lunch rather than a hot meal. I recall that one of the bag lunches I enjoyed was tasty and nutritious, containing a ham sandwich, freshly-baked cookie, apple, and container of juice.

The work of providing access to the lunch program engages the staff member located at the reception desk in admitting women and, at times, instructing women when to arrive. On several occasions when women came to the door early to seek entrance to the building, personnel advised or reminded them that the door would open at 2 p.m. to admit them for lunch. I did not observe any occasions when women were admitted earlier into the foyer where they might have been able to stand out of the cold and wait for entry to the kitchen area.

To describe women's efforts to access lunch as 'dropping in' obscures the actual efforts that women make to access this service, and also how much some of them depend on it. An entry in my field notes on February 13th indicates that, among the many women who entered the door for lunch, were thirteen Chinese-speaking women. Judging by the stooped posture of some, and slow gait of others, they appeared to be quite elderly. According to staff, a growing number of

elderly women who live in ‘Chinatown’ walk a number of blocks to reach the centre for lunch on the days it is open.

On several occasions, I noticed a queue forming outside Crabtree where women were waiting for a staff member to open the door. At a cursory glance, standing in a line appears to be effortless, but one day I saw several women waiting for almost twenty minutes in the chill winter air. I was also learning from talking with women that, for some, their efforts to access food in the setting were only a small part of their daily work of seeking meals and sources of food. For example, one woman explained that she stood in a ‘soup kitchen’ line several days per week to wait for her supper. She also said that she was selective about where she would line up for a meal because of the pushing and conflicts that developed outside some ‘soup kitchens’. Her comments reveal that she had researched different sources of food supplies to make a good choice, not only for the food, but also for the safest place to ‘wait’.

One day early in my field work at Crabtree, I noticed another type of queue developing. The waiting area in front of the desk, where a staff member greets and assists women, seemed to be getting quite congested as women gathered to speak to a staff person. When I asked one woman what was happening she said that they were all waiting to see if they could get a spot for their children in the daycare that day.

### 5.3 The daycare

The daycare at Crabtree is one of the services that women say is “essential” to them. Crabtree offers an ‘emergency’ daycare, where parents may access up to 72 hours of daycare time per month. This provision allows too little time for a parent to attend a regular job, but it does help with time to attend to other children, personal needs and concerns, and to provide respite from caregiving. The daycare, which is open on weekdays from 9 a.m. to 3:30 p.m., has

24 spaces for infants and children ages 6 weeks to 6 years. These spaces fill rapidly for each of the days the centre is open.

Crabtree personnel provide a system of booking into the daycare that divides women into different 'access' groups. Women who are attending a regularly scheduled program, such as CAPC, Single Mothers, or FAS/D Prevention groups, can book their children into the daycare in advance for each day in the week they attend a program, within the restricted monthly quota. Otherwise, women who are not attending groups can call after 1 p.m. on Wednesdays to try and book any remaining available spaces. One informant told me that the most difficult day to gain access to the daycare is Tuesday morning because there are two groups running and, as well, a number of women (and in my observations, one man) are trying to go on the weekly run to the Food Bank. Ann, who has two children, describes the process of booking:

It's only emergency [daycare] so you have to phone every Wednesday. The only thing guaranteed – the only day I know I'll have daycare is Thursdays – cause I have the group, but otherwise, it's kind of a toss of the dice whether or not I'm going to get daycare or not.

Ann depends on the daycare, especially for one of her children who has behavioural issues with which daycare personnel are assisting. She told me that she is also undergoing a major transition in her life, which is overwhelming. Ann explains that she needs to find regular daycare, but she doesn't want to take her children from this daycare because "this is the only place they've been comfortable with".

Ann has the assurance of one day per week of child care she can depend on. Some women who have not been able to reserve earlier or, who may have an unanticipated need, may come in to the centre in the morning to try and obtain a space for that day. At times there is a

cancellation or someone does not show and those who are waiting may be lucky enough in their “toss of the dice” to find a day of child care.

#### 5.4 Access work

I could see how much work staff members put into trying to find a space for women who are making the daily daycare requests, either in person or by telephone. In an attempt to ‘fit’ a child into the daycare, the work of staff members includes drawing on their own knowledge and expertise – knowing when a child is ill and may not be attending, or whether someone who had called to book a spot the week prior was likely to cancel, perhaps, as she had on previous occasions.

During the afternoon, one of the staff is often busy at the front desk answering the telephone while she enters bookings for the daycare into a large calendar chart spread out on the desk. Women are permitted to start phoning in the afternoon, to put their names forward for a space that may be available the following day. Some women, like the ones I observed clustered around the desk one morning, sought any remaining openings or cancellations that might be available that day. I heard one woman say she needed to see her social worker. Another woman asked if she could get a spot in the daycare the following day to attend a custody hearing. I could see the relief on the faces of women standing at the desk when they learned that a space in the daycare was available for their child.

I began to appreciate how women’s own efforts to access the daycare involve physical, mental, and emotional work on an ongoing basis. One of the contradictions concerning ‘respite’ is that while allowing mothers to take time away from their children, the child’s presence in the daycare engages mothers in work activities that become part of the organization of mothers’ unpaid ‘child care’ work. For example, one of my participants, who was trying to access the

daycare for her child so she could go out and look for work, explained that to get a space in daycare also involved getting to a phone and finding the money for the cost of her calls. Her other option was to make a request in person, but this meant walking to Crabtree with children in tow or finding the money to go by bus. What her explanation was showing is how common-place and ‘invisible’ work activities, such as using a phone to obtain child care, actually involve effort, money, and planning for someone who does not have ready access to the things that so many people take for granted. Yet women’s efforts are necessary in order for them to get these rationed services and, in the case referred to here, to get ‘respite’.

An abbreviated entry in my journal for February 9 shows how much work there is, even in the ‘waiting’ for services:

*I’m going to carry this image of women lining up: women must queue for the number that they need at the Food Bank, in order to access a second line so they can pick up food items, for getting into lunch at 2 p.m. when the door [at Crabtree] will open, and for waiting for a spot to see if they can get their children into daycare.*

The image of women, and sometimes children, lining up to access food or other services contrasts with discourses about people on ‘welfare’ and how they ‘cannot be bothered to work’. My observations were showing me just how hard women work for the goods and services that I/others can take for granted.

Even going to a Food Bank is not simply a matter of picking up food. People lining up as first time registrants have to show identification, such as their Care Card<sup>12</sup>, as well as an income slip to demonstrate they are on welfare or low income. A statement of income is taken as evidence that the individual actually requires the food. Each person is given a number and some tickets that allow her to select some of the preferred items such as eggs and baby food. Since our

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<sup>12</sup> This is the BC Medical Card, which identifies the individual’s eligibility to publicly-funded medical services.

group was only one of many arriving at the Food Bank, it took the group I was with about an hour of waiting before people began to progress through the line. Some people watched anxiously as choice items disappeared. One young woman in my group was hoping for oriental noodles and baby food. Another young mother said it didn't matter what she got, the choice was not as good today as it is sometime.

These various examples offer only a glimpse of women's efforts to access food, daycare, and other services. All that queuing women must do is exhausting. The physical effort of trying to get to a phone, wait in line, contact a social worker, or find food for the family, represent only a small portion of women's everyday work. In addition, the emotional toll women face in trying to find food, shelter, and income to care for their families may be made worse, as the next segment of data shows, by work processes that also extract women's compliance with legal, administrative, and other organizational requirements.

In her effort to gain much needed respite and help with her children, one woman I will call 'Lorna' contacted the ministry (MCFD), who offered her a 'family preservation worker' for support. The worker was supposed to relieve some of this mother's work of trying to manage her apartment and care for her children on limited means, time, and emotional resources. Initially, this support looked promising, however, Lorna explained that when the worker discovered that the family cupboards routinely contained only rice, cans of beans, and other supplies from Food Bank offerings, the worker reported the mother to the social worker, who then criticized the mother for failing to provide her family with more nutritious meals. My informant concluded that she and her family would be safer without the aid of the 'preservation worker', whose help heightened her sense of vulnerability and also, as it turned out, the degree of surveillance by her social worker.

## 5.5 Housing

Some of the women who attend Crabtree live in the transition housing units located upstairs in the building. The housing is ‘YWCA’ housing, which Crabtree oversees. The units are intended for pregnant and parenting women who are involved in treatment or programs to overcome problem substance-use. Sheway allocates the twelve subsidized self contained units to their clients, some of whom may also be clients of Crabtree. Women who live in the housing are not permitted to use drugs or alcohol on site or while attending programs in the building.

While this housing fills an urgent need for shelter, safety, and support for the women who are able to access it, it is only an interim measure in the lengthy struggle for suitable shelter that so many women face. Women who are pregnant when they enter housing can remain until their infants are up to, but no older than, 18 months of age. Similarly, Sheway’s support services are also discontinued when the child reaches 18 months of age.

When I talked with Ashley, whose child has just turned 18 months, she stated she was still waiting to see if she had another place to live. She also explained that this was the last week during which she could obtain support from Sheway and that she was very worried about losing her “safety net”. She explained:

Eighteen months is too early for people to quit Sheway because if they just stopped doing drugs, like two years is the point where they can actually go back to using. There’s like a 90% chance of uhmm – relapse. But if you make it past two years then it reverses.

Ashley’s story suggests that institutional work processes for managing and rationing resources and services to women and their children are not serving her interests when the services are withdrawn leaving her with nowhere else to go for similar support. While Ashley knows she is lucky to have had this housing and support in her child’s early life, her need for support and



housing does not end when her child reaches eighteen months. The experiences of Leslie, Emily, Ashley and others I interviewed demonstrate that these access limitations are shaped, not by women's interests or "what women say they need", but by ruling practices.

#### 5.6 Routes to alternate sources of help

From my own observations and the reports that women provided, Crabtree personnel make every effort to provide help to women, within the constraints they face. When Crabtree personnel are unable to provide the assistance that someone is seeking, they make considerable efforts to look for other resources to help them.

I was at the reception desk on the morning I recall seeing Shelley and her children shyly approach the desk and I heard her explain why she was there. The staff member at the time greeted her warmly and arranged for her to return to see another staff person at a specified time. The staff member then talked with Shelley about services and programs at the centre and explained how she could book a space for her children in the daycare. Personnel later made arrangements for Shelley to see a lawyer who works in a not-for-profit agency that offers legal advice and assistance to women.

Staff referrals may connect women and their children with programs, services, and workers at other sites that may assist them in their search for housing, child care, medical and other forms of professional support and advocacy. Members of Crabtree staff also offer assistance and advocacy, and make their support available to women and children where they request it – in the hospital, a courtroom, a clinic, school, or at home. Crabtree staff also offer one-to-one support and referral for women dealing with violence in relationships, support during court proceedings, and individual/family support and home visiting through the Key Worker and

Parent Support Services, a government-sponsored program intended to assist families who have a child who has, or may have FASD.

Despite all the efforts of personnel to advocate for services or to gain improvements in supports for women, I have been learning about some of the barriers both women and their advocates encounter. One informant tried to summarize the difficulties women face in gaining access to sources of ‘help’ outside Crabtree:

Money and housing. Food. Access to food. They [women at Crabtree] get a very minimal amount of money, so therefore, they have to live in below standard housing. Housing, like cockroaches and infested with mice, landlords don’t keep up well, or illegal suites. They don’t have choice. The ministry, when I am talking about the ministry right now, the Ministry of Employment and Income Assistance<sup>13</sup>. They seem to think that, “What do you mean? You get \$530 a month. What are you doing with that money that you can’t afford a place to live?” I’m serious, that’s the attitude. Food. They’ve got four, maybe three or four hundred dollars. That’s supposed to pay cable, telephone, hydro, if they can’t find a place that doesn’t have hydro – food, transportation, daycare, clothes, and any other, like prescriptions, medical or any kinds of sports maybe the kids are in. And the social workers, these employment assistance workers will say, “Well, what about your child tax credit? Why don’t you use that?” “Well of course they are. But I, I don’t eat much, but I alone spend \$400 a month on food you know...They are very resourceful.

In light of all the barriers to ‘help’ that women and their advocates encounter, it becomes possible to understand the importance of the non-judgmental and caring attitudes of personnel.

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<sup>13</sup> At the time the study was conducted, a single ‘expected to work’ parent with two children received \$881 per month to cover basic costs of shelter, food, and other requirements of daily living. The ‘expected to work’ category required that a parent had in place a ‘return to work’ plan. The Ministry of Employment and Income Assistance has since been re-named Ministry of Social Development.

Women's efforts to access services, and the constraints they encounter, reveal disjunctures between what women say they need to improve their lives and the social organization of the 'help' available to them. They also reveal how women's experiences and work activities offer ethnographic ground for an analysis of how those engaged in the work of 'ruling' – visible in this chapter as actions and inactions – organize women's and children's everyday lives.

## **6.0 Summary**

In my ethnographic exploration of the setting I have been introducing material aspects in and around the building, the types of programs and services, and my observations of interactions related to routine activities. I have also been discovering aspects of the embodied experiences and work activities of the women who come to Crabtree. Women have been showing how hard they work, and also, that regardless of their efforts they cannot provide nourishing meals for their families by relying on Food Bank offerings and emergency meal programs. Similarly, while access to the emergency daycare is vital, the limitations in hours/spaces do not enable women to find and manage paid work, obtain safe affordable housing, or continue their education.

Crabtree personnel, in my observations, make every effort to create a supportive 'family-like' environment responsive to women's needs and concerns. However, at the same time, all the queuing up women must do as part of their efforts to access emergency and stop gap services for the provision of food and childcare is exhausting and reveals that, in some respects, this setting is highly regulated. Forms of regulation, visible in the locked doors, queues, and restrictions in access to services, leave something wanting from what might be construed as a 'grassroots', family-like setting responsive to the needs and wishes of 'vulnerable' women and their children.

Crabtree's participation in providing 'informal' surveillance for women who are under orders to maintain 'community visibility', reveals work activities that are implicated in the state

apparatus of child welfare, practices that also seem to contradict descriptions of the setting as a ‘safe haven’. At the same time, I have been learning that when personnel take on the work of advocating with representatives of government services on behalf of women and children, they also come up against a ruling apparatus that makes inflexible demands on women and poses barriers to improving the conditions of their lives. My observations make visible contradictions between the agency’s goals to provide safety and support for vulnerable women and institutional work processes that may actually compromise women’s safety.

My exploration of Crabtree has also made visible how institutional discourses, textually-mediated in categories and concepts such as ‘at risk’ and ‘FAS’, have entered the setting and are routinely heard in the talk of personnel and the women who come to Crabtree. These observations point to a knowledge disjuncture concerning women and children, which is represented by “different versions of reality – knowing something from a ruling versus experiential perspective” (Campbell & Gregor, 2002:48). As I follow women at work in the setting, I am discovering how an individual-institutional interface may be shaping women’s concerns and even their children’s embodied experiences in this setting.

‘Institution’, as I have been observing, is not the place, the personnel and the programs, the sources of funding, or a well-concerted organizational effort to support vulnerable women and their children. Institution is discoverable *in* the social relations being established in this local setting by women’s participation in definite forms of activity. The data concerning women’s work and women’s talk in this setting offer glimpses into women’s engagement with institutional processes, which I will continue to explore in the following chapters.

As I conclude this chapter, I am left with many more questions and puzzles to explore. How am I to understand the contradiction between the notion of Crabtree as a safe, family-like

setting and, on closer examination, a centre that engages in activities which also regulate women? What forms of knowledge and institutional relevancies are entering this local site and how are they shaping women's work, and even how women and children are known? What are the social relations at work for women and their children in *this* setting that restrict access to services through the 'door' which opens for the "parent with a car, and a home, and the ability to fill out forms"? How do these different 'doors' or entry points to services organize or possibly change women's lives, for better or worse? In the next chapter, I move from my initial exploration of this 'back door' work site, to a more detailed discovery of the work activities of Crabtree's women clients as they interface with their professional and lay helpers. I will be looking for the social relations that rule the setting and also querying how women's work becomes integral to their own ruling.

## Chapter Six

### Women at work, Part I: Producing and managing the ‘at risk’ child

*We are become a society which is essentially defined by the norm.  
(Foucault in Lotringer, 1996:197).*

#### 1.0 Introduction

In this chapter, my attention shifts from the concerns mothers have been expressing with regard to housing, safety, child care, and other challenges in their daily care of their children, to concerns some mothers are expressing about their children’s behaviours and whether they are ‘normal’ or not. As I begin this more detailed exploration of women’s talk and text-mediated work activities, I am also exploring the social relations of the setting, identifying a work interface between mothers and professionals in regard to their children, and discovering discourses and work practices concerned with identifying children’s risks.

My exploration derives from the analytic ground of my problematic where I discovered a line of fault between women’s standpoint in their everyday concerns about their children to a standpoint in objectifying forms of knowledge concerned with preventing and managing children’s risks. I am querying how the embodied ways of knowing children, which mothers tend to rely on are transformed into objectifying ways of knowing that are authoritative, medical, and or psychological. How does Crabtree’s engagement with women and children who use their services re-organize their talk, their ideas and beliefs, and even how women come to understand their children’s – and their own – behaviours?

To explore these questions, I introduce Allie, Anne, and Emily and interview data which allows me to examine their various concerns and differing professional responses to them. A large portion of this chapter is devoted to Emily and her child, Alix, as I examine how professional practices for establishing knowledge about them take an oppressive turn, which

contrasts with the help that Allie and Anne are receiving. To bring to light how Emily and her child interface with experts, I will follow a text that is part of the daily routine through which each mother gains her child's admission to the daycare. I discover and show later how the text activates ruling relations involving Emily and her child.

## **2.0 Organizing a 'risk' discourse in a local daycare**

Crabtree's emergency daycare is a professional work site staffed by certified, authorized Early Childhood Educators. Daycare personnel provide caregivers opportunities for respite from the round-the-clock demands of caring for children. In Chapter Five, I made visible some of the work efforts women engage in to try and access the daycare and, thereby, revealed the vital place that child care support holds in women's lives.

In their provision of care for children and respite for parents, daycare personnel are present, not only to feed, clean, and manage children's bodies at meals, toileting, sleep, or play. They also interact with parents, particularly during those periods of transition when the mother is leaving or picking the child up at the end of the child's day. Early childhood educators are trained to be astute observers of children's behaviours, and their expertise allows them to offer support and guidance that may assist mothers who are struggling to manage or make sense of their children's fears, 'acting out', and other troubling behaviours. Childhood educators in this setting can also draw on or engage the work of experts, including health care professionals knowledgeable about early childhood development, who can offer professional consultation to personnel and/or parents in response to specific issues or concerns. I now turn to some of mothers' concerns and I explore different stages in mothers' work with personnel and professionals who are available to help mothers with their concerns.

## 2.1 Beginning in mother's everyday/night work: "My baby cried all night"

Mothers at Crabtree, like parents anywhere, enjoy talking about their children and concerns they have about them. As I listened to mothers talk about their lives, I have also been learning from them about their children – when this child began to walk, what new words a child has begun speaking – as well as mothers' own worries and what kinds of services are helpful to them. During informal visits to the daycare, I became familiar with children by observing them and also talking informally with daycare staff. Observations and talk often took place while I held a child who needed comforting or offered an extra hand at lunch-time to help with feeding an infant. Observing and assisting in the daycare gave me an opportunity to recognize some of the children I had been hearing about from their mothers and to learn about mothers' own efforts to help their children.

In the following presentation of data, I introduce a young mother who is struggling to care for one of her children. I show how Allie arranges to bring her children to daycare and begins to engage with professional providers in the site. The analytic usefulness of introducing Allie is to show how she draws from her experiential knowledge as she talks about her child in contrast to the professional discourses that I later discover in Anne's and Emily's talk.

I first saw Allie with her two small children, one still an infant, when she entered the building one day and asked about the daycare program. She looked worried and anxious and I was unable to hear in her quiet, hesitant voice what questions she was asking. Several days later, she left her children at the daycare and I had a chance to talk with her during a trip to the Food Bank. Allie said she was worried about her infant's crying. She told me she seldom had enough sleep and that on this particular day she was exhausted because "my baby cried all night". Allie told me how her infant's cry filled the room and distressed her so that she could not sleep or



comfort her child. Allie said that in the months since her child had been born, she had never been away from him and had no one else to help her in the care of this infant and her other young child.

Later, in the daycare, when I held and tried to comfort her infant, I too heard the child's persistent cry and felt my heart rate rise in my own bodily response to it. I also heard staff members express concern about their difficulties settling this child and how the child's cry caused distress to other children in the room. Daycare personnel had been talking with Allie and listening to her concerns about her child's crying. They have suggested that she try leaving the child in the daycare for only short periods. It remained unclear whether this plan might assist the mother and the child or minimize the disruption in the setting caused by his persistent crying. Perhaps both goals can be achieved.

Allie's talk reveals her 'embodied' knowledge gained through her daily (and nightly) experiences of caring for her child, holding him in her arms, trying to comfort him and silence his cries now, in this cold dark room where she struggles to stay awake. In contrast to Anne, whom I introduce next, Allie is still at an early stage in her engagement with professionals in the daycare.

### 2.2 A mother develops expertise: "Ok, that's normal"

Standing outside one morning in the outdoor play area, I noticed a young child who was in constant motion. Moments after he began circling a space in the play area with a small push toy at his side, he discarded the object in preference for a different toy that another child held at her side. In his activities of taking up and discarding toys, the child circled at a dizzying pace.

A few days later, I sat with 'Anne' as she talked about experiences and concerns that had initially brought her to Crabtree. Anne said that before she came to Crabtree, she was homeless

and had a “drug addiction”, from which she has since “recovered”. Among Anne’s present concerns are some ‘behaviours’ that her child has been exhibiting. As Anne talked about her child’s behaviours and her engagement with an expert who assisted her in understanding them, I could hear how she drew from a body of professional knowledge to explain her concerns about him. For example, Anne explained that her child has “separation anxiety” and an “anxiety disorder”. It was only later when I heard her child’s name that I recognized he was the busy little child I had been observing. Had Anne identified her son through her embodied knowledge of him, that is, as the child who was in constant motion, rather than as one with an ‘anxiety disorder’, I would almost certainly have recognized him!

Anne said that her child often “freaked out” if he was on the other side of the room from her, and she had been struggling to understand how to manage his reactions to being away from her. She said that for most of her child’s life, he had never been separate from her, and that despite frequent moves and her own challenges of recovering from substance use, she has been the only “constant in his life”. Anne drew my attention to how that otherwise ‘constancy’ was interrupted, at one point, when the child was apprehended and placed in foster care for several months.

Anne explained that after she began bringing her child to Crabtree, Anne’s engagement with staff included discussions about his slow speech development and his “behavioural issues”, along with a trial of various parenting strategies at home and in the daycare. Eventually, daycare personnel connected Anne with health professionals who offer consultation, including education, strategies, and support to parents whose children are having behavioural difficulties. One of the experts observed her child and exchanged notes with staff that helped to coordinate efforts to assist Anne and her child, and later, conducted a psychological assessment. This professional

assessment assisted Anne to understand that Billie has an ‘anxiety disorder’. She also learned that her child’s apprehension by welfare authorities during a sensitive period in Billie’s development would account for some of his anxiety, which is characterized by his excessive activity and “acting out”. The health professional also informed Anne that some of her child’s anxiety may be “genetic” and tends to run through families. Anne said that a family member does have problems with anxiety, a recollection which seemed to confirm that the knowledge frame, ‘anxiety disorder’, had been correctly applied to her child. Anne is learning, therefore, not only how to think of her child’s behaviours and concerns, but also how to understand the causes of them.

One of the puzzles motivating my inquiry has been hearing mothers talk about how they ‘knew’ that their children’s problems were caused by their alcohol use. In a setting where I had been hearing/observing talk and visual reminders concerning FAS and women’s alcohol use, I found it curious that a discourse on ‘drug addiction’ or FAS did not also enter into Anne’s (or apparently the professional’s) causal explanations of Billie’s troubles. What might account for differences in how mothers come to *know* the cause of children’s problems? Perhaps, I wondered, are there different experts who draw on different ‘authoritative’ knowledges in the setting?<sup>1</sup> One could also speculate that Anne’s social location as one of the few women who did not self-identify as Aboriginal, may also account for her particular expertise. I even wondered if Anne’s social location, in this case, her ethnicity, may account for how authoritative knowers, such as those she has been working with, select the relevant knowledge frame that will inform her knowing. Anne was also one of the few women I encountered who had not attended the FAS

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<sup>1</sup> Although public discourses which link women’s illicit drug use with children’s problems are widespread (see Boyd, 1999), they are not, in my view, as well-coordinated and ubiquitous as the text-mediated discourses on maternal alcohol consumption and fetal harm, visible in bars and other drinking establishments in British Columbia, as well as on the walls at Crabtree. I also note that Anne, unlike most of the other women I talked with, has not attended the FASD prevention group which, as I show in the next chapter, instructs women in the FAS/D discourse.

Prevention group work, which I discuss in Chapter Seven, and this suggests that she may not have been introduced to an FAS discourse or, at least, has not developed expertise in it.

When Anne talks about her child, Billie and the concerns she has about him, her talk implies the presence of psychology/medical texts and a child development discourse, which are shaping her knowledge of her child. Anne says that by talking with the health professional, she has been learning more about her child and can now distinguish between his experiences: “Ok that’s normal, that’s not a behavioural problem, that’s just a two year old boy thing.” Anne’s talk reveals different aspects of her engagement with normalizing discourses, one that constructs a version of ‘normal’ chronological male development and another that inserts a psychological discourse on ‘abnormal’ behaviour. In each case, discourses on ‘normalization’ inform Anne’s knowledge about her child and engage her in the work of making her child known discursively.

Normalization discourses, which coordinate the practices of health professionals and those in the ‘early childhood development’ (ECD) field, organize expert knowledge about children’s growth, development, cognitive, and behavioural experiences at a given chronological age. Experts, notably in the medical and psychological sciences, have developed a body of knowledge and normalizing practices for assessing, measuring, and producing valuations of people’s behaviours, to which names are then applied that represent people’s ‘differences’ from an idealized norm. Until recently, experts often applied the label ‘deviance’ when naming people’s differences, however, this label, which has been criticized as stigmatizing, is no longer widely used (Brock, 2003). Anne’s talk demonstrates how she is developing expertise in one of the distinctive practices of ‘normative institutions’<sup>2</sup> (Malacrida, 2003) – that of producing

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<sup>2</sup> Malacrida (2003) observes that the labelling of children with a disorder occurs at the nexus of a number of institutions and discursive practices at which “the family, education, psychiatry, medicine, motherhood, and childhood meet” (p. 24). She particularly references the discourses and practices of professionals which Castel (1991) calls the ‘psy sector’, or the disciplines of psychology, psychiatry, and social work.

‘normality’ or making distinctions between what is ‘normal’ and what is not (i.e. the concept of *abnormal* differences). Her talk also reveals how these practices organize standardized versions of human experiences which can be applied to render an authoritative account of the normal/abnormal child.

Smith (1990a) argues that discourses and practices in producing differences among people are ‘ideological’ because they are at odds with knowledge or knowing that begins from people’s experiences. These objective and expert practices of knowing produce what is ‘true’ within a field of knowledge, but they also exclude alternate knowledges or ways of knowing which may be possible (Mills, 1997; Smith, 1990a). The shift from experiential knowledge to authoritative biomedical frames also offers avenues of understanding how knowledge practices are exercised in relations of power (1990a). I have been discovering, as De Montigny has observed in another context, how “power is realized day by day as individuals work together and build relations of trust ... inside the logic and sensibilities of organizational life” (219). As I proceed with my analyses, I am querying how these institutional discourses and practices work as ‘help’ or treatment and I am also asking, what do they accomplish, for better or worse?

### 2.3 Knowledge for action: “*We can help if we can get a hold of it now*”

I have been showing how, in contrast to Allie’s experiential descriptions of her child, Anne’s account of her child’s problems and ‘differences’ reveals an engagement with an external authority whose text-mediated practices over-ride her embodied everyday knowledge of her child, helping her to understand him in the language and terms of professional discourses. The latter operates as part of the support that Anne has gained from the centre. In the following segment of data, I show how Anne’s newly acquired knowledge of her child’s abnormal behaviour articulates with discourses that generate action.

Anne has been explaining to me her understanding of the causes of Billie's variances in experiences, which she understands according to the concept and category 'anxiety disorder'. In the next segment, Anne states: We can help [with the anxiety] "if we can get a hold of it now". Anne's talk expresses an urgency concerning the need "to get a hold of it now" – to continue her work engagement with experts in order to apprehend or intervene in the problem [Billie's anxiety] *before* things get worse. Anne's talk implies the presence of texts that reference discourses on 'prevention'. 'Prevention' is a call to action in order to minimize the 'risk' of the dangers or harms that may arise if early intervention fails. Anne's talk implies the presence of a discourse on levels<sup>3</sup> of prevention and associated practices for minimizing 'risks', which are common features of professionals' 'early intervention' work. Concern for her child has motivated Anne to learn as much as she can in order to manage Billie's risks.

Billie's behaviours, which identify him as a child who is 'at risk', position him on a trajectory that poses possible future dangers and unknown risks should his 'acting out' behaviours get out of control. 'Help', offered as actions to minimize risks for children with 'anxiety disorders', often includes the use of medications, as well as parenting, behavioural, and cognitive strategies that prevent an escalation of the behaviours identified. At present, the experts involved in intervening with Billie are engaged primarily in developing Anne's expertise for managing him. Anne is learning to apply behavioural management strategies to help contain his unruly behaviours, now categorized as 'anxiety disorder'. Thus far, Anne is pleased with the progress she and Billie are making. One must speculate that if Anne and the experts she works with are unsuccessful in managing Billie and the risks he poses it may follow that experts may eventually intervene with more stringent behavioural or medical interventions to control him. Anne's efforts to intervene to manage Billie's behaviours motivates her participation in the work

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<sup>3</sup> See Chapter Three regarding what experts call the 'levels of prevention'.

processes through which these objectifying forms of knowledge about a child become authoritative, influential, and persuasive for Anne or others at work in this setting.

I have been showing that discourses on ‘prevention’ and ‘risk’ operate as a subtext or ‘subdiscourses’ (Smith, 2006) to the authoritative professional discourses and practices for identifying and intervening with the normal/abnormal child. Smith employs the term ‘subdiscourse’ in reference to professional discourses that establish a common language of knowing that “subsumes experiential knowledge” (2006:4). Power is realized as professionals instruct a mother in how she is to think about her child, and as she learns new skills to manage him according to the interpretation provided by an expert in child behaviour.

What I describe is not intended to imply that the information and knowledge that Anne is gaining about her child is not helpful to her or to her child. In Anne’s situation, the professional discourses in which she is developing expertise, appear to be consistent, at this stage, with her concerns and the kind of help she says she needs to manage his behaviours. In this discussion of Anne’s work I am making apparent how, as a mother, she learns to make sense of her child’s behaviour in the particular way that the organizational and professional work going on here helps her to do. Her child is a child ‘at risk’ and she is learning how to manage his risks before things get worse for both of them.

In the next section, I introduce Emily and her account of what she feels she needs by way of help for her child. I observe differences in how Anne and Emily orient to professional practices in the setting and different discourses concerning their respective children. In order to bring to light how ‘help’ is organized for Emily, and how she and her child are to be acted upon, I must first turn to mothers’ work engagement with a routine text through which mothers gain their children’s admission to the daycare. My analyses in the next section will reveal how

women's text-mediated work with a routine intake form is a central feature in the organization of help for mothers and children attending Crabtree's daycare. Subsequently (section 4.0), I will show the courses of action this text-mediated work generates for Emily and her child, Alix.

### **3.0 Women at work: authorizing consent**

Texts or the implied presence of texts are routine features of people's everyday work activities. In human services organizations, images, words, forms, and policies are directed to specific purposes, people, or activities in a work site and they are the forms through which coordination occurs (Rankin, 2001). Texts, and the materiality of texts, enter into what people do and connect what they do here, at this site, to activities and doings organized elsewhere (Smith, 2005). Because texts are integral to what people do, text-mediated work can be investigated to reveal what texts intend and what they accomplish, organized in the 'administrative' terms that make people 'actionable' (2005; Smith, 1990a). In the next segments of data I trace my discovery of a simple text and show how reading, writing and otherwise working on it enters women and their children into an extended field of social relations.

#### 3.1A 'routine' activity: *I hereby consent for my child...*

During the course of my field observations, I noticed that each time a mother/caregiver entered the building to take her child to the daycare she stopped at the reception desk. At first I assumed that, in this 'family-like' setting, where women and staff members regularly exchange greetings and information about their everyday lives, the activity at the desk was simply part of a social interaction. However, it gradually became apparent that *every* time a mother enters the building to take her child to daycare – even when the child enters on three consecutive days – the staff member hands a copy of the same one page form to the mother, which she fills out and signs before she and her child make their way with the completed form to the daycare.



The text I had been observing at the front desk is titled, *YWCA Crabtree Corner Child Care Daily Intake* (Figure IV, next page). Crabtree's daycare is a licensed child care facility. The intake form is an expression of government licensing regulations that require an agency to develop specific policies and procedures concerning the care and supervision of children in licensed daycare settings. Personnel explained that because Crabtree is an 'emergency' daycare, parents are expected to supply information at each 'intake' that will assist professional daycare staff in their care and supervision of children.

The first section of the text collects routine information that identifies the child/parent, including the child's name, sex, birthday, mother/father/s name, time of entry to the daycare, who will pick up the child and at what time. The text also asks for information on basic care requirements: when the child last ate and slept, the type of nutritional formula, presence of allergies, sleep position, and eating routines. Another line asks the caregiver to document the child's fears/dislikes. There is also a space for the caregiver to enter comments related to the day of admission to the daycare, such as where she/he can be reached by telephone, and the name and telephone number for an alternate contact in case of emergency.

The next section of the text contains a black rectangular box that demarcates the agency's requirement for parental consent and the items for which consent is needed. My interest is in this section of the text, which I display below. The content is highlighted just as it appears on the form below.

**Figure IV: YWCA Crabtree Daily Intake**

<p><b>CHILD WILL NOT BE RELEASED TO ANYONE NOT DESIGNATED ON THIS FORM</b></p> <p>Authorization/consent</p> <p>I hereby consent for my child, .....</p> <ul style="list-style-type: none"><li>• <b>To be taken by child care staff to the hospital for emergency treatment if I cannot be reached and if immediate attention is necessary.</b></li><li>• To be taken by child care staff for field trips which would include neighbourhood walks, walks to Crab Beach Park,</li><li>• Skytrain and Seabus excursions, public transportation to special events, etc.</li><li>• <b>For my child to be examined by Vancouver Medical Coastal health Department Staff.</b></li></ul> <p><b>PAYMENT</b></p> <p><b>I understand in order to cover the cost of this service: I must be eligible for <u>Subsidy</u> or pay \$5.00 per hour. <u>I will notify YWCA Crabtree Corner receptionist of changes to original registration information.</u></b></p> <p>Parent Signature.....Staff initials.....</p> <p>Date.....</p>
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The first three bullets refer to routine requests for parental consent to ensure the child’s access to emergency treatment or to trips and special events. The highlighted sentence at the fourth bullet asks the parent to authorize her child’s examination by Regional Health Authority medical personnel. The final statement, preceding the space for the parent’s signature, outlines the parent’s obligations for payment.

When I first read the sentence, highlighted at the fourth bullet, it appeared to me as another routine feature in the ‘daily intake form’ requiring a parent’s consent. However, re-reading the sentence, I noticed that there is no explanation indicated as to why medical personnel might examine a child. The usual ‘routine’ requirement for a parent to authorize emergency medical treatment, which presumably may include an examination, is already covered by the first bullet in the text. If a child is in a life- or limb-threatening emergency, parental consent for treatment is not required (Ball & Bindler, 1999). The language in the text, and the requirements for consent which parents must authorize, express features of an organizational mandate (Smith,

1990b) involving medical experts and state-delegated administrative functions. In the next section, I follow a mother's engagement with the text, and discover the institutional work processes she authorizes.

### 3.2 Text-mediated work processes: "Can I put in loud noises and pain?"

Most of us, in our daily lives, are surrounded by texts and become habituated to finding out what the text says, either as a resource, or source of direction to us (Smith, 1990b).

Analyzing a text, on the other hand, can make visible how people's 'routine' engagement with a text coordinates them with institutional functions and administrative practices in rather ordinary ways. I draw on an excerpt of observational data to illustrate how a text, and a mother's reading of and writing in it, engages her in activating the text (Smith, 2005). The assumption in this method of analysis is that the reader's interpretive reading and writing practices conform to those intended by the text (Smith, 1990b). *Activating* the text coordinates people's local practices with institutional processes that take place elsewhere (2005).

On the particular day in which I made the following observation, three women and one man were standing at the front desk. Each of the individuals is a parent who has booked a space for their children in the daycare. Three of the parents have received their 'daily intake' forms and are busy completing them. My attention is drawn to one woman who is bringing her child to the daycare for the first time. The staff person working at the desk hands the 'daily intake' form to her and asks her to complete it. The mother stands to the side of the desk and begins to fill out the form. Suddenly, she stops writing and turns to the staff person seated at the desk and asks, "Can I put in loud noises and pain?" I realize she is addressing the question on the text that asks the parent to identify the child's fears and dislikes. Once assured that her entry is appropriate, the

mother continues her writing and hands back the completed form. The staff person asks her to take it to the daycare staff.

In observing how this young woman, in her work of completing the text, asks if she can enter “loud noises and pain”, I am noticing how she engages with the text and responds to the authority that the text imposes. Working with organizational texts requires a special form of ‘literacy’, wherein the reader brings into effect an organizational process (Darville, 1995). As this young woman, who has just been introduced to the text, begins to develop ‘literacy’ in how to complete it, she does not pause to ask *why* her child might be examined – that is not the work required of her. The work of reading and completing a text draws the reader/writer into a type of ‘text-reader conversation’ (Smith, 2005) that requires attention to accuracy – in this case, the ‘correct’ filling in of answers that the form requires. The reader/writer learns to work with the text as a “constant point of reference” that guides her interpretation and work with it (Smith, 2001: 175).

The mother’s work in completing the text articulates to organizational and ‘administrative’ requirements. Completing and authorizing the ‘daily intake’ form establishes a relationship of ‘accountability’ between the caregiver and Crabtree. The text confirms respective obligations concerning the care of the child in the daycare, on trips, and so on, and the costs associated with that care. In putting her name to the text, the parent confirms her obligation to make payments for services the agency renders.

The statement at bullet four invites another level of accountability that organizes the mother’s textual work in ‘sequences of organizational action’ (Smith, 1990a). Here, the text inserts a governing body, the Coastal Health Authority, into the relationship of accountability with the caregiver. The parent who completes the consent form authorizes access by Coastal

Health medical practitioners to the child's body for purposes of an examination or, as I later show, observations. It is not apparent that anything in the text establishes the purposes, consequences, outcomes, or the Health Authority's accountabilities for the courses of action this textual practice intends.

The features of 'accountability' that appear in (or disappear from) the text place the mother/parent in a contradictory position where the text both establishes the mother's authority to act on behalf of her child, that is, to 'give consent', and also requires that she subjugate her authority to the text and to the work processes that the text mediates (operationalizes). The mother's ability to *access* child care in the centre *hinges on* her signing the text and, thereby, authorizing the work processes that the text intends. She has, in effect, no authority to refuse to give consent if she wishes to obtain daycare services.

To consent implies 'informed consent' – an exchange of information wherein one individual pre-authorizes whether another individual can take an action that affects or will affect his/her person (Hardingham, 2006). Formal or signed consent, according to ethical health care practices, must be given freely without any fear of reprisal (Ball & Bindler, 1999). The person who 'gives consent' is *giving* authority for another to act. If the individual to be 'acted upon' is a young child, the parent has the authority to make an informed decision, consistent with their beliefs and values, as to whether that action may occur. Giving consent in a medical or health care context is a regulated practice wherein one individual accedes or 'hands over' power to a professional to take a specified action.

The following exchange I had with two informants suggests that the work activities that involve staff in obtaining the parent's authorization, also places personnel in a contradictory position, or at least, an uncomfortable one. I began by asking one informant about the 'daily

intake' form and whether the request for a parent to authorize a medical examination would be a 'routine' practice in daycare settings. My informant responded to my question with an emphatic: "No", which underlined the *unusual* nature of the practice, as it occurs in *this* setting. In the next statement, my informant refers to the course of action that the 'consent' activates: "The consent does allow for [name of a health professional] to come in to observe the children".

The explanation offered by my informant, that the consent allows for health professionals to observe children, implies that this practice may be 'helpful' to the parent or child. However, this notion of 'help' obscures the relations of power at work in the setting and how professional accountability requirements to establish 'informed consent' have been breached. Power is realized as professionals, accounting for their practices as 'help', appropriate the right to make decisions about what is relevant (De Montigny, 1995). What I have been showing is that the text mediates ruling practices (Smith, 1990b) that enable health professionals to observe and examine children for purposes that are not stated and may not even be known, at least by the consenting person. The 'courses of action' that the text mediates are not identified. Nor in all likelihood will the full implications of giving their textual consent be apparent to the mothers who authorize the text.

The work processes I have been tracing point to contradictions in the organization of 'help' in a setting that, on the one hand, is 'oriented to achieving women's equality' while, on the other, obscures relations of power. The official textual accountabilities for 'informed consent' have not been rigorously managed in the setting to ensure that women's consent is *informed*.

The administrative, rational procedures of bureaucratically-organized texts, while appearing neutral may, in some instances, conceal "class, gender, and racial subtexts" (Smith, 1990a: 65). The work of this particular text authorizes a work practice that is a unique

constituent of the social relations of this setting. Any mother/caregiver who brings her child to this daycare, regardless of the number of occasions her child enters the setting, must complete the textual work that authorizes a professional to examine her child on behalf of a provincially-delegated authority. I am showing that the social relations of this setting organize different conditions of work for professionals who are concerned with producing and identifying women's and children as 'risks'. My analysis bears similarities to Manicom's (1995) analysis, in which Griffith and Smith (2005) argue that low versus middle or high income neighbourhoods create different conditions of work for parents and teachers.

The social relations of 'difference', such as those involving class, gender, and/or race appear to be at work in this particular 'back door' setting to undermine women's capacity to provide informed consent on behalf of their children. That the mothers in the setting are for the most part poor, First Nations women suggests that how human service workers see and *know* their 'differences'<sup>4</sup> discursively may account for the unusual practices at work in this daycare. What I am suggesting is that because this setting operates as a 'back door' for poor women to access services it also offers access to professionals who can slip in by the back door to conduct observational work and examinations that may not be tolerated or even deemed to be necessary in other social sites. In the next section, I turn to my own observations of these practices the text activates.

#### **4.0 Activating the text: Confirming the child 'at risk'**

I have been showing that the language in the text and the requirements for consent which parents must authorize express features of an organizational mandate (Smith, 1990b) involving

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<sup>4</sup> Culhane (2011) suggests something similar when she describes how representatives of Indigenous communities point to the historical continuities of objectification of their members as "sources of intellectual and biovalue, and their exclusion from benefits or profits so derived" (3).

health professionals working on behalf of Health Authorities and state-delegated administrative functions. That the text allows health professionals to observe and examine children also invites the questions: How do these practices work and what organizational functions do they serve?

In an institutional ethnographic investigation, the researcher traces observable activities involving texts in a setting, in order to situate the text “back into the action in which it is produced, circulated,” or read, or where it has consequences in time and place (Turner, 2006:140). I am now turning from my descriptions of the text and how people engage with it, to situating this textual work in the institutional actions and ruling relations the text brings into effect. In the following four sections I discover and explicate work practices in the daycare that the consent form activates. My investigative work includes sequences of talk and socially organized practices which are integral to discovering the textual coordination (Smith, 1990b) of work and of people’s everyday lives in the setting. I begin with the text-mediated work of screening children which, I discover, is also in the history of this setting and in people’s practices.

#### 4.1 ‘Screening’ practices: “*little mini counting heads*”

Professionals rely on particular kinds of knowledge and practices in the routine conduct of their work. Screening’ offers a relatively quick and inexpensive approach by which professionals may identify a condition or potential problem within their field of expertise and take steps to prevent or minimize associated problems. It is a prominent feature in ‘population health’, where professionals screen a population, a subgroup, or individuals to prevent or minimize their ‘risks’ for possible or future health problems (Petersen & Lupton, 1996). Some ‘screening’ tests, such as a community nurse’s practice of checking an infant’s weight, are



applied so routinely that parents may not recognize them to be a practice of screening for variances from ‘normal’ measures of growth and development.

During one morning each week, one or more health professionals visit the daycare. In the following interview segment, I learn about the form of professional involvement, which has been a routine feature in the setting for many years. My professional informant describes how health professionals have gained and continue to gain knowledge about the children through screening methods involving such simple techniques as looking (observing) and listening:

[Someone would] come down [and do] a little mini counting heads. Denver Development exams, interview moms, play with kids, and just have a – of the kids that came in randomly on a Thursday to this emergency daycare. What [name of person] did find – that over a quarter of these kids had easily recognizable early significant developmental concerns. These were without any in-depth testing, this was with a Denver and just listening to staff and looking. Their development was significantly off – more than we would say might be the five to ten per cent risk. We were looking at rates that were three to five times higher. Why? And we could see why. What [people] learned is that these women who didn’t have access to support, they didn’t have mothers themselves, uhmm, they themselves might have FAS, and this [Crabtree] was one safe haven for them to come where their kids and they got some information about [pause] around child development. And that twelve week, half a day a week experiment ended up being something that continued and then added to that was another piece we were doing with the Vancouver schools for doing outreach for kids with developmental concerns...

The Denver Developmental Screening Test (DDST) my informant refers to is a standardized tool for screening children from birth to six years according to knowledge in the field of Early Child

Development (ECD). The DDST is based on standardized measures derived from authoritative knowledge about children's developmental, cognitive, and behavioural experiences at a given chronological age. DDST screening involves measuring children against a set of 'norms' according to four areas of early child development: 1. social, 2. fine motor (small muscles) coordination 3. language, and 4. gross motor (large muscles) coordination (Ball & Bindler, 1999). The application of these standardized measures organizes evidence about children's developmental, cognitive, and behavioural experiences at a given chronological age. Variances in growth and development may then be used to construct 'facts' about those children. For example, children who do not measure up against the 'norms' may, depending on the extent of their variances, be identified as children 'at risk' for more serious problems.

The screening conducted on these children was not a routine public health project. It was, as my informant indicates, an 'experiment', funded by a short term federal grant. The professionals involved were *looking* for variances in children, drawing on an expert knowledge frame for how to see the children. They were also listening to what personnel had to tell them. As my informant explained, when professionals 'looked' they could see that there were an unusually high number of children who did not measure up to child development 'norms' in this setting, *and* they could also "see *why* [my emphasis]".

Their ability to explain *why* these children did not measure up relied on listening to what personnel had been learning about the mothers. Professionals and front-line workers learned that the *mothers* lacked support, proper 'mothering', and also that some of them possibly had FAS. The early cohorts of children and mothers, who have been screened and measured against discursive norms for 'healthy' children and, as previously inferred, for better-classed<sup>5</sup> mothers,

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<sup>5</sup> I refer to an interview in Chapter Five, which contrasted the women who attend Crabtree's 'back door' to those in upscale neighbourhoods where the mothers have "a home and a car and the ability to fill out forms". However,

apparently fell short. In this informal setting, the approach to *measuring* mothers against idealized ‘norms’ for mothers<sup>6</sup>, is apparently accomplished by talking with the personnel, a practice that appears to be even less standardized<sup>7</sup> than those applied to the children.

I am not disputing that the mothers lacked support or ‘mothering’. I have been hearing mothers talk about some of their experiences of losing their mothers when as children some of them were forcibly placed in residential schools. Some women in the centre also told me they had not learned to parent; the residential school system had destroyed not only Aboriginal families but also their culture and communities. However, my informant is not simply making an observation about how women in this setting “didn’t have support”; s/he is also assuming they have FAS. These observations both blame mothers for their children’s problems and also pathologize mothers as FAS, implying that they are not capable of mothering (see also Tait, 2003 for her analysis of intergenerational effects and FAS).

In this informal setting, the knowledge that professionals gain about children articulates with professional practices of *measuring* mothers. Mothers’ variances in experiences: – that they lack support, have not had mothers – an oblique reference to the role of residential schools and the tragic disruption of family relations among First Nations people – and had or may have fetal alcohol syndrome – are selected and constructed as ‘problems’ which are then used to *explain* variances in children’s growth and development.

Children’s developmental variances – measures that deviate from established norms – are constituted as developmental ‘failures’ which establish a fact about the child’s ‘risk’. Variances

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Malacrida’s (2003) cross cultural research (UK and Canada) on Attention Deficit Disorder suggests that the practice of blaming mothers for this condition is not confined to a particular class or country or other variables.

<sup>6</sup> The tendency for professionals to explain children’s ‘problems’ by blaming the parent, typically the mother, are well documented (see for example, Armstrong, (2003), Boyd, (2004), Malacrida, (2003).

<sup>7</sup> As a former public health nurse, my colleagues and I conducted our DDST assessments of children in ‘well baby clinics’ with questions we devised in a ‘risk’ assessment tool we used to also screen the mothers.

in mothers' experiences are also constituted as failures which are then used to provide the factors that determine the degree of 'risk' mothers pose to their own children. The practices of looking for variances in children's and mothers' experiences and explaining those variances in the context of pre-determined norms and causal frameworks substitute an "expert's 'reality'" for people's own knowledge and 'doings' (Smith, 2001:161). In the next two sections, as I continue to follow the text (the consent form) and the ruling relations it activates, I draw from my own observations to explicate how an individual child and her mother are screened and how they are recruited for this practice.

#### 4.2 Recruitment and screening practices: "I've got a concern"

The health professionals who visit the daycare to observe and screen children generally confine this aspect of their work to one morning per week. I arranged to be present in the daycare when health professionals arrived one day for this 'routine' visit. I gained permission to sit with them while they talked and conducted observations and measurements. Through piecing together various sources of data, I discovered that, contrary to the usual public health practice<sup>8</sup>, in which all members of a population or 'at risk' group are screened, the practice of screening is neither generalized nor random in this setting.

On this particular day, the professional 'gaze' was directed toward two children. One of the children who would be an object of interest on this occasion was Emily's child, Alix, whom I had previously encountered. When I learned that Alix, unknown to Emily, was to be an object of screening on this day, I understood how a mother's voiced concerns may initiate a sequence of work activities, previously authorized by her textual work at the front desk, which allows a health professional to observe or 'examine' her child. The following account of my observations

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<sup>8</sup> In my experience as a public health nurse, the nurses conducted basic screening tests such as DDST, on all the infants who attended the clinic. Further individual tests might then be applied when certain 'risks' were identified.

and interviews reveals how Alix came to be recruited for screening and how her mother's concerns helped to enter her as a suitable and eligible recruit.

I had already met Alix with her mother, Emily, in and around the centre. Alix was a lovely three year old who appeared quiet and watchful toward activities going on around her. On one occasion, I noticed her in the daycare sitting at a table, smiling while she placed animal shapes in the spaces cut out for them within a wooden puzzle. I remind readers that Emily, whom I introduced in Chapter One, offered one of the puzzles motivating my inquiry when I learned from Emily how she *knew* one of her children, a sibling of Alix's, had FAS even though s/he had never been diagnosed.

I had an occasion to talk with Emily previous to my visit to the daycare and it was through our discussions that I first learned she was concerned about Alix. She explained: "She's a beautiful child. But she can't talk. A speech therapist told me she's a bit behind. Well, obviously. She says, 'no, mom, dad, juice, milk' but can't put sentences together."

In addition to having an assessment by a speech therapist, Alix also had received an assessment to rule out a hearing impairment. But Emily explained to me that she has been asking personnel to help her arrange an assessment for Alix at Sunny Hill. "I want to know what I'm dealing with", she said. Personnel at Crabtree had been advising her that it was too early to have her assessed at Sunny Hill. Emily told me that daycare personnel have been telling her, "We'll wait and see if she doesn't change and we'll get her assessed."

Professionals concerned about a child's speech development generally consider early assessment and intervention to be a priority. Therefore, I could not understand why a formal and, presumably, a more comprehensive assessment that could be helpful to Alix and possibly relieve Emily's concerns, might be delayed. It was only later that I learned that 'Sunny Hill' is a

euphemism mothers and personnel often use when talking about a formal expert assessment for diagnosing FAS or FAS/D, which may take place at a specialized centre for children called Sunny Hill. I begin to understand that Sunny Hill is not only a place but it is also a complex field of socially organized activities that engages the participation of certain mothers and their children in this form of knowledge work. When Emily said she wanted to “know what she was dealing with”, she was revealing how a discourse on FAS had already entered her own consciousness and was organizing her concern that professionals might find FAS in Alix.

Childcare personnel whose work activities interface with those of children<sup>9</sup>, their mothers, and professionals who offer expertise in the setting, are well positioned to ‘recruit’ children for screening and for a possible later trip to Sunny Hill. They are also well positioned to recruit the mothers for informal screening – listening to mothers’ talk and relaying to the experts any information which may be relevant to assessing and confirming children’s ‘risks’.

In the following interview segment, I draw from one informant who elaborates on the work processes involved in recruiting Alix for work practices to establish her ‘risks’:

[y]ou have at Tier One, the front line. You have early childhood educators who see kids, and say, “I’ve got a concern”. They need to have a way to link with someone at Tier Two, which is sometimes specialized services, whether it’s infant developmental, or the community speech and language pathologist, someone to say: ‘We’ve got this little child in our centre, and we’re concerned’. And so [staff person] – that connection was made. [Name] picked up the phone and said: ‘Ok, so I’d come in on Thursdays, I see [Alix’s] applied skills, she’s active, mom [Emily] has shared her substance use history with

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<sup>9</sup> I am referencing a common discourse in the child development field which says that children’s ‘play’ is actually children’s work.

[personnel], she's getting her feet on the ground, starting to develop trust'. So the idea was to connect her...with [health professionals] who come to the site.

The work of recruiting children for screening involves gathering relevant knowledge and concerns, not only from those working with the child, but also from the mother, to activate a more informed observation and later diagnosis. In settings where 'accountabilities' are more rigorously managed, recruiting a child for observation by experts would likely involve texts and text-mediated processes such as referral forms, letters, or 'case recordings'. Here in this setting, through informal work activities involving 'talk' and trust, front-line workers gather and pass-on the relevant facts about the child and her mother to those who have the professional authority to make sense of them. In this setting, screening<sup>10</sup> brings a particular type of gaze on the child's mother. Among the particular 'facts' that front-line personnel may [and do] relate to health care professionals is that a mother has a concern regarding her history of substance use. In the context of a trusting relationship with personnel, Emily has shared her history and her concern, which will accomplish a "particular coordination of knowledge and action" (Campbell, 2001:233) directed toward, Alix, her child.

I am naming as *recruitment* the practices which coordinate the work of experts from extra-local sites with personnel, women, and children in this local agency to show that these are work practices that are institutionally relevant to the work of experts that is being accomplished. In this setting, recruitment practices identify who is 'at risk' and what those 'risks' may be. What I have to show next about Alix and her mother, Emily, reveals how professionals extract one particularity in Emily's experiences, which will stand as a 'fact' and as a factor that will confirm her child's risk status.

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<sup>10</sup> See also Kaufert (2000) analysis of screening practices as part of a detached medical gaze.

#### 4.3 Framing the child and her mother: “*The child has ...a ‘biomarker’*”

As I sat with three health professionals who were observing and discussing Alix, I was an uncomfortable participant-observer of their expert clinical work. Among the activities I was observing is how people, in their efforts to assist and help children who may have troubles in experiences such as speaking, interacting with others, or in moving their body [gross/fine motor coordination] with purposeful ease, exercise their power and authority to know the child’s experiences ‘objectively’. My discomfort was and is in recognizing, not only the knowledge practices at work, but also how I have, in my own nursing work with mothers and children, participated in them. As a mother myself, I also wondered what Emily’s response would be if she were to learn that the gaze of three health professionals and a researcher were fixed upon her child?

Through my own observations and the interactions that follow, I discover how the observational or ‘disciplinary’ gaze works and what it may accomplish. This ‘gaze’ is not one of merely looking at the child. It is, as my analytic data show, a practice of power concerned with gathering information “to inform and create a discourse” on its subject and, I would add ‘object’, in this case, the body of a child and the behaviour of her mother (Fox, 1997: 35).

During the course of the observation and discussion, one of the health professionals moved to sit next to Alix. S/he handed Alix an animal picture puzzle and an assortment of shapes to play with, and watched as Alix took up one of the shapes and held it before she set it back on the table. A short while later, s/he handed Alix a coloured block, and asked her the colour. Alix returned her attention to the puzzle and did not reply.

According to the DDST interpretive schema for measuring a child’s performance, a three year old should succeed in naming at least one picture – such as that of a cat, dog, horse, or bird.



By the age of three, some children, but less than 50% as measured against the ‘norm’, will name one colour (Ball & Bindler, 1999). The brief interaction I observed over picture puzzles and blocks appeared, at first, to be an effort in screening the child to measure for ‘delays’, accomplishments, and developmental ‘risks’ established by this measurement schema. However, this interaction was incomplete and did not involve the usual standardized set of questions or observations that would, in my experience as former public health nurse using the DDST, qualify as the usual ‘screening’ practice.

What I heard next suggests that someone had already discussed the ‘facts’ about Alix, and that the observations and activities were intended, not simply as ‘screening’ for developmental risks, but also as a learning event for some health professionals. As we observed the interaction between Alix and one of the professionals, one of the other authorized observers made a statement that alerted me to how clinical ‘observation’ is a practice organized in relations of power. The health professional stated to his/her colleague: “The child doesn’t look like FAS.” Power relations are enacted in this instance in which the observer, drawing from the authorized discourse on the ‘FAS face’ interprets the child’s face. Interestingly, I soon discover how the authority of this observer to make this pronouncement is over-ruled.

According to the FAS diagnostic schema (Astley, 2004) for assessing and measuring children’s faces the physical expression or ‘signs’ of fetal alcohol syndrome can be *read* in a child’s face. The reader’s interpretation of the face conforms to the interpretive schema of the diagnostic text that instructs the ‘reader’ in how to find FAS in the textual image ‘printed’ on the face. This speaker is revealing her/his attempt to read whether or not there are significant ‘differences’ in the face of the child. The statement, “The child doesn’t look like FAS”, suggests that either the reader is concluding that the child does not have FAS, or the reader is uncertain.

Either this reading does not '*activate*' the text with institutional processes that have been taking place elsewhere (Smith, 2005) in the production of the diagnostic schema, *or* this reader is not yet 'literate' in reading and authorizing children's faces as FAS. I understand from further discussions that some of the observers, who were *looking* for FAS that day, may have been *learning* how to 'find' it in children's faces.

To counter any confusion about Alix's facial appearance and how to read it, a second professional, apparently with the authority to do so, provides the others present with a set of 'facts' which establish the child's 'abnormality'. S/he states: The child "has a developmental delay, speech and language concerns, and a biomarker". Two of the 'facts, rendered in technical terms, demonstrate the child's failure, measured against a set of discursive 'norms', to achieve age-appropriate speech and development. Apparently, the facts about Alix are not in her face. This speaker's expert technical account objectifies Alix, while also subduing any questions or disputes that might arise in naming the embodied experiences of the child who was playing nearby, or in naming what could/could not be read on the face. Here, surely, the umbrella term FAS/D, once applied, will also be useful in subduing disputes about the face and whether or not it [the object] looks like FAS.

When I heard the set of 'facts' about the child, it was not immediately apparent to me that one of the facts that the speaker 'knew' was *about* Alix's mother. Unclear regarding the statement that the child "has developmental delays...and a biomarker", I asked the speaker what the term '*biomarker*' meant. The succinct reply was: "Significant alcohol exposure." I then recalled that a health professional had told me earlier [section 4.2] that *this* "mom has shared her substance use history". This fact obscures the knowers who, earlier, had passed on the account of the mother's concerns about her alcohol use. The evidence of a 'biomarker' and as [one who has]

‘significant alcohol exposure’ also obscures that the subject/object of the account is an actual person, a mother. In medical terms, a ‘biomarker’ offers objective evidence – the ‘gold standard’ of evidence – for the presence of a disease or disorder (Dumit, 2000: 222). In this form of evidence, this ‘risk factor’, there is no room for dispute. When the speaker told me what s/he meant by ‘biomarker’, s/he objectified the mother and inserted her *referentially* into an authoritative explanation for what is wrong with the child. Experiential knowledge or variances in the child’s or mother’s experiences, or even in the child’s face, that might allow for alternate knowledges concerning either, can then be discounted. The mother, discarded as ‘subject’, is the object perceived and referred to as the ‘biomarker’.

Referencing the mother and her substance use as a ‘biomarker’ provides a way to ‘make sense’ (Smith, 1990b) of the child’s failures and the ‘risks’ those failures pose. The production of the account of the child relies on procedures for telling ‘stories’ about a child/children “that isolate them from their own lives and the settings of their lives, constructs what is going on” as it is expressed by an expert, and as if it were an individual personality attribute and deviation (Smith, 2006: 77). ‘Biomarker’ *individualizes* the mother’s accountabilities for a wide range of variances in her child. Naming the mother as a ‘biomarker’ will accomplish all we need to know about the mother in order to establish that the child is ‘at risk’ for FAS/D. Establishing that the child has a biomarker also establishes the facts about what is wrong with the child and ensures that the “long transition of the patient from mostly subject to completely object” (Dumit, 2006: 580) may soon or possibly be confirmed. The final confirmation of FAS/D will require an authoritative textual account or medical diagnosis – work that can be later accomplished in the trip to Sunny Hill that Emily has been seeking. Even if the mother is ‘in recovery’, as is the case

with Emily, her *history* of alcohol use will ensure her accountability for any future pregnancies and the risks she poses to those.

When I sat at the front reception desk and first observed mothers signing the consent form that would admit their children to the daycare, I noted a ‘moment’ in their daily lives which, as I have learned, situates the mothers, children and the text the mother completes in local ‘course of action’ (Smith, 2005). Discourses and practices for recruiting children and screening them to establish their risks produce a ‘knowledge frame’ for action – action that may involve further practices of knowing. In discovering the clinical work that health professionals are conducting with children in the daycare, I have also been showing how a routine everyday activity – staff and parents’ engagement with the ‘daily intake’ form – initiates and authorizes practices in looking for variances in the experiences of children and their mothers which experts then convert to ‘risk’ factors – factors which make children and their mothers institutionally actionable.

In the next and final analytic segment for this chapter, a simple query I make about when Alix may be able to have her assessment at Sunny Hill, reveals that the work sequences accomplished by the ‘intake form’ may also initiate future courses of action in a field of extended social relations that will concert the activities of many more actors in multiple social sites (Smith, 1999).

#### 4.4: Preparing for future work sequences: “*It’s not a trip to Disneyland*”

Thus far in the chapter, I have been showing that mothers’ need for help generates mothers’ participation in relations of ruling including the objectifying FAS knowledge practices that are a prominent in this setting. Emily’s concern, which she has expressed as her need “to

know what I'm dealing with", is motivating Emily to have her child assessed for FAS at Sunny Hill.

Sunny Hill is a tertiary assessment centre or what one informant calls, "Tier Three". Agencies and health professionals in multiple settings throughout the province make referrals for Tier Three assessments which cannot be managed in local communities. Tier Three, as I learn from my informant, offers a higher level of expertise and, possibly a higher level of accountability than the informal work activities in Crabtree have demonstrated.

In the following interview exchange with a health professional, I began by reminding my informant that I had been present during the recent observation of Alix in the daycare, at which my informant was also present. Recalling Emily's desire to have an assessment at 'Sunny Hill' as soon as possible, I inquire about the work required to coordinate an assessment of Alix and I ask when the assessment might take place. My informant responds with a description that I come to see contains the institutional relations of service provision. My informant explains that there are often barriers such as transportation for families to go to Sunny Hill and that it "makes more sense [for a group of professionals] to go out for that Tier Three assessment". S/he explains that this concept of an 'outreach' service is called a "balloon model of support". I learn that Sunny Hill is the "large healing balloon", which has the "charts, the records, the professionals, the test materials, and then you see these balloons that come out to the inner city [location] [and] inner city schools". Here, my informant is showing that the outreach services offered to Crabtree are also offered to other 'back doors' and the people within them, notably those in "inner city schools". My informant's comments reveal that there are different conditions of work for professionals, front-line workers, and mothers in Crabtree than might be found in daycares or schools that are outside 'inner city' locations.

In the following interview segment, as I hear about the institutional work processes that will determine how, when, and where Emily's child will be assessed, I am also hearing how administrative discourses and practices situated in institutional relevancies, displace a mother's concern and request for a timely assessment:

And when you look at kids at her age, the best time to really do a full assessment for her for the concerns is just before kindergarten to really know kindergarten readiness. So the tests plus psychologists are not valid really until age four and if they [children] are delayed, closer to five, the better the validity [for] cognitive learning, prekindergarten readiness. So is this a child we're looking at who has a mild intellectual disability, is this a child who has a specific language based communication disorder? Is she not talking because she's not hearing, [or] is not talking because she has a specific language disorder, or is she not talking because it's a more global developmental disability? So by having a speech and language pathologist observe here to see her social play, that this isn't autism, to see that her fine and gross motor are developing adequately, we have a little better idea that we're observing her here and then there will be a time that she's being tracked, she's in the system, and then we'll bring her forward for a pre-kindergarten assessment.

What my informant's talk reveals is how the informal work of screening children and offering professional consultation and support at Crabtree, may be 'worked up' (DeVault, 2008) through more formalized assessments and later work sequences, in order to enter children into a standardizing administrative system for 'tracking' and monitoring children 'at risk'. The key time for assessing a child is not based on the standpoint of the mother or child, such as in Emily's request for help or with the child's troubles communicating. The timing of an

assessment articulates with ruling interests, including the administrative functions and admission requirements concerned children's schooling.

I remain concerned whether Emily's request for help will be addressed any time soon, and I ask my informant: "When you're seeing a child [locally] and have some concerns about the child's development, do you talk with the mom so she knows that Sunny Hill is available as a place [to go]?" In the exchange that follows, my informant responds, not to the issue of Alix's well-being and questions about her development, but to the work that Crabtree personnel do with the mother.

Informant: Yeah. Yeah. It's – it's – a whole lot again is done for us by the people who these women trust. So they come to trust the daycare workers here, [name] upstairs in the FAS/NAS program, the nurses, the IDP workers, so by the time they say "It's OK", they want to see the paediatrician, the doctor that comes – they've really – they know we're not there to take their child away or blame them, but we're there to support.

Researcher: Someone's talked to them about FAS/D or - ?

Informant: Or if it's FA – it's a touchy subject – "I'm worried about my child". "Is there something wrong with my child?" You know, many of them have had trouble in schools themselves; they have all kinds of worries so that it's, it's a process of developing relationship and trust and from that so they would see that going to Sunny Hill isn't like, it's actually, well, it's not like a trip to Disneyland, but it's actually something that's more support; but we might even find that it doesn't need to happen, that the support could be done at the schools. We just try to make it the same as it would be if this were my child on the north shore where I have access to a physician and a paediatrician and

transportation and a phone, so we try to remove the barriers and develop the trust and more important, that after Sunny Hill, there's something afterwards...

Apparently Emily's concerns about Alix will not be addressed anytime soon. In stating that assessments to Sunny Hill are not "like a trip to Disneyland", my informant seems to suggest that Emily might be relieved to know that this trip may not even be required of her. However, my informant is showing that the production of the final account of what is causing Alix's troubles, and where and how the diagnostic assessment occurs, is situated in institutional relevancies and not in Emily's concerns. Observations and discussions on Alix, which took place in the daycare, show that much of the investigative work concerning Alix and her mother (the 'biomarker') is already complete. Further assessments of the child prior to school entry will ensure that administrative requirements, which serve institutional purposes for tracking children 'at risk' in the educational system, will be completed.

I am discovering that the 'active' text and the sequences it generates may lead to courses, not only of action, but also inaction. Contrary to my informant's assertion that local practices for identifying the FAS/D child at Crabtree make the diagnostic work "the same" as it would be for a child on the north shore, medical encounters at Sunny Hill appear to be less available for Crabtree mothers and children than for those who gain referrals through their family physicians. According to one informant, less than five per cent of the children of birth mothers are assessed at Sunny Hill. It appears that Sunny Hill's 'early diagnosis and intervention' program, intended to help prevent secondary disabilities in children is thought to be unnecessary for Emily and her child. As my informant suggests, "the support could be done at the schools".

The issue I am raising is not to contest the relative merits of informal work processes for assessing children and their mothers in Crabtree against those of the more formal and expert



work processes at Sunny Hill. I am drawing attention to the social relations of this setting and how the “actualities of class, gender, and race”, which are dispersed over a range of sites within the institutions of ruling (Smith, 1990a:65), are at work in Crabtree. The social organization of children’s experiences and women’s concerns here in Crabtree reveal a work interface with institutional fields concerned with gaining knowledge about poor, primarily First Nations women and children who are already constructed as ‘risks’ even before they enter Crabtree’s door. My analyses of text-mediated ab/normalizing practices at work in this setting make prominent how discourses on ‘risks’ and on *the* child ‘at risk’ arise and become established. They reveal how local practices that occur at the interface between those who seek help and those who offer help “coordinate their actions so they produce the particular institution’s” discourses, sequences, or outcomes (Turner, 2006:140).

## **5.0 Summary**

When mothers bring their children to the daycare they also bring their concerns about their children – concerns which are an organizing feature of the work interface with professionals in the daycare setting. I have been explicating how mothers’ concerns and children’s activities and behaviours are the actual ground for professional work. Ab/normalizing discourses on mothers and children coordinate work practices that engage health professionals, front-line workers, and mothers themselves in identifying and producing the ‘at risk’ child.

These work encounters arise in everyday activities, within un-explicated helping relationships, established in an atmosphere of safety and trust. My analytic work pulls apart and exposes some of the actual practices in this setting, which are involved in the social organization of discourses concerning children, mothers, and their ‘risks’. My analyses expose the social relations of the setting and the historical practices of looking for risks that are embedded in them.

Professional efforts to identify and manage children's risks play out in different ways for the three mothers I have introduced in this chapter. Allie's level of professional engagement is at an early stage of risk-identification and management. Daycare personnel are responsive to her concerns and to helping her manage her child's crying. At this point, there is no particular work engagement on Allie's risks as a parent. Anne, on the other hand, is fully engaged in working with experts to manage her child's behaviour – a risk to be managed before things get worse. Billie's medical diagnosis of 'anxiety disorder' detaches his risks from any that might otherwise be seen in relation to his mother. His risk factors are individualized to him, attributed to anxiety, fear of separation, and genetics. Anne is developing her expertise in managing Billie's behaviours and it remains unclear what actions might follow if Anne had failed or should fail in her risk management work.

For mothers such as Emily, however, concerns about an older child have already introduced to her the relevancies of an FAS/D discourse and have shaped her knowledge and concerns about Alix. Emily's concerns makes her amenable to talk and to participation in work practices for finding out whether or not her child has FAS/D. Emily's efforts to help Alix also make both her and her child objects of surveillance. Through her interactions with personnel, gained in relationships of trust, those who are concerned with identifying a child's risks for FAS/D have relied on particular information gained from the mother to confirm the risks. No further action or professional 'help' is apparently indicated despite Emily's request for an assessment.

My discovery of mothers' work with a routine text reveals how mothers' access to daycare services depends on consenting to professional practices of screening and monitoring children for their risks. The textual coordination of work sequences involving mothers, children,

professionals, and front-line workers thereby result in the ‘proper’ enactment (Bell & Campbell, 2003) of policies and practices for identifying children ‘at risk’ for FAS/D.

Screening tests are not usually considered to be diagnostic, but they are intended to identify ‘risks’ or to raise suspicions about possible abnormalities. However, I have been showing that practices of recruiting and screening children are also methods of surveillance and monitoring for the presence of socially unauthorized or unacceptable ‘differences’ or ‘risks’ in, not only children, but perhaps, more importantly, in their mothers<sup>11</sup>.

The construction of mothers’ risks involves moralizing judgments about the mothers, which appears to contradict the notion of this setting as a “safe haven”. It is important to note that the methods of surveillance employed in this setting rely on relations of power which insist on mothers’ compliance in consenting to observations of their children. It is the very routineness, the ordinariness through which ruling is accomplished, that obscures how relations of power are enacted through women’s everyday text-mediated work and caring encounters.

In the next chapter, I turn to the institutional work processes that are organizing mothers’ activities in or related to the FAS/D Prevention group. I detail their work engagement with text-mediated discourses on FAS/D and I show how the knowledge mothers acquire shapes their responsibilities and even their consciousnesses and subjectivities.

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<sup>11</sup> My conclusions resonate with those of Armstrong (1995), who argues that surveillance is grounded in the day-to-day of screening programs, health promotion campaigns, and the budgets allocated for public health and prevention.

## Chapter Seven

### Women at Work, Part II: Producing the ir/responsible mother

*It is hard to learn to see what we so much take for granted as we do what we know so very well how to do*  
(Smith, 1987:213).

#### 1.0 Introduction

As I continue to examine Crabtree's helping interface with women and children, I discover and will show how the concepts FAS/D and 'prevention' arise and become established in women's talk and work. The formulation of 'help' I refer to is one that operates with and teaches definite ideas, concepts, and practices that have organizing and coordinating functions. In my exploration of women's concerns and their work engagement in the forms of 'help' that are available to them, I will be attending to "the generalizing relation[s] accomplished by the process of conceptual coordination" (Walker, 1995: 66).

In this chapter, I explicate how an FAS/D prevention discourse is put together and works in the local setting where I conducted my ethnographic work. The analysis aims to show that FAS/D prevention is a widespread text-mediated discourse that coordinates women's talk and activities, and as Smith (2005) says, works with the "categories and concepts expressing the relationship of local courses of action to institutional functions" (225). In the first section, I learn more about Crabtree's history and, thereby, I enter more deeply into the social relations that are organizing the work women are to accomplish here.

#### 2.0 Organizing an FAS/D prevention discourse locally

*Fetal alcohol syndrome* prevention activities have been a feature of 'helping' services at Crabtree for almost twenty years. When personnel and other service providers in the setting talk about FAS/D, they often point to the work of those involved in offering the FAS/D prevention group programs. The original program was established as an 'FAS/NAS prevention' program,

also called ‘pregnancy outreach’, which is directed at pregnant women and mothers who use alcohol and illicit drugs. The acronym NAS refers to ‘neonatal abstinence syndrome’, a contested medicalized category that some professionals apply to infants whose variances in experiences are attributed to their mothers’ use of illicit drugs during pregnancy. The term ‘abstinence’ implies that the infants experience withdrawal symptoms when the drug they have been exposed to in-utero is no longer available to them.

My interest in language and how it signals institutional work processes alerted me to attending to people’s talk and to what it reveals concerning professional work activities and relevancies. In the following three sub-sections, I discover how three discourses, prominent among professionals in multiple work sites, operate in this setting.

### 2.1 Harm reduction: “*Keep the woman drug free*”

While some things about Crabtree, such as its location, have changed over time, people working in the setting express concerns about the prevalence of drug and alcohol use among the women who come seeking help. In the interview segment that follows, one of the professional informants identifies her/his concerns about the women and his/her judgment about how to help them:

[Some] colleagues think as long as [professionals] keep the woman drug free or harm reduction – *less* [speaker’s emphasis] drugs – and we cut that umbilical cord and this baby’s going to do great, and it’s like, ‘Noooo, not necessarily.’ If you want to do women-centred care, these women really care about their babies, and [professionals] need to be there to reassure her when – when reassuring should happen, and also to be there when the child is starting to skew off, because these women get set up for false accusations of abuse and neglect when nobody’s listening to them...

‘Harm reduction’ is a prevalent discourse which coordinates the work of many advocates, policy makers, and professionals concerned with minimizing the harms and ‘risks’ associated with problem-substance use. Harm reduction advocates argue that, since not all substance use (including licit and illicit drugs) is problematic, support and treatment options should not be confined to promoting or insisting on abstinence but rather, abstinence is considered one option among many (Boyd, 1999). A harm reduction approach to working with women is apparently contested in this setting.

My informant insists that even when women are ‘drug free’ or using *less* drugs, they continue to pose a risk to their child. This discourse-oriented talk on ‘risks’ implies that, at any time, women’s behaviours may go awry and warrant expert or state intervention. My informant proposes ‘women-centred’ care to be a preferred alternative to a harm reduction approach for supporting women in Crabtree.

## 2.2 Women-centred care: “professionals need to be there...when nobody’s listening”

‘Women-centred’ care is grounded in the assumption that policies and practices for ‘helping’ women should arise from and in response to women’s lived experiences and the priorities women give to their needs and concerns (Boyd, 2007). In previous discussions with personnel, I had already been hearing that Crabtree’s grassroots programs are ‘women-centred’, and arise from “what women say they need”.

Women-centred care is a popular discourse among those in health and social agencies and research settings, where people work with or on behalf of women. However, when my informant tells me that women need reassurance from professionals who can be there to intervene when the child “is starting to skew off”, h/she proposes a form of ‘help’ that my research has been problematizing, one that appears to subordinate women’s needs or concerns to

institutional relevancies for managing children's risks. My informant's talk suggests that professional work and 'reassurance' operate as forms of *intervention* in women's lives, which are relevant to institutional work processes for managing women's risks rather than responding to women's concerns.

It is through querying the "taken-for-granted underpinning of talk" that an inquiry can begin to expose the social organization of it (Jackson, 1995:168). As I continue my analyses I am also examining how discourses underpin and organize women's own talk and their work in this setting. In the next section, I explore how an apparently minor change in a name signals another institutional discourse and the work processes and relevancies it mediates.

### 2.3 FAS/D: "Such a little change"

In the past few years, experts in the field of FAS research, policy, and medical practice, have been applying a text-mediated discourse on fetal alcohol spectrum disorder (FAS/D) to children, in place of the category, FAS, and other diagnostic categories that flow from it (Astley, 2004). Among the features of women's talk in Crabtree is the frequency with which I heard women apply the category FAS or FAS/D to their children. I was curious to learn how this latter and relatively new way of naming has become a generalized and generalizing feature of women's talk.

In discussion with one young mother named Alice, I learned that the application of 'fetal alcohol spectrum disorder' (FAS/D) to a child is now the *authorized* category for naming children thought to be 'alcohol-affected', including those diagnosed as FAS. I also discovered through sequences of talk with Alice and other informants, self-identified as Aboriginal women, how a discourse on FAS has colonized women's talk, possibly even their consciousnesses.

Alice has several children, one of whom has recently been diagnosed with *FAS*, which experts consider to be the most severe expression of the fetal alcohol spectrum disorder. Alice explained to me that she does “not mind talking about the *FAS*” or saying: “I am the mom who has a kid with *FAS*”. However, when a professional in a clinical setting where Alice had previously gone for help, remembered Alice’s child by recalling: “Oh well, he has *FAS*”, Alice described her reaction:

And that bothers me, like it’s not being helpful. She’s being judgmental and she didn’t even know all the new terminology for *FAS/D*. I said, “Like I think you need to take a refresher course or something. You’re a social worker working in the hospital and you shouldn’t be treating – like, you’re lucky that it’s me.

Alice is troubled by this social worker’s comments and she feels that she herself is being judged. She may also be troubled by this objectifying way of identifying her son as one who “has *FAS*”. Alice draws attention to the ‘utterance’ *FAS* and seems to suggest that the use of the current category *FAS/D* may, unlike *FAS*, diminish her sense of being judged or possibly improve her regard for the social worker. What Alice tells me draws attention to the importance of language and discourse as ‘coordinators’ of a person’s consciousness or subjectivity – a way of being known (Smith, 2005).

Language, according to Mead, comes into being only as there is a conventionalized vocal gesture that activates in speaker and hearer the same response or assembly of responses. A vocal gesture or word activates responses stored from people’s experience...(2005:80-81).

Through my interviews in this setting, I have been discovering that *FAS* constitutes, for many women, an experience they know in common. Words abstract and suppress “attention to



the particularities” of people’s experiences and what is going on, and subordinate them to verbal generalizations (Smith, 2005: 83). For one self-identified First Nations woman who tells me that her child, mother, and self are FAS, ‘fetal alcohol syndrome’ generalizes their experiences and standardizes how each is known and knows herself as FAS. When she explains that FAS is a “cycle”<sup>1</sup> among her people, and a tragedy she wants to stop, she is pointing to the social organization of a generalizing discourse that coordinates how First Nations people have come to know themselves and how they have been made known.<sup>2</sup>

Another woman told me that in the experiences of First Nations women, naming children FAS is such a widespread practice that in some communities, babies are considered to be FAS even prior to their mothers giving birth to them because people in the community *know* that their mothers drank alcohol. This act of naming is an exercise of power (Armstrong, 1998). But when First Nations people name new infants FAS, even prior to birth, they have subordinated their knowledge of their children and of one another to an external and ruling authority, one with colonizing force.

*Naming* children as FAS or FAS/D also names and implicates the mother. In light of Alice’s concern about the professional who called her child FAS, and the social organization of the FAS discourse in First Nations children and communities, the category FAS/D may be, for First Nations women such as Alice, a less stigmatizing label for women to hear and to bear.

My interest in language and naming also prompted my queries about the practice of changing the name of the Prevention group at Crabtree from FAS/NAS to FAS/D. In the

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<sup>1</sup> Some women also referred to the devastating intergenerational effects of alcohol abuse in their families/communities as a ‘cycle’.

<sup>2</sup> Critical researchers (e.g Tait, 2003) have examined how experts involved in diagnostic and research practices have targeted people in First Nations communities (see Chapter Three).

following interview segment with a professional, I discover that naming is a way of re-framing women's behaviours:

[t]he language we use – there's a small shift in language and it was such a *little* [speaker's emphasis] one, and it was *better* [speaker] because people saw this umbrella term [FASD], instead of separating FAS as physical and FAE as invisible. It was, we have a spectrum. [People] used to say FAS was a light switch diagnosis. People thought you had it or you didn't as opposed to seeing it as a continuum and then, I think, this place [Crabtree] has worked to de-stigmatize that. There has been, in my view, this old perpetuation of alcohol and drugs and it grew out of, you know, it was FAS and NAS, and I kept saying, "These women mix them together"...mix the drugs and alcohol together...and it wasn't so simple to separate the drinkers from the illicit drug users...

Under the former system of naming, FAS would be one of the diagnostic categories applied to a child whose mother drank alcohol during pregnancy, and neonatal abstinence syndrome (NAS), would be the diagnostic category applied to children whose mothers used illicit drugs such as 'crack' or 'heroin'. My informant's response suggests that women's behaviours, both as 'drinkers' and/or 'illicit drug users', are *better* accounted for by the generalizing claims of the FAS/D 'umbrella' category. FAS/D relieves 'experts' of making distinctions between women and also between which particular substances women use and it is, therefore, offering a wider scope for generalizing about women and their children and, possibly for 'acting' on a wider number of them.

I have been problematizing how discourses generalize women's and children's experiences and querying what institutional relevancies they may accomplish. If the discourse on 'fetal alcohol spectrum disorder' relieves experts of the responsibility of making distinctions

between physical and behavioural variances in children, does FAS/D also lend more credibility and authority to diagnostic practices of naming which, to date, have been plagued with criticisms of imprecision, such as those I point out in Chapter Two? If FAS/D is a less stigmatizing label, will it better promote acceptance of an FAS/D prevention discourse that makes maternal alcohol use relevant to the concerns and experiences of almost any mother and her child?

I have also been showing instances in professionals' talk of text-mediated discourses on 'harm reduction' and 'women-centred care' and discovering how a discourse on risks competes with or even over-rides the advocacy positions and activities those discourses promote. However, discourses are not just in talk; they are found in people's practices. In the next section, I discover generalizing features of FAS/D discourses in various work activities and show how they shape women's work and also their concerns.

### **3.0 The social organization of women's concerns**

When I began conducting my ethnographic inquiry in Crabtree, I initially assumed I would discover FAS/D prevention activities in a specific work-site in Crabtree, perhaps, primarily in the FAS/D Prevention program. My approach to 'looking' for FAS/D in a work-site initially obscured my recognition of the generalizing institutional relations accomplished by FAS/D discourses and the activities they were generating in the setting. As I became increasingly acquainted with the accounts and concerns of women, many of whom were current or former members in the FAS/D Prevention group, I discovered *in* women's exchanges how FAS/D discourses and work processes come into view.

#### 3.1 Engaging 'Single Mothers' concerns: "*We never get enough sleep*"

Crabtree offers a regular Single Mothers support group where, through weekly three hour sessions, mothers are encouraged to share personal experiences, learn strategies for addressing

their issues and concerns, develop supportive relationships with one another, and learn about how they can access more formalized sources of support. A work activity that I learned about and I had observed taking place at the front reception desk some time earlier is an instance, I suggest, of Crabtree's effort to engage and even re-organize a mother's concerns.

During the lunch that followed the group session I sat next to Shelley and listened to some of the concerns she had begun talking about with the women and personnel in the group – concerns about her own fatigue and her worries that one of her children was crying a lot. She told me, “We never get enough sleep.” I had first observed Shelley when I saw her enter Crabtree with her two small children one morning and I recall that I left just as she was beginning to talk with a staff person about these and other concerns to learn about what assistance Crabtree might offer. As Shelley and I talked over lunch, I asked how she had learned about the Single Mother's group.

Shelley said that when she came to Crabtree, a staff person at the front desk told her about the agency's services, including the Single Mothers and FASD Prevention Groups, and explained that she could attend either one or both of the groups. Shelley understood that each of the groups would give her an opportunity to talk with other women and with staff, and discuss any concerns she might have about her children. She also learned she would receive a ten dollar food voucher and bus pass for each group session she attended. I asked Shelley how she had decided which group to attend.

Shelley explained that when she heard the term ‘FASD’, “I didn't know what FAS/D meant”. Later, she asked one of the staff, who told her that FAS/D was a medical term applied to children with problems caused by their mothers' use of alcohol during pregnancy. Shelley also learned that the FAS/D group offers support and education to women who are concerned about

their children's behaviours and want to learn more about how to help them. Shelley *was* concerned about her children's behaviours, in particular their lack of sleep, but she explained that after learning what FAS/D meant, she concluded that the FAS/D group was not relevant to her concerns. And Shelley also explained why.

Shelley offered a detailed description of what her life had been like growing up in a family in which one of her parents was a 'drug dealer'. She described the distress that she and her siblings and mother experienced in a series of living situations fraught with fear and threats of violence. Shelley explained that, because of the distressing childhood she had experienced, she had never consumed alcohol or used drugs. Shelley's explanation reveals that her self-knowledge – *knowing* she had never used alcohol – made the FAS/D discourse irrelevant to 'concerns' she held about her children and also made irrelevant her involvement in the FAS/D Prevention Group. In Shelley's situation, knowledge of herself and hence, of her children, is not constrained by this particular discourse and its relevancies (Griffith & Smith, 2005).

This account reveals how a work interface between a staff member and new 'client' may engage a mother who has concerns about her children in an institutional discourse that can begin to organize how a mother is to understand her children's experiences and her own concerns. This activity of inviting women into the FAS/D group is a practice I call 'recruitment', to emphasize (as I did in Chapter Six) that it is a practice relevant to the institutional work that is to be accomplished. Through my next set of observations I discover how a generalizing FAS/D discourse, applied during routine work encounters, coordinates mothers' knowledge and concerns.

### 3.2 Aligning mothers' concerns to FAS/D: "I think my child may be affected"

During the session of the Single Mothers' group I attended, a member of staff who was present invited two women who have been attending the group for over a year, to facilitate the session. Shelley and Allie<sup>3</sup>, whom I also introduced earlier, were attending the group for the first time. Shelley, Allie, and the other women present had placed their children in the daycare earlier that morning in keeping with the agency policy that allows women attending groups to have a space in the daycare on the day of their work session.

At the start of the session, one of the facilitators explained that the group offers women a place to meet and share any concerns and stresses they experience as women and mothers. The facilitator is trying to establish, in the analytic terms of my analysis, women's standpoint, that is, she invites women to begin in the local particularities of their daily and embodied experiences (Smith, 1987). To facilitate discussion, she presented a deck of 'oracle' cards, which contain healing affirmations, and suggested that participants could draw a card from the deck to focus their talk. The plan was for each person to read an affirmation and, if willing, to tell the group how this affirmation had meaning for them by helping them to deal with concerns or troubling experiences. This activity generated a discussion on women's concerns regarding their children, finances, relationships, and other stressors in their lives. Allie, for example, talked about her embodied concerns related to the fatigue and despair she was experiencing with her distressed infant and how, as a single mother with limited means, she had no one she could turn to for relief and support. Another mother talked about the effort of trying to manage a two year old child, who cried and 'acted out' (running, throwing things) whenever she tried to attend to her younger

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<sup>3</sup> My readers will recall Allie as the young woman with concerns about her baby, who cried "all the time", even while in the daycare setting, and that Shelley and her children have been moving from shelter to shelter after each thirty day period expires at one of them.

child. The exchange of concerns also generated strategies, such as how to respond to crying infants – “it’s OK to let them cry sometimes” – and how to develop a plan of ‘self care’. My next analytic steps are to consider and follow how the next work exchanges take their particular form.

During further discussions about strategies such as accessing resources to ‘help’ women with their concerns, an FAS discourse begins to emerge. The first speaker – Speaker 1 [a member of staff], introduced Crabtree’s ‘FAS key worker program’<sup>4</sup> and described how the ‘key worker’ could help to address women’s concerns. She explained to the women in the group, “The FAS key worker can offer support, do home visits, or help you talk with the teacher at school if you have concerns about your child’s behaviours”.

This ‘informational’ talk orients women to an FAS/D discourse and work activities geared to helping women talk about FAS/D. The talk directs women to understanding that FAS may be relevant to their concerns about their children’s ‘*behaviours*’. At this point, my observations suggest that women may be engaged, not so much by the discourse, but by the notion that some form of ‘help’ is available to address their concerns about their children. My analysis does not lose sight of the importance of the ‘helping’ interface and how women’s concerns are present in and part of the work.

After Speaker 1 used the term *FAS*, Allie [Speaker 2] asked the woman seated next to her: “What’s FAS?” The question she posed suggests that she has not been previously introduced to this particular discourse. No one responded directly to her question, however, another woman [Speaker 3] seated nearby turned to Allie and said, “I think my child might be affected”. After this brief exchange, Speaker 1 explained that agency personnel can help arrange

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<sup>4</sup> The Key Worker and Parent Support program is an expression of provincial FAS/D policy, which is intended to provide support to families of children or youth with FASD and similar neuro-developmental conditions (MCFD, 2008). I discuss this further in the next chapter.

for an FAS assessment by putting a concerned mother in touch with a health professional who does the assessments. She concluded: “If your child is having behaviour problems, you may want to get them assessed”.

Speaker 1 has made apparent to the women that help is available to address concerns they have about their children’s behaviours. She is also orienting women to the type of help available in the setting to address those specific concerns. In specifying the help available – specifically an FAS assessment – Speaker 1 establishes a shift in standpoint. This shift is from a standpoint arising in women’s actual concerns – articulated earlier when, for example, Allie expresses her embodied experiences of her infant’s crying, or what I call a ‘standpoint’ arising in her experience – to a standpoint in a text-mediated discourse that shapes women’s knowledge and understanding of children’s behaviours and how to address them.

These moments of interaction within the Single Mothers’ group can be examined to show *how* women’s talk reveals “features of the institution” (McCoy, 2006: 118) and of the individual-institutional interface which connects work here with text-mediated activities taking place in multiple other settings. An FAS/D discourse, which carries widely-shared, authoritative ways of knowing about children and their behaviours, coordinates the work and talk in this local group. It is an extra-local organization of activities that brings institutional work processes into view.

Each of the speakers in the preceding exchanges is located somewhat differently in relation to the discursive work processes that shape their knowledge and activities (DeVault & McCoy, 2002). Shelley’s lack of alcohol consumption has apparently already limited her engagement, or at least interest in the FAS/D discourse. However, the young mother, Allie, [Speaker 2] who asks, “What’s FAS?” can be understood as beginning the work of developing ‘organizational literacy’ (Darville, 1995) in the FAS/D discourse. Organizational literacy is



concerned with effecting institutional work processes, rather than with telling individual experiences (1995). This mother's question, "What's FAS?" invites instruction in the discourse and engagement in the institutional work it mediates. While work activities may differ between various settings, the terms and concepts relevant to the discourse will orient local 'workers' to its institutional relevancies.

When Speaker 3 responds to Speaker 2 with the statement, "I think my child might be affected", she is responding with an organizational, rather than experiential, understanding of her child. Her response reveals her engagement in work processes that are displacing her experiences and signal a disjuncture in her knowing. Taking up the discourse allows her to talk about her child in institutional relevancies that make the child known in the abbreviated medicalized version of an ['fetal alcohol'] *affected* child.

As Speaker 1 concludes, "If your child is having behaviour problems, you may want to get them assessed", she signals an actual work practice that re-organizes how mothers are to think about children's behaviours – a re-organization which makes the children institutionally actionable. This speaker's talk establishes a standpoint that moves from women's concerns and embodied experiences with crying or distressed or over-active children, to a standpoint in a complex of institutional relations concerned with assessing children and accounting for children's and mothers' behaviours.

Speaker 1 offers the (FAS/D) 'assessment' as a possible solution for knowing about and addressing children's behaviours and mothers' concerns in relation to mothers' child care work at home and also, as Speaker 1 shows, a work interface with teachers in schools. The expertise this speaker has developed in the FAS/D discourse enables her to make sense of mothers'

concerns in a manner authorized by the discourse. This practice of ‘making sense’ is what she has learned to do as she has developed expertise in the discourse.

Such practices in knowing rely on sorting out and arranging conceptually the lived world of people’s everyday experiences (Smith, 1990a:43) that Allie and others have been talking about. Where children’s experiences and how they are to be known are still questionable, mothers will learn to sort them in compliance with the relevant category (Campbell & Manicom, 1995). This shift to objectified ways of knowing defines and discursively determines the subject positions (Smith, 1996) of children, making them known as FAS/D. Once known as FAS/D, the institutional authority of the discourse ensures that we could not know them in any other way.

I have been showing how a feature of the work of recruiting women to the agency’s FAS/D Prevention activities involves introducing them to the specialized language and generalizing relations of the FAS/D discourse, which are not confined to work in any single activity or program within the setting. Work activities that orient to and interface with women’s ‘concerns’ are consequential to explicating how these institutional work processes organize and shape women’s everyday experiences (McCoy, 2006). The discourse that the speaker and her listeners use locates women and children in a social relation to medicalizing institutional work processes and authoritative ways of knowing that appear, unproblematically, as ‘relevant’ to women’s concerns. The discourse establishes the correct way for women to address their concerns. Women’s concerns, and how women are to be instructed to talk and think about their concerns, invite further attention to how the work being done in this setting, which is part of an institutional regime, hooks women and children into the regime itself (McCoy, 2006).

The introduction to the FAS/D discourse that I observed in the Single Mothers’ group offered little instruction regarding the kinds of behaviours, criteria, or concerns that constitute

‘membership’ (Smith, 1990b) in the FAS/D category, either for children or the mothers involved. Yet FAS/D language and instruction is slipped in as ‘help’ in response to mothers’ concerns. A detailed form of instruction will become much more visible and audible in the voices of women who describe their work and what they learn in the FAS/D Prevention group. As I continue to trace the work of aligning mothers’ concerns to the institutional relevancies of an FAS/D discourse, I am also discovering the ‘workings’ of discourse and how women and their concerns are shaped by it.

#### **4.0 FAS/D Prevention Group work: Developing knowledgeable subjects**

There are two FASD Support Groups, the FASD Prevention Program and the Intergenerational<sup>5</sup> FASD Support Group, in which women can participate. A member of staff coordinates activities in both groups, generally with the aid of an assistant. Consistent with the agency’s peer-support model, personnel who coordinate this work are usually women who have been mentored into paid employment following their participation as former group members.

Work activities in the FAS/D Prevention Group are specifically intended for women who are pregnant or mothering. Over the course of a three month period, the women meet weekly in a three hour session with a coordinator to learn about FAS/D and to share information and concerns, participate in activities, and have a meal together in a supportive, informal environment.

This FAS/D instruction, which personnel describe as the ‘first stage’ of teaching/learning in the group, deals with a number of topics which include: FAS/D and Children’s Behaviours, Shame and Guilt, Importance of Assessments, Strategies for helping address the Behaviours, and

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<sup>5</sup> The constraints of space and time do not allow me to introduce the rich data this group provided. This will have to be another project, one which explores how women, who recognize knowledges that are alternatives to the FAS discourse, are nevertheless knowingly ruled by it.

Self-Care. The second stage of the FAS/D prevention program, available to women who ‘graduate’ from Stage I, involves what one mother described as “getting out in the community” and ‘telling their story’ in order to instruct other women about the dangers of alcohol consumption and offer advice on how other women, too might turn their own lives around.

Due to unexpected changes in the leadership of the group, the regular work schedule for the ‘first stage’ was suspended at the time I had hoped to make observations. However, I draw from women’s own accounts to explicate how an FAS/D prevention discourse organizes women’s knowledge and work in this setting. I first draw from a mother’s experiential account of her child and her concerns about him; in the second section, I explicate how the mother’s efforts to help her child engage her in an authoritative discourse and a form of instruction that develops her expertise in managing him.

#### 4.1 Seeking help for a mother’s concerns: “Listen – and help me with this child”

I first introduced Leslie in Chapter Five, when she expressed concerns about her lack of safe housing and her fears about her young child, Anthony’s safety, whose outdoor play near where they lived took place in a vacant lot littered with condoms and needles. Leslie had many concerns. She told me about her daily efforts to find good sources of nutrition to feed her family. And she explained that the limited supply of fresh fruits and vegetables available at the weekly food bank she attended forced her to rely on pasta and canned foods. She recalled it was her experience of finding food at Crabtree and Sheway, when she was pregnant with Anthony and living in a women’s shelter, which first drew her to the centre:

They gave me milk tickets [food vouchers] and orange juice, it was so helpful. They offered me a place to go for lunch, and other moms to be around. They provided me with the nutrition I needed, orange juice, milk, beans, spaghetti sauce; they offer to do

nutrition with you, make a meal with you if you don't know how to cook. They had the donations [donated clothing and other items] and other information and resources.

Leslie told me that she does not know how she would manage now without the help and support Crabtree offers and she is hopeful that with all her efforts, she can make a better life for her children.

Reflecting on her present circumstances – the seedy hotel unit, the sounds of violence in the night outside her door, Leslie said if she could change one thing, it would be access to daycare for her child. Leslie is confident that if she had consistent, affordable child care she could find a job, provide nourishing meals, and make a better life for her children. As Leslie talked, I could sense her despair and also how much effort she has put into her ongoing search for better housing and charitable donations of food. It becomes clear that her attendance and work in Crabtree's programs is part of Leslie's efforts to improve the conditions of her life and that of her family.

Leslie also talked about her worries regarding Anthony and explained that she had been having difficulty managing him for some time. She said that, at one point, when she was pregnant with another child and living in a shelter, she was so desperate that she "had to call in welfare and tell them, 'Listen, you need to come in and help me with this child'". She explained that 'welfare' responded by offering a 'preservation worker', "someone to really help preserve my family". Some of the workers assisted her in physically managing Anthony: "My son was taking off, climbing underneath and over the fences of the shelter to get out, and he learned very quickly how to push doors open."

The 'preservation program' did not address Leslie's concerns about and need for housing, safety, child care, or her ongoing concerns about managing her everyday life on income

assistance. This government-sponsored program did, however, keep the family intact and relieve ‘welfare’ of taking the child into a formalized system of ‘care’. Leslie told me that with the help and knowledge she is gaining in Crabtree’s FAS/D program, she no longer requires a preservation worker to help her manage her child.

Leslie’s accounts of her embodied experiences as she makes efforts to provide daily care for her child also reveal her engagement with institutional work processes involving child welfare and other government services, that are shaping her/her child’s experiences. I would suggest that Leslie’s engagement in the FAS/D prevention program operates on behalf of ruling interests, and displaces the actual everyday concerns that Leslie has about her child and the conditions of their daily lives.

In the first of two interview sequences/sections that follow, Leslie develops her knowledge of the FAS/D discourse. She also begins to learn the ‘interpretive schema’ (Smith, 1990b) experts use to diagnose FAS – and how to make this way of knowing relevant to her child.

#### 4.2 A mother develops expertise: “He has all the ‘soft signs’”

Personnel in the FAS/D prevention group offer ongoing opportunities in weekly sessions for mothers to talk about the stresses and concerns in their daily lives. Combined with offering opportunities for women to express and share concerns, personnel also provide instruction on ‘Children’s Behaviours’ and ‘How FAS/D affects our Children’. When Leslie talked about the kind of help the FAS/D group offers, she became animated as she described the knowledge she has been acquiring:

Leslie: My son, [name], I do believe is FAE [fetal alcohol effects].

Researcher [R]. Did someone tell you or - ?

Leslie: No, he's just not right. He doesn't sleep through the night; he's very aggressive, he's very angry quickly. He's very exceptionally amazing at sports, which you don't see in 3 year olds, well, even at 18 months, children are good at sports but they're not – he's just a little overly exceptionally good, and things are just not right. He bites too much and so, I started noticing, so I came here [to Crabtree] and started asking questions and stuff and I was like, OK, I drank with this child. I had a few here and a few there. I didn't drink through my whole pregnancy but I had some bad moments in life where I made some bad decisions. And that's how he turned out.

R. When you say you started asking questions, you got the idea from talking with people that he might have FASD?

Leslie: No. I figured that out by drinking. I know that. All the posters – when you go in the bar you see all the posters. I've seen that from the first time I went to Sheway with [another child]. There were posters.

R. I just want to understand this: Because you drank periodically during your pregnancy with Anthony and then you saw Anthony, you felt some things weren't right?

Leslie: Yeah. I had seen children with temper tantrums and his were, like, he would smash his head. It just was not right. Children will learn not to touch something if it's hot. He will continually touch it. He's got no boundaries, no sense of fear, no sense of knowing consequences for his actions. He doesn't have them – he doesn't get it.

R. So those things made you think that he had FAS or FAE?

Leslie: He's got a little bit – either that or he's super intelligent; his brain doesn't slow down and think.

R. So someone hasn't told you.

Leslie: No. He's not assessed yet. All the programs I am taking, and all the way he is, he has all the – what they call the 'soft signs'. I just learned about that I think last week in the FAS/D program. He has all the soft signs. Very cuddly with animals, very loving with animals, very territorial in defending what he believes is his even if it's not his.

Leslie's description of the 'help' she has been gaining reveals a disjuncture between her everyday concerns and embodied experiences (running through doors and over fences to find her child) and an objectified way of *knowing* about and naming her child's behaviours as FAE. Here is how I understand what Leslie was saying.

Prior to her involvement in the FAS/D group, a text-mediated discourse on maternal alcohol consumption and fetal harm, prevalent in bars and other public settings, had already shaped Leslie's consciousness, organizing a way for her to begin to think about her alcohol consumption as the cause of the troubles her child is now having. Through her engagement in the prevention group, Leslie's learning activities orient her to other features of the FAS/D discourse and she develops her expertise in it.

Leslie's talk about her child as FAE<sup>6</sup> is an example of her developing expertise. Through Leslie's work in the group she is acquiring terms and concepts that enable her to speak knowledgeably about her child's behaviours as well as her own behaviours and how they account

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<sup>6</sup> The terms FAE and 'partial FAS' are no longer authorized by experts who have introduced the current term, FASD. However, proponents of the term FAE have argued that it is useful for describing children who have behavioural characteristics rather than the 'physical' characteristics that distinguish the FAS diagnosis. A number of women in this setting still referred to terms that are no longer 'authorized'.



for the way her child “turned out”. Later, Leslie said, “I always assumed it would be the physical”. This statement shows Leslie expected her son would turn out bearing the facial signs which, according to the FAS diagnostic (interpretive) schema, are associated<sup>7</sup> with severely alcohol damaged babies or FAS, rather than the behavioural signs Anthony exhibits, which she attributes to her periodic alcohol use. With the knowledge about FAS/D diagnostic categories Leslie is acquiring, she can now distinguish the relevant, although somewhat outdated FAE category, to apply to her child.

Leslie is also acquiring the specialized medical language, the terms and concepts for how to speak knowledgeably about FAS/D. When she refers to her son’s behaviours as ‘soft signs’ of fetal alcohol damage, she reveals her engagement with the latest revision of the FAS/D discourse that coordinates an authoritative way of knowing about FAS/D as a ‘primary brain-based disability’ and FAS/D children as ‘brain-damaged’. In the terms made relevant by the discourse, ‘soft signs’ are both a descriptive term for behaviour problems as well as “psychological signs of FASD brain damage” (Kellerman, 2000-2008).

Among the ‘soft signs’ of FAS/D are a diverse range of ‘indicators of brain damage’, of which a few are overly immature social development, hyperactivity, overly friendly with strangers, fond of animals, lack of consistent impulse control, good expressive language skills, talented in art, music, or mechanics, vulnerability, naivety, and inappropriate social interactions (2000-2008). These and many other behavioural indicators ‘alleged’ to be signs of ‘brain damage’ are listed on numerous FAS/D prevention web-sites and other texts. Concerned parents and caregivers can read these lists and develop expertise in matching their concerns about their

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<sup>7</sup> My readers will recall how Emily emphasized the beautiful appearance of her child possibly as a ‘sign’ that her child was not fetal alcohol affected (Chapter Five). Emily had learned from her experience and knowledge of her other child that fetal alcohol damage is inscribed on the child’s face.

children's behaviours with the text-mediated discourse on 'soft signs'. I would suggest that the scope and number of behaviours listed as 'soft signs' contain so many variances that the behaviours of many children may, at some point, be matched to any number of 'soft signs' of 'brain damage'.

In her analysis of the social organization of factual accounts, Smith (1990a) insists that the "interpretive schema established by the account" governs the practices of selecting and assembling actualities from people's everyday lives (78). Hearing Leslie's descriptions and selection of her child's behaviours – whether his exceptional abilities at sports, his fondness toward animals, or his biting and temper tantrums – and how she matches the behaviours to items on the list of behavioural signs of brain damage established by the FAS/D interpretive schema – reveals how a mother's concerns engage her in an objectifying field of social relations where she learns how to abstract from her child's experiences some actuality that can be grasped as real (Smith, 1999). To Leslie, her son's behaviours are the 'real' signs of his brain damage and of her responsibility for causing it. Her engagement in the learning activities in the group put in place a method of reasoning about her child's behaviours – and her own – that she takes to be a fact, what actually is. In the next section, Leslie's talk reveals how she learns another discourse that will engage her efforts to prevent further harm.

#### 4.3 Learning risk management: "Without these programs, my son would end up in YDC"

As her child continues to grow and develop, Leslie says that she has mounting concerns about him. Some of Leslie's concerns arise from her own everyday embodied experiences with him which, as the next interview segment reveals, also include those of other children:

I can't get him on the buses. I can't get him to go places with me. I can't get him to walk without him running into the traffic 'cause now he thinks he's a brick wall and the car

will smash...He scratches and bites the other children and the other children in the daycare are getting scared of him.

According to the authoritative knowledge rendered by FAS/D experts, behaviours such as ‘poor impulse control’ or the failure of the affected individual to understand the ‘consequences’ of their actions, are ‘soft signs’ of the damage caused by fetal alcohol exposure (Kellerman, 2001-2002). These FAS/D ‘facts’ explain why many FAS/D children can have normal IQs but may remain unable to take responsibility for their actions and consequences (2001-2002). Leslie’s is concerned about the consequences of her child’s behaviours, and she tells me why they frighten her: “Without the help from these programs, my son would end up in YDC [Youth Detention Centre]. He will *not* [speaker’s emphasis] have a childhood,” she said. Leslie is showing that an FAS/D prevention discourse and the instruction she is gaining in it is organizing her understanding and also her fears about her child.

A number of mothers I interviewed have, like Leslie, voiced concerns that their children might fail in school, or end up on the streets, detention centres, or jail. Leslie, Emily, and Georgina were among those who knew other children who had ended up that way, which suggests that what they have learned outside [or prior to] their engagement in the FAS/D prevention group is also informing their concerns. I am referring to how the particulars of (past) events may have also been made categorically and discursively relevant to them (Darville, 1995). FAS/D discourses are widespread and the fears they generate are not confined to any one time, person, or place. Similarly, the practices that are in the social relations of this setting disclose a social organization that has both preceded and will follow the work that is happening at this time (Smith, 1990a).

People who generate and circulate text-mediated discourses about FAS/D youth or adults have produced a list of secondary disabilities which, according to experts, develop after birth and can possibly be ameliorated and managed through better understanding and earlier diagnoses and interventions (Streissguth, Barr, Kogan, & Bookstein, 1997). This FAS/D prevention discourse on what experts call ‘secondary disabilities’, makes generalizing claims about risks secondary to fetal alcohol damaged brains, which may arise in the youth and adult the FAS/D child is to become. The list of risks and social ills that FAS/D experts produce includes “unemployment, mental health problems, trouble with the law, inappropriate sexual behaviour, disrupted school experience” (Chudley et al, 2005: S2; MCFD, 2008:8). This ‘nominalizing’<sup>8</sup> discourse (Smith, 2005) on secondary disabilities suppresses the presence of subjects/agents and generates a view only that something must be done [or undone] to address such serious problems, while offering no solutions as to who will do it. However, Leslie’s talk about her work in the FAS/D prevention group shows how the instruction she is gaining in the discourse is a strong motivator for her to take responsibility to prevent or at least manage her child’s future risks.

In the narrative sequences that follow, Leslie describes some of the work strategies she has been learning in the group that will help her in the work of ‘secondary’ prevention, and she also introduces different experts from whom she is learning. For example, she has learned from one of the women in the group to make changes in Anthony’s diet that she believes will help him sleep better. Leslie explains, “The starches in it [potatoes] fill him up enough that it calms him down so maybe at night time they sleep better.” Following this instruction, Leslie has taken away all the sources of sugar and gives him potatoes. A child health professional has visited the

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<sup>8</sup> Smith (2005) says that in institutional discourses the ‘agents’ tend to be deleted and a basic ambiguity remains. I am suggesting that the discourse on secondary disabilities is a nominalising discourse which leaves the reader or listener only with the certainty of the seriousness of the problem of FAS/D.

group to provide instruction on the use of a board with Velcro and stick pictures. Leslie is now applying this instruction to assist Anthony with his daily routines and activities. She explains that she has learned her son is very visual and therefore, by making use of pictures that convey the instructions – “wake-up time, get dressed, brush teeth” – she finds “it makes the tantrums less.” Leslie tells me that with all the expertise she is gaining, things are “a little bit manageable” and she adds, “I can now walk two blocks to get onto a bus without him running into traffic.”

Leslie is also learning from others how to talk to her child in ways that make some of his behaviours more manageable. She draws on her knowledge of the FAS/D discourse on ‘soft signs’ to demonstrate her developing expertise:

What I got from [the program] was: children with FAE, part of the soft signs for children with FAE is, they’re not mean, but they’re labelled as bullies, they’re labelled as mean, they’re labelled as stupid, can’t do the work, lazy, but they’re not lazy and they’re not stupid... If I hadn’t been taking these programs, I’d be telling my kid, “God, you’re such a meanie, why are you so mean?” Now I don’t call him mean anymore. Now I understand that he’s not mean. He’s just not getting it. And I watch closer now when he hits and bites to see what’s triggering him.

Leslie is showing how her developing expertise in FAS/D articulates with concepts and methods drawn from childhood education and child development, which will help her to manage her child’s behaviours and how she is to think about them. Re-framing the negative labels and terms a parent or others may apply to a child is an authorized and often helpful approach to encouraging self esteem in a child. This notion of ‘framing’ – e.g. where the child is not ‘mean’, he has FAE – is also a practice of power that names and objectifies people’s experiences and also generates ‘social courses of action’ (McCoy, 2006). When Leslie explains that the child is not

mean, he's "*just not getting it*" she draws on an FAS/D discourse that re-frames a child's experiences (as brain damage and attendant failures) in terms that also make his mother responsible for them.

Crabtree's orientation to offering help by listening to mothers' concerns about their children, is also *re-organizing* their concerns – even generating new ones – in line with the FAS/D discourse. As mothers develop their expertise, they learn to express their concerns in terms organized by an FAS/D discourse on brain damage and the secondary disabilities and risks which, according to the discourse, will follow. Crabtree's work in producing subjects knowledgeable in FAS/D also lays the basis for instructing mothers' in strategies for managing their children's behaviours. These forms of 'help' generate endless demands for women's ongoing work, including their engagement in risk management work with their children and even with the adults they are to become. In the next section, I discover and will show that the FAS/D discourse also propels mothers to engaging in working upon themselves and in extended courses of action.

### **5.0 FAS/D Prevention Group work: Producing ir/responsible subjects**

In my exploration of women's work activities in the FAS/D Prevention group, I have been showing that much of the actual work in this group is organized in and accomplished in women's text-mediated 'talk'. In this section, I explicate how concepts relevant to and part of an FAS/D prevention discourse, organize 'talk' and practices, which also lay the basis for a mother's *self*-management work – work through which a mother makes of herself both an ir/responsible subject, one who claims both irresponsibility for her actions and a willingness to act responsibly.

### 5.1 Claiming irresponsibility: “Coming clean”

‘Shame and Guilt’ is another one of the designated topics in the FAS/D prevention group program. In acknowledging the importance of this topic to women in the group, one informant described the group’s approach to ‘helping’ women as one of listening to women’s experiences and concerns: “No matter what you have done, no matter what you have on the outside, we don’t care. We want to hear about your inside.” My informant explained that, although women struggle with “poverty, not enough food, not enough money from social services, daycare, nowhere to take their children except to places like this”, the most helpful thing is that “they learn to be themselves and not disguise who they are”.

In the following interview segment, I draw from Jennifer’s description of the FAS/D group and the members’ work orientation:

We have to [talk] because a lot of the women are still using or have not stopped using for very long and there’s a lot of feelings when you’ve been an alcoholic or a drug addict and you come clean and all the work you need to do and how your body changes and how you’re feeling the changes of your body and how it really affects you and without the right support or the help, it will always affect you.

Here is how I understand Jennifer’s statements. The membership of the FAS/D group is comprised of women who are (self-identified as or thought to be) alcoholics /and or drug addicts. In applying these categories – ‘alcoholic’ and ‘drug addict’ – to women in the group, Jennifer standardizes their experiences as those of ‘addicts’<sup>9</sup>, and thereby, excludes the possibility of any variances in women’s experiences with (moderate or minimal) drug or alcohol use. This appears

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<sup>9</sup> In Chapter Two, the terms ‘addict’ and ‘addiction’ are problematized.

to be the case, even though the invitation to Shelley<sup>10</sup> to attend the FAS/D group shows that any mother, regardless of her use or non-use of alcohol or drugs, may be recruited. The categories also exclude the relevance of other experiences or concerns in women's lives – experiences such as poverty or abuse, which may contribute to substance use and also to feelings of shame or guilt that can be associated with them.

Jennifer's talk about women's work of 'coming clean' introduces a subtext of 'dirt and guilt' – an “archetypal link between cleanliness and innocence” which is built into language<sup>11</sup> (Ashenburg, 2007) and also, I suggest, for women in my study, their consciousnesses. When women I interviewed talked about 'coming clean', they generally referred to how the supportive environment which the FAS/D group offered, enabled them to open up about their use of alcohol and express the guilt they felt in relation to their children. I suggest that the notion of 'coming clean' invokes deeply ingrained Euro-religious traditions which hold that a woman's behaviour, particularly during pregnancy, reveals her morality – or lack of it – as well as her 'fitness' to be a mother (Armstrong, 2003; Campbell, 2000).

The language of 'clean/coming clean', also resonates with the language and work of self-help movements such as Alcoholics Anonymous (AA), which can play a significant role in the practical management of people's lives, including people's practices of 'self management' (Valverde, 1998). Feelings of guilt and moral failure are prominent in text-mediated discourses on 'alcoholics' and in the AA 'Twelve Steps' guide, where the first nine steps are preparatory to entering the tenth step of admission of wrong: “Continued to take personal inventory and when we were wrong promptly admitted it” (Alcoholics Anonymous, 1953: 8). The recovery of an

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<sup>10</sup> Earlier in this chapter, I showed how Shelley decided that the FAS/D discourse and group work was not relevant to her experiences or concerns about her children, because she had never used drugs or alcohol.

<sup>11</sup> Ashenburg's (2007) work refers not only to western languages and traditions. She observes that in almost every religion, acts of cleansing are symbols of grace, forgiveness, and redemption or healing.



individual depends upon the acceptance of the group and the individual's self-management work, which is depicted as "obedience to spiritual principles" for admitting and correcting defects (1953: 9 -10) and demonstrating oneself to be responsible.

Following on the work of Foucault, Mills (1997) observes that the 'confessional' is a discourse which involves processes through which power operates in disciplinary societies. 'Disciplinary' societies<sup>12</sup> rely on techniques and regulatory practices for governing and producing 'obedient' and responsible citizens (Brock, 2003). Confessional practices help to produce responsible subjects, while also epitomizing practices of discipline or 'self-regulation' (Mills, 1997). These notions of confession, which work as a type of regulatory practice, resonate with what I am learning about women's responsabilizing work in Crabtree.

Curious to discover how Crabtree personnel manage to engage women's participation in a method of talk that produces confessions of shame and guilt, I turn to Alice, who explains how the 'help' the group offers actually works:

This place is really good. Like once people feel comfortable and can open up, they will really help you. If it hadn't been for Crabtree, I don't know where me and [name of son] would be right now. You know what I mean, and everything, cause without that he wouldn't have got diagnosed with [a health condition] or FAS. I never would have talked about the drinking. I never would have thought that it affected him or whatever. I think that just being able to open up, even if you feel guilty, just letting parents know that they can still be there for their kids even though they made mistakes.

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<sup>12</sup> Discipline (disciplinary societies) in Foucault's earlier work (birth of prison), sought to reform designated (and often unruly) groups through supervision and confinement, e.g. in prisons, asylums, and schools, whereas, later modes of intervening in people's lives have involved attempts to "shape human conduct by calculated" and non coercive means (Li, 2007; 5; Mills, 1997).

The work that women accomplish in the group depends, as Alice shows, on the support and comfort the group provides. Without the comfort and, by inference, the assurance that they will not be judged, Alice insists “she would never have talked about the drinking”, nor would she have made the connection to the effects of alcohol on her child. Alice is also showing that she has been learning that even though she and other women have made mistakes, they can make amends and “still be there for their kids”.

The talk and work involved in ‘opening up’, ‘coming clean’, or ‘making connections’ that Jennifer and Alice identify can be (and often are) taken as a ‘natural’, un-explicated feature of ‘helping’ relationships by which women, confronted with a ‘reality’ of their irresponsibility<sup>13</sup>, gain support in confessing and dealing with their shame and guilt. However, ‘coming clean’ and ‘making connections’ do not just happen as part of an individual intellectual or therapeutic exercise. I am showing how the women’s group work alters women’s consciousnesses. As Smith (1987) has argued elsewhere, something has to happen to make the movement between a consciousness organized in the local particularities of a woman’s life and her concerns for her children, and a consciousness that is organized within and by the relations of ruling, which coordinate the conceptual ordering of them. Helpful as this confessional work at Crabtree may be to the women, it carries ruling relations. The work sequences, whether of thinking, feeling, deducing, talking, or ‘coming clean’, hook women into extended social relations (Smith, 1999) that make this form of ‘bifurcated consciousness’ (1987) possible and actual.

Explicating these work activities reveals how an institutional FAS/D discourse coordinates not only women’s confessional work, but also women’s subjectivities, bringing them

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<sup>13</sup> Current initiatives in FAS/D policy and practice ‘spheres of activity’, even among those which take a ‘women-centred’ approach, implicate mothers as responsible for fetal harm. At the same time, and in a contradictory manner, women-centred advocates will argue against blaming mothers.

in line with a way of knowing themselves as ‘ir/responsible’ mothers. The FAS/D discourse also orients and subordinates the work of personnel to the authority of the discourse<sup>14</sup> and to that of experts whose work produces and textually coordinates it. The language at work in this setting actively draws “people into relations and organizes what can be thought, said, and done in getting on with the practical tasks” (Turner, 1995:236). The self-regulatory work the mother accomplishes in Crabtree makes the mother, as confessor, both ‘responsible’ and ‘actionable’. In the next section, I explicate another stage in the work sequences, when a mother learns and takes steps to demonstrate how to act responsibility for having harmed her children.

### 5.2 Called to account: “Oh my gosh, what did I do to my kids!”

Another topic covered in the FAS/D group is instruction in the ‘Importance of Assessments’. Mothers have been learning strategies to help their children and in this discussion, they also learn how an assessment – the questions and practices for assessing whether or not a child has FAS/D – can help their children. Many of the mothers wanted to know what was wrong with their children – why do they act the way they do and why are they having trouble in school? As women become knowledgeable in the FAS/D discourse the group work prepares them to *account* for their irresponsibility. In the following interview segment, Jennifer shows how she learns to render an account of herself, through which she can also make amends<sup>15</sup> for her behaviour:

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<sup>14</sup> My analysis draws from that of Griffith and Smith (2005) whose examination of the work mothers do in schooling their children, reveals how a ‘mothering discourse’ orients mothers’ work and constitutes them as subjects to and participants in the discourse.

<sup>15</sup> In Step Nine in the AA (1953) guide, the ‘addict’ progresses in her/his work of recovery when s/he makes amends and takes responsibility for others. Some of the women I interviewed attend or have attended AA, but women did not tell me they were following the precepts of AA. However I draw attention to how their talk/work in the FAS/D group bears strong similarities to the AA tradition of ‘self help’ for those with addictions. Possibly, AA discourses have been imported to coordinate the practices of the FAS/D group, or both the AA and FAS/D working groups coordinate similar discourses of ir/responsibility and similar practices in demonstrating it.

I took the FAS course for about three weeks, then I quit because I realized that two of my children possibly have FAS, so you know, the whole guilt and “Oh my gosh, what did I do to my kids?” Then I quit [the course]. Then after about two months I realized, no, I need to learn. My kids got apprehended so, I decided, nobody made me do anything, this is something I thought I should do on my own, so I came and I took the course, I completed it – ummm, got my kids back, worked with [staff] to get my child assessed.

Jennifer’s poignant statement: “Oh my gosh, what did I do to my kids?” underscores the guilt she experienced after she entered the course of instruction in the FAS/D group. From her expressions of guilt and distress, it is apparent that Jennifer had gained enough instruction in the discourse for it to shape her consciousness, wherein she began to make connections between her use of alcohol and problems in her children. [However, Jennifer also shows that she resisted the discourse by quitting the group.] After her children were apprehended, Jennifer re-engages in her learning activities in the group and responsabilizes herself – “nobody made me do anything...”, she said.

As Jennifer develops expertise in the discourse, she also brings her concerns about her children in line with the concepts and relevancies of the discourse. She explains: “Well, just learning about FAS and looking at my kids, seeing all these things that were happening, all the stuff I was learning, my kids were going through that and you know, the learning thing [in school] was really hard on them”. Jennifer’s work of matching her concerns to the terms of the discourse also requires ‘sorting’ work, for among the many variances in experiences that the FAS/D umbrella encompasses, Jennifer must select those which match her specific concerns about her own children – in her situation, their learning difficulties in school. Jennifer

demonstrates how, following completion of the group work, she prepares to make amends by having one of her children assessed for FAS/D.

Jennifer explained that after she decided to have one of her children assessed, personnel at Crabtree coordinated the arrangements for the work at Sunny Hill. These arrangements demonstrate how institutional work processes enter into the organization of women's work in Crabtree and generate further courses of action involving both mother and child. Once at Sunny Hill, Jennifer submitted to the authority of experts where, she explained, she answered their "questions about my pregnancy, the alcohol, the drugs and everything..."

A mother's interrogation will, as I discover in Jennifer's description of the assessment, organize an account – or truth claims – about her child, his dis/abilities, and her ir/responsibility in 'causing' them. Jennifer's disclosure of her drinking during pregnancy allows her to tell the story about the particular experience that is relevant to the FAS/D discourse and assessment practices. I suggest that in Jennifer's telling of this experience, professionals will welcome the mother's expertise, which will ensure that professional concerns about the child's behaviours can be matched with the interpretive schema for determining a child has FAS/D.

Jennifer's efforts (including her anguish), which eventually lead to having her child assessed appear, from an initial examination, to be the individualizing work of a mother making amends and claiming 'responsibility' for the risks and harms she has posed to her child. However, my analyses have been revealing how expert medical knowledge is part of an expanding 'institutional complex' (Smith, 2005) of ruling practices which organize women's daily lives, their subjectivities, and those of their children – operating, it appears, as a new form of self-regulation.

My analyses have been showing that Crabtree's techniques are not coercive, at least, not in the usual sense of using formal supervision and control mechanisms to gain specific ends. However, for those constructed and persisting as 'irresponsible' other forms of state intervention, including legal and statutory forms of control may be called into action. Making subjects 'calculable' or 'knowable' also makes them 'actionable' – amenable to being acted upon and also to acting on themselves (Rose, 1999; Smith, 1990a).

I have been tracing work sequences by which Jennifer (and other mothers) makes of herself a new responsible subject who is prepared to give a formal account of the harm she caused her children. Account/accountability refers, not only to how people come to understand their actions in the everyday world, but also to how this everyday world and "people's actions in it are administered through complex textually mediated social organization" (Campbell, 1995: 222).

That birth mothers such as Jennifer, graduates of Crabtree's FAS/D Prevention program, make the decision to take their children to Sunny Hill for FAS/D diagnostic assessments, attests to the accomplishment of coordinating work processes in Crabtree which positions birth mothers and their children on a trajectory toward Sunny Hill. Instruction in the group prepares mothers for making a trip to Sunny Hill to have their children assessed. This assessment of their children for FAS/D is mothers' accounting work and it is, I am arguing, the institutional work that mothers are organized to do.

## **6.0 Summary**

Issues of 'concern', a mother's worries about her child expressed to a member of staff, are part of routine everyday encounters which articulate mothers' worries, mothers' work, and children's experiences to the relevancies of the FAS/D institutional discourse. Local work

practices, which engage personnel in ‘helping’ women, also establish relationships of trust. ‘Trust’, I discover is central to the work sequences by which women disclose to personnel the cause of their concerns about their children – their alcohol use. Discourses on the risk of FAS/D and mothers’ responsibility for it are generalizing feature of the social relations of this setting and they are shaping work practices and mothers’ concerns.

I have also discovered from various interviews and observations, the manner in which the specialized language of FAS, its particular meanings, implications, and attitudes are *taught and learned* by participants in the FAS/D prevention group. As women become knowledgeable in the FAS/D discourse, they learn to apply terms and concepts such as ‘soft signs’ and ‘secondary disabilities’ to their children, representing children’s variances in experiences according to the relevancies of a discourse that establishes children as objects of risk and as ‘brain damaged’. This objectifying field of institutional relations also engages mothers in the work of identifying, and/or trying to manage their children’s ‘risks’.

Institutional practices, which reside within the scope and rationalities of public powers set up to regulate the conduct (Rose, 1999; Smith, 2005) of mothers are in the social relations of this setting. I argue that these practices are shaping mother’s risk management work. The organization and coordination of ‘help’ in this setting thereby generates endless demands on these now responsible mothers to manage their children and prevent the secondary ‘risks’ in the adults they will become.

Techniques of governance are “visible in discourses of responsabilization”, which shift problems in the social realm to individuals, who must act responsibly to manage themselves (Teghtsoonian, 2009: 29). Through the expertise women develop in the FAS/D group, they learn to apply the relevancies of the responsabilizing discourse to themselves. In a series of work

sequences involving disciplinary forms of talk, women accomplish the exclusion of their own knowledge and experiences, making themselves subject to and subjects of this responsabilizing discourse. How women come to know and make of themselves ir/responsible, accountable subjects is in their self-management work – the work women learn to accomplish in the social relations of this setting. This work holds consequences and further courses of action for themselves and their children. In the next chapter, I detail a mother's work engagement in formalized accountability practices and I show how the account that is produced will enter her and her child into an authoritative record and part of a special management or monitoring system.



## Chapter Eight

### Producing the authoritative account of a mother and child (1223)

*The world that people live in and in which their troubles arise is inscribed in the systems set up to control it by fitting them and their troubles to standardized terms and procedures under which they can be formally recognized and made actionable (Smith, 1990a: 125).*

#### 1.0 Introduction

In my analytic chapters thus far, women's concerns have provided an entry point for my exploration of women's engagement in Crabtree's informal work processes. In this chapter, a mother's concerns about her child's performance in school coordinate an individual-institutional work interface in the more formalized practices of bureaucratic organizations concerned with FAS/D professional diagnostic services and care. While these practices are, like those in Crabtree, text-mediated, they also include the formalized accountabilities which are features of objective administration. I show how the textualization of a mother and child, initiated in sequences of work activities in Crabtree and progressing to a work interface with diagnostic experts at Sunny Hill, develops and is concluded. I am querying how the diagnosis may work as 'help' or treatment for a child and also how it may address the mother's concerns.

I enter as data a four page diagnostic account of a child named Arthur, and his mother, Georgina. Georgina had been given a copy of Arthur's report following his assessment for FAS/D, and she gave a copy to me. I also include as data another text, *The Diagnostic Guide for FASD: The 4-Digit Code*<sup>1</sup>, 3<sup>rd</sup> Edition (Astley, 2004) or 'Guide' for short. This prominent text, a feature of the inter-textual work of large scale organizations, frames the over-arching concepts

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<sup>1</sup> In my analysis, I also make references to previous versions of the 4-Digit Code (Sterling & Clarren, 1997; 2000) as well as to the 2005 Canadian guidelines of the 4-Digit Code, which closely follows the American versions. Of the various guidelines that follow the publication of the 4-Digit Code, the Canadian guidelines are most similar to this 2004 version of the Code (Astley, 2006).

on FAS/D and provides the interpretive instructions, measurement techniques, categories, and code sequences which coordinate the diagnostic practices for identifying FAS/D in a child.

My analysis identifies the mother and child's textualization in a process that, I will show, organizes disjunctures between an objective, organizational account, generated in the properly accountable and professional manner of FAS/D professionals, and the experiences of a child and his mother. I also track and explicate how particular experiential evidence obtained from the mother is made relevant to the production of the child's diagnosis – evidence which Georgina is authorized to provide about herself. I also introduce a final segment of data that will show how the 'second stage' classes offered in Crabtree's FAS/D Prevention group also generate further work and responsibilities for mothers.

## **2.0 Engaging a mother's concerns**

To explore the disjuncture between two different ways of knowing, I begin in the everyday world in which Georgina and Arthur live. I first introduce Georgina, who describes some of the experiences which preceded and led to her work engagement in Crabtree. I then introduce Arthur, whom I learn about from Georgina's descriptions and her expressions of concern. I also draw on my own observations and brief interactions with him. I then introduce as data the diagnostic report that Georgina obtained and gave to me following the trip that she and her child made to Sunny Hill.

### 2.1 Beginning in the experiences of a mother and child: *"I want to stop the cycle"*

Like many of the women I interviewed, Georgina grew up on a First Nations reserve in rural Canada. She recalled with fondness the extended family members that cared for her after the death of one of her parents. The way Georgina talked about her family and things she had learned from them reminded me how oral traditions and stories are a vital part of the traditional

modes of education<sup>2</sup> for many First Nations peoples (Maracle, 1996; McIsaac, 2000). For example, Georgina recalled how some of her family members made use of healing plants and herbs from the forest that helped her to recover from illnesses she had as a child. I could also hear when she talked about her own children and the skills that she had learned as a child, that she hoped her children too might be recipients of some of the First Nations traditions.

Georgina's recollections were also mixed with sadness as she described multiple losses of family members. Her recollections included accounts of abuse and shame some family members experienced in residential schools, and her own youthful experiences with child welfare authorities and the youth justice system. Georgina told me that she started drinking alcohol at a young age, and as a young teen she began a hard life on the streets. While still a teenager, Georgina lost a child to welfare authorities. She described many difficulties, including domestic violence, physical illnesses, and despair. Eventually Georgina stopped using alcohol. She discovered Crabtree one day when a friend told her that she could have a nourishing free lunch at the centre. She and a friend decided to check it out. Shortly after she began attending, she began using the emergency daycare services and attending the FAS/D prevention group.

When Georgina described her concern for the well being of her children, she referred to "the cycle" that has affected their lives, and she expressed the hope that, in her love and care for Arthur, this cycle could be stopped. In her talk about 'the cycle', Georgina was orienting her concerns to the inter-generational use of alcohol, the abuse family members suffered in residential schools, and their effects on members of her family. When she spoke of the effects, she pathologized herself and her own mother as she explained, "I probably have FAS too." My

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<sup>2</sup> This and other traditional methods of educating the young were largely lost or suppressed when Europeans colonized First Nations lands and imposed their methods of education, including their values, beliefs, and assimilation practices (Barman, Hebert, & McCaskill, 1987).

analytic work has been helping me to attend to how women's use of language signals the social relations at work in their lives and how talk about FAS is already embedded in them, coordinating a way of knowing and being known.

The social relations organizing Georgina's experiences and work activities in Crabtree are also engaging her concerns about Arthur. The knowledge and expertise Georgina has been gaining in FAS/D is 'knowledge-for-action' (Smith, 2005) and it is organizing Georgina to act responsibly by having Arthur assessed.

## 2.2 A child struggles in school: "We talked in class about getting tested"

While women learn in Crabtree that they cannot change what they have *done* to their children, they also learn that by having their children assessed for FAS/D, they will help to minimize their risks, gain access to special help in school, and thereby, improve their children's chances for better lives than they have had.

When Georgina spoke of Arthur, she expressed her concern that he was having "a hard time reading and learning to write sentences" in school. Arthur's difficulties in school played a part in how Georgina understood his need for what she called "testing<sup>3</sup>" at Sunny Hill Health Centre for Children. Georgina expressed her hope that by getting Arthur tested he would also get extra help in school and thereby, succeed in his schooling.

When Georgina talks about Arthur's challenges in school, I can hear not only her concern about his school experiences, but also her pride in him. She tells me how they support and love one another, and her descriptions of Arthur reveal a sensitive and loving child. For example, Georgina tells me that one time when she and Arthur were feeling sad, they held one another and cried. Then Arthur told her: "Don't cry, Mom. I'll stop crying if you do." Georgina explains that

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<sup>3</sup> By way of clarification, many of the women used the term 'testing' rather than 'diagnosing' in reference to the work that was to be carried out with their child.

although Arthur is having trouble with reading and writing, he is “smart in other things”, such as the things he does to help at home, his creativity, and his kindness to others. On the occasions I met Arthur with Georgina, I saw how responsive Arthur was to Georgina when she asked him to sit quietly and draw while she attended to her own activities.

In the following interview segment, Georgina explains how she finally reached her decision to take Arthur to Sunny Hill for “testing”, and how she understood the result of the test outcome from Arthur’s test, which she later received. Here, Georgina’s talk shifts from relating her embodied experiences with her child to the objectifying forms of knowledge about children prevalent in the talk and work in Crabtree’s setting:

So I had Arthur – well – we talked about it in our class, about getting tested, so I finally had him tested. He does have FAS. He’s got learning problems...

This segment of data provides a window into how work activities in Crabtree, combined with a child’s efforts and troubles in school, enter Georgina and Arthur into a sequence of actions involving the text-mediated practices experts use for identifying and producing the FAS/D child. Work activities in the class have guided Georgina on the intended course of action.

Personnel in Crabtree coordinate<sup>4</sup> the work interface between Crabtree’s informal text-mediated work processes, and those involving experts, who will establish the proper, diagnostic account concerning the child. Georgina explained that with the help of personnel in Crabtree, she talked to a doctor, and then decided to have Arthur tested. Georgina insisted that the decision to take her child to Sunny Hill was hers: “*I’m the one that said I wanted him tested,*” she said.

Georgina’s talk about herself and her child reveals an interface between her/their experiences and a vast network of institutional relations, FAS discourses and practices which are

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<sup>4</sup> In Chapter Six, personnel in the daycare coordinated knowledge about Emily’s history of alcohol use to professionals who visit the daycare, which helped to set in motion the observations of her child, Alix.

organizing the work that is to follow. As I shift my attention to the interface between a mother at Crabtree and the professional expertise involved in FAS/D diagnostic care and services, I am discovering how a mother's efforts to help her child gear into accountability processes. This textual and textualizing work provides a now 'responsible' mother access to medical expertise and to certain resources, such as Sunny Hill, which are associated with the organization of FAS/D diagnostic services in this province.

### **3.0 'Help' for children: "*It's just a little piece of the puzzle*"**

Parents who arrive at Sunny Hill may enter the agency's FAS/D services through various access routes. According to an informant the Crabtree birth mothers are a small and unique group among the larger population of caregivers who take their children to this specialized FAS/D resource.

#### 3.1 Access to help for different groups of mothers

The usual route for a parent/caregiver to access FAS/D professional care is by physician or specialist referral to one of the designated assessment and diagnostic agencies in the province, among them Sunny Hill. The majority of parents/caregivers who seek the FAS/D diagnosis are foster parents. Children-in-care comprise seventy per cent of physician referrals to Sunny Hill's diagnostic clinic, while the children of adoptive parents account for another twenty-five percent. With programs to assess and diagnose children with challenging needs and variances in behaviours, Sunny Hill is a key resource for foster and adoptive parents seeking help with children's troubled and troubling<sup>5</sup> behaviours.

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<sup>5</sup> The distress, agitation, anger, and despair that children in foster care may exhibit have now been well documented (see for example Walmsley, 2005). Often, children have been forcibly removed from their biological parent(s), as my interviews with birth mothers demonstrate. For many children in care, the experiences of apprehension by child welfare authorities, combined with repeated placements in foster homes, are cited as causes of severe emotional trauma. The majority of children in care in BC are Aboriginal children. It is not surprising that the work of foster

I asked one informant who has been part of a team effort for determining a child's diagnosis to explain the actual purpose and value the diagnosis held for parents:

The FASD diagnosis is mainly used for certain designation in schools to get the one on one assistant or whatever it is ....And ummm, you know, if the Ministry's involved, the diagnosis doesn't really give them more support that way, however, it's just a way of trying to unravel why this child is acting a certain way. So it's just seen as a little piece of the puzzle, it's not seen as a way of describing the child or a way of helping the parents at home with the daily challenges of raising the child so, yeah, we give a diagnosis.

My informant's response suggests that the diagnosis is oriented to institutional relevancies concerned with children's schooling and also with relieving foster parents of the burden of responsibility for how the children are acting, rather than to helping mothers, children, and families with difficulties in their everyday lives. According to my informant's response, the diagnosis (I am referring here to a medical category, a work practice, and a text) articulates with and coordinates administrative functions in and across institutional fields including medicine and education. Apparently, foster and adoptive parents find 'help' and reassurance through obtaining the diagnosis for the child/children in their care. According to one informant who works in the FAS/D system of care, foster parents are often relieved to learn that the child has FAS/D. The relief is from that of responsibility:

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parenting is challenging and demanding. By the mid 1990s, the number of First Nations children under state supervision (children in care) was six times higher than those in the general population (Canada, RCAP) (1996) cited in Walmsley (2005). As of September 2009, approximately 50% of children in care are Aboriginal (MCFD, 2010).

Yes, your intuition is right. There is something different about this child in terms of his learning or behaviours, so that is a relief, because they think they're going crazy or they're not good enough parents.

Because this unique diagnosis attaches responsibility to birth mothers, it offers both foster and adoptive parents the relief of knowing that it is not *their* 'bad' parenting that is causing children's problems.

One informant estimates that only five percent of mothers who take their children to Sunny Hill for FAS/D assessments are birth mothers. In part, the usual route taken by foster/adoptive parents is not often available to birth mothers because many of them do not have family doctors. Nor is a doctor's referral a likely route for mothers who are often reluctant to express their concerns that their children might have FAS. Another informant explained: "Because of the shame and stigma, birth mothers don't normally want anything to do with this diagnosis". Women in Crabtree have also revealed their level of distress but their readiness to disclose has hinged on the prospect of help.

Georgina has learned at Crabtree that the 'help' she is seeking for Arthur in school relies on the work of experts who will determine whether or not he has FAS/D. Here is the intertextual institutional work my informant and the mothers, too, have been alluding to. One text, a diagnosis, will coordinate textual work for accessing<sup>6</sup> services in school. It is this prospect, a promise of help that has engaged Georgina's concerns and led to her decision to have Arthur tested at Sunny Hill.

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<sup>6</sup> Readers of Chapter Four will recall how teachers must write up children into a text called *Form 1701*, to meet government's accountability processes for accessing special needs funds to help children in school.



### 3.2 An authoritative health care site

The Sunny Hill Health Centre for Children is a tertiary care resource within the Provincial Health Services Authority (PHSA) and a part of a complex of provincial health care services for children and families. The PHSA is the provincially-mandated ‘sixth’ health authority (HA), established under the current Liberal government to provide specialized health services and consultation to five regional health authorities. The Sunny Hill centre is also associated with the BC Children’s Hospital (BCCH) provincial remit and is the Coastal Health Authority’s primary regional resource for children with disabilities from birth to age 19 and their families (BCCH, 2009). Each of these organizations has mandates and policies that help to frame Sunny Hill’s lines of accountability and authority and direct how agency personnel carry out their practices within institutional fields of activity concerned with children’s health. Sunny Hill’s mandate specifies that the services at the centre are available to children with ‘special needs’ and those who have ‘disabilities’ (2009).

The categories, ‘special needs’ or ‘learning disabilities’, signals fields of social relations and text-mediated work practices which turn children’s experiences, such as their struggles at home or with tasks put before them in diagnostic centres or schools, into the standardized categories<sup>7</sup> that are relevant to the terms and concepts of the organizational work that is conducted. The ‘umbrella’ category, FAS/D incorporates ‘learning disabilities’ as an expression or sign of the syndrome (Astley, 2004).

The variances in Arthur’s learning experiences along with his mother’s alcohol use during pregnancy, position him as a child ‘at risk’ and as an eligible candidate for the FAS/D

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<sup>7</sup> It was during my tenure as a policy consultant with the Ministry of Health in BC and while I was involved in the initiative to close Sunny Hill’s long term care beds occupied by children with ‘disabilities’ such as cerebral palsy that I began to query the practices I participated in – those of tying categorical designations to work activities for rationing resources among different groups of children and their families.

diagnosis. Arthur's diagnostic report identifies the 'Complex Development and Behavioural Program' as the specific program in Sunny Hill responsible for conducting FAS/D assessments and generating the diagnostic accounts that follow.

In 2005, the provincial government announced plans for a \$14 million expenditure over three years to establish a province-wide 'CDBC Network' to improve and coordinate diagnostic and assessment services provincially for children with so-called Complex Developmental and Behavioural Conditions (CDBC), including FASD (MCFD, 2008; Ministry of Finance, 2005, September 14). The overall scope of the CDBC Network is to assess children and youth who demonstrate functional difficulties in "development and learning, mental health, and adaptive<sup>8</sup> and social skills" (MCFD, 2010:1). Each of the five Health Authorities (HA) in BC has designated CDBC assessment sites within their HA region. Sunny Hill is the Coastal Health Authority's CDBC assessment site within this Network.

'CDBC' was, at the time, a new term for me, and apparently a new one for some mothers. One mother, explaining to me the results of her child's assessment for FAS, tried to tell me the "other" name of his 'condition'. I have been learning from Smith (1990a; 2009) not to take categories and concepts as givens in my inquiry. So later, when I had done some sleuthing work, and discovered how CDBC is relevant to people's practices for categorizing children as FAS/D, I realized CDBC was the 'condition' the mother had been talking about. Through my analyses of the various concepts and terms mothers in Crabtree have been learning, reading, and talking about, I have also been discovering how professional practices for categorizing children may

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<sup>8</sup> The Ministry of Children and Family Development established an alternate site, BC Autism Assessment Network (BCAAN), for assessing and diagnosing children who may have Autism Spectrum Disorder (ASD) (MCFD, 2007b; 2007c). These services were established in response to a BC Supreme Court ruling.

confuse, mystify, and, at times, overwhelm their mothers. I suggest this too may be intended by their social organization.

While the names of the categories, programs, public agencies, and services I have been introducing may appear unremarkable, I am making them visible in order to illuminate some of the institutional arrangements, knowledge categories, and textual work involved in assessing and producing FAS/D children and in authorizing the textual accounts about them. I am also showing that Sunny Hill is a government-authorized work site for people who know how to conduct FAS/D assessment and diagnostic work. That the work of FAS/D professionals is located in the standpoint of government authority legitimates and authorizes their objectifying work (De Montigny, 1995).

### 3.3 The authoritative knowers

Experts claim that FAS/D diagnostic work is complex and requires specialized training (Astley, 2004). At Sunny Hill, expertise in conducting assessments is accorded to a multidisciplinary team of professionals, including people from psychology, medicine, rehabilitation therapy, social work, and speech pathology, who are involved in Sunny Hill's Complex Developmental and Behavioural program. According to professional informants, each member of the participating discipline conducts and contributes her/his expertise to the assessment findings, including the final diagnosis and recommendations.

While each professional within a discipline will be guided by the authority ceded to the respective governing and licensing body and the theories and the conceptual practices relevant to his/her profession, power will also arise as people's activities are "coordinated to give the multiplied effects of cooperation" (De Montigny, 1995; Smith, 1990a:70). The work processes of determining whether or not a child will be diagnosed with one of the categories under the FAS/D

umbrella will coordinate the work of each professional to the FAS/D discourse and the FAS/D interpretive schema will direct the technical practices and procedures for finding FAS/D in a child. The hierarchical organization of FAS/D ‘fact-finding’ will also ensure that each professional co-operates with the physicians who have the final authority to confirm and authorize the diagnosis.

In western societies, a medical diagnosis can generally be authorized only by a qualified physician. In order for Arthur’s text to be authoritative and accountable it must be ‘signed off’ by a physician. Arthur’s text includes the name of two medical specialists, one of whom finalized the report and is noted as the contact person for any questions pertaining to it. The names of the other members of the assessment team, whose authority is not required to validate the diagnosis, are not indicated in the text.

In the following section, I introduce a segment of analytic data from Arthur’s diagnostic report in order to explicate how objective knowledge concerning a child and his mother is established and what this form of knowledge accomplishes. I show how the practices of writing and reading the text are crucial to activating the ruling relations the text carries.

#### **4.0 Establishing the facts about a child and, by implication, his mother**

The diagnostic account of a child with FAS/D is shaped, not by a reality or ‘entity’ that is apprehended from the child and documented, but rather by the processes of production and social organization. There is a concerted process of working up a proper professional account that relies on standardized practices, questions, and procedures that will frame the problem that is to be addressed within an acceptable, ‘objective’ professional schema (Smith, 1990a). Anything going on in the child’s everyday life that does not fit the conceptual frame will generally be left out.

#### 4.1 Framing the problem with Arthur

Arthur has been experiencing difficulty with reading and writing in school, a common difficulty with school-aged children. Schools are consistently dealing with children who require special help to assist them to achieve the age-related norms<sup>9</sup> expected of them for their performance in school. Arthur's teacher had tried to reassure Georgina that Arthur was not the only child who was having difficulty in school. In Arthur's situation, however, the problem with his schooling has come to be identified as one that requires medical attention and expertise rather than alternate knowledges or educational approaches to providing help.

The work of identifying a problem within the institution of health care usually involves attention to the cause. In western medicine, the work of determining 'etiology' is fundamental<sup>10</sup> to medical practice and the investigations and interventions that follow. By reading Arthur's text and the *Guide* that coordinates the diagnostic work, I can see how the problem of a child's struggles with reading and writing are framed and how the etiology is made authoritative. It is through the processes of framing the diagnostic account that much of what makes up an individual's life and her/his experiences will simply disappear (Smith, 1990a).

The introduction below, from page one of Arthur's text directs me – and any other interested reader – to learning how Arthur's problem is framed in a particular medicalized discourse. An interpretive schema, in this case, the one within the *Guide* I referred to earlier, proposes the name of the problem and by implication, it also frames the cause:

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<sup>9</sup> Here, of course, is another practice organizing Arthur (see also Chapter Five).

<sup>10</sup> The centrality of etiology to western medical practices has been addressed more fully in Chapter Two.

## ***Introduction***

*'Arthur' was seen with [his family member] for evaluation of a possible diagnosis of Fetal Alcohol Spectrum Disorder (FASD). The following findings and conclusions were discussed with [family member].*

'Fetal Alcohol Spectrum Disorder' points to the 'systematically developed knowledge' (Griffith & Smith, 2005) frame for how people who read Arthur's text are to begin to think about him and the problems he is having in school. FASD is not an authorized medical diagnosis<sup>11</sup>, but rather encompasses FAS and other alcohol-related diagnoses (Astley, 2004). The Introduction implies that the work processes for finding FAS/D in the child are authorized by experts who know how to do this diagnostic work. The Introduction, thus, alerts the writer and now the reader of the text, to that which they are to discover: a subject who is also likely to be known as an FAS/D object. As Smith (1990a) shows in a different context, discovering that someone has a 'possible' diagnosis sets up instructions for how to find what is to follow.

In the professional manner of writing the text, this next entry on page one of Arthur's report will appear, to anyone reading the text, as the facts that have now been 'discovered' about Arthur:

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<sup>11</sup> Astley (2004) states that FASD is not a diagnosis but an umbrella category that encompasses the diagnoses. While the introduction, which misrepresents FAS/D as a "*possible* diagnosis", may be a minor error, I have observed that this representation reflects a common practice in this field of medical and advocacy work. I repeatedly heard parents, clinicians, and other human services workers describe children as having a *diagnosis* of FAS/D, a term which in my view helps to establish that the FAS/D 'umbrella' is now an authoritative framing of the children's problems and what has caused them.

***Etiological Diagnoses:***

*On the basis of today's history and physical findings [Arthur] fits the diagnostic criteria for Neurobehavioural Disorder – Alcohol exposed, using the University of Washington criteria: 4 Digit Diagnostic code (1223).*

Here, in short, are the facts about Arthur that are written up in his etiological diagnosis:

1. Evidence (instances) that establishes his diagnosis has been extracted from Arthur's experiences (his history) and his body (physical signs discovered through expert examination), and
2. The evidence establishes that the diagnostic category 'Neurobehavioural Disorder – Alcohol exposed' is the one that applies to Arthur. Of note, this category is one of 22 categories subsumed under the umbrella term, FAS/D.
3. Arthur's diagnostic code – expressed as (1223) is a sequence of numbers or 'digits' – indicates the severity of Arthur's disorder/exposure.

Smith's social organization of knowledge brings a different way of reading professional writing. In this case, the facts eliminate the presence of the knowers/doers who have been involved in the assessment and textual work. A fact is "construed to be external to the particular subjectivities of the knowers", and thereby makes it the same to everyone and anyone to whom it is applied (Smith, 1990a:169). That Arthur's medical diagnosis of 'neurobehavioural disorder – alcohol exposed' (1223) is independent of knowers, *authorizes* the account of his disorder and eliminates any questions a reader may otherwise have about the judgment of those who are defining him as such (Smith, 1990b). The numbers (1223) in the diagnostic code sequence confirm the facts and establish their scientific objectivity. The presentation of the 'facts' about

Arthur at the outset of this textual account of him, also establishes that the writer/experts have the ‘definitional privilege’ (Smith, 1990b) to authorize their version of the variances they have discovered in him.

When I turn to the definition for Arthur’s diagnosis, ‘Neurobehavioural disorder – Alcohol exposed’, in the *Guide*, I discover that the facts are not expressed as facts but as indeterminacies and possibilities:

[T]here was *not* [my emphasis] strong evidence that the patient’s cognitive/behavioural problems were clearly due to CNS [central nervous system] damage, but there were suggestions that this was the case. In this situation we use the term ‘neurobehavioural disorder’ to emphasize the possibility that the problems may not be entirely due to postnatal experiences. Certainly a number of other factors could be contributing to the patient’s condition such as genetic background, other potential exposures or problems during gestation, and various experiences since birth (Astley, 2004: 67).

The *Guide* lays out in uncertain terms relationships between ‘cause’ and a person’s cognitive and/or behavioural experiences: This definition introduces uncertainties, inferring that Arthur’s struggles in school may *not* be related to his mother’s prenatal use of alcohol, nor are they necessarily an expression of brain damage. There could be also be other factors in Arthur’s experiences which are contributing to his difficulties and examples of these are suggested. If Arthur’s troubles are open to interpretation and possibilities, perhaps the classroom is too noisy, the teacher too harried to spend time with him – any number of possibilities could be considered.

However, while the definition in the *Guide* raises these uncertainties, the textual account of Arthur as a child known as Neurobehavioural Disorder – Alcohol exposed (FAS/D) eliminates



them. Arthur's text conveys the facts about Arthur, just as other texts diagnosing other children as FAS/D would make them similarly known.

The power of a text bearing the marks of authority when it is launched into public space is considerable. As readers are captured [by the text] it comes to provide the terms of discussion with others similarly caught (Smith, 1999: 214).

Fetal alcohol spectrum disorder is proposed as a spectrum, a "continua from normal to clearly abnormal" (Astley & Clarren, 2000: 400). However, in the objective way of identifying and framing Arthur's problem as FAS/D, he is written up like any other child with FAS/D. If the final account of Arthur is to be seen and read as 'factual', then the writer and reader too must discard indeterminacies and attend only to the facts of the matter. The uncertainties that appear in the *Guide* are obscured in the final account.

#### 4.2 Techniques in producing and ordering the facts

Numbers are impervious to doubt – they are facts that can be trusted (Porter, 1995). The diagnostic category, devoid of knowers with their biases or uncertainties, provides a factual representation of Arthur's problems in school. And in case there are any questions about the facts, Arthur's diagnostic code (1223) has the numbers to substantiate them.

Arthur's diagnosis 'neurobehavioural disorder – alcohol exposed' – which experts identify as one of the disorders in the FAS spectrum – is matched with a code sequence (1223) or 4-digit code, which expresses the severity of his disorder. Each digit in the sequence of numbers establishes how one may know objectively about three of the diagnostic features pertaining to Arthur: his growth experiences (deficiency), facial appearance (the 'FAS' face), and cognitive/learning experiences (brain damage). The fourth and final digit in the sequence

provides objective knowledge about ‘exposure’<sup>12</sup> – a mother’s ‘prenatal’ experiences of alcohol use during pregnancy (Astley, 2004).

A major section in the *Guide* is devoted to providing detailed instructions for determining the four ‘digits’ that establish the child’s diagnostic category within the spectrum of disorders. The determination of the diagnosis includes generating a numerical ‘code’ made up of four sequenced numbers and then, matching it with the relevant alphabetical category and diagnostic name that the code generates. For example, Arthur’s code (1223) is specific to his diagnostic name ‘Neurobehavioural disorder – Alcohol exposed’.

<b>Code</b>	<b>Category</b>	<b>Diagnostic Name</b>
1223	H	Neurobehavioral disorder (alcohol exposed)

(Astley, 2004: 53; see also Chapter Two Figure III)

The FAS/D coding system and the instructions in the *Guide* for ranking and ordering the four digits in the coded sequence, work as set of instructions that tell an expert, and those who read the expert account, how to make sense of a child and the difficulties he may be having. The child’s outcomes – any variances in the child’s growth, facial appearance, behaviours and so on and his ‘exposure’ to alcohol, are the independent variables. The concept, FAS/D and the interpretive schema, orders the diagnostic work (the examinations, measurements, observations and so on), the interpretation of the variables and the particular observations that the schema makes relevant, thus enabling the diagnosticians to produce and make sense of the facts about the child.

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<sup>12</sup> Could we find a more ‘objective’ form of knowledge than a word that has neither object nor subject? – yet both are implied and present if ‘exposure’ is to have an effect.

Evidence is computed into ‘coded’ facts, which ‘stand in’ for the assessors’ observations of a child’s growth, facial features, and so on and for the determinations they draw about them. The assessors read/write, interpret, and order the coded facts – (1223) for Arthur – as instructed, so that the variables in the interpretive schema produce the outcome FAS/D that the schema intends. The evidence that will be discovered in the child is, I propose, the evidence that is necessary to preserve the integrity of the schema for producing a child who will be known as FAS/D. Any disagreements or uncertainties must be discarded. This requires that the child as subject disappears and so too, therefore, must his knowers. In the next section, I detail how Georgina’s subjectivity is ruled – as I show how a particular experience is selected and represented to confirm her responsibility for problems in Arthur.

### **5.0 Establishing the facts about the mother’s use of alcohol**

Earlier in this chapter, I introduced Georgina, to show some of the richness and complexity of her experiences. I heard in what Georgina told me about her life, the many challenges she has faced – difficulties that she attributed to the painful family history and experiences of residential school abuse, family disruption, poverty, the oppressive circumstances of living the life of a young First Nations woman on city streets, her experiences of inadequate food, shelter, substance use, and domestic violence. I also heard of her love for her family, her pride in the First Nations culture, language, and skills that she has been re-discovering, and her commitment to making a better life for her child than she had experienced herself. I am arguing that once the diagnostic code sequence (1223) is applied to Arthur and his mother, only the objectified version of the mother and child remains.

### 5.1 Sorting out the relevant experience: making mothers' alcohol consumption count

Before the code sequence is complete, the assessors must deal with the mother and, to the extent they are able, sort out the facts concerning her alcohol use. Through reading the *Guide*, I discover contradictions between the instructions in the *Guide*, which express the need to recognize a full range of women's experiences, and the practices of writing up their experiences. In the following excerpts, notice how Astley's (2004) instructions for establishing the correct rank (number) for Digit IV dispel any claims of attribution between prenatal alcohol exposure and 'outcomes' in the child.

First, the author of the *Guide* acknowledges that women have a variety of experiences, or "pre and postnatal events" (Astley, 2004:45), which must be taken into account and documented. As Astley notes, "many of the outcomes observed in individuals with prenatal alcohol exposure are not specific to (caused only by) prenatal alcohol exposure" (45). Astley insists that experiences that should be taken into account are those that may apply to mother and/or fetus/child, including poor prenatal care, prenatal complications, learning problems thought to be unrelated to alcohol, cigarette smoking during pregnancy, exposures to or use of other drugs such as marijuana or heroin or other harmful substances, disrupted placement histories, abuse, failure to thrive, and so on (45-46).

However, while the author of the *Guide* acknowledges that these diverse experiences of children and their mothers can have an 'outcome' (such as learning problems) observable in children which is not necessarily related to alcohol exposure – when the assessors produce the diagnosis, it is the mother's experience with alcohol use that counts. *Writing up* the fourth digit for the mother into the coded account of the child will complete the diagnosis and obscure the

contradictions about which experiences are relevant, as proposed in the *Guide*. It will also establish, objectively, the mother's accountability for the etiology of her child's problems.

Confirmation of alcohol exposure (mother's alcohol use) is not a necessary requirement for a child's diagnosis<sup>13</sup>, however, confirmation of 'exposure' will ensure a more *authoritative* diagnosis (Astley & Clarren, 2000; Astley, 2004). According to informants, those involved in FAS/D assessments generally make every effort to assess and confirm maternal alcohol consumption. The recommended standard for confirmation of prenatal alcohol use/exposure is when the birth mother confirms it (Chudley et al, 2005). Here is the 'gold standard' for this accountability process: the birth mother who is authorized to be an expert in knowing how much she drank and is willing to talk about it. However, if the mother is unwilling or unable to provide the information, others who have observed the mother drinking may offer their account (Astley & Clarren, 1997). A family member, foster parent, and social worker are among those who can inform the experts who are attempting to objectify this experience of the mother.

To demonstrate how informal observations of women drinking alcohol can be made authoritative, I draw from my own observation of an assessment of two children – an observation I chose as a learning<sup>14</sup> opportunity when I worked as an FAS consultant. During this diagnostic assessment, the professionals who were conducting the event authorized the ex-husband of the children's deceased mother, himself a self-acknowledged 'alcoholic', with the authority to confirm that the mother drank during her pregnancies. While a mother's expertise in reporting her own use of alcohol is often held suspect, apparently this man's authority to make knowledge

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<sup>13</sup> In contrast to previous schemas for diagnosing FAS, which depended on confirmation of prenatal alcohol exposures (Abel, 1998), the 4-Digit Code dispels the requirement for confirmation of 'exposure' in order to render a diagnosis of FAS or to apply the umbrella term FAS/D.

<sup>14</sup> At the time, there was a major advocacy effort by foster/adoptive parents, FAS experts, and other professionals to expand and improve diagnostic services for FAS (the term FAS/D was not yet in vogue) in the province. Decisions were being considered about how to allocate resources and I felt I needed to be better informed about the diagnosis and how it could be helpful to the children and families that I believed public policy was intended to serve.

claims concerning his former wife's drinking was not. This and many other puzzles I encountered during my work marked the early beginnings of this project.

I learned from an informant, formerly a professional working on contract with a multi-disciplinary team in one of the CDBC Networks in the province, that s/he had also encountered puzzling events when participating in the diagnostic work. My informant observed some heated disputes among team members when there was a lack of consensus on the mother's use of alcohol and at times, these indeterminacies affected their ability to finalize the diagnosis. My informant explained his/her understanding of what was going on:

There is a lot of pressure in the team for people to agree on the diagnosis, even when the findings are uncertain. Parents want the dollars so that children can get the help they need.

Here, bureaucratic and administrative practices in institutional sites involving state, medicine, and education coordinate work in a local setting to a specific ruling function, the allocation of funds to help children in schools. Pressure to render a contested and stigmatizing diagnosis appears to be triggering the concerns of some professionals about their own accountabilities. Or as my informant suggested in the interview, some team members are weighing the benefits against the harms and questioning the cost of this objectifying form of help, particularly, in light of the indeterminacies about the alcohol exposure.

Confirmation of alcohol consumption has been an ongoing problem for those conducting this diagnostic work. I introduce a segment of data to show how the numbers in the code sequence are crucial to producing a factual representation of the mother. I begin by asking my informant, whom I call Kelly, about the importance of determining, for the purposes of the diagnosis, a mother's use of alcohol.

Kelly: Well, you know, technically, it's very important if you're looking to give that FASD diagnosis. But in reality, the day to day of what the parent needs, we can still give them – provide them a good service, because I would say half the time the alcohol exposure is suspected, or unknown.

Researcher: If it's suspected or unknown, would you give the diagnosis?

Kelly: It depends on the doctor, and ummm [long pause]. This is an issue. This is an issue, yeah, because there's been a lot of work in the last six months to standardize assessments across BC and lots of training about the 4-digit codes and what does that mean and how does it all come together, yet the doctors do not agree. If alcohol exposure's unknown, how do you interpret that? And I know one doctor, if it's unknown, [he/she] will not give the FAS/D diagnosis, *period* [speaker's emphasis], even if it's like, ummm, probable, like if it's coming from a foster mother and it's, “Oh yeah, I heard from the aunt or the grandmother that the mom's drinking” – that's not good enough for [her/him]. Another doctor will be like, “Well, it's unknown, but it's *possible* [speaker's emphasis], so they'll give it a score of, you know, two – two on the 1 – 4 [scale] so it's on there.

Researcher: Two is possible, is it? [Here, I am picking up on the statement above, i.e. that although exposure and risk is ‘unknown’, which is ranked as 2, it is ‘possible’ the child was exposed and is ‘at risk’].

Kelly: Yeah. And four is, like, definite. So then working with that number [two] they *could* [speaker's emphasis] give ‘FASD’, ‘static encephalopathy’, or ‘neurodevelopment

behaviour whatever disorder’, and then ‘alcohol exposure unknown’, so they could still give that diagnosis but it’s [pause], I don’t know if doctors will ever agree really [laughs].

My informant indicates that the diagnosis does not offer parents help in the day to day care of their child, which suggests that it does not work as a form of help or treatment for the child or as a guide to medical intervention. And s/he too, shows how determinations about maternal alcohol consumption are contested.

My informant explains that the BC government funded a training sessions for physicians in the province, as part of a concerted effort to standardize doctors’ measurement practices. Yet, as my informant also points out, doctors’ diagnostic practices reveal differences in standards and variances in clinical judgment. Some doctors *will not* authorize an FAS/D diagnostic category for a child on the basis of hearsay or other indeterminacies related to the mother’s alcohol use, while others *will* apply the diagnosis. This analytic segment underlines the importance of numbers as a way to establish the facts and, thereby, appear to eliminate any doubts or disagreements about what is to be made known.

## 5.2 Standardizing practices: Managing the controversies

Standardization is a practice of attempting to create uniformity among many entities (Timmermans & Berg, 2003). The *Guide* offers instructions on how to standardize the assessment of mother’s drinking and the risk she poses to her fetus, now a child at risk for FAS/D. The fourth digit of the code sequence is intended to establish both the degree of ‘evidence’ of prenatal alcohol exposure and the degree of ‘risk’ such exposure poses to the fetus (Astley, 2004). To determine the actual rank (numeric) for digit IV (see Figure V next page), the assessor estimates, on a scale from one to four, the degree to which the fetus is exposed to alcohol and the degree of risk that the exposure is thought to pose (2004).



According to the documentation in Arthur’s text, Arthur’s mother had confirmed that she drank during his pregnancy. Therefore, to complete Arthur’s code sequence, a rank of ‘3’ was applied (1223). The rank of 3 establishes that the mother’s alcohol use is confirmed and that it

**Figure V. Criteria for Prenatal Alcohol Exposure Ranks 1 through 4 (Astley, 2004: 44).**

4-Digit Diagnostic Rank	Prenatal Alcohol Exposure Category	Description of Alcohol Use During Pregnancy
4	High Risk	<input type="checkbox"/> Alcohol use during pregnancy is CONFIRMED. <i>and</i> <input type="checkbox"/> Exposure pattern is consistent with the medical literature placing the fetus at “high risk” (generally high peak blood alcohol concentrations delivered at least weekly in early pregnancy).
3	Some Risk	<input type="checkbox"/> Alcohol use during pregnancy is CONFIRMED. <i>and</i> <input type="checkbox"/> Level of alcohol use is less than in Rank (4) or level is unknown.
2	Unknown Risk	<input type="checkbox"/> Alcohol use during pregnancy is UNKNOWN.
1	No Risk	<input type="checkbox"/> Alcohol use during pregnancy is CONFIRMED to be completely ABSENT from conception to birth.

poses ‘some risk’ to her child (Figure V above). The instructions<sup>15</sup> in the *Guide* thus reveal how the mother is to be objectively accounted for in the child’s diagnosis.

Distinctions between the amounts of alcohol consumption (exposure) and risk to the fetus are highly contested<sup>16</sup> (Dell & Roberts, 2005; Plant, 2000). Persistent efforts to provide empirical and standardized evidence of maternal alcohol consumption in regard to fetal ‘risk’ have met with failure. Astley’s (2004) work (cited in Stratton et al, 1996) acknowledges that there is a “lack of consensus on the amount of alcohol that can actually be toxic to a fetus” (43). However, despite the disputes and uncertainties, even a rank of ‘2’, defined as “unknown alcohol use during pregnancy” (2004: 44), carries weight and forebodes ‘unknown’ but possible risks.

That there continues to be so much uncertainty and controversy concerning alcohol ‘exposure’ and the risk of fetal harm demands a method that obscures uncertainties. The practice of applying numbers and codes standardizes the diagnostic accounts of FAS/D children and their mothers, and thereby, provides a standardized way of knowing that is replicable in and across multiple settings. In all of the FAS and FAS/D diagnostic schemas<sup>17</sup>, the focus on and identification of the mother’s prenatal alcohol consumption displaces and subordinates her experiences and constructs her as a danger to her fetus and ultimately to her child. Generalizing claims for constituting mothers as risks also constitute the ‘at risk’ child. The *Guide* claims that *any* mother [my emphasis] who consumes alcohol during pregnancy places her child ‘at risk’ for physical, neurodevelopmental, and neurobehavioural problems (Astley, 2004).

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<sup>15</sup> The rank for a mother who never drank alcohol – when the assessor has confirmation that the mother never drank — would be ‘1’, which stands for ‘no risk’, a situation that Astley claims is rare (43). The highest rank – a code 4 – is purported to confirm a ‘high’ alcohol exposure and a ‘high risk’ that mother’s alcohol use will harm the fetus (Astley, 2004; Astley & Clarren, 2000: 407). Even a child with a rank of 1 in digit IV can be diagnosed as FAS/D, e.g. (code) 1241 (category) R (Diagnostic name) Static encephalopathy (no alcohol exposure) (Astley, 2004: 53)

<sup>16</sup> I have dealt with this topic at length in Chapter Two.

<sup>17</sup> There are other interpretive schemas, as noted in Chapter Two. Astley’s (2004) is the most prominent in western Canada.

The finalized account of the FAS/D child will obscure any of the indeterminacies the assessors find in a mother or in her child. The ‘umbrella’ term, FAS/D will also help to weaken or at least manage disputes among experts who may choose between a range of measurements, including 256 possible code sequences and 22 different diagnostic categories under the FAS/D umbrella. FAS/D allows for considerable discretion for measuring the risk of and evidence for alcohol exposure and it offers many possibilities in determining the levels of ‘evidence’ for brain damage from alcohol exposure. There are even FAS/D codes and categories that can be applied to children whose mothers have not used alcohol, although Astley (2004) insists this is rare. Because the FAS/D category is so broad or, I would argue, indeterminate, I suggest that an effect of its scope and variability is that it also provides for a considerable expansion in the number of children – and by (de)fault, mothers – that clinicians can fit into it.

I have been explicating how the work of coding relies on numbers, and how numbers establish objective ‘evidence’ for producing and ordering the ‘facts’ about the FAS/D child and his mother. It is this view of how producing, writing, and reading an authoritative account is a definite set of practices carried out by actual knowers and doers, which disappears when all we have are ‘the facts’. In the next section I return to the concern that motivated Georgina’s trip to Sunny Hill and to whether or not Arthur will get help in school.

## **6.0 Authorizing school management practices**

When Georgina talked about her decision to have Arthur tested at Sunny Hill, she expressed a hope that Arthur would get extra help in school for his difficulties with reading and writing. Georgina told me that after she learned that Arthur had what she calls *FAS*, she learned from his teacher that Arthur would get the extra help she felt he needed. The puzzle of how a medical diagnosis coordinates help in schools has been one of the puzzles that first motivated my

inquiry and subsequent research. The recommendations in Arthur's text reveal how medical practices of diagnosing children articulate with educational and state practices. In this section, I examine the recommendations and trace how the textual account produced at a diagnostic clinic authorizes and coordinates objectifying practices at work in other institutional sites.

#### 6.1 Recommendations in Arthur's text: generating further courses of action

The final section in Arthur's report, titled *Recommendations*, reads as follows and in the format presented on pages three and four of his text.

##### RECOMMENDATIONS:

*On the basis of today's findings, the following are recommended.*

##### *1. IEP/Educational Placement Eligibility:*

*We refer to the Special Education Services manual which states, "Students who present with conditions which may or may not carry a specific categorical designation should be identified for funding purposes in the special education category that best reflects the type and intensity of interventions documented in the IEP." If [Arthur's] school team can put together an IEP that reflects [his] very high need for support in both learning and behaviour, there is a strong case for the designation for "Chronic Health Impairment" on the basis of his **diagnosis of fetal alcohol spectrum disorder** [my emphasis], attentional weakness, and multiple needs in the areas of language, memory, planning, and social development.*

*The following diagnosis may support a Chronic Health Impairment Designation: a. Neurobehavioural disorder: In the context of prenatal alcohol exposure.*

Two additional courses of action were recommended, one for a comprehensive psycho-educational assessment and the other for a follow up CDBC assessment when Arthur is entering Grade Four. These courses of action indicate that Arthur will continue to be monitored as he

progresses through the educational system. I suggest that he will also be further ‘acted upon’ if his experiences or those of his ‘moderately risky’ mother warrant further actions.

When I initially read the first recommendation, I had to re-read the page to determine whether it had been erroneously attached to Arthur’s assessment and diagnostic report. I had just been reading an organizational account that presumed certain background knowledge related to child development, brain function, and medical diagnoses. Unexpectedly to me, in this recommendation the account also presumes background knowledge of educational texts and practices concerned with eligibility to government funding.

A text authored by a physician or physicians and pertaining to a medical diagnosis would usually generate recommendations or ‘courses of organizational action’ (Darville, 1995), which would likely be directed to a family physician, a local health centre, or even to personnel at Crabtree, where Georgina and Arthur might go for FAS/D professional support and possibly intervention. Instead, Arthur’s text refers to the *Special Education Services Manual* (see Ministry of Education, 2006) and an IEP<sup>18</sup>, and thereby, implicates other texts that coordinate people’s work<sup>19</sup> in other times and in other places (Smith, 2001) concerning educational practices and special needs policies.

The diagnostic text is not coordinating, as one might expect, some form of help for Georgina to manage her concerns about Arthur’s FAS/D or to offer support for improving his health, following his diagnosis. Nor is there a recommendation for professional support for Georgina, who is dealing with an authoritative claim that her child is brain damaged because of

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<sup>18</sup> IEP refers to a child’s ‘individual education plan’.

<sup>19</sup> These references also implicate my own work in other times and places (including Chapter Three). Readers may recall my reference to beginning stage of this research (Schellenberg, 2003), where I conducted an analysis of how ‘access’ to educational services is organized and restricted for children with special needs, including those with FAS or FAS/D.

her use of alcohol. However, it is likely that the caring personnel at Crabtree will offer that form of support.

Instead, the text is coordinating administrative practices for managing access to resources in a child's school. The IEP referred to in the recommendations, involves all the textual work that teachers must do to demonstrate 'evidence' of the child's difficulties as well as their own accountability for meeting school requirements and children's learning goals. There is still more work to be done by teachers to make Arthur's diagnostic category count.

## 6.2 Making categories count

Under the terms and conditions already established by the Ministry of Education, access to funding for children with special needs has to be established through one of the existing twelve fundable categories listed on a Ministry text, *Form 1701*. There is no category for FAS or FAS/D on the text, which manages eligibilities to these special funds. However, one of the twelve categories, 'Chronic Health Impairment', has been a catch-all for a number of health conditions. And under new arrangements, it can now include FAS/D.

When the government funded the establishment of the CDBC Networks to provide FAS/D assessments and diagnoses in the province, an inter-ministerial committee of policy makers agreed on a new category, 'chronic developmental behavioural conditions', that would include FAS/D. One policy informant explained that, since the CDBC Network was established, the "CDBC assessment is a validator for [i.e. validates] the 'chronic health impairment category'". Therefore, any child who has been categorized as FAS/D can be slipped into this eligible category, and thereby, gain access to funding for special help with his learning activities in school. The teachers must first do the IEP – the work of writing up the child into this category.

My analyses reveal how institutional fields of socially organized activities concerned with state, medical and schooling practices, rely on categorical forms of knowledge that objectify children. These ideological practices translate children and their experiences, such as their struggles at home or in diagnostic centres or schools, into relevant categories that make children objects and also amenable to further courses of authoritative action. The experiential knowledge that teachers and parents have about children, nor the knowledge children may express about their own difficulties, do not validate people's claims that children need some help.

While the diagnostic report I have examined is specific to one child and mother, the knowledge practices involved in the production of the FAS/D child and his now 'accountable' FAS/D mother are not unique to either individual or to their local setting. Administrative institutional practices at work in Arthur's and Georgina's lives are also at work in other women's and children's lives. The institutional and objectifying forms of knowledge that make an FAS/D object of Arthur and produce the accountability that will follow his mother throughout her lifetime, coordinate standardizing knowledge about many other mothers and children also made known. The social and ruling relations of FAS/D can be explicated as sequences of social actions that begin in local settings and extend into other settings where [other] people work upon and take actions that enter children and their mothers into administrative systems that may be used for monitoring and, when necessary, taking further actions upon them.

While all this ruling work directs attention to multiple institutional fields and work processes, the institutional text-mediated forms of activity that made all this work possible and actual began in Crabtree. However, after mothers have demonstrated their accountability for themselves and their children, Crabtree offers another work project, through which mothers may take on even more responsibility – this time, for other women and their children.

## **7.0 After Sunny Hill: Empowering mothers and expanding their responsibilities**

After Georgina and Arthur completed their work engagement at Sunny Hill, Georgina talked with Arthur's teacher and learned that help would be available to him. The teacher told Georgina not to feel too bad and said: "He'll have special help in the classroom. And he won't be the only one. There'll be other little kids". Georgina responded to the teacher: "I know. I'm just sad. I want the cycle to quit."

Women participate in the diagnosis, as I have been showing, because they learn it is something they can do to help their children. But the experience of engaging in the FAS/D diagnostic processes also confirms the concerns mothers had and were expressing. One of my professional informants, reflecting on the difficulty that mothers face when they take their children to Sunny Hill, explained: "So we try to remove the barriers and develop the trust and more important, that after Sunny Hill, there's something afterwards." Will there, perhaps, be a more coordinated effort now to address the conditions of women's lives – other than those related to FAS/D?

Back at Crabtree, when women graduate from the first stage of their FAS/D Prevention classes and have demonstrated their accountability at Sunny Hill, they can enter the second stage of FAS/D Prevention work, where they learn how to apply their expertise in FAS/D discourses by helping other women and children in the community. I first learned of this work project when Jennifer told me that after she had her children assessed she was very busy with other work activities, which she described as "getting out in the community" and "telling my story".

In the following interview segment, another informant, Sandra, who has entered the second stage of FAS/D Prevention, fills in details about her 'story' as she talks about her work with other women. I ask how her work is helpful to them:



To be honest, I think just from having, letting them know what you have accomplished, and giving them that information. I think they, as their own person, would be able to figure out how it is, I believe, it can work for that person or that mind or that soul. It's just by teaching them your experiences, and you're not the only one that has had it.

That's so, I had it, and that person right beside you has had it, and so I think on and on... I understand from Sandra's oblique descriptions of helping women "figure out how it is" and "you're not the only one that has had it", that 'it' references a mother's concern – the concern about FAS/D in their children, the same concern that has been engaging mothers in Crabtree in this responsabilizing discourse. Sandra says that she thinks women "would be able to figure out how it is" – suggesting that FAS/D is already informing their consciousnesses, and how they are to understand their children's difficulties. Sandra's work project, it appears, is aimed at helping mothers along the courses of action which make more accountable and responsible mothers.

This form of work resonates with discursive practices in the AA tradition. In Step Twelve, the final step in the AA group work activities, the individual who has entered a new "state of consciousness", achieves the preparation and readiness to "carry the message to [other] alcoholics" (Alcoholics Anonymous, 1953). 'Helping' others, in this tradition, ensures that the relevancies of the 'alcoholic' discourse are carried to other alcoholics who may also achieve new consciousnesses by learning to make themselves subject to the discourse and the work it will accomplish in them.

For some women, *telling* their story is not confined to telling other mothers in the community. For example, Leslie has been telling her story to her child's daycare workers and she explains why the daycares need to know: "If they're not educated about him, they won't be able to help him". Alice has spoken at an FAS/D conference where, as she explained, she represented

the voice of birth mothers and had an opportunity to tell her story to professionals and policy-makers.

Some of the women I interviewed have been personally recruited by government officials where they have revealed the social accomplishment of their engagement in the discourse. Some years ago, for example, Linda Reid, then Minister of State in the government ministry concerned with Early Childhood Development and FAS/D prevention, invited several birth mothers to attend a conference in the north where they could ‘tell their story’. I happened to be the policy consultant at the time and, because I was responsible for coordinating FAS prevention activities, Linda Reid’s office ‘recruited’ me to make the funding arrangements for birth mothers to attend this northern conference, where they could help educate policy makers, advocates, and others involved in FAS/D prevention work. I see now, in retrospect, how the mothers who attended the conference and I, were engaged in different stages of institutional work processes for disseminating FAS/D discourses.

Sandra plans to tell her story to social workers and doctors. In the following interview segment, she explains why teaching other mothers to carry the discourse is the ‘responsible’ thing to do:

Like I feel like social services, lawyers, police officers, doctors, a lot of that big higher standard people, do not know, some do and some don’t know, you know, you walk in, they don’t know why your son is acting up like that or why this teenager is acting up like that so why, they don’t have that information, they don’t know what FAS is so, the more you put it out there, and the more you teach these mothers, they can go out there and tell the doctor, “Here, here’s some information that I got from this program. Why don’t you read about it and then tell me if my son is FASD or FAE.” And also I think that some

mothers worry because some of them were born FAS or FAS/D. Their parents drank and they didn't know themselves that they had this, you know, and so the more they know, the more they realize that themselves, we are FAS, and maybe if we know, then we feel comfortable letting our children know or letting that doctor know...

Women's work in telling others about how to understand their children as FAS, FAE, or FAS/D and themselves as 'responsible', also engages and produces other knowers in the objectifying relations of the FAS/D discourse. Sandra understands that when she instructs other mothers in the discourse, they too, will educate doctors, teachers, police and other workers in multiple institutional sites. The practices of telling and re-telling, which Sandra describes, 'activate' the text-based 'institutional discourse' in multiple institutional settings, and thereby, enter many more women and their children into the generalizing social relations of FAS/D.

In recent years, the BC government has developed a province-wide Key Worker Program (see Hume, Rutman, Hubberstey, & Johnson, 2007<sup>20</sup>) which helps mentor mothers into the social relations of this generalizing discourse and the objectifying practices that follow. Drawing from my interviews with key workers and my reading of the relevant policy texts, I argue that the government has engaged key workers as a way to make mothers responsible 'agents' who are trained to help accomplish the government's FAS/D prevention work. It appears that the Crabtree mothers are encouraged to mentor other mothers in the 'community' as a way of demonstrating their responsibility.

These forms of dissemination and coordination of discourses by mothers and key workers bring to mind Smith's (1999) theorizing about the 'ideological code', which she likens to the reproduction and replication of nodes of DNA molecules that comprise the human 'genetic

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<sup>20</sup> For a final evaluative report on the program, see Hume, Rutman, Hubberstey, Lentz, & Van Bibber (2009).

code'. Like a genetic code, an ideological code generates the same order in different sites (1999) – a discursive ordering of the behaviours and responsibilities of many more mothers.

Smith also conceives text-mediated discourses as “skeins of social relations mediated and organized textually, connecting and coordinating the activities of actual individuals” that may be located in geographically, temporally, and institutionally diverse sites (158). People enter into practices organized and mediated by the discourse and become active participants in its relations. I have been showing how Crabtree’s FAS/D program and now the government’s key worker program, act as nodes in a skein of ruling relations through which women are recruited – first by Crabtree, and later by key workers and even government officials such as Linda Reid – to act as ‘agents’ of the government for doing FAS/D prevention.

When Sandra, a mother I have not previously introduced, spoke about her participation in educating others in the community, she claimed a sense of accomplishment in being able to act responsibly, but at the same time help others: “Yes, I am *FAS*, I’m forty years old, and yeah, I can’t do this, I can’t do that, but if you teach me, and if you help me get more information, then I’ll be able to help you help others.” The concepts of ‘agency’ and ‘freedom’ to choose her own course of action resonate in Sandra’s talk. However, my analyses have been showing how women’s “participation in the text is directly scripted” (Smith, 1999: 148). While women feel themselves to be free, their freedom to speak, to act ‘responsibly’, and to improve the conditions of their own lives is shaped by and constrained within the terms of the FAS/D discourse, which hooks women into the particular forms of consciousness that have been properly institutionally authorized for them.

## 8.0 Summary

The building of the authoritative report on a mother and child relies on the production of a particular kind of expert rendering – the production of numerical facts which dispel any controversies about a diagnosis which is contentious. The effort of dispensing with knowers or, at least, of standardizing their practices is essential to maintaining the appearance of objectivity.

My analyses make apparent that variances in mothers and children's experiences can be better managed if the diagnosis is to meet professional standards for reliability and accountability. Accountability demands an orderly process. The "representation is designed by the conceptual organization of an institutional discourse to which the actuality it represents must be fitted" (Smith, 2005:186). This is shown to be the case even when a detailed reading of the interpretive *Guide* reveals inconsistencies and indeterminacies. In the production of a proper professional account, the actualities of a mother's and child's experiences must be factually and textually represented.

The professional work of producing the 'objectified' FAS/D child depends on practices that objectify the mother, and make her an object amenable to authoritative action. The diagnostic work depends on making a case that the child has brain damage secondary to his mother's alcohol consumption. Digit IV: prenatal alcohol exposure is, I have discovered, an 'organizing' digit acting as the subtext in all the discourses and practices for producing the FAS/D child. Simply by reading or hearing that a child is FAS or FAS/D, or by looking for evidence of 'alcohol exposure', the stage is set for how the characterization of a child and his mother is to be interpreted. FAS/D directs attention to only one of the birth mother's experiences – her use of alcohol during pregnancy. Anything else that may be told or known of her experiences or other concerns she has simply disappear from the account. FAS/D thus establishes

a permanent account of how the mother is known and how she is to know herself as responsible for the problems of her child and of the adult h/she will become.

My analysis of Arthur's text brings into view how a hierarchy of intertextual relations coordinate and authorize work practices within in a widespread FAS/D institutional complex involving the state, medicine, and the system for schooling children. My examination of Arthur's text, has signalled a path for further investigation into how objectifying forms of knowledge and individualizing discourses, imbued – as FAS/D is – with medical expertise and authority, are useful to systems for administering state resources and also for governing groups within the population ('problem mothers') who may have a higher requirement for them. Through examining practices of this discursive organization, I have begun to map how people relate purposively in a local setting to other people, organizations, and resources. While this work of accounting for children's risks and maternal responsibility for them is established in actual practices in Crabtree, I am showing that an FAS/D institutional complex of work processes coordinates the courses of action that make mothers and their children actionable and institutionally knowable – and for mothers – also accountable.

I have been showing how responsabilizing discourses and practices, variously framed as 'women-centred' and 'empowering' forms of care, generate practices that displace state responsibility onto women, as though it were an accomplishment of women that they take on added burdens. Yet while the state displaces responsibility, those who rule still retain the power to define the 'problems' of women and children, establish their risks and responsibilities, and ration resources in a manner that offers little state-sanctioned help to women and children or relief from the responsibilities mothers must bear. My next and final chapter provides an overview and my concluding analyses.

## Chapter Nine

### *Ruling at work in the everyday*

*Investigating develops from within the local worlds of people's everyday experience, exploring the social relations and organization that coordinate people's activities across local sites, and explicating the workings of powers that are deeply implicated in our everyday lives (Smith, 2001: 161).*

#### **1.0 Introduction and overview**

When I entered the research field to begin my ethnographic exploration, I assumed that I would discover 'social organization'. Where I would find the actual practices that accomplish ruling and how ruling would organize women's everyday experience or the contours of my inquiry, were puzzles to be considered and questions to be explored. This openness to discovering how an investigation will proceed has been both challenging and exciting. At times, I took wrong directions or was 'captured' by the discourses I was attempting to investigate. In each situation and its accompanying doubt, I had to stop, take a deep breath, and return to where my inquiry begins – in women's and children's everyday lives.

In keeping with the theoretical underpinnings of institutional ethnography, I began my inquiry in a particular standpoint, on the side of women and their children. The women who are my primary informants are the recipients of helping services provided in a grassroots, women-centred agency in an impoverished inner city location. People engaged in various locations and institutional activities concerned with the work of governments, health, and education are also key informants. My own insider (subjective) experiences also inform my study and have shaped my early puzzling about the contested knowledges and practices that produce FAS/D children and responsabilized mothers.

My analysis developed from puzzles I encountered in my field work as I listened to women's talk. In talk, I heard women's concerns and also learned that what women knew about themselves and their children from their embodied, everyday experiences often disappeared – displaced by the names and concepts of authoritative medicalized discourses, which most of the women call 'FAS'.<sup>1</sup> My research goal has been to discover how this happens. While I have been querying a problem in the social organization of knowledge – a problem in knowing and how we/people know – my material investigation and discovery of how things actually happen as they do is in the social organization of mothers' work.

Institutional ethnography has provided the tools for this empirical investigation, which maps my discovery that an FAS/D institutional complex of ruling discourses and practices coordinates how mothers *know* their children have FAS. This way of knowing arises in women's participation in explicit and routine work activities. I discover *how* women become willing participants in institutional processes that actually re-shape their talk, their concerns, their responsibilities, and the kind of help they seek for their children. I learn how social organization actually works in the doings of mothers' everyday as they go about accessing the help available for them to improve their lives and those of their children.

My analysis of how routine helping practices reconstitute women's and children's experiences, makes a unique contribution to the research literature. While a number of writers examine the social relations of health and medicine in Western societies, few have examined how medical discourses and practices are taken up, negotiated, or coordinated (Lupton, 1997: 94). My study would be of particular interest to those in the social sciences who have identified a knowledge deficit in understanding *how* medical diagnoses actually organize people's lives.

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<sup>1</sup> Most of the women applied the term 'FAS' to their children, rather than the category, FAS/D.



I have identified useful intersections between my analysis and arguments put forward by scholars who criticize the diagnosis of FAS as a moralizing discourse arising in the work of experts who claim, for the most part, unproblematically the authority to name social problems and prescribe interventions for managing them. One notable FAS expert, Ernest Abel, provides valuable critique of the expansion of the diagnosis as questionable science and challenges expert claims which have produced ‘moral panic’ in the US. Abel argues that practices which measure children’s learning and behaviours generate unwarranted diagnoses (‘over-diagnoses’), primarily among children of poor women, First Nations women, and people of colour in the US where he lives and work. He insists that poverty and smoking are the primary risk factors for the relatively small number of women who give birth to children with FAS and he argues that “we need to search for the causes of this disorder” rather than focus on *the* cause (2).

A prominent tradition in western societies is the discursive representation in media and policy texts of mothers, particularly, of poor mothers, Aboriginal<sup>2</sup> mothers, and mothers who drink alcohol or use certain kinds of drugs. Text-mediated practices which coordinate abnormalizing representations of bad, degenerate, neglectful, or irresponsible mothers accomplish institutional processes for constructing and managing women as social ‘problems’. These literatures<sup>3</sup> resonate with my assertion that the ideological methods of reasoning which produce discursive knowledge about women, children, and FAS accomplish institutional work processes for managing ‘problem’ mothers and their FAS/D children.

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<sup>2</sup> Stevenson (1999) observes that the “European ideal of womanhood was projected on Aboriginal societies throughout the colonized world” and this projection of morality was the standard against which Aboriginal women were judged (57). See also Boyd (1999) on how maternal alcohol and drug use is based in racist, classist, and gendered assumptions used to control women seen to be deviant or dangerous.

<sup>3</sup> Many of these writers draw on Foucault’s (1991) conceptualization of governmentality and current neoliberal modes of governing or rule (see also my Chapter Three).

Current neoliberal projects of ‘government’ rely on constructing specialized forms of knowledge which play a crucial role in shaping the problems and the knowledge about people who must be governed. Teghtsoonian’s (2003) analysis of emerging neoliberal ideologies<sup>4</sup> in recent governments in British Columbia, makes apparent how ideologies discursively frame women’s interests and produce detrimental shifts, for example, in funding, that negatively affect the “social and economic well-being of diverse groups of women” (29). While women in general fare poorly under neoliberal agendas, women who use drugs and alcohol are even more likely to be subject to punitive rather than supportive measures (Boyd, 1999). This view is also supported by Alexander (1998) who catalogues the devastating effects of neoliberal ideologies on people who are constituted as ‘addicts’ or ‘drug problems’ in British Columbia.

Prominent neoliberal discourses related to ‘self-help’, ‘choice’, ‘empowerment’, and ‘community’, which emerged in my analysis as actual practices, have wide appeal but they also mask changes in relations of power and re-define the responsibilities of citizens (Petersen & Lupton, 1996). Some writers have shown these relations to be a mode of ‘governing from a distance’ in order to “conduct the conduct of others” and even to bring the ‘self’ in line with the categories, diagnoses, or explanations by which people can be judged, understood, and acted upon (1996b: 3; see also Nettleton, 1997). The ‘good’ citizen is, thereby, an autonomous subject who conforms to state goals voluntarily and constantly exercises the ‘right’ choices in a quest for self-improvement (1996; Li, 2007b). Societal regulation is thought to be more stable and secure when people’s interests and self-management practices are aligned with the interests of those who rule (Brock, 2003, Castel, 1991).

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<sup>4</sup> The term ‘ideology’ as it is used here, draws on its common formulation as systems of beliefs, values, or perspectives, in contrast to Smith’s (1987; 1990a) discussion of ideology (Chapter Four).

In contrast to this idea that people have the freedom to choose how to conduct their lives, some writers (see Tait, 2003; 2008, for example) point specifically to a lengthy history of oppressive ruling relations and colonizing practices which have acted – continue to act upon the lives of Aboriginal peoples in Canada, and construct Aboriginal mothers as ‘risks’ and their children as ‘FAS’.

These research papers resonate with my own findings where I discovered, that among the women who attend Crabtree, are many who have grown up in Aboriginal communities or homes where FAS is a language known in common with others in their family or community. My analysis suggests that for Aboriginal women, in particular, the word FAS is ‘stored in their experience’ (Smith, 2005) and it is shown to be organizing – possibly ‘colonizing’ – women’s consciousnesses. How FAS actually ‘arrived’ in Aboriginal homes and communities with such ideological force as to apparently over-ride so many other possible subjectivities, is one of the puzzles that warrants further investigation. Evident in my analysis is that hearing FAS talk or seeing FAS texts *activates* women’s memories and responses, including their fears and concerns.

FAS/D prevention and risk discourses attribute mothers’ concerns about their children’s problems to mothers’ individual actions, poor choices, and irresponsible behaviours. A field of possible actions or interventions lies open to a ruling complex intent on preventing the risks and the costs which both mothers and their troublesome children pose to society. My analysis shows how abnormalizing, responsabilizing discourses and practices, which intersect and articulate with those for managing risks, organize mothers’ work in this setting. Here is what I have discovered about how an ‘FAS/D institutional complex’ – that section of it that I found at work in Crabtree – manages mothers and children.

## 2.0 Constructing and managing problem mothers

The women arrive in the setting with many day to day concerns – among them their worries about housing, safety, jobs, education, and child-care. Even before they enter Crabtree’s door, many of the women have had to negotiate complex fields of social relations in which they are already constructed as ‘risks’, often on the basis of their own risks *from* poverty and oppressive child welfare practices. ‘Institutionally differentiated fields’ (McCoy, 2006) of ruling practices associated with women’s concerns about poverty, spousal violence, abuse<sup>5</sup>, unsafe housing, or unreliable child care also rely on constructing women and their children as ‘risks’, which further isolate, responsabilize, and marginalize rather than help them.

The women who enter the door at Crabtree are known (made known) as poor mothers, single mothers, Aboriginal mothers, welfare mothers, mothers who drink and do drugs, mothers who are “probably FAS”. These generalizing terms reveal little about women’s actual everyday lives but, instead, direct attention to their construction as problems and their engagement with institutional systems designed to administer, govern, and control them. And these same institutionally-relevant categories or ‘factors’ of risk, which standardize women and their experiences as threats, are also made relevant to the risks women pose to their children, to possible future fetuses and, in the terms of the FAS/D discourse on ‘secondary disabilities’, to the community and the ‘public good’.<sup>6</sup> In short, these are not just mothers with problems; they are ‘problem’ mothers and problem children who must be managed.

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<sup>5</sup> Often overlooked is that many Aboriginal women and children experienced abuses in Indian residential schools and foster homes *following* their removal from their family sphere (Tait, 2003).

<sup>6</sup> Prominent claims about government efforts to serve the ‘public good’, once prevalent in many policy texts, are now widely contested and ‘community’ is now seen to be an ambiguous term that may also mask oppression (Schellenberg, 2000; Wuest, 1993; Yanow, 1996). Nevertheless, such claims can still be persuasive.

But how does this management of mothers and children actually work? It works, as my research explicates, in Crabtree. The method of management in Crabtree is organized in the social relations of the setting and in the disjuncture between mothers' embodied concerns about their children and those that are shaped and organized in mothers' FAS/D prevention work. Crabtree is intended for vulnerable women – and in the centre's lengthy history of working to identify children 'at risk', I am beginning to understand women's 'vulnerability' in relation to FAS/D discourses and identification practices. It is also a 'one-stop' shop of vital sources of help and emergency services for women who have often faced people's judgment and failure to understand their circumstances in other settings. Crabtree's 'grassroots' mentorship model provides caring and compassionate personnel whose participation in FAS/D prevention may also be shaping their understanding of "what women need". Women at Crabtree want to help their children and they very much want to improve their lives. The services and the non judgmental support at Crabtree engage women at the level of their concern for their children and their desire for change and self-improvement.

The social relations of the setting – the actual work practices for identifying children 'at risk' for FAS/D and by implication, their mothers include the help of professional experts who offer support and expertise to the staff. Crabtree also has an authoritatively-sanctioned system in place for their risk identification and management projects – a consent form which each caregiver/mother signs everyday that her child is admitted to the daycare. Mothers' work with this text mediates a relation between professionals who visit the setting and mothers and their children. This text reveals, therefore, how another site – a Regional Health Authority also coordinates work in Crabtree.

Crabtree's routine use of this particular text makes mothers amenable to giving professionals who visit from other Health Authority work sites, such as Sunny Hill<sup>7</sup>, access to their children's bodies for observations that 'screen' their children for the risk of FAS/D. The institutional-individual interface in Crabtree, shown here to be mothers' work with a consent form, appears to insert a reliance on professional expertise<sup>8</sup> in identifying mothers and children at risk, which undermines the capacity for personnel to rely on their 'grass roots' commitments<sup>9</sup> to responding to what women say they need.

When power operates in the taken for granted practices I discovered in women's work with this text the question of consent does not usually arise because people are not aware that power is operating or that their conduct is being managed (Li, 2007). At Crabtree, mothers can refuse to consent, but it would also deny women access to much needed respite that the emergency daycare provides. If mothers did have questions about consent or what consent might imply, the relationship between the daily consent form and access to the vital and scarce source of child care may, at the very least, persuade mothers' silence. The mothers at Crabtree are intent on helping their children and, in the FAS/D Prevention Group women learn that when children are diagnosed with FAS/D, special help is available in school. Here is something the mother can actually do – make use of this resource – to help her child.

The prospect of professional help and support for their children engages women's concerns about why children are having difficulties in the first place. A routine system of communication between Crabtree personnel and mothers in their everyday encounters, established in relationships of trust, enables mothers to communicate concerns they have about

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<sup>7</sup> Sunny Hill provides services on behalf of both the Coastal Health Authority and the Provincial Health Services Authority (PHSA), of which it is a part.

<sup>8</sup> See Chapter Five on tensions between Crabtree and Sheway, where the latter was seen to be reliant on expertise.

<sup>9</sup> See Walker (1995) and Chapter Five, footnote 2, on how ruling practices co-opt a grassroots movement.

their children and thereby, also assists personnel in recruiting particular children for screening and professional observations. Expert practices that measure children and their mothers against idealized norms, ab/normalize their experiences in the terms of the discourses, which I have shown to be relevant to this setting. These practices are not necessarily malign. For those of us who work as professionals, practices of observing or measuring people or their behaviours are tools we rely on as part of our efforts to help. We fail to recognize their ideological function in subjugating subjectivities to standardizing discourses and ‘norms’.

There are many forms of helping work taking place in this supportive, family-like setting, but I discovered a consistent thread tied to FAS/D prevention in the institutional interface between personnel and the women who come for help. For women who are poor, the regular food vouchers, bus passes, and a space in the daycare when they attend any regular program, such as the FAS/D Prevention Group are vital forms of help and they are also persuasive to women’s group participation. Women are not coerced into joining or doing anything against their will; they are engaged at a deep level of concern – their worries that their children need help and that there is something going on for which they may be responsible.

Mothers are thereby persuaded and, indeed, recruited to participate in the FAS/D Prevention program. The group will offer support for mothers’ concerns, and strategies for them to help their children. Assisted by caring personnel, women in the group share concerns they have about their children and through their instruction in the FAS/D discourse mothers learn how to match FAS/D terms and concepts to the bodies, behaviours, or troubles of their children. At the same time, mothers learn to talk about themselves, their concerns, and irresponsible behaviours, which they can also match to one of the relevancies in the discourse – alcohol

consumption during pregnancy as the cause of damage to the developing brain. Women learn that any amount will suffice to cause FAS/D – even “one drink will do.”

A particular and ambiguous type of freedom is achieved when supportive personnel guide women in disciplinary practices by which they “come clean” and disclose how they have been irresponsible mothers. This confessional work is, I argue, part of the responsabilizing work women are organized to accomplish. It is a practice of knowing and of *ruling*, which individualizes to mothers their responsibility for harming their children, in the terms of the discourse. My analysis suggests that mothers who do not align themselves to this discourse remain ‘at risk’ from agents of the state who may decide to extract their compliance. Many mothers in this setting have already experienced state intrusion in their lives and their own families – many when they were only children<sup>10</sup>. For mothers who are ‘risks’ there is little freedom to resist the authority of the FAS/D discourse or this form of self management work.

Therefore, I am arguing, that while Crabtree’s women-centred orientation offers women the freedom to be themselves, there is also a contradiction and constraint in the freedom and safety offered. If women are to be assured some safety from institutional forms of intrusion in their lives, they must make themselves amenable to the courses of action Crabtree offers. The sequence of work activities through which this form of freedom – an actual ruling practice – is enacted takes place primarily in the FAS/D Prevention group where women learn to claim responsibility and also learn how to manage their children’s risks.

Locating women’s concerns *in* their children’s bodies, struggles or behaviours provides material ground for the social organization of mothers’ work in this group. Mothers’ concerns come to reside in their children’s bodies in two different modes of knowing – in women’s

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<sup>10</sup> See Chapter Eight, footnote 9 regarding Aboriginal children placed in residential schools or in foster care.



embodied knowledge of their children's difficulties, for example, in children's struggles at home or in school, and in the knowledge women acquire about their children in a particular objectified form. The social organization of mothers' responsibility and their risk management work coordinates a relation between mothers and their children where mothers learn how to construct their own children as FAS/D objects.

The social relations in Crabtree, and the objectifying practices embedded in them combine to make mothers amenable to being acted upon even as they too take actions to objectify their own children. My analysis suggests that racialized and classist practices are embedded in the social relations in Crabtree where well intention professionals enact relations of power in routine practices of observation and identification of children and their maternal 'biomarkers', many of whom are poor First Nations women and children.

The social organization of mothers' work also establishes a relation between the informal work processes in Crabtree and the formal work processes and accountabilities of a diagnostic and health services organization. Crabtree personnel facilitate this work engagement, which advances to a higher level of expertise the objectification of children and of the mothers themselves. I argue that this engagement works in ruling interests and that diagnosing children as FAS/D is a ruling practice, which is exercised in routine ways in Crabtree.

### **3.0 Managing FAS/D children and making their mothers accountable**

Professionals doing responsible accountable work on behalf of formal organizations construct authoritative accounts and records in the language that is relevant to their area of expertise. When children are diagnosed, the category relevant to the particular defect, disturbance, or symptoms the child is thought to exhibit is applied and written up in a diagnostic text that will inform others, usually other health care workers or specialists who may also have a

part in managing or treating the child's or his mother's particular health concern or risk. This practice of re-writing women's and children's experiences into forms of knowledge that make women and children institutionally actionable is a practice of power and it is also one of the taken for granted ways by which ruling actually works.

When women take their children to Sunny Hill for the diagnostic work-up of their children's experiences and their own, the diagnostic text that is produced mediates a work relation between professionals and the mother and her child. Through working with the text, professionals confirm the mother's responsibility for damaging her child and produce evidences of the degree of risk she posed to the fetus. Evidence, expressed in the body, brain, or behaviours of the child is measured and calculated in technical formulations, which make the problems of the mother and child authoritatively knowable.

Authority is established in the diagnostic category and in a numerically sequenced 4-digit code (1223, for Arthur and his mother), which offers an objective account of a mother, a child, their calculated risks, and the mother's responsibility. The professionals who assess and diagnose children apply an FAS/D discourse, which subordinates individual subjectivities to institutional numerical 'realities'. The numbers establish the facts.

This authoritative way of knowing opens up specific possibilities, the sought-after course of action by which a mother can access help for her child in school – help which would otherwise be unavailable if his 'needs' or, in this case, *risks* did not match one of the special needs 'fundable' categories. As I have shown, before classroom help is finally available, teachers must also do their objectifying work. In this system of ruling, teachers' claims that they need help in class are, like mothers' claims that they need help, not suitably objective or properly accountable.

I am arguing that this authoritative way of knowing about mothers and their children produces knowledge for ruling – knowledge for the medical management of children’s problems and for the special needs administrative system of monitoring the FAS/D child’s performance in schools. This form of knowledge establishes government accountability for the judicious, practical allocation of funds according to objective measures. As a proper accountable governing practice, the diagnosis will assist in the monitoring and management of this population of children who are ‘at risk’ for the secondary disabilities thought to be associated with the disorder. A monitoring system whereby professionals will review the child’s FAS/D status when he reaches grade four is in place.

How knowledge about the mother, encoded in the child’s 4-digit code as a ‘level of risk’, may also apply to a system for monitoring mothers would require future study. I suggest that if knowledge is needed to better manage the mother or prevent risks to possible future fetuses, this objective, coded knowledge may be useful to systems that manage mothers and conduct surveillance on them.

Fetal alcohol spectrum disorder, and the codes and categories that fall under the FAS/D umbrella, also establish a unique and contentious relation between a mother and her child. When the diagnostic account is written up as a child who has ‘fetal alcohol spectrum disorder’, the diagnosis seals the mother’s accountability for her child’s problems along a spectrum of variances from ‘normal to abnormal’. My analysis<sup>11</sup> of the variances in experiences that can fit under the FAS/D umbrella convinces me that almost any problem or variance will suffice because the diagnostic codes and categories obscure variances and render invisible any

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<sup>11</sup> My analysis of Arthur’s diagnostic text (Chapter Eight) is an abbreviated version of a more extensive analysis that I intend for publication.

likelihood that the child or the mother may ever be known, or know themselves as ‘normal’. This objective account establishes that the FAS/D child has an ‘irreversible’ disability.

Yet children do not *have* ‘fetal alcohol spectrum disorder’, in the sense of possessing a disease entity<sup>12</sup> that awaits diagnosis or discovery. ‘Fetal alcohol spectrum disorder’ is an authoritative conceptual frame that can be traced to texts and the objectifying work practices that organize how we are to *know* about the experiences of children and their mothers. The professionals who write up and authorize the diagnostic account of a mother and child apply the discourses, interpretations, diagnostic categories, and code sequences that organize disjunctures between an organizational account and the experiences of children and their mothers. This ‘ideological organization’ displaces subjects and creates a new account of the facts (Smith, 1990a). This work upon a child and his mother, explicated in Chapter Eight, is a different kind of project than it would be if Arthur were only a child who was having learning difficulties in school.

I understand and have observed that diagnostic practices are a form of accountable professional work, which orient the person doing the work, not to the child or his experiences, but to a particular way of making the child’s needs for help and supervision objective, authoritative, and thereby, administrable. A web of medicalized, ab/normalizing discourses and institutional practices which measure, produce, and name children’s risks also coordinate children’s experiences to standardized ‘special’ categories used in systems for schooling and managing them. This intersection of governing, medical, and educational practices brings into view an FAS/D institutional complex involved in the extra-local coordination of mothers’ work in Crabtree.

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<sup>12</sup> In a similar view, Nadesan (2005) suggests that a biomedical model of disease produces the ‘autistic child’ as an object that is “ontological – a thing in itself” (20).

The work up of the actual mothers who are also made objects of FAS/D discourses does certain things to them, displacing their concerns related to material poverty, child care, and housing with discourses that match particular risks to specified 'irresponsible' behaviours. Establishing mothers' accountability brings into view institutional practices that rely on producing responsible subjects who must manage themselves and their children. Any accountability the government or concerned citizens may hold for addressing the embodied concerns of this group of mothers will tend to disappear. The dangers that poverty poses to women and children's lives are obscured in light of the grave risks these mothers are thought to have posed to children and adults of the future.

The social organization of mothers' work in this setting is aimed at the systematic management of a troublesome sector of the population – poor and, for the most part, Aboriginal women and their children who are constructed as subjects and objects of 'risk'. The professional expertise which supports the efforts of personnel to help women reinforces women's accountability for harming their children. This particular configuration of help means that 'women-centred' care, in this setting, cannot be taken for granted.

#### **4.0 Contradictions in the organization of 'help' for mothers and children**

Through my exploration of this setting and the forms of help that are offered, I have discovered unintended consequences and tensions in the social organization of help. Many of the women who come to Crabtree have lives that are already burdened with difficulties and responsibilities before they enter Crabtree's door. Combined with its inner city location, the agency's mandate to help vulnerable women is well suited to its description as a 'safe haven'. I have come to understand, however, that safety in this setting is fraught with contradictions. On the one hand, Crabtree offers a place where women gain not only temporary physical safety,

support, and respite, but also freedom from judgments that have already shaped many of their work encounters with doctors, nurses, social workers or other forms of ‘help’ in the individual-institutional work interface. At the same time, the locked doors, rules, responsabilizing work, and informal kinds of risk identification, reporting, and surveillance point to how women’s lives are to be highly regulated if they hope to remain temporarily safe.

I have also come to understand that the agency’s mandate to help vulnerable women and children – to minimize *their* vulnerability to harm – is squeezed, indeed, ruled by over-riding institutional priorities. On one side are the imperatives of responsible governments to adhere to international agreements for minimizing the harms posed by individual/family experiences such as poverty and the serious consequences to individual and public health. The Canadian government, acting on behalf of its citizens, has signed authoritative texts on the rights of Canadian children to live free from poverty (see United Nations, 1989), thereby, appearing to substantiate such claims.

On the other side, are institutional imperatives (or ideological preferences) and work processes for preventing the risks that FAS/D children and mothers are thought to pose to society. FAS/D discourses on *how* the developing FAS/D child and the adult he will become place a burden of truancy, homelessness, lawlessness, and monetary costs on society make a compelling case for different levels of government to take preventive measures and actions *on* mothers and children rather than provide resources and supports *for* minimizing harm to them. The comparatively large numbers of Aboriginal children in care or of Aboriginal adults in jails, whom medical and legal experts claim are, to a great degree, FAS or FAS/D suggests that FAS/D discourses and practices may be one of the ways that different levels of government in Canada

are attempting to manage the ‘Aboriginal problem’. Further study would be required to substantiate this view.

I am arguing that institutional priorities in British Columbia for managing (perceived) social risks take precedence over the vulnerabilities the mothers and children in Crabtree face. However, power is not operating ‘from a distance’ in Crabtree; it is operating in the social organization of routine work practices in this setting. And while Crabtree personnel make considerable efforts to advocate for better housing, sustainable incomes, and childcare, their options to address mothers’ embodied concerns are limited. Crabtree’s engagement with the government’s Key Worker program, aimed at empowering women by encouraging them to take responsibility for educating the ‘community’ about FAS/D is, I would argue, a work practice that also deflects the responsibility of the provincial government to offer actual material help to mothers and their families. But these work projects provide something that Crabtree can offer to women when there are so few public funds and resources available to actually help them.

Women’s engagement in their work at Crabtree brings into view how a busy women-centred agency intended to help vulnerable women and children also recruits, disciplines, and regulates the work and responsibilities of mothers. FAS/D practices have ideological force, subjugating women’s knowledge of themselves and their children to ruling knowledge and processes that do not serve well their children’s interests or their own.

## **5.0 Summary**

Through my exploration of the work practices in Crabtree, I have discovered how FAS has come to be a “huge issue in the building” and also how mothers *know* their children have FAS, even without a diagnosis. And I have learned that, while the diagnosis does not help

children or families manage their daily lives, it helps them access one vital service they may otherwise go without – extra help for their children in school.

My investigation of the ‘social organization of mothers’ work’ in this setting brings to light how objectifying forms of knowledge enact relations of power in women’s helping encounters. My study illuminates how access to ‘helping services’ works *differently* for vulnerable women and children who come to Crabtree’s door than for – in the words of one informant – women who have a home, a child, and a car, and know how to “fill out forms” for their doctor. The differences are not, however, with women in their social *locations* but in *how* social relations and work practices give rise to and *produce* differences.

My inquiry recognizes that many children, mothers, and families have complex and troubled lives. My research takes issue with *which* experiences are discursively constructed as ‘problems’ and how women and children are named in this construction. Professionals and front line workers and mothers too maintain that FAS/D prevention activities are ‘empowering’. I am arguing that the discourses and practices at work in Crabtree veer from addressing mothers’ actual embodied needs and concerns. In this authoritative way of knowing about the problems of mothers and children, women’s needs for practical child care programs, a sustainable income, nutritious food, and safe housing for their children simply disappear.<sup>13</sup>

My analysis points to a particular configuration of help in this setting which relies on coordinating work activities which ‘hook’ women, including Crabtree’s caring personnel, into FAS/D discourses and practices that are relevant to interests aligned to the work of ruling. I am showing how Crabtree and women’s work in it are part of an FAS/D institutional complex,

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<sup>13</sup> Overlooked is that BC has the highest rate of child poverty in Canada. In prevention messaging (Ministry of Health, 2007; Province of BC, 2012), which advises women not to drink during pregnancy and instructs people how to keep fit and healthy – children who arrive at school hungry disappear.



penetrated by institutional work processes involving government, medicine, and education. The work that begins in Crabtree's helping encounters generates courses of action and forms of knowledge that make women and children institutionally actionable – administratively, medically, and professionally.

The strength of my thesis is that it explicates how ruling works – not from a distance – but in a local setting as one part of an FAS/D institutional complex. My thesis is not, however, a critique of individuals, professionals, or agencies, nor does it diminish the advocacy efforts and good intentions of front-line workers and professionals to help women and children. It does reveal how those of us who do ruling in our everyday work may unknowingly and even, at times, unwillingly compromise our best intentions. It is an explication of how an FAS/D complex of objectifying knowledges and practices shapes everyday experience, including the experiences of those in this setting who are simply doing their best to help.

This thesis is a study about how power is implicated in women's and children's everyday lives, shaping and submerging their subjectivities, their knowledge of themselves, and even their concerns. I have been showing how mothers' concerns and their need for help have initiated their engagement in professional practices. The way that help has been rendered is shown to be contradictory: help brings mothers and children into the institution as actors or participants in ruling relations that I have been making visible. And as willing participants anxious to help their children and improve their own lives, mothers learn to enact their own ruling, organizing their risk management work, and even taking on more responsibilities for preventing and managing FAS/D.

Authoritative accounts of women and children as FAS/D obscure the richness and complexity of their experiences, including their strengths and capacities for growth and change –

and indeed their very real aspirations to provide a better life for their children than they themselves have had the opportunity to live. FAS/D discourses individualize responsibility and construct women and children as different and damaged or damaging. They work to suppress alternate knowledges about women's and children's experiences, holistic approaches to healing, and publicly-funded responsibility for the provision of actual material help.

This inquiry is intended as an alternate knowledge for women and children, which contests this way of knowing about them as FAS or FAS/D. It is a knowledge that begins in women's and children's everyday lives and as such, it is knowledge produced *for* them and in a very real sense, by them. It is only by exposing the relations of power organizing mothers' work that it may be possible to re-direct attention to mothers' embodied concerns and to relieve mothers of the overwhelming responsibility for which they are held and hold themselves to be accountable.

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## APPENDIX A

### Participation consent form

You are invited to participate in a research study titled:

**“Knowledge for living with or preventing fetal alcohol syndrome: An institutional ethnography”**

If you have a child with special needs or you have been told that you may be at risk for having a child with alcohol syndrome (FAS) or FASD, I would like to talk with you. I want to understand how services for women work and how policy decisions affect women’s everyday lives. The goal of the research is to develop policies and services that fit with what women experience and say they need.

**What is involved?** Your involvement will take no more than one hour of your time. I will take notes during the interview. If you agree, I will make an audio-tape of our discussion.

**Possible benefits and concerns** Your participation in the study involves no direct known benefits for yourself. Some people may experience fatigue, stress, or discomfort during a discussion. If this should happen to you, please let me know and we can stop the interview.

**Participation is voluntary** If you choose not to participate or you wish to withdraw from the study at any time, it will not affect your relationship with me or with anyone at the agency. A small honorarium is available for your time.

**Information is confidential** All information is confidential and no names or identifying information will appear in any of the written reports. All tapes and notes will be kept in a secure place until they are erased. The information obtained will be written into a thesis and may be presented at conferences or in publications to educate others and inform policy makers. I will also offer you a summary of the information by mail or by returning to speak in your group.

**Questions?** If you have any questions now or at any time during the study please contact: **Researcher:** Carolyn Schellenberg, RN, doctoral candidate, Studies in Policy and Practice, University of Victoria. Telephone (cell) 604-880-5440

Supervisors: Dr. Marie Campbell: 250-595-7364 ; Dr. Mary Ellen Purkis 250-721-8049  
University of Victoria ethics contact: Tel. 250-472-4545 or email: ethics@uvic.ca

**I understand the nature of this study and give my consent to participate. I acknowledge receipt of a copy of the information letter and consent form.**

**Signature:** \_\_\_\_\_ **Date:** \_\_\_\_\_

**Witness:** \_\_\_\_\_ **Date:** \_\_\_\_\_

## APPENDIX B

### Participation consent form for providers

You are invited to participate in a research study titled:

**“Knowledge for living with or preventing fetal alcohol syndrome: An institutional ethnography”**

If you are a staff member who works with women who have children with special needs or have been told they may have a child with FAS or FASD, I would like to hear about your experiences in providing services. I want to understand how services for women work and how policy decisions affect women’s everyday lives. The goal of the research is to develop policies and services that fit with what women experience and say they need.

**What is involved?** Your involvement will take no more than one hour of your time. I will take notes during the interview. If you agree, I will make an audio-tape of our discussion.

**Possible benefits and concerns** Your participation in the study involves no direct known benefits for yourself. Some people may experience fatigue, stress, or discomfort during a discussion. If this should happen to you, please let me know and we can stop the interview.

**Participation is voluntary** If you choose not to participate or you wish to withdraw from the study at any time, it will not affect your relationship with me or with anyone at the agency.

**Information is confidential** All information is confidential and no names or identifying information will appear in any of the written reports. All tapes and notes will be kept in a secure place until they are erased. The information obtained will be written into a thesis and may be presented at conferences or in publications to educate others and inform policy makers. I will also offer you a summary of the information by mail or by returning to speak in your group.

**Questions?** If you have any questions now or at any time during the study please contact:

**Researcher:** Carolyn Schellenberg, RN, doctoral candidate, Studies in Policy and Practice, University of Victoria.

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Supervisors: Dr. Marie Campbell: 250-595-7364; Dr. Mary Ellen Purkis 250-721-8049  
University of Victoria ethics contact: Tel. 250-472-4545 or email: ethics@uvic.ca

**I understand the nature of this study and give my consent to participate. I acknowledge receipt of a copy of the information letter and consent form.**

**Signature:** \_\_\_\_\_ **Date:** \_\_\_\_\_

**Witness:** \_\_\_\_\_ **Date:** \_\_\_\_\_

## APPENDIX C

### Data Gathering <sup>1</sup>

<u>Research locations</u>	<u>Planned (formal) interviews</u>
Primary site: Crabtree Corner, Vancouver, BC	Individual: 12 Focus Group: 8
Second level data collection with professionals and service providers Prince George, Vancouver, and Victoria, BC	10

Some of this second level data was collected during my field work investigation but some of the interviews were conducted over the subsequent six month period in order to develop and clarify my understanding of government policies and practices current at the time.

I also established communication with Crabtree personnel in 2009 to determine whether any significant changes in policy or practices relevant to my inquiry may have occurred since my initial field work. It is my understanding that they had not.

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<sup>1</sup> See also Chapter Four section 4.4