“THE TIP OF THE ICEBERG”
THE “MAKING” OF FETAL ALCOHOL SYNDROME IN CANADA

BY

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For my son, Skender Ben Boubaker and my mother, Shirley Tait

In memory of my father, Leslie Tait

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ABSTRACT

The knowledge production and practices associated in Canada with the diagnostic category “fetal alcohol syndrome” (FAS) have identified Aboriginal populations as groups who are most at risk for birth defect caused by prenatal alcohol exposure. In this context, Aboriginal peoples are most closely associated with the central risk factor, alcohol abuse and with the “primary” and “secondary disabilities” associated with FAS. The diagnostic category exists within a medical context in which consistent standardized tools and measurements for diagnosing illnesses caused by in-utero alcohol exposure do not exist. Medical assessments, partially due to a lack of diagnostic tools and related factors such as the high cost associated with patient assessment and a shortage of physicians who are trained in FAS diagnosis, are very difficult to obtain in all regions of the world, including Canada. This has resulted in very few individuals actually being evaluated, and even fewer diagnosed with FAS. In Canada less than one-percent of the estimated population believed to have FAS are currently diagnosed. Clinical diagnostic inconsistencies have also been shown to be common and widespread and epidemiological evidence is inconclusive and/or methodologically questionable. Despite this, a sense of urgency has arisen in North America, leading to campaigns to stop all pregnant women from drinking alcohol.

This dissertation examines the relationship between public representation of events, social groups and individuals, and social action, and moves beyond contested descriptions of what exactly FAS is, and who is said to be at risk, into an examination of the motivation behind the discourse, the grounds upon which it is legitimated and reproduced over time. Particularly, the specific implications the association of FAS with Aboriginal peoples in Canada has had in the lives of Aboriginal women, their children, and their communities.

Section One
INTRODUCTION

In the summer of 1996, Winnipeg Child and Family Services filed two petitions against a young First Nations[1] woman, "Ms G"[2] that focussed national media attention in Canada on claims by health care professionals about an association between prenatal exposure to alcohol and birth defects. At the time of the petitions, "Ms G" was five months pregnant and it was reported that she had been regularly sniffing paint thinner, glue, and other substances. Even though the petitions were filed against her because of her solvent abuse, it was alcohol use by pregnant women and the diagnosis "fetal alcohol syndrome" (FAS) that became the central focus of media attention. Media reports linked prenatal exposure to alcohol to a number of physical "deformities," not specifically defined in their reports, and to central nervous system (CNS) damage and dysfunction in affected offspring. Cocaine, which was also commonly discussed in media reports, was associated with low birth weight and with premature and still births. Only limited attention was given to the harmful effects of inhalant abuse, even though this was the substance used by "Ms G."

Through media reporting, Canadians learnt that children affected in-utero by exposure to alcohol, cocaine, solvents, and other harmful substances were "doomed to a life of misery." While it was reported that the number of affected children in Canada was "still not high," journalists quoted medical and addiction experts who stated that these numbers were "clearly on the increase" (see, for example, Chisholm 1996). As the "G" case unfolded over the next year, eventually ending up in the Supreme Court of Canada, Canadians discovered that consideration of the "rights" of the fetus in relation to a pregnant woman's autonomy and bodily integrity went beyond questions of "pro-choice" and "pro-life" debates that they were accustomed to hearing about.

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[1] First Nation refers to the North American Indian population in Canada. They are divided into 54 linguistic/cultural groups such as Cree, Ojibwa, or Blackfoot. In 1991 the population was estimated to be 550,700. Of these 438,000 are registered under the *Indian Act.* The remainder are not registered under the *Indian Act,* and in 1991 this population was estimated to be 112,700. Roughly 58% of registered First Nations people live on reserves and in Indian settlements. A large percentage (42%) live in non-reserve areas, mainly urban centers. Sixty-two per cent live in southern Canada, while the other 38% live in the north. Approximately 80% of non-status First Nations live in southern Canada, 17% live in the mid-north and two per cent in the far north (Royal Commission on Aboriginal Peoples 1996a:15-18).

[2] The woman's name was not used during the court case in efforts to protect the identity of her children.

In the year leading up to the Supreme Court of Canada case, various "experts" and "advocacy" groups weighed in to the emotionally charged debate with their opinions about whether Canadian society had a moral obligation to use legal and legislative means to detain pregnant women who consume substances that are potentially harmful for the fetus. In this debate, apart from the larger discussion about comparative "rights," the key argument made by supporters of mandatory addiction treatment or confinement was that a woman's intention to give birth obligated her to protect her future child from in-utero exposure to harmful substances. If a woman failed to do so, then the burden of protection became the responsibility of society at large.

Those opposing mandatory confinement of pregnant women argued that legal or legislative measures would erode the "hard-won rights of women." Others argued that not enough support existed for women struggling with addictions and that mandatory treatment could have unforeseen negative outcomes. Specifically, concern was expressed about the possibility of increased surveillance, control, and confinement of pregnant women, and the likelihood that women who were at "highest risk"—those who were alcoholic—would not make use of support services, prenatal care, and addiction treatment because of fears of incarceration and of child welfare services "apprehending"[3] their infants at birth.

As the "G" case made its way to the Supreme Court of Canada, the issue of abortion and the comparative "rights" of women and fetuses overshadowed arguments that were meant to be specific to substance abuse by pregnant women. In the petitions filed by Winnipeg Child and Family Services, the agency argued that confinement of "Ms G" to an addiction treatment center until the birth of her child was necessary in order to prevent further risk of fetal damage due to her addiction. The agency argued that "Ms G's" intention to give birth to the child and her continued abuse of substances represented a violation of the "duty of care"[4] that she owed to her fetus. However, while the agency tried to avoid the issue of abortion, pro-life advocates criticized them for trying to protect

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[3] The term "apprehension" is commonly used by social workers and lay persons to refers to situations in which a child and family service agency removes a child from the care of their parent(s) or guardian(s) because of concerns over "neglect" and/or "abuse" of the child.

[4] "Duty of care" is a legal term used in legal arguments concerned with compensating an innocent victim for harm suffered from the actions of another.

certain fetuses and not others. On the other hand, pro-choice advocates argued that the fetus did not have a separate existence from its mother; therefore, no "duty of care" as suggested by the agency could be recognized. They argued that if the courts did so, this would open the door for pro-life advocates to challenge a 1991 Supreme Court of Canada decision which held that a fetus has no legal rights, and thus bring into question the legality of abortion services[5].

In his court order concerning the petitions, Manitoba Justice Perry Schulman avoided the question of fetal rights by shifting the focus to "Ms G" and ruling that she was mentally incompetent to make her own decisions. As a result of the ruling, "Ms G" was placed under the care of Winnipeg Child and Family Services and ordered to be confined to a drug treatment center until the birth of her child[6]. A few days later the order was stayed pending an appeal. Later that summer, Judge Schulman's decision was overturned at the Manitoba Court of Appeal, which was supported the following year by the Supreme Court of Canada.

In October 1997 the Supreme Court of Canada ruled on the "G" case arguing that a pregnant woman could not legally be confined or mandated into addiction treatment. The Court ruled that Canadian law did not recognize the fetus as a legal person possessing rights and therefore there was no legal person in whose interests Winnipeg Child and Family Services could act or in whose interest a court order could be made. Public outcry after the ruling demanded that some type of preventative action be taken to protect the fetus from harm caused by prenatal exposure to substances. Even among those who applauded the Court's ruling, significant concern existed about pregnant women abusing substances and about what could be done to better support women and children who were at risk.

This dissertation examines the explosion in Canada of federal and provincial government interest in substance use by pregnant women following the 1997 Supreme Court of Canada ruling on the "G" case. I examine the ways in which the diagnostic

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[5] *R. v. Sullivan* [1991] 1 S.C.R. 456: "a foetus is not a 'person' or a 'human being' for the purposes of criminal negligence provisions under the Criminal Code."

[6] A psychiatrist at the request of the court examined "Ms G." Serious long-term risks were identified including chronic solvent use and suicidal tendencies. However, there was no evidence of mental disorder or incompetence and no basis for detention under the *Mental Health Act*, according to the examining doctors (Women's Health Clinic et al. 1997).

category FAS became the focal point upon which governments built their strategies for preventing substance abuse by pregnant women and the implications that this has focus had for Aboriginal[7] women, their children and their communities. I argue that prior to the "G" case, interest and concern about the association of prenatal substance abuse with negative birth outcomes was limited to a small group of clinical researchers, practitioners, and advocacy groups in western and northern regions of Canada, specifically British Columbia, Manitoba, and the Yukon. However, as a result of public outcry following the "G" case and the Supreme Court of Canada ruling, along with lobbying efforts by special interest groups, the federal and western provincial and territorial governments were prompted to identify prenatal substance exposure and FAS as a new health concern for children.

As the "G" case unfolded in the national media, photographic images and descriptions of "Ms G" cemented a perception across the country that substance abuse during pregnancy was a problem affecting primarily Aboriginal women and their children. This perception, which was reinforced by findings from a limited body of FAS research (see for example, Asante 1981, Asante & Nelms-Matzke 1985, Robinson 1987) and by claims made by FAS advocacy groups, became entrenched in federal and provincial government strategies to prevent, identify, and intervene around issues related to substance use by pregnant women and apparently related birth defects. Aboriginal populations became the central target group for these strategies, with the majority of clinical services, as well as prevention and intervention programming and services, being designed and implemented in ways that directly target Aboriginal peoples in urban and reserve settings. Following the "G" case, FAS-related services were developed in western provinces, northern territories, and reserve communities—the geographical regions where the vast number of Aboriginal peoples live. Fewer FAS-related services exist in provinces east of Manitoba with the exception of eastern reserve communities.

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[7] The term "Aboriginal" is used throughout this dissertation to collectively refer to First Nations and Métis people of Canada. While the experience of the Inuit falls under this term at different times throughout this dissertation, the main focus is on First Nations, and to a lesser extent, Métis people. The term "indigenous" is used in discussions concerning early contact between indigenous peoples and Europeans, and in discussions of cross-country comparisons (i.e. with Australia). Terms such as "Indian" or "native" are used in keeping with the work of individual authors. First Nations, Inuit, and Métis are used when referring to these groups specifically.

In this dissertation, I examine the relationship between public representation of events, social groups and individuals, and social action. I argue that representations of "Ms. G" and the implications that her substance abuse was perceived to have on the future of the child she carried transcended questions of fetal "rights" and ethical and legal debates about the role Canadian society should or should not play in the lives of pregnant women with substance abuse problems. As images of "Ms G's" "devastatingly thin" pregnant body, her "addiction" to glue sniffing and her "overall poor health" entered the public arena, her image held little resemblance for Canadians to that of the "Woman" whose rights to autonomy and bodily integrity were being challenged by the petitions filed by the agency. As national media reported that the twenty-two year old "Ms G" had previously given birth to three children, all of whom were in the care of social services, and two of whom were "injured by her glue-sniffing addiction," the resemblance seemed even less plausible, as did the argument that her "rights" should supercede those of her unborn child.

The representations of "Ms G," however, did have a certain familiarity for Canadians in that these images signified a notable difference from the usual image of a generic woman because "Ms G" was clearly Aboriginal. The choice of substance for abuse, glue[8], the descriptions of her poor health, and the news of her other three children in the care of social services, reinforced a commonly held assumption made by many Canadians about Aboriginal people. Within the dominant society, particularly in western and northern regions where the largest percentage of Aboriginal people live, a widespread perception exists that Aboriginal people place a significant "burden" upon the Canadian state, which is entirely caused by their individual and collective inability or unwillingness to properly govern their bodies and actions. For the dominant society, images of "Ms G" validated a growing concern about the increasing number of young Aboriginal people living in urban ghettos characterized by high fertility rates, high unemployment, widespread substance abuse and violence. No longer hidden away on reserves or in residential schools, the "Indian problem," as embodied in "Ms G," was for

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[8] The use of solvents or inhalants such as glue is a substance of choice found almost exclusively among Aboriginal people. Inhalants or solvents as substances of choice are also very difficult for most Canadians, even those with "addiction" problems, to imagine using.

the dominant society becoming increasingly visible and served to contradict claims to rights of self determination and government that First Nation, Inuit[9] and Métis[10] peoples argued were being withheld by federal and provincial governments. The case of "Ms G" signified for many Canadians, particularly those who oppose Aboriginal self-determination, that the "future" of Aboriginal people was not best served outside of the control and regulation of the dominant society.

Outline of the argument

This dissertation is divided into four sections. Section One is an introductory discussion of the research problem, and of the methodological considerations in designing and carrying out the project. In this section I discuss the larger discursive arena attached to the "reproductive body" and how the category FAS has influenced the meanings now attached to pregnancy, the fetus, and motherhood. I further discuss the adoption of the category FAS in Canada and its particular association with Aboriginal populations. I argue that within the Canadian context, the evolution of knowledge and practices attached to FAS has occurred in a discursive arena in which the lives of Aboriginal women, their children, and their communities have been targeted. I suggest that this association has influenced perceptions about Aboriginal peoples in Canada and in addition has specific implications for negotiations between Aboriginal nations and federal and provincial governments in connection with self-determination and self-government. Moreover, I suggest that the larger discursive arena attached to FAS has influenced individual and collective perceptions that many Aboriginal peoples have about themselves, which in turn has resulted in FAS being identified by a growing number of

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[9] The Inuit population is estimated at roughly 38,000. The large majority (89%) live in the far north—Labrador, northern Quebec, the Northwest Territories and the Yukon—and only 10 per cent live in southern Canada. Most Inuit live in rural locations or small urban areas (Royal Commission on Aboriginal Peoples 1996a:19).

[10] Métis originally referred to the descendents of intermarriage between indigenous people and Europeans. A constitutional amendment in 1982 included the Métis people as one of the three Aboriginal peoples of Canada. In 1991 the population self-identifying as Métis was estimated at 139,000. Most Métis live in the prairie provinces, with an estimated population of 101,000. About 24,000 live in Ontario, Quebec and the Atlantic provinces, and 14,000 live in British Columbia and the northern territories. The majority of Métis people reside in urban areas (65 %), and the remainder in rural areas (32%) and on reserves (3%) (Royal Commission on Aboriginal Peoples 1996a:19).

Aboriginal leaders and communities as a serious health and social problem in need of immediate attention and resources.

Section Two provides an in-depth look at the evolution of the diagnostic category "FAS." In this section I analyze the knowledge production attached to the diagnosis from various vantage-points, framing the discussion around the introduction of the diagnostic category into the United States and a subsequent debate among American researchers as to the "scope of the FAS problem." I do so in order to illustrate that this debate has had limited impact upon the knowledge production attached to the diagnostic category in Canada, in that most Canadian researchers and clinicians have concurred with the beliefs held by one side of the American debate: that FAS and other alcohol-related birth defects are common, costly and preventable. This argument hinges on the association of risk with low threshold levels of maternal alcohol exposure.

I further examine why, despite concurrence with one of the positions articulated in this debate, the knowledge and practices attached to FAS have evolved differently in Canada than they have in the United States. From the outset, FAS research, clinical practice and public health strategies in Canada have overwhelmingly targeted Aboriginal populations and stressed that FAS is a problem affecting Aboriginal groups in disproportional numbers. This differs from the United States where, despite a similar over-representation of Native Americans in FAS research and clinical practice, emphasis has been placed by researchers, clinicians and advocacy groups on the "universal nature" of FAS and how all fetuses and pregnancies across ethnic, "racial" and class lines are equally at risk.

Section Three provides a historical analysis of relations between Aboriginal and non-Aboriginal peoples in Canada and looks specifically at how definitions of, and interventions directed at health and related social "problems" associated with Aboriginal communities have contributed to the framing of this relationship. In this section I argue that throughout Canadian history, representations of Aboriginal people as biologically and socially inferior have been used to mobilize various forms of social action by colonial and neo-colonial governments. While my focus in this dissertation is on the knowledge and practices attached to FAS prevention, identification and intervention, I examine in this section four intersecting areas: 1) alcohol use among Aboriginal peoples;

2) the residential school system; 3) the large scale apprehension and placement of Aboriginal children in foster care by child welfare services during the 1960s, 70s and 80s; and 4) the recent explosion of interest in substance abuse during pregnancy. I argue that these four areas represent historical processes that have directly and indirectly undermined Aboriginal women's status in their role as mothers and have entrenched within the dominant society the perception that Aboriginal women present a hazard to their children and communities.

I also examine in Section Three the ways in which historically Aboriginal peoples have resisted and actively fought against increased European incursion into their lives, a resistance that persists to the present day. As a way to counter negative representations of their people that are used by the dominant society to mobilize social action targeting their communities, such as the image presented of "Ms G," Aboriginal groups have advanced their own accounts of the impact that colonial processes have had upon them. In this counter discourse, Europeans are made responsible for significant negative transformations within Aboriginal populations across Canada. Alcohol, for example is portrayed as a destructive weapon used against indigenous people by Europeans, and the "residential school experience" has come to signify a shared traumatic experience of colonization and a reason for creation of a transgenerational group-identity. Portrayed as remnants of the negative impact of colonization, "intergenerational addiction to alcohol" and "collective intergenerational trauma" are invoked within this discourse as obstacles to "wellness," "reconciliation," and "self-determination," that will be diminished through processes involving "healing," "apology," and "negotiations leading to self-government."

In Section Four I situate my argument within an ethnographic analysis of the lives of a group of Aboriginal women who are considered to be at greatest risk for giving birth to children with FAS/ARBEs. In doing so, I examine the claim made within lay and scientific discourse that maintains FAS is entirely preventable. I argue that the claim that FAS is one-hundred percent preventable is grounded in a moral sentiment rather than in an awareness of the challenges and problems that mark the daily lives of women with substance abuse problems. Further, if consideration is given to the complexities of these women's lives, including their substance abuse and pregnancies, and to the numerous gaps and barriers in service provision and support for the women and their children, the claim that FAS is entirely preventable serves more to blame and stigmatize women than to highlight a goal that is achievable.

In Section Four I further ground my argument in an examination the concept of "secondary disabilities" as a category that has come to describe health and social problems experienced by adolescents and adults believed to have FAS/ARBEs. I discuss secondary disabilities in relation to the increased labeling of individuals as having FAS/ARBEs that occurs because of barriers preventing patients from easily accessing medical assessment and perceptions of the commonness of FAS. I conclude Section Four by bringing together the issues discussed in this dissertation through the examination of an ethnographic setting—a workshop in Vancouver—in which various health and social service providers and FAS researchers attempt to develop a women-centered research agenda for FAS prevention.

In this dissertation I argue that knowledge about substance abuse by pregnant women and FAS is generated in various social arenas, and, despite Aboriginal and non-Aboriginal peoples offering different accounts of colonial processes and strategies to ensure a better future for Aboriginal children, there is convergence and agreement between them that substance abuse by pregnant women and FAS/ARBEs are serious health and social problems in Aboriginal communities. I argue that the impact of specific colonial processes and the meanings that are attached to those processes reinforce arguments that significantly more Aboriginal than non-Aboriginal children are at risk for FAS, and that despite, very few people being diagnosed, high prevalence rates exist in the Aboriginal population. I examine the grounds upon which these assumptions are legitimated and reproduced over time, and the impact they have in the lives of Aboriginal women and their offspring.

While I challenge taken-for-granted assumptions that are made about alcohol use by pregnant women and FAS, I situate my argument within an awareness that alcohol is a human teratogen that can cause birth defects in exposed offspring. Following arguments made by American researcher Ernest Abel (1998a), I take the position that all of the birth effects attributed to alcohol use by pregnant women are due to binge drinking—and especially to chronic alcohol abuse—during pregnancy. Further, by taking this position I also acknowledge that certain women, including some Aboriginal women, and populations, especially communities where alcohol abuse and poverty is endemic, are at increased risk for FAS/ARBEs. Working against the metaphor of the “iceberg,” I introduce a second metaphor—that of the forest. It is my contention that within the discourse and practices attached to the category FAS in Canada, individual “trees”—those individuals (women with alcohol addictions and alcohol-affected offspring) in greatest need of attention and support—are being obscured by an imagined “forest” produced by the association of risk with low threshold levels of prenatal alcohol exposure. As will be examined in this dissertation, the real “forest” is hidden by the inaccessibility of medical assessments for FAS, practices such as non-medical labeling of persons with FAS/ARBEs, and by public health education that mistakenly inflates the number of persons in Canada thought to be affected in-utero by alcohol exposure. As will be shown, this current context has specific and long-reaching implications for Aboriginal women, their children, and their communities.

Chapter One
FETAL ALCOHOL SYNDROME IN CANADA

How much is too much when you're pregnant?
Alcohol consumption during pregnancy—any amount of alcohol—could be a sentence of lifetime disability for an unborn child.
Health Canada, internet site
http://www.hc-sc.ca
March 2003

Introduction

This dissertation takes as its point of departure the "G" case and as its object of study the diagnostic category "fetal alcohol syndrome." The methodological decision to make a diagnostic category my object of research stems from work within medical anthropology that takes biomedical categories as points of departure in order to theorize and comment on larger issues both within and beyond anthropology. These works have individually and collectively contributed to important developments in theoretical understandings of, for example, the body (Lock 1993a, 1995, 1997, 1998, Lock & Kaufert 1998, Martin 1994, Odshoorn 1994), the production of scientific and biomedical knowledge (Lock 1993a, 1995, 1996, 1997, Rabinow 1996, Young 1995), and the politics of reproduction (Franklin & Ragoné 1998, Ginsberg and Rapp 1995, Rapp 1988, 1993,Strathern 1992), areas that until recently had received limited attention within anthropology (Lock 1993b). This dissertation proposes to draw from, and build upon, each of these areas of research to critically examine, within the Canadian context, the knowledge production, practices and technologies associated with the category FAS.

In the prologue to her book, *Encounters With Aging: Mythologies of Menopause in Japan and North America* Margaret Lock discusses the challenges medical anthropologists face when focusing on biomedical categories that are assumed to be "real" and "concrete" objects. Lock highlights a philosophical position that makes anthropology interesting and important in the eyes of some, and confusing and contradictory in the eyes of others (1993a:xviii). Referring to her work on menopause, she writes,

> In trying to bring a common language to this tower of Babel, we may be tempted to offer a definition of it. But menopause is not a "fact," and hence it cannot be neatly packaged or contained in a single precise term that transcends time and space, history and culture. On the contrary, it is a concept with boundaries and meanings that shift depending upon

> the viewpoint and interests of speaker and listener. Such variation interests me, most particularly the way in which, even as we strive to produce clarity on a few points, we descend deeper and deeper into an abyss of contradictions (Lock 1993a:xviii).

An attempt to discuss substance abuse by pregnant women and FAS brings with it its own abyss of contradictions. In common with Lock, my interest lies in the midst of these contradictions, which is where much of this dissertation will focus. Any clarity which emerges from my discussion will no doubt bring with it not only further contradictions, but also for many readers, controversy, disbelief and even anger. For example, one such area of contention will no doubt be my criticism of the now taken-for-granted viewpoint that FAS is a "revised" disorder which, although recently named and described was, according to some researchers, originally identified and referred to in biblical times (Jones & Smith 1973, Warner & Rosett 1975, Streissguth 1997, Clarren 1998) or, according to a physician from northern British Columbia, is the disorder upon which the body and the face of the original Irish Leprechaun was fashioned (personal communication).

In this dissertation I argue that FAS does not have such a history, and that it is neither timeless nor unified, as some would have us believe. Rather, I will argue that the category "FAS" is "glued together by the practices, technologies, and narratives with which it is diagnosed, studied, treated, and represented and by the various interests, institutions, and moral arguments that mobilized these efforts and resources" (Young 1995:5). I will examine how FAS became naturalized and "purified" (Latour 1993), and how, as this process unfolded, Canadian Aboriginal peoples became the group who were identified as being most "at risk" among the world's populations for this illness. I will further examine how "FAS" has been "made" real in the lives of individuals, families, and communities, and how their self-knowledge has become intrinsically tied to the diagnosis.

In this dissertation I examine the relationship between representation and social action, and move beyond contested descriptions of what constitutes FAS, and who is said to be at risk, into an examination of the motivation behind the discourse and an explanation of the grounds upon which it is legitimated and reproduced over time (Lock 1998a:xxxix). However, in no way should the reader take my analysis as an argument that FAS is not real. The reality of FAS is confirmed empirically by the role it plays in people's lives, by their experiences and convictions, and by the personal and collective investments that have been made in it (Young 1995:5). Anything written in this dissertation in no way is meant to suggest otherwise or to minimize the experience of people diagnosed with FAS, the mothers of these children, their families, or communities.

The Environmental Womb

> *From the moment of conception until delivery nine months later, the human being is more susceptible to his environment than he will ever be in his life again.*
>
> A. Montagu, *Life Before Birth*, 1965

> *Fetal alcohol syndrome is a major public health problem in this part of the world. From the child's point of view, intrauterine exposure to alcohol is an environmental disaster which can undermine his potential life…Every child is worthy of respect for what he may one day become, and society is responsible for protecting him in order to allow him to develop that potential.*
>
> Dr. Geoffrey C. Robinson, Opening Remarks,
> Alcohol & Child/Family Health Conference,
> October 1988, Vancouver, British Columbia

Pregnancy and birth are biological processes but simultaneously the "reproductive body" is inscribed with social significance and meaning through knowledge and techniques, both professional and popular. Increasingly throughout the 20th century, the inscription of meanings associated with pregnancy and childbirth has occurred as the result of the transformation of female bodies into sites for medical practice, and through the creation, mainly due to imaging technologies, of the "fetal patient" (Lock & Kaufert 1998:1, Lock 1993, Ginsberg & Rapp 1995). As part of these professional and technological developments, a group of medical experts and specialized knowledge has emerged, drawing upon a technical language of environmental risk to lay claim over the reproductive body as a "microenvironment" in which the future potential of the developing fetus is understood as being vulnerable to toxic and teratogenic[1] agents (see for example, Jones & Smith 1973, 1974, McCuen 1994, Streissguth 1997, Stratton et al. 1996).

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[1] Teratogens are substances or conditions that disrupt typical fetal development as a result of gestational exposure and cause birth defects.

The placenta, once thought to provide a wall of protection for the developing fetus, is no longer seen as an impermeable barrier (Armstrong 1998:2037). From the 1960s onward, a growing perception that the microenvironment of the womb is vulnerable to some of the worst imaginable environmental disasters has occurred alongside the increased medicalization of pregnancy and birth. The recognition that certain substances that were thought to be benign could penetrate or seep through the placenta wall, resulting in serious birth defects, suggested that increased surveillance and monitoring of the bodies and behavior of pregnant women was necessary and justified by the preventative benefits it was believed would be gained.

One of the most dramatic and well-known examples of an "environmental disaster" being caused by a teratogenic substance is the thalidomide tragedy. Between 1959 and 1962, the drug thalidomide was prescribed to thousands of pregnant women in various parts of the world, primarily in Europe, resulting in exposure of their fetuses to this toxic substance during different periods of gestation. All fetuses exposed during organogenisis[2] were born with a range of effects, including missing limbs, damaged organs, and other serious birth defects. The "thalidomide babies" came to signify a modern tragedy, one in which scientific advancement in pharmacology had inadvertently altered in devastating ways the "natural" life course of hundreds of children.

In the mid-1960s, an outbreak of rubella (German measles) in the United States resulted in an estimated 20,000 babies being born with congenital rubella syndrome (CRS). CRS occurs in 20 to 25 percent of babies born to women who get rubella in the first trimester of pregnancy and results in congenital heart disease, deafness, mental retardation, and other fetal anomalies (Stratton et al. 1996). This second tragedy raised further concern throughout the world about prenatal risk and fetal vulnerability, particularly in countries that had seen significant drops in infant mortality and morbidity rates (Armstrong 1998:2037). Referring to the United States, Armstrong writes:

> Just as the environment became an unsafe place, full of hazardous toxins against which the public was powerless to defend itself, the womb too came to seem increasingly

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[2] After implantation, the embryo begins receiving nutrients from the maternal circulation. Various organs of the body begin forming and become functional. Structural organization occurs during discrete "critical periods" of development called *organogenesis*. In humans this last from gestation day 20 to day 55. An agent such as thalidomide can only cause a malformation if encountered during organogenesis, when cell groups and tissues are forming into organs (Abel 1998a:5).

> threatened by external forces as well as by substances the pregnant woman was exposed to or even ingested herself (1998:2037).

Pregnancy, cloaked in the language of environmental risk and protection of the fetus, became the focus of new types of medical knowledge, management, and surveillance of women’s bodies.

Teratology, the science of birth defects, is at the center of research concerning the “environmental womb” and fetal vulnerability to teratogenic agents. Although interest in teratology has a long history in medical science, it formally emerged in the early 1970s as a specialized field that sought to understand the impact on gestation of specific substances or conditions that disrupt “typical” fetal development (Streissguth 1997:56). The discipline involves a marriage between laboratory research involving animal models and clinical studies (dysmorphology) concerned with the identification and management of structural and functional birth defects. The microenvironment of the womb is linked to the larger physical environment through the materiality of the pregnant body; teratogenic agents enter the maternal body through ingestion, exposure, or infection. A language of risk threads its way through discussions of these “two mutually interacting biological systems” (Stratton et al. 1996:41), which is supported by an understanding of prevention as a straightforward exercise involving the minimization of “risk factors” that could potentially bring the fetus into contact with harmful agents.

In the early 1970s a great deal of attention was directed by teratology researchers and public health professionals toward “substances of abuse,” namely illicit substances such as crack cocaine, that were identified as potential sources of birth defects (Armstrong 1998, Armstrong & Abel 2000, Viadero 1994). During this period, alcohol was identified as a teratogen when it was linked to a specific pattern of anomalies, both structural—a group of facial characteristics and growth retardation—and functional—CNS impairment—that were found in newborn babies of alcoholic women (Jones et al. 1973, Jones & Smith 1973, Jones et al. 1974, Jones & Smith 1975, Jones 1975). This pattern was termed “fetal alcohol syndrome” (FAS) by Kenneth L. Jones and David W. Smith in 1973. The identification of a birth defect syndrome corresponding to a specific cluster of anomalies caused by a single environmental teratogen is, however, very rare, as clusters of anomalies are almost always found to be the result of more than one environmental cause (Clarren 1988:23). This claim, therefore, makes the diagnosis FAS quite unique in teratology research.

As noted above, teratology research identified two types of birth defects caused by teratogenic substances—structural and functional. Structural damage affects organ development and occurs only during organogenesis (from gestation day 20-55 in humans). Functional birth defects, most generally manifest in behavioral and cognitive dysfunction, can occur throughout the entire gestational period (Abel 1998a). While alcohol is believed to cause both structural and functional birth defects, its impact on CNS development is thought to be particularly damaging and disabling (Streissguth & Kandels 1997, Barr & Streissguth 2001). For example, in 1996 the Institute of Medicine (IOM) in the United States announced that of all the substances of abuse, including heroin, cocaine, nicotine and marijuana, alcohol produced the most serious neurobehavioral effects during fetal development (Stratton et al. 1996). Currently FAS is the subject of the largest and most comprehensive line of research in behavioral teratology, the science devoted specifically to ”functional birth defects” (Streissguth 1997:57, Riley & Vorhees 1986).

The etiology of FAS: debates over necessary and sufficient factors

In comparison to infectious and pharmacologic agents or even to environmental toxins, alcohol is thought to pose a greater public health challenge because it is assumed that large numbers of fetuses are vulnerable to exposure (Stratton et al. 1996). In North America, the scope of this challenge has been compounded by public health policy that states there are no known safe levels of alcohol exposure for the developing fetus. This has meant that prevention is conceived as not only changing the behavior of alcoholic women, a significant challenge in and of itself, but also changing the behavior of all women of childbearing age who drink alcohol.

However, researchers have been at odds to explain a curious phenomena, namely why the majority of women who are heavy drinkers, including those labeled alcoholic, have given birth to unaffected babies. Significant controversy also exists over the percentage of alcoholic women who give birth to affected offspring. Estimates given in the scientific literature range from 34%[3] (Hard et al. 2001) to 80% (Little et al. 1990). As will be discussed in Section Two, the discrepancy between studies is due partially to several methodological challenges and problems in this body of research, including operational definitions of “alcohol abuse” and “alcoholism,” and the problem of prevalence rates commonly being based on very small cohorts of alcoholic women.[4]

Some research studies suggest that differing birth outcomes are linked to specific physiological processes. For example, findings indicate that a necessary factor in producing FAS is a biological inability to process acetaldehyde, one of the by-products of ethanol breakdown. This inability leads to particularly high blood concentrations of acetaldehyde in the fetus, therefore making these fetuses susceptible to damage (Véghelyi & Osztovics 1978, Dunn et al. 1979, Abel 1982).

Other clinical researchers suggest that alcohol, while necessary, is not sufficient to cause FAS (Abel 1998a). They argue that the interaction of alcohol use with other factors, such as the woman’s socioeconomic status, her nutritional intake, the stage of alcoholism that she is in, her genetic makeup as well as that of the fetus, use of other substances, such as nicotine, and the presence of maternal alcohol-related illnesses, such as cirrhosis of the liver, are factors that ultimately interact with alcohol abuse to cause FAS (Abel 1998a).

One argument that is receiving increasing support in scientific and lay circles states that, in apparently unaffected offspring born to alcoholic women, the effects are probably present, but are in some way masked or hidden at the time of observation (Streissguth et al. 1997, Barr & Streissguth 2001). For example, Ann Streissguth, a psychologist and well-known American FAS researcher writes,

> The fact that some offspring appear unaffected by prenatal alcohol at any point does *not* mean that alcohol is not teratogenic or that an individual who is free of alcohol-caused disabilities at one age will necessarily be free of them at another (1997:66 emphasis in text).

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[3] This estimate was determined based on an examination of the scientific literature reporting alcohol-related birth defects in heavy drinkers.

[4] For example, the study by Little and colleagues that determined 80% of alcoholic women give birth to affected offspring was based on a sample of five women (Little et al. 1990).

Barr and Streissguth (2001, see also Streissguth & O'Malley 2000) recently suggested that prevalence rates of fetal alcohol spectrum disorders (FASD)[5] could be "conservatively" estimated in North America at 1 per 100 births. They add that many of the "affected" children who make up this high prevalence rate go undetected because of inadequate screening and diagnostic tools (Barr & Streissguth 2001). The argument, most common among North American researchers, that the effects of prenatal alcohol exposure can be latent or undetectable during different periods of the life span, supports the belief of many who work in fields of FAS prevention, identification and intervention program development, that rates of FAS and alcohol-related birth effects (ARBEs) are much higher than is generally perceived. Accordingly, this has led, in some instances, most especially in Canada among Aboriginal groups, to the life span of offspring believed or known to be alcohol-exposed in-utero being observed through a lens of FAS. In this context, the bodies and behavior of alcohol-exposed offspring are continuously scrutinized for "signs of pathology" by health and social service providers, teachers, and by their mothers, families and communities. Because, for various reasons, diagnostic assessments are difficult to access (see, Section Two), these individuals are increasingly labeled as having FAS/ARBEs without medical confirmation that damage has occurred.

The public health message

Ongoing debates among researchers conducting clinical and animal studies as to the precise etiology of FAS, including debates about whether alcohol is sufficient to cause FAS and at what threshold alcohol becomes dangerous to the fetus, have not influenced the standard public health message that was adopted over twenty-years ago in North America. This message states that there are no known safe levels of alcohol exposure for the fetus, and therefore all alcohol use should be considered potentially dangerous. To ensure an unaffected child, complete abstinence during pregnancy is required. The message also suggests that every maternal/fetal dyad is equally "at-risk" if gestational exposure to alcohol occurs.

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[5] FASD is an umbrella term used to collectively describe the categories FAS, fetal alcohol effects (FAE), neurodevelopmental disorders (ARND), and static encephalopathy, alcohol exposed (see, Chapter Four for further discussion).

The position that all alcohol consumption is potentially dangerous, coupled with the perception that "risk behavior" is widespread, has led to calls by public health experts in North America for "risk-management" through self-regulation by pregnant women. Calls for self-regulation have occurred within a larger risk-management framework in which women are increasingly encouraged to avoid more and more substances present in the foods, beverages, and medications that they normally consume (Armstrong 1998). However, the fact that many women in their first trimester are initially unaware that they are pregnant, and that a certain percentage still consume some alcohol after they have knowledge of their pregnancy, supports the position that self-regulation by pregnant women is not enough to manage risk. The response to the perceived danger of women drinking alcohol before they know that they are pregnant has led to a shift in "risk-management," whereby it is recommended to all women of childbearing years that they refrain from alcohol use even if there is only a slight possibility that they could become pregnant (see, for example, Clarren 1981, Stratton et al. 1996:9, Streissguth 1997).

The response of North American health care and social service professionals, and even of the public at large, to women who know that they are pregnant and still consume alcohol has become increasingly harsh over the past decade (see for example, Daschle & Nighthorse Campbell 1994, Szabo 2001, Wente 2001). Public pressure, reinforced by the public health message, has led to a situation in which alcohol consumption by pregnant women is increasingly being viewed as socially unacceptable in any context or at any level. While this has led to significant decreases in alcohol use by most pregnant women, with more and more choosing complete abstinence, the success of the public health message has been overshadowed by limited decreases in alcohol consumption levels by those women thought to be at highest risk for having an alcohol-affected child (Clarren 2002).

For pregnant women with severe alcohol abuse problems, the challenge of trying to stay sober is compounded by a public health message that assumes abstinence is an uncomplicated choice (Tait 2000). For example, the medicalization of many conditions with behavioral sequelae, including alcohol addiction, functions to exculpate individuals from responsibility for their sickness. This has been usurped in connection with alcohol addiction in pregnant women, and similar to the behavior of non-addicted pregnant women has been viewed as being simply a matter of choice (Armstrong & Abel 2000). Framing alcohol unnecessarily as a choice to use or not use has effectively demonized all pregnant women who drink alcohol, most specifically those who are the heaviest drinkers, as it suggests that they are placing their own interests ahead of the interests of their unborn child (see, for example, Waldman 1989:435).

The moral politics of fetal alcohol syndrome

Terms such as "child abuse" or "fetal abuse" (Daschle & Nighthorse Campbell), or most recently the use of the term "fetal torture syndrome" (Clarren 2002), to describe gestational exposure to alcohol, coupled with growing public condemnation, has meant that it is increasingly difficult for pregnant women to speak about, and seek treatment for, their alcohol abuse problems. Legal attempts in North America[6] to detain pregnant women who abuse substances, sometimes with success, have also reinforced in the minds of women with such problems that their behavior is morally reprehensible, even if not always proven to be so legally.

Metaphors describing the bodies of pregnant women as "toxic environments," and the equating of their substance use as a "selfish" or "intentional" act and as "child abuse," reinforces an image that fetal development is both risky and precarious when left unchecked by medical and legal surveillance and control. For example, terms such as "maternal alcoholic environment" (Corrigan 1976:73), "fetal hazard" (Green 1974, Hanson et al. 1978), "acute fetal poisoning" (Kline et al. 1980: 176), "fetal damage" (Little and Streissguth 1981) and "embryotoxin" (Lindor et al. 1980, Sokil 1981) have all been used by researchers from various medical fields to describe pregnant women and

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[6] Children's Aid Societies in Canada have tried to use child abuse laws to ask the courts to protect the fetus (Bessner 1993, see for example, *Joe v. Yukon Territory* [1986] 5 BCLR [2d] 267). The most visible attempt was *Winnipeg Child and Family Service v. "G"* that drew national media attention over the question of legal confinement of pregnant women who abuse substances (see earlier discussion). While the court ruled that pregnant women could not be mandated into treatment, there was significant public debate and outcry over the ruling (see, for example, Coyne 1997). Women most likely to be subjected to judicial intervention are disproportionately impoverished, Aboriginal, or members of an ethnic minority (Royal Commission on New Reproductive Technologies 1993:953). Legal action against pregnant women who abuse substances when pregnant is much more common and harsher in the United States. For example, in 1997 a Wisconsin woman was charged with attempted murder for drinking during pregnancy. In 1998, South Dakota enacted a law criminalizing substance use during pregnancy (Armstrong 1998:2038). In North America, however, the social vulnerability of women most likely to be targeted for court-imposed treatment or incarceration means that they are less likely to be in a position to resist pressure from health care and social service workers and therefore will most likely comply with the wishes of service providers (Royal Commission on New Reproductive Technologies 1993:953).

their bodies (Armstrong 1998:2035). Armstrong points out that while some of these terms are standard medical jargon, they nonetheless exert metaphorical force, as researchers typically focus on the "harsh intrauterine environment" (Krous 1981:306) created by women who drink during pregnancy and who, in their eyes, fail to fulfill their role as nurturers (1998:2035). In this context, the act itself becomes morally reprehensible, regardless of the impact it may or may not have on the fetus.

In the public arena stigmatizing images associated with substance use by pregnant women are reinforced by the media and in public health awareness campaigns. For example, a November 1997 article in the *Montreal Gazette* discussing the Supreme Court Case, *Winnipeg Child and Family Services v G,* described "Ms G" as "slowly poisoning her unborn child" and argued that it should be "within the court's power to restrain her from such harmful behavior" (Coyne 1997). Public health education and awareness campaigns commonly use the image of a pregnant woman drinking alcohol or injecting or smoking drugs that flow through her body and into the fetal body as a means to map risk and locate the source of pathology. The woman and the fetus are depicted as two separate entities, with the fetus appearing as if trapped inside the womb at the mercy of the pregnant woman and beyond the protection of the larger society.[7]

Armstrong points out that in some cases, even the effects of the woman's own poor health on the fetus are made to seem intentional and almost willful, as illustrated in a statement by researcher H.F. Krous, who writes,

> The intrauterine environment of the alcoholic mother is a risky and complex milieu within which the fetus develops and grows. She inflicts upon her fetus the potential teratogenic effects of not only alcohol but also often adds the insults of malnutrition, hepatic cirrhosis, infection, smoking, drug abuse, hyperpyexia (fever), and trauma (Krous 1981:301 in Armstrong 1998:2035).

Armstrong suggests that it is as if Krous believes the woman is deliberately choosing to be malnourished, sick, addicted and traumatized herself and intentionally acts to under-

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[7] Critiques from feminist advocates about these images have led to some rethinking of the ways in which the public health message is delivered, with the focus being situated on support for the pregnant woman by the larger community. Posters developed by Aboriginal organizations and communities have typically taken a broader focus for their public health campaigns that situate the needs of pregnant women within a community support framework.

nourish, infect, addict and traumatize her fetus (1998:2035).

Embodiment and pregnancy

Central to this discussion is the embodiment of pregnant women. Pregnancy challenges conventional notions of individual autonomy in connection with behaviors that effect the body, because pregnancy literally represents both singularity and duality. As Lock points out, the question of the body brings with it "the difficulty of people both having and being bodies; subjectivity and its relation to biology and society cannot be ignored" (1993:136). This is particularly true for pregnant women because the physiological process of pregnancy changes the way they experience, and live within, their bodies. The relationship of a woman to her family, her community, and the larger society is also transformed during this liminal period. These transformations are informed by the culture and society in which the woman participates, and the particular circumstances surrounding the pregnancy itself.

In North America, pregnancy is embedded within larger cultural and social representations of "motherhood" in which women are believed to be "naturally" nurturing and self-sacrificing with reference to their children (Irwin & Jordan 1987, Tsing 1990). Increasingly, these representations are being extended to pregnant women, who are described as having a "relationship" with their "unborn baby" (Mitchell & Georges 1998, Taylor 1998). This shift is reflected in scientific and lay theories, for example, that link mother/child "bonding" with similar notions of mother/fetus "bonding." In this context the pregnant woman's relationship with her unborn child is seen to mirror that of her future role as a mother, as Sterling Clarren, a prominent American dysmorphologist and FAS researcher, indicates in the following statement: "The notion of mothering from conception, not birth, must be fostered in the nonpregnant. Few parents would give an infant an ounce of liquor; they should understand that gestational drinking is the same thing or worse"[8] (1981:2439).

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[8] On many occasions during my field research I heard versions of this statement being expressed as justification why pregnant women should not consume substances, such as alcohol, nicotine, or caffeine. An American public health poster displayed on buses in Seattle, Washington in 1978 used the slogan: "Mothering Begins Before Birth: Did you know that even moderate use of alcohol may affect your unborn baby?" The poster displayed a drawing of a sleeping baby's face resting alongside the slogan (see Streissguth 1997:13).

Provincial and federally funded pregnancy outreach programs in Canada spend a significant amount of time and resources reinforcing in the minds of pregnant women that they and their fetus are "separate persons." A pregnancy outreach worker from a small city in northern Manitoba whom I interviewed for this project uses soft plastic models of a fetus at various stages of development as a way to encourage women to refrain from drinking alcohol and to better care for themselves during pregnancy. In showing the models to me, the outreach worker stated:

> I find a lot of these younger girls have difficulty seeing their baby as a separate human being from them…I'll use my fetal models and I have fetal models that are from 10 weeks, 15 weeks, 20 weeks and 30 weeks and they're the actual weight and they're sort of, just to make them see that there is a different human being inside them and this is actually how much your baby weighs…and the moms when they're holding them it's funny some will even rock them while they're talking and they'll hold them throughout the whole time. But it's really making them realize that this is somebody that needs to be cared for. And you have to feed your baby and you have to take care of your baby. I find these help a lot with them seeing their baby as a separate person.

Even though the fetus is increasingly being seen as a separate entity—"patient," "baby," or "person"—the increased medicalization of pregnancy through prenatal genetic testing and the use of abortion as a preventative intervention has meant that women are faced with contradictions in their role as "pregnant mothers" (Press et al. 1998, Rapp 1988, 1998). For example, social labels, such as "baby" or "person," are with held when prenatal testing is done. At this stage the language of probability and risk predominates, while the fetus is measured, monitored, and tested for genetic anomalies. During this liminal period, ambiguities impose themselves upon the ways in which women understand and experience their pregnancies, and it is only when the tests are concluded and the fetus is pronounced "normal" that the existence of a baby/person as a separate entity is inscribed by genetic counselors and obstetricians upon the trajectory of the pregnancy.

Disruptions in nature, disruptions in society

Margaret Lock argues that disruptions of what are assumed to be the "natural" human relations basic to moral order in any given society will undoubtedly create national concern (1997). This is certainly true in situations involving pregnant women who consume large amounts of alcohol—and increasingly in relation to any amount of alcohol use by pregnant women—because their use of alcohol is seen to “disrupt” the “natural” responses that a pregnant woman is expected to feel toward her unborn child. Unlike pro-choice and pro-life debates, or debates over prenatal testing and the use of abortion as prevention, the pregnant woman’s “intention” to give birth and her “choice” to consume substances that are known to be toxic to the fetus have resulted in a blurring of the boundaries of personhood and of bodily autonomy and integrity beyond those debated by “pro-choice” and “pro-life” positions and those that raise concern around prenatal testing. In this context, the pregnant woman’s use of alcohol is believed to inscribe on, and within, the fetal body a life-long trajectory of physical and social suffering. In this way, persons with FAS are conceptualized as being “made” during pregnancy, because the “natural” life course of the “person who will come into being” is believed to be altered.

Just as persons with FAS are believed to be “made” by the alcohol use of their pregnant mothers, so too is their relationship with the larger society believed to be altered from its natural course. This is evident in a statement commonly made in conjunction with FAS, that “children with FAS are society’s children” (see, for example, Buxton 1998), as their illness has come to signify not only a breakdown in the “natural” relationship between the mother and child, but also to signify a social breakdown of significant proportions. For example, Streissguth writes, “Our children, our families, our schools, and our communities are suffering because of FAS/FAE…Misunderstood children are dropping out of school and often having babies for whom they can’t care. Their parents are unable to cope with their problems, which go beyond the demands of normal parenting…Communities are uncertain how to respond…it is essential and urgent that we as a society spend resources to attack this problem” (1997:xxiii). Rather than being “productive” members of society, persons with FAS are believed to place upon the larger society a significant financial and social burden that is entirely preventable (Streissguth 1997, Szabo 2000, Wente 2001).

In North America, the creation of a heightened sense of urgency to stop all pregnant women from drinking alcohol is as much about finding ways to sanction control over the behavior of women as it is about improving the health and wellbeing of alcoholic women and their offspring. A reductionist view of alcohol abuse as simply a matter of choice, now commonly embodied in community and government prevention campaigns and programs, represents a typical Euro/American approach, one that assumes health is a condition that should be sustained largely through individual effort, and that individual women should be made responsible for behaviors believed to place them, or in this case, their fetuses, “at risk” (Lock 1998).

However, Kleinman and Kleinman argue that cultural representations authorized by a moral community and its institutions, especially one as powerful as biomedicine, elaborate certain modes of suffering while downplaying or ignoring others (1997:2). With FAS, it is the quality of life of the affected offspring that is central in the discourse on suffering (Dorris 1989, 1997, Streissguth 1997, Streissguth & Kanter 1997). Limited attention is given to the realities faced by woman with substance abuse problems, even though research has shown that women who give birth to a child with FAS have severe alcohol-related pathology, and three quarters die within five years of giving birth if they continue to abuse alcohol (Clarren 1981, Olegard & Sabel 1979, Stressguth et al. 1987). Mothers of children with FAS have also been found to have high rates of both mental health problems (Kessler et al. 1997, Astley 2000b) and histories of being subjected to sexual and physical abuse (Astley 2000b). As will be discussed in Section Four, numerous barriers and gaps in health and social services for women with substance abuse problems exist, even within local contexts where prevention of FAS is viewed as a prioritized health issue.

Aboriginal peoples and fetal alcohol syndrome

> *Drinking in Canada is most common in the northern territories and western provinces and children with alcohol-related birth defects are more frequently seen in these regions. One mother has had seven children with FAS. Tragically, the pattern is more common among the aboriginal peoples, a lingering reminder of the economic and cultural injustices of the colonial past. We anticipated criticism from some native people to the effect that this conference placed unfair emphasis on native drinking and that the stereotype of Indian drinking patterns was perpetuated…The fact is, however, that FAS is largely a problem of the native children in British Columbia and there is nothing to be gained by pretending otherwise. Rather we must continue to do everything we can to stop this ecological tragedy.*
>
> Dr. Geoffrey C. Robinson,
> "Opening Remarks"
> Alcohol & Child/Family Health Conference,
> October 1988, Vancouver, British Columbia

So far as the diagnostic category FAS is conceived, the gaze of scientific researchers, medical and social service providers, and the larger society in North America, has been shaped and supported by suppositions about women who abuse alcohol while pregnant. In the United States, emphasis has been placed on the "democratization" (Armstrong & Abel 2000) of FAS and efforts have been made to illustrate how, regardless of ethnic, "racial" and socioeconomic group, pregnant women who drink alcohol are equally at risk for giving birth to prenatal alcohol affected offspring (see Chapter Five). In Canada, a long history of normalized relationships between Aboriginal and non-Aboriginal peoples, in which gender and racial discrimination is prominent, has resulted in numerous First Nation, Inuit, and Métis women living on the margins of society, and has greatly influenced the focus of attention to FAS. Despite government figures which show that fewer Aboriginal women (60.6%)[9] than non-Aboriginal women (67%)[10] choose to drink alcohol, the bodies and behavior of Aboriginal women have come under significantly greater scrutiny by clinical researchers and by health and social service providers.

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[9] Statistics Canada (1993).

[10] Poole (1997:5), see also Addiction Research Foundation of Ontario (1996), Health Canada (1996).

The medical and social gaze directed at FAS in Canada from the outset focused on Aboriginal communities, and risk was assumed to be much greater among pregnant Aboriginal women than among their non-Aboriginal counterparts (see, for example, Asante 1981, Robinson & Armstrong 1988). The bodies and behaviors of Aboriginal newborns and children have been increasingly scrutinized for signs of FAS by individuals working in fields of medicine, social services, education, law, and government. In the 1990s, the interest of these professionals expanded to include all age cohorts of Aboriginal people, with significant attention directed toward "high risk" groups of adolescents and adults. Specific attention was paid to individuals in institutional environments such as youth detention centers, jails and prisons, and toward impoverished women of child bearing ages (see for example, Anderson 2002, Boland et al. 1998, 2002, Conry & Fast 2000, Fast et al. 1999, Wente 2001).

Clinical researchers in Canada and the United States set Aboriginal peoples apart from other ethnic or "racial" groups in two specific ways. First, genetic predisposition was raised as a possible variable contributing to the presumed high prevalence rate of FAS among Aboriginal populations (see Chapter Five). Researchers such as psychiatrist and sociologist Philip May criticized this claim because it invoked arguments that were largely discredited in the scientific literature or which would be impossible to prove empirically (1981). However, despite such criticisms, an image of Aboriginal peoples as being biologically susceptible to alcohol abuse remains a commonly held belief among professional and lay groups, including among some Aboriginal groups (May & Smith 1988).

Second, arguments have also been made that "Aboriginal culture" is a risk factor contributing to prenatal alcohol abuse and FAS (see, for example, Asante 1981, Aase 1981). As with population genetics, culture as a "risk factor" is considered within scientific and lay discourse only in relation to Aboriginal populations and not to any other ethnic or cultural groups. The alcohol use of other groups of people is generally characterized as "social patterns of drinking," implying that such patterns transcend ethnic boundaries and are influenced more by factors such as the moral beliefs and laws of the dominant society, socioeconomic status, gender, or age[11]. Reference to "Aboriginal cultural patterns of drinking" suggests that these patterns are part of the worldview of all Aboriginal individuals and communities and, therefore, imply to a certain degree an inevitability that Aboriginal people will engage in this behavior because it is to some extent supported within a single unified belief system.

The politics of FAS: the "making" of a bio-underclass

> *Every day in Canada, one child is born with fetal alcohol syndrome or fetal alcohol effects (FAS/FAE). Children with FAS/FAE can suffer from: learning disabilities, hyperactivity, attention or memory deficits, inability to manage anger, poor judgement, difficulties with problem solving. These problems may lead to others in later life, such as crime or alcohol and drug abuse…Initial studies suggest that rates of FAS/FAE in some Aboriginal communities may be significantly higher.*
>
> Health Canada internet site
> http://www.hc-sc.ca
> March 2003

The diagnostic category FAS exists within a medical context in which consistent standardized tools and measurements for diagnosing illnesses caused by in-utero alcohol exposure do not exist (Abel 1998a, Astely & Clarren 2000). Medical assessments, partially due to a lack of diagnostic tools and related factors, such as the high cost associated with patient assessment and a shortage of physicians who are trained in FAS diagnosis, are very difficult to obtain in all regions of the world, including Canada. This has resulted in very few individuals actually being evaluated, and even fewer diagnosed with FAS/ARBEs. According to clinical researchers in Canada, less than 1% of the estimated population believed to have FAS/ARBEs are currently diagnosed. Clinical diagnostic inconsistencies have also been shown to be common and widespread (Roberts & Nanson 2000, Abel 1998a), and epidemiological evidence is inconclusive and/or methodologically questionable (Bray & Anderson 1989, Tait 2002). Despite this, a sense of urgency has arisen in North America, leading to campaigns to stop all pregnant women from drinking alcohol.

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[11] For example, children adopted from countries where alcohol use is known to be common, such as former countries of the Soviet Union are believed to be groups of adopted children with high rates of FAS/ARBEs. However, it is not culture but societal views—namely a lack of awareness of risk—that is attributed to producing the presumed high rate.

The sense of urgency attached to the category FAS has been fueled in North America by three perceptions commonly held by medical researchers and practitioners, public health and social service providers, educators, parent advocates, government bureaucrats, and the media. First, it is believed that persons with FAS and other alcohol-related illnesses are sentenced to life-long physical and psychological suffering. Second, FAS and ARBEs are thought to be entirely preventable. And, third, diagnostic difficulties and methodological problems in establishing precise prevalence and incidence rates are assumed to mask the true extent of the FAS "problem."

In Canada, perceptions that FAS is a widespread health and social problem have been further supported by a re-interpretation of what is assumed to be valid knowledge about the lives of Aboriginal peoples. This is evident in three ways. First, research and professional discourses (medical, social work, legal and education) (see for example, Asante 1981, Godel et al. 1992, Robinson 1988) and the media (Wente 2000) reinforce the belief that pregnant Aboriginal women engage to a greater degree in behavior believed to be most risky, such as chronic alcohol abuse or binge drinking, than do other groups of pregnant women.

Second, Aboriginal peoples, particularly youth, experience high rates of health and social problems, including disrupted school experience, alcohol and drug problems, trouble with the law, incarceration, and mental health problems, that have been described as "secondary disabilities" associated with FAS (Boland et al. 1998, 2000). "Secondary disabilities" are thought to arise from an interaction between primary disabilities, particularly neurodevelopmental anomalies, and the environment in which the person lives (Streissguth et al. 1997:34). In a context where few people are assessed or diagnosed with FAS/ARBEs, the common occurrence of this set of health and social problems in Aboriginal populations is believed to be indicative of high rates of FAS/ARBEs.

Third, all epidemiological and cohort-based FAS research conducted in Canada has occurred either in a reserve community, or in a clinical or regional setting with high concentrations of Aboriginal research subjects, and where maternal alcohol use is known to be high. This has led to the world's highest prevalence rates (190/1000) of FAS and fetal alcohol effects (FAE) (referring to a situation when there is the presence of some but not all of the features of the full blown syndrome) being identified in a First Nations community in northern British Columbia (Robinson et al. 1987).

The perception that FAS is a widespread problem within Canada's Aboriginal population is best illustrated by a 1997 editorial in the *Canadian Medical Journal* by David Square, a freelance journalist from Manitoba. The article, entitled "Fetal alcohol syndrome epidemic on Manitoba reserve," begins with a discussion of a study conducted by Dr. Albert Chudley, one of Canada's leading experts in the field of FAS, and Dr. Michael Moffatt, a pediatrician and head of Community Health Sciences at the University of Manitoba. Square writes:

> A recent study on a First Nations Reserve in Manitoba indicates that 1 in 10 children is the victim of alcohol teratogenesis. And that, says a researcher [Albert Chudley] involved in a seminal investigation of fetal alcohol syndrome (FAS) and possible fetal alcohol effects (FAE) in Canada's aboriginal population, is just the tip of the iceberg (Square 1997:59).

Square goes on to quote Chudley as saying that for every child identified with FAS/FAE in this northern Manitoba community, 2 or 3 more children are likely to have behavioral and learning problems caused by exposure to alcohol *in utero* (Square 1997:59). If the study by Chudley and Moffatt, which is neither referenced in the editorial nor appears in indexes of published medical journal literature, is taken as an accurate account, or, as suggested, as an under-estimation of the prevalence rate of ARBEs in Canada's Aboriginal population, then it suggests that a serious health crisis currently exists.

If one in ten Aboriginal children is the "victim of alcohol teratogenesis," the prevalence rate is 100/1000. Estimates of incidence rates of FAS in the general North American population, in contrast, are estimated to be considerably less than 1/1000 (0.67/1000). "Partial FAS" or FAE,[12] although estimated to be significantly higher at 9.1 cases/1000 or about 1% of all births in the United States (Sampson et al. 1997), still does not bring the rates estimated in the general population anywhere near the figures estimated for Canada's Aboriginal population.

An important observation about the knowledge production associated with FAS is the manipulation of language to suggest that the scope of the FAS problem is at a crisis

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[12] "Partial fetal alcohol syndrome" and "fetal alcohol effects" are generally used interchangeably; however, FAE is a more commonly used term.

level in the Aboriginal population. For example, Square does not state that the children are diagnosed with FAS or FAE but is careful to write that in this First Nations community 1 child in 10 is a "victim of alcohol teratogenesis." As will be discussed in Section Two, the teratogenic effects of alcohol are believed to exist on a broad continuum of structural and functional birth effects that range from very mild (basically no disability or developmental delay is evident throughout the life span) to very severe effects. Therefore, a statement that 1 in 10 children are the "victim of alcohol teratogenesis" tells us nothing about how this actually affects their structural and functional abilities and where on the continuum of effects the children's anomalies lie.

However, use of the term "victim" suggests to the reader that the effects have in some way negatively affected the lives of the children. This is particularly true in Square's editorial because he and Chudley, in order to highlight the impact of gestational exposure to alcohol, directly link behavioral and learning problems experienced by the children to alcohol teratogenesis. Factors such as poverty, inadequate education, and family dysfunction, which are common to First Nations communities with high rates of alcohol abuse and are likely to negatively influence behavior and learning, are ignored. So too is any acknowledgement of protective factors that exist in families or communities that may ameliorate cognitive and behavioral difficulties in affected children. The picture that Square paints is one of widespread chronic pathology that stems directly from the alcohol use of the women in the community.

The suggestion that a prevalence rate of 100/1000 in one First Nations community is only "the tip of the iceberg" in Canada's Aboriginal population also suggests that the percentage of Aboriginal women in Canada abusing alcohol while pregnant is significantly more than in the general population. It also implies, given the strong moral sentiments that filter through FAS discourse, that if these women are unwilling or unable to stop abusing alcohol while pregnant, then they will most likely continue to abuse alcohol after they give birth. According to this reasoning, large numbers of Aboriginal children are being born into home environments where the mother abuses alcohol, behavior that is strongly associated in social work discourse with the occurrence of "child neglect" and "abuse" (Swift 1995).

Children with FAS/ARBEs who grow up in a home environment where the mother regularly abuses alcohol are believed to experience a wider range and greater severity of the “secondary disabilities” associated with FAS. It is also generally agreed that the risk for “secondary disabilities” is compounded by the inability of most biological mothers, as well as many foster parents, to cope with the demands of caring for an alcohol-effected child. This is said to result in children with FAS/ARBEs being at greater risk for multiple placements in a series of different foster homes throughout their childhood years. Therefore, a suggestion that prevalence rates of FAS/ARBEs are significantly higher in the Aboriginal population supports the perception that many Aboriginal mothers are unable to care for their children and families, and that a central reason behind the overrepresentation of Aboriginal children in the foster care system is due to a combination of FAS/ARBEs and maternal alcohol abuse.

A further implication of a purported prevalence rate of 100/1000 is that it implies that a significant number of Canada’s Aboriginal population have chronic brain dysfunction. Because alcohol abuse has been identified as an “inter-generational problem,” in that it is found in different generations in the same family or community, it is now generally assumed that FAS is just as serious a problem in adolescent and adult Aboriginal populations as it is among neonates, infants and children. Making a diagnosis is particularly difficult in adolescents and adults, and therefore much more attention has been paid to the manifestation of “secondary disabilities,” which, as stated above, are usually social and health problems that occur at higher-than-average rates among the Aboriginal population in Canada.

Currently, cohorts of Aboriginal people, the most recent being women on social assistance with low levels of education, substance abuse problems, and whose children are in the care of social services, and men and women serving time in provincial and federal jails and prisons (see for example Boland et al. 1998, Boland et al. 2000, Fast et al. 1999), have been identified as populations where high rates of FAS/ARBEs exist.

Even though there is no research that verifies this assertion,[13] the identification of these groups as having high prevalence rates of FAS/ARBEs is quickly becoming entrenched in professional, government and lay discourses.

A final implication is that high rates of FAS/ARBEs in Canada's Aboriginal population have the potential to influence negotiations between Aboriginal peoples and federal and provincial governments on issues of self-determination and self-government. It takes no stretch of the imagination to see how a general perception that a significant percentage of Canada's Aboriginal population has a chronic brain dysfunction could be used as justification by government negotiators to impede the negotiation process.

A dramatic and worrisome claim in this context is the assertion that many Aboriginal people live their lives in a "culture of addiction" (Wente 2001). The collapsing of the category "culture" as applied to North American indigenous peoples into other categories signifying "addiction" or "abuse" is common in scientific and lay discourse about alcohol abuse and other social problems, such as "violence," "child abuse and neglect," "gambling," "sexual deviancy" and "substance abuse." In the discursive arena attached to the category FAS, references to "a culture of addiction" (Wente 2001) and "cultural patterns of drinking" are made only in relation to Aboriginal peoples and not to any other ethnic or social group. Because no one lives outside of "culture," the correlation implies that certain Aboriginal peoples not only experience having "addictions" but that the "culture" they live in is inherently pathological and destructive.

An even more serious collapsing of categories has recently occurred, this time not in relation to addiction per se, although the "culture of addiction" is implied, but to FAS. This is best illustrated in a statement made by Streissguth. She writes,

> On some Indian reservations, where alcohol abuse is common among women, FAS has been reported in 1 in 100 children (May et al., 1983). In one small Native American [Canadian] community, the incidence of FAS was 1 in 8 (Robinson, Conry, & Conry, 1987). At that frequency, FAS is a community catastrophe that threatens to wipe out any culture in just a few generations. However, FAS is not a Native problem or a problem of poverty per se. It is an *alcohol* problem, and it is *our* problem (1997:8-9).

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[13] Boland and colleagues (1998, 2000) review the FAS literature and speculate about the prevalence of FAS/ARBEs in the Canadian Federal prison population. The study by Fast and colleagues (1999) is a preliminary study examining prevalence rates of FAS/FAE among incarcerated populations in British Columbia. Due to the methodological design and limited scope of the study it is impossible to draw any significant conclusions about the larger prison population.

The intention of Streissguth's statement, which is implied by her argument that high FAS prevalence rates exist across multiple generations, is not to suggest that the people living in these communities are at risk of dying as a result of endemic gestational exposure to alcohol. Rather the implication is that in only a few generations the "culture" will die out and in its place a "culture of FAS," a type of "bio-underclass," will emerge. In this vision, whole communities are transformed into a "post-cultural state" in which their humanity is lost with their "culture." Streissguth's argument further implies that if a culture could be wiped out by multiple generations of high rates of FAS, then, given the patterns of alcohol abuse that have existed over several generations in some communities in North America, this process has already occurred.

As will be discussed later in this dissertation, this type of argument, even though it has no scientific or empirical basis, may have far reaching implications for Aboriginal people, as they are the group Streissguth and others associate most strongly with this type of phenomenon. The logic used in this argument effectively portrays a very stigmatizing image of Aboriginal women, their children and communities, and of people with disabilities. In a national context where Aboriginal self-determination and self-government is not strongly supported by the dominant society, implications that 1 in 10 Aboriginal people have a chronic brain dysfunction and that this has resulted in a "bio-underclass" with "little sense of consequences, and understanding of right from wrong" (Roberts 1998) is a compelling and convincing argument against the goal that Aboriginal people hope to achieve.

Consensus on the issue of FAS

Within a sociopolitical climate in which Aboriginal groups invoke health issues as simultaneously being political issues, the portrayal of Aboriginal populations suffering disproportionately from a chronic disabling brain dysfunction has failed to generate controversy or concern by Aboriginal peoples that they maybe unduly targeted or stigmatized. FAS and ARBEs in fact exist not only as uncontested labels, but they have also come to signify for Aboriginal peoples a major health and social "crisis" in their communities that warrants the application of significant human and financial resources for prevention, diagnosis and treatment (see, among others, Anderson 2002, Fourneir & Crey 1997). For example, the Assembly of First Nations, an umbrella organization representing all the First Nations of Canada, has identified FAS as a health priority in First Nations communities; the *Royal Commission Report on Aboriginal Peoples* describes FAS as a "troublesome problem" (1996a), and the Institute for Aboriginal Peoples Health (IAPH) recently had a call for research proposals on three prioritized topics, FAS being one.

A theory that provides a causative agent, in this case alcohol use by pregnant women, and at the same time furnishes an explanation of sorts for the discrepancies in the health and social status of Aboriginal populations in which the larger society is not a primary source, is both compelling and convincing for most Canadians, including many of those individuals involved in FAS research, prevention, identification, and intervention. At various levels, as will be shown in this dissertation, the same holds true for many Aboriginal people who struggle to understand and cope with the realities that they see and experience in their own lives and in the lives of the people living in their communities. For them it is not surprising that alcohol has again impacted upon their lives and the lives of their children in a devastating way, and FAS has been added to a litany of alcohol-related problems that they associate more broadly with colonization, marginalization, and oppression (see for example, Royal Commission on Aboriginal Peoples 1995, Tait 2002).

Conclusion

The goal of this dissertation is to provide an anthropological assessment of the knowledge production and practices associated with FAS in Canada. Central to my analysis is an examination of the general consensus among medical experts, provincial and federal governments, and the general public, including Aboriginal peoples, that FAS is a widespread, serious public health and social problem in the general Aboriginal population. Unlike the United States, the sense of urgency that has been generated in Canada in relation to FAS is focused almost entirely on one "racial" group. Aboriginal peoples are most closely associated with the central risk factor, alcohol abuse, as well as with the "primary" and "secondary disabilities" associated with FAS.

Of equal importance are the ways in which Aboriginal peoples are portrayed in the media and elsewhere as collectively failing to profit from what Canadians generally perceive to be the inherent health and social benefits to be gained from modernization, progress, and economic prosperity, despite receiving “substantial” government funding, services and training. Unlike immigrants and refugees whose experiences are often compared to those of Aboriginal groups, Aboriginal people are perceived to be unable or unwilling to effectively embrace Canada’s collective prosperity (see for example, Dolphin 2002). The contrast between the health and social status of the general population and that of Aboriginal populations is an embarrassing blemish on Canada’s claim to being a healthy, safe and prosperous society in which all ethnic and social groups prosper. The introduction of the “FAS problem” and the argument that a significant number of Aboriginal people suffer from a chronic brain dysfunction caused by their mothers drinking alcohol while pregnant provides a compelling and convincing explanations for these discrepancies for many people. As will be examined in this thesis, this argument arises directly out of the knowledge produced in scientific, professional, media and lay arenas.

Chapter Two
DESIGNING THE RESEARCH PROJECT: METHODOLOGICAL CONSIDERATIONS

Introduction

In 1996 two articles in *Maclean's* magazine initially sparked my interest in pregnancy and substance addiction. The first article discussed the court case in Winnipeg involving "Ms G," and the controversy over the rights of Canadian courts to detain pregnant women who abuse substances (Chisholm 1996). The second article had a broader focus and discussed the contradictions and ambiguities in connection with how Canadian society deals first with pregnancy and abortion in light of scientific developments in new reproductive technologies (NRTs)[1], and second a better understanding of the relationships between teratogenic agents and fetal health (Wood 1996). Centrally situated in both articles was the question of when life begins, and when personhood, and all the rights afforded to this designation, is granted—topics which were central to my original doctoral plans to do research at an in-vitro fertilization clinic in Montreal.

In comparing the articles it was obvious that ethnic and class lines divided the discussions of the pregnant women who have problems with substance addiction and those who make use of NRTs. The articles presented an interesting juxtaposition relevant to my research interests because, in Canada, in-vitro fertilization is a procedure mainly used by middle and upper class white women and sits in stark contrast to the impoverished Aboriginal and Black women who were featured in the article on substance abuse and pregnancy. It was also a timely contrast as only a few weeks prior to reading the articles, one of my mentors at McGill University, Abby Lipmann, had suggested that I think of shifting my research to Aboriginal women's health because I am a Métis woman. Although others had also suggested this, Abby's urging, coupled with a growing awareness of the significant problems I would face in securing access to patients and staff at an in-vitro clinic, meant that I was easily prompted to consider research in connection with Aboriginal women's health. Reading these articles, specifically the linkage made

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[1] The term 'new reproductive technologies' (NRTs) is associated with those technologies which assist in reproduction, such as in-vitro fertilization, and those which assist in prenatal testing, such as amniocentesis.

between NRTs, toxicology, fetal personhood, and pregnancy, quickly aroused my interest, and shortly thereafter I became committed to changing the direction of my research.

The day that I found the articles in *Maclean's*, I had just finished working as a support person at a community wellness conference for Aboriginal men. My brother, Darren, who worked for a First Nations community near where we grew up in Saskatchewan, had invited me to assist him and his colleagues at the conference which took place shortly after the death of our father. During two days of interesting interaction with participants it became evident to me that with the death of our father, my siblings and I had lost the parent who had tied us to our Métis heritage, and who had carried with him so much of the history and stories of our ancestors. This realization brought yet another feeling of loss, and I found myself considering ways in which I could maintain a connection to my Métis heritage, a consideration that did not seem necessary when my father was alive. I also found myself being drawn to my brother's work in the addictions field and his current employment as the Child and Family Services Director of a First Nations community. As I sat and read the articles in *Maclean's*, all the pieces for a much more meaningful research project began to materialize, one in which I could be involved in Aboriginal health through my research, and at the same time maintain my interests in feminist anthropology and reproduction.

Métis to Aboriginal-Métis: shifting identities and field research

My identity as an Aboriginal-Métis has significantly shaped my research interests and analysis. This hybrid identity is linked to my living outside of Saskatchewan for the past twelve years. During my childhood and adult years in Saskatchewan I had always thought of myself as Métis, and never as Aboriginal, as this identity was not common for either Métis or for First Nations peoples during this period. Being Métis in Saskatchewan, unlike in my current home of Montreal, means belonging to a distinct cultural group, and most Métis people make significant efforts to make clear that they are neither First Nation nor "white."

The constant need to reinforce a distinct identity is partially shaped by the tension that exists at the core of Métis identity, because inherently we are mixed-*métis*. This "mixing" becomes even more precarious for Métis like myself, who have one parent who is Métis and the other who is non-Aboriginal, as we embody a blurring of the boundaries of Aboriginal identity and the "Other." As such, within the Métis person flows the "blood" of both the colonized and the colonizer, a tension that situates us at different times in or out, or on the margins of both mainstream and indigenous societies. It is from this position that my research was conducted, a position that fortunately did not hinder but facilitated my ability to move with relative ease between different cultural and social milieus. This freedom of movement, as will be discussed, was extremely important for this project, something which I suspect would have been much more difficult had I been First Nation, Inuit, or non-Aboriginal.

A shift in identity to that of an Aboriginal-Métis took place for me when I moved to Montreal in the late 1980s and became involved with the local grassroots movement based at the Native Friendship Centre. Because only a handful of anglophone Métis live in Montreal, there are no community organizations or planned activities that reinforce a Métis identity and, like Inuit and First Nations peoples, anyone who is Métis accesses community activities or employment under the umbrella categories of "Native" or "Aboriginal."

This enforced transformation in identity has been experienced by many First Nations, Inuit and Métis peoples in other parts of Canada, especially for those living in urban centers. Increasingly the category Aboriginal is the umbrella term used by First Nations, Inuit, and Métis to refer to their collective indigenous identity and experience, and many national organizations, such as the National Aboriginal Health Organization (NAHO) and the Aboriginal Healing Foundation (AHF) have adopted this category. Federal and provincial governments are increasingly using the term "Aboriginal" in their allocation of funding and in policy making. For example, the newly formed Canadian Institutes for Health Research (CIHR) funded by the federal government has created the Institute for Aboriginal Peoples Health (IAPH) as one of its branches. In relation to this research and the community work that I was involved in as part of this project, my shared Aboriginal-Métis identity with First Nations and Inuit peoples situated me within a specific social, cultural, and political context that significantly influenced the planning, data collection, and analysis of this research project.

Early in the research process I became self-consciously aware that I was one of only a handful of Aboriginal health researchers in Canada, and that this research would be the first in-depth examination of FAS from a national viewpoint by an Aboriginal person. Within Aboriginal circles, I was also told by my mentors that my research would draw attention from Aboriginal leaders, activists, and community members, as well as government departments. This interest surfaced far in advance of the research being completed, and ended up facilitating access to and use of certain information and data that would have been otherwise difficult to bring into this project. One such activity involved a research contract for the Aboriginal Healing Foundation. I was asked to review the scientific and "gray[2]" literature to examine intergenerational links between the residential school experience of Aboriginal peoples and current rates of FAS in Aboriginal communities (Tait 2003). This opportunity allowed me to conduct an in-depth review and analysis of FAS-specific literature, as well as related reviews of historical and clinical literature on topics such as residential schools, child abuse, and alcoholism.

In 1997, as the Research Coordinator of a grassroots organization, Aboriginal Women of Montreal, Inc. (AWM), I was given a small research grant from the Centre de l'excellence pour la santé de femme (CESAF) to conduct a study on barriers to addiction treatment for pregnant Aboriginal women in Montréal. At the time I was one of a handful of researchers in Québec who was interested in research on FAS, which facilitated my participation in a wide range of workshops, committees, and meetings on FAS that were closed to the general public. For example, in 1999 I was asked to be a Québec representative on a national committee funded by Health Canada to determine "best practices" for FAS prevention, identification, and intervention.[3] This committee was comprised of a number of experts in the field of FAS, including scientific researchers, addiction and medical professionals, government bureaucrats, and parent advocates.

A related factor that assisted in the evolution of my thesis research was an on-

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[2] "Gray" literature refers to articles and documents that are not published in scholarly journals or books. This includes government documents, and documents produced by community organizations. The "gray" FAS literature is particularly rich, as governments have produced several documents, as have several community FAS coalitions.

[3] Two documents were produced from this committee (Roberts & Nanson 2000, Legge et al. 2000).

going involvement with the Centres of Excellence for Women's Health, and the Canadian Women's Health Network (CWHN). During the course of the research project for AWM, I was invited to give input to a coalition of women's groups[4] who had been given *Intervenor* status at the Supreme Court of Canada case, *Winnipeg Child and Family Services (Northwest Area) v. G.* The groups were writing a factum to the Court and had asked for my input on issues specific to Aboriginal women. When the case was heard in June 1997 in Ottawa, I was able to attend along with some of the women who were responsible for producing the factum, including Madeline Boscoe, the Executive Director of CWHN.

Madeline Boscoe was instrumental in raising national awareness about the potential harm to women, their children, and families if mandatory addiction treatment for pregnant women was allowed by the Court. She did this through her contribution to the writing of the factum and other forms of knowledge for dissemination in the media and newsletters. Attending the "G" case, and spending time in Ottawa with Madeline and other feminist activists, highlighted for me the importance of raising public awareness about the lives and experiences of pregnant women with substance abuse problems. This was particularly apparent because the arguments at the court case were clearly divided along ideological lines, pro-choice and pro-life, and paid virtually no attention to the realities of daily life faced by women such as "Ms G," beyond their behavior and role as pregnant women/mothers.

As I prepared to begin full time field research in January 1999, a call for research proposals was given by the Prairie Women's Health Centre of Excellence (PWHCE) in conjunction with the department of health of the Manitoba government. PWHCE was looking for someone to conduct a study on barriers that prevent pregnant women addicted to substances from accessing treatment services in the province of Manitoba. The timing of the project could not have been better for me, because the issues the PWHCE wanted to examine and my doctoral field research plans were almost identical.

The impetus behind the call for proposals by PWHCE and Manitoba Health was the "G" case, and the lobbying by community activists and service providers, including

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[4] The group included, Women's Health Clinic Inc., Métis Women of Manitoba Inc., Native Women's Transition Centre Inc., and Manitoba Association of Rights and Liberties Inc.

Madeline Boscoe, that more be done for women, like “Ms G,” who struggle with substance addiction. The response by Manitoba Health to the lobbying was the “Pregnant Addicted Women” (PAW) research project, which they decided would be housed by PWHCE in order that the study be somewhat independent of Manitoba Health, since the research would be examining some of the programs funded by that department. Shortly after my proposal submission in March, Linda DuBick, the Executive Director of PWHCE, offered me a contract, and within three weeks I was on a plane heading to Manitoba to begin my field research.

Methodology

The data collected for this dissertation spans a four to five year period,[5] from 1997 to spring 2002, although the bulk of the research took place in 1999 and 2001. The project is national in its scope, with the majority of research being conducted in Manitoba, especially Winnipeg, and in Montréal, Québec. Interviews and meetings with service providers, researchers, and health care practitioners also took place previously in Prince Albert and Saskatoon, Saskatchewan; Calgary, Alberta; and Ottawa, Ontario. On several occasions I attended conferences and workshops in Vancouver, British Columbia, a hub in Canada for research, diagnostic assessments, and medical and lay advocacy related to FAS. Discussions and interviews, while conducted in the above mentioned places, involve individuals from the majority of regions of Canada, including northern regions and the Maritime provinces. All of the interviews were conducted in English; however, some of the meetings attended in Montréal were in French, with translation provided. Discussions were also held with a few individuals from Québec who work with the Francophone Aboriginal community and who were willing either to speak in English or to patiently field my poorly constructed questions in French.

The study funded by Manitoba Health, which serves as the basis for this dissertation, followed government ethical guidelines for research with human subjects. All of the information that identifies the women who participated in the study has been kept strictly confidential. The findings of the PAW study were presented as a general

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[5] There were interruptions in my field research as I was involved in course work, and had a baby during this period. Most of the field research was on a part time basis, with the exception of the Manitoba field research, which took place from April 1999 to November 1999.

report (Tait 2000) to Manitoba Health through PWHCE. None of the primary data collected, including the women's identities was given to Manitoba Health or PWHCE, as they required only aggregated data and completed analyses in the final report.

Data for this dissertation was obtained through various collection methods, including unstructured interviews with women (n=104), semi-structured interviews with service providers (n=97), focus groups (n=3), participation in community meetings, conferences and other activities, collection of public health literature, newspaper and magazine articles, and an extensive review of scientific and gray literature. As opportunities presented themselves, spontaneous interviews and informal conversations took place with several categories of persons, including persons diagnosed with FAS or an ARBEs, parents of children with FAS or an ARBE, parent FAS advocates, medical practitioners, social service and outreach workers, feminist activists, and FAS researchers.

Two groups were the main target population of this study: women who currently or in the past have experienced substance abuse problems when pregnant, and service providers and government departments who contribute to the continuum of medical and social service care that target these women and their families. Women were referred to the study in three ways: by service providers, by a friend or relative, or by self-referral upon seeing an announcement calling for research participants. Interviews with women for the Montreal AWM study targeted Aboriginal women only. Due to Manitoba Health's interest in examining the experience of all groups of women in the province in accessing addiction treatment programs and related health and social services, these interviews were open to all women who met the study's criteria. However, Aboriginal women were over-represented in the Manitoba study (52/74), with First Nations women living off-reserve making up 47% of the study sample.[6]

Methods used to identify research subjects

In the Montreal and Manitoba studies, a combination of judgment and snowball sampling were used. Judgment sampling refers to a situation where the researcher decides what types of participants (or community) will best serve the research purpose and then

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[6] The reasons behind this over-representation will be dealt with briefly in the final section of this chapter, and in greater detail in Chapter Seven.

locate participants accordingly (Bernard 1994). This type of sampling has been used in life history and qualitative research in connection with specific populations. The benefit of this approach is that it allows the researcher to seek out as diverse a sample population as possible.

Snowball sampling refers to a situation where the researcher locates one or more key individuals and asks them to refer others who would be likely candidates for the project (Bernard 1994:98). Both methods were effective in identifying women, service providers, and other possible participants. Snowball sampling was especially useful in understanding how local social networks involving service providers and women operate, and in identifying women with substance abuse problems who were not accessing social or medical services.

The problem with judgement and snowball sampling in research that deals with sensitive subjects such as pregnancy and substance addiction is that certain subgroups are under represented, or in extreme cases, not represented at all in the study sample. This is true for the Manitoba study with regard to women from certain ethnic, religious and cultural groups, women belonging to certain social categories such as refugee and immigrant women, and women who are socio-economically advantaged. This deficiency was partially addressed through interviews with service providers to determine whether substance abuse during pregnancy was a behavior common among the under-represented groups. However, in many instances it was not clear as to whether the lack of referral of a particular population to the study was due to substance abuse being unusual among pregnant women in the group, or instead was a reflection of the barriers that prevent women from speaking about or seeking treatment for their substance abuse problems (Tait 2000).

Honoraria

Due to the sensitive nature of the study's research questions, identifying, and enlisting women to participate in the study was a concern from the outset. The research budgets for the AWM project in Montreal and the PAW study in Manitoba allowed for each participant to be paid an honorarium and to have their costs covered for child care and transportation incurred by participating in the interview[7]. The practice of giving honoraria to research subjects did not raise concern during the Montreal study; however, some concern was expressed during the Manitoba study by service providers.

Concern over honoraria focused on three related issues. The most common was expressed in ethical terms, the argument being that it was unethical to give a pregnant woman with substance abuse problems money as she was likely to use this money to buy drugs, alcohol, or other substances that would be harmful to the fetus. Related to this was concern that the motivation of a woman's participation would be based on receiving the honorarium, rather than on her recognition that the research was being conducted "for her benefit." This led, much to my surprise, to a questioning of the truthfulness that could be expected from research subjects who were believed to be motivated by money rather than by social consciousness. At the extreme, some service providers argued that because the research was for the "benefit" of the women, it was unethical to pay them for something that was created "for their own good."

The moral discourse around the "benefits" of research, as one can imagine, has little salience in the lives of impoverished women who are trying to pay their rent, buy food for their children, struggle with a substance addiction, and negotiate the myriad of demands placed on their lives by social service agencies, family members, and partners. A small infusion of money, while having only limited value in their lives, will have an immediate impact, that, one hopes, could at some level be positive. However, "a positive impact" must be understood in the context of the lives of the women in this study, as illustrated by the comments one pregnant woman made at the end of our interview. As I was thanking her for her candidness, she in turn thanked me for the honorarium, explaining that she would not now have to "give some old guy a blow job" that afternoon so that she and her boy friend could get money to buy hair spray to get high with[8]. Walking home after the interview, four months pregnant myself, the concerns raised by service providers about the ethical implications of giving honoraria seemed trivial and

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[7] Women in the Montreal AWM study were given a $10.00 honorarium and women in the Manitoba PAW study were given a $40.00 honorarium.

[8] The woman did not actually specify which substance she and her boyfriend planned on buying that afternoon. I assumed that it would be hair spray or something similar because she had explained to me in the interview that this was usually her substance of choice.

even misguided when placed within the context of the lives of at least some of the women. Focus instead seems better directed on what pushes women to levels of desperation such as those expressed above, so that they can acquire a three dollar bottle of hairspray with which to get high.

A second ethical concern was raised about the predicament in which economically disadvantaged women may be placed by receiving an honorarium. Some service providers believed that the honorarium would make women feel obligated to speak about issues that they would prefer not to divulge. To counter this concern, one that I felt was not grounded in knowledge of these women's lives, but rather in a paternalistic view held by some service providers, I gave each woman her honorarium at the beginning of the interview and explained to her that this payment was made because she had shown up to the interview. I went on to explain that if she chose to leave the interview at this point she could do so and was under no further obligation to me. I further explained that at no time was she obligated to answer questions or discuss subjects that she did not want to address. Of the 104 women interviewed, not one chose to leave after receiving the honorarium. As money is a key expression of value in our society, I believe that most of the women understood the honorarium to be an acknowledgement on my part that their knowledge and experiences were valuable and important.

Final concerns came from other researchers who expressed that giving honoraria to the women was setting a dangerous precedence in that impoverished participants would now expect honoraria for their participation in research. With only limited funds available for research, this would put further constraints on research budgets and design. Concern was also expressed that "professional research subjects" would emerge as a new category of impoverished persons, who would spend their time filling out questionnaires and surveys and being interviewed by a series of researchers leading to increasing commodification of information and narratives essential to the research process.

The above concerns raised by researchers are ones that I share to a certain degree. In the Aboriginal community of Montreal I have witnessed increasing demands by community members to be paid for their participation in research projects, with some individuals over the course of a year being subjects in a number of unrelated, but similarly focused, projects. I have observed individuals becoming very adept at recounting their life histories through a lens of trauma and traumatic events. While at some level I find this troublesome, I am not convinced that providing honoraria is the real catalyst behind this emerging phenomenon.

My counter argument to concerns over honoraria and research design is that I have observed some individuals putting a great deal more investment in, and gaining satisfaction with, projects where honoraria have been given to participants. It is also clear that at least some individuals think and speak about their lives in a much broader conceptual framework, partially because of their involvement with research projects. This I believe is not necessarily a negative outcome despite the common focus on trauma, but rather it appears to be a positive unanticipated development that occurs for some people after they reflect upon their lives through the lens of various research questions. In the end, whether the practices of awarding honoraria to research subjects inhibits the research process to a greater or lesser degree is yet to be determined. In my opinion the benefits of valuing the input of participants through the awarding of honoraria has important symbolic, if little practical impact on the lives of research subjects, as they engage in interactions with researchers and the priorities set by them.

Interview Styles

An unstructured, open-ended format was used in the interviews with women. This methodology seeks to have people express themselves in their own way, on their own terms, and at their own pace (Bernard 1988:204). This allowed for very relaxed and informal interactions between the women and myself, and was especially important for building a positive rapport and level of trust with participants.

The response by women to this interview style was very positive. Many expressed surprise at how comfortable they felt throughout the interview process, even though very sensitive topics were being discussed. Each participant was given contact information before the interview so that if they changed their mind about being included in the study they could withdraw at anytime. The length of the interviews varied, with the shortest being forty-five minutes and the longest being three two-hour meetings. The interviews took place in different settings: in the homes of the women, community and outreach centers, shelters, in parks, and in my office at the University of Winnipeg. The interviews in Manitoba were conducted in three geographical locations: Winnipeg, The Pas, and Thompson. When possible, I also took the opportunity to spend time with different women outside of the interview context, which I found to be of great benefit to data collection, as well as being a very relaxing and enjoyable experience.

The interviews with the women generally took the form of life histories, as they recounted their experiences with substance abuse. Keesing (1992:10) argues that subjective narratives help to control against excessive projections of both the ethnographer's theoretical biases and the logic, assumptions, motives and categories of the dominant mainstream society onto local groups. Lock argues that formalized interviews that follow a strict protocol make arbitrary decisions concerning criteria for inclusion and exclusion of questions, that may simultaneously act as moral decisions about what is normal and abnormal (1993a:xxiii). They may also prevent connections and associations from emerging during the interview process that are apparent and logical to the participant, but not to the researcher.

Lock (1993s:xxxix) points out that subjective experience cannot be measured by scientific methods but must be narrated. She states:

> This kind of information, usually neglected by biological and social scientists alike, allows us to enter vicariously into the life world of individuals. Narratives of subjectivity do not permit broad generalizations and abstractions but encourage instead a contextualization of specific pieces of the puzzle and provide a very important constraint on the way in which we obtain and interpret biological and statistical information (1993a:xxxix-xl).

Lock (1993a:xl) and Scarry (1985) suggest that because the experience of subjectivity—and the language that is used to describe it—is a cultural product, personal narratives are inevitably circumscribed in specific ways, with narratives emphasizing certain features while leaving others unrecognized or unspoken. What people (in this case, women with problems of substance abuse) "experience and report in connection with their bodies is not in essence the same type of information produced through observation, measurement, and abstraction" (Lock 1993a:xxiii).

The second group interviewed were service providers (n=97) who work in health and social service fields. Interviews with service providers took place throughout the project, with most conducted at the sites where women in the study sample access services. This gave me the opportunity to see where interaction between the women and service providers occurred. Interviews with service providers were as short as thirty minutes and as long as three hours. Some service providers were interviewed more than once, while others—especially those in Winnipeg—were contacted by telephone at different times after the interview to gain further information as the project progressed. The majority of service providers dealt with women either because of their substance abuse problems or because of their pregnancy. Some service providers, such as those who work in women's shelters, who have contact with this group of women for reasons other than substance abuse or pregnancy, were also included. These interviews were especially important in gaining knowledge about services that the women frequently access but which are unrelated to their abuse problems.

Interviews with service providers were semi-structured, and an interview guide was employed to shape the discussion. According to Bernard (1988:205), this form of interview is particularly useful when interviewing managers, bureaucrats, and elite members of a community, namely those people who are accustomed to efficient use of their time, while permitting the researcher the discretion to follow specific leads. This style also allows for recognition that each group of professionals has its own discourse, practices, and technologies into which an understanding of pregnant women with substance abuse problems has been incorporated. Semi-structured interviews allow for comparative analysis of important topics, such as the ways different professions conceptualize consumers as being "high-risk," or as candidates for particular services.

In its original design, this study was to focus only on women who had abused substances when pregnant, and on the health and social service providers who are mandated to provide support services for them. However, as the project evolved, it became evident that knowing more about persons diagnosed with FAS, and the families they grow up in, was also essential. Numerous informal interviews and conversations with persons who are diagnosed with FAS/FAE and with parents of children diagnosed took place over the course of the project, as did my participation in conferences and community meetings in which persons from both of these groups spoke publicly about their experiences. Interviews and conversations with health and social service providers and FAS researchers also contributed to my knowledge about how persons with FAS are perceived within the larger health and social service delivery system, and within mainstream society.

Methodological Limitations

There are several methodological limitations inherent in this study. The first involves the use of interviews to collect research data without carrying out the traditional anthropological method of participant observation[9]. While the interviews yielded important information about the experiences of women, and about persons labeled as having FAS, service providers, and other related groups, an opportunity to live in the same neighborhoods, transitional housings, shelters, or treatment centers as the women, for example, would have been of great benefit to the project. However, given the national scope of this research, and the mandates of the two research contracts that supported it, including time constraints, long term participant observation in local settings was not possible.

Collection of research data, especially sensitive data such as levels of alcohol consumption, raises questions about data validity. Given the qualitative nature of the data and my reliance on information obtained through open-ended and semi-structured interviews, it was necessary to build into the methodology a means by which this data could be verified. This was accomplished through a series of data comparisons. The experience of individual women was compared to the overall collective experience of women in the study to determine levels of consistency among participants. Similarly, the experience of service providers were compared and analyzed for consistency and areas of departure, as were the collective accounts of service providers to the collective accounts of women. Recent ethnographic and medical studies that target similar study populations in different geographical regions of Canada, and North America more generally were used for broader comparative purposes.

Individual interviews were analyzed for internal consistency, which in some cases revealed contradictory information during the course of the interview. This was not necessarily taken as misrepresentation by the person interviewed; rather it generally

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[9] Participant observation is a research method in which the researcher participates in the everyday activities of a research setting while observing the ways in which a community or group of people go about their daily lives (Bernard 1988).

revealed something about the dynamic of the interview/interviewee relationship. It was found that as service providers and women relaxed during the interview, they were more likely to report information that placed them in a negative light. For example, some service providers were reluctant to report areas of service provision where they were having little or no success in making a positive impact upon the lives of certain subgroups of targeted women. This reluctance generally diminished as the service provider became comfortable with me and came to understand that my purpose was not to evaluate their work per se. Similarly, women at times under-reported their use of substances early in the interview, and subsequently changed this information as they became more comfortable with the interview process and felt safe to disclose the extent of their use.

"Researched To Death": Anthropology's Legacy in Aboriginal Communities

As a Métis and an anthropologist, I was aware that entering the field of Aboriginal health research placed me in a precarious position, as it is commonly stated by Aboriginal peoples, particularly First Nations, that they have been "researched to death." Added to this perception is the specific historical role that Aboriginal peoples believe anthropologists to have played, namely that of collectors of indigenous knowledge and artifacts that were classified and then written about in scholarly books and journals, or placed on display for non-Aboriginal peoples in museums and art galleries. In both locations, scholarly publications and museum exhibitions depicting Canadian Aboriginal peoples for the larger world have remained relatively inaccessible to Aboriginal peoples, even in today's more sensitized research milieu. In many cases, Aboriginal people within Canada and beyond regard anthropologists as the epitome of all that continues to be wrong with academia (Smith 1999:67).

Linda Tuhiwai Smith, a Maori scholar, writes that the word "research" "is probably one of the dirtiest words in the indigenous world's vocabulary. When mentioned in many indigenous contexts, its stirs up silence, it conjures up bad memories, it raises a smile that is knowing and distrustful" (1999:1). The practice of "research" has come to represent an invasion of privacy, a form of surveillance that has little or no benefit for Aboriginal peoples, and is regarded as an activity that exploits, invades, and, in some cases is believed to directly damage the lives of Aboriginal peoples. Anthropologists' research appears to be the most questionable for Aboriginal peoples because of its apparent self-serving purposes, unlike, for example, medical research. Anthropological research is very much on the margins of what is considered "acceptable" or "useful" at the community or local level[10].

For a number of reasons, conducting research in Aboriginal communities, including many urban centers, has become very difficult over the past ten years for researchers who are caught between the requirements of funding sources, including timelines and budget allocations, and the need for negotiation and adherence to protocols that have been put in place by Aboriginal groups. Moreover, a number of Aboriginal communities have adopted the principles of OCAP, which stand for "ownership" and "control" of data and research dissemination, "access" to data collected and to subsequent publications, and "possession" of the data, whereby it is housed in the community itself. This has resulted in some very positive partnerships between Aboriginal communities and researchers at times, but where there is confusion about this newly defined relationship, tension has arisen as both researchers and communities struggle with how best to protect their interests.

With this in mind, I was aware that approaching the topic of FAS and alcohol abuse during pregnancy at a national level would require that my research not perpetuate what was seen as a typical graduate student project of studying the "Indian problem," but instead would have to be understood as an attempt to bring a fresh approach to the value of research that benefits Aboriginal peoples. My approach, therefore, was not to focus solely on Aboriginal peoples, but rather to "study up" in the words of Laura Nader (1972), and thereby take as my subjects of research medical research, government public health policy, provision of community public health and social services, and health care

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[10] It is important to note that many anthropologists who work in Aboriginal communities have long-standing relationships with those communities, and their research is viewed by the communities as being important for recording the history of the group, particularly Aboriginal and non-Aboriginal relations. Many of these scholars have also been centrally involved in community-driven research projects, as expert witnesses for Aboriginal communities in court cases, and in negotiations to have museums repatriate Aboriginal artifacts to the communities where they came from. Criticism from Aboriginal peoples toward anthropologists are generally focused on those individuals who conduct a single project, leave the community and never return research findings or disseminate publication of the data.

practices, that, along with Aboriginal communities, produce knowledge and practices that have come to define FAS in Canada.

When I designed the project for Manitoba Health and PWHCE, I was aware that impoverished Aboriginal women would make up a significant percentage of the women in the study. This is due mainly to the fact that these women are easy to identify and approach for interviews because of the amount of surveillance that their lives come under from various government and non-government agencies. Knowing this, I felt it was important to give due importance to the examination of the perceptions that health and social service providers and government agencies have about Aboriginal women and their families. While some of the results of this examination are discussed in the PAW report (Tait 2000), this dissertation expands this analysis to a national level, and analyzes the data through a theoretical lens that could not be utilized in the earlier report.

Conclusion

A central value of this research for Aboriginal people is the use of the conceptual framework of "studying up" through an examination of the knowledge, practices, and policy suggestions of scientific researchers, and people employed in government, and community health care and social service systems. Throughout colonial and neo-colonial periods, Aboriginal groups have critically questioned the ways in which health and social services are provided to them by the state. However, they have given limited consideration to how research that critically examines the production of scientific knowledge, government departments, and the range of health and social services mandated to address their needs, could shed light on relations between Aboriginal and non-Aboriginal people and on local and national health and social "problems" facing their communities.

In this dissertation I attempt research that may benefit Aboriginal peoples through the unpacking of a widely used stereotype, the "Indian problem" (see Section Three) that underlies the dominant discourse about Aboriginal people in Canada. I do this by situating these concepts within a historical and social context, and examine how in relation to the diagnosis FAS, the "Indian problem" is re-conceptualized through the bodies and behaviors of Aboriginal women and their offspring. I will offer a counter narrative to the master narrative of the "Indian problem" that I contend has been inextricably linked to claims that very high rates of FAS exist within the Canadian Aboriginal population. While I have no illusions that my research will spark a vast rethinking for Aboriginal peoples of the value of research, it does re-situate or broaden the discussion about how Aboriginal peoples and “Indian problems” are conceptualized in the larger Canadian context, including the ways in which knowledge is produced and interventions are generated and implemented. This dissertation seeks, therefore, to provide “thick description” about a set of particular health and social issues that Aboriginal peoples and the larger dominant Canadian society have identified as of great significance. It also shows how the location of the “problem” has been entirely taken-for-granted from the beginning, in large part because of a widely dispersed, ideologically infused discourse about Aboriginal women and the communities in which they live.

Section Two
HISTORICAL OVERVIEW OF THE EVOLUTION OF THE DIAGNOSTIC CATGEGORY "FETAL ALCOHOL SYNDROME" IN NORTH AMERICA

Introduction

In this section I discuss the production of first, the scientific knowledge associated with the assumed effects of alcohol use during pregnancy on the fetus and, second, the diagnostic category fetal alcohol syndrome (FAS). I do this through an examination of a controversy that has arisen among North American researchers that is best described as one of differing perceptions about the extent of the "FAS problem." It involves questions relating to etiology, risk, identification, and prevalence rates of conditions among different patient cohort including the unborn, neonates, infants, children, adolescents and adults. Currently standardized tools and measurements for diagnosing illnesses caused by gestational exposure to alcohol do not exist, and referrals to these diagnostic services that are available are difficult to obtain (Astley & Clarren 2000).

Medical assessments for FAS in Canada, as elsewhere, are expensive and labor intensive because ideally they involve a multi-disciplinary team of physicians and social workers. Due to the high costs of assembling diagnostic teams in a national context of overburdened provincial health care budgets, all provincial governments, to greater and lesser degrees, have been reluctant to allocate sufficient resources to meet the perceived patient demand that exists for FAS assessment. This has led to very few individuals in Canada, as elsewhere, being evaluated for, or diagnosed with FAS or alcohol-related birth effects (ARBEs). Diagnostic assessment of patients and the application of diagnostic criteria and classifications vary across clinical and research sites (Abel 1998a, Astley & Clarren 2000). Epidemiological evidence is inconclusive due partially to so few individuals being assessed and diagnosed, and because studies of prevalence and incidence rates have purposely targeted populations where maternal alcohol abuse is known to be high and rates are expected to be elevated (Abel 1998a).

Controversy and consensus over the "FAS problem"

As stated above, controversy has arisen among North American researchers about the extent of the "FAS problem." Of significant importance for my discussion is that the controversy has had little impact upon the knowledge production associated with FAS within Canada, in that Canadian researchers and clinicians generally accept the position held by those on one side of the debate. This position maintains that FAS and ARBEs are common, costly, and preventable (Streissguth 1997). The strongest supporters of this position are two well-known American researchers at the University of Washington School of Medicine, Ann Streissguth, and Sterling Clarren[1].

Medical researchers at the Dysmorphology Unit at the University of Washington School of Medicine where FAS was first described, have been key actors in the production of scientific knowledge about FAS. At the same time they have assumed advocacy roles for patients that embrace the idea of fetal rights and support services for families as part of their clinical and research strategies. For example, Sterling Clarren has for many years advocated for fetal rights and a "mothering from conception" prevention model (1981) and has recently referred to gestational alcohol exposure as "fetal alcohol torture syndrome" (2002). In her text, *Fetal Alcohol Syndrome: A Guide for Families and Communities* (1997), Ann Streissguth devotes considerable attention to the importance of advocacy for pregnant women[2] and persons with FAS/ARBEs. The role of patient and family advocates adopted by these researchers and similarly by some of their Canadian colleagues has allowed them to have significant influence in the larger discursive arena about substance use by pregnant women, and FAS. This influence has been central in their ability to successfully lobby governments for increased funding for FAS-related research, programming, and service development.

Members of the Washington group have had a long-term relationship with researchers in Canada, especially with those from the University of British Columbia. This north-south relationship located along the northern-Pacific coast partially explains why FAS has received significantly greater attention in western than eastern provinces of Canada. Other key FAS research groups in Canada are at the Universities of Manitoba and Saskatchewan and in Toronto at the Hospital for Sick Children and St Joseph's

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[1] Ann Streissguth is the Director of the University of Washington FAS Research Unit and Sterling Clarren is Director of the Infant Inpatient Services for Children's Hospital and Regional Medical Center and medical doctor for the University of Washington FAS Diagnostic and Prevention Network clinic.

[2] Advocacy for pregnant women in this context is really a form of advocacy for the fetus as the focus here is on "fetal health" and the goal is to prevent women from giving birth to alcohol-affected offspring.

Hospital. The majority of FAS research in Canada that is published in scientific journals has been generated from these four groups. However, because most of these researchers are practicing clinicians and teaching in medical schools, the number and range of their research studies and publications is quite limited, with some of the most visible and well-known FAS researchers in Canada having only one or two publications related to FAS[3]. A similar research/clinical/advocacy role to that put forward in the United States has been adopted by many of these individuals, some with more zeal than others, and there is a general consensus that the extent of "the FAS problem" in Canada is much greater than is currently estimated (Clarke 2001, Conry & Fast 2000).

The Controversy

In their understanding of alcohol teratogenesis and prenatal alcohol birth effects, the majority of Canadian researchers maintain a similar position to the one taken by Streissguth and Clarren. This position makes five basic claims: 1. gestational exposure to alcohol, even at "moderate[4]" levels, is sufficient to cause a unique pattern of structural and functional birth defects in offspring, now called FAS (Clarke 2001, Conry 1990, Streissguth 1997); 2. any amount of exposure to alcohol in-utero should be considered by pregnant women as potentially dangerous to the fetus because research has not determined that a "safe level" of exposure exists (Barr & Streissguth 2001, Streissguth 1997); 3. the actual prevalence and incidence rates of FAS/ARBEs are significantly higher than that currently estimated (Streissguth 1997); 4. the "normal" life course of an individual is altered in tragic ways when damaged from gestational exposure to alcohol occurs. Neurobehavioral damage and dysfunction is particularly injurious and is directly correlated with aggressive, antisocial, disobedient, emotionally disabled, impulsive, hyperactive, and insecure behavioral characteristics. The severity of this group of behaviors is compounded for those affected individuals who are not diagnosed before six years of age (Streissguth et al. 1997); and, 5. offspring who are exposed in-utero to

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[3] These individuals are generally quite busy with clinical and teaching responsibilities and for some of them recognition of their expertise comes mainly from these activities rather than from scientific publications. Generally they participate in numerous national and international conferences, workshops, and committees, and act as advisors or collaborators with federal and provincial government departments.

[4] I will discuss the different definitions of alcohol exposure in Chapter 5. "Moderate" is referred to a little as one ounce of alcohol per day.

alcohol but appear unaffected may experience difficulties at a later life stage due to undetected ARBEs (Streissguth 1997:66).

A second position argues that American researchers, particularly those involved in FAS research at the University of Washington, have created a "moral panic" in North America in connection with alcohol use by pregnant women (Abel 1998a, Armstrong 1998, Armstrong & Abel 2000, Golden 1999). Ernest Abel, Scientific Director of the Fetal Alcohol Research Center[5] at Wayne State University in Detroit is the researcher whose work is most associated with this position[6]. Abel and others, particularly sociologist Elizabeth Armstrong, argue five basic points: 1. the estimated prevalence and incidence rates of FAS have been exaggerated through a misrepresentation of risk and a continuing expansion of diagnostic boundaries (Abel 1998a, Armstrong 2000, Armstrong & Abel 2000); 2. the relatively low rate of occurrence of FAS among heavy drinkers means alcohol is a necessary but not sufficient cause of FAS (Abel 1998a:159); 3. alcohol abuse and not simply alcohol use is necessary for FAS/ARBEs to occur (Abel 1998a:13); 4. the characteristic physical and behavioral anomalies associated with FAS/ARBEs can occur apart from gestational exposure to alcohol, potentially contributing to over diagnosis or misclassification of individuals (Abel 1998a); and, 5. there is inconclusive evidence to suggest that FAS/ARBEs can be directly correlated with aggressive, antisocial, disobedient, emotionally disabled, impulsive, hyperactive, and insecure behavioral characteristics (Abel 1998a:138).

FAS as a vocation

To understand the discursive arena associated with the diagnostic category FAS, one must be aware that scientists such as Clarren and Streissguth, along with many of their American and Canadian colleagues, see their research as no less than a "vocation" or "calling" of significant scientific *and* moral importance for the larger society. Their meshing of research with advocacy is most probably the best visible indication of this. For example, in the preface to her text *Fetal Alcohol Syndrome: A Guide for Families and Communities* (1997), Streissguth situates the writing of her book within a larger

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[5] This is the first federally funded FAS research unit in the United States.

[6] The position is described in detail in his book, *Fetal Alcohol Abuse Syndrome* (Abel 1998a).

moral discourse of what a “just society” should do to address the issue of FAS. She writes:

> This book was written because it is essential and urgent that we as a society spend resources to attack this problem. Research on recommended practices and model programs must be carried out and replicated in community after community throughout the United States if we are to save future children from prenatal alcohol damage and prevent secondary disabilities in children already born with prenatal alcohol effects (1997:xxiii).

Streissguth reinforces her role as a scientist and an advocate by actively publishing and presenting her research in both scientific and non-scientific arenas. The dual role that she has actively fostered over the span of her career has allowed her to successfully draw the attention of governments and the lay public to FAS-related issues in North America and beyond. Her approach and that of others at the University of Washington has had significant influence on the roles and strategies for FAS knowledge production adopted by Canadian researchers, especially researchers at the University of British Columbia such as Christine Loock, Diane Fast and Julianne Conry.

Reassessment of the knowledge production and practices associated with FAS

Similar to Ann Streissguth, Ernest Abel has devoted a significant amount of his career to research of FAS-related issues. For nearly thirty years, he has prolifically researched and published on FAS issues, and during this time has gained significant recognition and respect as one of the early pioneers in this field. In recent years, Abel has published a series of journal articles that collectively assess the scientific literature on FAS (among these are, Abel 1995, 1997, 2001). In the latest edition of his text, *Fetal Alcohol Abuse Syndrome* (1998a), Abel re-evaluates his and other’s claims about FAS and uses this opportunity to challenge some of the commonly held assumptions appearing in the FAS literature about etiology, risk, prevalence rates, and birth outcomes.

The most controversial component of Abel’s argument is his position that alcohol abuse/addiction, not just alcohol use, is necessary for fetal damage to occur and for offspring to be born with FAS/E. Abel’s position directly challenges the one taken by Streissguth and others and critiques their claim that the estimated prevalence rates of FAS/ARBEs are only the “tip of the iceberg” of a much larger problem. In making his argument, Abel suggests that the diagnostic category FAS be changed to “fetal alcohol abuse syndrome" in order to focus attention on the specific group of women and offspring who are at risk.

In scientific circles in North America the position adopted by Abel receives less support among researchers than that taken by Streissguth and Clarren, however, because it is well researched and argued, it has been difficult for even those scientists who are highly critical of it, to ignore or out-right reject it. Outside of scientific arenas, Abel's position is highly criticized, and in some contexts it generates considerable anger, emotion, and outrage from individuals belonging to health and social service professions and from parent FAS advocate groups.

In 2000, Abel published a journal article with sociologist Elizabeth Armstrong that was highly critical of FAS researchers in the United States, particularly the research group at the University of Washington. The article followed an earlier publication by Armstrong in which she argued that the moral dimensions of the medical classification of FAS are not unique in that they resemble the evolution of other diagnoses whereby society's conception of the disease is weighted by moral, as well as biological realities (1998:2038). Armstrong argues that "moral entrepreneurship" is particularly strong in the discursive arena of FAS in the United States. This, she suggests, is evident in the decision by researchers and clinicians who dominate the field to frame the discourse around claims that high prevalence rates of FAS contribute to "social turmoil" and "moral disorder" and that alcohol use by pregnant women is therefore a root cause of a certain degree of societal distress (Armstrong 1998).

Armstrong's criticism has not gone unnoticed by FAS researchers in the United States, however it is her co-publication with Abel that draws the greatest amount of attention and criticism. In their article, Armstrong and Abel argue that a "moral panic"—an exaggerated concern about a perceived "social problem"—has been generated in the United States by inflated fear and anxiety about FAS beyond levels warranted by evidence of its prevalence or impact (2000:276). This, they suggest, grew out of societal perceptions about alcohol use and the current anti-alcohol/drug crusade in the United States that attributes rampant crime and the deterioration of inner cities to a breakdown in public morality in which alcohol and drug use are centrally figured (2000:276).

Armstrong and Abel argue that the emergence in the 1960s and 70s of a new social problem, the victimization of children and the associated medicalization of categories of child neglect/abuse, also came to be powerful signifiers of "America's moral decay." As a result public concern about high prevalence rates of abused child contributed to the emergence in North America during the 1990s of images of prenatal alcohol exposure as "child abuse in the unborn fetus" (Armstrong & Abel 2000:276-278).

Armstrong and Abel direct their criticism specifically at the group of researchers at the University of Washington who they argue fuelled a "subtle broadening of the problem" (2000:278). This, they suggest, occurred through an exaggeration of prevalence rates of FAS, diagnostic expansion, a distortion of etiology through an inflation of risk in relation to low threshold levels, and the "democratization" of risk that effectively masks the importance of lower socio-economic status in birth outcomes (2000). In their critique, Armstrong and Abel challenge the foundation upon which many of the scientists who dominate clinical FAS and prenatal alcohol exposure research have built their researcher/advocacy roles. They further critique the ways in which FAS-related studies are designed and implemented, and the way public policy and public health initiatives are developed.

Outline of the argument

In this section I discuss the various components of the debate within scientific circles around prenatal alcohol exposure and the diagnostic category FAS. Chapter Three begins with a discussion of the evolution of FAS in North America by examining the difficulties researchers and clinicians face in demarcating diagnostic boundaries and in applying classifications to different patient populations. Chapter Four examines the research challenges in producing knowledge about alcohol teratogenesis in exposed offspring. Chapter Five discusses FAS research within Canada and the identification of Aboriginal peoples as the group most at risk among the world's populations for FAS/ARBEs. Chapter Six examines clinical application of diagnostic categories associated with prenatal alcohol effects, and highlights issues of particular importance for Aboriginal populations.

Chapter Three
THE EVOLUTION OF THE DIAGNOSTIC CATEGORY “FETAL ALCOHOL SYNDROME”

Introduction

> *…people diagnosed with FAS can have IQs from well within the normal range to the severely mentally retarded range. The physical anomalies can be slight or quite striking. Some with FAS live fairly normal lives if given adequate and structured support throughout their lives, whereas others are severely impaired. The defects may or may not be apparent or easily diagnosed at birth. Although the manifestations of the damage might change with age, FAS never completely disappears and, as with many developmental disabilities, there is no cure, although there might be some amelioration in some individuals. FAS does not refer to signs of acute alcohol exposure or withdrawal at birth. Newborns can have blood alcohol levels high enough to affect acutely their central nervous system function and not have FAS. Newborns can also have no alcohol in their bloodstream at time of delivery but still have FAS. FAS is not a ‘drunk’ baby.*
>
> Committee to Study Fetal Alcohol Syndrome[1]
> Institute of Medicine (U.S.)

In this chapter I trace the evolution of the diagnostic category FAS from its original description in 1973 (Jones & Smith 1973) through to present day attempts to address issues of diagnostic reliability and validity. Over the past three decades interest in the teratogenic effects of in-utero alcohol exposure and resultant birth defects in exposed offspring have caused a disparate assemblage of scientific disciplines and activities to be linked together. In North America some medical schools have assembled groups of scientists in research units specifically devoted to alcohol teratogenesis and FAS/ARBEs that has opened up new discursive arenas that occupy the boundary areas between disciplines such as teratology, dysmophology, neuroscience, psychology, psychiatry and obstetrics. Collaborative efforts by researchers attempt to piece together information that cannot be produced in any one scientific discipline. As researchers attempt to answer fundamental questions about alcohol teratogenesis and human reproduction, specifically concerning etiology, risk, identification, prevalence,

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[1] Stratton et al. 1996:19.

prevention, and intervention they are challenged to modify or create new hypotheses and theories about the body and bodily processes, mind, cognition and behavior, and populations and probabilities.

Margaret Lock argues that a characteristic feature of modernity, particularly from the beginning of the 20th century, is the way in which experience and portrayal of reality is fragmented (1993:xxi; Frisby 1986). Increasingly the generation of scientific knowledge has occurred across differentiated disciplines and sub-disciplines that claim their methods as scientific and complete in assessing what counts as truthful (Lock 1993:xxi). In FAS-related research the differentiated scientific disciplines all stake claims to scientific integrity and "objectivity," however the knowledge that is generated does not intersect consistently to produce a neat or comprehensive picture (Lock 1993, Abel 1998a).

As the body of research about the teratogenic effects of alcohol on the fetus has grown, so too has controversy and disagreement over the significance of research findings and the ways in which to apply these findings to the circumstances of individual lives. Lock points out that sometimes interdisciplinary struggle over the signifying process itself can emerge "in that the units used for analysis—how the body is classified, framed, and measured, or segmented in order to explain it—generate debate and argument" (1993:xxii). She suggests that scientists from differing disciplines may disregard each other's work, and moreover may "selectively plunder, ignore, or actively dismiss subjective accounts as invalid" (Lock 1993:xxii). Lock adds that despite the fact that "objectivity" is sought in all of these approaches, the body is nevertheless carved up and interpreted differently by them (1993:xxiii).

To grasp the complexity of disciplines and training of scientific researchers that contribute knowledge about FAS, one needs only to peruse the indexes of scientific journals. The journal literature on FAS can roughly be divided into three areas: studies that examine pregnancy and alcohol use (the object of research being women and fetuses), studies involving persons diagnosed with FAS/ARBEs (the offspring of the women), and animal studies examining alcohol teratogenesis. The range of disciplines and sub-disciplines with which researchers in North America are associated include, obstetrics and gynecology, family and social medicine, pediatrics, psychiatry, psychology, genetics, addictions, nursing, teratology, neurobiology, dysmorphology, anatomy, epidemiology, public health, and physical therapy. While these are the most common disciplines that researchers have been trained in, this list does not represent the entire range of scientific disciplines involved in FAS-related research.

The introduction of a new syndrome

It is generally agreed that the initial report linking gestational exposure to alcohol and negative birth outcomes is an article published in 1968 by Paul Lemoine and his colleagues in Nantes, France. Lemoine and colleagues observed a cluster of features in 127 children born to alcoholic women who exhibited a similar pattern of physical anomalies, growth deficiency, and problems of comportment (the children were excessively lively, ceaselessly agitated and/or irritable) (1968). Because the link between alcohol use during pregnancy and birth defects had not been made prior to this time, Lemoine and his colleagues had difficulty finding a scientific journal that would accept their findings and publish their research. They finally published their work in an obscure local French journal and because of this their research remained hidden for some years from the larger scientific arena.

In the United States speculation began to occur during the 1960s that high rates of alcohol abuse among certain Native American communities was linked to birth defects and developmental delays in children (Pauley 1992:27). In 1973, American researchers at the University of Washington described a pattern of anomalies that had not previously been described in mainstream scientific literature. The description of eleven detailed case reports involving children of alcoholic women were presented by the researchers in two separate papers (Jones et al. 1973, Jones & Smith 1973). In the second of the two papers, David W. Smith, an eminent scholar of genetic and environmental birth defects, and his then-current research fellow, Kenneth L. Jones, named this pattern of anomalies "fetal alcohol syndrome" (FAS) (Jones & Smith 1973).

The clinical recognition of FAS in the professional literature mirrors the introduction of virtually every previously recognized multiple malformation syndrome. Normally the introduction of a new syndrome involves the description of a small number of case reports of individuals who "typically have a highly similar (but not identifiable) set of anomalies that is made unique from previously described syndromes by the inclusion of some very rare anomalies or by an unusual association of more common anomalies" (Stratton et al. 1996:70). The hallmark features of FAS are a characteristic set of facial features, evidence of growth deficiency, and evidence of structural or organic brain dysfunction (see Table 3.1). Of these anomalies, the "facial gestalt" is thought to be clinically unique and CNS dysfunction is considered the most significant (Stratton et al. 1996:71).

Table 3.1
Criteria for Diagnosis of Fetal Alcohol Syndrome
Developed by the Alcohol Study Group of the Research Society of Alcoholism[2]

Prenatal and/or Postnatal Growth Retardation
Weight, length, or head circumference below 10th percentile when corrected for gestational age.

Central Nervous System Dysfunction
Signs of neurological abnormality, developmental delay, or cognitive impairment.

Distinctive Facial Features with at Least Two of the Following Signs:
- Short Palpebral fissures
- Poorly developed philtrum
- Thin upper lip
- Flat midface
- Microphthalmia
- Head circumference below 3rd percentile

Generally the hallmark features that first describe a syndrome such as FAS remain part of the diagnosis, however the list of associated features is usually modified and revised over time by further clinical research (Stratton et al. 1996:71). As recently as 1996 the Institute of Medicine (IOM) in the United States wrote that a circular effect characterized the development of the diagnosis. They write:

> Experience with the FAS diagnosis remains somewhat circular at this time which is a typical problem in clinical syndromology and hardly unique to FAS. Clinical experts assert that certain patients have fetal alcohol syndrome and the abnormalities found in

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[2] Rossett 1980.

> those patients are then used to refine the diagnosis. A truer case definition will be established only when a reliable biologic marker for alcohol teratogenesis is found or when a diagnostic tool is developed that can demonstrate high sensitivity and specificity in identifying dysmorphic individuals who are exposed in utero to potentially teratogenic doses of alcohol (Stratton et al. 1996:71-72).

The expansion of symptoms, diagnostic classifications, and FAS experts

Shortly after the description of FAS in the research literature the diagnostic label underwent expansion in terms of symptoms and expertise (Armstrong 1998, Armstrong & Abel 2000). Articles exemplifying this often appeared in journals of medical specialties and delineated what authors thought were previously unrecognized symptoms of FAS (Armstrong 1998:2029). The articles, written mainly by American researchers, typically reported on individual case studies or small, non-random samples. Armstrong argues that this resulted in two things, the expansion of the criteria used to recognize and diagnose FAS, and the range of specialists who could claim authority to contribute knowledge of, and research on, FAS (1998:2029).

In reviewing the scientific research literature, Armstrong and Abel found that between 1973 to 1984, 1.4% of all the articles in journals listed by *Index Medicus* dealt with alcohol and pregnancy (2000:278). In contrast, fewer articles dealing with tobacco and pregnancy (0.9%) or narcotics and pregnancy (0.7%) were published during the same period (Abel & Welt 1986). An infusion of federal funding in the United States for FAS research helped to support many new initiatives leading to researchers in virtually every subspecialty of medicine responding to the new funding initiatives (Armstrong and Abel 2000:278). In a critique of diagnostic expansion, Armstrong and Abel argue:

> As attention to and anxiety around FAS and drinking during pregnancy grew, the clinical symptoms of FAS multiplied (Armstrong 1998)…physicians and researchers in a wide variety of subspecialties heralded with entrepreneurial zeal this ‘exciting new field’ (Clarren & Smith 1978) and the ‘new opportunities for research’…These new conditions [anomalies found by various researchers] were heralded as ‘a new feature associated with fetal alcohol syndrome’ (Azouz et al. 1993), a new symptom ‘not previously described in connection with fetal alcohol syndrome’ (Adebahr and Erkrath 1984), an ‘under emphasized feature in FAS’ (Crain et al. 1983), and ‘heretofore unreported symptoms’ (Johnson 1979)…More often than not, such reports were based on single isolated coincidences…[and] most of the ‘new features’ are so atypical they have only been seen in a single case of FAS and in fact are excluded from the most recent American diagnostic paradigm for FAS (Stratton et al 1996) (2000:279).

As a result of diagnostic expansion, new classifications such as fetal alcohol effects (FAE), and alcohol-related birth defects (ARBDs), were adopted in the 1970s and 1980s to describe the presence of alcohol-effects in the absence of the full-blown syndrome. These categories generated significant controversy because of their lack of specificity making it even more difficult to apply consistently across clinical settings than a diagnosis FAS.

FAE was originally developed to describe abnormalities observed in animal models, but was quickly adopted by clinicians to refer to children affected by in-utero alcohol exposure but who did not manifest the typical diagnostic features of FAS (Stratton et al. 1996:70). While FAE is a commonly used label, a formal diagnostic criteria for it has never been developed and therefore it is not officially recognized as a medical diagnosis (Streissguth 1997). The term “possible fetal alcohol effects” (PFAE) was suggested in 1978 by Clarren and Smith. However, the category created confusion because it was not clear if the “possible” modified the “alcohol” or the “effects.” When health care providers gave a diagnosis of PFAE, educators and parents reportedly dropped the “possible” as it undermined their efforts to access support services for these individuals. The term alcohol-related birth defects (ARBDs) was suggested by Sokol and Clarren in 1989 but did not prove to be clinically useful because it is an umbrella term without specific criteria.

Children labeled as FAE are typically of normal size and have some, but not all the facial anomalies and CNS dysfunction associated with FAS (Streissguth 1997:29). However, controversy over the degree of neurobehavioral dysfunction that patients with FAE experience is a central debate among researchers and clinicians. Originally the children were believed to experience less severe behavioral and cognitive dysfunction than persons with the full-blown syndrome, however in recent years a growing number of researchers and clinicians maintain that FAE involves similar CNS dysfunction as occurs with FAS (Streissguth 1997, Streissguth et al. 1997, Clarke 2001).

In a reassessment of diagnostic paradigms associated with FAS, the IOM argued that because of the problems involved in measuring exposure to alcohol, coupled with the difficulties inherent in quantifying or demarcating behavioral and cognitive problems, the precision of the term FAE had gradually been reduced (Stratton et al. 1996:70). Some researchers suggest that the term FAE should be abandoned altogether (Aase et al. 1995, Astley & Clarren 2000, Sokol & Clarren 1989), although this is unlikely to happen in North America in the near future as it is commonly used by researchers (see for example, Fast et al. 1999) and by health and social service professionals, judges, lawyers and lay persons.

Despite the significant difficulties in delineating diagnostic boundaries for FAE, PFAE and ARBDs and in identifying alcohol-affected individuals and patient populations who are associated with these classifications, the majority of researchers and clinicians in North America assume that the prevalence rates of FAE/PFAE/ARBDs are significantly higher than that of FAS. Prevalence rates of FAE/PFAE/ARBDs are generally estimated to be between 5 to 10 times the prevalence rate of FAS (Clarke 2001:68). The diagnostic difficulties associated with these categories are assumed to be the result of inadequate diagnostic tools and measurements and the likelihood of "false-negative" diagnoses—the exclusion of affected persons—rather than "false-positive" or over-diagnosis.

Early standardization of the diagnosis

In efforts to curb a perceived rapid expansion of clinical symptoms attached to the diagnostic category and to standardize the new diagnosis, the Fetal Alcohol Study Group of the Research Society of Alcoholism in the United States (Rossett 1980) developed a diagnostic paradigm based on the description originally given by Jones and Smith (1973). This paradigm has remained in use alongside more recently described paradigms and has three major categories of anomalies that collectively define the syndrome (see Table 3.1). Each individual anomaly refers to an example of commonly occurring abnormalities that are representative of the category to which it belongs (Abel 1998a:21). For a clinician to make a diagnosis using this paradigm, one characteristic, or two in the case of facial characteristics, must be present in each of the three major categories. An important feature of this paradigm is that a history of maternal alcoholism during pregnancy is not required for the diagnosis to be given, however it is preferred whenever possible as it strengthens the basis for the diagnosis (Clarren 1981, Abel 1998a:21). In a critique of this paradigm, Abel writes:

> The major bias connected with this paradigm is that it is more inclusive than exclusive, thereby increasing the likelihood of a "false positive" diagnosis (over-diagnosis). In other words, the possibility of inaccurately labeling someone as having

> FAS is more likely to be increased than decreased when using this paradigm. This bias arises because to qualify for a diagnosis a patient need only have one characteristic in the growth and CNS categories and two features in the facial dysmorphology category, no matter how mild those effects might be. Under this paradigm, an underdeveloped philtrum (the groove between the base of the nose and upper lip) has the same importance as mental retardation and greater importance than organ pathology, which is not even considered to be diagnostic. Although cardiac and limb defects are relatively common in FAS, this paradigm does not include them or any other organ pathology (1998a:21).

Abel's argument suggests that the correspondence between the classification's boundaries and the boundaries of the natural phenomenon that it represents are to a certain degree arbitrary decisions made by researchers about inclusion and exclusion of different signs of pathology within the paradigm. The exclusion of cardiac and limb defects and organ pathology apart from CNS damage, draws a specific diagnostic line. The characteristic facial feature and growth retardation associated with FAS together serve as visible physiological markers that can signify to diagnosticians that CNS damage which is non-specific to FAS is probably caused by in-utero alcohol exposure or that CNS damage that is not apparent at the time of assessment may be present.

In Canada virtually every FAS-related study has used this early diagnostic paradigm to assess persons for FAS (see for example, Asante 1981, Asante & Nelms-Matzke 1985, Conry 1990, Fast et al. 1999, Robinson et al. 1987, Smith et al. 1981) or involved persons already diagnosed based on this criteria (see, for example, Nanson & Hiscock 1990). As recently as 1999 researchers from the University of British Columbia (Fast et al. 1999) used versions of this paradigm (Clarren & Smith 1978, Sokol & Clarren 1989) to determine the percentage of occurrence of FAS/FAE in the youth population remanded to the Inpatient Assessment Unit of Youth Forensic Psychiatric Services in Burnaby, British Columbia.

Diagnostic paradigms

Several diagnostic paradigms currently exist for diagnosing FAS (Burd & Martsolf 1989, Dahaene et al. 1981, Loser 1995, Majewski 1981, Rosett 1980, Stratton et al. 1996, Vitez et al. 1984). Each begins with the premise that FAS is characterized by a pattern of anomalies rather than one single anomaly (Abel 1998a:26). Abel writes:

> This premise is implicit in the concept of a *gestalt,* which means the whole is greater than the sum of its individual parts. In other words, each of the individual parts that go into the diagnosis may be slightly unusual, but meshed together, this collection of

> slightly unusual features has something unique about it… Because it is the gestalt that diagnosticians rely on when making a clinical judgement, the need to operationally define what is or is not an abnormality is less important in the clinical setting than it is in the research environment, where such definitions are typically a sine qua non.
>
> In the laboratory, researchers are usually intent in breaking gestalts down to their individual parts. The goal is often to isolate each part of the gestalt and then figure out their recondite relationships. One of the first problems is deciding on whether a part is normal or abnormal (1998a:25)[3].

In attempts to address the problem of diagnostic variability and expansion, the IOM, under the guidance of an expert committee[4], introduced in 1996 a standardized set of diagnoses that would demarcate diagnostic boundaries but still encompass the range of effects associated with prenatal alcohol exposure. The goal was to introduce standardized guidelines approved under the authority of the IOM that could then be applied consistently across clinical and research settings. While the IOM revisions have been applied in some research studies and clinical settings in North America and elsewhere, considerable concern exists that the diagnostic paradigm is still not sufficiently sensitive to assure diagnostic accuracy and precision (Astley & Clarren 2000). Furthermore, while there is evidence of some use of the paradigm, it is not clear how often and how consistently the guidelines have been adopted in research and clinical practice.

A review of the IOM paradigm is important for this discussion as it illustrates the increasing complexity of FAS-related diagnostic guidelines and the attempts by clinical researchers to attach patient populations to the FAS category who do not meet the diagnostic criteria for the full blown syndrome. In the IOM diagnostic paradigm, five categories of patient populations are distinguished: 1. “FAS with confirmed maternal alcohol exposure” and including evidence of facial dysmorphology, growth retardation, and CNS dysfunction; 2. “FAS without confirmed maternal alcohol exposure” and

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[3] A shift in criterion can have a significant impact on who receives a diagnosis (Abel 1998a:27). For example, Streissguth and colleagues at the University of Washington are trying to determine if brain-imaging technologies can precisely detect structural or functional brain damage caused by gestational exposure to alcohol that can then be used in diagnostic assessments for FAS/ARBEs (see below). If their efforts are successful, it is likely that some individuals previously diagnosed with FAS/ARBEs may no longer warrant a diagnosis, and some individuals not previously identified will be detected.

[4] Joanne Weinberg, Professor of Anatomy, University of British Columbia was the only committee member based outside of the United States.

including evidence of facial dysmorphology, growth retardation, and CNS dysfunction; 3. “partial FAS” with confirmed maternal alcohol exposure, facial dysmorphology, and either growth retardation or CNS abnormalities; 4. “alcohol-related birth defects” (ARBD), the presence of congenital anomalies (e.g. cardiac, skeletal, renal, ocular, auditory) known to be associated with a history of prenatal alcohol exposure; and 5. “alcohol-related neurodevelopmental disorder” (ARND*)* with confirmed maternal alcohol exposure and evidence of CNS abnormalities (Stratton et al. 1996:76-77).

Table 3.2
IOM Criteria for Diagnosis of Fetal Alcohol Syndrome[5]

Category 1: FAS with confirmed maternal alcohol exposure

A. Confirmed maternal alcohol exposure

B. Evidence of a characteristic pattern of facial anomalies that includes features such as short palpebral fissures and abnormalities in the premaxillary zone (e.g. flat upper lip, flattened philtrum, and flat midface).

C. Evidence of growth retardation, as in at least one of the following:

- low birth weight for gestational age
- decelerating weight over time not due to nutrition
- disproportional low weight to height

D. Evidence of CNS neurodevelopmental abnormalities, as in at least one of the following:

—decreased cranial size at birth

—structural brain abnormalities (e.g., microcephaly, partial or complete agenesis of the corpus callosum, cerebellar hypoplasia)

—neurological hard or soft signs (as age appropriate), such as impaired fine motor skills, neurosensory hearing loss, poor tandem gait, poor eye-hand coordination

Category 2: FAS without confirmed maternal alcohol exposure
B, C, and D as above

The IOM diagnostic paradigm includes three important changes from earlier guidelines. First, they add the category “FAS without confirmed maternal alcohol exposure” in order to address those cases where gestational exposure to alcohol cannot be

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[5] From Stratton et al. 1996:76.

confirmed (e.g. the biological mother's drinking history is unavailable), and those for whom the exposure history is unclear (e.g. differing accounts of the biological mother's drinking patterns) (see Table 3.2). The criteria for Category 2 (Table 3.2) comes closest to those traditionally used in making a diagnosis of FAS because it reflects the reality that as many as 50% of children with FAS are in adoptive or foster homes when they are diagnosed, and because of this, information about their biological mother's alcohol use is commonly unavailable or unreliable (Abel 1998a:23 Aronson 2000, Burd & Martsolf 1989, Robert & Nanson 2000, Spohr et al. 1993, Streissguth & Randels 1988).

Table 3.3
IOM Diagnostic Criteria for Category 3,
Partial FAS with confirmed maternal alcohol exposure

A. Confirmed maternal alcohol exposure

B. Evidence of some components of the pattern of characteristic facial anomalies

Either C or D or E

C. Evidence of growth retardation, as in at least one of the following:
—low birth weight for gestational age
—decelerating weight over time not due to nutrition
—disproportional low weight to height

D. Evidence of CNS neurodevelopmental abnormalities, as in:
—decreased cranial size at birth
—structural brain abnormalities (e.g. microcephaly, partial or complete agenesis of the corpus callosum, cerebellar hypoplasia)
—neurological hard or soft signs (as age appropriate) such as impaired fine motor skills, neurosenory hearing loss, poor tandem gait, poor eye-hand coordination

E. Evidence of a complex pattern of behavior or cognitive abnormalities that are inconsistent with developmental level and cannot be explained by familial background or environment alone, such as learning difficulties; deficits in school performance; poor impulse control; problems in social perception; deficits in higher level receptive and expressive language; poor capacity for abstraction or metacognition; specific deficits in mathematical skills; or problems in memory, attention, or judgment.

A second change in the IOM guidelines is the dropping of the category FAE. Because of the controversy surrounding this category, the IOM replaced it with "partial

FAS" (see Table 3.3). In Category 3, gestational exposure to alcohol and the facial features are intrinsic to the diagnosis and individuals must have either small stature, a physically observable CNS anomaly, or some behavioral/cognitive disorder (Abel 1998a:24). In critiquing the Category 3 diagnosis, Abel writes:

> An added rationale for this category, the IOM said, was the need to have a diagnostic paradigm for identifying adults with FAS. Other paradigms were unable to do so reliably, it contended, because some of the salient characteristics associated with FAS in childhood, such as facial dysmorphia and growth retardation, often do not extend into adulthood. A Category 3 diagnosis could thus be made in the absence of good medical records of growth retardation or early infancy. However, this was its weakest rationale because the facial features so intrinsic to this diagnosis in children are usually not recognizable in adults. The paradigm is also far from explicit in its list of "Ps" and "Ds" [the behavioral and cognitive anomalies under category E]. For instance, what is "metacognition?" What are problems in "judgement?" How high is a "higher level?" The focus on "receptive" language is also dubious since most studies have found receptive language intact (1998a:24).

The third change in the IOM paradigm was the inclusion of issues of patient care and research into the formulation of Categories 2 and 3 (Abel 1998a:23). In discussing Category 2, "FAS without maternal alcohol exposure," the IOM committee suggested that because many patients with FAS are in foster or adoptive placements and their prenatal exposure histories are unavailable, it is unfair to deny them the clinical benefits of a medical diagnosis (Stratton et al. 1996:74). However, they argued that it seemed imprudent to combine these cases with those in the first category, "FAS with confirmed maternal alcohol exposure," when carrying out some forms of research, therefore they recommended that these cases be grouped separately (Stratton et al. 1996:74-75).

In delimiting Category 3 the IOM factored in issues of patient care and research in reference to the diagnostic label. Three terms were put forward, "probable," "partial," and "atypical" to be used as a prefix to FAS (Stratton et al. 1996:75). The term "probable" was rejected because the committee considered it to denote uncertainty about the etiology of the condition and because of concerns that appropriate services or reimbursement for these services would not be made for a "probable" condition (Stratton et al. 1996:75). The term "atypical" was rejected because it had recently been discarded by the DSM-IV and because the committee did not believe that the patients in Category 3 were "not typical," but rather they believed that all of their signs and symptoms were typical of FAS. The term "partial FAS" was decided upon, although with reservations because of concern that "partial" could be mistakenly understood to imply less severe, however the committee believed that of the three categories "partial" best reflected the IOM's intention (Stratton et al. 1996).

Category 3 was designed by the IOM to "include people with signs and symptoms attributable to significant prenatal alcohol exposure and who need medical, social services, and other attention" (Stratton et al. 1996:75). The IOM stated that Category 3 should act as a "holding" category as a means to defer a diagnosis of Category 1, "FAS with confirmed maternal history of alcohol exposure"…"until more data collection or evaluation, including documentation as to whether behavioral and cognitive abnormalities persist over time, can support a more definitive diagnosis" (Stratton et al. 1996:75). The IOM committee argued that the diagnosis should be "flexible" and evolve to be consonant with new data and could be used to categorize such patients for future study and understanding the condition (Stratton et al. 1996:78).

The introduction of issues of patient care and research are indicative of the advocacy role embraced by many researchers and of the desire to "hold" and monitor patient populations that are believed to be alcohol-affected but do not meet the criteria for the full blown syndrome. Central in this process is the pathologization through arguments of prenatal alcohol damage of an increasing number of individuals who appear "normal" in their physical appearance, but who exhibit behavioral "problems" that are generally understood as socially inappropriate or deviant, and/or may be attributed to environmental influences or an alternative underlying pathology.

Diagnostic reliability and validity

Over the past twenty-five years, diagnostic paradigms for FAS/ARBEs have ranged from minimalist, such as the guidelines introduced by the Fetal Alcohol Study Group[6] (Rossett 1980) to more inclusive, such as that introduced by the IOM (Stratton et al. 1996). The hallmark features described by Jones and Smith (1973) that originally defined the syndrome have remained relatively stable in each of the paradigms. In clinical practice and research studies however, the exact definition of each feature has

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[6] Related diagnostic guidelines are Clarren and Smith (1978) and Sokol and Clarren (1989).

remained vague with high variability from clinician to clinician when making decisions as to whether a finding is normal or abnormal (Clarren 1998:141, Abel 1998a, Astley & Clarren 2000). For example, one study reported a one hundred percent failure rate to accurately diagnose the syndrome in a cohort of newborns who were born in a large teaching hospital in Dallas, Texas (Little et al. 1990).

Confusion or difficulties in applying diagnostic terminology consistently across clinical research sites and studies is also common. This is illustrated for example, by the following description of diagnostic categories used in a study by Streissguth and colleagues. They write:

> For this report, PFAS (partial or probable FAS) and FAS are combined. Fetal Alcohol Effects (FAE) and PFAE (possible or probable FAE) are terms that have been used clinically to apply to individuals who manifest some, but not all of the characteristics of FAS, but were exposed prenatally to significant alcohol. The terms FAE and PFAE, as they have been used by Seattle dysmorphologists since 1974, *are* consistent with the new diagnostic category of ARND (Alcohol Related Neurodevelopmental Disabilities) suggested by the IOM (Stratton, Howe, & Battaglia, 1996). For this report, the FAE and PFAE categories are combined (Streissguth et al. 1997:28 emphasis in text).

As indicated by this description, diagnostic categories across paradigms are commonly interchanged with one another, especially as the number of paradigms increase and as researchers attempt to talk to one another across clinical and research sites and disciplinary divides.

For a new diagnostic category to have scientific integrity it must achieve and maintain diagnostic reliability and validity, the scientific hallmarks of any diagnostic paradigm (Young 1995). The anomalies that collectively make up FAS, however, are not individually diagnostic (Abel 1998a:20), meaning that each anomaly is found in children born to abstinent mothers and to mothers who use substances other than alcohol (Clarren et al. 1987, Hingson et al. 1982), or are part of syndromes with different etiologies (Zuckerman & Hingson 1986). Several syndromes with features such as growth deficiencies and facial anomalies that are suggestive of, but different overall, are easily confused with FAS. These include Aarskog syndrome, Williams syndrome, Noonan's syndrome, Dubowitz syndrome, Bloom syndrome, fetal hydantoin syndrome, maternal PKU (phenylketonuria) fetal effects, fetal dilantin syndrome, and fetal toluene syndrome

(Stratton et al. 1996:79, Clarke 2001:75). Other syndromes are confused with FAS based on their similarities in complex cognitive and behavioral profiles, although the external phenotype is not really similar to FAS. These include, fragile X syndrome, velocardiofacial syndrome, Turner's syndrome, and Opitz syndrome (Stratton et al. 1996:79).

From the outset these issues raised significant concern among researchers and clinicians about the reliability and validity of the diagnostic category FAS. For example, following the first article describing FAS (Jones & Smith 1973), a number of researchers questioned the parameters of the diagnostic description (Armstrong 1998). Some challenged Jones and Smith to define what they meant by "severely chronic alcoholic" women (Sturdevant 1974). Others criticized the data for being uncontrolled and retrospective (Mankad & Choksi 1976), and yet others questioned whether a "similar pattern" of defects among the original eleven cases on which the diagnosis was based did in fact exist (Johnson 1974). These early debates quickly led to a range of research projects that attached themselves to the new diagnosis and to an increasing exchange of ideas and findings across a growing number of disciplines (Armstrong 1998).

Diagnostic reliability

Diagnostic reliability means that a diagnostic paradigm "induces a diagnostician to (correctly) label a disorder when he observes it in a given patient on different occasions (*test-retest reliability*), and it induces multiple diagnosticians to give the same diagnosis to the same patient on a given occasion (*inter-rater reliability*)" (Young 1995:102). Test-retest reliability, Young states, is especially important for diagnosing disorders where symptoms oscillate or fluctuate over time, such as occurs with FAS (1995:102).

By delineating the particular features to be stressed, the diagnostic criteria operationalize the steps that are used in making a diagnosis. Their design is typically comprehensive and general in order that clinicians can apply them at any point in the patient's history. In the creation of the diagnosis the components that are used, such as the characteristic symptoms, are selected because good inter-rater agreement can be achieved for these specific symptoms. Once criteria are developed, their reliability can be assessed "objectively" through well-designed clinical studies that examine inter-rater or test-retest reliability. Statistical methods for measuring reliability have reached a mature state, and consensus has been reached by nosologists that reliability coefficients at a minimal level of 0.5 or 0.6 are acceptable, while coefficients of 0.7 through 0.9 are preferable (Stratton et al. 1996:64-65).

Abel points out, that despite hundreds of case reports and hundreds of clinical research and epidemiological studies, the inter-rater reliability of the various diagnostic paradigms for FAS has not as yet been tested (1998a:25). Determination of test-retest reliability is more typical in FAS research but is complicated by the fact that many of the features associated with FAS, such as the facial features, behavior, and degree of growth retardation change in the normal course of development (Abel 1998a:25).

Two German studies using the early FAS diagnostic paradigm found that the reliability of the diagnosis over time was problematic. In the first study, forty-four German children diagnosed with FAS in early childhood were reassessed ten to fourteen years after the original assessment. Researchers found that at the time of follow-up, 70% (31/44) had only “mild” expressions of the syndrome, and 20% (8/44) could no longer be identified as having FAS. Only ten percent of the original sample (5/44) was still recognizable as having FAS (Spohr et al. 1994 in Abel 1998a:25). A second study (Ernhart et al. 1995 in Abel 1998a:26) reported that seven out of eight children previously diagnosed with FAS during infancy no longer warranted the diagnosis at four years of age. Abel concludes that the test-retest reliability of differing diagnostic criteria for FAS is not very high, and it is unclear whether this is because of inherent weaknesses in the diagnostic paradigms, or because features may be more plastic than was previously thought (1998a:26).

Diagnostic validity

Validity is used to evaluate diagnostic criteria to determine whether or not what is being agreed upon is relevant to the conditions being examined (Abel 1998a26). This ensures that diagnostic criteria “contain components that are clinically meaningful and that lead to correct inferences about the nature of the pathological process” (Stratton et al. 1996). For example, if nosologists were to use height as a criterion for diagnosing mental retardation because it can be measured in a reliable manner, they would be choosing a criterion that had excellent reliability, but questionable validity (Stratton et al. 1996:65).

Typically validity is divided into three components. Face validity means that the selected criteria conform to common sense in that it includes features that are familiar to most clinicians and are based on some consensus that they are beneficial as diagnostic criteria. Construct validity is when a diagnosis and its criteria are believed to conform to a conceptual construct or theory. In making a diagnosis of FAS one of the major components of its construct validity is the documentation of exposure to alcohol. The third category is predictive validity, which assists clinicians in making some prediction about the future. This prediction may involve decisions about treatment or guidance about prognosis (Stratton et al. 1996:65).

Young (1995) points out that the three types of validity compose a hierarchy with face validity being situated on the lowest rung. Face validity is the most easily compromised by contingency such as a shared cultural bias that leads experts to pathologize behaviors that are normative within certain ethnic communities (Young 1995:105, Abel 1998a). The next in the hierarchy is predictive validity "since it is generally a product of statistical operations and in principle at least, is less vulnerable to contingency" (Young 1995:105). Construct or independent validity allows the strongest claims, particularly when it is based on biological evidence (Young 1995:105).

The strongest evidence supporting the validity of the FAS diagnosis is its construct validity (Abel 1998a:26). Researchers agree that facial characteristics arise from the same embryonic tissues that give rise to the brain. On the basis of construct validity, "one would expect the more aberrant the facial features, the greater the insult to the brain and behavior—a relationship that has, in fact, been repeatedly noted in the context of FAS" (Abel 1998a:26, see for example Autti-Ramo et al. 1992, Iosub et al. 1981, Majewski 1981, Streissguth et al. 1978).

Diagnostic validity, Abel argues, can also be discussed in relation to alcohol use and pregnant women. He writes:

> …from the standpoint of validity, we can be reasonably certain in our predictions that someone characterized as an alcohol abuser will develop liver damage and experience marital instability and poor job performance (U.S. Department of Health and Human Services, 1993). If she becomes pregnant, her children are likely to develop birth defects. We can be just as certain someone characterized as a moderate drinker will be more highly educated, have higher socioeconomic status, lower parity, stronger social networks, and typically will be living a healthier lifestyle than either alcohol abusers or

> abstainers (Mills & Graubard, 1987; Skog, 1996). Where ARBEs are concerned, we can be reasonably confident alcohol abuse is involved, and even more confident moderate drinking is not (Abel 1998a:18).

Abel argues that because it is not alcohol per se but its abuse that leads to the pattern of anomalies, "fetal alcohol abuse syndrome" is a more appropriate diagnostic term than FAS (1998a:7).

Improving diagnostic sensitivity and specificity

Reliability and validity are closely connected. Young states that "when the reliability of diagnostic criteria and technologies is low, the validity of the disorders that they identify is moot. That is, without reliable resources, researchers cannot establish, to the satisfaction of their public [scientific and medical professions], the homogeneity (shared identity) of the aggregated cases (diagnosed patients) on which they are basing their statistical evidence" (1995:105). A solution to the problem is to establish an independent (construct) validity of the disorder in conjunction with some highly reliable signifier, consisting of a test and a telltale outcome (Young 1995:106).

The 4-digit diagnostic code

Researchers at the University of Washington are attempting to develop diagnostic tools with high degrees of sensitivity and specificity[7] based on the construct validity of FAS. Susan Astley and Sterling Clarren have introduced a quantitative approach for diagnosing FAS called the "4-Digit Diagnostic Code" (Astley & Clarren 1999, 2000). The four digits of the diagnostic code reflect the magnitude of expression of four key diagnostic features of FAS; growth deficiency; the FAS facial phenotype; brain damage/dysfunction; and gestational alcohol exposure (Astley & Clarren 2000). There are 256 possible 4-Digit Diagnostic Codes ranging from 1111 to 4444 and each 4-Digit Diagnostic Code falls into one of 22 unique clinical diagnostic categories. Astley and Clarren write:

> The 22 diagnostic categories are named to reflect the Likert ranking of each digit in the 4-Digit Diagnostic Code. The names are constructed sequentially from four terms: 'sentinel

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[7] Although these are very important developments in FAS research and diagnosis, as yet they have had limited impact upon patient populations in North America apart from those individuals involved in the developing and testing the diagnostic code. As stated above, most Canadian researchers and clinicians follow early FAS guidelines, therefore I will limit my discussion to a brief description and analysis about these new diagnostic paradigms.

physical findings,' 'neurobehavioral disorder,' 'static encephalopathy,' and 'alcohol exposure status' (Astley & Clarren 2000:402).

The 4-Digit Diagnostic Code is designed "to meet the needs of a broad range of professionals in an equally broad range of settings" (Astley & Clarrren 2000:401). Astley and Clarren claim that they have designed a highly sophisticated but user friendly method of diagnosis that potentially can meet the growing demand for diagnostic assessments and to address the problem of diagnostic reliability.

Diagnostic assessments using the code involve a series of measurements, testing, and gathering of information aimed at ranking patients in each of the four categories on a continuum from "no evidence" to "clear evidence." Precision measurements are used in assessing growth deficiency and facial features such as the use of digitized facial photographs that are analyzed using image analysis software (SigmaScan 1996) (Astley & Clarren 1996; Astley et al. 1999). An age-appropriate battery of tests in the areas of intelligence, adaptation, academic achievement, language and neuropsychology are given to patients and are assessed by a multidisciplinary team (Astley & Clarren 2000:405). Alcohol exposure is ranked according to the quantity, timing, frequency, and certainty of exposure during pregnancy. The case definitions differentiate "four clinically meaningful exposure groups" that are ranked according to level of exposure: 1:confirmed absence of exposure; 2:unknown exposure; 3:confirmed exposure, but level is low or unknown; and 4:confirmed high exposure (Astley & Clarren 2000:407).

According to Astley and Clarren, the inter and intra-rater reliability in randomly selected patient files of 20 subjects was 100% at their FAS clinic at the University of Washington. In a examination of their six FAS regional clinics and the core University of Washington clinic, a 94% (15 of 16 patients) match across all four digits, and a 100% match on the exact diagnostic category was reported. The difference of coding in the 16th patient was attributed to human error in measuring and not to a problem with the coding system (Astley & Clarren 2000).

Astley and Clarren argue that the 4-Digit Diagnostic Code can be used to correctly diagnosis individuals of all ages and ethnic groups who present across the full spectrum of exposure and outcomes. This is possible, they argue, because they have developed age-, "race-," and gender-adjusted anthropometric and psychometric measures.

They also argue that this method of diagnosis "can be taught to a wide array of healthcare and social service providers, thus greatly expanding the availability of diagnostic services" (2000:409).

At the time of their publication, multidisciplinary clinical teams from six states in the United States and three Canadian provinces had been trained to use the coding system (Astley & Clarren 2000, Clarke 2001). In summing up the benefits of the 4-Digit Diagnostic Code, Astley and Clarren write:

> The 4-Digit Diagnostic Code presents with many strengths. It offers an intuitively logical digital approach to reporting outcomes and exposure that reflects the true diversity and continuum of disability associated with prenatal alcohol exposure. Preliminary assessments of precision, accuracy and power [statistical significance] appear to be greatly increased over the 'gestalt' method of diagnosis. This can be attributed, in large part, to the use of objective, ordinal and continuous measurement scales, specific, comprehensive case definitions (Polit and Hungler, 1995), and the use of a multidisciplinary clinical team approach…The 4-Digit Diagnostic Code serves as a standardized, descriptive language that will allow clinicians and researchers to communicate clearly and objectively the exposures and outcomes of their patients (2000:409).

The efforts of Astley and Clarren are based on the assumption that a quantitative approach to diagnosis and the use of precision measurements will increase diagnostic reliability and validity while simultaneously meeting the challenge of providing standardized diagnostic tools to be used by a broad spectrum of medically trained researchers and clinicians. They also suggest that the code can be used in "active and passive screening and surveillance efforts" in other contexts. For example, currently the 4-Digit Diagnostic Code is being used to screen all children entering foster care in one county in Washington State (Astley & Clarren 2000:409).

Quantification, as pointed out by Daston, presupposes a moral commitment to a certain form of sociability among colleagues who may never meet face to face, and who may differ from one another in nationality, skill, training, assumptions, and/or material resources such as laboratory equipment (1993:10). Quantification is believed to filter out local knowledge such as individual skill and experience, and local conditions because there is agreement by the scientific collective over time and space as to what is being understood (Daston 1993:10). Quantification "is not to secure individual conviction, but rather to secure the acquiescence of a diverse and scattered constituency" through systematic erasure of local detail that creates the impression of the uniformity of nature (Daston 1993:10-11).

Daston's point is that "impersonality and impartiality are cultivated by quantifiers as much for moral as for functional reasons" (1993:12). For example, in proposing the 4-Digit Diagnostic Code, Astley and Clarren state that the benefits of their diagnostic paradigm is that it solves the problem of misclassification of patients by controlling "meaning variance" (Young 1995). They write,

> For trained clinicians, dysmorphologists, or clinical geneticists, 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. But the features are not dichotomous, that is either normal or clearly abnormal. Rather, the features, and indeed the history of alcohol exposure, all range along separate continua from normal to clearly abnormal and distinctive. In the absence of accurate, precise, and unbiased methods for measuring and recording the severity of exposure and outcome in individual patients, diagnoses will continue to vary widely from clinic to clinic (Chavez et al. 1988, Aase 1994) (Astley & Clarren 2000:400 emphasis added).

They argue that misclassification can lead to inappropriate patient care, increased risk for "secondary disabilities," such as becoming a school drop out, drug and alcohol problems, and criminal behavior, and missed opportunities for primary prevention (Astley & Clarren 2000:400).

Misclassification, Astley and Clarren add, can also lead to inaccurate estimates of incidence and prevalence rates which if one reads their argument closely, implies that they are concerned about under, not over, diagnosis. They write,

> Inaccurate estimates thwart efforts to allocate sufficient social, educational, and healthcare services to this high-risk population and preclude accurate assessment of primary prevention intervention efforts. From a clinical research perspective, diagnostic misclassification reduces the power to identify clinically meaningful contrast between groups. Non-standardized diagnostic methods prevent valid comparison between studies (2000:400).

Astley and Clarren claim that the use of quantification, precision measurement, and computerized analysis filters out local knowledge and individual experience and skill thereby demarcating a series of diagnostic boundaries that map the range of "true diversity and continuum of disability associated with prenatal alcohol exposure" (2000:409).

Fetal alcohol spectrum disorders and the FAS behavioral phenotype

In contrast to the efforts by Astley and Clarren, their colleague Ann Streissguth has directed her attention away from two of the original criteria and focused on alcohol exposure and its relation to behavioral and cognitive dysfunction. Unlike the expansion of diagnostic categories attached to the coding system developed by Astley and Clarren, Streissguth and colleagues have introduced a new category, Fetal Alcohol Spectrum Disorders (FASD) that encompasses patients diagnosed with FAS, FAE, alcohol-related neurodevelopmental disorders (ARND) and static encephalopathy, alcohol exposed (Streissguth & O'Malley 2000, Barr & Streissguth 2001). Streissguth contends that a unique "behavior phenotype" for FASD exists, and that early diagnosis is essential in ameliorating behavioral problems in affected offspring (1997). Because of this she has directed her attention toward developing screening tools with high sensitivity and/or specificity in order to identify alcohol-exposed offspring[8] particularly newborns, and to identify individuals with a typical FAS "behavioral phenotype." By bringing all alcohol-affected patient groups under a single category associated with a "unique behavioral phenotype," Streissguth is suggesting that similar brain damage is present across the spectrum of patient groups.

Streissguth and her students at the University of Washington have over several years gathered data from hundreds of parents and caregivers of people of all ages falling under the category of FASD (1997:126). From clinical examinations of 78 behavioral characteristics they have developed the "Fetal Alcohol Behavioral Scale" (FABS) which consists of 36 behavioral characteristics used in screening for FAS/FAE (see Table 3.4) (Streissguth et al. 1996). In research involving persons diagnosed with FAS/FAE they found that the "average" person with FAS/FAE is characterized by three times as many of the 36 FABS items as the average person without fetal alcohol damage.

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[8] Barr and Streissguth introduced the Frequency-Binge Aggregate Score (F-BAS), a screening tool for determining levels of alcohol use by mothers and to identify offspring for follow up FASD assessment (2001).

Table 3.4[9]

Items in two general categories of the Fetal Alcohol Behavioral Scale (FABS)

Difficulty Modulating Incoming Stimuli: Poor Habituation

Gets over stimulated in social situations, as in a crowded room, or among strangers.
Overreacts to situations with surprisingly strong emotional reactions.
Displays rapid mood swings set off by seemingly small events.
Possesses poor attention spans.
Has trouble completing tasks.
Tends to misplace things.

Poor-Cause-and-Effect Reasoning, Especially in Social Situations

Seems unaware of the consequences of his or her behavior, especially the social consequences.
Shows poor judgment in whom to trust.
Interrupts with poor timing.
Cannot take a hint; needs strong, clear commands.
Loves to be the center of attention; draws attention to self.

Streissguth argues that better understanding of the "qualitative aspects of the disease" can be useful in devising interventions for people with FAS/FAE across the life span (1997:126). She writes: "understanding the behavioral phenotype of FAS/FAE helps us listen to and interpret the behaviors we observe. Fortunately, articulate adults with FAS/FAE can help explain what it feels like to live with this disease. Their insights can help guide the interventions of parents, caregivers, and professionals" (Streissguth 1997:127).

In a recent presentation in Montreal, Christine Loock, a clinician and researcher from the University of British Columbia, reported that the term Fetal Alcohol Spectrum Disorder is becoming widely used by health care providers in British Columbia and other parts of Canada. The FAS behavioral phenotype is also increasingly considered in diagnostic screening and assessment which Loock suggests has the potential to allow Canadian clinicians and researchers to move beyond identifying only the "tip of the

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[9] From Streissguth 1997:126-127.

iceberg" of the FASD patient population that is typically identified. If the FABS can be proven to have a high degree of sensitivity and/or specificity this, Loock argues, will diminish the importance of the presence of facial features and growth retardation in patient assessment.

Magnetic resonance imaging studies

Related to her interest in the "behavioral phenotype" of FAS, Streissguth has also directed her attention to identifying particular biomarkers in the brain that could improve diagnostic reliability and sensitivity for FASD. In conjunction with colleagues at the University of Washington, she has engaged in a number of brain-imaging studies using magnetic resonance imaging (MRI) to determine if this form of imaging shows sufficient specificity and sensitivity to be used in diagnostic assessments. The group of patients used in these studies come from the same cohort of patients used in the development of the FABS. While preliminary findings suggest MRI may have diagnostic value, the research at this time is still inconclusive.

Important in this context is the attempt by Streissguth and others to move away from reliance on the other three diagnostic categories, facial features, growth retardation and alcohol exposure by delineating a "behavioral phenotype" that distinguishes CNS effects caused by prenatal alcohol exposure (1997:126). The independent validity of the category FASD and the use of FABS would be greatly improved upon, these researchers believe, if they could be applied in conjunction with a highly reliable signifier, in this case a recognizable alcohol-effected brain that is made visible through "objective" imaging and precision measurement.

Conclusion

The above discussion describes the evolution of the diagnostic category FAS as it took place in North America, particularly in the United States. As indicated by this discussion, FAS is the "product" or "achievement" of researchers, rather than a discovery of a corresponding natural phenomenon (Young 1995:121). Central in this process are a group of researchers at the University of Washington who strongly believe that prenatal alcohol effects are common in the North American population, and that with the creation of more sophisticated diagnostic tools and measurements they and other clinicians will be able to identify increasingly more individuals who are alcohol-affected. Embedded in this argument is the assumption that only the “tip of the iceberg” of the “FAS problem” is presently recognizable.

Young argues that diagnostic technologies can be an integral part of the historical formulations of the disorders that they identify and represent (Young 1995:107). An analogous point is made by Hacking in the context of laboratory science:

> Theories are not checked by comparison with a passive world with which we hope they correspond. We do not formulate conjecture and then just look to see if they are true. We invent devices that produce data and isolate or create phenomenon, and a network of different levels of theory is true to these phenomena…Thus there evolves a curious tailor-made fit between our ideas, our apparatus, and our observations (Hacking 1992:57-58 in Young 1995:107).

As pointed out by the IOM, the evolution of the FAS diagnosis remains circular in that criteria is used to identify patients whose characteristics—physical, cognitive, and behavioral—are then used to refine the diagnosis which will be used to identify new patients. From 1973 onward new hypotheses and theories about alcohol teratogenesis, the response of “the body” to in-utero alcohol exposure, and the impact on individuals and populations have been put forward, debated, refined, and at times, discarded. What the implications of this historical process are in relation to the practices of researchers and clinicians, and for individuals and populations in local and national contexts will be discussed in the remainder of this section, and in the broader historical and social analysis in the remainder of this dissertation.

Chapter Four
RESEARCH CHALLENGES AND THE PRODUCTION OF KNOWLEDGE ABOUT FETAL ALCOHOL SYNDROME

Introduction

In the previous chapter I discussed the difficulties scientists have experienced in delineating diagnostic categories and boundaries for prenatal alcohol effects and some of the controversies that have arisen in North America over the meanings attached to those categories. In this chapter, I resume my analysis of the differing perceptions of the "FAS problem" by continuing to compare and contrast the differing positions taken by two groups of American researchers. The first group, which includes Ann Streissguth and her colleagues at the University of Washington, has sought to raise awareness about the risks associated with prenatal alcohol exposure and to secure support and resources for FAS research and clinical services by claiming that FAS is a "common, costly and preventable tragedy" (see for example, Streissguth 1997). To support their position they emphasize that low threshold levels of alcohol exposure are potentially dangerous to the fetus, and that FAS is inherently universal in that no particular class, race, ethnic group, or any other socially constructed category of people is singled out as differentially affected if pregnant women in the group consume alcohol (Goode & Ben-Yehuda 1994, Thompson 1998).

The position taken by Streissguth and others at the University of Washington is framed by a heightened sense of moral urgency as it is implied within their arguments that tens or hundreds of thousands of "victims" of in-utero alcohol damage, most of whom are unidentified, live in the United States. Researchers such as Streissguth contend that "it is essential and urgent" that the American federal and state governments spend resources to "attack this problem" (1997:xxiii). For example, she argues that it is imperative that research on recommended practices and model programs for FAS be carried out and replicated "in community after community throughout the United States in order to "save future children from prenatal alcohol damage and prevent secondary disabilities in children already born with prenatal alcohol effects" (Streissguth 1997:xxiii).

In contrast, Elizabeth Armstrong and Ernest Abel argue that the approach taken by Streissguth and others, by the 1990s, resulted in FAS being transformed in the United States from an unrecognizable condition to one that is now characterized as a "major public health concern" (see, for example, Stratton et al. 1996) and as a "national health priority" (see, for example, Egeland et al. 1998). They argue that the "moral panic" generated by Streissguth and others is based upon an inflation of fear and anxiety about alcohol use by pregnant women and about FAS beyond levels warranted by evidence of its prevalence or impact. The exaggerated claims which support this "moral panic," Armstrong and Abel argue, have important implications for pregnant women and their offspring that are often masked by the moral sentiment that has been ignited (Armstrong & Abel 2000:280).

In this chapter I continue to examine the debates within North America that have framed the knowledge production about the teratogenic effects of prenatal alcohol exposure and FAS/ARBEs. I begin by discussing early research challenges in the production of knowledge about FAS in order to highlight some of the methodological difficulties and research limitations inherent in human studies. As part of this discussion, I turn my attention to studies that focus on levels and patterns of prenatal alcohol exposure, and arguments about the threshold level at which alcohol becomes dangerous to the fetus, the relationship of alcohol exposure to birth outcomes, and constructions of risk. In concluding the chapter, I discuss the ways in which understandings of universality and difference have been used to support various arguments about etiology, risk, and prevalence rates in light of the difficulties inherent in human studies of prenatal alcohol exposure and FAS/ARBEs. I examine three specific areas; the role of ethnicity, "race," and socio-economic status in FAS discourse, debates over the "history" of FAS, and the importance of animal models in the production of knowledge about FAS.

Challenges faced by researchers in early FAS studies

In the early development of knowledge and activities associated with the diagnostic category FAS, researchers were concerned not only with demarcating the diagnostic boundaries associated with prenatal alcohol effects, but were equally anxious to address a range of research questions related to the diagnosis. Researchers needed to support claims that there were risks associated with prenatal alcohol exposure in order to convince granting agencies that funding was necessary and justified for further research. The questions that were focused on in early FAS-related studies include: 1. Is alcohol teratogenic? 2. At what threshold level does alcohol become dangerous to the developing fetus? 3. What are the mechanisms through which the teratogenic effects of alcohol are produced? 4. What is the relationship between dose, timing, and pattern of exposure in producing prenatal effects? 5. Are the anomalies identified in offspring with FAS caused solely by gestational exposure to alcohol? 6. Are the anomalies, specifically behavioral and cognitive anomalies, permanent across the life span? 7. What role does the genetic make up of the mother and the fetus play in modifying the effects of gestational exposure? 8. What are the incidence and prevalence rates of FAS and ARBEs?

In early FAS research, scientists were faced with the reality that human studies would involve “long, complex, expensive years of research” to produce a set of “facts” that would legitimate and entrench diagnoses related specifically to prenatal alcohol exposure (Streissguth 1997:56). A central problem was the difficulty in confirming causal links between prenatal alcohol exposure and certain anomalies found in exposed offspring. For example, researchers had difficulty distinguishing the effects of alcohol teratogenesis from other factors because most pregnant women who abuse alcohol simultaneously consume other substances that are potentially harmful to the fetus such as nicotine, illicit, and licit drugs (Abel & Hannigan 1995, Abel 1998a, Tait 2000).

Researchers were also faced with the challenge of adjusting for a range of factors other than alcohol use that effect birth outcomes such as poor nutrition, poor overall maternal health, and environmental toxins and contaminants. Methodological constraints, such as researchers having to rely on self-reports by women about the timing, pattern, and level of alcohol use when pregnant, along with the difficulties in comparing this data across various study sites, inhibited their ability to generate conclusive evidence about alcohol teratogenesis and birth outcomes. Researchers were also faced with the challenge of diagnostic differentiation because the physical phenotypes and CNS dysfunction they associated with prenatal alcohol effects resembled those found in patient populations diagnosed with other disorders[1].

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[1] See Chapter Three for further detail about the disorders.

A specific challenge of FAS research in the years following the introduction of the diagnosis was, on the one hand, the need to conduct population or cohort-based studies and, on the other hand, the reality that only a small number of individuals, most of whom were infants or small children, were diagnosed with FAS. Although Jones and Smith first described FAS in 1973, the identification of larger cohorts of persons diagnosed with FAS for population-based research happened only years later. Even today in FAS research, there is a dearth of information about FAS/ARBEs across the life span, with very limited data existing for adolescent and adult populations (Tait 2003). This is mainly due to a lack of diagnosed cohorts, and most longitudinal or follow-up cohort-based studies in North America are based on data from a single cohort of individuals who were diagnosed with FAS by researchers at the University of Washington and then followed-up by them (see for example, Streissguth et al. 1985, Streissguth et al. 1996)[2]. Of the remaining follow-up studies of FAS patient populations in North America, individuals of Aboriginal ancestry are significantly over-represented (see for example, Streissguth et al. 1991), including in the single Canadian study by Habbick and colleagues at the University of Saskatchewan who examined mortality rates in a cohort of individuals previously diagnosed with FAS.

Studying prenatal alcohol exposure

> *A great deal of time and money is currently spent interviewing light drinkers and abstainers, while those who drink enough to be of interest are lumped together in a vast heterogeneous category of "heavier" drinkers. A more detailed study of heavier drinkers would enable us, for one thing, to arrive at a better idea of what we are talking about when we speak of "problem drinkers."*
>
> G. Knupfer[3]
> British Journal of Addiction

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[2] Lemoine and Lemoine published a follow-up study of 99 former patients from their 1968 study in France (Lemoine & Lemoine 1992).

[3] Knufer 1987 in Abel 1998a:2.

The myth that small amounts of alcohol are not dangerous to the unborn child is common. Many pregnant women want proof that having a drink actually does damage their baby…The burden of proof is coming up with the numbers that show X-amount of alcohol causes X-amount of damage…There is no known safe amount of alcohol consumption during pregnancy.

Tracey Remkes[4]
The Canadian Nurse, June 1993

Although the data strongly support a relationship of chronic high levels of maternal alcohol intake to the full FAS, what remains is whether there is a continuum of dose-response effects ranging from anatomic and behavioral changes at low to moderate maternal dose to full-blown FAS at high maternal doses, or if there are two or more thresholds resulting in degrees of impairment in function and structural malformation. As yet undefined is whether there is a LOEL [lowest observable effect level] for alcohol exposure in the fetus.

Committee to Study Fetal Alcohol Syndrome[5]
Institute of Medicine (U.S.)

A core question in FAS research is whether a "safe" level of alcohol exposure exists for the fetus. Many clinical researchers in North America maintain that even at low doses, alcohol exposure is potentially harmful to the fetus. For example, in an article published in February 2001, Barr and Streissguth argue that "there is no known low dose that appears to be safe for every pregnancy" (2001:283). In a review of the research literature on alcohol dose-effects, Abel found that researchers have a tendency to lean toward arguments that suggest relatively low levels of alcohol consumption by pregnant women can cause teratological effects (1998a:9).

Abel argues that several problems arise from this type of argument including how threshold levels are determined. He writes:

> Low dose-effects would be possible if teratological effects were conceived in terms of a monotonic dose-response relationship with the etiological agent. But there are no monotonic dose-response relationships in teratology or pharmacology. Instead, every substance has a "threshold" or *no observable effect level (NOEL)* for every response (Hutchings 1985). In teratology, dose-response relationships are generally "S" shaped-at relatively low doses there is no observable effect. If the dose is increased, a threshold is exceeded and an effect is triggered. Relatively small increments above that threshold

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[4] Remkes 1993.
[5] Stratton et al. 1996.

> trigger larger effects, until every response capable of being affected is affected and the organism is either severely disturbed or killed (Abel 1998a:9, emphasis in text).

This suggests that even if alcohol is present in the pregnant woman's system, it does not necessarily mean it will have a harmful effect on the fetus. Abel suggests that because individuals differ in their response to alcohol, this implies that there are inherent physiological susceptibilities to its effects (1998a). Wheeler argues that the influence of physiological, genetic, and environmental factors may cause the threshold dose to vary with each pregnancy (1993:194). This is reflected, for example, in the fact that some alcohol-abusing women have children that meet the diagnostic criteria for FAS, others have children who meet the criteria for partial FAS or FAE, and still others have children that are apparently unaffected (Abel 1998a, 1995, Streissguth & Martin 1983).

Averaging

In alcohol research, the easiest way to determine how much alcohol an individual drinks is to ask them how much they drink during a typical week or month, divide this amount by the appropriate number of days, which gives the "average number of drinks per day" (Abel 1998a:9). Typically, a single drink in North America contains about 0.5 ounces of alcohol, which is expressed as average ounces or "absolute alcohol per day" (AA/day). In most studies that look at alcohol consumption levels, a woman who consumes seven glasses of wine once a week, for example, is treated the same way as a woman who drinks an average of one glass of wine per day, even though their drinking patterns are very different (Abel 1998a:9). Abel argues that because averaging of alcohol consumption has been used in FAS/ARBE research, some study findings suggest a low threshold level at which alcohol use by a pregnant woman can have deleterious effects on the developing fetus. He writes:

> Although there are several research reports stating that drinking an average of two drinks a day can cause 'significant' effects on offspring, that average of two drinks often turns out to be the result of seven or more drinks on 1 day and the balance spread out over others. It is hardly ever two drinks a day, each day (Abel 1998a:10).

The measurement of "average drinks per day" therefore conflates very different consumption patterns amongst pregnant women.

Armstrong and Abel argue that only a handful of researchers have been forthright enough to clarify this issue in reporting their findings (2000:279). They further suggest that the "biomedical research community" involved in FAS research has continued to have a certain pragmatic interest in framing the issue in terms of low thresholds. Lower thresholds, Armstrong and Abel argue, suggests a greater number of potential "victims" (the proverbial "tip of the iceberg"), leading to greater national panic and guilt and thus to higher research budgets to do something to combat this "national health problem" (2000:279). This bias in the medical literature, they add, has been magnified in the popular press and in lay pregnancy manuals and public health educational materials, in which the distinction between the number of drinks per drinking episode and number of drinks per week or month is largely glossed over, and a tendency exists to present any type of alcohol consumption as dangerous (Armstrong & Abel 2000).

Definitions of drinking

Abel argues for an unifying principle to operationally define the terms used to characterize the low levels of consumption believed by some researchers to cause FAS/ARBEs (1998a:13). In his review of the literature, he points to several discrepancies that exist around terms such as "moderate" and "heavy" drinking (1995, 1998a, Wheeler 1993). Abel writes:

> Some [studies], for instance, defined *moderate* as an average daily consumption ranging upward from one and one-half drinks a day (Little, Asker, Sampson, & Renwick 1986) to an average of three drinks a day (Kaminski, Franc, Lebovier, Du Mazubrun & Rumeau-Roquette 1981). A *drink* is defined [in the United States] as 12 ounces of beer, 5 ounces of wine, or 1.5 ounces of 80-proof distilled spirits. Although heavy drinking implies greater consumption than moderate drinking (Abel & Kruger 1995), in many cases the operational definition of *heavy* is less than what others call moderate. For example, the threshold for heavy drinking has been defined in some studies as an average of 0.89 drinks a day (Day et al. 1989), 1 drink a day (Shiono, Klebanoff & Rhoads 1986), or 2 drinks a day (Virji 1991)(Abel 1998a:13-14).

Abel adds that because the concept of "heavy" drinking is used as a standard referent in research studies, differences in criteria for heavy drinking undermine comparisons between studies that rely on this concept, and are especially troublesome for estimating the incidence of FAS among heavy drinkers (1995:440). He further suggests that labeling a pregnant woman a "heavy drinker" may affect the readiness of some researchers or clinicians to identify her child as having FAS (1995:440, Abel & Sokol 1991).

The concept of "heavy" drinking is based also on the amount of alcohol in a single drink, however, this amount varies from country to country. For example, in the

United States a standard drink is equivalent to about 1.6 standard drinks in the United Kingdom (Abel 1995:440). Abel suggests that this difference may, for example, account for the percentage of "heavy" drinkers in countries, such as Scotland, being high but their incidence rate of FAS being low. Therefore, differences in alcohol content of a drink between countries make international comparison as to the relationship between the amount of drinking and FAS, or the relationship between heavy drinking and FAS, very tentative (Abel 1995:440). Abel argues that by clarifying our understanding of the amounts of alcohol involved, it also allows us to examine previously reported studies with a more critical eye (1998a:14).

Binge drinking

Despite differing opinions about the threshold at which maternal alcohol use becomes dangerous to the fetus, a general consensus exists among researchers that binge drinking—drinking large quantities of alcohol in short spans of time—and, especially chronic binge drinking, is more dangerous for the developing fetus than consumption of the same amount of alcohol over an extended period of time (Abel 1998a:160, Stratton et al. 1996). Chronic binge drinking extends the period of alcohol toxicity over a longer duration of pregnancy and as a result, exposure is more likely to occur during critical periods of fetal development (Abel 1998a). Abel argues that since the potential for damage is related to binge drinking, there is little point in describing drinking in terms of "average drinks per day," because that statistic yields virtually no information about binge-like patterns of consumption and therefore little about risk. He suggests that to be biologically relevant "researchers would be well advised to abandon the average-drinks-per-day measure in favor of one that reflects maximal drinking per occasion and its frequency" (Abel 1998a:161).

Self-Reporting

Alcohol quantification is complicated by self-reporting of alcohol intake, variability of drinking patterns, and beverages of differing strength (Walpole et al. 1990:297, Ernhart et al.1988). Self-reporting of alcohol use is the research methodology used to determine levels of alcohol consumption and patterns of alcohol use by pregnant women. The accuracy of self-reports is a concern in connection with the design, conduct, and interpretation of studies of FAS/ARBEs (Ernhart et al. 1988, Robles & Day 1990).

Controversy exists over when women are most likely to report accurately their prenatal alcohol use. For example, Rosett and Weiner suggest that women may report more accurately their use of alcohol while pregnant than afterwards because of concern for the well-being of the fetus (1984, Hingson et al. 1982). By contrast, Ernhart and colleagues found that under-reporting appeared to be more common among pregnant women than over-reporting (1988). Others suggest that a greater social stigma regarding alcohol use during pregnancy may lead to an underestimation of reported drinking patterns by women (Celentano & McQueen 1984, Erhnart et al. 1988, Duimstra et al. 1993). The accuracy of self-reports in FAS research may also be compromised by the length of time from the birth of the child to the collection of a woman's drinking history when she was pregnant (Robles & Day 1990). In some studies this has been as long as eighteen (Robinson et al. 1987) to twenty (Williams & Gloster 1999) years after the birth of the child.

Ernhart and colleagues argue that role expectations are a central concern for women who are asked to give self-reports of prenatal alcohol use (1988). They state:

> Role expectations for pregnant women are probably more stringent than for nonpregnant women. The onus of drinking in pregnancy may thus be sufficiently great so that tendencies toward denial and under-reporting are particularly strong. When a woman has had a reasonably healthy child and when sufficient time has passed for her to distance herself from the behavior, the need to protect herself through underreporting is reduced and a more valid report may be obtained (Ernhart et al. 1988:506).

Ernhart and colleagues suggest that under-reporting has a significant impact on the creation of public policies that inform public health education about the risks associated with drinking during pregnancy (1988). They argue that the use of under-reported information in setting threshold figures, for example, confounds the task of physicians advising patients about "safe" levels of alcohol use during pregnancy. Ernhart and colleagues add, in extreme cases "the uncertainty regarding a threshold for alcohol-related birth defects may affect decisions regarding therapeutic abortions for alcoholic women" (Ernhart et al.1988:510).

Threshold levels and birth outcomes

Abel argues that because biological definitions of "abnormal" generally rely on forcing continuous variables into categorical classifications, bias in research and diagnosis is inevitable. What researchers label as "abnormal" is often influenced by their preconceptions and expectations (1998a:26-27). In research discussing threshold levels of prenatal alcohol exposure, Abel points out that deviation from the norm in exposed offspring is typically defined in terms of a statistically significant difference between an experimental group and a control group. However, statistical significance does not necessarily mean biological significance (Abel 1998a:27). For example, in critiquing a study by Streissguth and colleagues, Abel writes:

> …in discussing their finding that infants whose mothers drank moderately during pregnancy were less easily aroused than infants whose mothers did not drink, the authors interpreted this difference as a harmful effect associated with drinking. However, their criterion for "low arousal" was that these infants were "very easy to console, frequently self-quiet, and seldom very upset or excited" (Streissguth, Barr & Martin, 1983a). Rather than being negative attributes, most parents, I believe, consider these as signs of a "good" baby.
>
> That statistical significance does not mean biological significance is reason enough to carefully scrutinize interpretations of any association between drinking during pregnancy and prenatal outcomes. Such scrutiny is especially necessary when behavioral outcomes are being assessed because these interpretations, as noted in the context of self-quieting and excitement, are susceptible to the experimenter's personal bias. Unless these interpretations and the methodologies on which they are based are reviewed and discussed candidly and incisively, we will have no basis on which to agree whether the diagnostic paradigms we use for deciding who has a problem are valid or if the solutions for correction or prevention of that problem are reasonable or effective (1998a:27).

In a later study, Streissguth and colleagues (1989, Streissguth & Randels 1989) reported that "moderate" or "social" drinking by pregnant women, defined in the study as above 1 ounce of absolute alcohol per day on the average, tripled the risk in 7-year-olds of having an IQ score lower than 85, and also impaired performance on memory tests, problem solving, visual/motor performance, and academic skills. Abel argues that if extended to the general population, their claim that "moderate" drinking by pregnant women can result in a decrease in IQ of this magnitude, would constitute a major national health crisis in the United States (1998a:130). He again questions the methodology used by Streissguth and colleagues, particularly the practice of averaging alcohol consumption and thereby "lumping" women with major alcohol-related problems with women who drink moderately, a concern echoed in a similar critique of the Streissguth study made by Russell (1991).

Abel points out that even a single occurrence of misclassification can give an otherwise statistically non-significant association between drinking and pregnancy statistical significance. To make his point, he refers to a study by Greene and colleagues (1991a, 1991b), in which the exclusion of the single FAS/ARBEs case in the study cohort meant that the statistically significant association between prenatal alcohol exposure and cognitive dysfunction ceased to be significant. Abel writes:

> Especially noteworthy is the fact that although the child excluded was clearly identifiable as having FAS, his mother's score on the MAST and her drinking during pregnancy self-report indicated no alcohol-related problems and negligible alcohol consumption. This incongruity reflects the difficulty researchers have avoiding misclassifying alcoholic women as moderate or light drinkers based on self-reports. However, when such misclassification is clearly evident, studies should follow the rectitude of Greene and his co-workers in recognizing that children with FAS, by definition, must have had an alcoholic mother and removing them from analyses examining the effects of moderate drinking (1998a:130).

As illustrated in the above discussion, several methodological problems exist in the FAS literature that examines alcohol use by pregnant women. Added to these difficulties are a number of other factors that impact upon the health of the pregnant woman and upon birth outcomes, such as inadequate maternal diet and under-nutrition, tobacco use, environmental contaminants, high parity, poly-drug use, and alcohol-related illness, that when present compound the risks associated with prenatal alcohol exposure.

Universality and difference

Since its initial description in 1973, FAS has been described in patient populations in most countries of the world (Stratton et al. 1996). The recognition of similar patterns of birth defects in diverse populations is especially important in the evolution of a diagnostic syndrome because it implies that the category and the features in it correspond to a natural phenomenon that transcends the local clinical or research setting in which it is "discovered." This contributes significantly to the diagnosis gaining scientific and medical recognition and legitimacy.

The difficulties experienced by researchers in standardizing diagnostic categories and assessment measures and tools, and in determining the precise risks associated with differing amounts and patterns of alcohol use by pregnant women has not inhibited most researchers from arguing that FAS/ARBEs are "common, costly, and preventable[6]" conditions. Their claims are based on an argument that maintains that all fetuses share a similar physiology, as do all pregnant women, and because of this similar birth outcomes are produced by prenatal exposure to alcohol independent of socioeconomic, “racial,” ethnic, geographical or historical divides. When this claim is made in conjunction with the argument that “low” or “moderate” levels of alcohol exposure are dangerous to the developing fetus, the number of women and fetuses “at risk” expands significantly.

Supporting this argument is the “history” of FAS which has been pieced together mainly by researchers at the University of Washington. These researchers have reinterpreted historical documents, literature, and art work, some reaching as far back as Biblical times, through a lens of prenatal alcohol exposure and FAS in their efforts to illustrate that FAS is not a new disorder, but one that has existed where and whenever pregnant women have consumed alcohol. They invoke their reinterpretation of these historical artifacts, as “evidence” that the “risk” to the fetus resulting from alcohol use by pregnant women is universal and that this risk was recognized to a certain degree by at least some individuals or groups prior to 1973.

Teratology research involving animal models has been invaluable as a way for researchers to address some of the challenges in producing knowledge about alcohol teratogenesis and FAS. Animal studies allow scientists to factor out a range of environmental and maternal characteristics that impact upon fetal development and birth outcomes, such as poor maternal health, tobacco use, and poverty. In this way a type of biological reductionism occurs in which evidence about the maternal/fetal dyad is reduced to physiological processes that produce particular birth outcomes. Information gained from animal studies can then be compared with human studies. This is made possible because agreement amongst researchers exists that animals and humans are in some way comparable. In early FAS research, teratology studies with animal models provided a means by which researchers, in a relatively short period of time, could produce conclusive data about alcohol teratogenesis that could then be compared with less conclusive data from human studies.

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[6] Two recent presentations, both given in Montreal, one given by Ann Streissguth in September 2002 and the other given by Christine Loock in December 2002 both described FAS in this way.

Ethnicity, “race” and socioeconomic status

Constructions of a maternal/fetal dyad that is susceptible to alcohol teratogenisis across ethnic, “racial” and socioeconomic divides is commonly invoked in scientific and lay circles to support the claim that all pregnancies are equally “at risk” when prenatal alcohol exposure occurs. For example, the public health message in North America at once isolates women in its message and at the same time lumps all pregnant women together as being equally “at risk” if they consume alcohol. In most studies in the United States, researchers in their portrayals of FAS have chosen to emphasize its “universal nature” and downplay difference, even though the majority of their patient populations come from lower socio-economic and minority ethnic and “racial” groups.

In FAS research, ethnicity initially was used as a marker to argue that FAS transcended social divisions. In the article where Jones and Smith first describe FAS, they emphasize that the eight cases they present come from three different ethnic groups with the common denominator being that each child has an alcoholic mother. They write:

> Eight unrelated children of three different ethnic groups, all raised in the fetal environment provided by an alcoholic mother, had a similar pattern of craniofacial, limb, and cardiovascular defects with prenatal-onset growth deficiency and development delay (Jones & Smith 1973:1270).

Armstrong points out that what they fail to acknowledge is that the original “eight children, and virtually all the other children they and others subsequently examined, were seen in hospitals serving a predominantly lower socio-economic status population” (1998:279, Abel 1998a).

Socioeconomic status

Socioeconomic status has also been used as a marker that FAS transcends social divisions. Arguments that children with FAS are born to women across the socioeconomic spectrum are common (Jones et al. 1974, Streissguth et al. 1985). For example, in three presentations given recently on different occasions by leading North American FAS researchers, each presenter singled out as a risk group where alcohol use during pregnancy is of particular concern, “well-educated women over the age of thirty”[7]. This claim, however, contradicts what is generally found in studies of women whose offspring are diagnosed with FAS (Abel 1995, 1998a, Armstrong 1998). Research evidence suggests that children of lower-income women who abuse alcohol are at significantly greater risk for prenatal alcohol effects than those children born to middle or high income women who abuse alcohol[8] (see for example, Asante & Nelms-Matzke 1985, Bingol et al. 1987).

The response of some researchers to the over-representation of individuals from lower SES groups in studies of FAS is to suggest that prenatal alcohol effects are “more pronounced” in populations from lower socio-economic classes (see for example, Streissguth 1990). What this suggests is that damage occurs universally, however factors characteristic of lower socio-economic groups exasperate the effects. For example, in the study by Streissguth and colleagues that examines the effects of “moderate” prenatal alcohol exposure on child IQ and the appearance of learning problems, they argue that two “environmental conditions” when occurring in conjunction with maternal drinking, compound the effects of prenatal alcohol exposure so that the combined effects are larger than would be predicted if they did not occur, or by either one alone (Stressiguth et al. 1990).

The two factors identified by Streissguth and colleagues are lower paternal education and larger numbers of young children in the household, both of which are associated in their study with low SES families. They report that despite experiencing learning problems stemming from CNS dysfunction originating from in utero alcohol exposure, children with middle class backgrounds and moderate levels of alcohol exposure were more often within the “average range of intelligence” than children from lower socio-economic status families with similar prenatal alcohol exposure histories.

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[7] The presentation were given by Ann Streissguth, Kieran O’Malley (a colleague of Ann Streissguth’s) and Canadian researcher, Christine Loock. There are no research studies that have been conducted with this group of women and therefore, the claim remains at the level of speculation.

[8] An argument can be made that the over representation is due to study methodology and easier identification and access to impoverished “at-risk” alcoholic women and children than to those women and children in higher income groups. While this is partially true, researchers (Abel & Hannigan 1995, Abel 1998a, Nanson 1997) have found that factors associated with poverty such as poor nutrition, poly-drug use, poor maternal health, smoking, and environmental contaminants that negatively impact upon pregnancy and birth outcomes in women of lower-socioeconomic status increase the risk of having an alcohol-effected child.

Among children with low SES, Streissguth and colleagues report that the effects caused by prenatal alcohol exposure were more "pronounced" and a larger proportion fell into the "subnormal IQ range" (1990:667).

Difference in susceptibility

In research studies where differences between pregnant women has been invoked, it has generally been done so with reference to the concept of "race." These arguments are based on the assumption that a racially based genetic difference makes the pregnancies of women from some "racial" groups more biologically susceptible to alcohol exposure. As stated in Chapter One, "race" has been invoked primarily as an explanation to suggest that Aboriginal women are at increased risk for having a child with FAS (see, for example, Asante 1981, Aase 1981). However, a small number of studies in the United States have focused on African American women and "race" as a compounding risk factor in poor pregnancy outcomes (see, for example, Sokol et al. 1986). Abel and Hannigan argue that research suggesting that a lower threshold of risk exists for Aboriginal or African American women as compared to Caucasian women, mistakenly invokes different genotypes among "racial" groups as an explanation. They argue that the appearance of increased risk for women belonging to these "racial" groups stems from any number of methodological problems in data collection of levels and patterns of prenatal alcohol exposure, and from differing social drinking patterns between different groups of women (Abel & Hannigan 1995:447).

In a review of the research literature, Abel found that certain "racial" groups, Black (African American), Aboriginal (Native American, Canadian First Nation, Inuit, Métis), and Hispanic were over-represented in the research literature on FAS. However, when examined in relation to low SES, this variable, rather than genotype, was the critical factor that tied together the women and children across the various research studies. Abel writes:

> The major determinant for the occurrence of FAS is poverty. FAS is more common among minorities in the inner city of the United States, not because some minorities are genetically at-risk for FAS but because a high percentage of minority women eke out an existence at incomes below the poverty line (30.4% for African Americans compared to 8.8% for Caucasians). Poverty, not genotype, provides the kind of host environment that exacerbates alcohol's toxic actions…Although twin studies indicate genotype can be a factor in susceptibility to FAS, it is individual difference in

> genotypes rather than population differences that seem to be involved. This, in turn, suggests that population studies comparing racial genotypes for rates of alcohol metabolism or susceptibilities to alcoholism will be less fruitful in preventing FAS than studies which identify the socioeconomic risk factors contributing to FAS (1995:441).

In his review, Abel identifies a number of risk factors associated with low SES and heavy alcohol consumption, including smoking, poor nutrition, poor health, increased stress, and use of other drugs. While none of these individual factors produces FAS, he suggests that it is highly possible that they exacerbate the effects of heavy alcohol intake, resulting in FAS. Abel argues that the relatively low rate of occurrence of FAS among heavy drinkers means alcohol is a necessary, but not sufficient cause of FAS (1998a:159). To better understand this Abel has developed a model that identifies predisposing behavioral, social and environmental factors, called "permissive conditions" that create the differential reaction to alcohol responsible for the occurrence/nonoccurrence of FAS/ARBEs. In his analysis, Abel tries to understand how permissive conditions produce or "provoke" the physiological changes needed to increase vulnerability to alcohol's toxic effects. He writes:

> Without an explanation as to how permissive factors create a biological environment that increases or decreases the susceptibility to alcohol's effect, identifying such factors would mean little more than acknowledging the fact that the alcohol abuser does not live in a vacuum. By characterizing these personal and environmental conditions in terms of their biological consequences, a model such as the one proposed here offers a heuristic explanation as to how these factors produce the sufficient conditions that act in conjunction with alcohol to produce FAS (Abel 1998a:159).

The permissive factors identified by Abel include levels and patterns of drinking, with binge drinking being particularly harmful, individual genetic susceptibilities of the mother and the fetus (as yet unidentified in the research literature), tobacco use, maternal health status, maternal age, parity, family planning, psychiatric co-morbidity, culture/ethnicity, and environmental factors[9].

Universality and public interest

The universalizaton of FAS through dissociation from ethnicity, "race," and socioeconomic status of the diagnostic category has helped to generate public interest in FAS prevention. Currently in many regions of Canada and the United States significant

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[9] The permissive factors identified by Abel will be discussed in greater detail in Chapter Eight.

attention is given to FAS, especially in connection with prevention. The public, mainly through media reports and public awareness campaigns, has increasingly come to associate all alcohol use by pregnant women as risk behavior. The public has also been educated to believe, especially in western and northern regions of North America, that they share responsibility for an economic, social, and moral investment in reducing alcohol use by pregnant women and in eliminating FAS. This perception grows out of an “abstinence is best” public health message; a belief that lower thresholds of maternal alcohol exposure are dangerous to the fetus; claims that alcohol teratogenesis is the leading cause of preventable birth defects; and, arguments that individuals with FAS/ARBEs over their life span experience enormous physical and psychological suffering and impose a significant social and economic burden on the larger society. The one exception to this in North America is the province of Quebec, where the provincial government has adopted a more tempered message similar to that in most European countries which states that pregnant women who choose to drink alcohol should drink in moderation.

The medicalization of politics

Armstrong and Abel argue that the language of "democratization" generally characterizes discourse on most “social problems” such as “child abuse,” “alcoholism,” “cocaine addiction,” “teenage pregnancy,” and “domestic violence,” even though a significant overrepresentation of these “problems” occurs among certain visible minorities and lower socioeconomic status groups (Abel 1995, Wagner 1997, Swift 1995). They argue that problems such as FAS are “typically scaled up into the middle and affluent classes to draw greater attention to the problem at hand and to overcome any charges of racism, classism, elitism, or any other accusation of discrimination” (Armstrong & Abel 2000, Wagner 1997). Armstrong and Abel contend that the universalization of FAS masks the extent to which the “moral panic” generated as part of the dominant discourse on FAS stems from social unease about changing gender roles, class relations, and “racial” difference (2000, Armstrong 1998).

Armstrong and Abel argue that the “moral panic” created around alcohol use by pregnant women and the universalization of FAS has diverted attention away from social inequality by displacing blame for poor pregnancy outcomes to individual mothers

(Armstrong & Abel 2000:280). They suggest that this is one more way in which women in their childbearing and child-rearing roles are held responsible for the "future of society" (Armstrong & Abel 2000:280). Armstrong argues that a dominant theme of "personal responsibility" in American thinking about health and illness, coupled with intense gender agitation brought on by the demands of women for equality in the work place has contributed to the "democratization" of FAS in the United States (1998). She suggests that the paradigm of maternal-fetal conflict, implicit in much of the discourse on both FAS and abortion, underscores an image that women cannot be trusted to act in ways that are assumed to be "natural," and innate to their status as "mothers" or "potential mothers" (Armstrong 1998)

Armstrong agues that this shift embodies social unease "not only over the changing roles of women, but social distress about women's growing propensity to act in ways that were independent of and perhaps in opposition to the maternal role as socially constructed" (1998:2037). In her criticism, Armstrong takes particular aim at Sterling Clarren and his position that to prevent FAS "the notion of mothering from conception, not birth, must be fostered in the non-pregnant" (Clarren 1981:2439). Armstrong argues that Clarren's position and others like his "enmesh women further in a cult of motherhood." She writes:

> …concern about drinking before as well as during pregnancy was something of a bellwether for the "preconception" movement that is gaining prominence today and that exhorts women to begin changing their diets, taking vitamin supplements and avoiding alcohol, tobacco and other substances when they are *considering* becoming pregnant. Thus, the ritual of prohibitions of pregnancy now extend to women who are not more than potentially pregnant (Armstrong 1998:2037-2038 emphasis in text).

The creation of the "history" of fetal alcohol syndrome

In the article by Jones and Smith (1973) where they first introduce the category FAS, these authors begin with a "historical review" in which they suggest that an association between "maternal alcoholism and faulty development of offspring" is alluded to in early Greek and Roman mythology, present in ancient Carthaginian custom, and reported in 1834 to the British House of Commons (Jones & Smith 1973). In a 1978 article in *The New England Journal of Medicine*, Clarren and Smith begin their discussion of FAS with an epigram from the *Old Testament* and the "Book of Judges." In the verse an angel speaks to a woman, telling her, "Behold now, thou art barren, and barest not: but thou shalt conceive, and bear a son; Now therefore beware, I pray thee, and drink not wine nor strong drink, and eat not any unclean thing" (Judges 13:7).

This biblical verse is now one of the most commonly cited references given as "evidence" in scientific and lay publications and public presentations by FAS experts that an awareness of the dangers of alcohol use by pregnant women existed in biblical times (see for example, Smith 1979, Krous 1981, Wilson 1981, Streissguth 1997). By invoking the notion of universality in that the bodies of pregnant women and fetuses have been equally susceptible to the effects of gestational exposure to alcohol across historical periods, and that in some contexts at least the risk posed by drinking was acknowledged, allows researchers to situate FAS squarely within the realm of biological pathology, and sets it apart from the controversy and inconsistencies that continue to plague research and clinical application of FAS related diagnoses.

In North America it is now common practice for researchers to refer to "evidence" in their writing and presentations that FAS has "existed" and the dangers of alcohol use by pregnant women "recognized" during different historical periods. For example, in a recent presentation to a group of psychiatrists and researchers in Montreal given by Christine Loock from the University of British Columbia, she spent a considerable amount of time discussing the face and body of a woman who appears in a painting by Henri de Toulouse-Lautrec, *Au salon de la rue des Moulins* [In the Moulins Street Salon]. In the painting, which was completed by de Toulouse-Lautrec in 1894, this particular woman stands out from the other four women in the painting because she is dressed more conservatively and appears pregnant. The reason why Loock chose to focus on this particular painting and woman is because it appeared on the cover of *Le Concours Médical* on April 23, 1994, with the question: "Quel est votre diagnostic? [What is your diagnosis?]. The answer, fetal alcohol syndrome, was given by Dehaene and Stressiguth and later was published in the journal as an appropriate diagnosis for the woman (1994:1271-1273).

From this point onward, de Toulouse-Lautrec's painting was considered another piece of historical "evidence" that FAS "existed" prior to its recognition in the early 1970s. Interpretations of the woman's presence in the brothel were also created.

Generally it is argued that the woman's situation, that of "an unwed pregnant prostitute" typifies the inability of persons with FAS to lead "normal" lives and their vulnerability to exploitation. In her discussion of the painting, Loock argued that Toulouse-Lautrec's painting reflected "reality" as he depicted exactly what he saw at the brothel. She argued that the painting captured the reality of two things; the "obvious" features of FAS that must have been present in the young woman's face and her vulnerable social position as a pregnant prostitute. The association between FAS and prostitution was then raised later by Loock in a discussion of the growing concern by her and her medical and social service colleagues who work in Vancouver's Downtown East Side, about the number of women with FAS who are involved in illicit street activities and who are giving birth to large numbers of children believed to be alcohol-affected[10].

In a review of the FAS literature, Armstrong (1998) found numerous references in scientific journal articles citing "historical evidence" that FAS is not a new discovery, but rather, a rediscovery by 20th century researchers. Armstrong argues that the biblical reference from the "Book of Judges," as well as other "historical evidence," held significant moral weight in the early discourse on FAS as they functioned to refute the dearth of empirical evidence of a correlation between drinking during pregnancy and poor birth outcomes. She writes:

> Those medical observers who sought to locate FAS in the later twentieth century were faced with the task of explaining why, when women have been drinking and giving birth for thousands of years…an association between drinking and birth defects had never been, in their collective memory, commonly acknowledged…the early FAS entrepreneurs believed that there was very little to suggest that doctors or lay people had noted such an association, much less drawn firm conclusions about drinking during pregnancy and birth outcomes. Thus, observers of FAS in the late twentieth century cast their nets far back into the past, creating a history of FAS that relied on questionable "evidence," in order to persuade their audience that prior human experience *had* demonstrated the ill effects of drinking during pregnancy (Armstrong 1998:2034).

Armstrong argues that a "rhetoric of rediscovery" in FAS discourse took on a life of its own and any historical mention of alcohol, pregnancy and birth defects was made inappropriately into hard evidence (1998:2033). For example, Armstrong (1998) and Abel (1984, 1997b) found that when placed in the context of the larger scripture, the

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[10] Very few women, if any, who would fall within this group of women referred to by Loock have been medically assessed or diagnosed with FAS/ARBE.

prohibition against drinking referred to in the “Book of Judges” was not based on an awareness of the dangers of drinking during pregnancy. Rather it was about the child’s status as a Nazarite, with the consumption of intoxicants being one of many cultural prohibitions. In a set of articles, Abel (1984, 1997b, 1999b, 2001) critically questions the claims that a link between maternal alcoholism and birth effects had been made at various historical moments by different groups of people. For example, he found that in ancient Greece, Rome, and Carthage, the belief was not that drinking during pregnancy harmed the child, but that intoxication at the moment of conception led to deformity.

Armstrong argues that the particulars given of the “historical evidence” is commonly wrong, such as incorrect dates being cited for when statements were first made (Streissguth 1978, Streissguth 1977, Lindor et al. 1980, Turner 1978), and the rituals and customs of one group being falsely attributed to another (Streissguth 1978). Such historical evidence, she writes, is repeated uncritically from one article to the next, with errors proliferating throughout the literature (1998:2033).

Teratology and animals studies

As with other types of medical research, animal models have been used in FAS research to examine questions that cannot for ethical, economic, or pragmatic reasons be addressed either in part or in whole through human studies. In this context, researchers use controlled laboratory experiments with animal models to systematically monitor and measure the bodies and behavior of different species in order to produce knowledge about the teratogenic effects of in-utero alcohol exposure. Physiological, cognitive, and behavioral characteristics found in humans are correlated with those observed in different animal species. While this is not unique to FAS research, data from animal studies, for example, the “FAS face” which has been produced in a mouse model (Sulik et al. 1981), are powerful signifiers that alcohol is sufficient to produce certain birth outcomes in exposed offspring, mouse or human, when all other variables are controlled for.

As noted in Chapter One, teratology, the science of birth defects, was formally introduced as a sub-field of research at approximately the same time as Jones and Smith (1973) described FAS in the research literature. The introduction of FAS raised many questions in scientific and lay circles concerning alcohol teratogenesis. Researchers, such as the group at the University of Washington, were anxious to provide answers because the “discovery” of FAS and the growing concern about the effects of prenatal alcohol exposure had widespread implications for pregnant women and their offspring. Specialists in teratology and dysmorphology, including David W. Smith, also recognized prenatal alcohol effects as a research issue that could emphasize the societal importance of their work, and simultaneously generate funding and interest. This, they believed, was especially true because the potential for fetal exposure to alcohol was high in many countries, and the resulting birth defects viewed as preventable.

In teratology research, the use of animal models in controlled environments creates phenomena that never, or rarely occur in a pure state in cohorts of pregnant women who abuse alcohol. Animal models allow for a type of biological reductionism in which evidence such as physiological and behavioral changes can be compared and debated apart from other influences such as poor maternal health, nutrition, and poly-substance use, and then compared to studies describing human physiology and behavior. This is made possible because of agreement amongst researchers for example, that rats and humans are in some way comparable, and by shared laboratory objects such as standardized animal models, artifacts, apparatuses, skills, practices, and standards. In early FAS research, teratology studies with animal models provided a means by which researchers, in a relatively short period, could produce conclusive data about alcohol teratogenesis that could then be compared with less conclusive data from human studies.

Over the past thirty years, teratology research has produced vast amounts of information about alcohol teratogenesis that both supports and enhances information acquired through clinical and epidemiological research. Researchers, such as Streissguth, argue that teratology studies have demonstrated the following: 1. alcohol can impact upon, and disrupt, the developing embryo and fetus; 2. the genetic make-up of both the mother and fetus modify the severity and effects of alcohol exposure; 3. the teratogenic effects of alcohol are not limited to heavy chronic exposure, more moderate and episodic exposure can also produce deleterious effects; 4. prenatal alcohol exposure can cause CNS dysfunction in offspring; 5. brain damage can occur without physical manifestations and from lower doses and frequency of exposure; 6. disrupted brain development caused by prenatal alcohol exposure can cause aberrant behavior in the offspring; and 7. ARBEs, such as those that contribute to aberrant behaviors, last into adulthood (Streissguth 1997:66-67).

Ernest Abel (1998a), while acknowledging the important contribution of animal research, suggests that caution be taken in applying the information produced from animal studies to the lives of pregnant women and their offspring. He argues that while animal studies can be used to validate occurrences of anomalies in humans, animal studies should not be relied upon to formulate diagnostic paradigms for humans. For example, some anomalies common in specific animal models may occur in humans, but only rarely (1998a:84, 90). Differential susceptibility to developmental toxicants such as alcohol can occur between species and within species, and susceptibility can vary with genotype (Stratton et al. 1996).

Kalter (1968 in Stratton et al. 1996:40) points out that both inter- and intraspecies variability can manifest in several ways: 1. an agent that is teratogenic in some species may have little or no teratogenic effect in another; 2. a teratogen may produce similar defects in various species, but these defects will vary in frequency; and 3. a teratogen may induce certain abnormalities in one species that are entirely different from those induced in another. A further problem in comparing the effects of alcohol dosages in different species is that differences exist in rates of absorption (the rodent equivalent of miscarriage), metabolism, metabolic pathways, and placental structure and maternal-fetal pharmacokinetics (Stratton et al. 1996:40, Abel 1998a:11).

Dose-response effects are the most critical issues in developmental toxicology. However, they are commonly misunderstood, oversimplified, or simply neglected (Stratton et al. 1996:41). Definitions of what constitutes "high," "moderate," and "low" doses of alcohol in the animal literature varies and difficulties exist in applying these to equivalents in humans (Stratton et al. 1996: 42). Abel writes:

> …to obtain a blood level of 3 μg/liter for some drugs requires administration of 200 mg/kg if the subject is a rabbit compared to only 1 mg/kg if the subject is a human (Abel 1979). One pathway through the comparison maze is to base equivalents on blood levels. Because the amount of a drug in the blood is generally the same as its effective concentration at its site of action, the effective dose is not the same as the administered dose…Returning to the criterion of "threshold," in the rat brain, damage only begins to occur when the blood alcohol level reaches 150 mg% (Bonthius & West 1988; West, Kelly, & Pierce, 1987), and the overwhelming body of behavioral studies in animals have involved exposures resulting in blood alcohol levels 200 mg% and above (Abel 1984a).

> If the blood alcohol thresholds 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 pounds would be the equivalent of a daily binge of nine drinks over a 5-hour period (University of Michigan, n.d.) (Abel 1998a:12).

Abel further points out that while in most behavioral studies in animals blood alcohol levels of 200 mg% and above are typically used, these threshold blood alcohol levels are usually maintained over several days which would be comparable in humans to chronic bingeing over almost the entire course of gestation (1998a:12-13*)*.

Conclusion

This chapter has discussed the challenges faced by researchers in studying the teratogenic effects of alcohol and FAS/ARBEs, and the controversies that have arisen between researchers as a result. As discussed above, many of the ruptures that exist in the knowledge production attached to the diagnostic category FAS have occurred because of methodological difficulties and research limitations inherent in human studies of prenatal alcohol exposure. To a certain degree these challenges have been addressed through teratology research involving animal models, however controversy exist in the research too over methodological designs, the comparability of animal models to human subjects, and the conclusiveness of the data. An outcome of the dissimilar positions taken by researchers is that each position has very different implications for pregnant women and their children, and for the larger society; a point of tension in the discourse on FAS, that I will continue to explore in the remainder of this section.

Chapter Five
ABORIGINAL PEOPLE AND FAS-RELATED RESEARCH IN CANADA

Introduction

In this chapter I explore the question of why Aboriginal women and their children became the central target group for FAS-related research and services in Canada. Questioning how the diagnostic category FAS became so strongly associated with Aboriginal peoples requires an analysis of the social and historical processes that implicated Aboriginal women and their offspring to a far greater extent than any other "racial," ethnic or social group. Although few FAS studies have been undertaken in Canada over the past twenty-five years, Canadian researchers have almost exclusively pursued research that involves the assessment of children living either in First Nation reserve communities, in geographical regions with high concentrations of Aboriginal people, or in clinical settings with a high ratio of Aboriginal patients.

In this chapter I frame my analysis around early FAS studies in Canada and how this body of research determined the ways in which issues related to prenatal alcohol exposure and FAS would be understood by federal and provincial governments, the general public, and by Aboriginal groups. I argue that from the outset the problem of detection bias in both community- and clinical-based research implicated Aboriginal women and their children, while ignoring the issue of prenatal alcohol exposure and FAS/ARBEs in other groups. I further argue that despite the over-representation of Aboriginal children in these studies, it is still uncertain as to whether Aboriginal women and their children are at greater risk for FAS/ARBEs than are other groups, and if so, to what degree.

Early FAS-related activities in Canada

In North America during the 1970s and 1980s, the link between prenatal alcohol exposure and birth defects increasingly elicited interest and concern from various politicians and levels of government. Shortly after the introduction of the diagnostic category FAS in the scientific literature, clinical researchers, mainly made up of developmental psychologists and pediatricians in Canada and the United States were asked to take on advisory roles to politicians and government departments who wanted information on how best to intervene directly in connection with the conditions believed to be liable to increase risk for high alcohol use. For example, a National Symposium on Fetal Alcohol Syndrome held in Winnipeg in 1983 brought together psychologists, pediatricians, addiction experts, nurses, and representatives from different levels of government to discuss the occurrence and degree of risks in Canada related to prenatal alcohol exposure and FAS. At this meeting it was suggested that the number of women alcoholics was increasing in Canada and that the ratio of male to female alcoholics had gone from 8:1 in 1960 to 1:1 in 1980 (Ouellet 1988:17). The reasons postulated at the meeting for this increase included a greater willingness to identify the problem of alcoholism in women and "women's use of alcohol in dealing with their changing roles in society and the pressure and conflicts brought on by these new roles" (Ouellet 1988:17). At the National Forum, Aboriginal women were identified as a group in need of particular attention because of a consensus among those attending the meeting that rates of maternal alcohol abuse were highest among Aboriginal women, and because of the high fertility rates in Aboriginal communities.

The British Columbia provincial government was the first to assemble a group of researchers to act as advisors to the government on issues related to FAS. This group was based at the University of British Columbia (UBC) and included, Robert Armstrong, Kwadwo O. Asante[1], Julianne Conry, Robert L. Conry and Geoffrey C. Robinson. The expertise of the University of British Columbia group lay in areas of childhood development and pediatrics, rather than in addictions or mental health issues associated with alcohol abuse among women, where the locus of "risk" was perceived to lie. However, despite their lack of expertise in areas of addiction and mental health, this group of researchers assumed that they possessed a level of expertise across a range of factors associated with FAS, including expertise concerning the patterns and levels of alcohol abuse by pregnant women who give birth to alcohol-affected offspring.

At the time that the government of British Columbia was seeking answers about prenatal alcohol exposure and how best to intervene in what was understood as a major

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[1] Dr. Asante was one of the first researchers to publish on FAS in Canada (1981). At this time he was a pediatrician and pediatric consultant to Mills Memorial Hospital, and Terrance and Kitimat General Hospital in British Columbia. Dr Asante had worked for many years in northern communities with high concentrations of Aboriginal people. After his initial study he collaborated with Robinson, Conry & Conry on a second survey study in Northern BC. (1987).

social problem, this group of researchers were looking at ways to fund their research interests and expand clinical services for patient assessment of FAS. The expertise that they assumed for themselves coincided with their efforts to lobby provincial and federal governments for increased funding for research, clinical services, and outreach prevention programming (see, for example, Robinson & Armstrong 1988). During this period they drew upon the research and clinical experience of American FAS researchers, particularly Streissguth and Clarren at the University of Washington, and framed their approach as did their American colleagues around research and advocacy.

As knowledge of FAS was disseminated from clinical researchers in the United States to researchers and clinicians in Western Canada, the first FAS advocacy group was formed in British Columbia. Geoffrey C. Robinson, a Professor Emeritus in the Department of Pediatrics at the University of British Columbia along with his colleagues formed the British Columbia FAS Resource Group in 1985. The group was originally comprised of ten individuals from the fields of education, nursing, addictions, and medicine (Robinson 1988:2). According to Robinson the advocacy group, was created in response to research findings from northern British Columbia and the Yukon that indicated high prevalence rates of FAS existed in these regions (among these are, Asante 1981, Robinson et al. 1987, Asante & Nelms-Matzke 1985). These findings, Robinson stated, gave rise to the need for researchers and others to "learn more about the problem" and "play the role of a catalyst to mobilize action" (1988:2). Of central concern for the group were four issues, identifying risk factors, prevention strategies, assessment and diagnosis, and the development of treatment interventions. The British Columbia FAS Resource Group began by meeting three to four times a year and made presentations to government departments, including the Liquor Review Board, local communities, and the media. The central goals of the group were to raise awareness about the risks of prenatal alcohol exposure and to secure increased funding for FAS research across a broad spectrum of research questions (Robinson 1988).

The British Columbia FAS Resource Group organized the first Canadian conference on FAS in 1988 in conjunction with the Sunny Hill Health Centre for Children and the University of British Columbia (Robinson 1988:2). At this conference the provincial government of British Columbia announced funding of $450,000 for the

Pregnancy Outreach Project (POP) that was granted by Alcohol and Drug Programs of the Ministry of Labour and Consumer Affairs to be implemented through the Ministry of Health. The goal of POP was described as the promotion of "positive health practices in at-risk pregnant women, particularly native women which will contribute to the reduction of FAS" (Robinson 1988:viii). As indicated by the goals of the POP, Aboriginal women and their children were the central target group of early FAS advocacy and outreach services. Simultaneously, they were also the central target group in Canada for FAS community- and clinical-based research.

Fetal alcohol syndrome research in Canada

Within the scientific literature, estimates of the prevalence and incidence rates of FAS vary widely and it is difficult to determine regional and national levels based on the research findings that are currently available[2]. The diagnostic criteria for FAS has tended to vary from study to study, and along with other methodological factors, such as the method of case ascertainment and population bias (particularly an over-representation of Aboriginal populations) has meant that cross-study comparisons are difficult (May 1991).

Incidence rates of FAS in the general North American population are estimated to be at less than 1 case/1000 (0.67/1000). Partial FAS or FAE is estimated to be significantly higher, 9.1 cases/1000 or about 1% of all births in the United States (Sampson et al. 1997). Prevalence rates in Canada are based on American estimates however rates among Aboriginal populations are believed to be much higher (Roberts & Nanson 2000).

Two early contributions by Canadian clinical researchers significantly shaped FAS research, prevention, and the structuring of clinical services in Canada. The first contribution was to show that in concentrated geographical areas FAS prevalence rates could reach staggering levels. The estimated FAS/E prevalence rate of 190/1000 in an Aboriginal community in northern British Columbia studied by Robinson and colleagues in the early 1980s, still remains the highest prevalence rate ever recorded among any group in the world (1987). The second contribution made by early FAS studies in

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[2] Prevalence rates refers to either the frequency of a condition among identified cases regardless of when they entered, or the frequency of a condition in a population at a particular time. Incidence refers to the number of new cases of an anomaly entering a population at a particular time (Abel 1998a:139).

Canada was to clearly identify Aboriginal women and their offspring as the group who were most at-risk for FAS/ARBEs. However, these studies not only placed Aboriginal women and their children at higher risk, they suggested that the risks to Aboriginal children were in some contexts up to twenty times that of the general population.

Early North American studies contributed further to the perception that all Aboriginal women were at greater risk than were other women because of their portrayal of Aboriginal peoples as homogeneous in their alcohol consumption patterns across geographical and cultural divides. Binge drinking, a pattern of maternal drinking that has been identified as especially dangerous for the fetus, was strongly associated with Aboriginal women. For example, Asante argued that Aboriginal women in northern British Columbia and the Yukon engaged more frequently than non-Aboriginal women in binge drinking, which he argued was “a common part of the northern lifestyle” (1981:335). Aase argued that “cultural attitudes towards drinking” meant that American Indian women living on reserves in the southwest United States were more likely to engage in binge drinking patterns of alcohol use than any other group of American women (Aase 1981). However, limited research data was collected to confirm whether in local communities, or in general, binge drinking was a common practice among Aboriginal women, or if indeed binge drinking was higher among this group, to what degree.

Given the high prevalence rates of FAS/E estimated for Aboriginal communities in these early studies, it is not surprising that Canadian federal and provincial government agencies and departments were concerned over what should be done to decrease risk and improve prevention. It is also not surprising that they responded with plans to prioritize Aboriginal communities in their allocation of resources for FAS research, programs, and services. However, while Canadian governments based their funding and program development strategies on arguments made in early FAS studies, critiques of the research methods used in these studies, and the conclusions put forth by the authors have been questioned within the scientific community.

Assessing the epidemiological research

In 1989, Bray and Anderson conducted an appraisal of the epidemiological research on FAS involving Canadian Aboriginal populations. Their appraisal raised several serious questions about detection bias and the over-representation of Aboriginal people in the research literature. They begin by asking two questions: “Is it merely coincidental that Indians are [over] represented in various case studies or is there reason to believe that Native children suffer an increased prevalence of FAS? *Is there epidemiological evidence that suggests FAS occurs more frequently in Native populations?*” (Bray & Anderson 1989:42 emphasis in text). A key concern expressed by Bray and Anderson is the difficulties researchers face when applying a standard diagnostic criteria for FAS to Aboriginal groups. They write: “since anthropomorphic features of Indian children generally differ from Caucasian children, the use of facial characteristics as a diagnostic criteria is questionable. Educational assessment across cultures, especially the use of IQ tests in the evaluation of CNS dysfunction as a criterion, requires special attention” (Bray & Anderson 1989:44).

In their appraisal, Bray and Anderson (1989) discuss the lack of published research in Canada on the prevalence of FAS in non-Aboriginal populations. The absence of this research, they argue, makes it difficult, if not impossible, to make valid comparisons of prevalence rates for Aboriginal and non-Aboriginal populations, and to draw inferences regarding high prevalence rates (1989:44). This shortcoming has persisted because Canadian researchers continue to focus FAS studies on Aboriginal groups or geographical areas with large concentrations of Aboriginal people (among these are, Godel et al. 1992, Williams & Gloster 1999).

At the time of Bray and Anderson’s publication, only two studies estimating prevalence rates of FAS in Canada existed. One study involved a small First Nation reserve community (Robinson et al. 1987) and the other had a significant over-representation of Aboriginal patients in the study cohort (Asante & Nelms-Matzke 1985). Both of the studies involved sub-populations living in the West Coast region of Canada and therefore were not representative of either the general population, nor of all Aboriginal populations (Bray & Anderson 1989:44). Despite this, the high prevalence rates of FAS/E estimated for Aboriginal populations, 25/1000 (northwest British

Columbia) and 46/1000 (Yukon) given in the study by Asante and Nelms-Matzke (1985) and 190/1000 in the study by Robinson and colleagues (1987), continue to be interpreted as representative of prevalence rates amongst the general Aboriginal population in Canada. Bray and Anderson write:

> The investigations themselves may lack methodological sophistication and therefore warrant scientific conservatism in accepting the prevalence rates prima facie…Native peoples should not be stigmatized by a condition such as FAS which is difficult to prove as factual and which may have a negative impact within the Native community. Caution is warranted before we conclude that FAS is more prevalent in any Native peoples (Bray & Anderson 1989:44).

A concern raised by Bray and Anderson (1989), as well as other researchers (May 1991) is the question of detection bias, especially the targeting of Aboriginal populations where alcohol use by pregnant women and prevalence rates of FAS/ARBEs are expected to be high. Associated with this type of detection bias are certain characteristics of reserve (Canada) or reservation (American) communities in North America that make them contexts that are desirable sites of research for scientists who investigate prenatal alcohol exposure and FAS.

The right site for the research question: detection bias and reserve communities

Four inter-related characteristics common to reserve communities in Canada have made them desirable research sites for scientists who investigate FAS, and also ideal sites for the application of prevention strategies, identification of the problem, and for providing intervention services that track and measure outcomes[3]. First, reserve communities have a defined population based on a band membership. The members, especially in more isolated reserves, usually share similar genetic characteristics, and have in common cultural and environmental influences that are believed to impact similarly upon their bodies, as well as upon their cognitive and behavioral development. In the reserve context, researchers are also able to use control groups to determine local standards for comparative use in diagnostic assessment. Second, communities, especially the more isolated reserves, are marginally affected by in and out migration. Because of this, longitudinal health and social histories of individual members and of the entire

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[3] Intervention services that track and measure outcomes are just now being put into place and there has been only limited evaluation and analysis of the success of most prevention and intervention programs in local contexts.

community are relatively easy to access through medical charts and records (Egeland et al. 1998, Hay et al. 1998), government health records and statistics (Moffatt et al. 1996), and school records (Moffatt et al. 1996).

O'Neil argues that one of the reasons epidemiologists are attracted to working with data derived from Aboriginal communities is because of the comprehensiveness and relative completeness of the databases (1993:34). He suggests that because of the highly centralized surveillance system of federal government departments that oversee Aboriginal health and social issues, such as First Nations and Inuit Health Services Branch and the Department of Indian and Northern Affairs, little escapes the attention of institutions involved in service provision (O'Neil 1993:34).

A third factor is that pregnancies in northern Aboriginal communities, including "high risk" pregnancies that involve prenatal alcohol abuse, rarely go unnoticed by community members and from their initial recognition are generally closely monitored by health care providers. All pregnancies that are determined for any reason to be "at risk" are referred to southern hospitals for delivery and the hospital is made aware of the medical history of the woman and the risks associated with the pregnancy[4]. This differs, for example from urban centers where impoverished pregnant women who abuse substances commonly try to avoid the surveillance of child welfare services by avoiding prenatal care and outreach services. In many instances these women are able to conceal their pregnancies for many months from those around them, sometimes even until they give birth. They may also try moving to a city or community where they feel it is less likely that child welfare services will "apprehend" their baby at birth (Tait 2000, see Section Four). In an urban context it is more difficult for local health and social service providers to track prenatal alcohol exposure levels and patterns, and more difficult to obtain or confirm information about alcohol use by pregnant women from other members in the community. This contributes to the difficulties that researchers can experience when trying to conduct FAS-related research among "high-risk" women in urban contexts.

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[4] With the exception of a few communities, all Aboriginal women in the north are transported out of their communities to southern hospitals to give birth (see for example, Kaufert & O'Neil 1990, 1993, O'Neil & Kaufert 1995).

Lastly, because research and intervention strategies that take place in reserve communities are often initiated by and/or require the approval of the band council, once this is gained, cooperation from women and the community is generally high. This allows for easier access to information not given in formal records, such as measures of alcohol exposure (self-reports or reports by others) that can be difficult to obtain, for example, from a dispersed urban population who do not feel supported, or who feel coerced by community or social workers to participate in the project.

FAS-related studies in reserve communities in Canada

In Canada, as noted above, only two studies have been completed that determine the prevalence rate of FAS/E in a general population. Both of the studies were conducted in reserve communities where prenatal alcohol exposure and rates of FAS/E were expected by the researchers to be high. In both instances the researchers were invited by a First Nations community to assess all of the children in the community for behavioral and learning problems. Results from the studies suggest extremely high prevalence rates of FAS/E in both communities. According to individuals that I spoke with who were familiar with the studies and the communities involved, the high prevalence rates determined by the studies devastated community members and contributed to a breakdown in communication and partnership between the researchers and the local band councils[5]. Furthermore, because there were no follow-up interventions designed at that time for diagnosed children that could be built into either study's design, the communities were confronted with the results but with no identified way to effectively intervene to improve the circumstances of the children who were diagnosed, or to decrease risk among pregnant women.

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[5] Several individuals spoke to me about the controversies that arose between the communities and the researchers involved in these studies. In both cases it was reported that disagreement arose over confidentiality agreements and the identities of the communities as well as other information in the reports becoming public against the wishes of the communities. While two publications in the scientific literature report on the findings from these studies (Robinson et al. 1987, Square 1997), the identities of the communities are not given. However, in my collection of FAS documents for this research both confidential reports intended only for the communities inadvertently came into my possession, one through a library search of FAS-related literature, and a photocopy of the other was given to me by a service provider. I contacted one of the communities to notify and assist them if necessary to have the report returned and have not used information from the reports in my discussion.

The study by Robinson and colleagues

In 1984, pediatricians Geoffrey C. Robinson and Kwadwo O. Asante along with child educational psychologists, Julianne and Robert Conry were asked by the band council of an isolated First Nation reserve in British Columbia to examine alcohol-related birth defects among the children in the community. At the time of the study, the reserve had 350 registered members, including 155 children aged 18 years or less, of whom 123 were living on the reserve. One hundred and sixteen of the children participated in the study, with fourteen being diagnosed with FAS (a prevalence of 121/1000) and eight with FAE (a prevalence of 69/1000). The overall prevalence rate of FAS/E for the children in the community was 190/1000 (Robinson et al. 1987:206).

As stated earlier, the prevalence rates found by Robinson and colleagues are the highest rates of FAS/E ever recorded in the world. However, Bray and Anderson suggest that the high prevalence rates found in the Robinson study should be interpreted cautiously, including any assumption that they reflect the general Aboriginal population. They state:

> …the statistics would be more convincing if the authors had conducted a prevalence study of FAS in a non-Native comparison group using the same FAS criteria and method. Instead, the authors refer to the research which reports the prevalence of FAS/FAE to be 19.5, 2.7 and 2.5 per 1000 births for three Indian tribes of the Southwest United States. Rather than strengthening Robinson's position, these data indicate significant variation in the prevalence rate across cultural groups with the statistics from two tribes comparable to FAS prevalence rates for the general American population. None of these statistics compare with the rate of 190 births per 1000 (Bray & Anderson 1989:43).

Forty-five mothers participated in the study by Robinson and colleagues. Of the 116 children to whom these women had given birth, in-utero alcohol exposure was reported in fifty-four pregnancies. Of these fifty-four cases, thirty-two children were found to be unaffected by the exposure. Robinson and colleagues found that fourteen of the forty-five mothers in the study had given birth to one or more of the twenty-two children with FAS/FAE, and five of these women accounted for twelve (54%) of the children who were diagnosed. Abel points out that population-based studies often count each sibling as a single case, thereby failing to give proper weight to what may be a serious problem among a relatively small proportion of the mothers. Researchers generally determine prevalence rates based on a mother-child ratio of one-to-one, when in fact a single mother may give birth to a number of affected children, as is suggested by the Robinson study (Abel 1998a:142).

The study by Robinson and colleagues has several methodological limitations within its design. For example, the children in the study are assessed using a minimalist diagnostic criteria suggesting that misclassification may have occurred. Robinson and colleagues point out that the recognition of some of the craniofacial characteristics is especially difficult in Aboriginal children, which they argue probably led to under-diagnosis in the study cohort (1987:206). However, Bray and Anderson argue that the presence of epicanthic folds and other anatomical features common in Aboriginal populations and to the FAS diagnostic criteria may have led to over-diagnosis thereby contributing to the high prevalence rate. The children assessed also ranged in ages from 0 – 18 years of age. This raises questions about the ability of the researchers to apply the diagnostic criteria appropriately across age-cohorts because it has been found that significant difficulty exists in applying the criteria to certain age groups such as infants and adolescents (Abel 1998a, see also Chapter Six).

The research methodology used by Robinson and colleagues makes it difficult to successfully control for confounding variables such as alcohol use patterns and the impact of tobacco use (May 1991:241). The failure to adjust for confounding variables other than alcohol is typical in early FAS studies in Canada. Bray and Anderson write:

> A careful maternal history is needed to differentiate effects of alcohol from those due to anticonvulsant medication because of similarities in dysmorphology, CNS dysfunction may be associated with other known teratogenic drugs and chemicals, infection during pregnancy and perhaps a host of unidentified teratogens (1989:43).

Bray and Anderson state that the problem "is to distinguish in utero alcohol exposure from the myriad of other experiences of the prenatally exposed child, which is especially the case for the child who is diagnosed mentally retarded" (1989:43). For example, diagnostic criterion, such as growth retardation are also criterion associated with other prenatal variables such as maternal smoking. A more sophisticated analysis, Bray and Anderson suggest, would have collected confounding variables in the same way as information on alcohol use was collected and then performed multiple logistic regression or a stratified analysis (1989:43). A further methodological limitation in the Robinson study is the inability of some women to recall the amount of alcohol they consumed when pregnant. This might be expected given that many of the pregnancies had occurred several years prior to the interview, sometimes as long as eighteen years.

Many of the early FAS/E studies provided very limited information about the mothers of the children assessed, including the women's perceptions of alcohol use and pregnancy, and information about the various factors that contributed to their alcohol use. For example, in the Robinson study the pregnancies reported upon by the women occurred over an eighteen-year period when the risks associated with prenatal alcohol exposure were either unknown or only coming to light through medical research and public health education. This can also be said for other studies completed in the 1980s (Asante 1981, Asante & Nelms-Matzke 1987). Women in the communities that were studied, as was the case for most women in Canada at this time, were unlikely to make a link between negative birth outcomes and their alcohol use when pregnant. As well, it is very likely that the perception of the risk of damage to the developing fetus held by women generally was, and continues to be, greatly influenced by the experiences of other women around them. Although Robinson and colleagues were unable to explore the perceptions women had of their children, it is likely that some of the women, along with their family members did not perceive their child(ren) to have a disability prior to the diagnosis given by the researchers[6]. It is also likely that disabilities that were obvious to the mother and her family were not attributed to prenatal alcohol exposure. This may have had a direct impact on a woman's decision about drinking during subsequent pregnancies, as well as influencing the perceptions of younger women around them who were becoming pregnant for the first time.

When researchers involved in early FAS studies in Canada discussed alcohol use by pregnant women, they mainly speculated about "racial" susceptibility or about "cultural" beliefs about drinking that placed specific women and their children "at risk." The lack of expertise of the researchers in areas of alcohol addiction/abuse is evident in these studies, particularly evidenced by the limited importance they place upon the complexities of maternal alcohol use. For example, Robinson and colleagues make no mention of improved addiction treatment services for women as a way to prevent FAS/E.

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[6] This is assuming that the diagnoses given to the children in the community are correct.

Instead they assume that alcohol use for women in the community is an uncomplicated choice and focus their recommendations on finding ways to change the behavior of pregnant women through public health education.

The study by Chudley and Moffatt

Apart from the Robinson study, few researchers in Canada have attempted to determine FAS/ARBEs prevalence rates. Of these studies none has come close to finding rates anywhere near those determined by Robinson and colleagues. The study that comes closest was completed by two researchers, geneticist Albert Chudley and pediatrician Michael Moffatt from the University of Manitoba. Chudley and Moffatt were invited in the 1990s by band elders from a First Nations community in northern Manitoba to assess the children in the community for behavioral and learning problems after teachers complained that half of the children in their classes were incapable of learning (Square 1997:59).

Chudley and Moffat received permission to examine the medical records of 179 families in the community and to assess the children between the ages of 5 to 15 years for "discriminating features related to FAS/FAE, such as short palpebral fissures, flat midface, short nose, indistinct philtrum and thin upper lip" (Square 1997:59). In an interview with freelance writer David Square, Chudley reported that approximately 40% of the children had been exposed to alcohol in utero, with 11 children being identified as having FAS and an additional 6 with FAE. Moffatt reported that the children with FAS exhibited many of the characteristic CNS dysfunction associated with alcohol teratogenesis, including learning or attention problems, hyperactivity, microcephaly, seizures and below-average scores for intelligence (Square 1997:59). A prevalence rate for FAS/E among the study cohort was determined to be approximately 100/1000.

Although the findings from the Chudley and Moffatt study suggest that epidemic rates of FAS/E exist in this community, details of the study's design and methodology are not published in the scientific literature. Rather, freelance writer David Square in the *Canadian Medical Association Journal* (1997), published a brief description of the study based on interviews with Chudley and Moffatt. In their interview with Square, Chudley and Moffatt emphasize the epidemic prevalence rates found in the study cohort which they argue represent “just the tip of the iceberg” in Canada’s Aboriginal population (Square 1997:57).

In their interview with Square, Chudley and Moffatt propose that a lack of awareness about the risks associated with prenatal alcohol exposure are a central reason for the high prevalence rates in the community. Square then quotes Jack Armstrong, former president of the Canadian Medical Association, and Diane Malbin, cofounder of the FAS/Drug Effects Clinical Program in Portland, Oregon who both emphasize that high prevalence rates of FAS/E are not unique to impoverished Aboriginal or Black populations. Square quotes Malbin as stating that the group of women most at risk in North America and the most under identified are white, middle-class, and educated (Square 1997:57).

As discussed in Chapter One, Aboriginal and “white,” educated middle class women are commonly identified as the two groups who are at significantly greater risk than other women for having an alcohol-effected child. However, in both cases, scientific evidence supporting these assumptions is limited. From the studies available, at best it can be speculated that specific communities, with high alcohol abuse rates, some of whom are Aboriginal, are at increased risk. No evidence exists in the scientific literature to support the assumption that middle or upper class educated women from any particular ethnic group drink alcohol when pregnant at higher rates than other groups of women, nor that their children have higher prevalence rates of FAS/E than those found in the general population.

Detection bias in clinical-based research

Detection bias in clinical-based research in Canada has contributed to the over-representation of Aboriginal people in the FAS literature. These studies have added further to a perception that Aboriginal women and their offspring are at significantly greater risk for FAS/ARBEs than other groups in Canada. Three studies conducted in British Columbia in the 1980s helped to reinforce this image. They include two studies completed by Asante, one in collaboration with Nelms-Matzke, and a third study by Smith and colleagues. In all three studies detection-bias played a role in the ascertainment of the study cohort and contributed to an over-representation of Aboriginal children.

The study by K. O. Asante

In 1981, Kwadwo O. Asante reported on 74 children that he had diagnosed with FAS. All 74 children were from northwest British Columbia and the Yukon and were referred to Asante between 1972 and 1980 for clinical assessment and follow-up for specific pediatric medical or developmental problems. Ninety-five percent (59/62) of the biological mothers of the 74 children were Aboriginal. However, while this is a striking percentage, the significance of this number is unclear as the percentage of Aboriginal children in the entire patient population referred to Asante for clinical assessment is not given. The study cohort also had an over-representation of children who had been involved with child welfare services. Asante reported that fifty-three (72%) of the 74 children, on at least one occasion, had either been taken into care by child welfare services, or else there had been close involvement of social workers in their family (Asante 1981:331).

Based on data collected for this study, Asante is unable to provide an estimation of the prevalence rate of FAS for northwest British Columbia and the Yukon. Despite this, he concludes that in these regions "FAS is a frequent and significant cause of physical malformation, growth failure, developmental delays and mental retardation" especially among Aboriginal children (Asante 1981:335). Asante suggests that the incidence of FAS appears to be a much larger problem in this geographical region than previously thought, and most likely is also higher in other regions of Canada, with Aboriginal peoples being at greatest risk (1981:335).

Asante speculates on several possible reasons for the large number of Aboriginal children found in his study cohort. He lists higher alcohol consumption and more frequent binge drinking among Aboriginal women as two possibilities, although he does not reference studies that support his assumptions. Asante also suggests that the surveillance of Aboriginal women and children, for example, by social services and outreach agencies, as opposed to Caucasian women living in the region, may also account for some of the discrepancy. He further speculates that Caucasian women may "drink more discreetly at home" (1981:335). However, it would be expected that due to their compromised health the alcohol-affected offspring of Caucasian women would be as visible as the alcohol-affected Aboriginal children because, like their Aboriginal counterparts, it is their compromised health, not the visibility of their mother's drinking which would draw the attention of clinicians to them. This raises questions about whether or not the bodies and behavior of Caucasian children who present with similar symptomology are being assessed for the possibility of prenatal alcohol effects to the same degree as Aboriginal children.

Asante raises the possibility of "racial differences in the rates of alcohol metabolism" between Aboriginal and non-Aboriginal women as a way to further account for the high percentage of Aboriginal children in his patient cohort (1981:335). He also cites social, economic and psychological factors, along with the "northern lifestyle" as contributing to the high incidence of FAS in the Aboriginal population of this region. However, he does not go into detail as to the relationship between any of these factors and negative birth outcomes. The article ends with recommendations for further epidemiological research and "a greater need to educate women in the childbearing years, especially native women, in the serious effects of alcohol on the unborn child" (Asante 1981:335).

The diagnostic criteria used in the study by Asante are based on the original minimalist FAS diagnostic description described by Clarren and Smith (1978). However, he departs from the paradigm in two important ways. First, each of the three diagnostic criteria, growth retardation, neurological anomalies, and physical malformations, have a larger number of anomalies included in them than is in the original description. For example, skeletal, cardiac, palatal abnormalities, abnormal palmar creases, genito-urinary anomalies, and cerebral palsy are included[7] (Asante 1981:333). Second, while Asante reports that all of the children exhibited "morphologic features of FAS, evidence of developmental delay or mental retardation" (1981:331), only 50 (68%) had the characteristic face associated with FAS; 51 (69%) post-natal growth delay; 38 (51%) microcephaly (small head size); 34 (46%) had general developmental delays, and 10 (14%) were mentally retarded (Asante 1981:333), indicating that at least some of the children did not meet the basic diagnostic criteria for all three diagnostic areas as

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[7] Some of these anomalies, such as skeletal and cardiac problems have been linked to prenatal alcohol exposure in several studies but are generally not part of the FAS diagnostic criteria. They also occur in patient populations where prenatal alcohol exposure is not a factor.

intended in the original paradigm. Assessment tests and measurements were also based on standard North American guidelines and were not adjusted for local ethnic phenotypes, or for cultural or socioeconomic variation that could impact upon child development.

The study by Asante and Nelms-Matzke

A study by Asante and Nelms-Matzke (1985) determined that out of 586 Aboriginal and non-Aboriginal children referred for clinical assessment of handicaps, 82 warranted a diagnosis of FAS and 94 of FAE. From this data they estimate the prevalence rates of FAS/FAE among Aboriginal children to be 25/1000 in northwest British Columbia and 46/1000 in the Yukon. They contrast these figures to an estimate of 0.4/1000 for non-Aboriginal children in the same regions.

Bray and Anderson suggest that detection bias is a problem in the design of the study by Asante and Nelms-Matzke. They write:

> Subjects were selected for study by various agencies who identified children in their communities as ‘chronically handicapped.’ From the subpopulation, Asante et al. estimated the prevalence of FAS and/or FAE in the total population. The authors are aware that this is less than an ideal way to estimate prevalence. The sample was based on children identified by the health care system and social services, as being handicapped, and this in itself may lead to a biased estimate of prevalence (1989:43).

A similar critique can be made of the earlier study by Asante (1981), even though in that study he does not estimate but only speculates about FAS/E prevalence rates.

Bray and Anderson point out that Asante and Nelms-Matzke offer no documentation regarding diagnostic assessments apart from their acknowledgment that to some degree developmental assessment for evaluation of CNS dysfunction was not systematic across the study cohort. They argue that this makes it difficult to know if the criteria for FAS/E are applied equally to both Aboriginal and non-Aboriginal children, and what impact differential assessment had, if any, on research outcomes (1989:43).

The study by Smith and colleagues

In 1981, a group of researchers from the University of British Columbia described 76 diagnosed cases of FAS found in a patient cohort seen at two teaching hospitals in

Vancouver. The patients ranged in ages from birth to eighteen years. Seven of the patients were Caucasian, and the remainder were children born to Aboriginal mothers and whose fathers were of either Aboriginal or Caucasian ancestry. No other "racial" groups were represented in the study cohort (Smith et al. 1981:147).

A diagnosis of FAS was based on confirmation of heavy prenatal alcohol exposure and clinical findings of characteristic facial appearance, alteration of brain function, and growth retardation assumed to be typical of FAS patients. Developmental delay was confirmed through pediatric neurological assessment or by an educational-psychological assessment for children over five years of age (Smith et al. 1981:146). In their methods section, Smith and colleagues provide no information on how heavy prenatal alcohol exposure was confirmed in patient assessments, nor if standard measurements for assessing facial characteristics, growth retardation or neurological development were adjusted to reflect ethnic, cultural and socioeconomic variation in the patient cohort.

The focus of the study by Smith and colleagues was to examine skeletal and heart abnormalities in patients diagnosed with FAS. Children fulfilling the standard criteria for a diagnosis of FAS underwent skeletal surveys, intravenous pyelograms, and cardiac assessments as part of the broader clinical investigation of the study cohort. Significant skeletal (microcephaly 54%, cervical spine abnormalities 43%, tapering of the terminal phalanges 72%) and cardiac (41%) malformations were found to exist among the patient cohort. These findings suggest a notable correlation between a FAS diagnosis and both skeletal and cardiac abnormalities.

In concluding their discussion, Smith and colleagues, while acknowledging that the rates of FAS/E are underdetermined in the scientific literature, estimate rates in North America to be between 1-5/1000 live births. In discussing their study cohort they state:

> With only 2 1/2% of the population in British Columbia being native Indian our statistics reveal a 10.9 to 1 ratio of native Indian children to Caucasian from our population with FAS. This raises the significance of racial susceptibility to the teratogenic effects of alcohol, a very difficult point to satisfactorily answer. The question of the role of different metabolic pathways of alcohol and possible deleterious effects of acetaldehyde rather than ethyl alcohol has yet to be clarified. Further work may

determine susceptibility of different maternal genotypes and give rise to selection of prospective mothers at risk (Smith et al. 1981:151)[8].

However, even though Smith and colleagues suggest that "racial susceptibility" may play a role in negative birth outcomes, they do not define how "race" and increased susceptibility are linked, apart from observing that a large number of Aboriginal children were in their diagnosed cohort and speculating that susceptibility may lie in "different maternal genotypes." Abel submits that if authors such as Smith and colleagues had focused attention on the socioeconomic status of the mothers rather than focusing on "race" as the significant variable, they likely would of found that socioeconomic status rather than "race" was a stronger determinate of negative birth outcomes (1997a).

Smith and colleagues acknowledge that because their patient population is derived from two Vancouver hospitals that may see only the more serious FAS cases, their study could actually distort the view of affected children (1981). In their analysis they also fail to report on whether Aboriginal clients are excessively referred to the particular tertiary care units in the study which, if true, could distort the importance of Aboriginal ancestry as an important variable associated with risk and high prevalence rates (Bray & Anderson 1989:43). The study by Smith and colleagues also fails to provide information about whether the children and/or their mothers come from specific Aboriginal communities with high rates of alcohol abuse, or whether any correlation can be made between community of birth and birth outcome. This information would allow targeted intervention and prevention programs to be developed if certain communities or areas were identified as high risk sites for alcohol abuse.

Instead, Smith and colleagues suggest that FAS/E is a widespread problem for Aboriginal people in general in British Columbia and the Yukon. However, without definition of the populations from which these children were derived, no conclusion can be made about rates or ratios (Bray & Anderson 1989:43). While their findings are notable, the large number of Aboriginal patients may also be a reflection of an increased willingness of Aboriginal families and/or social service agencies who have Aboriginal children in their care to explore the possibility of a FAS diagnosis. It may also be a

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[8] Bray and Anderson found that they could not repeat the calculation determined by Smith and colleagues which resulted in a 10.9 to 1 ratio; instead they found a 9.9 to 1 ratio (1989:43).

reflection of physician detection bias in assessment of Aboriginal children, an issue that has been raised by Nanson and colleagues in relation to physicians in Saskatchewan (1995:1974).

Conclusion

In this chapter I have discussed the contribution of FAS research in Canada to the larger North American scientific and lay discursive arena associated with the category FAS. As presumed alcohol abuse by pregnant women and the condition of FAS gained the attention of Canadian researchers, an association between increased "risk" for FAS and the behavior and bodies of Aboriginal women became firmly entrenched in the epidemiological literature. The circumstances that led FAS researchers to conduct their studies in "high-risk" Aboriginal communities contributed significantly to the perception that in general, alcohol abuse by pregnant women and FAS/ARBEs are serious health and social problems for Aboriginal peoples.

Early studies in Canada that provided prevalence rates for FAS either reported epidemic rates of FAS/E in a local reserve community (Robinson et al. 1987), or they estimated epidemic rates of FAS/E in Aboriginal populations in a particular region (Asante 1981, Asante & Nelms-Matzke 1985, Smith et al. 1981). This led to the federal and some provincial governments prioritizing all First Nation reserves for identification, intervention and prevention services related to FAS which further entrenched the perception that Aboriginal people are at greater risk than are other groups (see for example, Robinson & Armstrong 1981, Asante & Robinson 1990).

O'Neil argues that the systems of surveillance that produce data about Aboriginal health are powerful social instruments for the construction of Aboriginal identity, problem identification, and resource allocation (1993:34). When applied to the context of FAS research, assumptions about high prevalence rates in the general Aboriginal population have widespread implications for both policy and resource allocation. Bray and Anderson write:

> If the prevalence rates of FAS for Canadian Indians were accepted without scrutiny, FAS might be seen as a public health problem of massive proportion. If this were so, subsequent policy and allocation of resources might be misdirected to programs aimed at widespread efforts of preventing FAS. Given the weakness in the data from which these

prevalence rates were calculated, this could represent a waste of both human and financial resources (Bray & Anderson 1989:44-45).

Chapter Six
CLINICAL APPLICATION OF FAS-RELATED DIAGNOSES

Introduction

The consistent application of diagnostic paradigms associated with prenatal alcohol effects across clinical and research sites has been extremely difficult, even in light of recent developments in diagnostic technologies (Abel 1998a, Astley & Clarren 2000, Stratton et al. 1996). A range of diagnostic challenges impact upon the ability of diagnosticians to apply FAS-related diagnoses to patients. Young points out that in situations where diagnostic consistency is low, this can be accounted for by "meaning variance" whereby, in the absence of standardized technologies or instruments, local knowledge, untransformed by regulations and standards is a potential source of polythetic categorization (1995:123).

Young states that clinical ideology and science are interdependent practices. On the one hand, clinical ideology "is a local system of knowledge, embedded in a particular institutional hierarchy and production line" that "provides science with the institutional surfaces on which its invisible object is inscribed" (Young 1995:199). Science, on the other hand, "provides an ideology with a distinctive object," in this case FAS, which is naturalized "giving it an existence that is independent of the clinical practices through which diagnosticians and therapists encounter it" (Young 1995).

In North America, the current expansion of diagnostic and screening services for FAS/ARBEs is based on the belief that the category FAS corresponds to a "natural" phenomenon that negatively impacts upon the bodies and behavior of large numbers of offspring who were exposed to alcohol in-utero. However, despite efforts to identify individuals that warrant a diagnosis of FAS or a related ARBEs, clinicians and researchers struggle with the problem of meaning variance.

In this chapter I will discuss the challenges associated with the standardization and implementation of screening and diagnostic assessments for FAS/ARBEs in Canada. A number of inter-related issues influence clinical assessments and screening of patients for prenatal alcohol effects. They include: the relationship between the diagnostic category FAS and FAE, prenatal screening, detection bias in screening and assessment, clinical differentiation of physical, behavior and cognition features, and the difficulties in applying diagnostic criteria across the life span (Stratton et al. 1996). An added factor that influences the availability and accessibility of diagnostic services for FAS/ARBEs is the associated costs and coordination of experts needed to make a diagnosis. Diagnosticians familiar with assessment of patients for FAS/ARBEs generally agree that a multidisciplinary team that includes some or all of the following individuals, a pediatrician or geneticist, psychologist, psychiatrist, physio- and speech therapists, and social worker are needed for clinical assessment of patients. In this chapter I will examine each of these areas giving particular attention to issues that impact upon and influence screening and assessment of patients in Canada, especially detection bias in referral and assessment of Aboriginal women and their offspring.

The relationship between FAS and FAE

As discussed previously, the category fetal alcohol effects (FAE) is not an official medical diagnostic category even though it is widely applied to patients in both clinical and research contexts in North America. The existence of the category FAE is entirely dependent upon the existence of the category FAS. Without the existence of the diagnostic criteria for FAS and the identification of persons who meet this criteria, clinical researchers would not have been able to successfully argue that a population of individuals affected in utero by alcohol exposure, but without the associated characteristic facial features and growth retardation, existed. Even with the category FAS as a touchstone, the precision of the category FAE, its reliability and validity, is low, making it very difficult for clinicians to differentiate patients with FAE from other patient populations with similar symptoms (see Chapter Three). It is equally difficult for clinicians to distinguish cognitive and behavioral problems as signs of underlying pathology caused by in utero alcohol exposure when they resemble problems associated with negative socio-environmental factors.

It is notable that the sense of urgency or “moral panic” embedded in the discursive arena attached to prenatal alcohol exposure and FAS hinges on the argument that a significantly larger population of persons exists with FAE than with FAS. Prevalence rates of FAE are generally estimated by researchers to be 5 to 10 times higher than for FAS (Sampson et al. 1997, Stratton et al. 1996). In recent years, clinical researchers have argued that the behavioral and cognitive dysfunction found in patients with FAE is as debilitating as those found in patients with FAS (Streissguth & Kanter 1997, Clarke 2000). Therefore, FAE is no longer understood to be a less severe condition than FAS, but rather that the typical physical phenotype is absent in this patient population.

North American researchers, mainly developmental pediatricians and psychologists, argue that despite the behavioral and cognitive dysfunction found in persons with FAE being as debilitating as those found in patients with FAS, persons with FAE generally do not fit easily into recognized disability categories. For example, persons diagnosed with FAE commonly have IQ scores in the "normal" range which clinical researchers argue contribute to under-diagnosis in this patient population. Researchers also argue that persons with FAE are less likely than individuals with FAS to access specialized services and supports that target persons with disabilities. This, they contend, contributes to a greater likelihood that these individuals will experience a wider range of the "secondary disabilities" associated with FAS, such as drug and alcohol problems, dropping out of school, and incarceration (Streissguth et al. 1997).

Armstrong and Abel (2000) argue that biomedical researchers in the United States have engaged in a type of biomedical entrepeneurship that has exaggerated prevalence rates of FAS/FAE and purposely framed the issue in terms of a low threshold of alcohol exposure. The lower the threshold at which alcohol becomes dangerous to the developing fetus, "the greater the number of potential victims (the proverbial 'tip of the iceberg'), and consequently the greater the national guilt for condoning such a moral lapse" (Armstrong & Abel 2000:279). The introduction of a second diagnostic category, FAE, which could account for a population that was believed to exist but was not easily identifiable, supports arguments that low thresholds of alcohol exposure could cause serious neurobehavioral damage.

In Canada, only a very small percentage of the population estimated to have FAS, approximately 1% according to experts, have been diagnosed. The percentage of diagnosed persons is even smaller for those estimated to have FAE. In both cases because of difficulties in applying diagnostic criteria to adolescent and adult patients, diagnosis has been limited largely to infants and pre-adolescent children (see Chapter Three). Apart from the question of whether the estimated prevalence rates are in fact accurate, it is unlikely that in the current Canadian health care climate of budget constraints and rising costs for providing services that the number of diagnosed persons with FAS/FAE/ARBEs, will ever come anywhere near the estimated prevalence rate that is believed to exist in the general population. What is likely to continue to occur is that children and adolescents in foster care, group homes, and youth detention centers, many of whom are Aboriginal, as well as First Nations children living in reserve communities will make up a large percentage of individuals who are assessed and diagnosed.

While issues related to misdiagnosis of patients will be discussed below, the continued overrepresentation in the FAS/ARBEs patient population of individuals who come from very disruptive childhood environments with multiple harmful factors influencing their cognitive and behavioral development contributes to a specific image of the "FAS or FAE person." Knowledge production about symptom manifestation and severity, and the growing discourse of "secondary disabilities" effectively privileges prenatal alcohol exposure as the underlying cause of the range of problems these individuals experience. As will be discussed later in this chapter, experts argue that the severity and range of cognitive and behavioral problems, as well as problems of "secondary disabilities" is increased significantly in those individuals who are not diagnosed. According to experts this would be more than 99% of the individuals estimated to have FAS/ARBEs.

Prenatal screening

> *"When a pregnant woman drinks alcohol, her unborn baby drinks alcohol too."*
>
> First Nations and Inuit Health Branch
> Fetal alcohol syndrome/fetal alcohol effects internet site
> http://www.hc-sc.gc.ca/fnihb
> March 2003

The purpose of screening pregnant women for substance abuse problems is to provide a preliminary evaluation about whether or not key indicators of alcohol or drug problems are present (BC FAS Resource Society 1998:56). Screening gives service providers such as outreach workers, physicians, and other health care providers the opportunity to refer women to prenatal education and counseling and to other services such as substance addiction treatment programs (Roberts & Nanson 2000:21). Screening also identifies "fetal risk" and infants who may require a FAS assessment. Because several problems exist in identifying FAS/ARBEs in infants, knowledge of prenatal alcohol exposure levels and patterns aid clinicians in identifying infants who are at greatest risk.

Theoretically, early identification of infants assists in their quick referral to appropriate services, and is believed to be key to the prevention of FAS/ARBEs as this also identifies women who are at risk of having a future child who is alcohol affected (Roberts & Nanson 2000:51). However, because of the difficulty in diagnosing FAS/ARBEs in infants and a lack of diagnosticians who are willing to make a FAS assessment, quick referral of infants is unlikely to happen in most regions of Canada. Screening of pregnant women and newborns is mainly about the surveillance of pregnant women on social assistance, decreasing "fetal risk" of alcohol exposure during their pregnancies (e.g. by aiding or coercing women into treatment), and deciding whether these women are "fit" to parent their newborn babies. As will be discussed in greater detail in Section Four, the identification of prenatal alcohol use is commonly brought to the attention of child welfare services by service providers either prior to, or after the birth of the child. The involvement of child welfare services commonly leads to the apprehension of a newborn from the mother's care at birth. Once the infant is apprehended, in order to regain custody the woman is generally expected by child welfare services to complete an addiction treatment program and attend parenting classes. In most instances, as will be discussed in Section Four, women face a range of personal and structural challenges that result in them never parenting their child, and in many instances becoming pregnant with another child thereby beginning the cycle of surveillance and apprehension once again.

Calls for initiatives to screen pregnant women for alcohol use imply that services are currently available for women who are identified as needing further evaluation, or in need of immediate and easy access to specialized services such as detoxification and addiction treatment programming. It also assumes that women will want to go on to the next step of evaluation or to receive treatment if they are identified by an initial screen. However, adequate detoxification services for women do not currently exist in many regions of Canada (see for example, Poole 1997, Tait 2000), and several barriers including long waiting lists, prevent women from accessing addiction treatment programs (Jacobs & Gill 2002, Poole 1997, Tait 2000). Some women are also reluctant to access health services if they feel they will be pressured or forced to accept services that they do not want, or if they fear information gained by health care or social service providers will be used against them (Benoit & Carroll 2001, Browne & Fiske 2001, Tait 2000). For example, Browne and Fiske found that First Nations women in northern British Columbia are commonly reluctant to participate in screening programs because of a widespread concern that the health care system embodies racist-based perceptions of them and does little to acknowledge or counter patterns of individual or institutional discrimination (2001:21). The same holds true for the majority of women whom I spoke with in Manitoba and in Montreal. However a growing number of outreach health and social service providers, particularly in Manitoba, are incorporating screening tools into their programs as a requirement for women who want to access their services. The justification for this type of measure is that it leads to identification and referral of pregnant women with substance abuse problems to appropriate addiction treatment services. However, for a range of reasons, including fear that child welfare services will be notified of their use, and an unwillingness of pregnant women to travel away from their communities and families to residential treatment programs, concealment and under reporting of use is a way for women to resist these measures.

Clinical screening

Prenatal screening of pregnant women for alcohol abuse is inconsistent across clinical sites in Canada. If screening occurs, it can involve as little as a single question inquiring about alcohol or drug use posed by an obstetrician or nurse, or can involve a pregnant woman answering a more in-depth screening questionnaire designed to identify women who are at risk. Physicians and nurses in Canada are increasingly being urged to screen all pregnant women for alcohol use and to make appropriate referral if they believe a woman has an alcohol abuse problem.

The most commonly used screening tools are short questionnaires consisting of a few questions that are designed to identify women who require further assessment. A small number of screening tools that use bio-marker testing such as Carbohydrate-deficident Transferrin (CDT) and Gamma glutamyl transpeptidase (GGT) have been designed to detect maternal alcohol abuse. Toxicologic tests to detect current or recent drug use have also been developed. This type of screening raises serious ethical concerns as the tests can be applied without a woman's knowledge[1]. Even when given with a woman's consent the knowledge gained has only minimal value as it cannot determine any information about whether fetal damage has occurred, and most tests do not distinguish between occasional and heavy use (Roberts & Nanson 2000:23).

Pregnant women from lower-income groups are more likely than other women to be screened for alcohol, tobacco and illicit drug use. For example, community clinics in Winnipeg that serve low-income neighborhoods with high concentrations of Aboriginal families are much better organized for screening and referral of pregnant women with substance abuse problems than are mainstream clinics who serve mainly middle and upper income women. Prenatal care provided in reserve communities is also more likely to incorporate screening of pregnant women or have knowledge of prenatal alcohol exposure levels and patterns.

The incorporation of screening techniques is inconsistent across clinical sites in Manitoba. While it has become standard practice among most physicians in the province to ask pregnant women about their use of alcohol, tobacco, and illicit drugs, many of the women I spoke with had not been screened by their health care providers during recent pregnancies beyond a single question about whether or not they used drugs or alcohol. Of those women who did have discussions with health care providers, none were referred to an addiction treatment program even though many of them have serious substance abuse problems. Instead they were either instructed to stop or cut down their use, advised to go to an addiction treatment program, or encouraged to have an abortion. In some instances, women reported that their physician downplayed their reports of substance abuse even though their accounts suggested risk of a substance abuse problem. In other instances women concealed or under-reported their use to their doctor or nurse, especially if they feared the doctor would report their use to child and family services. Some women were also afraid of the reaction by health care providers if they reported the true levels and frequency of use.

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[1] The use of this type of testing does not appear to be common. However, to my knowledge there is no data existing as to the number of women in Canada who are being screened by these methods.

The current climate in which prenatal care is provided to pregnant women in Manitoba is one in which they spend long periods in clinic waiting rooms only to be quickly moved through their appointments once their name is called. This experience is not unique to Manitoba but is similar for pregnant women throughout Canada. The initial appointment is generally the longest and if screening for alcohol or drug use occurs, it is usually at this time. The examination and discussion with the obstetrician routinely takes less than ten minutes leaving little opportunity for pregnant women to raise concerns they may have about their use of substances with their doctor. In some instances other medical staff, such as nurses are in a better position to discuss prenatal alcohol use with women. However, as with obstetricians, most nurses are bound by very tight schedules that leave limited time to attend to individual women.

In the broader discussion among healthcare providers including pediatricians, psychologists and obstetricians, government departments and policy makers, there is significant debate over the role that doctors should and can play in the identification, education, and referral of pregnant women with substance abuse problems. Among physicians there is debate about what role they should play. Three concerns are most commonly expressed in this debate. The first is about the extra time that screening and especially referral adds to patient appointments. In Canada many obstetricians carry very heavy patient loads due in large part to a shortage of obstetricians and general practitioners. Extra time screening, educating, and referring women to services translates into physicians seeing fewer patients, an even greater shortage of available doctors, and into a loss of revenue per patient.

The second issue deals with questions of risk and the difficulty in communicating in a clinical setting a public health message that effectively suggests any level of alcohol exposure is dangerous to the developing fetus. As pregnant women weigh questions of risk with “preventative measures” such as abortion, the uncertainty about what exactly are dangerous threshold levels and what message to pass onto pregnant women becomes a constraint on many healthcare providers. This concern has at times placed obstetricians who advocate for a more moderate public health message at odds with the dominant discourse that advocates for complete abstinence and maintains that low thresholds of risk exist.

The third issue centers around questions of confidentiality and screening, and how pregnant women can be ensured that the information gained by their obstetrician through screening for alcohol or drug use remains confidential and will not be used against them after their child is born. A question that concerns at least some physicians is how this information is used. For example, if screening of pregnant women is used to identify infants who at birth warrant a FAS assessment, will this information then be available to child welfare services and used as justification to either monitor the woman's behavior more closely or to apprehend her child? The potential for a breach of confidentiality dissuades women at highest risk from discussing their substance use with their doctor, and encourages concealment of their use, or avoidance of prenatal treatment altogether.

Detection bias in FAS-related diagnosis and screening

As discussed in Chapter Five, detection bias may play a role in the over- or under-representation of certain populations in FAS screening and assessment. Perception that physicians and other service providers have about risk can further influence this bias. For example, in a 1996 study of 500 obstetricians, pediatricians, and general practitioners in Michigan who were asked to respond to a questionnaire about FAS, one third of study participants stated that FAS could be the result of the consumption of as little as one drink of alcohol per day (Abel & Kruger 1998). This belief is held, Abel states, despite there being not a single instance in hundreds of case reports and clinical studies within the scientific literature where the mother of a child with FAS was not an alcoholic (1998a:7). Hans-Ludwig Spohr a clinician whose experience with FAS diagnosis spans several decades, notes that where once clinicians were skeptical that a condition such as FAS even existed, this skepticism has given way to glib diagnosis. He states:

> When FAS was first detected, pediatricians didn't believe it was a specific syndrome. Now they start to make a diagnosis by association…They see a 'funny-looking child, they have heard about FAS and if somebody says the mother is drinking they make the diagnosis" (Spohr et al. 1984:153 in Abel 1998a:7).

Abel argues that because use of the diagnosis FAS has created this false impression, large numbers of clinicians now believe that even minimal amounts of alcohol consumption during pregnancy can produce FAS (1998a:8). This is also reflected in scientific writing, especially in the alcohol and public health literatures where many studies clearly state there are “no known safe levels of alcohol” (among these are, Funkhouser & Denniston 1985, Sedula et al. 1991).

In a review of the literature on FAS research in Aboriginal populations in North America, May (1991) raises the problem of detection bias in clinical assessments for FAS/ARBE as a contributing factor to the overrepresentation of Aboriginal people who are diagnosed. He discusses a study by Chavez and colleagues (1988), who conducted a national survey of all major physical anomalies in the United States by examining birth certificates. The researchers found that “in some instances, physicians may tend to look for a particular malformation more in certain racial [and] ethnic groups than they would in others” (Chavez et al. 1988 in May 1991:241).

In a survey of 273 pediatricians and general practitioners in Saskatchewan in December 1990 and January 1991, Nanson and colleagues found that physician detection bias may have played a role in the high prevalence rates of FAS in the Aboriginal population. They noted that 27.5% (75/273) of the physicians in the study responded that they thought FAS occurred primarily in ethnic minority families (Nanson et al 1995:1974). This, Nanson and colleagues add, may simply reflect the realities of the particular client base of these physicians rather than detection bias. Burd and Moffatt (1994) suggest that studies of physician bias should seek to determine the frequency with which each physician makes a diagnosis of FAS. This type of inquiry may have provided further insight into the finding reported by Nanson and colleagues. For example, these authors found that 48% of the physicians they surveyed reported having diagnosed at least one case of FAS however, they do not examine if factors such geographical, ethnic or socioeconomic status correlate with patient populations where diagnostic rates are highest.

Screening for FAS

Screening of persons in North America who may warrant a diagnosis of FAS/ARBEs currently takes place in a number of clinical, community, and institutional settings such as schools, prisons, and child welfare services (foster care). The number of individuals being screened has increased substantially in the past five years, however most screening still occurs in provinces west of Quebec and in northern regions. Infants and young children are the groups most commonly screened. Recently, however some institutions such as youth detention centers, provincial jails and federal prisons have raised the possibility of in-take screening for FAS/ARBEs as a program that will assist them in improving rehabilitation services for individuals who enter their institutions. Although these programs are not yet in place, it is likely that within the next five years some type of in-take screening program will be adopted in at least some of these institutions.

Currently there is no information being collected about the number of persons screened in Canada for FAS/ARBEs, or about the percentage of individuals with positive screens and who are successfully referred for clinical assessment. A difficulty in determining this information is that screening is not coordinated by either provincial or federal governments, and standardized screening tools and protocols are not in place. One of the reasons why coordination of screening has not occurred is because the majority of individuals who screen positive will not have the opportunity, as will be discussed below, to be clinically assessed.

Risk of detection bias in FAS/ARBEs screening is very high because the individuals who are doing the screening are generally not trained in the medical assessment of patients for FAS and are using screening tools that are likely to produce a high percentage of false positives. In some instances, screening of individuals is based solely on the perception that a teacher, outreach or social worker has about the physical appearance and behavior of a person.

In the past five years a growing number of FAS training programs mostly designed for front-line workers, teachers, and other community workers who work with Aboriginal populations have been created. The goal of the programs are to train community workers so that they can go back to their communities and educate others about the risk of prenatal alcohol exposure and FAS/ARBEs. Some programs are funded in whole or in part by the federal and/or provincial governments and others are run as private consulting businesses. The trainers are generally individuals who do not have medical training but have experience working as front-line, addiction, or community workers, and have themselves attended training workshops on FAS/ARBEs. This group plays a central role in disseminating information about FAS/ARBEs, including information about various screening tools to teachers and community, outreach and social workers.

The individuals or organizations who operate these programs accept the estimated prevalence rates of FAS/ARBEs as accurate, and in their training convey the message that prenatal alcohol effects are common and that damage can occur at low threshold levels. While the programs have been instrumental in both raising awareness that alcohol is a teratogen that can cause birth defects, and in opening up a discursive space in which members of a community can speak about alcohol abuse and pregnancy (see for example, Anderson 2002:13-14), the programs nonetheless reinforce an image that FAS/ARBEs rates are considerably higher among the Aboriginal population, and that a substantial amount of the social problems experienced by Aboriginal peoples stem from birth effects caused by pregnant women drinking alcohol.

Of the people who screen positive for FAS/ARBEs only a small percentage will be successfully referred for an assessment, and the majority of these will be young children. The reasons why this situation exists will be discussed later, for the moment it should be simply noted that at the community level a common practice of informal labeling of individuals with FAS/ARBEs has emerged. A label of FAS/ARBEs can be applied by anyone to anybody however, generally there is a pragmatic reason behind someone assuming or being given the label. The most common reason for why someone is labeled FAS is so that they and their family can access specialized services, disability benefits, or other supports that they cannot access without the label of FAS. In some instances schools will label the behavioral or learning problems of a child as FAS because there is funding available for FAS rather than for other possible disorders or contributing factors[2]. While generally access to services and special funding involves a medical assessment and diagnosis of the child, in some instances an assessment and "diagnosis" by a school psychologist, for example, is enough to access certain supports and funding.

In other instances biological or foster parents, social workers, and teachers will label a child with FAS as a way to make sense of their behavior and learning problems,

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[2] According to teachers, this also happens with other labels such as attention deficit disorder (ADD).

and as a way to move the process along for receiving a medical assessment. In some contexts an entire group or population may be labeled as having FAS/ARBEs. For example, a principal from a small northern First Nations reserve community explained to me the difficulty that he was experiencing with non-Aboriginal teachers coming into the community and deciding that all the children were alcohol-affected and therefore could not learn. He expressed frustration at this growing phenomenon among teachers who had attended FAS training sessions and who now have the perception that large numbers of Aboriginal children are alcohol-affected. The concerns raised by the principal are echoed in accounts by a number of service providers who reported about their experiences after attending FAS training sessions. One front-line worker reported “seeing FAS everywhere” as he walked through the shopping mall in the northern city in which he lived.

Meconium[3] screening of neonates

According to many clinicians and researchers, identification of FAS/ARBEs in the first three years of life and appropriate follow-up clinical and support services can significantly improve the life trajectory of alcohol-affected persons. Recently neonatal meconium testing for prenatal alcohol exposure and neonatal hair testing for prenatal exposure to drugs have been introduced by the Motherisk Laboratory for Drug Exposure at the Hospital for Sick Children in Toronto. The meconium test involves the collection of a small sample of meconium from the diaper of a newborn which is then tested by the Motherisk laboratory for the presence of alcohol by-products called “fatty acid ethyl esters” (FAEE). Minimal amounts of FAEE are found in the meconium of neonates who are not exposed to alcohol prior to birth, as compared to larger amounts being present in the meconium of neonates exposed in utero to alcohol before birth. The justification for the design of the tests is that it will assist in determining whether an infant warrants a diagnostic follow-up. As further justification given by the creators of the test reads as follows:

> Together, FAS and ARND [alcohol related neurodevelopment disorder] affect nearly 1% of all children in Canada, yet only a fraction of these children is properly assessed. Some are misdiagnosed with conduct disorders, but most go undiagnosed. Those who eventually find their way to FAS/ARND specialists are often not seen until

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[3] Meconium is the first stool of a neonate after birth.

> major problems have occurred—problems that will lead many to failure in school, trouble with the law, inappropriate sexual behavior, depression, homelessness and a renewed cycle of alcohol and drug dependence. Only early diagnosis and treatment can save these kids from the burden of FAS and ARND before it takes hold of their lives. That’s why the Motherisk Laboratory for Drug Exposure has developed a screening tool using meconium (Motherisk 2003).

This type of screening is said to be justified despite the negative stereotyping of persons who are alcohol-affected, and even though the test lacks the ability to pinpoint the specific time (day, week, or month) during the pregnancy when the drinking occurred. The test is also unable to determine a correlation between the number of drinks a woman had during pregnancy and the concentration of FAEE found in the meconium. A positive test has no diagnostic value apart from indicating that a woman consumed an undetermined amount of alcohol during the last two trimesters of her pregnancy. It cannot provide information on patterns and levels of exposure or information about fetal damage.

The development of the meconium test raises several ethical questions about the surveillance of pregnant women and mothers of newborns including questions about how decisions will be made about screening and how this measure infringes upon their privacy. The creation of such a test also implies that women cannot be trusted to provide truthful information about their use of alcohol, and that other means of gaining “accurate” information is needed in order for society to “save” children that are harmed by their mother’s behavior. A further question is why, with overburdened health care budgets and a general consensus that inadequate treatment and support services for women with substance abuse problems exist, including pregnant women, that a decision would be made to invest health care resources into the development and implementation of a test that has limited diagnostic value. Added to this question is the reality that for the infants who are at risk for having FAS/ARBEs, awareness of their mother’s alcohol abuse is most likely already known by health care, social service, outreach providers and/or family members prior to the woman giving birth. While it is likely that meconium testing will involve an overrepresentation of low-income women and their offspring, there are other possibilities that should be considered. Specifically, that meconium testing will be used to detect alcohol use that is easily concealed by pregnant women but not a risk to their fetus, for example moderate and occasional drinking, and/or among women whose behavior is less likely to be under the surveillance of social or outreach workers and less likely to be screened, in particular among white, educated, middle class women.

Clinical assessments for FAS/ARBEs

In Canada, as in other parts of North America, obtaining a medical assessment for FAS is very difficult and for some patients virtually impossible. Assessments are more easily obtained in the western provinces, and in large urban centers, especially in Vancouver and Winnipeg where specific clinical services for FAS assessments are offered, and they are less frequently made in the provinces from Quebec eastward. The waiting list to access the services offered by the clinics are generally long, due partially to the significant amount of coordination and resources needed to bring together an expert team to undertake an assessment. The assemblage of a multidisciplinary team involves bringing together a pediatrician or geneticist to assess growth and dysmorphology, a psychologist or psychiatrist to assess the behaviors that would support the findings of CNS anomalies, such as mental retardation, learning disabilities or adjustment problems, physio- and speech therapists, and a family social worker. In some instances a physician will undertake patient assessment alone, this is especially true if the doctor has had previous experience in FAS assessment and if the physician believes that rates of FAS are high in the population they serve.

In Canada, the federal and some provincial governments have tried to address the long waiting lists for FAS assessments by providing screening and diagnostic training for physicians. However, while they are becoming increasingly familiar with the diagnostic criteria for FAS and other related diagnoses, there remains a certain level of reluctance on the part of most physicians to make a diagnosis of FAS/ARBEs (Loock 1998:169). This is mainly due to five intersecting factors: 1. physicians have limited training and experience in FAS diagnosis combined with the difficulties and expenses attached to the coordination of an interdisciplinary team of experts to make the diagnosis, 2. the lack of a “gold standard” diagnostic test, 3. the range of characteristics associated with a FAS diagnosis is diverse, with many distinctive not only of FAS but of other disorders (see Chapter Three), 4. the diagnostic features associated with FAS/ARBEs varying widely in severity from patient to patient and, 5. CNS impairment and facial abnormalities associated with FAS are difficult to identify or distinguish in some patient cohorts, particularly in infants, adolescents, and adults.

Some provincial governments have responded to the lack of availability of diagnostic assessments for FAS/ARBEs by creating innovative diagnostic programs. For example, traveling FAS clinics consisting of a pediatrician, psychologist, social worker, physiotherapist, and occupational and speech therapist have been formed to travel to remote Aboriginal communities in Saskatchewan. A similar outreach service delivery model is offered in British Columbia through the Children and Women's Hospital, in which a developmental pediatrician, psychologist, geneticist and psychiatrist see patients referred to this program (Roberts & Nanson 2000:56). Manitoba has operated a telediagnostic program for the past few years that links, through teleconferencing, specialists in Winnipeg with physicians and other health care providers in remote communities (Square 1999:627). As a result of these initiatives in Canada, a larger percentage of the Aboriginal than non-Aboriginal population has been screened and diagnosed with FAS/ARBEs.

Diagnostic paradigms and standardized measures in clinical assessment

In most clinical contexts in Canada, a minimalist diagnostic paradigm[4] has been used in the assessment of patients for FAS/ARBEs. As new diagnostic and screening technologies have been introduced, such as the 4-Digit Diagnostic Code (Astley & Clarren 2000) and the Fetal Alcohol Behavioral Scale (FABS) (Streissguth et al. 1996) these technologies, either in whole or in part, have been incorporated into clinical assessment and diagnosis. However, the incorporation of new diagnostic and screening technologies and their application has been inconsistent across clinical and research sites. Assessment of patients generally involves the use of standardized measures for features such as height, weight, facial characteristics, cognition, intelligence, and behavior. These measures are typically based on population averages from the United States and in a clinical context are rarely adjusted to reflect ethnic, cultural, and environmental variations that influence physiological and behavioral characteristics of the patients (Abel 1998a). Adjustment of standard measures to reflect local norms does occur in some

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[4] See Chapter Three for details of the diagnostic paradigm..

research studies through the use of control groups, however this is very difficult in clinical based research and services where patients are referred from diverse geographical regions.

Assessment of physical features

> *“Fetal alcohol syndrome refers to a specific cluster of anomalies…[including] characteristic facial features.”*
>
> Health Canada internet site
> http://www.hc-sc.gc.ca
> March 2003
>
> *“FAS/FAE can deform a baby’s face for life.”*
>
> First Nations and Inuit Health Branch
> Fetal alcohol syndrome/fetal alcohol effects internet site
> http://www.hc-sc.gc.ca/fnihb
> March 2003

The most clinically distinctive feature of prenatal alcohol effects is believed to be the “FAS face.” In early FAS research, the face of FAS was used as a way to identify affected children across ethnic, racial, and socioeconomic groups. Researchers have also produced the face of FAS in a mouse model (Sulik et al. 1981), which has been an important touchstone in supporting the link between prenatal alcohol exposure and morphological and neurobehavioral damage in offspring. While the face of FAS is recognized as the most clinically distinctive feature of prenatal alcohol exposure, researchers have found that the pattern of facial features typical of FAS patients—short palpebral fissures (shortened eye slits), thin upper lip, flattened philtrum (the ridge between the nose and lip), and flat midface—mirror features found in certain ethnic groups, including Aboriginal groups, independent of prenatal alcohol exposure (Roberts & Nanson 2000:54). For example, Jo Nanson, a Saskatchewan researcher stated: “the facial dysmorphology in native children with FAS can be somewhat confusing as many aboriginal children have epicanthus and a depressed nasal bridge. This appears to occur so commonly in aboriginal children that the physicians I work with feel it is simply a genetic variant and is not representative of fetal alcohol syndrome” (Nanson, personal communication in Abel 1998a:74). Nanson also reports that in her experience in Saskatchewan, an Aboriginal child with an unusual appearance and a mother who drank even a small amount during pregnancy is likely to receive a poorly substantiated diagnosis of FAS by primary care physicians (Nanson, personal communication, 1995 in Abel 1998a:7). To address the problem of misclassification, some researchers have called for diagnostic standards to be developed that reflect ethnic variation of the FAS facial phenotype (Godel et al. 2000). Others caution that until these differences are reflected in diagnostic assessments, diagnosticians need to guard against over-diagnosis and avoid using facial characteristics alone to support a diagnosis (Roberts & Nanson 2000:54).

Scientists who research FAS in Aboriginal populations have raised several other issues related to the misclassification of Aboriginal people. The use of standard growth measurements in diagnostic assessments have been identified as a possible source of patient misclassification because these standards may not reflect the local growth norms among a specific population (Roberts & Nanson 2000:54). For example, Chudley and colleagues (1999 in Roberts & Nanson 2000) found that children in an isolated Aboriginal community in Manitoba were typically taller and heavier than standard growth curves would predict. This, they suggest, may mask growth retardation caused by prenatal alcohol exposure, as children may not appear to have retarded growth based on the universal measures, but in fact may be small relative to other children in the community (Roberts & Nanson 2000:54). Average head circumference in some Aboriginal groups has been identified as being above North American averages, which according to some researchers, may mask decreased head size caused by prenatal alcohol exposure (Robert & Nanson 2000:54).

Critiques made about the application of diagnostic measurements based on "universal" standards to Canadian Aboriginal people almost always frame the problem of misclassification in terms of the potential for under, rather than over-diagnosis. However, it is as likely that Aboriginal children will be over-diagnosed if universal standards are used. For example, because a large percentage of Aboriginal children live in chronic poverty this will inevitably contribute to many of them falling below standard growth measurements due to the impact of environmental factors on their development, particularly under nutrition. In some Aboriginal populations, typical physical features such as short stature, could falsely suggest to diagnosticians that large numbers of children are alcohol-affected. While most community-based research attempts to adjust for local growth curves through the use of a control group (see for example, Conry 1990), this is not generally true for clinical studies or in patient screening and assessment where patients come from a number of different communities.

Growth deficiencies in some patients have also been found to decrease over the life span, and in "at-risk" populations where poverty, maternal use of tobacco and/or poly-drug use are common intersecting variables with prenatal alcohol exposure, measures such as low birth weight and growth retardation become unreliable bio-markers for FAS. When questions concerning standard measurements are combined with concerns over assessment of facial characteristics in Aboriginal children, the potential for over diagnosis in Aboriginal populations appears to be significant in two of the three diagnostic criteria used in patient assessment.

The importance of behavioral and cognitive dysfunction

> *"Children with FAS/FAE can have trouble learning and controlling their temper…An individual with FAS/FAE can have drug and alcohol problems, have difficulty keeping jobs, and get in frequent trouble with the law."*
>
> First Nations and Inuit Health Branch, internet site
> Fetal alcohol syndrome/fetal alcohol effects
> http://www.hc-sc.gc.ca/fnihb
> March 2003

Within the diagnostic paradigms that define FAS, behavioral and cognitive dysfunction is identified as the most debilitating birth outcome resulting from damage caused by prenatal alcohol exposure. Over the past thirty years researchers have been especially interested in correlating fetal alcohol exposure with functional and structural birth defects that affect the CNS. Research studies have ranged from postmortem examination of the brains of infants who, while in-utero, were exposed regularly to large quantities of alcohol and subsequently died after birth (Clarren 1986), to brain imaging studies involving patients diagnosed with FAS (see for example, Mattson et al. 1992, 1994, Sowell et al. 1996, Hannigan et al. 1995), to clinical research (see for example, Coles et al. 1997, Mattson & Riley 1997, Miller et al. 1981, Morse & Cermak 1994, Robinson & Conry 1986, Robinson et al. 1987, Spohr et al. 1993, Stromland 1985, Streissguth & Randals 1987, Streissguth et al. 1997) and animal studies (see for example, Eli & Krsiak 1976, Barron & Riley 1985, Hard et al. 1985).

Abel argues that beyond cataloguing behavioral and cognitive dysfunction, growth in our appreciation and, more importantly, our understanding of FAS/ARBEs and its uniqueness has been disappointing (1998a:134). Compounding this problem is the fact that behavioral and cognitive anomalies that researchers associate with prenatal alcohol exposure are impacted upon by environmental factors. They can also resemble dysfunction that stems from negative environmental influences independent of prenatal alcohol effects. Abel argues that this has inhibited the ability of researchers to clearly differentiate the uniqueness of FAS/ARBEs. For example, most of the children that have been identified in North America as having FAS/ARBEs, particularly those identified in the 1970s and 1980s, have experienced a very disruptive childhood that typically involves inadequate or inappropriate care by biological parents and other caregivers, and/or they have experienced multiple foster placements[5]. This, coupled with the lack of diagnostic tests that can precisely correlate fetal exposure with CNS damage makes it extremely difficult for researchers to confirm causal links between in-utero alcohol damage and cognitive and behavioral dysfunction (Abel 1998a).

In assessing behavioral and cognitive features, standard measurements are used to distinguish "normal" from "abnormal." What has emerged is the "typical" person with FAS or more recently the "FAS behavioral phenotype" (Streissguth 1997). Over the past thirty years, researchers have proposed a number of behavioral and cognitive features as indicators of brain dysfunction caused by prenatal alcohol effects, such as poor performance on tests of intelligence and educational achievement, impaired language development, poor impulse control, and problems with memory and judgement (Stratton et al. 1996:69). In the most recent addition of his text on FAS, Abel points out that after twenty-five years of FAS research, impressions of the syndrome are still largely derived from descriptive studies and anecdotes (1998a:111). He writes:

> The sheer number of behavioral and cognitive abnormalities associated with FAS/ARBE are now so extensive that at least three inferences seem warranted: (a) FAS/ARBE is a very destructive disorder; (b) it has a great many effects; and (c) it is so inscrutable that it has become a magnet attracting every problem for which alternative explanations are not

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[5] It is not uncommon for children in foster care to be moved more than five times before being placed in a more permanent foster home or with an adoptive family. In my field research many women reported as children being moved more than five times, with one young woman who was diagnosed with FAS reporting that she had been moved twenty times from the age of 0 to 18 years of age.

otherwise evident. In this context, greater attention to the syndrome's behavioral and cognitive aspects has meant more studies but not necessarily a better understanding of these problems (Abel 1998a:111).

The Institute of Medicine (IOM) in the United States echoes Abel's concern. It points out that a consensus has not been reached as to which behavioral and cognitive features are most appropriate for the diagnosis of FAS, or indeed, whether any are appropriate (Stratton et al. 1996:69). A central difficulty is that, like physical features, behavioral and cognitive features exist on a continuum that ranges from "normal" to "impaired." These features are also influenced by other factors such as parental intelligence, educational experience, an impoverished postnatal environment, and other social and cultural influences (Stratton et al. 1996:69). The IOM writes:

> In addition, these cognitive and behavioral features are less specific to FAS than are the physical features; they tend to change with time, and they also tend to occur in association with a wide range of childhood neurodevelopmental and psychiatric conditions, for example, fragile X syndrome and attention-deficit hyperactivity disorder. Further, the teratogenic effects of alcohol on such cognitive and behavioral features are less well established through studies using rigorous experimental designs, although ample anecdotal evidence has been presented in the clinical literature (Stratton et al. 1996:69).

However, as pointed out by Abel, "*the plural of anecdote is not data*" (1998a:131 emphasis in text).

Standardized psychological testing is routinely used to assess behavioral and cognitive dysfunction associated with FAS/ARBEs. These tools have been criticized for not being sensitive to variables such as culture, ethnicity, and socioeconomic status (Abel 1998a). Measurement, such as IQ may not reflect in a meaningful way levels of intelligence in individuals belonging to certain groups. For example, some Aboriginal children, especially those living in northern regions of Canada, receive much of their early childhood education in their indigenous language which makes psychological assessment in children very challenging (Nanson, personal communication, 1996 in Abel 1998a:136). Abel suggests that biases associated with such measurement tools may account, in part, for why Canadian Aboriginal children are reported to have the highest rates of FAS/ARBEs in the world (1998a:136).

Anti-social behavior as justification for diagnostic standardization: a case example

In the summer of 1999, I was approached by the Project Officer from Health Canada's Population Health Fund, to review a proposal for the standardization of FAS diagnosis that was submitted to them from a research unit in a large hospital in one of Canada's major cities. The goal of the project, as outlined in the proposal, was to "promote national understanding and agreement among healthcare professionals on the methods, measures, and biological markers for early diagnosis of FAS." This proposal sought to address the problem of meaning variance at a national level and had several merits as well as a number of shortcomings.

The goal of standardizing diagnostic criteria for FAS is not surprising given the range of difficulties clinicians experience in controlling meaning variance. However, in the researchers' justification for the project's funding they chose to emphasize almost exclusively the "scientific evidence" that adolescents with FAS exhibit anti-social behavior. This behavior, they argue, occurs particularly when individuals who have prenatal alcohol effects are not diagnosed at an early age, and can lead to a range of personal and social problems. Standardization and training of clinicians to properly diagnose FAS/ARBEs at an early age, the proposal suggests, has the potential to decrease anti-social behavior in alcohol-affected adolescents across Canada, and in turn to decrease youth violence and crime.

It is not entirely clear to me why the researchers chose to justify the benefits of diagnostic standardization by emphasizing the anti-social behavior in undiagnosed "FAS adolescents." However, it is clear that there is minimal scientific evidence to support their contention that either a direct or indirect link exists between FAS and anti-social behavior. What their argument is representative of is a growing discourse that associates FAS with anti-social behavior, especially violence. Their decision also reflects a certain reality that exists in federal government decision-making in conjunction with health research funding. These researchers are right in their assumption that the federal government is more amenable to supporting a proposal that shows a clear societal benefit that will be strongly supported by voters, in this case, the reduction of anti-social behavior that is apparently directly linked to a preventable cause, in-utero alcohol exposure, and to its under diagnosis. They are also right in assuming that a causal explanation for high rates of youth violence and crime appeals to government politicians and bureaucrats who are in the position of justifying funding to Canadian taxpayers. However, the dangers of arguments such as the one presented in the proposal, and the one described above in the Motherisk meconium testing pamphlet, is that they fuel a misperception that a range of societal problems, especially among youth, can be explained by a single underlying cause, prenatal alcohol effects. While this type of argument generally does not ignore the influence of environmental factors, it does privilege the importance of FAS/ARBEs over other causal explanations, thereby placing the greatest burden of blame upon the behavior of pregnant women and upon brain pathology.

Life span

The degree of "abnormality" in any one measure of the three diagnostic criteria of FAS, growth deficiency, facial characteristics, and behavioral and cognitive features, have been found by researchers to vary greatly between individuals and, in any single individual can change, sometimes dramatically, across the life span (Stratton et al. 1996:17). The IOM points out that indicators used to diagnose FAS were first codified in neonates, infants, and young children, however later research illustrated that the "FAS phenotype" varies with age, making it difficult to identify appropriate features for inclusion in diagnostic criteria that are not age specific (Stratton et al. 1996:70).

Conclusion

In this chapter I have discussed issues relating to the clinical application of the diagnostic category FAS and highlighted problems that have hindered diagnostic assessments across clinical sites. In this discussion I raise several diagnostic issues that are of particular importance in the assessment of Aboriginal patients and populations that may account for the significant over-representation of Aboriginal people in clinical research and assessments in Canada.

Section Three
THE “INDIAN PROBLEM” AND FETAL ALCOHOL SYNDROME

Introduction

In this section I will argue that a master narrative of the “Indian problem,” which has evolved from the early contact period onward in Canada, has framed relations between Aboriginal and non-Aboriginal groups. Despite various transformations in Canadian society, this master narrative has continued to be reproduced through colonialist and neocolonialist[1] strategies aimed at controlling, monitoring, and intervening in the lives of Aboriginal people. While first invoked by the both the Church and the State as justification for various assimilation strategies, the “Indian problem” has persisted as an organizing narrative in medical, social service and government surveillance and interventions that target Aboriginal groups. In this process a social and moral landscape that reinforces the perception that Aboriginal people are biologically and socially “inferior” to their non-Aboriginal counterparts has been reinforced. Many of the practices that have been supported by this narrative, such as the establishment of the residential school system, and more recently the practices of child welfare services, have inflicted significant harm upon Aboriginal individuals, families and communities, while simultaneously going virtually unchallenged and unchecked by the larger society.

In this section I discuss how the knowledge and practices attached to the category “fetal alcohol syndrome” have come to mark a re-making of Aboriginal bodies and populations in the current moral and social landscape in Canada. I argue that the association of FAS with Aboriginal people is one in which constructions of “Aboriginal inferiority” are re-scripted onto the bodies and behavior of Aboriginal women and their offspring, reinforcing a perception of failed parenthood and widespread pathology that is used to explain social problems, especially among urban Aboriginal youth populations, such as high rates of school drop-out, alcohol and drug abuse, criminal behavior, and “sexual deviancy,” including teen pregnancy.

Further, I argue that FAS has emerged as an internalized problem for Aboriginal communities and individuals in that it has come to signify for many, including national,

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[1] I use the term neocolonialism to refer to the present day context in Canada *vis a vis* Aboriginal peoples. I do so in light of the fact that there has not been a process of de-colonization in Canada as has occurred in

provincial, and local leaders, one of the most devastating and serious problems facing their communities in the twenty-first century. This has occurred in conjunction with broader beliefs held by First Nations, Inuit, and Métis about the health, social and economic problems that confront their communities, and what they believe should be done about them.

Technologies of discipline, surveillance, and governance

From the contact period onward in Canada various forms of discipline, surveillance, and governance have characterized the relationship that Aboriginal people have had with European colonizers. During the nineteenth century a shift in indigenous-European relations marked the beginning of a new era of colonialist incursion into the lives of indigenous peoples in Canada. Where once relative cooperation had defined this relationship, it now was characterized by antagonism and disinterest on the part of the colonialist government which realized it had little reason to foster an equitable relationship with indigenous groups (Miller 1991a:xi). Europeans and Euro-Americans found they no longer had a direct use for indigenous peoples as had earlier fur traders and settlers who relied on indigenous people to teach them survival skills and to provide them with furs for trade. With the decline in the fur trade and increased immigration and agricultural settlement, indigenous people became far less attractive commercial partners to Europeans (Miller 1991a, 1991b). Military alliances with indigenous groups were also far less important with the end of the War of 1812 and the Rush-Bagot Convention of 1817, which brought enduring peace between the United States and British North America (BNA) (Miller 1991a:xi).

For Europeans, indigenous people had become irrelevant to their long-term objectives of peace and settlement (Miller 1991b:84). Miller argues that with indigenous people no longer being needed for military purposes, and because they no longer posed an obstacle to settlers' development of an agricultural economy, two options were open to Euro-Canadians: assimilating indigenous people through coercively making them adopt European ways and behaviors, or exterminating them through disease and violence (1991b:94). Extermination through violence, however was not a real option for various

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some other colonized countries, and that Aboriginal people are in effect engaged in processes towards self-determination and self-government which would bring them into a "post-colonial" context.

reasons, including the economic cost and the loss of European lives that this violent strategy would require. Moral outrage from humanitarian organizations in Britain also had the potential to cause enormous political trouble for the imperialist government if it followed an overtly violent strategy (Miller 1991b:94). However, extermination of indigenous people by disease was already occurring, and indifference by Europeans proved to be a viable passive strategy. Miller writes that it was easy for colonialist society to let populations of Aboriginal people wither away largely as a consequence of disease brought by Europeans (1991a:xi).

Assimilation became the central strategy for colonialist governments after indigenous groups were no longer needed militarily or economically. According to Tobias, protection, civilization, and assimilation have always been the goals of Canada's Indian policy (1991). The perception held by the government of Canada was that indigenous people were incapable of dealing with Europeans without being exploited. The government thus took the position that the best way to "protect" indigenous people was by designating them special status within the political and social structure of Canada (1991:127). This special status became part of the constitutional structure of Canada through Section 91, Subsection 24, of the British North American Act of 1867, and gave the government exclusive jurisdiction over "Indians and Indian land" (Tobias 1991:127). Tobias adds:

> …the legislation by which the governments of Canada sought to fulfil their responsibility always had as its ultimate purpose the elimination of the Indian's special status. The means to achieve this goal was by training, that is, 'civilizing,' the Indian in European values, to make him capable of looking after his own interests. Eventually, through this training, the Indian identity and culture would be eradicated, and the Indian would be assimilable and no longer in need of special status (1991:127).

Biopower

In this section I examine the discourse and practices adopted by Europeans in their efforts to deal with indigenous populations in a context of expanding settler society, economic growth and globalization. I draw upon the work of French social theorist Michel Foucault and his discussion of technologies of discipline and surveillance. According to Foucault, the West has undergone a profound transformation of power away from the right of the sovereign to seize things, time, bodies and ultimately life through violent means, such as public executions and military occupations, to an apparently benevolent, but equally invasive and effective form of social control "situated and exercised at the level of life, the species, the race, and the large scale phenomena of population" (1978:136-137). Foucault argues that "bio-power" began to emerge as a coherent political technology in the seventeenth century, and was constituted around two poles: "anatamo-politics of the human body" and "bio-politics of the population."

"Anatamo-politics of the human body" refers to knowledge of and power over the individual body through disciplinary technologies that represent the body as machine. The body is disciplined, its capabilities optimized, its forces harnessed, its usefulness and docility increased as it becomes integrated into systems of efficient and economic controls (Foucault 1990:139). Disciplinary practices are situated within social institutions such as hospitals, schools, and prisons, and in micropractices of everyday activities and habits of individuals. The effectiveness of disciplinary power is not through threats of violence or force but instead by creating desires, attaching individuals to specific identities, and establishing norms against which individuals and their behaviors and bodies are judged and against which they govern themselves (Foucault 1978, 1990).

"Biopolitics of the population," the second pole, refers to control over and regulation of the species' body and is concerned with the basis of the biological processes, such as propagation, births and mortality, the level of health, life expectancy and longevity, as well as with the conditions that can cause these to vary (Foucault 1990:139). This form of bio-power is inscribed in policies, laws, and interventions governing a population. The collective body is the target of state interventions and the object of study in fields such as epidemiology, demography, public health, and health economics (Foucault 1990).

These two poles of bio-power deploy the organization of power over life. As a result a rapid development and expansion of new forms of discipline and surveillance that coincided with the emergence of new techniques of quantifying "problems" expressed through categories such as birthrate, longevity, public health, housing and migration emerged (Foucault 1978:140). All subjugated bodies and controlled populations. Biopower effectively produces "objective measures" that are invoked to do "work," meaning that they are made central in a commentary on social life that, as Lock points out, forces itself, selectively into our consciousness (1997:273).

Bio-power was an indispensable element in the development of capitalism because it made possible the "controlled insertion of bodies into the machinery of production and the adjustment of the phenomena of population to economic processes" (1990:141). As well, capitalism needed the growth, reinforcement, availability and docility of bodies offered by both poles of bio-power: "it had to have methods of power capable of optimizing forces, aptitudes, and life in general without at the same time making them more difficult to govern" (Foucault 1990:141).

Normalizing technologies

A primary outcome of bio-power is the emphasis placed on normalization. A whole set of disciplinary techniques and institutions for measuring, supervising and correcting the abnormal in the social body were brought into play, and functioned to impose a standard of normalization that appears to be "naturally" the only acceptable one (Foucault 1979:199; Dreyfus & Rabinow 1983:193). An essential component of these technologies is that they themselves are an integral part of the systematic creation, classification, and control of anomalies (Dreyfus & Rabinow 1983:195). "Their *raison d'etre* comes from their claim to have isolated such anomalies and their promises to normalize them" (Dreyfus & Rabinow 1983:195).

Foucault argues that the advance of bio-power is contemporary with the appearance and proliferation of the very categories of anomalies that technologies of power and knowledge were supposedly designed to eliminate (Dreyfus & Rabinow 1983:195). Dreyfus and Rabinow add that the spread of normalization operates through the creation of abnormalities that it then must treat and reform. By identifying the anomalies scientifically, the technologies of bio-power are in a perfect position to supervise and administer (1983:195-195).

Normalizing technologies effectively transform political problems into technical problems in that they remove the problem from the realm of political discourse and re-situate it within the neutral language of science. This means that the problem is now a technical one for specialists to debate, an aspect of normalizing technologies that is essential as it establishes a technical matrix (Dreyfus & Rabinow 1983:196). Dreyfus and Rabinow write:

> Bio-power spread under the banner of making people healthy and protecting them. When there was resistance, or failure to achieve its stated aims, this was constructed as further proof of the need to reinforce and extend the power of the experts. A technical matrix was established. By definition, there ought to be a way of solving any technical problem. Once this matrix was established, the spread of bio-power was assured, for there was nothing else to appeal to: any other standard could be shown to be abnormal or to present merely technical problems. We are promised normalization and happiness through science and law. When they fail, this only justifies the need for more of the same (1983:196).

The examination

The procedure that brings surveillance and normalizing judgement together is the examination. The examination acts as "a normalizing gaze, a surveillance that makes it possible to qualify, to classify and to punish. It establishes over individuals a visibility through which one differentiates them and judge them" (Foucault 1979:184). Within the highly ritualized context of the examination, disciplinary practices allow for the subjection of those who are perceived as objects and the objectification of those who are subjected (Foucault 1979:184-185). Disciplinary power in this context is exercised through its invisibility, while simultaneously it imposes on those whom it subjects to its gaze a principle of compulsory visibility. This visibility assures the hold of power that is exercised over them. "It is the fact of being constantly seen, of being able always to be seen, that maintains the disciplined individual in his subjection. And the examination is the technique by which power, instead of emitting the signs of its potency, instead of imposing its mark on its subjects, holds them in a mechanism of objectification" (Foucault 1979:187).

Foucault argues that the examination leaves behind a "whole meticulous archive constituted in terms of bodies and days. The examination that places individuals in a field of surveillance also situates them in a network of writing; it engages them in a whole mass of documents that capture and fix them" (1979:189). A "power of writing" became an essential part of the mechanism of discipline: in the example of the examination, the constitution of the individual was a describable, analyzable object that maintained him in his individual features, in his particular evolution, in his own aptitudes or abilities, under the gaze of a permanent corpus of knowledge (Foucault 1978:190). Documentation enabled the constitution of a comparative system that measured overall phenomenon, the descriptions of groups, the characterization of collective facts, the calculation of the gaps between individuals and their distribution in a given “population.” Foucault argues that these small techniques of notation, of registration, of constituting files, of arranging facts in columns and tables, that are very much taken for granted to us now, were instrumental in the “epistemological ‘thaw’ of the sciences of the individual” (1979:190-191). The examination is only one example of this new modality of power “in which each individual receives as his status his own individuality, and in which he is linked by his status to the features, the measurements, the gaps, the ‘marks’ that characterize him and make him a ‘case’” (1979:192; see also Gigerenzer et al. 1989).

Foucault’s study of clinical medicine illustrates that writing and imaging technologies produce new ways to argue, prove and believe. He argues that medicine did not become scientific in the mind or eye of its practitioners, but rather in the application of new fact sheets inside new institutions such as the hospital (1975). Foucault did not limit his analysis to inscriptions such as files, accounting books and timetables, but he also examined the kinds of institutions in which these types of inscriptions figured so prominently.

The “panoptic gaze”—the gaze of the guard who in his tower can watch over all the prisoners in the building without being seen—has become synonymous with apparatus of social control (Escobar 1995:155). The “panoptic gaze” allowed penology, pedagogy, psychiatry and clinical medicine to emerge as full-fledged sciences from their systematically maintained files. The panopticon was one way of creating the perfect disciplining apparatus that made it possible for a single gaze to see everything constantly.

Technologies of discipline reconstituted the spaces and reorganized the timing within which people functioned. Foucault writes,

> Hierarchized, continuous and functional surveillance…was organized as a multiple, automatic and anonymous power; for although surveillance rests on individuals, its functioning is that of a network of relations from top to bottom, but also to a certain extent from bottom to top and laterally; this network ‘holds’ the whole together and traverses it in its entirety with effects of power that derive from one another: supervisors, perpetually supervised…This enables the disciplinary power to be both absolutely indiscreet, since it is everywhere and always alert, since by its very principle it leaves no

> zone of shade and constantly supervises the very individuals who are entrusted with the task of supervising; and absolutely "discreet," for it functions permanently and largely in silence. Discipline makes possible the operation of a relational power that sustains itself by its own mechanism and which, for the spectacle of public events, substitutes the uninterrupted play of calculated gazes (1979:175-176).

For Foucault, knowledge grants power which is a precondition for knowledge; and power is diffuse and involves the collaboration of the consumers of knowledge as well as the producers. However, Foucault's argument rejects any suggestion of false consciousness. To understand power in it materiality, its day-to-day operation, he argues, it is necessary to examine micropractices, the political technologies in which practices are formed (1979, 1990). Power, therefore, is a general matrix of force relations at a given time in a given society; in these relations, power comes from below as well as above (Dreyfus & Rabinow 1983:186). Foucault concludes:

> The individual is no doubt the fictitious atom of an 'ideological' representation of society; but he is also a reality fabricated by this specific technology of power that I have called 'discipline.' We must cease once and for all to describe the effects of power in negative terms: it 'excludes,' it 'represses,' it 'censors,' it 'abstracts,' it 'masks,' it 'conceals.' In fact, power produces; it produces reality; it produces domains of objects and rituals of truth. The individual and the knowledge that may be gained of him belong to this production (1979:194).

Taking ownership

Foucault (1979) claims that more subtle tactics of disciplinary power have replaced the violent tactics of the sovereign. He represents power as exercised rather than possessed, as decentralized rather than exercised from the top down, and as productive rather than repressive (Sawicki 1991:52). Individuals and groups do not possess power but rather occupy various and shifting positions in this network of relations—positions of power and resistance (Foucault 1979). The art of government, therefore, lies both within the art of self-government by individuals, which is linked to morality, and within the art of governing populations, which belongs to the science of ruling the state (Foucault 1982).

Foucault's argument provides a framework in which to situate Aboriginal and non-Aboriginal relations in Canada. As will be illustrated in this Section, both repressive and disciplinary power exercised at different periods and at different sites, such as in residential schools or within the reserve system, has simultaneously defined the relationship that Aboriginal people have had with European colonizers. The impact of colonization upon Aboriginal communities has led in many contexts to a loss of indigenous language, traditional knowledge and cultural practices, and a breakdown of traditional political and social structures. While in recent decades Aboriginal groups have attempted through a resurgence of activities associated with traditional indigenous knowledge, language, and practices, to regain and restore some of what was lost, they nevertheless are firmly entrenched in the larger dominant social and political structure of Canada, and within an increasingly homogenized Western cultural and moral landscape.

Within this dissertation I have used the term "Aboriginal" as a homogenous category that refers to First Nations, Inuit and Métis individuals and populations, and I have implied that their indigenous identity and shared experience of colonization has demarcated them from the dominant "non-Aboriginal" society. However, in order to fully understand disciplinary power as a concept that applies to the lived experience of "Aboriginal people" in Canada, we must acknowledge the heterogeneity of those individuals and populations who are placed, or place themselves, within this category. Most specifically, it must be pointed out that European colonization and assimilation was not uniform across Aboriginal communities and nations. For example, some indigenous groups have had contact with Europeans since the 17th century, while for others, contact with Europeans has been much more recent. As well, the different categories that have come to demarcate Aboriginal groups, such as "status-" and "non-status Indian," or First Nation, Métis, and Inuit commonly have fluid and shifting meanings for those who occupy these categories. They are inclusive and exclusive, self-imposed and imposed by government, and have the power to define a person's relationship to the Canadian State. The category "Aboriginal," as discussed in Chapter Two, has also been embraced by a growing number of First Nation, Inuit, and Métis to express their collective identity; however, some individuals and groups reject this category and a collective Aboriginal identity, and instead stress other identities such as First Nation or Mohawk.

Heterogeneity among Aboriginal groups also falls along the lines of economic and social stability and prosperity. For example, while some Aboriginal groups have experienced relative economic prosperity and social stability despite the undermining by colonialist forces upon their social, economic, and political structures, other groups for several generations have experienced endemic poverty, poor health, and unstable social and political structures at local and regional levels. Factors such as geographical proximity to urban centers, and whether a group controls local and regional infrastructure such as education, law enforcement, and social welfare, have further added to the diversity found across Aboriginal populations in Canada. The growing number of educated middle-class Aboriginal professionals who are trained in Western traditions of education, law, social work, medicine, and social sciences further add to the various and shifting positions that Aboriginal individuals and groups occupy within networks of relations with non-Aboriginals and within the Aboriginal collectivity.

Resistance by Aboriginal groups to government surveillance and control over their populations is neither uniform nor consistent. Ideas about what "post-colonial" Canada should look like for First Nations, Inuit and Métis in relation to Aboriginal self-government, including issues concerning land and resource allocation, as well as social and political structures, are contested at national, regional and local levels. However, increasingly First Nations, Inuit and Métis use the metaphor of "ownership" to re-conceptualize their position *vis a vis* the dominant health, social service, legal and educational systems that are mandated by federal, provincial and territorial governments to address the "problems" that exist in their communities. Taking "ownership" of health and social problems implies for Aboriginal communities a level of control and autonomy, particularly a recognition that they are collectively willing and, more importantly, able to take on the responsibility and burden of effectively dealing with these problems within local communities, Nations or the national Aboriginal collectivity. However, while on the one hand "ownership" and "control" implies a level of autonomy and capacity on the part of First Nations, Inuit and Métis, such a metaphor risks, on the other hand, the elimination of non-Aboriginal responsibility for past and present behavior towards Aboriginal groups (Kelm 1998:viii).

Politics and the health, healing, and wellness of Aboriginal people

From the inception of colonization, Aboriginal people have not differentiated political resistance and unrest from local or national health, social, and economic problems (Royal Commission on Aboriginal Peoples 1996). Collective and individual "health," "healing" and "wellness" are assumed to be necessary to overcome the challenges that Aboriginal people face in their communities and in their struggle for self-determination (Adelson 2000). In this context, health and wellness are simultaneously viewed as issues of politics and resistance. For example, Aboriginal people have collectively contested the ways in which an assumed Aboriginal "health crisis" has been created and perpetuated by the medical profession and by related policies and practices of colonial and neo-colonial governments that have been justified by a recognition of such a "crisis" (Kelm 1998:xvi). However, in their resistance to mainstream biomedical and social work institutions, Aboriginal people have emphasized the inability and ineffectiveness of the practices, interventions, and strategies attached to these institutions to address the needs of their people, and have been less critical of biomedical and social work nomenclature. While First Nations, Inuit, and Métis have sought to redefine issues negatively affecting their communities and by doing so to locate where the burden and responsibility lies if these issues are to be dealt with effectively, they have emphasized changing service delivery rather than emphasizing changing how specific medical and social "problems" are labeled and defined.

Consensus on the issue of FAS

Notably with respect to FAS, limited controversy exists between Aboriginal groups and the dominant society about etiology, diagnostic criteria, or the associated risks. When controversy does arise, it occurs in relation to resource allocation, the parameters of appropriate treatment, and support models provided for pregnant Aboriginal women who abuse alcohol and for persons with FAS/ARBEs. The tension around these issues is not specific to FAS, however, but part of larger debates over government health transfers, allocation of funding and programming, and control over design and delivery of culturally appropriate services by, and for, Aboriginal people.

As discussed in Section Two, several diagnostic issues exist that could be interpreted as controversial by Aboriginal groups because they indicate a significant risk for over-diagnosis and inappropriate labeling and surveillance, yet this has sparked virtually no concern or questioning from them. The diagnostic criteria for FAS are understood by Aboriginal groups, as by the dominant society, as a reflection of what actually exists. The category of FAS and the knowledge and practices attached to it are believed to be value-free, a status validated for both Aboriginals and non-Aboriginals by FAS having been diagnosed in diverse ethnic and cultural groups around the world and not just in Aboriginal populations. It is also validated for Aboriginal people by their broader perceptions about alcohol use, “intergenerational trauma,” and the processes and impact of colonization on their communities.

Outline of the argument

In Chapter Seven I discuss the master narrative of the “Indian problem” and the concept of “biopower” as an entry point to examine colonial and neo-colonial “management” in Canada of Aboriginal peoples. Chapter Eight examines the consensus that has arisen between Aboriginal peoples and the dominant society that the individual and collective bodies of First Nations, Inuit and Métis have to a considerable degree been re-made by processes of colonization that are filtered through understandings of “intergenerational trauma.”

Chapter Seven
THE “INDIAN PROBLEM”

Introduction

In this chapter I explore the master narrative of the “Indian problem” in relation to the control and surveillance of Aboriginal individuals and populations. I argue that this master narrative is currently situated within a larger context: indeed, a great deal of anxiety exists in Canadian society as a whole about the number of impoverished Aboriginal families living in reserve communities and the growing numbers moving to inner city ghettos. It is also situated within the larger global context, particularly the discursive arenas of international public health and programs for development. I argue that “poverty” acts as an organizing concept in these arenas where a technical universalizing language of quantifiable “problems” effectively locates the lived experience of Aboriginal peoples within national and global contexts in which historical processes and cultural differences are masked.

The “Indian problem”

The “Indian problem” for a succession of colonialist and neo-colonialist governments has generally been constructed in two, albeit overlapping, ways. The first, as a problem *for* government, at different periods has manifested itself in various forms of resistance and unrest by Aboriginal groups to colonialist expansion and government policies, specifically resistance to loss of control over land and resources and loss of collective autonomy through legislation known as the *Indian Act*. Aboriginal resistance, from the outset right through to the present day, as is evident from recent cases such as the “Oka crisis” (Kanasatake), has been of great political concern to all levels of government.

Protest by First Nation, Inuit and Métis groups has generally been viewed by the larger society as a barrier to assimilation, progress, and modernization within Aboriginal communities. Resistance to government strategies of assimilation, along with calls from Aboriginal groups for justice, apology, and compensation for past assimilation strategies, such as the residential school system, remain contentious and controversial issues which significantly influence Aboriginal and non-Aboriginal relations in Canada. Calls by Aboriginal leaders for negotiations of self-government and settling of land claims generate strong, often emotional, responses from many Canadians who picture reserve and urban Aboriginal communities as “nests of hopelessness” (Dophin 2002), where social problems such as alcohol abuse, chronic poverty, violence, crime and more recently, FAS/ARBEs are endemic. Self-government appears in this picture to most Canadians as misguided because it is viewed as not offering an appropriate solution to the “problems” that they believe plague Aboriginal communities.

Given this situation, it is not surprising that the second way in which the “Indian problem” is conceptualized is through arguments about how to resolve various health and social issues that are perceived to be endemic in First Nations, Inuit and Métis communities. From this perspective, Aboriginal peoples are seen to *have* problems, a great many in fact, and it is the “moral responsibility” or, as is commonly insinuated, the “moral burden” of the dominant society acting through organizations funded or housed within governments, to come up with solutions to address these problems.

In the latter half of the twentieth century, overt discourse about the “civilizing” of the minds and bodies of Aboriginal people has increasingly been replaced with the “neutral” language of science and medicine, and a focus on “inferior” health (epitomized by lower life expectancy and higher infectious disease rates) and social “problems,” including high rates of teen pregnancies, alcohol abuse, school dropout, and criminal behavior of Aboriginal peoples. Fetal alcohol syndrome (FAS) is one example of this transformation in the master narrative of the “Indian problem” from a “civilizing” discourse to one of “identification,” “prevention” and “treatment/intervention.”

While in recent decades the “problems” that have drawn the greatest attention are designated as health and social problems, “economic problems” also loom large in this context. However, economic problems are generally viewed by the dominant society as outcomes rather than the source of health and social problems. For example, chronic poverty experienced by many Aboriginal people is generally seen to be the outcome of social problems such as high rates of alcohol abuse, school drop-out, and teen pregnancies that are attributed to defects either in the character of individuals or, as discussed previously, in Aboriginal cultures.

Global culture and political economy

Concern by governments and the larger society about how best to address "Indian problems" has increased over recent decades because the impoverished state of many reserve communities in Canada has become more visible. A post-World War II restructuring of global culture and political economy generated by the "discovery" of mass poverty in many parts of the world led to Aboriginal peoples in Canada being linked in the latter half of the twentieth century to international public health and development endeavors (Escobar 1995:22). Comparison of the health and social indices of indigenous peoples in "developed" countries, such as Canada, the United States and Australia, with global indices identified these groups as "Fourth World" populations with comparable rates of poverty to that of some "Third World" countries.

Public interest in Aboriginal issues also increased significantly after 1945 largely due to the strong contribution by Aboriginal people during the war effort in the years 1940-1945. Tobias writes:

> The public was generally concerned with what was regarded as the treatment of the Indian as a second-class person and with the fact that the Indian did not have the same status as other Canadians. In fact, the Indian was not even a citizen. Veterans' organizations, churches, and citizen groups across the country called for a royal commission to investigate the administration of Indian affairs and conditions prevailing on Indian reserves. All wanted a complete revision of the *Indian Act* and an end to discrimination against the Indian (1991:139).

The circumstances of Canadian Aboriginal people have also received increasing international and national media attention, especially as the gaps in social and health indices between mainstream Canadians and Aboriginal groups persist despite development efforts targeting Aboriginal populations. First Nation, Inuit and Métis have also found more effective ways to voice their criticisms of governments, including various forms of protest and resistance that are often made in conjunction with global-based indigenous movements. Further, they have taken their concerns and criticisms to international organizations such as the United Nations and the World Health Organization. Aboriginal people have also voiced their criticism and resistance through international, national and local media venues, including Aboriginal-owned media outlets.

Visible and off the reserve

The growing number of urban Aboriginal "poor," especially in western cities like Winnipeg, Regina, Edmonton, and Vancouver, have emerged on the social landscape as a population that are perceived to be riddled with "problems." "Aboriginal ghettos" such as the North-end of Winnipeg or the Downtown East Side of Vancouver are associated with a number of social problems such as alcohol abuse, street gangs, violence, prostitution, illicit drugs, chronic unemployment, teen pregnancies, and crime. This litany of social problems, unlike those that are similarly perceived to exist in reserve communities, increasingly spill over into non-Aboriginal neighborhoods, leading to calls by urban dwellers for governments to do something about the "Indian problem."

No longer living out of sight in reserve communities or in residential schools, the urban Aboriginal population stands out not only as representing the poorest of the poor, but also as a population, mainly of youth, "in crisis." This new visibility shows them facing insurmountable internal health, social and economic problems, while simultaneously living within centers boasting widespread prosperity, stability and security among the general population.

High fertility rates among Aboriginal populations imply to many Canadians, especially in the western provinces where the large majority of Aboriginal people live, that the "Indian problem" will increase exponentially if solutions are not found. The added dimension of a serious illness such as FAS, which is believed to result in chronic brain damage to offspring, has further fueled the sense of urgency to address problems in urban and rural locales. In this context, the bodies and behavior of Aboriginal women, particularly when pregnant, have come under significant monitoring by medical, public health and social service agencies, as has that of their offspring, and the results of this monitoring are incorporated into ongoing government strategies to control Aboriginal reproduction, parenting and family life (see Section Four).

The "Indian problem" and biopower

Colonialist understandings of indigenous people in Canada often viewed culture and nature as two opposing poles in which the immoral, "wild nature" of the indigenous mind and body were understood as being in need of taming, or "civilizing," through colonialist strategies of transformation, conversion, and assimilation (Kelm 1998, Lux

2000). Aboriginal and non-Aboriginal relations were marked by an increase in overt discipline when governments, particularly the federal government, practiced systematic surveillance and introduced mechanisms of control over Aboriginal bodies and populations. This was carried out through the creation of social institutions such as the residential school and reserve systems, through legislation, specifically the *Indian Act*, and through increased medical scrutiny by public health and social service agencies.

Maori social theorist Linda Tuhiwai Smith suggests that within processes of colonization of indigenous peoples throughout the world, the master narrative of the “indigenous problem” or the “indigenous question” finds its origins in wider discourses of racism, sexism, and further ways of positioning the “Other” (1999:90). She argues that the neatness and simplicity of how the “indigenous problem” is framed, along with ongoing efforts of “mapping it, describing it in all its different manifestations, trying to get rid of it, laying blame for it, talking about it, writing newspaper columns about it, drawing cartoons about it, teaching about it, *researching* it, over and over…[has given the term its] power and durability” (Smith 1990:90-91; emphasis in text).

Nandy (1989) argues that colonization is marked by different phases that are driven by different economic needs, and differing ideologies of legitimization. Even the “well-meaning, middle class liberal” intention of salvation has translated into real consequences for the nations, communities, and groups of indigenous people being colonized. Nandy describes these consequences as leading to a “shared culture” for those who have been colonized and for those who have done the colonizing. In this context, colonized peoples share with one another a language of colonization, share knowledge about their colonizers, and, in terms of a political project, share the same struggle for decolonization. Further, the colonizers also share in a language and knowledge of colonization (Nandy 1989 in Smith 1990:45).

Historian Mary-Ellen Kelm argues that in Canada the bodies of Aboriginals have been central in the dialectic interplay between European colonizers and First Nation, Inuit and Métis groups. She suggests that talking about the “problem” of “Aboriginal health” and how it might be solved has situated the “Aboriginal body” over the last 200 years at the very center of how Canada’s colonizing relationship with First Nations, Inuit and Métis is understood by both Aboriginal and non-Aboriginal groups (Kelm 1998:xv). The bodies of First Nations, Inuit and Métis have been the targets of disciplinary practices such as regimes of hygiene, Christian conversion and piety, forced bodily restraint through institutionalized processes, and, most recently, intense medical and social work surveillance.

Central to colonialist surveillance, Kelm argues, was the question of how these bodies could be changed and how those changes would make Aboriginal people better able to deal with the "civilized" world (1998:xvi). Prescriptions about "appropriate" clothing, hair styles, language, religious expression, gender identity and behavior inscribed on the bodies of Aboriginal peoples, have acted as signifiers of local social and moral worlds that reinforced an image of biological and social inferiority of Aboriginal people in relation to their non-Aboriginal counterparts. For example, by the 1930s throughout Canada roughly seventy-five percent of all First Nations, as well as significant numbers of Métis and Inuit children between the ages of seven and fifteen, were forced by the Canadian government to attend residential schools (Fournier & Crey 1997:61). The philosophy of the school system was that expressions of Aboriginal cultures and individuality were to be suppressed. From the moment the children entered the schools, physical and cultural markers such as long hair and clothing were removed and replaced by European fashions (Fiske 1996, Gresko 1986, Haig-Brown 1988, Miller 1987, 1996). Each child was assigned a number and a European name and they were forbidden to speak their indigenous language. Strict regimentation of student activities characterized daily life at the schools and severe punishment, often performed in front of other students as a warning to them, was handed out to those students who disobeyed and broke school rules (Fournier & Crey 1997:57, Miller 1996).

In the early twentieth century, overt colonialist methods of discipline and surveillance of Aboriginal populations and individuals began to take on a subtler, yet equally controlling role in the lives of Aboriginal people. Aboriginal populations were increasingly monitored and measured through various statistical accounting of a range of health, social, and economic "problems" associated with their communities. Kelm adds that a central notion throughout colonization which continued into the twentieth century was that Aboriginal bodies were "naturally," inevitably stressed once in contact with Europeans (1998:xvi). In relation to British Columbia, for example, she writes:

> Medical surveys, beginning in the early twentieth century in British Columbia, sustained the persistent impression that Aboriginal people were, by nature, sick. This view contributed less to ameliorative efforts than to a general feeling of hopelessness around issues of Aboriginal health. In effect, Aboriginal bodies were made, in part, by the colonizing governance of the Canadian State and its allies, the medical profession, the churches, and the provincial government (Kelm 1998:xvi).

Aboriginal bodies and culture were seen as bearers of the social relations of health and illness (Kelm 1998: 41). For example, in the early twentieth century, public health problems in reserve communities were believed to be the result of unwilling First Nations people to adopt "civilized" methods of sanitation. In other cases, it was argued that Aboriginal people were incapable of adapting to non-Aboriginal standards of cleanliness (Kelm 1998:39). Colonialist governments particularly criticized women for endemic health problems found in Aboriginal communities (Carter 1996). This is indicated, for example, by the statement of the first Chief Medical Officer to the Department of Indian Affairs, Dr. Peter Henderson Bryce, who accused First Nations women of being the source of ill-health and filth because they were unable or unwilling to improve their domestic abilities (Kelm 1998:40).

High death rates from tuberculosis were attributed to the move to permanent dwellings on reserves and the inability of First Nation women to adapt their cleaning strategies, which Bryce firmly saw as a problem of indigenous consciousness. Bryce's assumptions indicate that the individualization of disease was overlaid early on in the colonial period with notions of "culture," implying that whole nations were collectively regarded as being implicated in their own ill-health (Kelm 1998:40) Kelm argues that, in particular, cultural practices became defined as disease-causing. For example, in British Columbia the potlatch was banned based in part on grounds that it was associated with ill health, and unkempt homes were thought to be customary among First Nations. In this way, "such perspectives attempted to de-politicize environmental health and to confine it to interpersonal or cultural arenas" (Kelm 1998:40).

According to Kelm, Aboriginal leaders were able to "indigenize" this environmental public health rhetoric and strategically deploy it in their efforts to secure resources for reserve improvements and in struggles over land claims (1998:39). They wanted to reverse the flow of cause and effect of Aboriginal public health issues away from interpersonal or cultural arenas to the system of colonization that allocated reserves that were without sanitary arrangement, thus making it difficult for their inhabitants to improve themselves. In effect, Kelm writes, “their arguments claimed hygiene, both figuratively and literally, as Aboriginal territory to which, like the land itself, they had inalienable rights” (1998:39).

“Poverty,” biopower, and the masking of difference

In the twenty-first century, “governmentality”—the art of governance of the self and the government of populations (Foucault 1989)—is firmly entrenched in the relationship between Aboriginal peoples and the Canadian State. Biomedicine has been integrated into an extensive network of government initiatives whose function is to regulate Aboriginal populations. Extensive research initiatives, and prevention and intervention programs that are designed to address given “problems” such as FAS, are funded by the state and undertaken with the support of medical and social service professionals, and in “partnership” with local, regional and national Aboriginal “communities.” This has led to significant medical and social management of the everyday lives of many Aboriginal people, including impoverished single mothers and their offspring. The focus on substance abuse by pregnant Aboriginal women and negative birth outcomes, such as FAS, is an extension of this surveillance and also grows out of the increased medicalization of pregnancy, birth, and life-cycle transitions which has occurred generally within North America.

While the medical and social management of Aboriginal people stems from national and provincial strategies that increasingly include Aboriginal input and decision making, First Nations, Inuit and Métis are also connected to a larger global discourse focused on poverty and inequality. In the latter part of the twentieth century, the impoverished conditions that most Aboriginal people found themselves in became visible through this larger discursive arena and the quantification of “Indian problems,” as well as discussions about “progress” and “development” or the lack thereof, at local, regional and national levels.

Aboriginal peoples in Canada are connected through globalized processes of biopower to a larger discursive arena of international public health and development. The early post-World War II period saw the “discovery” of mass poverty in Asia, Africa and Latin America, which provided the foundation for an important restructuring of global culture and political economy (Escobar 1995:22). "Poverty" became an organizing concept and the object of a new problematization. "As in the case of any problematization," Esobar writes, "that of poverty brought into existence new discourses and practices that shaped the reality to which they referred. The essential trait of the Third World was its poverty and that the solution was economic growth and development became self-evident, necessary, and universal truths" (1995:24).

Escobar points out that for European colonizers in general, their concern with poverty and indigenous peoples was grounded in the perception that indigenous peoples lacked the capacity for scientific knowledge and technological innovation, and thereby the basis for economic progress. They believed that even though indigenous peoples could be somewhat enlightened by colonial efforts, not much could be done about their poverty because economic development was unlikely (Escobar 1995:22). In reality, however, people did have ways of defining and dealing with poverty. Escobar writes:

> …within Asian, African, Latin or Native American societies—as well as throughout most of European history—vernacular societies had developed ways of defining and treating poverty that accommodated visions of community, frugality, and sufficiency. Whatever these traditional ways might have been, and without idealizing them, it is true that massive poverty in the modern sense appeared only when the spread of the market economy broke down community ties and deprived millions of people from access to land, water, and other resources. With the consolidation of capitalism, systematic pauperization became inevitable (1995:22).

Escobar argues that the "modernization" of poverty signified not only a rupture of vernacular relations but also the setting in place of new mechanisms of control (1995:23). "The poor increasingly appeared as a social problem requiring new ways of intervention in society. It was, indeed, in relation to poverty that the modern ways of thinking about the meaning of life, the economy, rights, and social management came into place" (Escobar 1995:23).

The concept of "poverty" stands as a defining "problem" of the field of international public health, and is a central way in which the circumstances of Aboriginal communities in Canada are measured as they are situated within understandings of global "progress" and "development." Poverty has become absorbed into the domain of power. In his discussion of public health approaches to developing countries, Kleinman argues that international public health is based on a radical technical discourse that views health as the progressive achievement of societies as they modernize (1995:85). He writes,

> This transition-variously called the demographic, epidemiological, or simply the health transition-is held to be one of the major milestones on the path of progress. The movement along this path is described in the objective measures of improving health and social indices: fertility, mortality, education, gross national product, and so on (Kleinman 1995:85).

Underwriting practical applications in this transition, Kleinman argues, is the link between objectivity and the idea of progress, which together constitute the moral basis of the profession of international pubic health (1995:85). The objectivist framework assumes a universal standard in which the "experience of different societies can be compared as evidence of greater or lesser success." Local contexts are ironed out to fit this universal metric so that whatever is particular or peculiar to a society or region is removed, leaving that which is shared and therefore generalizable (Kleinman 1995:85).

Kleinman states that scientific-based development builds mainly upon economic, epidemiological, and policy analyses that privilege transpositionally objective measurements of narrowly articulated professional categories, "the view from nowhere." Categories such as "poverty" become value-free objective domains of health and development which are articulated as "human problems" and are in need of technical remedies (1995; see also Escobar 1995). "Poverty" has been related to sub-categories of "problems" that are identified in relation to it, such as "illiteracy," and that correspond to categories of people such as "the illiterate" (Escobar 1995:41). However, Kleinman points out that these categories effectively mask sources of human misery, mainly the "dynamic effects of large-scale political and economic forces working within local worlds" (1995:89). The role of local as well as larger-scale historical events and processes, and factors such as ethnicity and culture, are masked by a litany of quantifiable "problems" and technical interventions.

The concept "poverty" inherently implies a category of people, "the poor." Escobar argues that the making of a separate class of the "poor" set in motion the creation of apparatus of knowledge, practices, techniques, and power that could provide an "objective" picture of "poverty" (1995:37). Pauperism was associated, rightly or wrongly, with features such as mobility, vagrancy, independence, frugality, promiscuity, ignorance, and the refusal to accept social duties to work, and to submit to the logic of the expansion of "needs." Management of poverty concomitantly called for interventions in education, health, hygiene, morality, and employment and the instilling of "good habits" among the poor, such as "proper" child rearing practices. The result, Escobar states, was a panoply of interventions that accounted for the creation of a domain now called "the social." He writes,

> As a domain of knowledge and intervention, the social became prominent in the nineteenth century, culminating in the twentieth century in the consolidation of the welfare state and the ensemble of techniques encompassed under the rubric of social work. Not only poverty, but health, education, hygiene, employment, and the poor quality of life in towns and cities were constructed as social problems, requiring extensive knowledge about the population and appropriate modes of social planning (Escobar 1992a). The "government of the social" took on a status that, as the conceptualization of the economy, was soon taken for granted. A "separated class of the 'poor'" (Williams 1973, 104) was created. Yet the most significant aspect of this phenomenon was the setting into place of apparatuses of knowledge and power that took it upon themselves to optimize life by producing it under modern, "scientific" conditions. The history of modernity, in this way, is not only the history of knowledge and the economy, it is also more revealingly, the history of the social (Escobar 1995:23).

Social work, child welfare and poverty

The consolidation of the welfare state in Canada and the development of social work as an agency for the structure and organization of work emerged out of the larger discursive arena associated with the concept of "poverty" and the management of "the poor." Swift, a sociologist and social worker, writes that the category "child neglect" was the impetus behind the first child welfare legislation, both in Canada and in the United States, and child welfare remains central to the profession of social work today (1995:3). While I discuss in greater detail in Section Four the role that child welfare practices play in the lives of Aboriginal women and their children, it is important to link the larger discursive arena associated with the concept of "poverty" with the organizing concept of "neglect" in the historical development of child welfare discourse and practice. I do so because of the central position that child welfare services has assumed in Aboriginal communities in the past sixty years, and the significant role they currently play in the lives of pregnant Aboriginal women with substance abuse problems and their offspring.

According to Swift, from its inception the profession of social work has been concerned not only with the poor but also with the socialization of the poor (Swift 1995:88). She writes,

> In its theoretical base, the profession has always linked explanations of poverty to ideas of ‘a weakness of will and poverty of the spirit’ (Loch, 1906, quoted in Jones, 1979:74). Social work later drew on Freudian theory, which Jones notes, at least held out the hope of treating the apparent deficiencies of the poor, whereas the moral legacy of the undeserving poor did not offer this route to improvement. Since the 1970s Polansky has been the foremost scholar studying neglect. He approaches his topic from a psychoanalytic frame of reference, attempting to distinguish, within a low-income population, those characteristics that lead to adequate or inadequate care of children by their mothers. His 1972 study was undertaken in rural Appalachia. An attempt to replicate the findings in a low-income urban setting is reported in the 1981 study *Damaged Parents*. Both studies conclude that although poverty and social deprivation are important factors in neglect, the personality features of mothers are primary causal factors. This view is highly influential, and Polansky’s findings have now entered the discourse as ‘fact;’ that is, his findings are taken for granted as true, and often reported without reference to their source (Swift 1995:89).

Swift states that because the issue of neglect invariably resolves itself into one of personal problems, a myth of “equal treatment of all” in which class and ethnicity are masked in child welfare discourse and practice is perpetuated (1995:9). In this conceptual framework, it is argued that parents from all walks of life are represented in the group of parents who neglect their children. However, neglect, as a socially constructed category, has never been intended to catch out “ordinary” people in parenting lapses, although it occasionally operates in this way (Swift 1995:9).

The myth, Swift writes, becomes confused with a second assumption, which is that a level playing field exists upon which all families carry out their child-rearing activities. All parents are subject to the same rules and scrutiny, and all parents who fail will be caught and punished by the same systems (Swift 1995:10). However, in child welfare practice, the category “parent” largely implies impoverished single mothers, and the role of fathers or partners in the family unit is marginalized, or in many instances is treated as a negative influence upon, or danger to, both the mother and her children. Women are penalized financially by child welfare services by seeing their support payments decreased substantially if they choose to live with a male partner, even when legally married to him. The penalization of the woman effectively increases her dependency on her male partner for financial assistance, making her vulnerable to whatever decisions he makes about what money she receives, if any. Swift adds that the fact that poor, single, and non-white women in disproportionate numbers occupy the category of parents who are found to neglect their children, is attributed within the myth of “equal treatment” to individual failures by these women, caused by the same “defects” that are believed to have placed them in the poor, single-parent category in the first place (1995:10).

Swift points out that despite the universalization of the category “neglect,” it is well established in social work discourse that neglect is a phenomenon of poor populations (1995:89, see for example, Pelton 1981, Horowitz & Wolock 1981). The interactionist approach, an argument that continued through to the present day suggests that maltreatment of children is an outcome of the interaction between personal and situational factors, including poverty (Swift 1995:89, see for example, Garbarino 1978). In this framework, Cohen points out, social workers have difficulties in distinguishing poverty and neglect. He states that “many believe that children are permanently damaged at least to some degree by the mere fact of growing up in a home of abject poverty” (Cohen 1992:217 in Swift 1995:89). Swift concludes that whatever the approach, virtually all authors in the field of social work concur that poverty is a factor almost invariably associated with child neglect (1995:89).

Categories of deviance such as “neglect” and “abuse” operate as part of a secondary level of socially and scientifically supported classification schemes, which allow for and promote social divisions based on ethnicity and/or culture under the rubric of “equal treatment” (Swift 1995:127). They effectively construct someone who can be blamed when society apparently is not working well. This strategy is often applied to the situation of many Aboriginal families in Canada today, where Aboriginal mothers are commonly stigmatized as being “bad” mothers. Swift argues that categories of deviance provide a legitimate means for designated authorities to enter into the private affairs of individuals and families. The category of neglect allows a range of government appointed authorities such as social workers, police, and judges to scrutinize, evaluate, and reorganize private family life. Similar to arguments about prenatal and neonate screening for alcohol exposure, the “rescue” and “saving” of children is the justification used for allowing such intervention. However, other social purposes are more effectively met through this process. Situating poor, female, and racial minorities into the neglect group assists in the less visible functions of controlling social costs and reorienting the behaviors of particular people in ways that benefit the dominant society (Swift 1995:12).

"Neutral" categories such as "neglect" and "abuse" mask the fact that in Canada, those parents who fall into this category are almost exclusively impoverished mothers, most of whom are non-white. Ostensibly this creates divisions among natural groupings such as women or mothers, giving the appearance of different characteristics and interests for subgroups (Swift 1995:12). In Canada, the strong association made by European colonizers between indigenous women and "failed motherhood," which threaded its way through colonialist assimilation strategies such as the residential school system, has been re-invented in the past sixty years through the technical "neutral" language of social work and child welfare practices. During the 1960s and 1970s, in what has become known as the "sixties scoop," large numbers of Aboriginal children were removed from their homes and placed in non-Aboriginal foster care homes, or adopted out to non-Aboriginal families. While education and assimilation to European culture were the "official" reasons given by the government for the removal of children from the care of their parents or traditional guardians to attend residential schools, the sixties scoop was based on a much more damning image of Aboriginal mothers.

As early as 1947, the Canadian Welfare Council and the Canadian Association of Social Workers argued that Indian children who were "neglected" by their parents lacked the protection afforded to non-Aboriginal children under social legislation (Fournier & Crey 1997:83). They condemned both the internment of any Aboriginal child, neglected or not, in residential schools, as well as traditional foster and adoption practices which existed in Aboriginal communities. In 1951, an amendment was made to the *Indian Act* which stipulated that all laws of general application in force in a province should also apply on reserves unless they conflicted with treaties or federal laws (Fournier & Crey 1997:83). The federal government effectively handed over the responsibility of Aboriginal health, welfare, and educational services to the provinces, although it remained financially responsible for Status Indians. In this agreement the provinces were guaranteed payment by the federal government for each Indian child they made a legal ward of the state. Statistics show that in 1959, only one percent of the children who were legal wards of the state were Aboriginal children, a figure which jumped to somewhere between thirty to forty percent by the end of the 1960s (Fournier & Crey 1997:83, MacDonald 1995).

During the 1960s, child and welfare services focussed on the prevention of "child neglect," which placed emphasis on the moral attributes of individual parents, especially mothers, and on enforcing and improving care of children within the family (Swift 1991:239-240). However, "neglect" in the case of Aboriginal families was mainly linked to factors associated with poverty and other social problems, which were dealt with under what social workers referred to as "the need for adequate care." Improving care within Aboriginal families was not prioritized as it was for non-Aboriginal families, nor did provincial child welfare policies include similar preventive family counseling services for Aboriginal families as they did for other families. In many situations a lack of resources such as flush toilets, running water, or a refrigerator were grounds to make an Aboriginal child a ward of the state (Fournier & Crey 1997:85). So also was the absence of the biological mother and the placement of her children by way of traditional fostering and adoption. The typical pattern of intervention was for non-Aboriginal social workers to "apprehend" children in "severe crisis situations" and seek court-ordered committals to care, followed by placement in a substitute home off the reserve (MacDonald 1995:381). Since there were no services to facilitate family re-unification on reserves, social workers usually chose adoption or long-term foster care for Aboriginal children separated from their parents. The result was that Aboriginal children experienced much longer periods of foster care than their non-Aboriginal counterparts (MacDonald 1995:381).

Not surprisingly, Aboriginal people view this period very differently from the representations articulated by members of the dominant society, including social workers, foster and adoptive parents, and governments. Evidence suggests that the large scale apprehension of Aboriginal children in the 1960s and 1970s was not simply about concern for Aboriginal children being "neglected," as suggested in social work accounts, but rather it was a further attempt at cultural assimilation by the dominant society, which picked up where residential schools left off, further facilitating the systematic breakdown of Aboriginal families and social structures (Fournier & Crey 1996:88). Apart from causing a great deal of suffering to the families concerned, widespread apprehension of Aboriginal children also posed a potential threat to the survival of First Nations, Inuit, and Métis communities from which large numbers of children were removed, never to return (MacDonald 1995:381). Due to criticism by Aboriginal leaders and activists, some legislative changes aimed at protecting the rights of Aboriginal families and children have been made (Swift 1991, MacDonald 1995), and steps have been taken toward educating more Aboriginal people in social service fields.

Aboriginal mothers in child welfare discourse

During the period of the "sixties scoop," the image of Aboriginal women as "bad" mothers who were "deviant," "neglectful" and "abusive" fully emerged within the child welfare services discourse. Swift writes that client files from the 1950s and 1960s show that social workers explicitly identified and spoke about Aboriginal families negatively and as distinct from mainstream society (1995:142). Many written comments, she states, were questionable as they insinuated that people with "decidedly Native features" were inevitably connected to histories of alcoholism and violence (1995:142). The reality of the negative stereotype about Aboriginal women is reflected in transactions in connection with the foster and adoption of Aboriginal children, and in the statistics for this period. By the late 1970s, one in four status-Indian children was separated from his or her parents for all or part of childhood. When non-status Indian and Métis children are included, it is estimated that one in three or, in some provinces, every other Aboriginal child spent part of childhood as a ward of the State.

Larger numbers of Aboriginal children are still being taken into custody by child welfare services today. For example, in British Columbia, one of every three legal wards of the state is a First Nation child (Fournier & Crey 1996:88, MacDonald 1995). While some Aboriginal-run child welfare agencies exist, they enforce provincial legislation and employ social workers, Aboriginal and non-Aboriginal, trained in Western social work practices. The apprehension of large numbers of Aboriginal children reinforces an impression that Aboriginal mothers are a risk to their children. The introduction of the diagnostic category FAS, accompanied by the view, now entrenched in the dominant society, that fetal damage can occur at low alcohol threshold levels, together with the unexamined assumption that Aboriginal women are at significantly greater risk for exposing their fetuses to alcohol, yet further reinforces the perception of Aboriginal women as "bad" mothers.

Internalized "problems"

The concept of "poverty" and associated techniques for managing the "poor" has had several implications for Aboriginal people in Canada. On the one hand, the impoverished state and the associated "problems" that characterize many rural and urban Aboriginal communities in Canada are now visible. On the other hand, this visibility has situated the lives of Aboriginal peoples within a technical discourse of public health and social work practices that mask historical processes and cultural difference. Under the rubric of "equal treatment for all," Aboriginal women have been placed under increasingly greater public health and social service surveillance—one which has also masked what is unique about their circumstances because they are Aboriginal. A similar tension is also found in the responses by Aboriginal communities to the dominant society's control over defining "problems" and "solutions" for the "Indian problem."

As a way to control the definition of "problems" and "solutions" in their communities, Aboriginal peoples have lobbied for control over services, particularly health, education, and social services. For example, a growing number of Aboriginal communities, Nations, and governing bodies have designed and implemented independent research projects on health and social issues. Many of these initiatives have been undertaken in conjunction with the federal government's transfer initiatives which required community health assessments as a preliminary phase prior to transfer negotiations (O'Neil 1993:34). Although external consultants conducted most of the studies, O'Neil states that there is a uniqueness about the studies. He writes:

> First of all, most are designed from a holistic perspective more reflective of Aboriginal cultural traditions. Not only do they integrate standard medical interests with broader social, emotional and spiritual concerns, but there is also an expanded interest in 'health' as opposed to the 'sickness profiles' common to mainstream epidemiology. Issues such as family violence, addictions, and mental and spiritual health are fundamental rather than secondary concerns. Perhaps more important, these studies are regarded as the property of the bands and tribal organizations that have commissioned them and are generally not available outside the context of negotiations with the federal government for transfer of health services. Ownership of health information has clearly been recognized by Aboriginal communities as a component of self-determination in health care. Interpretation of the information is protected by maintaining the holistic

integrity of the documents guaranteeing a more balanced picture of community health (O'Neil 1993:34-35).

Unlike epidemiological data generated by non-Aboriginal health scientists, Aboriginal people in these studies were able to define and study what they deemed to be of relevance and significance. O'Neil writes:

> While many people might argue that free and democratic access to scientific information precludes interpretive control over data, the fact is that most health scientists are members of an elite and dominant sector of society and cannot help but reflect the normative assumptions of that group in scientific work. Until Aboriginal communities have proportional representation in the institutions that structure public interpretations of community information (i.e. universities, health professions, scientific journals, media, etc.), their only recourse is to attempt to control the dissemination of information that reflects their everyday lives (1993:35).

Distinct conceptualizations of "problems' and "solutions" that are held by Aboriginal groups as opposed to the dominant governing and social bodies in Canada are not new and have always threaded their way through this tumultuous relationship. From the early contact period with Europeans, Aboriginal leaders have persistently pointed out the ways in which colonial policy detrimentally affected the health of their people (Kelm 1998, Royal Commission on Aboriginal Peoples 1995). In doing so, Kelm argues, these leaders situated social and physical pathologies apart from their communities and resituated cause and effect as being part of the European contribution to the North American epidemiological scene. She suggests that this positioning has acted as a powerful and highly political rejection by Aboriginal leaders of the assumed "naturalness" or inevitability of Aboriginal health and social "problems" (1998:xvii).

Aboriginal leaders have consistently critiqued colonialist and neocolonialist portrayals of their people as essentially pathetic, pathological, and powerless. Recent strategies to thwart these images have involved a discourse of "ownership" and efforts by Aboriginal leaders and communities to gain control over health and social service systems that are mandated to address problems found among their people. However, despite their goal of gaining control over local services, Aboriginal leaders and their communities have had mixed responses to the current policies involving transfer of health care from the federal government to individual bands and tribal councils. Their simultaneous response of eagerness and caution, Kelm writes, comes from, "on one hand, the desire to show how Aboriginal health problems have roots in the material conditions of wardship and therefore can be fixed once those conditions are removed, and on the other, the fear that taking control will eliminate non-Native responsibility" (1998:xvii). Referring to Sergai Kan (1989), Kelm adds that if "embodiment of inequality is a powerful tool in legitimizing authority, then we should remember that that same embodiment also serves to challenge authority by being both an icon of repression and a provocation to resistance" (1998:xvii).

The politics of inequality and poverty

Anthropologist John O'Neil points out that for Aboriginal peoples, a serious contradiction is inherent in the increased medicalization of the physical and social embodiment of poverty and inequality—one that has serious implications even in light of ongoing resistance by Aboriginal peoples to dominant representations and understandings of Aboriginal health and social circumstances (1993, O'Neil et al. 1998). He argues that "public health surveillance systems perform disciplinary and regulatory functions in society independent of their overt purpose of tracking health conditions." Therefore, they can construct knowledge about "sectors of society that reinforce unequal power relationships; in other words, an image of sick, disorganized communities can be used to justify paternalism and dependency" (1993:34). O'Neil adds, "external agencies and academics that analyze data also have the power to interpret the data and to construct an image of Aboriginal communities as desperate, disorganized, and depressed environments. This image is created ostensibly to support lobbying efforts to secure a larger share of national resources for community development. However, this image is reflected through the Canadian media and general public and is to some extent internalized by Aboriginal communities, reinforcing dependency relationships" (O'Neil 1993:34).

O'Neil and colleagues argue that a discourse on difference in health and social conditions in Aboriginal communities inevitably finds its way into the experience of community members. In some ways this is quite clear (for example, see O'Neil et al. 1998:231), but in other ways interference in the lives of individuals and communities is more subtle. They write,

> Less obvious perhaps is the way that this discourse has been, and continues to be, used to suppress the legitimate claims of Aboriginal people for full participation in Canadian society. The portrait of a sick, disorganized community implicit in this epidemiological discourse is increasingly dangerous in a tough world of negotiation for self-government and economic development. As justification for continued marginalization and paternalism, the repressive implications of the discourse are apparent (O'Neil et al. 1998:231).

As has been shown in previous chapters, the contention that an epidemic exists of Aboriginal persons with FAS in certain regions, and that in general the Aboriginal population is at significantly greater risk for FAS/ARBEs because Aboriginal women cannot control their drinking behavior, adds dramatically to a portrait of sick, disorganized communities. However, FAS is set apart from other "problems" such as "alcohol abuse," "family violence,' and "poverty," in that the "sickness" is understood as an untreatable physiological illness; "disorganization" is literally situated within the brains of individuals and is believed to inevitably reproduce itself at the community level in a number of "social problems," or, as suggested by Streissguth (1997), in a loss of culture. Through a discourse of FAS, marginalization and paternalism are masked by a highly medicalized discourse of "risk" and "disability" which increasingly threads it way through Aboriginal and non-Aboriginal relations—a discourse that has significant potential to hinder Aboriginal attempts to negotiate self-government and economic development in the coming years.

Conclusion

In this chapter I have introduced the concept of "biopower" as an entry point for a discussion showing how the lives of Aboriginal peoples in Canada have in recent decades come increasingly under medical and social management. However, this "management" has in many ways masked what is unique and significant about the history of the colonization of indigenous peoples in Canada, including past efforts to eradicate Aboriginal culture and values, because "management" of Aboriginal peoples has been organized around "problems" attached to the very broad concept of "poverty." I have suggested that a counter-discourse supported by Aboriginal notions of "healing," "health," and "wellness" has emerged and is intertwined with efforts of Aboriginal peoples to take control and "ownership" of the knowledge produced about them, and the services and intervention that target their communities.

Chapter Eight

TRANSFORMATION: FROM A "NATURAL STATE OF WELLNESS" TO "COLLECTIVE INTERGENERATIONAL TRAUMA"

> *Our Sto:lo life was stolen away. Our children were removed by priests, social workers and police to residential schools, foster care and jail. My own family was at the eye of the hurricane, and we are only now beginning to regain our bearings. All over North America, the experiences of other First Nations families parallel my family's trials and triumphs.*
>
> Ernie Crey[1]
> "Stolen From Our Embrace: The abduction of First Nations children and the restoration of Aboriginal communities"

Introduction

In this chapter I explore the consensus that has arisen between Aboriginal people and the dominant society that the individual and collective bodies of First Nations, Inuit and Métis have to a considerable degree been re-made by processes of colonization. I argue that a presumption in colonial discourse of the biological "inferiority" of the pre-contact "indigenous mind and body" has been replaced in mainstream liberal discourse by a focus on socially derived "Indian problems" that are believed to have arisen out of processes of colonization that in the past undermined the collective health of Aboriginal people and eroded traditional social and political relations. A similar perception is simultaneously reflected in Aboriginal discourse and practices; however, rather than an oppression situated in the colonial past, Aboriginal groups see an on-going neo-colonial oppression that continues to perpetuate harm against their people.

Colonialist oppression and assimilation is linked to present day health and social problems found in Aboriginal communities through a discourse of collective transformation from a pre-contact state of "wellbeing" and "health." An organizing theme of "intergenerational trauma" that arose out of narrative accounts beginning in the late 1980s and 1990s by former residential school students marks the transformation to a condition characterized by loss, suffering, trauma, and violence. The "trauma" is perceived to be greater than to the individual and collective bodies of First Nations, Inuit,

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[1] From Fournier & Crey 1997.

and Métis in contemporary Canadian society. As a result of the severity and nature of what happened to them at the hands of European colonizers, it is believed that many have internalized the brutality and violence of their oppressors, and even more have internalized the racist views of Europeans that then become manifest in forms of self-destruction and self-hatred that can be passed on to the next generation. The central example supporting this argument is the residential school system and the sexual, physical and emotional abuse that Aboriginal children experienced at the hands of priest, nuns, and teachers who were entrusted with their care. In this context, "intergenerational trauma" is defined as an internalized circular process whereby the child victim becomes the adult victimizer of the next generation of children. The catalyst of this transformation is alcohol abuse, and two figures, the "failed parent" and the "child molester," have emerged in both Aboriginal and mainstream narratives to signify the insidious "cycle of violence and dysfunction" that is believed to be prevalent in many Aboriginal communities today.

In this chapter I explore the concepts of individual and collective transformations that are connected by Aboriginals and non-Aboriginals to processes of colonization, alcohol abuse and the concept of "collective intergenerational trauma." The issues that I raise are complex and inherently resist a superficial reading and analysis. However, my purpose here is very specific to the exploration of how this larger discourse, and the practices attached to it, intersect and weave their way through the discourse attached to alcohol use by pregnant women and FAS. I argue that the link between alcohol use by pregnant women and FAS is situated within larger understandings shared by Aboriginals and non-Aboriginals, about the pervasiveness of alcohol abuse, "intergenerational trauma" and the impact of colonization on First Nations, Inuit and Métis.

Transformation: from a natural state of wellness to collective intergenerational trauma

In recent decades, Aboriginal people and the Canadian state have generally come to agree in principle, that the physical and social bodies of First Nation, Inuit and Métis groups have to a considerable degree been re-made by colonial processes. This ideological agreement has come about in part because of national attention being drawn to the widespread abuse of Aboriginal children who attended government and church run residential schools[2], the Royal Commission Report on Aboriginal Peoples (RCAP) (1996), and international attention directed at health and social disparities between Aboriginal and non-Aboriginal populations. What underlies the argument of "collective intergenerational trauma" are representations of the "indigenous mind and body" that in its "natural" pre-contact state was free of most illness, and in some arguments superior to that of "civilized man" (see, for example, James 1908).

This position is reflected, for example, in the Royal Commission on Aboriginal Peoples' discussion of pre-contact health. The Commission writes:

> There is considerable evidence to show Aboriginal people enjoyed good health at the time of first contact with Europeans. Historical records and the findings of modern paleo-biology suggest that many of the illnesses common today were once rare, and that mental and physical vigor once prevailed among Aboriginal people (1996b:111).

Support for the Commission's statement is drawn from the historical record and is illustrated in the following passages quoted in the Commission's report. The first is from the early twentieth century historian, George Wharton James, and the second from the classic historical study by Virgil Vogel that discusses Native American health during the colonial period:

> Before the Indian began to use the white man's foods, he was perforce compelled to live on a comparatively simple diet. His choice was limited, his cooking simple. Yet he lived in perfect health and strength…and attained a vigour, a robustness, that puts to shame the strength and power of civilized man (James 1908 in Royal Commission on Aboriginal People 1996b:111).
>
> Skeletal remains of unquestionably precolumbian date…are, barring a few exceptions, remarkably free from disease. Whole important scourges [affecting Europeans during the colonial period] were wholly unknown…There was no plague, cholera, typhus, smallpox or measles. Cancer was rare, and even fractures were infrequent…There were, apparently, no nevi [skin tumours]. There were no troubles with the feet, such as fallen arches. And judging from later acquired knowledge, there was a much greater scarcity than in the white population of…most mental disorders, and other serious conditions (Vogel 1970:159 in Royal Commission on Aboriginal People 1996b:111).

In these images the "indigenous mind and body" is robust and free from disease, and the transformation from "perfect health and strength" begins to occur as indigenous peoples

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[2] The residential school system will be discussed in detail later in this chapter.

are introduced to European foods, drink and culture, and are infected by European diseases.

Alcohol as an organizing theme of colonization[3]

> *So anyways, he's down there by the lake, pretending to be such an innocent, and you know what he's doing? Calling. Calling for the devil to come to him so he can sell his soul and have money to go to the Ol' Stope and drink some more…And the devil came for sure that time. Nobody could see him except for Ronnie of course, but they knew he was there all the same…You kids stay away from him. Who knows what somebody like Ronnie will do to a kid? Errrr, what a snake he is. Poor T'Atiste! The white man's drink has sent another one to the devil.*
>
> *I did my best for Suzanne I tell you and she treats me just like dirt. Nothing but men an' drink, men an' drink for her ever since her Louie was shot to death that one time in the fall when he went hunting…And a little while later, this little one came into the world without a father…and a mother gone straight to the devil…No, Suzanne's no mother. I'm the mother now to this poor little one….me! My God, my God, why me?"*
>
> Frances Beaulieu[4]
> *Little Buffalo River*

The introduction of alcohol during the early time of the fur trade marks for Aboriginal groups one of the most significant events to have framed their relationship with European colonizers, and for many it remains the poisonous thread that weaves it way through their history ever since. The present-day significance of alcohol in their lives is evident by the amount of attention and resources they have been directed toward addressing alcohol abuse in Aboriginal communities. Its importance is also reflected in Aboriginal literature, painting, and other forms of artistic expression in which alcohol figures as a central metaphor of colonization.

In the relationship between Aboriginal and non-Aboriginal peoples, alcohol acts as an organizing theme through which the "problems" of First Nations, Inuit, and Métis are filtered. For example, the Royal Commission on Aboriginal Peoples likened the introduction of alcohol to that of smallpox and other infectious diseases. They write: "Aboriginal people had no 'immunity' to alcohol, in the sense that social norms and

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[3] The scientific and lay literature on contemporary alcohol abuse patterns among Aboriginal peoples is quite expansive and a review of it is beyond the scope of this discussion. For a detailed review see (Tait 2003).

personal experience can ‘protect’ against over-consumption” (Royal Commission Report on Aboriginal Peoples 1996b:157).

As the introduction of alcohol marks for Aboriginal people a point of rupture with a traditional past, it also represents an act of violence against them from which collectively they have never recovered. This is illustrated in the following account by Glecia Bear, a Plains Cree grandmother from Sandy Lake, Saskatchewan, who compares the introduction of alcohol into the relationship between indigenous peoples and Europeans to the devil overpowering and ruining generations of Aboriginal people. Bear states:

> Also by making that alcohol, the White-Man has brought misery upon many people today. In the old days there was none of that. Many young women today are prematurely pregnant because of alcohol, some White-Man will give them drink, even when they have no intention of drinking, “Well, just have one drink” he will say to her, and when she has had one drink, “And another.” Well, then, when they have made them ‘feel good’, then they take them away, they drive away with them, that is the reason why they gave them drinks, now they go and take advantage of them, sometimes they give them booze as you open one beer, there already you open the door for the devil. You drink it, hey, and when you have drunk half of it, from that point on already the devil has you in his clutches for he has already overpowered you. He has completely ruined our young people, the White-Skin as he is called. How miserable, I tend to think, are things yet to become, there in the future, how miserable with the children be (Bear in Ahenakew & Wolfart 1992:229).

The importance of alcohol in the early contact period

The introduction of alcohol to indigenous groups in Canada can be traced back to the Hudson Bay region during the late seventeenth century. French fur traders eager to obtain furs used gifts of alcohol to entice indigenous trappers to trade with them (Brady 2000:440, Waldram et al. 1995). The giving and trading of alcohol quickly gained prominence in fur trading activities, becoming a way for rival trading companies to attract indigenous trappers to their posts (Waldram et al. 1995, Ray 1974). Several written accounts, particularly by the Jesuits, document the deleterious effects the introduction of alcohol had on indigenous groups during this period (Waldram et al. 1995:138). The early contact period was generally a time when indigenous people drank alcohol only when they were at the trading posts, as it was too dangerous to drink while

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[4] From Métis author, Frances Beaulieu’s novel, *Little Buffalo River* (2000).

living on their trap lines, and alcohol was too heavy to carry over the distances they travelled.

Alcohol use during the fur trade period was not limited to men, and some indigenous women regularly drank alongside their male counterparts. While many indigenous women who worked on the trap-lines abstained from alcohol use, others, when at trading posts, had patterns of alcohol use similar to those of men. Historian Sylvia Van Kirk writes that many traders noted in their journals that the indigenous "homeguard" women were particularly vulnerable to addiction to alcohol (1980:27). These women, along with their children, lived near or at the trading posts; most had either been abandoned by, or were widows of, European "husbands" or were the offspring of one of these unions (Van Kirk 1980).

The historical record indicates that indigenous women, whether they drank alcohol or not, were vulnerable, along with their children, to acts of violence committed against them by the men around them. Van Kirk writes that indigenous women during the fur trade period were vulnerable to sexual and physical abuse by indigenous and European traders, which increased significantly during the drunken days of the fur trade war (1991:181). Brian Maracle, a First Nation author (1993), found numerous accounts in historical archives of Aboriginal women trying desperately to hide the weapons of their drunken husbands and sons in efforts to protect not only themselves, but also their children.

Despite alcohol becoming a social problem for some indigenous groups in the early contact period, many abstained from alcohol use. In several regions, indigenous leaders stipulated that a ban on the trading and selling of alcohol to their people be written into the treaties (see for example, Morrison 1880:71-72). It was not uncommon for an entire indigenous group to reject alcohol for decades after their initial contact with settlers (Royal Commission on Aboriginal Peoples 1996). These examples demonstrate that there was great heterogeneity in the response to the introduction of alcohol by indigenous groups, and the rise of socially harmful drinking patterns was neither uniform nor inevitable (Frank et al. 2000:348-349).

Alcohol as a signifier of difference

In the history of Aboriginal and non-Aboriginal relations in Canada, alcohol has been invoked as a powerful signifier of difference. For example, the connection between alcohol abuse and a perceived racial "inferiority" of Aboriginal peoples reaches as far back as the days of the fur trade, where it was tied to larger notions that indigenous people were a vanishing inferior race doomed to extinction (Steckley &Cummins 2001:181, Brody 1988, Royal Commission on Aboriginal Peoples 1996b). The hypocrisy of Europeans turning alcohol into a highly sought after trade item and then blaming the results on the "nature" of indigenous peoples was expressed in the nineteenth century by Ojibwa Methodist cleric and missionary, George Copway. He writes:

> The ministry of this country, and the sluggards in the cause of humanity, say now: *There is a fate or certain doom on the Indians, therefore we need do nothing for them.* How blasphemous! First you give us rum by the thousand barrels, and, before the presence of God and this enlightened world, point to God, and charge him as the murderer of the unfortunate Indians. (Copway 1972:264-5 in Steckley &Cummins 2001:181emphasis in text).

Racial susceptibility as an explanation for alcohol abuse among Aboriginal groups continued to be expressed in scientific and mainstream Canadian discourse throughout the 19th and most of the 20th century (see for example Fenna et al. 1971). However, while scientists have largely discredited this position (Bennion & Li 1976, Marinovich et al. 1976, Fisher 1987), it has resurfaced as an explanation for "high rates" of FAS in Aboriginal communities in some studies (among these are, Asante 1981, Aase 1981), although the claims made are not scientifically substantiated by the authors.

Judicial and legislative measures controlling the purchase and consumption of alcohol by Aboriginal people were used to further mark difference and reinforce a perception that the behavior of Aboriginal people needed to be monitored and regulated for their own benefit. Controls over the sale of alcohol to Aboriginal people were in place prior to Confederation and the creation of the *Indian Act.* Legislation was formally passed in 1874 making it an offense punishable by one month in jail for an Indian to be intoxicated, on or off the reserve. In 1876, these provisions were included in the *Indian Act,* with the addition of the prohibition of alcohol possession by Indians on reserve (Royal Commission on Aboriginal Peoples 1996a:293). The Royal Commission on

Aboriginal Peoples state:

> The later 1951 *Indian Act* revision made one exception to the provisions by allowing an Indian to be in possession of alcohol if in a public place and in accordance with provincial law. It was still an offence to be drunk, however. No non-Indian could have been convicted of a similar offence. In the *Drybones* case the Supreme Court of Canada finally struck down the off-reservation intoxication offence for contravening the equality provision of the *Canadian Bill of Rights.* These provisions have been eliminated from the contemporary version of the *Indian Act*, and control over intoxicants on-reserve has been transferred entirely to the band and band council (1996a:293-294)[5].

Colonization and binge drinking

Within the discursive arena attached to alcohol abuse by pregnant women and FAS, binge drinking is the pattern of drinking, especially chronic binge drinking, most associated with fetal damage. Aboriginal women have been singled out as the group of women who most frequently engage in binge drinking. For example, in a Canadian-based study that examined smoking, caffeine, and alcohol intake during pregnancy in a northern population, it was determined that no statistical difference for alcohol use was found between "racial" groups—Inuit, Native Indian, mixed race, or white. However, Inuit and Native Indian women were found to be the two groups most likely to engage in binge drinking (Godel et al. 1992).

In the discursive arena attached to FAS, the association between pregnant Aboriginal women and binge drinking is based on limited research evidence, and relies mostly on anecdotal accounts by both Aboriginal and non-Aboriginal health care providers, and community and social workers. In this context, the history of colonization of Aboriginal people is invoked as supporting this association. Arguments that suggest a binge-drinking pattern was instilled in Aboriginal alcohol use from its introduction by Europeans have been made in relation to the larger problem of alcohol abuse in Aboriginal communities. For example, Maracle states:

> Compared to non-native drinkers, Indian drinkers are twice as likely to be binge drinkers, according to recent studies. The roots of Indian binge drinking may go back thousands of years—to a time when Indian people lived a cyclical existence, dependent on the harvest of fish, game and plant life. Then the harvest season was a time of feasting and celebration. The feast was a central element of Indian life and it was against this historical and cultural backdrop that Indian people came into contact with alcohol. If

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[5] The case the commission is referring to is *The Queen v. Drybones*, [1970] S.C.R. 282.

> their traditions were not reason enough, Indian people soon evolved a binge drinking culture under the influence of the first Europeans. Rowdy soldiers and adventurers set a hard-drinking example while greedy whiskey sellers and fur-traders actively promoted binge drinking. Whatever its roots, binge drinking is now a prominent feature of native drinking and is quite distinct from the "social" drinking of non-native people (1993:75).

Maracle further argues that laws prohibiting Indians from purchasing and possessing alcohol did not prevent Aboriginal people from drinking, but changed the way that they drank. Not only did it lead to frequently resorting to drinking other far more dangerous intoxicants, it also reinforced a pattern of binge drinking as the law forced them "to become furtive and drink in bushes and back alleys. More ominously, Indians also had to guzzle their beer, wine or liquor as quickly as possible to keep them from being arrested" (Maracle 1993:45).

As discussed in Section Two, in relation to Aboriginal peoples and FAS, binge drinking has been described as a "cultural pattern of alcohol use." The use of this concept risks presenting an image that this pattern is part of the worldview of all Aboriginal individuals and communities and, therefore, may imply an inevitability that pregnant Aboriginal women, if they drink, will engage in this type of behavior. While some Aboriginal women do engage in binge drinking patterns further research is warranted to determine how common this practice is and what community strategies have been identified as influencing the reduction of this type of alcohol consumption among pregnant women.

The "drunken Indian"

The stereotype of the "drunken Indian," which has been greatly exaggerated within mainstream Canadian society, is the clearest and most common example of the negative association between Aboriginal people and alcohol, and is closely linked to the master narrative of the "Indian problem." At a very basic level, this stereotype reinforces notions that Aboriginal people are unwilling or incapable of engaging in "responsible" consumption of alcohol and are prone to acts of reckless abandon, often with tragic results (May 1988).

An example of this stereotype is found in a 1998 article in *The Globe and Mail* newspaper in which journalist David Roberts discusses a Statistics Canada report about homicide rates across Canada. While Statistics Canada, he writes, does not breakdown the homicide rates in the report by "race" for either the victim or the accused, the Prairie Provinces are reported to have among the highest rates in the country. In his article, Roberts links alcohol and drug abuse, violence, and FAS together as common intertwining problems experienced by Aboriginal people that can account for the higher rate of homicides found among them in Manitoba. Roberts states:

> While native people are a significant and fast-growing minority…the homicide rate for this segment of the population is about 30 times higher than the rate for the population as a whole…"There certainly has been an overinvolvement of aboriginal people in homicide offences," said Rick Linden, a sociologist at the University of Manitoba. "But the native population has a much-higher-than-average rate of all kinds of violence and death," he said. "Suicides, assaults, accidents—much of this is alcohol- and substance-related. It has to do with a loss of cultural identity, with poverty, with a lack of hope. These things lead to destructive behaviour. The typical homicide in Winnipeg happens after a three-day drinking party." Mr Linden said. "We had a case last year where a woman was stabbed to death during a three-day house party. Everyone there was too drunk to even notice she was dying. That, unfortunately, is tragically typical." Mr. Linden said poverty in itself does not explain high rates of violence and murder. "Otherwise, Newfoundland would be the homicide capital of Canada, and it hardly registers on the scale," he said (1998).

The statement by Linden implies that he is giving a normative account of homicides in Winnipeg in which the victims and perpetrators are intoxicated Aboriginal men or women, the violence of the crime goes unnoticed by those present, and the local context in which the murder occurs is one that is enmeshed in self-destruction, violence and hopelessness.

Perry Bellegarde, Chief of the Saskatchewan Federation of Indian Nations, provides a similar explanation about the broader historical and social context. In the article, Roberts quotes Bellegrade as attributing the high rates of homicide among Aboriginal people to poverty, systemic racism, and loss of identity and self-esteem. Bellegrade blames the high rates on Europeans imposing a form of "cultural genocide" upon Aboriginal people through the residential school system, which in turn, he suggests, led to cycles of abuse, including alcohol abuse and family dysfunction emerging in Aboriginal communities.

The accounts given by Linden and Bellegrade agree that collective loss of cultural identity among Aboriginal people has led to a range of personal and social problems that perpetuate poverty and hopelessness. Linden locates the source of these problems in the colonialist past, while Bellegrade situates them as part of an ongoing struggle that Aboriginal people have had with European society from the contact period onward. However, in concluding his article, Roberts introduces a third factor, FAS. He writes:

> Mr. Linden issued a warning about the growing number of crimes in which the accused suffers from fetal alcohol syndrome—a physical brain disorder caused by mother's ingestion of alcohol during pregnancy. He predicted an entire generation of FAS youths are about to enter the criminal justice system—youngsters with little or no ability to comprehend the difference between right and wrong. These youngsters have little hope of rehabilitation, experts have said. About 79 per cent of inmates in Manitoba's prison system are native, as are 45 per cent of federal prisoners in Manitoba. Prison officials suggest at least half of these native inmates suffer from FAS or less severe fetal alcohol effects (Roberts 1998:A3).

In this enormous leap in reasoning, Roberts resituates the association between alcohol abuse and violence among Aboriginal people as being intrinsically intertwined with large numbers of Aboriginal women "ingesting" alcohol during pregnancy and giving birth to "youngsters with little or no ability to comprehend the difference between right and wrong." In this shift, Roberts and Linden collapse a range of assumptions into a circular argument; large numbers of pregnant Aboriginal women abuse alcohol, thereby giving birth to large numbers of offspring with FAS/E. Because persons with FAS/E cannot comprehend right from wrong they drink alcohol, commit acts of violence, end up in jail, live in poverty and have more babies who suffer from FAS.

In this reasoning, collective "loss of cultural identity" and "a lack of hope" take on new meanings as well. Similar to Streissguth's argument discussed in Chapter One, Roberts implies that a large segment of the Aboriginal population represent a bio-underclass within the social structure of Canadian society, whose collective identity is interwoven with the myriad of health and social problems they experience—alcohol abuse and FAS being the most prevalent. Urban "ghettos," such as the North-end of Winnipeg, or the now infamous Downtown East-Side of Vancouver, become reflections of a cycle of pathology, which is fuelled by the alcohol abuse of pregnant Aboriginal women.

Internalising the "drunken Indian"

> *I have yet to meet an Indian social drinker. Some say they're social drinkers and they can go out for a couple of beer, but at one occasion or another you see them drunk. They say they're social drinkers but they still get drunk. I have white friends who are social drinkers who every time they say, "Let's go out for a drink," they'll only have one or two, you know, every time. I've never seen them drunk. So I don't think drinking is for Indians.*
>
> Rebecaa[6]

The "drunken Indian" stereotype resonates within every level of non-Aboriginal society in North America; however, there is evidence to suggest that it resonates within some Aboriginal communities as well. For example, an American study by May and Smith that examined opinions about alcohol abuse held by members of the Navajo population found that only 30%-42% of Navajo adults drank alcohol, compared with 71% of the general population (1988:325). Despite this, study participants cited alcoholism to be the number one health problem on their reserve. Sixty-three percent of study participants believe that Aboriginal people in general have a physical weakness to alcohol that does not exist among the non-Aboriginal population (May & Smith 1988:324).

A belief about the pervasive effects of alcohol on Aboriginal families and communities across Canada is a common theme that runs through various discussions of Aboriginal issues. Henoch Obed, an addiction counselor from the Labrador Inuit Alcohol and Drug Abuse program, for example, described addictions to the Royal Commission on Aboriginal Peoples as a "chain reaction" in Aboriginal communities. He states:

> The chain reaction of addiction hurts many people…It can cripple individuals, families in our society, and even make [a whole] region dysfunctional…Myself, I am a sober alcoholic and drug addict. My sister perished when she was drunk. My nephew killed himself and his own father and mother while they were drunk. My older brother shot himself when he was drunk (Obed in the Royal Commission on Aboriginal People 1996b:158).

Many Aboriginal people see alcohol abuse as affecting their communities across

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[6] Quoted in "Crazywater: Native Voices on Addiction and Recovery" (Maracle 1993:76).

different generations and across geographical regions. The Royal Commission Report on Aboriginal Peoples argues that 80 to 100 per cent of Aboriginal people in Canada are directly or indirectly affected by alcohol and drug abuse (1996b). The perception of the pervasiveness of alcohol abuse and its associated negative consequences is tied directly by Aboriginal people to a broader discourse of "collective intergenerational trauma" and the need for "healing." Similar to alcohol abuse, individual and collective trauma, epitomized by the experience of Aboriginal children who attended government-and church-run residential schools, is believed to directly or indirectly affect all Aboriginal people. Problems such as alcohol abuse, violence, child abuse and, more recently, FAS are situated in this broader context as the outcomes of these experiences (see, for example, Fournier & Crey 1997). For example, alcohol abuse, while being understood as a source of individual and collective health and social problems, is also understood as a response by Aboriginal people to traumatic experience. The construction of alcohol abuse as a harmful, yet meaningful "coping mechanism" or form of "self-medication" to help people deal with their traumatic memories and to communicate their pain and suffering to others, is a common explanation within the larger discursive arena attached to addiction and alcohol abuse by Aboriginal peoples.

"Collective intergenerational trauma"

> *Most of our clients—probably 90 percent of them—are, in fact victims themselves of the child welfare system. Most of our clients are young, sole support mothers who very often were removed as children themselves. So we are dealing with perhaps the end product of the child welfare system that was apparent in the sixties scoop. Actually the sixties scoop lasted well into the '70s and we are seeing the reality of that on our case loads…We take the approach in our agency that it is time to break the cycle. The other interesting note is that while the mother may have been in foster care the grandmother—I think we all know where she was. She was in residential school. So we are into a third generation.*
>
> Kenn Richard[7]
> Executive Director
> Native Child & Family Services of Toronto

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[7] Testimony given to the Royal Commission on Aboriginal People (1996b:34-35).

The complexities that characterize Aboriginal and non-Aboriginal relations in Canada resist any account that reduces them to a specific feature, event, or process. However, in a discussion of "intergenerational trauma" and its emergence as a concept signifying the impact of colonization on Aboriginal people, it is inevitable that the residential school system and the experience of former students will be central. For Aboriginal people, individual and collective suffering, loss, and trauma mark the period of colonization. "Collective intergenerational trauma" emerged as an organizing concept in the late 1980s and early 1990s for Aboriginal understandings, particularly for First Nations and Métis, to describe historical events and collective and individual experiences underlying the elevated rates of poverty, alcohol and drug abuse, family dysfunction, child abuse, suicide and violence found in segments of their population. As former students of the residential school system came forward to speak publicly about the abuse they experienced as children while attending the schools, a recognition of broader collective suffering and loss congealed for many First Nation, Inuit and Métis individuals and communities around the "residential school experience."

For Aboriginal people in Canada, the "residential school experience" has come to mark what Volkan (2002 in Young n.p.) describes as a "chosen trauma". A "chosen trauma" can be described as "a collective memory that recalls an event in which an ethnic group was victimized and humiliated by another group. The event becomes a source of transgenerational group-identity" (Volkan 2002). Young describes collective memory as "a tangle of meanings and narratives…located in minds but also in all sorts of representations" such as images, monuments, rituals, texts, and so on (n.p).

For Aboriginal people who attended residential schools, the opening in recent years of a discursive space in which to articulate their experiences while attending the schools has dramatically altered Aboriginal narratives that portray individual and collective experiences of colonization. Narratives depicting the stripping away of indigenous culture, identity and language, and the replacement of these with European equivalents in social institutions that literally and figuratively "walled-off" children from their families and communities thread their way through accounts of the experiences of former students. Some former students have come forward to break decades of silence about the repeated physical, sexual, and psychological abuse that they endured while attending the schools. Central to their narratives are themes of individual and collective transformation. In some narratives, transformation is described as going from a state of “wellbeing,” “strength” and “harmony with nature,” to one of “illness,” “loss,” and “disharmony” within personal, natural and social worlds. Others characterize a much more violent transformation in which childhood innocence, purity, and trust is destroyed through the repeated beating, rape and torture of students (among there are, Fournier & Crey 1997). In these narratives, the victims often end up themselves becoming oppressors as they commit similar acts of violence against younger students and, when back in their community, against children including their siblings, and eventually their sons, daughters, and grandchildren. The “residential school experience” has been transformed metaphorically into an insidious virus that has spread across Aboriginal communities, penetrating the minds, souls, and bodies of multiple generations of Aboriginal people.

The Residential School System

> *...it is to the young that we look for a complete change of condition.*
>
> J.A. Macrae to Indian Commissioner, Regina December 1886

> *The most terrible result of my residential school experience was they took away my ability to hold my children. They took that from me, the ability to hold my children.*
>
> Inez Dieter[8]

Historical accounts provided by archival records and narrative accounts given by former school students demonstrate how devastating the residential school system—and the larger colonialist context in which it was created—was for Aboriginal children and their communities (see, for example, Chrisjohn & Young 1997, Fournier & Crey 1997, Million 2000, Milloy 1999). The first known boarding-school arrangements for indigenous children in Canada were put into place in 1620 under the control of the Récollets, an order of Franciscans who had settled in New France. The primary objective of the school

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[8] Quoted in “From Our Mother’s Arms: The Intergenerational Impact of Residential Schools in Saskatchewan” (Deiter 1999:11).

was the evangelization of indigenous peoples through the education of their children (Miller 1996:39). Several boarding schools were opened throughout the seventeenth and eighteenth centuries by other religious orders, such as the Friars and the Jesuits, and were characterized by intense competition between religious orders, a trend that continued throughout the duration of the residential school system.

The *Bagot Commission Report* (1844) formalised early assimilation policy and solidified the place of the residential school system in post-Confederate Canada. After a two year review of reserve conditions, the Commission asserted that indigenous communities were in a "half-civilised state" and further progress by communities would be realised only if indigenous communities were imbued with the primary characteristics of civilisation: industry and knowledge (Milloy 1999:12-13).

Of the initiatives undertaken by colonialist forces in the first century of Confederation, none were more ambitious or central to the "civilizing" and assimilation strategies than the residential school system (Milloy 1999:21-22). However, by 1858 the Department of Indian Affairs and the churches found that the system of manual labour schools was largely ineffective in achieving assimilation. A new strategy to re-socialise Aboriginal children through off-reserve residential schools was implemented in 1879 following recommendations made in the *Davin Report*[9] (Milloy 1999, Deiter 1999). The report suggested that the Christian obligation to indigenous peoples could be realised "only through the medium of children." Aboriginal adults, the report argued, could not be rescued from "their present state of ignorance, superstition and helplessness," because they were "physically, mentally and morally...unfitted to bear such a complete metamorphosis" (Davin 1879 in Fournier & Crey 1997:55-56). Department bureaucrats advised Prime Minister J.A. Macdonald that residential schools were a "good investment" to prevent indigenous children from becoming "an undesirable and often dangerous element in society" (Fournier & Crey 1997:55-56).

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[9] Nicholas Flood Davin of Regina, a Member of Parliament backbencher, was sent to the United States to evaluate the American system and then make recommendations on Indian education to the federal government. Davin strongly recommended the establishment of a similar system of education in Canada and he implored the Canadian government to entrust missionaries, because of their commitment to 'civilising' the indigenous population, with the task of running the schools (Milloy 1999).

Following the acceptance of the *Davin Report* (1879), the federal government began the construction of church-run residential schools across Canada. The preference was for large schools located away from reserves in order to minimise parent-child, elder-youth contact (Miller 1987, 1996, Ing 1991, Armitage 1995, Grant 1996, Milloy 1999). Commonly the school buildings were hastily constructed, clear evidence of the federal government's intense obsession with the economics of Indian education (Graham 1997, Milloy, 1999). Reports indicate that school buildings were generally over-crowded, poorly ventilated, and lacking in proper safety equipment such as fire escapes. These features, along with the children being overworked and poorly nourished, made residential schools sites for widespread disease and illness (Kelm 1996).

The practice of strict confinement of school attendees allowed infectious diseases, such as tuberculosis, scabies, influenza, pneumonia and whooping cough, to spread rapidly through school dormitories (Armitage 1995, Feehan 1996, Grant 1996, Kelm 1996, Miller 1996, Graham 1997, Milloy, 1999). The heavy disease load at many of the schools led to the death of a significant number of children. Mortality rates at residential schools were so high by the late nineteenth and early twentieth centuries that the federal government commissioned an investigation in 1909 to determine why. The *Bryce Report* (1909) concluded that every residential school student should be considered a potential tuberculosis sufferer.

The response to the *Bryce Report* by the Department of Indian Affairs was to state that the recommendations did not apply to the school system. As a result, Aboriginal families and communities continued to see their children taken away to the schools, which they increasingly associated with disease and death (Kelm 1996). In reaction to these dangers, many parents tried to resist compulsory education by keeping their children at home; however, under government legislation it was illegal for them to do so. Kelm points out that, ironically, the residential school system was predicated on the belief that the state and church were "saving" Aboriginal children from unhealthy home environments (1996). In actuality, residential schools were increasingly responsible for disease, illness and death among Aboriginal children and for establishing a legacy of poor health that continues to affect Aboriginal people today (Kelm 1996).

Daily operations and life at residential schools

> *In the residential school I was not really allowed to speak Cree, but they didn't know 'cause we just switched to English every time we saw a supervisor coming or something like that. There was not one single native tradition in the school. They just took you away from home, where you left everything, all the Indian-ness back there. They took you where all the supervisors were all white people.*
>
> Bette Spencer[10]
>
> *After a lifetime of beating, going hungry, standing in a corner on one leg, and walking in the snow with no shoes for speaking Inuvialuktun, and having a stinging paste rubbed on my face, which they did to stop us from expressing our Eskimo custom of raising our eyebrows for "yes" and wrinkling our noses for "no," I soon lost the ability to speak my mother tongue. When a language dies, the world dies, the world it was generated from breaks down too.*
>
> Former residential school student[11]

From 1910 to 1932 the residential school system expanded rapidly, and amendments to the *Indian Act* made school attendance mandatory for at least ten months of the year for First Nation children older than six years of age. By 1930, throughout Canada roughly seventy-five percent of all First Nations children as well as significant numbers of Métis and Inuit children between the ages of seven and fifteen attended the schools (Fournier & Crey 1997:61). The philosophy of the school system was that expression of indigenous culture and individuality was to be suppressed. From the moment the children entered the schools, the physical and cultural markers of indigenous identity, such as their clothing and long hair, were replaced by European fashions (Fiske 1996, Haig-Brown 1988, Miller 1987, 1996). Every child was assigned a number and a European name and forbidden to speak his or her language. Severe punishment was handed out to those who resisted or disobeyed (Fournier & Crey 1997:57, Miller 1996).

Residential schools are an example of what Goffman (1961) refers to as a "total institution." He defines a total institution as "a place of residence and work where a large number of like-situated individuals, cut off from the wider society for an appreciable

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[10] Quoted in "From Our Mother's Arms: The Intergenerational Impact of Residential Schools in Saskatchewan" (Deiter 1999:40).

[11] Quote from Law Commission of Canada (2000:29).

period, together lead an enclosed, formally administered round of life" (1961:xiii). Such institutions break down the barriers that ordinarily separate three spheres of life: work, play and sleep. Total institutions by their very nature prevent social intercourse with the outside world, a strategy built into their physical structures and chosen locations: for example, by locked doors, high walls, barbed wire, and geographical isolation (Goffman 1961:4).

Once someone enters a total institution, every aspect of his or her life is determined and controlled by the institution (Goffman 1961). A total institution is a world unto itself, where those in charge hold all formal power, and rules govern almost every aspect of daily life. Residents have little input into those rules, and in cases where abuse occurs, there is generally little effective recourse for victims and usually no independent procedure for handling complaints. Contact with the outside world—family, friends, community—is tightly controlled and infrequent (Law Commission of Canada 2000:24).

Residential schools were also predicated on the principle on which Jeremy Bentham's "Panopticon[12]" is based. A Panopticon is an architectural form that has two main purposes: to make each person under supervision constantly visible and through the use of individual cells, to make inmates thoroughly individualised (Foucault 1979). The surveillance of the "panoptic gaze" is both constant and immediate. Foucault states:

> Hence the major effect of the Panopticon: to induce in the inmate a state of conscious and permanent visibility that assures the automatic functioning of power. So to arrange things that the surveillance is permanent in its effects, even if it is discontinuous in its action; that the perfection of power should tend to render its actual exercise unnecessary; that this architectural apparatus should be a machine for creating and sustaining a power relation independent of the person who exercises it; in short, that the inmates should be caught up in a power situation of which they are themselves the bearers. To achieve this, it is at once too much and too little that the prisoner should be constantly observed by an inspector: too little, for what matters is that he knows himself

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[12] The Panopticon is made up of a central tower and a peripheral building that surrounds the tower. The tower is constructed so that windows face the inner ring of the peripheral building. The peripheral building is divided into cells that extend the width of the building. At either end of the cell is a window; the interior widow is situated so that it is in line with the windows of the tower. A person is placed within the central tower, and those who are to be supervised are placed individually in each cell. The windows on the outside of the cell allow for light to cross the cell. The cell is backlit by light from outside the building. With the aid of the backlighting, the supervisor can observe the movement of the inmate to the smallest detail and with the greatest precision.

> to be observed; too much because he has no need in fact of being so. In view of this, Bentham laid down the principle that power should be visible and unverifiable. Visible: the inmate will constantly have before his eye the tall outline of the central tower from which he is spied upon. Unverifiable: the inmate must never know whether he is being looked at at any one moment; but he must be sure that he may always be so (1979:201).

As with the Panopticon, the residential school system sought to alter behaviour, and to train and "correct" those whom it observed. The goal of the school system was for Aboriginal children to be assimilated and converted through various techniques of education, Christian conversion, labour, and punishment. A central tactic was the denouncement of indigenous culture and language as inferior and immoral. Children were socialised to internalise this belief so that they would not revert back to speaking their indigenous language and following indigenous cultural beliefs and practices once they left the schools and returned to their communities.

Standards of education were significantly lower in residential schools than in neighboring provincial schools for non-Aboriginal children (Haig-Brown 1988, Bull 1991, Knockwood & Thomas 1992, Miller 1996). Between 1890 and 1950, it is estimated that approximately sixty percent of residential school students failed to advance beyond grade three. In some decades that number increased to approximately eighty percent (Milloy 1999:171). Academic failure was attributed by the government and churches to under-funding, poorly qualified staff and the "stunted mental capacity" of Aboriginal children (Grant 1996, Miller 1996, Milloy 1999).

Discipline, control, and punishment

> *One day I got caught by one of the staff when I was passing notes...I was taken into a locked room and there I was left all day with nothing to eat. I couldn't get to a toilet or bathroom, so I wet myself. I was about nine or ten years old. I dried my undies on the radiator and, of course, they gave off quite an odor. When the matron came to get me at night she smelled the odor and slapped me around for wetting myself, but I couldn't help it; there was no place to go.*
>
> *She then took me up to the dormitory where the rest of the girls were in bed. She told me to get into my nightgown and lie across the bed on my stomach. Then she got a strap and strapped me on the back. Finally*

> *I go so numb that I couldn't cry anymore. But she kept on strapping me and telling the other girls that she was making an example out of me...*
>
> Eleanor Brass[13]

> *And you couldn't speak to your brother on the other side or your cousin, whoever. If you were caught talking to a boy, any boy, you'd get your hair cut right off. What was wrong with talking to the boys? It's a darn wonder we, any of us even got married. Because it was a sin to talk to a boy. Good grief.*
>
> Bette Spencer[14]

The residential school system incorporated both repressive and disciplinary power into the daily running of the schools. Strict regimentation of student activities, along with severe punishment for students who "broke the rules," were employed by school educators to control and re-socialise students (Feehan 1996, Colmant 2000, Johansen 2000). To prevent insubordination, many schools adopted disciplinary practices such as food deprivation, strapping, and solitary confinement as ways to punish children who "misbehaved" (Milloy 1999). Punishment of children was purposely handed out in front of other students as a way to warn them about the consequences of insubordination. Bed-wetting, communicating with children of the opposite sex, speaking an indigenous language, stealing food, running away, talking back to staff, and being outside of school grounds were acts considered in many schools to be insubordinate (Haig-Brown 1988, Bull 1991, Feehan 1996, Miller 1996, Graham 1997, Milloy 1999). The priests, nuns, and teachers who ran the schools maintained strict surveillance of children, including by assigning older children a younger child that they were responsible for, and by encouraging students to report each others' violations. While students found ways to resist the repressive context of the schools, they lived under the constant surveillance of not only the priests and nuns, but also an omnipotent Christian God.

The intention behind such excessive discipline and punishment of students was to cause pain and humiliation (Graham 1997). Humiliation, such as that caused by public strapping, sought to diminish the student's sense of dignity and value of self and identity

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[13] Quoted in "From Our Mother's Arms: The Intergenerational Impact of Residential Schools in Saskatchewan" (Deiter 1999:28).

[14] Quoted in "From Our Mother's Arms: The Intergenerational Impact of Residential Schools in Saskatchewan" (Deiter 1999:46).

(Graham 1997). Former students report that public humiliation was one of the most devastating aspects of their experience (Grant 1996, Graham 1997). At some schools, such as the Mohawk Institute and Mount Elgin, punishment was so frequently given that students were classified based on the number of punishments they received and the reasons why they received them (Graham 1997).

The Canadian government officially discouraged corporal punishment at the schools; however, they believed strict rules and severe punishments were needed to successfully assimilate Aboriginal children. No formal guidelines existed outlining the range of permissive disciplinary actions and corporal punishments that could be used by school staff (Miller 1996, Milloy 1999). Government Indian Agents were responsible for evaluating the conditions under which the students in their charge were living and learning. They also had significant power in the early twentieth century to determine which children were sent to residential schools, to recommend to the Department of Indian Affairs the dismissal of unsatisfactory teachers, principles and staff, and to discharge students. Numerous reports filed by Indian Agents attesting to the cruel and inhumane conditions at the schools can be found in federal archives (Satzewich & Mahood 1995, Milloy 1999, Johansen 2000). This does not mean, however, that the reports led to school reform, and in most cases the excessive disciplinary actions and severe punishment experienced by students went unreported.

Some of the complaints about excessive disciplinary actions and severe punishment filed against members of the church who ran the schools were brought to the attention of the Department of Indian Affairs; however, in these instances little was done to address the problem. Reasons for the inaction by the Department were rooted in the intense power struggle over residential schooling between the churches that ran the schools and the federal government. Reports of abuse were also easily covered up by government officials, and the federal government was particularly unwilling to disclose to the Canadian and international public the real conditions that children were living in at the schools (Satzewich & Mahood 1995).

Sexual abuse and residential schooling

> *The nightmare began as soon as Emily [eight years old] and her sister Rose, then eleven years old stepped on the small boat that would bear them away. "I clung to Rose until Father Jackson wrenched her out of my arms…I searched all over the boat for Rose. Finally I climbed up to the wheelhouse and opened the door and there was Father Jackson on top of my sister. My sister's dress was pulled up and his pants were down. I was too little to know about sex; but I knew he was raping her."*
>
> Emily Rice[15]
>
> *By the time Emily Rice left Kuper Island in 1959, at the age of eleven, she had been repeatedly assaulted and sexually abused by Father Jackson and three other priests, one of whom plied her with alcohol before raping her. A nun, Sister Mary Margaret, known for peeping at the girls in the shower and grabbing their breasts, was infuriated when Emily resisted her advances. "She took a big stick with bark on it, and rammed it right inside my vagina," recalls Rice. "She told me to say I'd fallen on the stick and that she was trying to get it out." The girl crawled into the infirmary the next day, too afraid to name the perpetrator. Nevertheless, when Emily returned to the dorm a few days later, the beatings by Sister Mary Margaret and the other nuns resumed without pause. In the years that followed, Emily would have to twice undergo reconstructive vaginal surgery, and she suffered permanent hearing loss. Father Jackson also wanted to make sure no one would talk. On the sisters' [Emily and Rose] first trip home at Christmas, he suspended Rose by her feet over the side of the boat, threatening to release her into the freezing waves unless she promised to stay silent[16].*
>
> "Stolen from our Embrace: the abduction of First Nation Children and the Restoration of Aboriginal Communities"
>
> *I was first sexually abused by a student when I was six years old and by a supervisor, an ex-Navy homosexual, when I was eight…I learned to use my sexuality to my advantage, as did many of the other students. Sexual favours brought me protection, sweets (a rarity in school) and even money to buy booze. But this had its long-term effects…including alcoholism, the inability to touch people, and "I don't care" attitude.*
>
> Former residential school students[17]

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[15] Quoted in "Stolen from our Embrace: The abduction of First Nation Children and the Restoration of Aboriginal Communities (Fournier & Crey 1997:47).

[16] From "Stolen from our Embrace: The abduction of First Nation Children and the Restoration of Aboriginal Communities (Fournier & Crey 1997:48).

[17] Quoted in Haig-Brown 1988:17.

Specific qualities of the residential schools, notably that the student population was almost entirely isolated from the outside world, allowed sexual predators access to hundreds of Aboriginal children. However, while a fairly comprehensive record documenting the range of physical abuses committed against residential school students exists in the Canadian government archives, these accounts are virtually bereft of any records of sexual abuse (Milloy 1999, Johansen 2000). As stated previously at the peak of the residential school system, roughly seventy-five percent of First Nations children as well as significant numbers of Métis and Inuit children between the ages of seven to fifteen years of age attended a residential school (Armitage 1995). Many of these students were the victims of, or exposed to, forms of physical, sexual and emotional abuse. While the literature fails to generate solid statistics on the number of students sexually abused at residential schools, the estimated numbers are very high, particularly in certain schools (Haig-Brown 1988, Knockwood & Thomas 1992, Satzewich & Mahood 1995, Feehan 1996, Grant 1996, Miller 1996, Chrisjohn & Young 1997, Fournier & Crey 1997, Milloy, 1999). An estimate given in an article in the *Globe and Mail* quoting a special advisor to the Minister of National Health and Welfare on Child Sexual Abuse suggested that at some schools, one hundred percent of the children were sexually abused (Milloy 1999:298)

Incidents of sexual abuse found in official government records are deeply encoded in a language of sexual repression that characterises the discourse on sexual matters at the time (Milloy 1999:296, Johansen 2000). The sexual behaviours identified by officials as deviant and in need of attention by authorities were acts that occurred between students, such as intercourse between boys and girls, and between members of the same sex. These accounts are highlighted in official files and records, while sexual abuse by caretakers such as priests, nuns, and teachers are virtually absent (Haig-Brown 1988, Milloy 1999).

Million argues that the failure of the Canadian government to address issues of sexual abuse in residential schools is a reflection of nineteenth and twentieth century colonialist understandings of Aboriginal people, which proclaimed them to be less “civilized,” less “mentally developed” and deeply lacking in Christian morals. Christian institutions portrayed indigenous people as “sexually immoral” (Million 2000:96), and their children as having been contaminated by their “Indianness” (Graham 1997). One school principal described Aboriginal children in his care as being inherently "immoral"—"nature," he stated, "is very strong in them...The problem, of course, is that these people with regard to sex mature much earlier than the whites, making it necessary to guide that part of their emotional make-up along sound and safe channels" (Milloy 1999:296).

The residential school system was seen as a means to reform the immoral sexual predisposition of Aboriginal people through their children. As such, residential schools were structured in a manner consistent with the highly gender-segregated structure of most contemporary western European societies of the day (Haig-Brown 1988, Knockwood & Thomas 1992, Miller 1996, Graham 1997, Milloy 1999 Million, 2000). Contact between boys and girls was restricted and heavily monitored by school staff. The penalties for communicating with members of the opposite sex were often severe and frequently resulted in physical punishment, and/or loss of some, or all, of the few individual freedoms children had in the institutions (Grant 1996, Miller 1996, Milloy 1999).

Sex and sexuality were not spoken about at the schools, nor was sexual abuse spoken about in political or public debates concerning residential schools. Prior to the recent disclosures in which former students have come forward to tell of the abuse, a public facade maintained that residential schools were institutions that repressed expressions of sexuality under the moral guidance of the church. However, recent accounts illustrate that sex and sexuality were very much a part of the residential school environment. For example, a report prepared by the Law Commission of Canada for the Minister of Justice, the Honourable A. Anne McLellan, examines abuse that took place in residential schools and in institutions such as orphanages, schools for the Deaf, long-term mental health care facilities, sanitoria and training schools. In the report, institutional child abuse is defined as "abuse inflicted on a child residing in an institution, as distinguished from abuse occurring at home, or 'domestic child abuse'" (Law Commission of Canada 2000:20).

In its report, the Commission argues that in a total institution like residential schools, children lack outside supports to offset abuse. It suggests that children in this situation live in fear of arbitrary or excessive punishment directed toward them. Added to this may be fear of a form of abuse that has nothing to do with the rules and discipline of the institution, but everything to do with the arbitrary excess of power: sexual abuse. Sexual abuse, the Commission states, "is an intensely private form of abuse, and a singularly potent expression of power and domination that totally undermines a person's autonomy" (2000:27). The Commission adds:

> Once that sense of the unchecked power of those in authority is firmly established, an atmosphere of insecurity and fear pervades an institution. Children do not have to experience arbitrary or excessive punishment to want to avoid it—they just have to witness enough of it to understand that they could be next (2000:27).

In schools where sexual abuse occurred, children quickly learnt that sexual relations were dictated by power and they lived in fear of their abusers. In some instances children learnt to use their own sexuality to gain special status with supervisors and other students (Haig-Brown 1988).

The Commission concluded that of all the institutions in Canada where children have been placed, the residential school system has done the greatest damage. This they attribute to a number of factors, including the children being very young when they entered the schools (some as young as six years of age), their removal from their families for ten months of the year or longer, their ongoing experience of physical deprivation and in many cases various forms of abuse, their being forbidden to speak the only language that they knew, and their being taught to reject their home, heritage, and, by extension, themselves (Law Commission of Canada 2000:24). In this way, the children were deprived of any emotional and support resources that could have assisted them in resisting repeated physical and sexual abuse. For these reasons, the Commission concluded, "It cannot be emphasised too strongly that, for all the elements of similarity with abuse in other institutions, Aboriginal children suffered in a unique way in residential schools" (2000:28).

Million (2000) suggests that the collective silence about sex and sexual abuse at residential schools created a discursive void which allowed predatory sexual behavior to persist over extended periods of time. This helps to explain why the Canadian public remained ignorant or the widespread and systematic physical and sexual abuse of Aboriginal students. Because government archives and official files are bereft of accounts of sexual abuse at the schools, most information has come from special inquiries into the problem, and from the personal testimonies of those individuals who experienced and witnessed the abuse. Older students, socialised primarily in the system, are reported to have commonly become sexual abuse perpetrators themselves, preying on the younger students (Haig-Brown 1988, Piatote 2000).

Sexual abuse was also not limited to the confines of the school, and many reports exist of students returning to their home communities where they themselves began to abuse younger children (Haig-Brown 1988, Fournier & Crey 1997). Considering the young age that most students were apprehended, and that the residential school system was their primary socialising influence in their childhood years, it is not surprising that dysfunctional relationships—predicated on the one hand by power, control and domination, and on the other, by internalised self-hatred and identity loss and confusion—were recreated once the students returned to their community.

It has been estimated that in some smaller Aboriginal communities, upwards to eighty percent of community members have been victims of sexual abuse at some point in their lives (Fournier & Crey 1997). Fournier and Crey argue that the pervasive sexual abuse of children at residential schools effectively resulted in the elimination of traditional cultural sanctions against physical and sexual abuse in many Aboriginal communities (1997). They write:

> Sexual abuse was not unknown historically in aboriginal societies. But the consensus among First Nations in BC, as reported by an aboriginal panel that travelled around the province in 1992 reviewing social legislation, is that traditional sanctions, laws and the clanship system among disparate First Nations did much to eliminate or control it. Because the laws "were motivated by internalized acceptance rather than external coercion," authors Evan Jacob of the Kwakiutl Nation and Haida elder Lavina Lightbown conclude in the panel's report, "they were much more binding on each individual." (Fournier & Crey 1997:117).

Residential school students internalised and normalised the systematic physical and sexual violence perpetrated against them. This arguably accounts for a higher-than-average prevalence of physical violence and sexual abuse found among some Aboriginal groups today (Bull 1991).

Parents and communities

> *Our parents were quite powerless in those times. They did not wish us to go to boarding school but they were threatened by the law if they didn't comply; we were all victims.*
>
> Georgina Gregory[18]

The removal of Aboriginal children from their families undermined the traditional role of the extended family and kinship networks (Fournier & Crey 1997). In the pre-residential school era, the extended family played a prominent role in child-rearing in Aboriginal communities (Haig-Brown 1988, Bull 1991, Ing 1991, Grant 1996), which contrasted greatly with the emphasis on nuclear families that was found in the settler society that was reinforced to Aboriginal children at the residential schools. Government officials, including local Indian Agents, generally failed to understand the role that the extended family and the broader community played in the rearing of Aboriginal children. By breaking up Aboriginal families by placing their children in residential schools, the government effectively removed the role of parenting from the family and community and placed it in the hands of the church and state.

Changes in the social structure of indigenous communities occurred as a result of the removal of the children to the schools, and again as the students returned to their communities. For example, a dramatic change occurred in parenting practices between those traditionally used and those learnt by students at the school (Ing 1991). This is illustrated in an account by a former student, G. Manual, who contrasts the treatment of children at home and in the schools:

> The priests taught us to respect them by whipping us, [while] our mothers and fathers, aunts and uncles and grandparents, failed to represent themselves as a threat when that was the only thing we had been taught to understand (Manuel & Posluns 1974:67 in Milloy 1999:43).

The loss of their children to the residential school system came at a time when many Aboriginal communities were simultaneously experiencing severe social and health problems, such as famine and accelerated social and economic dissolution (Miller 1996). Removal of children from their families and communities also led in some instances to

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[18] Quoted in "From Our Mother's Arms: The Intergenerational Impact of Residential Schools in Saskatchewan" (Deiter 1999:64).

increased levels of alcohol consumption by parents and community members (Haig-Brown 1988, Feehan 1995). Collectively this added to the inability of parents and communities to resist the government's removal of their children.

Transformation: "healing," "wellness," and hope for a better future

> *On a general level, what should be understood about native alcoholism is that the stereotype of the drunken Indian is much more than a dominating and unsightly phenomenon—it is a symbol of the holocaust that has wreaked destruction on the Onkwehonwe of Great Turtle Island for the past three hundred years, and the results are horrifying. On an individual level we are paying the legal, medical, financial, and social consequences in the form of beatings, accidents, injuries, suicides, murders, arrests, jail terms, fires, drowning, sexual abuse, child abuse, child neglect, poor health, child apprehensions, unemployment and welfare dependency.*
>
> *But our people have paid an even higher price. We have lost our languages, medicine and religions. We have lost our pride, dignity and confidence. We have lost our family values, social patterns and political structures. We have lost our stewardship over the land. We have lost control over our lives and our destiny. We have lost almost everything a race of people can lose.*
>
> Brian Maracle[19]

For Aboriginal people a history of oppression stemming from the arrival of Europeans and the subsequent unfolding of colonialist strategies of assimilation have brought a present day context in which individuals and communities struggle with a myriad of "problems" that are neither easily defined nor solved. The blurring of victim and victimizer characterizes many of the narratives depicting the individual and collective experiences of Aboriginal people. Alcohol, a powerful signifier of colonization that has persisted from the contact period onward, plays the role of catalyst in the transformation of victim into victimizer, the abused and neglected child into the abusive and neglectful parent, and the traumatized community into the community that injures and destroys the next generation.

The impact of colonization upon Aboriginal people in Canada, as it has been for other indigenous groups in various parts of the world, has been devastating. In this process, many of the traditional social structures, practices, and roles that defined family and community life were undermined and destroyed. The residential school system

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[19] "Crazywater: Native Voices on Addiction and Recovery" (Maracle 1993:9).

signifies for Aboriginal people the deliberate lengths to which the Canadian government and churches were willing to go in order to facilitate this process. As attention was drawn to the decades of abuse that children endured while attending residential schools, calls for individual and collective "healing" and a resurgence of interest in traditional ceremonies, teachings, and rituals emerged across Canada in urban, rural and reserve First Nations, Inuit and Métis communities. "Healing" and "wellness" centers were built in some communities and, as part of their apology to former students of residential schools, the Federal government established the Aboriginal Healing Foundation[20] (AHF) whose mandate is to address the wrong committed against former students of the schools through the creation of various community-based healing projects. Over the past six years, the AHF has funded a range of community-based initiatives and research projects aimed at addressing the tragic legacy of the residential school system.

Law suits against the federal government and churches, the recording of personal narratives of former students, and academic and community research on various topics related to the residential school system have also contributed to understanding "collective intergenerational trauma" and processes of "healing." However, for Aboriginal people, the residential school system and the larger colonial structure in which it emerged are still present today, embodied in the *Indian Act*, and evident by the reluctance of the Federal and provincial governments to negotiate self-government.

When Aboriginal people describe the challenges that collectively face their communities, and how these challenges should be addressed, they describe a different type of transformation, one that restores to them a sense of balance, harmony and holism. The Royal Commission on Aboriginal Peoples, for example, writes, "Aboriginal nations need a strong and durable foundation upon which to build self-government. That foundation is the people—healthy, educated individuals, strong in body, soul, mind and spirit" (1996b:3). The "de-colonization" of a collective and individual physical, spiritual, psychological and emotional being also involves the de-colonization of Aboriginal land, and social and political structures. A hope for a better future lies in transforming the remnants of colonization, such as family dysfunction, violence, child abuse, and alcohol abuse, into individual and collective "wellness" and "healing," "harmony" and "balance."

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[20] The AHF is run by an Aboriginal Board of Directors and employs an all-Aboriginal staff.

For First Nations, Inuit and Métis, hope for a better future is focussed on the next generation, and because of this, they place significant emphasis on re-instilling within family and social structures ways by which children can be protected, nurtured, and educated. Many Aboriginal families, and in some cases whole communities, are perceived to have lost their ability to properly parent their children, and community and family elders the ability to pass on local traditional teachings and ceremonies. This is linked by Aboriginal people to breaches in the passing of traditional knowledge from parent to child and from grandmother to mother, to the pervasiveness of alcohol abuse and addiction, and to the perpetuation of intergenerational trauma such as child abuse. Hope for a better future lies in internal transformation of individuals, as well as within the family and community.

Canadian society and hope for a better future

For mainstream Canadian society, the hope for a better future for Aboriginal people is situated both within and outside of Aboriginal communities. The residential school system has come to be viewed by many non-Aboriginal people, particularly those who work in health care and social services, as a main source of "Indian problems," specifically because of the strong association between the schools and widespread sexual and physical abuse of Aboriginal children. Many Canadians see the residential school system as a poorly conceived strategy of assimilation that had unforeseen negative consequences, namely harm being inflicted upon Aboriginal children through forms of assimilation and other more serious "trauma" secretly caused by sexual predators masquerading as priests, nuns, and teachers.

Increasingly, a link between the "residential school experience" and perceived high rates of FAS in Aboriginal communities is referred to within medical and social service discourse surrounding FAS. This is illustrated in a statement made by Jack Armstrong, former President of the Canadian Medical Association, to journalist David Square, who was writing an editorial on FAS for a Canadian medical journal. Armstrong states:

> The white population cannot point smugly at aboriginals and claim fetal alcohol syndrome is just a native problem. For one thing, we [white Europeans] helped to create the problem by refusing to acknowledge aboriginal culture and by sending Indian

> children to residential schools. People with low self-esteem often turn to alcohol for consolation (Armstrong quoted in Square 1997:60).

Within arguments such as this, a unidirectional link between the experience of residential school students and the current "problem" of FAS is made through the use of psychologized language such as low-self esteem and self-medication. Armstrong's statement suggests that the task of physicians, like himself, as well as that of government and other health and social service providers, is to treat the consequences of past oppression located in individual and collective bodies and minds of Aboriginal peoples. In present day "post-colonial" Canada, health and social service providers generally see the dominant society as an altruistic and benign caregiver that in its "enlightened" state sets itself apart from the misdirected, or as more liberal proponents argue, racist strategies of their colonizing ancestors. Oppression is something of the past, and intergenerational manifestations of its impact are re-labeled as "treatable conditions," such as fetal alcohol syndrome, low-self esteem, and alcohol abuse—conditions which mainstream health and social services are poised to address in efforts to improve the lives of Aboriginal peoples.

Setting themselves apart from their colonizing ancestors, the helping professions in Canada, such as health care providers and social workers, have with the help of federal and provincial governments re-framed their relationship with Aboriginal people as a "partnership" in which they share an equal stake with Aboriginal communities in improving the health and social status of individuals who are First Nation, Inuit and Métis. Simultaneously, by setting themselves apart from their colonizing ancestors, they distance themselves from responsibility and culpability in the creation of those problems.

Some Canadians, including some health care and social service workers, are not sympathetic to arguments that situate the source of "Indian problems" within historical processes of colonization. In fact, many Canadians simply do not know or are uninterested in knowing about what happened to Aboriginal people during colonization, or in why many Aboriginal communities are not faring well in "post-colonial" Canada. Often, Canadians perceive Aboriginal people as a societal burden and maintain that they unfairly receive social benefits, such as tax exemptions and funded post-secondary education, which are not available to other Canadians. This perception reflects the fact that many non-Aboriginal people are unclear about the differing relationships that each group of Aboriginal people (Métis, First Nations, Inuit; status, non-status) has to the larger state, the legislation contained in the *Indian Act*, and the history of Aboriginal and non-Aboriginal treaty making in Canada. This lack of understanding, coupled with the ongoing racial tensions between the two groups, has meant that many Canadians feel frustration and resentment toward Aboriginal groups, particularly in local settings where Aboriginals and non-Aboriginals live in close proximity but where little social integration occurs.

Conclusion

In this chapter I have argued that a consensus has arisen between Aboriginal people and the dominant society that the individual and collective bodies of First Nations, Inuit and Métis have to a considerable degree been re-made by processes of colonization. Through the examples of alcohol abuse and the residential school system, I explored a shift in the conceptualization that the dominant society has about Aboriginal people. I argue that mainstream liberal discourse has undergone a change in understandings of Aboriginal people away from a presumption of the biological "inferiority" of the pre-contact "indigenous mind and body," to a focus on socially derived "Indian problems" that are believed to have arisen out of processes of colonization that in the past undermined the collective health of Aboriginal peoples and eroded traditional social and political relations. I further explored a similar perception reflected in Aboriginal discourse and practices: that, rather than situating the problems found in their communities in the colonial past, Aboriginal groups see on-going neo-colonial oppression as continuing to perpetuate harm against their people.

Section Four
FETAL ALCOHOL SYNDROME: ONE-HUNDRED PERCENT PREVENTABLE

> *If women didn't drink anymore during pregnancy, there would never be another baby born with Fetal Alcohol Syndrome or Effect.*
>
> Ann Streissguth[1]
> Director of the Fetal Alcohol Research Unit
> University of Washington

Introduction

The claim that FAS is one hundred percent preventable is a commonly stated and powerful "fact" in the discursive arena associated with alcohol use by pregnant women. It is particularly salient because of its relationship to two claims made by scientific researchers that inevitably evoke an emotional response and a sense of urgency that some type of immediate action be taken. The first claim is that individuals with FAS/ARBEs are sentenced to life-long physical and psychological suffering (see, for example, Streissguth 1997). The second claim situates FAS/ARBEs in relation to populations, and states that in North America, alcohol use by pregnant women is at a "crisis" level and will impact negatively upon the larger society with enormous human, social, and economic costs (Streissguth 1994:15). The statement that "FAS is one-hundred percent preventable" therefore implies a moral and social responsibility on the part of the larger society to protect future citizens (those yet to be born) from exposure to alcohol.

In this section I examine the discourse and practices attached to "FAS prevention" in Canada and situate them within the larger social service and public health delivery system. Using Manitoba as an example of a province that has prioritized "FAS prevention" within health and social service delivery, I map the "continuum of care" that exists in the province for pregnant women with substance abuse problems. I then examine the programs and services that have been put in place to prevent FAS in relation to the subjective experiences of women who are considered to be at highest risk. The narrative accounts given by women directly challenge the claim that FAS is one-hundred percent preventable by illustrating the difficulties and challenges, including those

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[1] From "Fetal Alcohol Fact Sheet," (The Children's Trust Foundation 1994:33). This quote by Ann Streissguth (1997) is commonly used in a variety of public health documents in North America.

involved with a substance addiction, that are inherent in the lives of this group of women. The narratives especially highlight the central role that the profession of social work, specifically child and family services play in the lives of impoverished women with substance abuse problems, and how the experiences of Aboriginal and non-Aboriginal women differ in relation to the social welfare system.

Following this discussion I turn to the question of prevention and the discourse of “secondary disabilities” to explore representations of the “typical” adolescent and adult with FAS and how these images reinforce understandings of “risk” and “danger” in relation to Aboriginal peoples, and within a context where FAS experts agree that less than 1% of the estimated rate of persons with FAS/E are diagnosed. I argue that a practice of non-medical labeling of people as having FAS/E—either self-labeling or labeling by others—has arisen in contexts, such as the reserve and inner city, where rates are assumed to be high, and this labeling has emerged as a result of it being almost impossible to receive diagnostic assessments, especially for adolescents and adults. I then situate this practice in relation to the discourse of “secondary disabilities” and examine how this has led to the medicalization of what otherwise are considered “social” problems in these communities, such as youth crime, school drop out, and teen pregnancies.

In the final chapter, I return to the national context and describe the events that took place at a workshop that I attended at the end of my field research. I examine how, within this setting, the perception of an “epidemic” of FAS/ARBEs that is far greater than is substantiated in the scientific literature exists in Aboriginal communities and which, is mapped onto local knowledge and practices attached to “risk” and “prevention,” and to the surveillance and “predetection” of “at-risk” populations of Aboriginal women.

Risk and prevention

In her book, *Risk and Blame*, Mary Douglas argues that the language of danger in EuroAmerica has been turned into a language of risk that grounds itself within the technical discourse of statistical reasoning and thus stakes a claim to scientific objectivity (1992:14, see also Hacking 1990, Lock 1993, 1998, Young 1995). Our obsession with preventing risks, she suggests, stems from life in a global society in which, because of growing anonymity, people feel increasingly vulnerable to various dangers. Douglas argues that the idea of risk fits perfectly into a global context because of its universalizing terminology, its abstractness, its power of condensation, its scientificity, and its connection with objective analysis (1995:15). Risk, she argues, is inevitably tied to a type of blaming system in which someone, or something, is deemed accountable and in which prevention becomes an act of coding risk in domains where protection from risk is believed to be inadequately covered (Douglas 1995:15-16).

Castel argues that a rupture between the categories "danger" and "risk" occurred when risk became understood as the effect of a combination of abstract factors that render more or less probable the occurrence of an undesirable event, such as illness, abnormality, or deviant behavior (1991:287). The rise of "objective risks," those associated with statistical correlation between series of phenomenon, has led to the surveillance of groups who are now described as "populations at-risk" (Castel 1991, Lock 1998). Castel argues that to intervene no longer requires, or at least not to begin with, taking as one's target a given individual, who is to be corrected, punished or cared for. The relationship of immediacy with the subject in the discursive arena of "risk" and "prevention," for example, found in the doctor-patient relationship, is transformed because such subjects must first be produced through their positioning in populations. Castel writes,

> What the new preventative policies primarily address is no longer individuals but factors, statistical correlation of heterogeneous elements. They deconstruct the concrete subject of intervention, and reconstruct a combination of factors liable to produce risk. Their primary aim is not to confront a concrete dangerous situation, but to anticipate all the possible forms of irruption of danger. "Prevention" in effect promotes suspicion to the dignified scientific rank of a calculus of probabilities. To be suspected, it is no longer necessary to manifest symptoms of dangerousness or abnormality, it is enough to display whatever characteristic the specialists responsible for the definition of preventive policy have constituted as risk factors. A conception of prevention which restricted itself to predicting the occurrence of a particular act appears archaic and artisanal in comparison with one which claims to *construct* the objective conditions of emergence of danger, so as then to *deduce* from them the new modalities of intervention (1991:288-289 emphasis in text).

The presence of some, or at least of a certain number, of "risk factors," Castel argues, sets off an automatic alert that is associated with some form of appropriate action (1991:287). For example, a specialist like a social worker or public health nurse may be sent to visit a family "to confirm or disconfirm the *real* presence of a danger, on the basis of the *probabilistic and abstract* existence of risks." The starting point is not "a conflictual situation observable in experience, [but] rather one *deduces* it from a general definition of the dangers one wishes to prevent" (Castel 1991:287-288 emphasis in text).

This new form of surveillance or "systematic predetection" (Castel 1991:288) is especially important to consider in relation to the diagnostic category FAS and the targeting of Aboriginal communities for prevention programming. A certain tension currently exists within the discursive arena attached to the category FAS. On the one hand, the precise threshold level at which alcohol becomes dangerous to the fetus is unknown, the diagnostic boundaries for FAS/ARBEs is highly controversial, clinical diagnostic inconsistencies are common, several methodological problems hinder epidemiological studies of prevalence and incidence rates, and less than one percent of the estimated population of persons thought to have FAS or related ARBEs are medically diagnosed. On the other hand, in most regions of North America, especially in western and northern regions, widespread consensus exists among scientific researchers, health and social service providers, all levels of government, and the general public that rates of FAS/ARBEs are high (sometimes epidemic), especially in Aboriginal populations, the human, social and economic costs are enormous, and FAS/ARBEs is entirely preventable (McCuen 1994, Streissguth 1997).

The tension between very few individuals actually being medically diagnosed with FAS/ARBEs, and the perception that gestational exposure to alcohol has resulted in serious health and social problems across the life span for vast numbers of "affected" offspring, finds significant meaning and hope in the form of a preventative framework. Even though the sense of urgency that characterizes FAS prevention programming is derived from scientific and lay descriptions of FAS/ARBEs that invoke words like "disaster" (Streissguth 1997), "devastation," and "tragedy" (Waldman 1989) the framing of the "FAS problem" in relation to a single "preventable" etiological event—gestational exposure to alcohol—suggests that prevention is not only achievable, but more importantly, that it is morally and socially justified.

In a preventative framework, it is unnecessary to have a local population of persons diagnosed with FAS/ARBEs or even to have confirmation that pregnant women in the community are abusing alcohol in order for action to be taken. Instead, the presence of alcohol use within the population is enough to justify preventative action. The presence of at least some of the “risk factors” associated with FAS, such as high fertility rates, family dysfunction, a large percentage of children in foster/adoptive care, high rates of school drop-out, or “youth crime,” are then used to determine the level of preventative action that is warranted.

This type of reasoning is illustrated by the federal government’s decision to create a national FAS prevention strategy for First Nation reserve communities. For example, the risk factors listed above, especially high fertility rates and alcohol use, are statistically associated with the Canadian Aboriginal population and, as discussed in Section Two, epidemiological researchers argue that the correlation of these two factors contribute to high prevalence rates of FAS among the general Aboriginal population. Based on this information and the urging of a group of medical doctors, psychologists, and parent advocates in western regions of Canada, the federal government created the national strategy. However, in most local reserve contexts, virtually no individuals have been medically assessed for, or diagnosed with FAS/ARBEs that would confirm that some form of prevention is warranted in the different communities. As will be illustrated in my discussion, diagnosed individuals or populations of individuals are replaced in this context by specific understandings of the “typical person with FAS,” the “typical population where FAS is widespread,” and a set of “risk factors” that are associated with them, and with the behavior and bodies of pregnant women.

As discussed previously, in a context where diagnostic assessments rarely occur, the local context of the reserve community and the inner city ghetto became geographical sites where the mapping of “risk” onto individuals and populations has been the most reasonable for both Aboriginal and non-Aboriginal researchers, and health and social service providers. This is partially due to Aboriginal service providers being focused only on Aboriginal populations, and because of a general consensus by non-Aboriginal researchers, health and social service providers that Aboriginal populations are most at-risk. Further, a medicalized explanation for a range of social problems that are not easily addressed, as well as a medical-based justification to intervene to curb high fertility rates among Aboriginal women in reserve and urban ghettos, is viewed as providing a meaningful framework in which to intervene in the lives of Aboriginal peoples.

Pregnancy, reproductive technologies and FAS

Feminist anthropology provides important theoretical tools with which to interpret and understand the knowledge and ideas associated with pregnancy and birth. Recently this body of literature has attempted to provide a more nuanced understanding of the "reproductive body" through an exploration of issues related to self and body images of "women," "mothers" and "fetuses" (Edwards et al. 1993, Lock 1993, Ginsburg & Rapp 1995b, Lock & Kaufert 1998). Emphasis has been placed on techno-medical science, specifically on those technologies used to assist in procreation—"new reproductive technologies" (NRTs) (see for example, Martin 1987, 1990, 1997, Rapp 1988, 1990, 1991, 1993, 1995, Davis-Floyd 1992a, 1992b, Strathern 1992, 1995a, 1995b, Edwards et al. 1993, Sargent & Stark 1989, Browner & Press 1995, Franklin 1991, 1993, 1995, 1998, Petchesky 1995, Press et al. 1998, Cussins 1998, Hadwerker 1998, Lock 1998), and those that assist in preventing or terminating pregnancy (see for example, Ginsburg 1989, 1990, Barroso & Corrêa 1995, Kligman 1995, Rylko-Bauer 1996). Feminist anthropologists have argued that new forms of medicalization of pregnancy and birth effectively de-familiarize many of our most deeply taken-for-granted assumptions about the "naturalness" of reproduction (Franklin & Ragoné 1998, Strathern 1992). Increased medicalization of pregnancy and birth makes it difficult to maintain that reproductive acts are private, personal, domestic, and merely biological phenomena that have little to do with power, politics and commerce (Franklin & Ragoné 1998:4-5).

Ginsburg and Rapp (1991, 1995a) argue that despite the extraordinary developments in Western technology in areas of reproduction, to focus too narrowly on the technologies themselves misses what anthropologists often discover in their research generally: that the control and distribution of knowledge and practices concerning reproduction are contested in every society (see also Lopez 1997, 1998, Morsy 1997, 1998, Mullins 1995, Oaks 1998, Pearce 1995, Sargent & Bascope 1997, Sesia 1997, Stacey 1997, Wagner 1997, Wright 1995). They suggest that social actors, with a diversity of interests, promote their own versions of cultural continuity, and reproduction is always a central concern in this context (Ginsburg & Rapp 1995a:5). Therefore, anthropologists must pay particular attention to sources and relations of power that shape meanings associated with pregnancy and birth rather than just to the technologies themselves.

Lock and Kaufert take this further by suggesting that clarification of what is meant by the concept of "technology" is central to this discussion. Referring to Foucault's notion of the "political technology of the body" (Foucault 1979:25-26), they write,

> …we understand technology not simply as tools and machines, but, following Foucault, as also techniques of quantification, systematization, and routinization: in short, the gamut of human effort to manipulate and control what is available to it in order to produce an effect or an end-product perceived to be beneficial in some way to individuals and also society (1998b:21, see also Escobar 1995, Kleinman 1995, Oudshorn 1994).

In this way Lock and Kaufert challenge us to look beyond the machines and techniques that have so dramatically altered women's reproductive experiences in North America, and consider the technologies that are most taken-for-granted and seemingly benign.

To date, reproductive technologies such as sonograms or prenatal testing offer no distinguishable diagnostic information to assist in detecting or intervening where fetal risk, vulnerability, or damage associated with in-utero alcohol exposure is suspected. Because in the discursive arena associated with the category FAS understandings of "risk" are closely connected to impoverished Aboriginal women living on social assistance, determining the existence of "risk" and "risk behavior" has been situated within other technological processes situated outside of the clinical context: that is, situated within the practices of child welfare services and in the growing number of FAS prevention programs offered by community outreach services. As will be illustrated in the following chapters, social work practices play a central role in societal and self-perceptions of impoverished Aboriginal women.

Disciplinary power within the discourse and techniques employed by social service workers[2] is masked by their image as benevolent caregivers, and their perceived function to administer help to those in need. At the core of their work is the goal of normalizing or managing "the troubled," so that they conform as much as possible to

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[2] I use the term "social service workers" as an umbrella term for social workers, community and outreach workers, and addiction counselors.

societal standards of personal conduct and subjective states (Epstein 1999:3). At the same time, social service workers emphasize self-determination and individual autonomy. In their attempt to transform a person, they do so with the caveat that the person should want this, should consent to it, and should do it of their own free will (Epstein 1993:9, Swift 1995). In her discussion of social workers, Epstein writes:

> Social work collaborates with other occupations, mainly the "helping disciplines," all of which together manage the population. Social work is the Janus-faced one. To accomplish its purposes, social work must dominate its clients, although in theory and in its manner of interpersonal relations with clients it puts forward a democratic egalitarian manner. However, to be effective, to show results, it must influence people, motivate them to adopt the normative view inherent in the intentions of social work practice. It must produce without forces, without command, indirectly. It must be authoritative. It must enable its clients to be transformed, to adopt normative ways and thoughts *voluntarily* (1999:9).

The "panoptic gaze" is interwoven within social service practices to create a combination of disciplinary techniques (Moffatt 1999:224). For example, the constant preoccupation of social welfare with the eligibility of the client to receive assistance creates a dynamic whereby the surveillance by the worker is continuous and constant. Moffatt argues that the preoccupation with eligibility also situates the workers in an economy of power and therefore they are located within a peripheric zone (1999:225). Within the larger disciplinary structure, however, the workers themselves are under surveillance by their supervisors who review their work. The larger social service structure is also under surveillance by governments and by the entire society. This is evident, for example, in the degree of public condemnation and calls for inquiry to determine who is responsible for situations in which something goes very wrong, especially those involving the abuse or violent death of a child who a social services agency is following as a case.

The relationship that impoverished women have with social workers and with many outreach and community workers, even those who are most sympathetic to the complexities of their clients' lives, is characterized by normalizing judgement in which workers are continuously evaluating the behavior of their clients, some of which ends up being recorded in client dossiers. Foucault characterizes this as a kind of "micro-penalty" in which more and more areas of life, too trivial and local to have been included in the legal web, are now captured by power (1979, Dreyfus & Rabinow 1982). He argues a "whole micro-penalty of time (lateness, absences, interruptions of task), of activity (inattention, negligence, lack of zeal), of behavior (impoliteness, disobedience), of speech (idle chatter, insolence), of body (incorrect attitudes, irregular gestures, lack of cleanliness), and of sexuality (impurity, indecency)" exists (Foucault 1979:178). This type of surveillance and imposing of judgement has increasingly been extended further and further into spaces that are considered private in our society, particularly into client's homes where outreach and social workers make scheduled and unscheduled visits as part of their determination about a client's status and worthiness of support. Through the observation of the most detailed aspects of everyday behavior of their clients, almost anything becomes potentially punishable (Dreyfus & Rabinow 1982:158).

Social service providers and "FAS prevention"

As discussed in Section Three, the clinical examination is the procedure that brings together surveillance and normalizing judgement (Foucault 1979). Compiling individual "cases" and population "data" information about women and their children is of central importance in FAS-related clinical assessment, prevention/intervention activities, and research. Almost exclusively, the women in North America who are targeted by these activities are impoverished single mothers who receive social welfare benefits, and in Canada, a large percentage are Aboriginal. As a result, significantly more attention has been directed toward them and their children in areas of prevention, diagnostic assessment, and research (see for example, Robinson 1988).

The most vital forms of surveillance of "at-risk" women are interviews, screening assessments and observations made by outreach and community health and social service providers. Detailed information about women and their children is recorded and discussed by social service workers and stored in client dossiers that are then referred back to as the woman's situation changes: for example, if she becomes pregnant. While medical examinations and dossiers are also important, physicians generally have significantly less knowledge of and involvement in the lives of pregnant women than do social and outreach workers. For example, a social worker may have contact with a client on a weekly or monthly basis, and have very intimate and detailed documentation of many years of the person's life with which to guide their judgements about and interactions with a client. Outreach and social workers also commonly visit the homes of their clients, at which time they have the opportunity to observe private spaces that are never seen by medical doctors. As will be illustrated by the narrative accounts given by the women in Chapters Ten and Eleven, the subjective experience of being constantly seen by the social welfare system, particularly in relation to their roles as mothers, greatly influences the women's decision making, their perception of the agency and of other support services that are available to them, as well as their self-perceptions about who they are in their role as mothers, and as members of the larger society.

This level of surveillance through observation and inscription is even more exaggerated in cases where FAS-prevention "mentor" programs have been established. The goal of this type of program is to create a close client-worker relationship between "high-risk" pregnant women and outreach workers. The worker spends considerable time, commonly on a daily basis, with the woman in efforts to support her in "choosing" not to abuse substances, in negotiating social welfare and, legal systems, and outreach service delivery, and in dealing with the circumstances of her daily life, such as relationships with husbands or boyfriends, family members and friends. While this type of programming is considered to be a successful intervention in the prevention of FAS and in supporting women who are "high-risk", almost every detail of the woman's life is under constant surveillance and scrutiny.

Client dossiers have come to represent an "objective" accumulation of "facts" over time and space that describes women and their children in various technical language and images. Generally this information is compiled not by one, but by a diverse group of professionals and specialists who are interconnected through time and space solely by the circulation of client dossiers (Castel 1991:282). While medical, legal, and social service files are generally not compared or compiled together as a single dossier, comparisons of dossiers frequently occur in contexts where service providers, clinicians, or researchers are concerned with a child whom they think may have FAS, or in the case of a pregnant woman whom they suspect may be abusing alcohol and/or illicit drugs. A growing emphasis on the coordination of information gathered by various service providers about clients they have in common has meant that the lives of impoverished women are under increasingly greater surveillance, but not necessarily combined with an associated benefit of improved housing, employment, financial support, or health and social service support that will assist them in keeping their families together.

The client dossier is also an important source of knowledge that effectively replaces the necessity for the subject (woman or child) to be present. For example, a significant number of children who are medically assessed for FAS are not in the care of their biological mothers. Because confirmation of alcohol exposure is required for diagnosis, the mother's medical, social service, and legal files may be made use of in order to determine if the woman was using alcohol when pregnant with the child, and/or if she has a history of alcohol abuse. In a context such as this, the file literally *becomes* the woman and confirmation of maternal alcohol use, including levels and patterns, are derived from the dossier. Self-reports by women about their alcohol use during pregnancy are also commonly compared to information recorded about their use in medical and social service files, especially if under-reporting of use is suspected. In these instances, what a woman reports is viewed as less "objective" than what is found in her client dossier. Women in this study spoke about the power inherent in the dossier, for example, to support arguments in child custody cases with child and family services and ex-husbands that they were unfit to parent their children. They also spoke about their frustration of having no control over what was recorded in the file, and in their being prevented from seeing a file that was used at different time to represent who they were as a person.

Determining "appropriate" action

Client or patient dossiers have emerged as an essential part of the mechanisms of disciplinary power in fields of medicine, social work, and public health. As stated above, within a model of "systematic predetection," the presence of some "risk factors" sets off an automatic alert that is associated with some form of "appropriate" action (Castel 1991:287). Client dossiers act as the central technology where these risk factors are recorded and followed over time and space. For example, if a social worker becomes aware that a specific woman is pregnant, he or she can refer to the woman's dossier to determine the presence of risk factors for a range of health and social problems that the worker believes will impact negatively upon the pregnancy, such as the woman having an alcohol abuse problem. Alone, or in consultation with other social workers, health care providers or outreach workers, he or she can then make a decision about whether some form of action in relation to the woman should be undertaken.

In Manitoba, a common example of "appropriate" action for a social worker to take, upon gaining knowledge that a woman with a known alcohol abuse problem is pregnant, is to place a "birth alert" upon the pregnancy. As discussed in Section One, the Supreme Court of Canada ruled in the case of *Winnipeg Child and Family Services vs G*, that a pregnant woman could not legally be mandated to attend an addiction treatment program. However, the placement of a "birth alert"—a pending custody order that will come into effect when the woman gives birth—is a technique commonly used by social workers to essentially reach the same goal, that the pregnant woman attends an addiction treatment program. If the woman cooperates and successfully completes a program, the social worker will then consider lifting the order. While a social worker cannot order a woman to attend treatment, if the woman refuses, the apprehension order will be carried out when she gives birth, and most likely result in a court order in which her child is at least temporarily, removed from her care.

Because the goal of the social worker is also to foster self-determination and transformation among clients they place particular emphasis on having their clients "recognize" and internalize that the coercion used by social services is for their own benefit and that attending addiction treatment is something they should do for themselves and, more importantly, for their babies. The placement of a "birth alert" is hedged by an altruistic discourse of "mental healing," "caring," and "treatment" of the woman, and "prevention" and "protecting" of the "child yet to be born." Coercing pregnant women to attend addiction treatment becomes justifiable by the perceived outcome—a healthy baby. Once in the program, reinforcement by addiction counselors of a woman's "decision" to enter treatment for the sake of her baby reinforces for the woman the idea that she is acting as a "responsible," "caring" mother who places the needs of her baby before that of her own. If a pregnant woman relapses, either during or after completing the program, her relapse is not understood by her social worker as a problem that is common, and to a certain degree expected, in the context of substance addiction. Rather her relapses reinforce to her social worker that she is a "failed mother" and that her actions are "selfish" and "reckless," and prove that she is "unfit" to parent her baby when it is born. Women also commonly internalize their "failure" and see themselves through the representations that are created by the social worker.

Cases and "at-risk" populations

Foucault suggests that the medical and social work examination places individuals in a field of surveillance and situates them in networks of inscriptions that captures and defines them (Foucault 1979:189). Client dossiers constitute individuals as "cases"—describable, analyzable objects in which the individual receives as her status her own individuality. As important is the constitution of a comparative system in which the analyzing of dossiers in relation to one another allows for the measurement of overall phenomena, description of groups, characterization of collective "facts," and the calculation of the gaps between individuals and their distribution in a given "population" (Foucault 1979).

In FAS research, medical and social work dossiers representing women and their children are central sources of information about biological and social profiles of particular individuals. When compared with one another, they are also used to create a profile of an "at-risk population" of which certain inferences are then made. This is illustrated, for example, in Asante's early study of FAS in northern British Columbia. He writes, "a history of maternal alcohol ingestion…was confirmed by the mothers on direct questioning, or by a reliable third party, usually a close family member or by a social worker's report" (Asante 1981:331). Where possible, Asante adds, "both maternal and children's hospital records were reviewed" (1981:331). Based on the information he examined, Asante infers in his conclusion that higher alcohol consumption and more frequent binge drinking among Aboriginal women most likely accounts for the higher prevalence rates of FAS among Aboriginal children. He also adds that the surveillance of Aboriginal women and children, for example, by social services and outreach agencies, may also contribute to the identification of Aboriginal women and children as a particular population who is at higher risk for FAS (Asante 1981:335).

In this context, observations recorded in client dossiers takes on the power of "objective" facts that, when compared to one another, create a population profile of women who are "at-risk" for giving birth to children with FAS. While it is unclear in Asante's discussion as to the degree that the social work and hospital records contributed to his conclusions about Aboriginal women, it is clear that client dossiers are given particular weight in the defining of "at-risk" populations. However, as Swift (1995) points out, the information within these files is devoid of any consideration of the larger historical and social context. In discussing Aboriginal families and child welfare services, she writes:

> Each family, one by one, is identified, diagnosed, judged, treated, as though the problems, the deficiencies of caring and of living arose within this individual family and must be solved by this particular family, and as though behaviours are unrelated to historic and current power differentials. This process helps to remove the context of colonialism to the far background, both in everyday work with clients and in recording. Meanwhile, the individual family becomes accountable to child welfare authorities for its behaviour. Simultaneously, through attention to protocols within the agency, the appearance of dealing with "Native issues" is created and maintained (Swift 1995:143).

Swift adds that the numerous related problems appearing in case files tends to confirm that many Aboriginal families are "multi-problem" families (1995:144). In a context where increasingly more risk factors are associated with FAS, the plethora of problems found in client dossiers collectively serve to identify Aboriginal women and their children as being "at risk" for FAS. If an Aboriginal woman has any record within her file that she has used alcohol, or that her children have been taken into care by social services at some point in time (a step which is highly correlated by social workers with alcohol abuse), this is enough to indicate the existence of risk if she becomes pregnant, and put into motion forms of "appropriate action."

"Secondary disabilities" and predetection of "at-risk" populations

Margaret Lock (1993) argues that tacit culturally-informed meanings contribute to perceptions of the body and bodily processes, including those attached to "risk" and "risk behavior." As categories and classifications attached to fetal damage caused by alcohol use by pregnant women, including those created and employed by scientific researchers, resist standardization, definition, and measurement, the category FAS becomes what is known in anthropology as an "empty sign" open to multiple interpretations that are never arbitrary (Lock 1993xxxviii). These interpretations, Lock states, "are the product of culturally produced knowledge that in turn influences both popular and scientific discourse (1993:xxxviii).

In this section I further examine prevention in relation to an emerging discourse of “secondary disabilities” and how this has shaped recent understanding of what, in scientific and lay discourse of FAS prevention, is thought to be “prevented” by stopping pregnant women from drinking alcohol. I do so in order to illustrate where the sense of emergency attached to the category FAS and the “need” to prevent pregnant women from drinking alcohol has sprung from in Canadian society, especially in recent years.

As discussed previously, high rates of FAS/ARBEs were reported among Aboriginal children in early FAS/ARBE studies, which generated significant concern from the medical community, the federal government, and western and northern provinces. However, more recently a shift in focus to Aboriginal adolescent and adult populations has increased the stakes in the arena of FAS/ARBE prevention, as a new language of “secondary disabilities” and new populations of persons “suffering” from FAS/ARBEs has implied that the risk of pregnant women drinking alcohol is much more “dangerous” than was previously thought.

To understand the development of prevention strategies for FAS/ARBEs in Canada, it is important to distinguish how and why a sense of urgency was generated in scientific and lay arenas, which then prompted governments and communities to prioritize and sustain prevention strategies aimed at eliminating all alcohol use by pregnant women. As discussed in Section Two, most of the information in the scientific literature about persons with FAS/ARBEs comes from case reports or small cohort-based studies involving infants and children. Moreover, Aboriginal patients and populations are over represented in these studies. The contention that FAS/ARBEs was one-hundred percent preventable and that affected children suffer from a range of physical, cognitive and behavioral anomalies raised significant concern in North America in the 1980s and 1990s. A discourse of “child abuse” (see for example, Daschle & Nighthorse Campbell 1994) as well as a language of moral and social responsibility, was associated with FAS.

An important shift in discourse, however, took place in the 1990s as interest in prenatal alcohol effects expanded to include adolescent and adult populations. Whereas infants and children with FAS/ARBEs had come to represent a “preventable tragedy” in North American society, adolescents and adults with FAS/ARBEs were perceived as a “preventable social problem.” In Canada, this has been especially true in relation to

Aboriginal peoples, and, as will be illustrated in this section, FAS has become a meaningful explanation in medical, social service, and lay circles for many of the social problems that exist in Aboriginal communities. This explanation is based on the assumption that high numbers of adolescents and adults with FAS/ARBEs live in these communities, and that because of the difficulties involved with identifying and assessing these two patient populations, many remain invisible to the medical, educational, social service and judicial systems, and therefore are susceptible to "secondary disabilities."

Non-medical labeling

Within Canada, especially in the western and northern regions, the practice of non-medical labeling (by ones self or by others) of persons with FAS/ARBEs has become common in some local settings, as has the identification of "high risk" local populations. Social service workers, most having limited or no medical training, have been much quicker than physicians, many of whom are reluctant to diagnose FAS/ARBEs, to embrace the category of prenatal alcohol effects as an explanation for certain realities they see among the lives of the clients or communities they serve (see for example, Continuing Education in the Health Sciences 1998). Their willingness to do so is supported by the creation of government prevention programs that imply that a population of affected individuals exists. Furthermore, the information that has been given to community workers by governments and "FAS experts," such as a language of "secondary disabilities," is easily mapped onto the bodies and behavior of marginalized groups, most particularly Aboriginal peoples. This points to a situation in which a medical diagnosis is more often attributed to individuals and populations in non-medical settings by community workers—who have more contact with "high risk" individuals—than it is by medical practitioners within a clinical context (see, for example, Barnett 1997; Dorris 1989). It also points to a situation whereby the non-medical labeling of persons and populations not only goes unquestioned, but is actually interpreted and made use of by governments, advocacy groups, and even by some scientists as knowledge upon which to base government policy and programming (see for example, The Children's Commission 2001).

In this section I present a narrative account that describes a workshop that I attended in Vancouver, British Columbia, at the end of my field research. In this narrative I examine how the perception of an “epidemic” of FAS/ARBEs in Aboriginal communities is mapped onto knowledge and practices attached to “risk” and “prevention,” and to the surveillance and “predetection” of “at-risk” populations of Aboriginal women. Central to this analysis is the practice of non-medical labeling by social service providers of Aboriginal women with FAS/ARBEs, and it shows how, with the creation of this new population of “FAS persons,” prevention strategies targeting Aboriginal women have expanded beyond simply preventing pregnant women from drinking alcohol.

As descriptions about the high prevalence rates of Aboriginal women with FAS/ARBEs who give birth to epidemic numbers of babies with FAS/ARBEs have emerged within Canada, so too have arguments grounded in moral, medical, and social justification for “preventing” these women from giving birth to more babies. Underlying these strategies, as will be illustrated in this section, is the belief that to successfully prevent FAS/ARBEs in the Aboriginal populations, fertility rates in reserve and urban ghetto communities need to be dramatically curbed.

Outline of the argument

In Chapter nine I map the “continuum of care” for pregnant women with substance abuse problems. As will be illustrated in this chapter a range of services exist for women, however several systemic barriers exist that inhibit many women from accessing support services. This chapter also illustrates that service provision at different levels lacks coordination and limited mandates and financial and human resource constraints inhibit the amount of support that any single service provider can extend to any one woman and her family. Further, as is illustrated by the mandates of the services, the focus is individualized in that most programs attempt to change the behavior of individual women and by doing so largely ignore the social and domestic context in which she lives, and different historical processes that have shaped how she is defined and defines herself within the social structure.

Chapters Ten and Eleven situate the large discussion presented in the dissertation within the lives of four women who are viewed as being at highest risk for having an alcohol-affected child. In the narratives the complexities of the women’s lives are evident, as are the complexities that service providers face in providing support to this group of women. In each of the narratives the women place significant importance upon their need to be “good” and “deserving” mothers, in a context in which they continue to lose custody of their children to child and family services. The women’s ongoing struggles of trying to keep their families together while simultaneously dealing with an addiction, violence, poverty, and mental health problems challenges the assumption that FAS is preventable. The narratives also highlight that within the continuum of care, the role of child and family services workers is paramount for the women, despite the importance of this relationship having been only marginally explored in the larger discursive arena associated with FAS prevention. Further, as will be illustrated by the narratives, women who lose custody of their children to child and family services are not afforded moral space in which to grieve for the loss of those children. Because they are deemed to be the reason why their children are apprehended, there is limited recognition of the impact that this practice, even if the removal is necessary, has upon the woman’s perception of herself, how this negatively impacts upon her health and wellbeing as well as upon current or subsequent pregnancies and children, and her long-term wellbeing.

Chapters Twelve and Thirteen move away from individual narratives to resituate the discussion within a larger national discourse of populations and risk. I examine the growing discourse of “secondary disabilities” and the practice of non-medical labeling and how they together are transforming the discursive arena associated with the category FAS. I conclude my argument with a personal account in Chapter Thirteen of my feelings upon returning home from a workshop in Vancouver. The purpose of this chapter, apart from its contribution as an ethnographic example of the central role that non-medical labeling and secondary disabilities has taken on in FAS discourse, is to illustrate the precarious position I commonly find myself in as an Aboriginal-Métis woman involved in the knowledge production about pregnancy and substance use, and FAS.

Chapter Nine
MAPPING PREVENTION SERVICES FOR FETAL ALCOHOL SYNDROME

Introduction

Following the Supreme Court decision in the case of *Winnipeg Child and Family Services (Northwest Area) v. G*, in September 1997, a group of Manitoba community service agencies and advocates approached the provincial government to express their concern about the barriers pregnant women experience in accessing and completing addiction treatment programs. A meeting was scheduled between Manitoba Health, the service agencies and advocates, and addiction service providers in the province to discuss these concerns. The recommendations coming out of the meeting were, (1) for a provincial assessment of existing referral and service agencies for pregnant women with substance abuse problems and, (2) an examination of the experiences women have in accessing and participating in these services. The goal of this research would be to determine what services exist for pregnant women with substance abuse problems, and what specific needs of this population are not being met within the existing system. As discussed in Chapter Two, the Prairie Women's Health Centre of Excellence (PWHCE) was commissioned to oversee the research study, and I was awarded the research contract.

I arrived in Winnipeg, Manitoba in mid-April 1999. My first objective was to map the existing services in the province for pregnant women with substance abuse problems, and to identify representative service providers to be interviewed for the project. Apart from clinical prenatal services, most outreach and community services for pregnant women target impoverished women receiving social assistance. In Manitoba there is an over representation of Aboriginal women in this group. Women and men who receive social assistance are also the central target group for alcohol detoxification services and residential and day/outpatient addiction treatment programs in the province.

The broadest range and number of pregnancy outreach programs and addiction treatment services are available in the provincial capital, Winnipeg. Pregnant women who experience substance abuse problems can also access a number of services in Winnipeg that are unrelated to their pregnancies and substance abuse, such as transition housing and shelters, community, family and youth centers, drop-in centers, safe houses, and day care and parenting support programs (see Figure 9.1). Outside of Winnipeg, the range and number of services drop dramatically, and most services available to women are located in one of the smaller urban centers such as Thompson, Brandon, or The Pas. Block provincial and federal government funding for most services means that both pregnancy outreach programs and addiction treatment services are generally inclusive of all women who desire access to their services, although there are still some jurisdictional issues around, for example, the payment of transportation costs for some clients to and from treatment.

A range of addiction services have been specifically designed for Aboriginal clients. Generally they are located in First Nation reserves; however, addiction services specifically for Aboriginal clients also exist in urban centers. While the services are available only to First Nations, Inuit, and Métis, in some rare instances non-Aboriginal clients are allowed to access these services.

In this chapter, I outline the range of programs and services that fall under the umbrella of "prevention of substance use during pregnancy." I begin by first situating these services in relation to the broader North American context of pregnancy and birth, especially in relation to the scientific and cultural significance now given in our society to representations of the fetus. I then examine the claim that the diagnosis FAS implies the existence of two "patients"—the fetus and the woman. I argue that within the context of FAS prevention, the pregnant woman is conceptualized as the primary risk factor leading to FAS. I then explore what the conceptualization of the pregnant woman as a "risk factor" means in relation to the health and wellness of women who give birth to children with FAS.

In the final half of the chapter, I map FAS prevention services in the province of Manitoba. Prevention services can be divided into "primary," "secondary" and "tertiary" programs. With the exception of addiction treatment services, most of the FAS prevention programs in Manitoba were developed in the five-year period proceeding my research, and many had been developed within an already existing service for pregnant women. The majority of prevention strategies focus on the abuse of alcohol and the prevention of FAS, and less attention is paid to illicit drugs, solvents, or prescription drug use during pregnancy. While older women with chronic alcohol abuse problems have been identified as the group most at risk for giving birth to a child with FAS, most outreach and community prevention programs target younger women. Aboriginal women are over-represented in the client population of all levels of prevention services.

The emergence of the medical, public, and political fetus

To understand prevention services for FAS in Manitoba, they must be situated within the broader North American context of pregnancy and birth, especially in relation to the emergence of linked ideas about the "medical," "public," and "political" fetus. In Euro-North America, fetal images have increasingly been afforded greater significance in medical and lay understandings of procreation. Increased medicalization in Western countries has changed the subjective experience of pregnant women who have been increasingly conditioned to view and experience their pregnancies as states that require "scientific" management (Duden 1993:28), and their fetuses as separate "patients" with their own needs for medical surveillance and care.

Taylor found that in the United States ultrasound imaging was combined with other "non-medical" practices, in which, for example, "non-medical" features of the fetus are pointed out to pregnant women and women receiving ultrasound images to take home (1998). She suggests that as a result of these practices come an assumption that women want, and are entitled, to see images of their fetus, and that to do so is "beneficial" to the pregnant woman in her "bonding with her fetus." This means that the ultrasound examination blurs the boundaries between "scientific/objective" and "cultural/subjective" knowledge (Taylor 1998:25; see also Crouch & Manderson 1995).

Some medical and social service providers have suggested the use of ultrasound imaging as a prevention technology for FAS/ARBEs. Although ultrasound imaging has no diagnostic value specific to prenatal alcohol use and FAS, some service providers in Manitoba, particularly those who identify themselves as being "pro-life," argue that the visual images of fetal movement and audio sounds of fetal heartbeats can be used to reinforce to pregnant women that their fetus is a separate patient/being. They argue that as "pregnant mothers," women should be counseled that they have a moral responsibility to do whatever they can to stop drinking, and that society has a moral obligation to use whatever technology is available to reinforce bonding between the woman and her "baby-to-be-born."

This type of reasoning assumes, however that women are making an uncomplicated choice to use or not use alcohol. It also assumes that the witnessing by pregnant women of the movement and sounds produced by ultrasound images will transform their fetus into a “real” baby, and that this realization will be enough to motivate them to stop drinking. This type of reasoning also ignores the inherent power differential between pregnant women, especially impoverished pregnant women and medical and social service providers involved with this form of prevention. It also ignores the subjective experience of pregnant women with substance abuse problems and how the use of ultrasound images as a means to motivate abstinence may in fact lead pregnant women to internalize even more guilt and shame about their substance abuse/addiction, possibly resulting in an increase, rather than a decrease, in substance use.

Ginsburg argues that the image of the fetus has become a powerful public and political symbol. For example, pro-life advocates in North Dakota invoke knowledge and images of “fetal life” as mechanisms to “convert” women to the pro-life position (Ginsburg 1988, 1990, Taylor 1998:37-39). Petchesky argues that the strategy of anti-abortionists to make personhood a self-fulfilling prophecy by making the fetus a “public presence” and “oppressed social victim” addresses a visually oriented culture. Meanwhile, she adds, finding “positive” images and symbols of abortion are difficult to imagine, and therefore feminists and other pro-choice advocates have ceded this visual terrain (Petchesky 1994:402). Morgan argues that with the increased social value accorded to the fetus, feminists have rethought their strategy of the fetus in relation to pro-choice values. She states that feminists did this by privileging the “relational” over “individualistic” concepts of personhood. They argue that the fetus, devoid of sociality and relationality, could not, or should not, be considered a person until it is born (Morgan 1996:49).

As was evident during the Supreme Court Case, *Winnipeg Child and Family Services (Northwest Area) v. G,* the *intention* of a pregnant woman to give birth to her baby and her continued substance abuse during her pregnancy considerably blurs the boundaries of relationality, with the “fetus/baby” emerging fully as an “oppressed social victim” believed to be “sentenced to life long suffering” caused by his or her mother’s substance abuse. During the “G” case, feminist advocacy groups tried to counter this image in their written arguments to the Supreme Court of Canada and through the media by arguing that “Ms G” was herself an oppressed social victim (see, for example, Women’s Health Rights Coalition 1997, Women’s Legal Education and Action Fund 1997). They argued that because “Ms G” had a very disruptive childhood, including being forced to live in multiple foster homes and institutions, because she was impoverished, Aboriginal, and at the age of twenty-two had already experienced losing custody of three other children to child welfare services, and because the social supports and addiction services had failed in the past to adequately address the complexity of her substance addiction, that taken together these factors illustrated that she too was a social victim.

However, despite the efforts made by feminist activists, and the Supreme Court’s ruling that pregnant women could not be legally mandated into addiction treatment or confined to protect their fetus, the negative image of “Ms G” and of women, particularly Aboriginal women, who experience similar problems was reinforced in media accounts and in public discourse. As discussed earlier, the image of “Ms G” also reinforced a public perception that the future of Aboriginal people in Canada was itself in danger due to Aboriginal women “choosing” to abuse substances and to have multiple pregnancies.

Haraway, following Duden’s claim that the fetus functions as a modern “sacrum” in which the transcendent appears (Duden 1993), states that the fetus as sacrum “is the repository of heterogeneous people’s stories, hopes and imprecations” (1997:175). She argues that the “global fetus” and its “sibling,” the “spherical whole Earth,” have become powerful public objects which owe their existence to visualizing technologies, as they exist because of, and inside of, technoscientific visual culture (1997:174).

Haraway suggests that the sonogram is literally pedagogy for learning to see who exists in the world. “Selves and subjects are produced in such ‘lived experiences.’ Quickening, or the mother’s testimony to the movement of unseen child-to-be in her womb, has here neither the experiential or the epistemological authority it did, and does, under different historical modes of embodiment” (Haraway 1997:177). However, the gray, white and black blobs on the televised sonogram, Haraway adds, has given way to the refined anatomical form of the free-floating fetus. “The televised sonogram is more like a biological monster movie, which one still has to learn to view even in the latter twentieth century" (Haraway 1997:177). Instead the "global fetus," most specifically visualized in the work of Swedish biomedical photographer, Lennart Nilsoon, is anatomically sharp and self-evident (Haraway 1997:178, see also Duden 1993). Haraway states:

> Not seen as abortuses, these gorgeous fetuses and their descendants signified life itself, in its transcendence essence and immanent embodiment. The visual image of the fetus is like the DNA double helix—not just a signifier of life but also offered as the-thing-in-itself. The visual fetus, like the gene, is the technoscientific sacrament. The sign becomes the thing itself in ordinary magico-secular transubstantiation (1997:178).

As the sign has evolved into the thing itself, pressure on society to "protect" and "nurture" the "fetus" has led to greater surveillance and monitoring of the "reproductive body." The merging of "risk" and "prevention" has led to an increasing range of new discourses, practices, and technologies that reinforce to pregnant women the need for self-regulation. For example, pregnant women are encouraged to avoid more and more substances present in the foods, beverages, and medications that they normally consume (Armstrong 1998). It is also common in North America for pregnant women to be given advice, even by complete strangers, about what foods and drinks are safe or unsafe for the fetus.

The adoption of a public health message that counsels a pregnant woman to believe all levels of alcohol consumption are potentially dangerous to the fetus has been reinforced in public health campaigns by representations of the fetus as victim. In the development of public health material warning about the risk of alcohol on fetal development, the representation of the fetus as being trapped within the womb of the pregnant woman and therefore vulnerable to her decision to drink alcohol is the most common form of representation used. In these images, the pregnant woman and fetus are isolated from the larger society, thereby indicating that both "risk" and "prevention" lie within this relationship. Only in a few instances, mostly in posters developed by Aboriginal communities, in which a husband, family, and community surround the pregnant woman, is the prevention of FAS described as a community effort.

One diagnosis, two patients

Public health FAS prevention campaigns reinforce the idea that a pregnant woman and her fetus are two separate entities. This idea has been entrenched in the discursive arena attached to the category FAS from the outset. According to Sterling Clarren, the diagnostic label FAS was purposely constructed by its original authors, Kenneth Jones and David W. Smith (1973), to imply the existence of two "patients," the pregnant woman who abuses alcohol and her affected offspring (1998). In prevention discourse and practices, this designation was quickly extended to the fetus.

The contention that Jones and Smith purposely coined the term FAS in an attempt to imply the existence of two patients begs the question of whether there are in fact two visible patients. While the identification of two patients may or may not have been their intention, within scientific-medical, social service, and lay prevention discourse and practices, attention has been focused almost exclusively on risk to the "fetal patient," with the pregnant women being identified as the primary "risk factor." By focussing on the fetus, the complexities contributing to why pregnant women abuse alcohol and the impact that substance abuse has upon their own health and wellbeing is ignored.

That pregnant women who experience substance abuse problems are conceptualized as "risk factors" and not as "patients" explains why very little attention is paid to them when they are not pregnant. In the context of "FAS prevention," women are targeted for intervention services because of the health benefits that will be gained for the fetus. This is illustrated, for example, by pregnant women being prioritized in Manitoba for addiction treatment and, therefore being able to access almost immediately services that would otherwise be unavailable to them for weeks or months. A stark expression of this prioritization is expressed through research that found that three quarters of the women, all of whom were chronic alcoholics in their thirties or forties, who gave birth to a child diagnosed with FAS died within five years of the birth of the child (Clarren 1981, Olegard & Sabel 1979, Streissguth et al. 1987). This points to a public health issue that extends beyond the question FAS, to one of young women with chronic substance addictions being vulnerable to alcohol-related pathology, accidents, and death.

Women who have given birth to children that are diagnosed with FAS have been characterized in the FAS literature as having severe alcohol-related pathology, and if they become pregnant again will most likely give birth to another child who is affected if they continue to drink alcohol (Abel 1998a, Coles et al. 1985). Cirrhosis of the liver is the most common ailment found in this population, which has also been linked to increased rates of spontaneous abortion and preterm birth (Abel 1998a). Detectable levels of acetaldehyde in the blood are also more likely to be produced by alcoholics with cirrhosis than by those with nonalcoholic liver disease. Abel suggests that many of the effects directly attributed to alcohol exposure in utero may instead be due to combined effects of maternal cirrhosis and alcohol consumption (1998a:161). Apart from cirrhosis, health problems commonly found in mothers of children with FAS include DTs (detoxification), psychiatric hospitalizations, anemia and poor nutrition, tremors, gastrointestinal bleeding due to alcohol, and epilepsy and seizure disorders (Abel 1998a:162). Infertility, mentrual irregularities, alcohol-related cancer, hypertension, obstructive pulmonary disease, alcohol-related cognitive deficits, and HIV (and all the other health consequences associated with injection drug use) have been noted by Poole as added health problems experienced by women who abuse substances (1997:6).

Women develop a wider range of adverse health consequences from the use and abuse of alcohol and other drugs over shorter periods of time and with lower consumption levels than do men (Poole 1997:6). Abel points out that alcoholic women are typically emaciated, having very low pre-pregnancy weight and pregnancy weight gains (1998a:162). In one study, four mothers were found to actually lose weight during their pregnancies (Abel 1982). Although it has been assumed that all alcoholics are undernourished, this appears to apply most often to alcoholics in lower socioeconomic groups (Abel 1998a:176, Salaspuro 1993). Abel suggests that suboptimal maternal nutrition is a provocative factor for FAS because when it occurs, the nutrient pool necessary for supporting fetal growth and maintaining maternal health is reduced (1998a:176). He adds:

> Nutrition is compromised in alcoholism because alcohol has a high energy content and replaces other energy sources in the diet. While the nutritional factors alone cannot give rise to FAS, alcohol consumption alone cannot account for its occurrence. The two almost invariably go together (Abel 1998a:176).

Alcohol, in addition to contributing to a decrease in food consumption, can reduce nutrient absorption, meaning that even if nutrient intake were not decreased, the concentration of nutrients absorbed in the mother’s blood and potentially available to cross the placenta could be reduced (Abel 1998a:177).

Age and parity

Abel argues that women who have given birth to children diagnosed with FAS are not merely a variation of the general population of drinkers; they are the group that defines the risk for FAS (1995:5). Maternal age and parity increase have been identified in case reports and epidemiological studies as risk factors for FAS (Abel 1998a, Jacobson et al. 1996, May 1991, Sokol et al. 1986, Astley et al. 2000a, 2000b). These findings are directly related to findings that suggest women are at greater risk if they have given birth previously to an affected child (Abel 1998a, Clarren 1998), and findings that suggest younger siblings are more impaired than their older siblings when the mother continues to use alcohol at elevated rates during pregnancy (Abel 1998a:163, 1988, Majewski 1993, May 1991, Streissguth 1997). Abel points out that researchers have not been able to determine if the more important risk factor in this case is increased maternal age or increased parity (1998a:164). Animal studies, however, suggest maternal age as the greater risk factor (Abel & Dintcheff 1984, 1985, Vorhees et al. 1988).

The question of whether pregnant teenagers are less likely to give birth to children with FAS/ARBEs than older women has only recently been explored in the FAS literature (Abel 1998a:166). In a recent study, Barr and Streissguth examined 1,439 pregnancies and found that thirty-six of the mothers had given birth to a child with fetal alcohol spectrum disorder (FASD) (2001). Nine of the thirty-six mothers were teenagers (less than 20 years old) when they gave birth, and sixteen of the thirty-six infants were first born children (2001:285). Barr and Streissguth suggest that filtering of older multiparous mothers would, for this sample, not improve the classification of children presumed to be a risk for FASD (2001:285). However, the study did find that the mothers of FASD children who reported daily drinking with low or zero frequency of binges were also among the oldest mothers of FASD offspring. While the combination of older age plus daily drinking may reflect an age effect, an alternative interpretation may be that the number of drinks per day reported by these women is an underestimation (Barr & Streissguth 2001:286). An important added dimension in examining levels of risk for teenage pregnancies may be the number of years individual teenagers have been using alcohol and the severity of their use. For example, in some sub-populations where high rates of alcohol abuse occurs, some teenagers at the age of nineteen may have drinking histories as long as five to ten years.

Abel argues that if alcohol ingestion, especially binge drinking, were the only factor in the etiology of FAS, then the number of drinking years should not be an important factor. He states:

> …as far as the fetus is concerned, it would not matter whether a mother drank for 2 years or 12 years before becoming pregnant—the only important factor would be the amount of alcohol exposure during pregnancy. As of yet, there are no clinical or epidemiological studies addressing this question with respect to teenagers, but as noted earlier, older women are at greater risk for FAS than younger women. Whether this higher risk factor is because of a longer history of drinking, higher blood alcohol levels with the same amount of drinking, development of alcohol-related [illness] such as cirrhosis (Majewski 1981), or other factors has not been determined (Abel 1998a:166).

Advanced age/high parity can be provocative factors for FAS/ARBEs because of the relationship between age and history of alcoholism (Abel 1998a:178). Abel argues that the longer a woman drinks heavily, the more severe her potential medical complications (1998a, Ashley et al. 1977). Children who are born later to women may be more prone to FAS because they are exposed to higher blood alcohol levels (BALs). This higher exposure, Abel suggests, may in turn be due to lower body water, tolerance-related increase in maternal alcohol intake, and/or a greater severity of maternal alcohol-related medical problems interacting with continued alcohol exposure (Abel 1998a). Increased parity, Abel adds, is associated with increased uterine collagen and elastin content, a condition which can potentially decrease blood flow to the conceptus, contributing to fetal hypoxia and thereby exacerbating the impact of alcohol. Increased maternal age, however, remains the risk factor that is most predictive of FAS (Abel 1998a:178).

Tobacco use

The women who are reported to be at "high risk" for having a child with FAS/ARBEs generally use other substances during pregnancy, especially cigarettes. Research has shown that smoking tobacco can contribute to adverse pregnancy outcomes, especially decreased birth weight (Abel 1984). Abel points out that although the concurrent influences of alcohol and tobacco use can be examined statistically to assess the independent effects of each alone, statistically significant interactions between the two are very difficult to demonstrate, other than by stratification, because there are usually too few subjects in any study who are heavy drinkers and light smokers, or light drinkers and heavy smokers (1998a:174). In relation to the combination of socioeconomic status and smoking, Abel writes:

> Smoking cigarettes is not only an important permissive factor in FAS, it may be the reason FAS occurs in the rare occasions when it is not associated with poverty. The common link between poverty and smoking is that each provokes a common biological milieu that increases susceptibility to alcohol's teratogenic action (1998a:175).

Abel suggest that smoking is a permissive factor because it is highly correlated with poverty (1998a, Hogue et al. 1987, Nordstom et al. 1993, Polednak 1991) and alcohol consumption (1998a:180). Smoking is a provocative factor for FAS because the ingredients in tobacco, for example, nicotine and carbon monoxide, which directly reduce blood flow and oxygen content, respectively, which can cause ischemia and fetal hypoxemia, decrease nutrient availability to the fetus (Abel 1984), and promote teratogenesis through free radical formation (Abel 1998a:180). Abel adds that smoking can also increase blood lead levels (Ernhart et al. 1985), thereby increasing risk from that element (1998a:180).

Primary prevention programs for FAS

In Canada there are several ways that a general public health message about the risks associated with alcohol use during pregnancy has been disseminated. Current strategies include television and radio public health announcements, poster campaigns, and information pamphlets. This information is designed and distributed by government departments and agencies, health care providers, addiction services, and frontline and community organizations. Significantly less attention is given to the harmful effects of other substances such as cannabis, cocaine and inhalants, even though these are also perceived by this group of professionals to be very dangerous to fetal development. The emphasis placed on primary prevention for FAS varies across the country, with western and northern regions having had a wider range of primary prevention strategies and a longer history of disseminating information than in eastern provinces.

The national emphasis that the Canadian government has placed on preventing alcohol use during pregnancy as opposed to the use of other substances by pregnant women, is somewhat distinguishable from the United States, where until very recently cocaine use by pregnant women was perceived to be a far more serious problem both at the individual and population level (McCuen 1994). During the period of my field research I found no public health posters about the dangers of substance use by pregnant women other than those targeting alcohol use. The reasons behind so much emphasis being placed upon prenatal alcohol use, as opposed to prenatal drug use, are varied. First, a diagnosis is attached to negative birth outcomes caused by in-utero alcohol exposure. Second, significantly more women use alcohol than illicit drugs such as cannabis, and licit substances such as tobacco. Third, alcohol is believed to be toxic to the fetus at very low thresholds. Fourth, service providers have been educated by federal and provincial governments to believe that alcohol is more dangerous to the fetus than substances such as cocaine, cannabis, and tobacco. Five, the category FAS, as it is used, for example in “FAS prevention programming,” acts an umbrella category that includes alcohol as well as a number of illicit substances that maybe used by pregnant women.

In dissemination of public health literature in Manitoba, and in Canada generally, only limited information explaining the dangers of binge drinking during pregnancy exists, and none is in the form of public health posters, despite binge drinking being identified in the scientific literature as especially “high risk” behavior for pregnant women. Rather, public health campaigns concentrate on disseminating a message that all alcohol consumption by pregnant women is “risk” behavior and pregnant women are treated as a homogeneous group in that all pregnancies are considered to be equally “at risk,” which, as indicated in the discussion above, is not supported by the research literature.

In Manitoba, school-aged children and adolescents are primary target groups for prevention education about the dangers of alcohol use during pregnancy. Public health policy makers believe that to successfully shape societal attitudes and behaviors about pregnancy and alcohol use, they must devote time and resources to educating youth populations about the associated risks. There is general agreement among public health service providers and policy makers that some form of prevention education begin at the junior high school level and continue through the high school years. Some Manitoba schools have included education about the dangers of substance use during pregnancy in sex education, health classes, and family studies courses.

Secondary prevention and early intervention programs

"Secondary prevention" for FAS refers to efforts to slow or stop the progression of alcohol use though early detection of women who are "at risk" and referral of them to "appropriate" supports and addiction treatment. The setting for early intervention efforts lies not within the specialized addiction treatment sector, but within agencies and institutions that provide health and social services to women (Poole 1997:13). Within the continuum of care for pregnant women with alcohol abuse problems, these services are key to identifying women with alcohol abuse problems, disseminating information, providing immediate support and brief therapeutic interventions, and making referrals to addiction treatment programs.

Outreach pregnancy programs

In Canada, a range of pregnancy programs that focus on the general well-being of pregnant women exist, with the largest percentage of programs targeting impoverished young single mothers. In Manitoba, provincial and federal governments fund most of these programs; however, some are privately funded by religious-based organizations. Many of the programs operate out of community and family centers, such as the YWCA and Native Friendship Centres. In Winnipeg, a broader range of support programs and services for pregnant women exists, and unlike the programs offered in smaller communities in Manitoba, these programs tend to operate autonomously from one another. Some of the agencies in Winnipeg are equipped to provide one-on-one psychological counseling—a service usually not offered to women in smaller communities. While pregnancy outreach programs do not target only women with substance abuse problems, increasingly more emphasis is placed on FAS prevention in their service delivery.

Pregnancy programs typically offer special group services to pregnant women one day a week, although most programs have an "open door" structure where women can visit workers outside of scheduled meeting times. Some of the programs also provide home visits both pre- and post-partum to give support to women in their homes. Most programs provide milk to pregnant women, food at their meetings, parenting classes, nutritional education, information about “healthy choices” during pregnancy, and educational and resource information. Some programs actively assist pregnant women in accessing addiction treatment services or with other life circumstances. Others pregnancy outreach programs act strictly on a referral basis, leaving it up to the woman to follow-up with the referral. Some of the programs identify themselves as being either “pro-life” or “pro-choice.” The women who typically access pregnancy outreach services in Manitoba are under the age of twenty-five and single, and are therefore, not the group of women identified as being most “at risk” for having a baby with alcohol-related pathology.

Due to limited budgets, pregnancy outreach programs have been unable to develop the range of services that they feel are necessary for their clients. In some instances, programs duplicate each other’s services because they are not coordinated with one another as they are funded by different levels of government. Residential homes are available for pregnant women, and in some instances women are allowed to stay at the home after the birth of their child, eventually moving into transitional housing. However, these spaces are very limited, and typically adolescent and young women access this service.

Most residential homes for pregnant women are not in the position to accommodate women who have other children in their care. While at the home, women have an opportunity to attend several classes that prepare them for the birth of their baby. As well, some of the younger women are enrolled in school to help them finish their high school education.

For pregnant women with a substance abuse problem, residential homes offer an alternative to residential addiction treatment. This is especially true for young women. While the homes do not provide addiction treatment services, they do provide supports for women while allowing them to live outside of social environments that contribute to their substance use.

Community support services for women

Community services for impoverished women vary greatly in Canada, with the vast amount and range of services being located in urban centers like Winnipeg. The services include women’s resource centers, shelters, transition housing, youth programs, and services, support and self-help groups and outreach centers. While none of these programs deals only with substance abuse during pregnancy, they typically have clients that experience such problems. Most offer information literature and referral services for those clients who want addiction treatment and/or support sessions during their pregnancy. Other services include parenting classes, food and clothing depots, community gatherings, and counseling. Some organizations accompany women to medical appointments and meetings with their social workers, provide space where women can visit their children who are in the care of child and family services, advocate on behalf of women with other service providers, and provide short- or long-term day care.

Drop-in and outreach centers

A limited number of services for women and their children operate as drop-in and outreach centers. These include services such as women's resource centers, Aboriginal Head Start programs, family centers, and Native Friendship Centers. Women typically access these services on a "drop-in" basis, and what makes this type of service unique from most other services is that it operates as a "place" rather than a "program." In other words, women have access to the service without having to attend a program such as a parenting class or prenatal class (although these services are often offered).

Community-based outreach centers begin with a concept of "community" and build their programs and services around the benefits of a shared collective identity. Even though most of these services have limited hours of operation, in that they are closed on weekends, holidays, and in the evenings, they encourage clients to identify with the service as a place that they can come to and see other community members who are experiencing similar life challenges. Some of the outreach centers are specifically for women and simultaneously act as "safe houses" in that women are able to avoid violent men that they may fear running into at other centers. Outreach programs generally provide clients access to social workers, and in some cases to psychologists, legal advisors, and nurses. The majority of drop-in centers and outreach services have a zero tolerance policy towards drug and alcohol, and clients are not provided access to the centers or their services if they are intoxicated or high.

Child and family services

Social welfare and CFS agencies operate in all geographical regions of Canada. Provincial governments are responsible for funding and setting standards for these agencies. Some CFS agencies address the needs of specific groups and communities, such as the First Nation, Inuit and Métis agencies[1]. In Manitoba, First Nations have gained control over Child and Family Services for their reserve communities; however, they are required to enforce provincial legislation. Similarly, Métis communities have argued for the same rights for their people. In a recent publication, the Manitoba Métis Federation outlines its current position concerning Métis children and families, stating that a disproportionate number of Métis children are taken into care each year, the majority of whom are placed in non-Aboriginal foster and adoptive homes (1999:4). Despite this over representation only limited resources have been made available by the Manitoba provincial government for Métis Child and Family Services to assist Métis families in regaining custody of their children.

The general mandate of CFS agencies is to protect children from “neglect,” “abuse” and “exploitation.” Within this mandate the agencies provide and support various family programs and manage foster care and the adoption of children that they take into care. Typically, CFS deals only with families on social assistance, and especially with mothers, rather than fathers.

In recent years, CFS agencies have added substance use by pregnant women as a concern they have in relation to child “neglect” and “abuse.” As discussed earlier, the current response by many CFS agencies, particularly those in Winnipeg, is to notify pregnant women who they know are using alcohol or illicit substances that a “birth alert” or apprehension order has been placed on the baby they are expecting. If the woman has other children in her care when the “birth alert” is placed on her pregnancy, it is almost inevitable that these children will be taken into care when the order is placed, and will only be returned to her care if she completes an addiction treatment program. In some instances, children are returned to a woman earlier if she attends a treatment program that has accommodation and daycare/school facilities for children of their clients. CFS

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[1] During the period of this research Métis Child and Family Services had a limited mandate to operate as an advocacy service for Métis women and their families.

workers generally require pregnant women to go to a long-term addiction treatment program, and expect them to stay until the birth of their baby. In most instance, CFS requires the woman to return to her addiction treatment program with her newborn baby and remain there until they, and the treatment counselors, are convinced that she has control over her substance abuse problem and is capable of parenting her child(ren).

According to both the women and service providers the ultimatum inherent in the placing of a “birth alert” is usually enough to “motivate” women to seek addiction treatment. Since the provincial government of Manitoba has encouraged addiction services to prioritize pregnant women for treatment, they are usually successful in being admitted into a treatment program in a relatively short period of time (less than a week).

The placements of “birth alerts” are inconsistent across the province of Manitoba. It is likelier that women living in Winnipeg would have “birth alerts” placed on them, than it is for women in smaller urban centers or in rural locations. According to social workers, the placement of a “birth alert” is not their desired response to a situation where a pregnant woman is abusing substances. However, given their excessive caseloads and limited resources, they consider it the best of only a few options available to them.

CFS workers expressed similar concerns to other service providers about the need for better communication and flexibility among service providers. They were also very supportive of services, such as mentoring programs that are able to work with pregnant women once a “birth alert” is placed.

Other service providers, particularly experts in the field of addictions, voiced mixed feelings about the use of “birth alerts” to “motivate” pregnant women to enter addiction treatment. They felt this type of coercion meant that women were distracted during treatment because they were worried about CFS apprehending their baby at birth, and were psychologically ill-prepared to take advantage of the benefits that treatment could offer to them.

Mentoring programs

Over the past five years, the Manitoba Child and Youth Secretariat have funded “mentor programs” for “high risk” pregnant women. In 1999, there were three programs, two in Winnipeg, and one in the First Nation community of Norway House. The service is modeled on a program in operation in Seattle, Washington designed by FAS researchers from the University of Washington. Although the “Stop FAS” program was relatively new when I conducted my field research, the idea of “mentors” was not. For example, CFS agencies and public health nurses and outreach workers have in various capacities acted for years as “quasi-mentors” to women on social assistance. The most common example, is home support workers who go into women’s homes to help with infant care, home care responsibilities and child care. Most women on social assistance who I spoke with had at some point in time at least one support worker come into their home.

The degree of involvement a worker has in the life of a woman depends on a number of factors. In some cases, women see this relationship as very positive, while others view support workers with suspicion, and feel that they are in their homes to spy on them for CFS. In certain situations, women will go as far as turning down offers from CFS to have support workers come into their home because they fear the worker will give negative reports to CFS that will lead to the apprehension of their children. Becoming visible to CFS, according to many women, automatically places them at risk of having their child(ren) apprehended by the agency (see also Boyd 1999).

Aboriginal women and/or women who have been involved with CFS as children are the women most likely to be suspicious of support workers, whether they are from CFS or from other agencies. For many Aboriginal women, this suspicion is fueled by the long-term relationship that Aboriginal people have with CFS agencies in which a disproportionate number of Aboriginal children continue to be removed from the care of their biological mothers (Manitoba Métis Federation 1999:4, Fourneir & Crey 1997). Lifetime involvement with CFS has meant that many Aboriginal women see the agency as an enemy to avoid, rather than a resource that will assist them.

Of the seventy-four women I interviewed, 24 (33%) reported being placed in more that five foster homes during childhood. In one case, a woman reported being placed in over twenty different foster home before she was eighteen years of age. For these women, memories of moving from foster home to foster home has meant that they will do anything to prevent this from happening to their own children. This means that women miss taking advantage of support programs offered by social service agencies, and that their avoidance of services is commonly understood by social workers as non-compliant behavior or disinterest.

Support given by CFS is withdrawn from a woman's home if her children are apprehended. In this situation, the woman is given a list of requirements that must be met to regain custody of her children, including going to addiction treatment if the agency suspects that she uses alcohol or illicit drugs. According to women and frontline workers, this removal of support comes at a time when women most need it because of the loss of their children. However, because the welfare of the mother is not the mandate of CFS the mother does not warrant any kind of intense intervention, such as help in entering an addiction treatment program. Fortunately, some CFS workers assist women in accessing addiction treatment, however the heavy caseloads most workers carry prevent this from typically happening.

The relationship that a woman has with her children's CFS worker is very strained during this period, and in many cases women turn away from help offered by CFS and other service providers. Women reported a dramatic increase in their alcohol or drug use after the apprehension of their children, even when they were pregnant. This indicates that apprehension may increase the "risk" to the fetus, however, despite this CFS or FAS prevention services have not created special supports for pregnant women during this time.

The lack of support to help women cope at the times when their children are apprehended is vividly illustrated in the following discussion that I had with a pregnant Aboriginal woman, Nelly, who lived in Winnipeg's North-end. Notably, Nelly was aware of the support and outreach services available to her during the times that she was pregnant, and when we met was regularly visiting a safe-house for women that was open during the weekdays. The narrative illustrates several characteristics common to many impoverished women with substance addictions—multiple pregnancies, nonuse of contraception, poor and diminishing health status, mental health problems, limited support networks, and the central role of CFS in their lives.

What happened to you when they apprehended your baby?

I didn't care.

Was there any support there for you?

No

At that time did anyone say to you that you should go to an addiction treatment program to get your baby back?

No, right away they said, "permanent order."

I'm interested in how you felt when you gave birth in the hospital and they apprehend your baby.

With her [her older daughter] I just gave her up. I left the next day. I didn't bother staying. I left the very next day. I felt that I was strong enough to just leave her there and I was thinking that if I would have stayed a couple more days I would have got close to her and I wouldn't want to leave her. So the very next day I thought just leave her. So I just left.

So did anyone at all contact you and ask you if you were okay? Or if you needed any support?

No, well Child and Family started calling me and wanted to know if I wanted to visit. But when I found out that I really harmed her when she was inside of me, well, they're not going to give her back. So when they said the permanent order was on her, then I said, "Okay, whatever." After I have her they said they were going to go for a permanent on all three of them [her other children that were in the care of CFS].

And so even though she wasn't in your care you kept getting reports about her?

Yeah, I was visiting her up until she was maybe six months…

How do you feel about them saying that your use had caused problems for your child?

How did I feel? I felt really bad. I thought I fucked this kid for life. She's probably going to get older and maybe she'll know who I am. Maybe she won't understand anything. But if she does then she'll hate me for what I did to her. And I just thought I wasn't going to have anymore kids. But I ended up having another one after that…The best thing I ever did for her was to give her away. I think, look, after that I was still on drugs. Where would she be today? She probably would have been more fucked up than she is.

So then for you, what happened next in your life?

It was really mixed up after I had her. I broke up with my boyfriend and we were off and on.

So after you broke up with your boyfriend what happened?

I got pregnant with somebody else's kid.

What kind of support did you have?

I didn't have any support. Nothing.

In terms of family and friends?

No, my parents were really mad at me.

So you weren't seeing your parents at all?

No, I locked myself away for about six months. I didn't have no friends. I didn't have nothing. I just moved into a hotel. Went out prostituting. I sold myself. And I locked myself away for six months. I'd just go out to work, get my drugs, go out to work, get my drugs. I did that for six months 'til finally I went down to like 92 pounds...

So you were still living in the hotel when you gave birth to the baby?

I almost gave birth at the hotel.

So the day you gave birth were you using?

I think I did a shot maybe twenty minutes before I had him.

Did the doctor know that when you went into the hospital?

Yeah. Because when he was born they gave him something right away…

Did they take the baby?

Yeah, Apprehended him at birth.

Was there any support for you?

No.

Did a social worker come and see you and ask you how you were doing?

No.

How did you leave the hospital? Did you get up, get dressed, and walk out?

Yeah.

That was it? Nobody asked you where you were going? Or what you were going to do?

No.

So with that baby it was a permanent custody order as well?

Actually he was apprehended but I didn't really bother with him. I never visited him. I just gave him up, just like that.

So then you went back to the hotel and you still working?

Yup.

What was it like to go back to the hotel?

A very big emptiness. It was bad. Very depressing.

And so did you start using right away again?

Yeah.

When I met Nelly she had just completed a four-week addiction treatment program which she hoped would help to convince CFS that she could parent her baby when it was born. Unfortunately she started using again a few weeks later after the courts granted the permanent order on her son. As illustrated by the discussion of her pregnancies, the added knowledge that she had caused permanent brain damage to her children further added to the negative perceptions she had of herself and contributed to her decision not to try to regain custody of her children. Nelly's narrative also demonstrates that the needs of impoverished women with chronic substance addictions, reach far beyond what is possible to achieve in a four week addiction treatment program and that the lack of support services for women at the time of apprehension of their children adds further to their distress and decreasing health status.

"Stop FAS" programs

The "Stop FAS" program is designed to provide support to women determined to be most at risk for giving birth to a child with FAS. The difference between this model and other prevention strategies is that it focuses on the wellbeing of both the mother and child, and even if the child is apprehended by CFS the woman remains in the program. Once an intake assessment has been completed, women are matched to mentors who work intensively with them for the next three years.

Mentors from the "Stop FAS program" found that despite the early success of their program, their efforts were hindered by several systemic barriers within the continuum of care that prevent pregnant women from accessing support services. A central problem is a lack of communication and flexibility among service providers. In many instances, frontline workers are uncertain about the kinds of services other agencies offer and therefore, fail to make appropriate referrals. In other cases, appropriate services are identified, but clients face long waiting periods to access the service or they end up not meeting one or more of the admission criteria. For example, pregnant women may not be allowed into an addiction treatment program if their delivery date is before the date they are scheduled to complete the program. In one instance, a pregnant client with Hepatitis C was denied access to an addiction treatment program because of her illness.

Within the "Stop FAS" program, structural barriers also exist for women attempting to gain access. For example, because of government funding restrictions, a formal requirement exists that pregnant women must be abusing alcohol to gain access to the program. As a result, women who abuse substances such as inhalants or cocaine, but not alcohol, are ineligible for the program. While some frontline workers have found ways around this formal requirement, the barrier in theory still exists. The service providers fear that if the “Stop FAS” program reaches its full client load, the restrictions will be enforced more rigidly thereby excluding women who could benefit from the program. They also feared that some pregnant women would start abusing alcohol as a way to qualify for the program. Evidence that this was already occurring was noted by some of the mentors.

Mentors play a supportive role in the lives of their clients. However, the nature of their relationships with the women blurs lines of professionalism with friendship. For example, some of the women in the program said they considered the mentors friends more than service providers. From the point of view of most mentors, this was beneficial in that they were more successful in encouraging women to set goals and pursue support services. On the other hand, mentors were concerned that their pivotal role in the lives of their clients could result in women becoming too dependent on the mentor/client relationship and create future problems. For example, mentors were worried about how clients would respond if they resigned from their position, or after the three year period of support ended and they were no longer the client’s mentor. They also worried about being placed in a circumstance where by law they were required to report to CFS the occurrence of child neglect or abuse on the part of a client.

The mentors also pointed out that their relationship with women’s partners and family members could be very strained as their mandate was not to work with the network of family and friends of their clients. For example, women commonly do not have the support of their partners to attend addiction treatment. This potentially, could place the mentors in antagonistic relationships with women’s partners. Mentors reported that in the short time the project had been running they had already experienced feeling uncomfortable and unsafe around their clients’ male partners and/or family members.

Teritiary prevention: detoxification and addiction treatment programs

Addiction treatment services are offered by a number of different organizations throughout the province of Manitoba. “Addiction treatment services” can broadly be defined as a range of services: substance abuse identification, brief intervention, assessment, diagnosis, counseling, medical services, psychiatric services, psychological counseling services, social services, and after-care service, among these. The overall goal of these services is to reduce or eliminate the use of alcohol and other drugs as contributing factors to "physical, psychological and social dysfunction" and to "arrest, retard, or reverse the process of any associated problem" (Poole 1997:16).

The largest addiction treatment service agency in Manitoba is the Addictions Foundation of Manitoba (AFM), a provincial crown agency. The AFM's services include residential and non-residential treatment programs in almost every region of the province. The AFM operates programs specifically for women: the central service is a short-term (28 day) residential treatment program located in Winnipeg. A number of other addiction treatment services exist in the province for women, the majority of which are in or around Winnipeg. The programs for addiction treatment outside of Winnipeg are mainly located in First Nation reserve communities and only accessible to Aboriginal clients, or are addiction services provided by the AFM.

In 1999, Manitoba had nine residential and non-residential addiction treatment programs specifically for women (Roberts & Ogborne 1999:20). Several other mixed-gender addiction treatment programs offered special services for women, usually in the form of individual and/or group counseling. In general, pregnant women are admitted to all addiction services available to women, but in some cases they are only admitted if they have time to finish the program before giving birth. In other cases, pregnant women who may have medical complications or whose pregnancy may be considered "high-risk" will not be admitted to a residential treatment program. Addiction treatment services that have pregnant women participating in their programs do not usually include special services for pregnant women, such as prenatal care, nutrition programs, and parenting classes. Most residential treatment programs are not equipped to accommodate women with their children (including their newborns) and most outpatient and day treatment programs typically do not provide child care. In a limited number of programs, whole families are admitted into treatment.

Addiction treatment services specifically for women decrease significantly outside of Winnipeg. In some instances, addiction workers located in central urban communities cover a wide geographical region that limits the time that they can spend with individual clients and treatment groups. In other cases, women do not have access to female counselors in the region where they live. Even among the addiction treatment services for women in Winnipeg, many programs have long waiting lists—in some cases up to a year or more. While the majority of treatment programs prioritize pregnant women for admission, I found that women typically want to access addiction treatment at times when they are not pregnant.

Detoxification and outpatient withdrawal units

Detoxification and outpatient withdrawal units exist in some parts of the province, but in most areas services are limited or do not exist. The mandate of detoxification programs is to provide a safe place for individuals to withdraw from the physical effects of varying substances. In 1999, Manitoba had 40 detoxification beds, 15 which were allocated specifically for female clients (Roberts & Ogborne 1999:7). Despite beds being set aside for female clients, no detoxification, outpatient withdrawal units specifically designed for women exist in Manitoba.

According to service providers, many of the women who access addiction treatment services do not go to detoxification or outpatient withdrawal services first. While not all individuals who enter addiction treatment programs require withdrawal services, of the ones who do, many end up not accessing services because the service is simply unavailable to them. Primary medical detoxification services are offered by local hospitals but some hospitals are reluctant to set aside beds for individuals who need withdrawal services because of the general shortage of hospital beds in the province. In some communities, addiction service providers have advocated for more beds, but hospital administration staff have been reluctant to make these provisions.

Two secondary non-medical detoxification units, the Main Street Project and the AFM, exist outside of hospitals; both are located in Winnipeg. The Main Street Project offers an emergency shelter for both intoxicated men and women. The projects also admits individuals who police have taken into custody under "The Intoxicated Detention Persons Act."[2] While intoxicated pregnant women in Winnipeg are taken to the Main

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[2] The act permits police to take into custody individuals who are intoxicated and "may present a danger to themselves or others."

Street Project, where they are given the opportunity to be referred to other addiction treatment services, in other parts of the province intoxicated pregnant women who are taken into police custody are placed in “drunk tanks” for a few hours and then released. Because there are no addiction services for women that accept clients who are intoxicated, the police have no place to keep these women except in jail cells. The police do not normally offer any type of service that would assist pregnant women to seek out services or supports, nor do they refer women to such services.

Lack of shelter for intoxicated women is a problem in all regions of the province. Mainly because of safety concerns, emergency shelters for women and their children operate with a zero tolerance drug and alcohol policy. The emergency shelter at the Main Street Project in Winnipeg offers shelter to intoxicated clients and serves as a safety net when all other services have refused to take a client. However, this is the only service agency that does so in the province of Manitoba.

Outpatient and day treatment

Several addiction treatment programs in Manitoba provide services to clients on an outpatient basis. In 1999, there were twelve outpatient treatment programs and five day/evening treatment programs in the province. These programs offer addiction treatment in the form of group or individual counseling sessions. In some cases, outpatient or day clients attend residential treatment centers and participate in the same treatment activities as residential clients. Outpatient and day treatment programs are either short- or long-term. Some are a prerequisite for residential treatment, and/or provide immediate treatment for people who are on waiting lists for residential treatment. Among the women attending these programs, Aboriginal women are over-represented.

Outpatient/day treatment programs vary in their treatment modalities. Typically, programs that offer specific treatments designed for women have long waiting lists (in some cases, women have had to wait up to a year or more to access the program they want). For example, the Laurel Centre in Winnipeg offers outpatient counseling services for “women who have experienced childhood or adolescent sexual victimization and want to resolve long-term effects of abuse.” The uniqueness of the scope of this program has drawn the interest of many women, and in 1999, the Centre had a waiting period of a year and a half for someone wanting treatment. In the past, the Centre had offered a short-term program for women on the waiting list, but the approach resulted in women revealing very sensitive issues only to be stopped short in their treatment and placed back on the waiting list until a space became available in the central counseling service.

Addiction counselors argue that the best time to provide services to individuals with substance abuse problems is when they are ready to address their use and the factors contributing too it. Long waiting lists result in women falling through the cracks because their attempts at accessing treatment are unsuccessful. However, long waiting lists indicate that women, whether they are self-referring, or being pressured in some way by someone, want to enter a particular program.

Outpatient/day programs permit women to stay at home with their families while attending treatment. Service providers stated that women with supportive social networks were more successful in these programs than women who lived in social environments where everyone around them was abusing alcohol or drugs. This type of service was also important for women in communities where a residential program did not exist because it did not require women to leave their communities for treatment. This was especially true for women who were not willing to leave their homes during the duration of their pregnancy.

Outpatient/day programs, especially in Winnipeg, allow women more confidentiality when accessing addiction treatment than residential programs because they often offer individual counseling services and permit women to return home after each session. Issues of confidentiality for women living in smaller urban and rural communities are much greater because it is difficult to keep confidential the identity of local clients attending either residential or outpatient/day programs. Outpatient/day programs appeal to women from differing socio-economic groups more than residential programs, which typically draw women from disadvantaged socio-economic groups.

A drawback of outpatient/day programs for pregnant women is that while attending treatment they are still responsible for childcare, attending prenatal appointments, and negotiating their relationships with partners, family members, employers, or social workers. Attending to these other responsibilities and demands can be difficult when women are in treatment because the programs require regular daily attendance in the morning and afternoon. Addiction counselors pointed out that in some instances women, especially pregnant women, were overwhelmed by the commitments that they had outside of the treatment context. Clients also faced a number of barriers that could prevent them from participating in outpatient/day treatment programs, such as a lack of transportation services to and from programs, and available and affordable childcare.

Residential Treatment

In 1999, the province of Manitoba had eight short-term and ten long-term residential addiction treatment programs. Forty-two short-term beds and seventy-eight long-term beds were allocated to women, out of a total of 458 (Roberts & Ogborne 1999:7-8). In residential addiction treatment centers that are gender-mixed, women make up considerably less of the client population than do men. Aboriginal women are over-represented among the female client population in these programs.

Residential services specifically for women are offered by the AFM at River House in Winnipeg. This program has twelve beds and offers a twenty-eight day program that includes group and individual counseling. River House does not provide accommodation or support services for women to bring their children with them into treatment. The Salvation Army Women's Services/Anchorage Rehabilitation Program offers services to women with crisis and relocation issues, and mixed-gender addiction treatment. A number of mixed-gender residential treatment programs offer special services for women within the larger treatment structure, such as AFM residential treatment centers, the Native Addictions Council of Manitoba, and the St Norbet Foundation. Other residential services specifically for women are located in First Nation communities.

Women generally enter residential addiction treatment centers though a referral from a service provider in their community. A smaller percentage of women self-refer, particularly women who have previously attended a program that they liked. Residential treatment programs are based on either short-term (approximately 28 days) or long-term (usually between 28 days to a year) treatment. Some programs offer special services for women, including group sessions and individual counseling. In the majority of cases, pregnant women are given admission priority, and typically they enter the program as soon as a bed can be made available (usually less than a week). If they are in the last weeks of pregnancy, they may not be admitted if they do not have enough time to complete the program before giving birth.

A small number of residential treatment programs can accommodate women with their children. During the day the children are placed in day care or attend local schools while their mother is in treatment or attending to other responsibilities that are required of her by the program. Because the number of programs that can accommodate children is very limited, most women are faced with the decision of either placing their children in the care of CFS, leaving their children with friends or relatives, or declining treatment.

Residential addiction treatment programs in Manitoba use a range of treatment and counseling modalities. Modalities include "life skills programs," "self-help and empowerment approaches," "behavioral therapies," "harm reduction approaches," "therapeutic communities," "gender-sensitive treatment" and "relapse prevention." Treatment modalities used in First Nation treatment centers are typically based on traditional methods of healing, including the Medicine Wheel and holistic healing, combined with complementary mainstream treatment modalities. In most instances, treatment centers adopt one or more approaches for different components of treatment. A very small number of residential treatment centers offer transitional programs. These are located in Winnipeg and are attended by clients who have completed short-term residential treatment and are making the transition back into their home environments.

Aftercare services

Most addiction treatment programs offer some form of aftercare services that assist clients in making the transition from treatment back into their communities. These services generally consist of several meetings—either group or individual sessions—where the client returns to the treatment center for follow-up counseling. Aftercare can be short- or long-term, depending on the organization. If the client does not live in the same town or city as the treatment center, aftercare programs may be arranged with an agency that provides addiction treatment in the region where the person lives. However, aftercare services are commonly not accessible to women when they return home because of a lack of transportation and child care services.

In aftercare programs, it is left to the client to make the effort to attend program activities. This can be difficult for women who have children because the programs do not usually offer child care services. If the program is located far from where the client lives, even if it is in the same city, transportation problems can also become a barrier to accessing services. In the last few years, some programs have been trying to expand their aftercare services and have developed outreach services for clients who have not returned for aftercare upon completion of their treatment programs.

Self-help and Support Groups

Several self-help and support groups that address the needs of individuals with substance abuse problems exist in Manitoba. The largest is Alcoholics Anonymous (AA), and several spin-off groups such as Narcotics Anonymous (NA) exist to deal with other types of substance abuse. Typically these groups are made up of both men and women, with men in the program significantly outnumbering the women. According to many women I spoke with, self-help and support groups were instrumental in providing long-term support in their “recovery” process. These groups provide education about alcohol and drug abuse, support people before and after addiction treatment, and provide long-term community support.

The lay self-help movement plays a significant role in the continuum of care for women with substance abuse problems. This is especially true in Winnipeg, where the largest number of groups exists. Fewer self-help and support groups exist in other regions of the province, and they do not always meet on a regular basis. A limited number of these groups allow women to bring their children to sessions, but the children have to remain with the woman in the meeting. Most groups do not allow children to attend their meetings, nor are they able to provide child care services.

Conclusion

In this chapter I discussed the “continuum of care” for pregnant women with substance abuse problems. Despite the range of services available, most are located in Winnipeg and a number of structural, geographical, and psychological barriers were reported by women that prevented them from accessing services. Long-waiting lists, a limited range of treatment options, and the short duration of addiction treatment programs were the most common criticisms that women had of addiction treatment services. Relapse was commonly attributed by the women to the limited number of aftercare support services in their home communities, and to the daily struggles they faced in a social context where they had limited meaningful options to build their futures upon, particularly the option of parenting their children.

Chapter Ten
PREGNANCY: MORAL VALUE, SHARED EXPERIENCE, AND SOCIAL POLICY

> *…one to three drinks per day in the first two months of pregnancy can cause brain damage in the developing fetus…Maybe pregnant women should learn that "life is not a beer commercial." Their lament need no longer be, "if only we had known." Fetal alcohol syndrome is a 100-percent preventable tragedy.*
>
> H. Barry Walman[1]
> Journal of Dentistry for Children

In the previous chapter I mapped the "continuum of care" in Manitoba for pregnant women with substance abuse problems. As illustrated in my discussion, different levels of prevention programming for FAS have been implemented in the province, most of that targets impoverished women living on social assistance. Within the group of women who are typically targeted and who access these services, young, Aboriginal women are over represented. In this chapter, I discuss the experiences of women with substance abuse problems and their relationships with partners, family members, friends and the service providers who design and implement medical and social services for them. The narratives presented in this chapter are representative of the lives of women with substance abuse problems who are among those believed by health care providers to be at highest risk for giving birth to an alcohol or drug affected child. However, rather than situating the lives of the women in direct relation to the discourse and practices attached to the category FAS, I situate their experience with substance abuse within the daily struggles that they simultaneously have with poverty, marginalization, violence, racism, and social service surveillance.

FAS and alcohol or drug-related birth defects are issues that have been recently added to a host of concerns and challenges faced by impoverished women living on social assistance. They are also "problems" that have added further to the already existing tension that exists within the perceptions that the larger society has about impoverished women and their children, especially Aboriginal women, and about the autonomy and integrity of a woman's body. On the one hand, social welfare services are

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[1] Waldman 1989:437.

perceived generally within Canadian society as a necessary government expenditure that contributes to the collective good. There is also agreement that the "rights" of those individuals and populations who are most marginalized must be protected in the same way as the "rights" of other members of society, and marginalized groups are recognized as being the most vulnerable individually and collectively to having their "rights" violated.

On the other hand, individuals who receive social assistance are often perceived as failing to positively contribute to the larger society and are conceived as being both an economic and social burden. They are also perceived to be individually and collectively implicated in their poverty and marginalization, and are counseled by social workers that they are morally responsible for making effort to improve their situation and become "productive" members of Canadian society. Negative stereotypes such as laziness, immorality, and dishonesty are commonly associated with individuals receiving welfare benefits.

Similarly, on the one hand, there is societal agreement that individual autonomy and bodily integrity is valued and protected for all members of the society, including pregnant women. However, the extension of this "right" to impoverished women on social assistance, and who are perceived to have too many pregnancies, abortions, and babies that end up in the care of social services, is tenuous at best. For example, the idea that drug or alcohol exposure is harmful to the developing fetus has led to several court cases in which it was argued, in some cases successfully, that confinement of pregnant women with substance abuse problems is justifiable in order to prevent fetal damage. As discussed previously, these challenges were taken as far as the Supreme Court of Canada.

The perceived link between drug and alcohol use by pregnant women and fetal damage has added significantly to the uneasiness that exists within the larger society around questions of fetal "rights" and the autonomy and bodily integrity of women. This uneasiness, illustrated in the following narratives, is also embodied in the perceptions that women have about their bodies, their identities as mothers and women, and their substance use.

In their narratives about their lives—their childhood, families, pregnancies, children, substance abuse, and relationships with service providers—the women I spoke with pieced together a life history out of memories: happy, painful, resentful, and remorseful. Memories that wove together fact and fantasy in a complex series of events and processes that for them defined the essence of their life history. As with the Japanese women in Margaret Lock's ethnography on menopause, these women too created and re-created, evaluated and judged their narrative "against the incessant hum of ideological discourse about what a woman's life 'should' be like" (1993:171).

Within the narratives, a collective tension between conformity and resistance to the expectations and values of the larger society exists against a backdrop of chronic poverty, violence, sexism, and racism, and against the physiological and psychological realities of substance addiction. This tension blurs the distinction between individual agency and free-will of the women to define who they are and what happens to them, with the inevitability of the powerlessness and marginalization that characterizes their lives. In constructing the narratives, the women struggle to describe and analyze who they perceive themselves to be as mothers, partners, family members, and members of the larger society. They also struggle to explain their substance abuse within a context of competing explanations of substance abuse and addiction that has been given to them in their encounters with service providers over a number of years.

Moral value, "motherhood" and social policies

The two narratives below illustrate the shared struggles and yet differing experiences of two women, one Aboriginal and the other non-Aboriginal. However, before presenting the narrative I will situate them within a broader social context of moral value, "motherhood," and the making of social policies. A number of feminist authors (Tsing 1990, Lewin 1990, 1995, 1998, Ward 1995, Irwin & Jordan 1987, Heriot 1996, Gal 1997, Whiteford & Vitucci 1997, and Modell 1998) have examined how social categories linked to procreation, such as "mother" and "parent," are infused with moral value which is reflected in social policies and programs, laws, and public opinion. For example, Irwin and Jordan (1987) found that in the United States, cases of court-ordered cesarean sections, where the mother has refused to have a cesarean based on personal values, maintain medical authority by contributing to the reproduction of relations in which physicians control birthing (1992). They write:

> [Court-ordered cesarean sections] support current social relations by legitimating certain knowledge and disallowing other forms, and they do this by resorting to an agency of the state when normal, symbolic means of domination do not work. This is a situation in which collective power and privilege are maintained or challenged. The power of doctors (and judges) is contingent on the real situations where that power is both played out and reinforced. If the refusal of a section can be interpreted as resistance to the dominant ideology, a court-ordered cesarean section is an overt repression of alternative actions and alternative ways of knowing. A court-ordered cesarean section not only determines the authority of a particular doctor over a particular woman, it confirms medical authority in birthing (Irwin & Jordan 1987:331).

Central to the exercise of this authority is a view of fetal "vulnerability" and the moral obligation of the state to intervene on behalf of the "child-to-be."

In her examination of American women charged with endangering their newborns during or due to unassisted birth, Tsing found that this group of women were characterized as calculating criminals by legal and medical professionals, the media, and community members, as well as in police reports and psychiatric, medical and probation records (1990). She suggests that this is linked to a powerful cultural narrative in the United States in which the forces of compassion and morality are needed to intervene to save children from selfish neglectful "anti-mothers" or "monsters" who are enemies of the most basic innate characteristics of motherhood, nurturance and affection (1990:282-283). Tsing writes:

> I found the women's specific history eclipsed by a broader question: What kind of a woman could endanger her own offspring at the moment of birth, the moment which should most excite her maternal sentiments? This question generated its own answer: Only a person completely lacking in parental-and human-sensibilities could commit such an act. To those who considered their cases, these women were, as one prosecutor put it, "unnatural," "bizarre," and "without basic human emotions" (Tsing 1990:283).

Criminalization gains its importance within this cultural setting where the unsupervised death of a newborn is understood as a public tragedy which cannot be resolved without a renewal of the state's civilizing authority. "Unless blame is fixed and punishment meted, society might be held to blame for not protecting human life" (Tsing 1990:289). Tsing suggests that women charged with endangering newborns are differentiated through distinctive characteristics of what "kind" of "criminal" is involved. She argues that stories of inappropriate mothering are built from diverse symbolic resources. "What brings them together," Tsing states, "is their cultural opposition as ‘unnatural’ alternative to more appropriate forms of womanhood and maternity. By setting a ‘bad example,’ these women, in all their diversity, direct those who hear their stories toward the singular path of propriety” (Tsing 1990:296).

These stories, therefore, create a negative example for *all* women to avoid, and these pregnant women alone, and not, for example boyfriends, parents, community services, Tsing adds, are held responsible for the health and safety of the fetuses they carry and the newborns they deliver (Tsing 1990:286). Tsing argues that this responsibility does not put the woman “in-charge,” but instead, it is the basis of her dependency. “To be a good mother, a woman must recognize and internalize the connection between responsibility and dependency” (Tsing 1990:296). Tsing writes:

> Responsibility becomes appropriate female nurturance only when it is tied to an acceptance of female vulnerability. In no case that I studied was a woman blamed for not asking for help and protection from the father of the child, but women *were* condemned for not seeking help and protection from the state and the medical profession. They were also condemned for not demonstrating a yielding femininity in this relationship. If police, judges, and doctors are outraged when a woman does not cry for them, mourn her loss in front of them, or otherwise show her vulnerability, perhaps it is because their “paternal” responsibility for her child encourages them to claim a husband-like authority and protectiveness over her sexuality and reproduction (Tsing 1990:296-297).

Tsing concludes that this new perinatal vigilance results in the isolation of female reproductive experiences from every other aspect of a woman’s life, therefore requiring the pregnancy to be a “transcendent moment” that carries every woman outside the complexity of her particular history (1990:297).

Whiteford and Vitucci found the complex issue of pregnancy and addiction intersects with issues of race, class and ethnicity, as these variables often determine which pregnant women are routinely screened for drug and alcohol use (1997:1371). They found that in the United States, women who were African-American, who used illegal drugs while pregnant, and who gave birth in public hospitals were more likely to be targeted for prosecution. In some states, such as Florida, justification to jail a pregnant addict is premised on the assumption that this intervention will protect the unborn fetus from damage caused by substance abuse by the mother. However, Whiteford and Vitucci discovered that when these women were jailed, it was more likely they would be denied proper access to prenatal care and it was highly unlikely that they would be provided with treatment for their addiction. Instead, they found that jailing pregnant women for substance abuse was less about concern for protecting unborn babies than about punishing women for being poor, pregnant, and addicted (1997:1372). Whiteford and Vitucci add that making criminals of pregnant women who are addicted reframes who these women are in society's view, as they become "monsters" or "anti-mothers" (Tsing 1990), "symbolic of behavior that is considered irrational and out of the ordinary" (1997:1374). Behind this, however, is the real crime which Whiteford and Vitucci suggested is one of the political economy and structural racism: the reality of Florida's pregnant women and drugs laws is that they keep pregnant women out of prenatal care. While the law does not stop pregnant women from using substances, it does mean they are less likely to get involved in the public system for prenatal care because of fear of being caught and incarcerated (Whiteford & Vitucci 1997:1374). This results in women choosing to have their babies alone, outside of hospitals. They conclude that "to use a public health care system as a mechanism to ensnare poor women, coerce them into treatment and remove their children from their care is to create a Dickensonian welfare system designed not to support the rights of individuals, but to maintain the autocracy of the state" (1997:1374).

Ward argues that in the United States, a national preoccupation with controlling the actions of women, their bodies, and the products of their bodies significantly contributes to understandings of, and intervention in, the arena of teenager sexuality and teen pregnancies (1995:140). She argues that teen childbearing is often linked to other "social problems" such as child abuse, drug and alcohol use and abuse, runaways, poverty, and school dropouts (1995:141). Ward writes:

> The term *teen pregnancy* frequently connotes black, female and poor. Widely used terms such as *teen mothers, premarital sex, illegitimate children, welfare mother,* and *out-of-wedlock births* indicate that American society values female respectability. The words affirm a continuing double standard for a wide spectrum of prevention, intervention, educational, medical, social, and legal programs. They suggest a strong association between sexual activity and deviance in young women as well as the imperative for social agencies to exert control (1995:141, emphasis in text).

Despite a steady decline in relative and absolute numbers of births to teenagers in North America during the 1970s, the category "teen pregnancy" has been described as a new emerging "epidemic" and has become the impetus for the creation of new policies and legislation to handle this “serious social crisis” (Ward 1995:142). Ward attributes the framing of teen pregnancy as an epidemic crisis more to teenage girls choosing to keep their babies rather than giving them up for adoption, and to their choice of raising their babies without having a husband or father for the child.

Whereas in previous generations pregnant girls had married quickly to save their reputation and to legitimate their child[ren], currently, Ward argues, marriage frequently worsens a pregnant girl’s situation: “it increases her chances of closely spaced pregnancies, decreases her chances of ever returning to school, and cuts her off from childcare help from family and thus a chance to work, while pairing her with a man whose financial prospects are fragile at best” (1995:155). This “welfare dilemma,” Ward adds, is mainly structural: notably, “poor employment opportunities for males and females (especially minorities), and the lack of affordable quality childcare” (1995:155). This, however, is countered by a public outcry for teenage mothers to go to work, and by the popular belief that teen mothers are guilty of confiscating too large a segment of public funds through welfare benefits (Ward 1995:156).

Ward hypothesizes that professionals and policymakers view “with alarm” the independence of teenage mothers from authority structures, and see this as a direct result of giving birth while not being married. “Married pregnant women are socially invisible. Unmarried, they seem to cost more money; hence, they become visible. And denouncing the rising costs of social programs plays well politically; many Americans genuinely believe these costs are too high” (Ward 1995:142). Ward argues that the extreme concern about teenage pregnancies may result from a social construct about the nature of females and their obligation to the state. She concludes:

> An adolescent mother has no more problems than a mature woman does when socioeconomic class is factored in. It may be adaptive for poor and young girls to have babies when there is not a bright future for them to sacrifice…Having babies may be the most sensible and successful thing many young girls do. And the truth of this statement indicts those who make policies more than those who make pregnancies (Ward 1995:156).

Modell argues that foster care is a mode of reproduction that is especially politicized since it deals with the “distribution” and not just the “production” of children (1998:156-157). Rather than being only a micro-movement of children, it is also the replication and reproduction of a society and culture (1998:168, see also Goody 1982, Bledsoe 1990). Therefore, the person (or group) “who controls foster care is in a position of power, able not only to place and replace children but also to determine the terms of continuity from one generation to the next” (Modell 1998:157). This, Modell suggests, is especially true in late twentieth-century Hawaii, “where an increase in the number of fostered Hawaiian children coincide[d] with an increased emphasis on kinship and family markers of Hawaiian cultural identity” (1998:168). If where a child lives determines who the child *is*, then control over child placement becomes control over the next generation (Modell 1998:168).

In Hawaiian culture, Modell writes, “hanai” refers to the practices of informal adoption—a person gives a child to another person without having to go to court—and represents continuity of generations and kinship that does not depend on genealogy but on generosity, not on biology but on belonging (Modell 1998:159). The word, “‘ohana” refers to a group of co-residing individuals who consider themselves kin and also emphasizes the coming together of people who assume responsibility for and loyalty to one another (Modell 1998:159, Pukui et al. 1972:166-167). Both “hanai” and “‘ohana,” Modell argue, have become important public symbols in the Hawaiian struggle for cultural autonomy and national sovereignty. And the interface between traditional Hawaiian adoption beliefs and non-Hawaiian notions of “household,” children “at risk,” and children’s “best interest” has subsequently become an area of struggle, contestation and resistance.

Modell found that in Hawaii, experts who regulate child placement have enormous power as they determine, by their own definitions, which children are at risk. As well, they can place a child in a household where the understanding of fostering, and thus of care, is driven by non-Hawaiian values (1998:168-169). Therefore, Modell adds, government child welfare workers in essence have the ability to deprive people of Hawaiian ancestry for using one major strategy of social reproduction—the right, or moral, distribution of children (1998:169). She concludes:

> Forms of reproduction and distribution of children are the nodes of wider networks of relationships, whose supervision by the state contains the seeds for reconstructing the state. Whether or not Hawaiians are victorious in their demands for recognition of a cultural and sovereign identity, efforts to reclaim kinship provide a

uniquely clear and cogent agenda for an enduring society and "citizenry"…victory at a contested hearth is a crucial step in the battle for a contested homeland (Modell 1998:171).

The "Shared" Experience of Pregnancy

> *For many of the Canadian women interviewed, the first few months of pregnancy bring about a heightened sense of the possibilities of their own body. They talk at length about subtle changes in its shape and appearance and worry openly about its normality and potential for failure.*
>
> Lisa M. Mitchell & Eugenia Georges,
> "Baby's First Picture: The Cyborg Fetus of Ultrasound Imaging"

One of the most profound moments of my life occurred when I was given the news that I was pregnant with my son, Skender. Even though I was quite certain before going to the clinic that I was pregnant and considered it welcome news, the nurse's confirmation that I was going to become a mother left me speechless as I stared back at her in disbelief. The prospect of juggling motherhood, a new marriage and a dissertation, something I had given little consideration to previously, suddenly felt like a monumental undertaking and I was less than certain that I was up to the challenge. I assume the sudden wave of anxiety that swept across me was apparent to the nurse, as in her rush to get to another patient and avoid wasting time holding my hand, she suggested that I go home, relax, and celebrate this good news by having a beer.

The suggestion from the nurse that I celebrate my pregnancy by drinking a beer was a sure sign that I was not in Manitoba but back in Montreal, where I was scheduled to be for a month of teaching before resuming my field research in Manitoba. Feeling a bit more relaxed as I walked across Mount Royal, I smiled to myself as I thought how strange the nurse's suggestion sounded to me in light of my recent field research experience in Manitoba. I was certain that if a nurse in Manitoba made the same suggestion to a pregnant woman, she would be harshly criticized and, I suspect, disciplined for making such an "outrageous" suggestion. However, this was not Manitoba, but Quebec and even though the nurse's advice may have been viewed by many people as inappropriate, the consumption of one bottle of beer by a pregnant woman is generally not considered by most people in Quebec to be harmful to the fetus.

In most graduate student situations, becoming pregnant at the beginning of my field research, especially if I had been leaving Canada, would have presented a range of problems. However, given the fact that I was staying in Canada and studying issues concerning pregnant women, being pregnant did not, initially, give me cause for much anxiety. My concern was more with what would happen after the birth of the baby. I had little doubt that my pregnancy would be anything but healthy because my mother and sister both had easy and uncomplicated pregnancies and births. And although this meant I would be away from my partner, Adil, for most of the pregnancy, I felt that this was as good a time as any to be pregnant, given the fact that I was in my late thirties and this was my first child.

Often I have been asked to speculate on what my field research and subsequent writing would have been like if I had not become pregnant, and therefore had completed this project without ever experiencing what it is like to enter this liminal state of personhood. I do not believe that it was necessary for me to experience being pregnant in order to say something insightful about pregnant women with substance abuse problems. However, I do believe that my personal experience, including being able to share the experience of different stages of my pregnancy with the women in the study, strengthened my understanding of their lived experience. As importantly, it offered insight into the ways in which a woman can, and cannot, be pregnant in contemporary Canadian society. However, while I had in common with the women numerous experiences because I was pregnant, my pregnancy and the subsequent birth of my son were in many ways fundamentally different from the experience of pregnancy recounted by the women in this study.

Shared and not so shared experiences

The best way that I have found to describe the first four months of my pregnancy is to compare it to the equivalent of having a four-month long "hangover." Almost immediately after seeing the nurse at the McGill University Health Center, I began to experience "morning sickness" and increased fatigue. Over the next four months I continuously felt nauseated, and ten weeks into my pregnancy I felt so terrible that I sought medical advice. The doctor prescribed an anti-nausea drug that is safe for pregnant women; however, the medication provided only minimal relief, and each day of the next six weeks felt like an eternal battle to find ways to feel normal. Where once I had taken for granted feeling healthy, I now felt that my body was unpredictable and that each day required strategic planning to accommodate the sickness I was experiencing.

In the early months of my pregnancy, I in no way resembled the picture of the happy expectant mother that I had hoped to be. As much as I tried, I simply could not in my mind imagine the “baby” that I was carrying, nor be excited or happy about his or her arrival. My only strong feeling was that I wanted the pregnancy to be over and the nausea to end. I stopped taking my prenatal vitamins around the fifth week of pregnancy because I could not swallow them without gagging and because the vitamins seemed to heighten my sensitivity to certain foods. Strangely enough, vanilla milkshakes and French fries became the two foods that I could best cope with, and they quickly became my regular lunchtime combination. Although I had always incorporated exercise into my weekly routine, after the first six weeks of pregnancy I stopped trying because I was too exhausted and sick to imagine training. After eight weeks of being pregnant I could no longer recognize the pregnancy that I had expected to have with the one that I was experiencing. While I worried about my diet, lack of exercise, and even the effects of the medication I was taking on my baby, I felt paralyzed in those first months to do anything about it. I was simply doing the best that I could do.

The topic of nausea and vomiting came up in most discussions I had with women about their pregnancies. Interestingly, however, they, as well as their family members, social workers, and health care providers, related this experience to drug or alcohol abuse, rather than to a sign of pregnancy. The physiological changes that were so dramatically shaping my experience of pregnancy were given different meaning in the context of substance abuse. For most women, experiencing “morning sickness” over a few days signifies pregnancy; however, its lack of meaning in relation to the pregnancies of most of the women in this group contributed to many of them not suspecting that they were pregnant until three or four months into their pregnancies. Because many of them had irregular menstrual cycles, including not having menstrual periods or having spotting regularly in the first months of pregnancy, suspicion and confirmation of their pregnancies commonly occurred later than it does for most other women.

In an informal survey of my female friends (approximately 20), most said they suspected that they were pregnant in the first four to six weeks after conception, which was due to bodily changes but also to other factors such as the pregnancy being planned and therefore, expected. The combination of fewer bodily signs being recognized as an indication of pregnancy, along with the chaotic life styles of many of the women in this study, including a high number of unplanned pregnancies, contributed, in general, to later pregnancy recognition among them.

Fatigue, which was central to my experience, was also understood as a sign of substance abuse or life style choices rather than related to the pregnancies of the women, and contributed to normalized perceptions that the women were lazy and unmotivated. During my pregnancy I experienced a great deal of sympathy and support, including when it was necessary for me to cancel or reschedule appointments because I was feeling ill. However, many of the women recounted the difficulties they had with social workers and health care providers when they missed or asked to reschedule appointments because they were feeling sick or fatigued.

My experience of pregnancy was also different as I was surrounded by people, most specifically my husband, Adil, who were thrilled and excited about my pregnancy and who reinforced to me that I was going to make an excellent mother. The women in my home town gave me a baby shower at which all the women in the community brought gifts for the baby. Together Adil and I prepared the nursery, and when it came time for me to deliver my son, Adil and my mother in-law, Aziza were beside my hospital bed. After I gave birth, card, gifts and flowers arrived to congratulate us. I left the hospital with my son in my arms, the encouraging words from the nurses in my mind, and the sad reality of how very different from mine was the experience of giving birth for the women I had met in Manitoba.

Public health perceptions of time and the lived experience of women

An organizing theme about pregnancy and substance use in the public health message given to women in Canada is that the length of pregnancy (approximately 40 weeks) is a short period to refrain from alcohol, illicit drugs, or tobacco use. This perception of time is made in contrast to birth outcomes and the belief that children affected in-utero by alcohol and other drugs are sentenced to a life of suffering due to their mothers' drinking. Within this message the experiences of all pregnant women are lumped together; substance abuse is portrayed as an uncomplicated choice, and the forty weeks of pregnancy as a short period in which women should choose not to use.

In the lives of women who struggle with substance addiction, the "short" period in which they are pregnant is a period when a great deal generally happens in their lives, much of which can contribute to their substance abuse. While the public health message assumes that women are motivated to stop using substances because they perceive the "benefits" to the health of their "babies," pregnant women do not necessarily imagine a "baby" that is a separate entity from them, nor do they respond to the "needs" of the "baby." Rather than being "motivated" to refrain from drinking alcohol or using other substances by a "relationship" with their unborn child, the patterns of substance use by pregnant women are commonly determined by the extent of their addiction and by the experiences that they have with their partners, children, family members, health care and social service workers.

Maybe it's a fantasy world…but is it really a beer commercial?

I first met Jennifer, a twenty-six year old First Nation woman, at an outreach center in Winnipeg on a sunny fall afternoon. After settling into a quiet corner room where no one would disturb us, she began to tell me about her life and the events surrounding her pregnancy and the birth of her first child. Jennifer was born on a small reserve in northern Manitoba and placed for adoption at the age of four with a non-Aboriginal family that provided a relatively stable home for her in a small non-Aboriginal community in Ontario. At the age of fourteen she began drinking alcohol and smoking marijuana regularly with other teenagers from her school. During one of their evenings of drinking and partying, Jennifer was raped by two boys from her school. However, despite both her parents agreeing that criminal charges should be filed, Jennifer refused to do so, fearing that because she was the only Aboriginal person in the school, pressing charges against the boys would add further to her being seen as an "outsider."

At the age of seventeen, Jennifer moved with her parents to Winnipeg, Manitoba, and shortly after the move dropped out of her new school, left her parents' home, and applied for social assistance.

"They told me to go to this office and give them my ID and I'd get money. So I thought free money, all right! I went there and my cheque was blown within an hour, spent on beer, dope and smokes. I was staying at this blockhouse they used to call Le Chateau Skid Row. Believe it, there were cockroaches, and it was filthy. Just a bunch of guys living there and it was just a big party house. A short time after that is when I met my first baby's father. And the relationship started there. I didn't know I was pregnant until I was two and a half months and I was drinking constantly, all the time. Drinking hard stuff and beer, whatever I could get my hands on. I wasn't into any sniff or Lysol or anything like that. I used cocaine too. We were doing lines and somebody tried to introduce me to free-base. And I tried it, but after I didn't know what the big deal was. Then somebody introduced me again to it and I guess I caught that buzz and I understood what the big hype was. Why so many people blew all their money and, you know.

So when I was pregnant I drank for two and a half months before I found out and I kept drinking. When I found out I told him, "everything has to change," so we moved into a nice place. You know, he was doing stuff in order to get set up for when the baby came and that. So, he seemed a little excited about it and I thought "he wants to have a baby, right?" I don't know, maybe he was worried about it and whether it was going to be a damper on him or he didn't want any kids because it was an unexpected pregnancy.

And for awhile there, I was drinking occasionally. I really tried hard to cut down. And he was doing a lot of cocaine and his friends were over and I'd get mad at him for getting high or whatever. And then he'd give me one of those, like a little hoot or whatever…"sure babe." He'd never say "no." You know, I'd get a buzz and I'd get sick in the washroom and feel guilty for my baby. I started getting hooked on cocaine because he was always doing it and there were people coming over. And there's always a party or something. And after awhile I couldn't stop smoking the coke. And then I drank a couple times, and then I had my son. He was sick. He was diagnosed FAS. *Very sick*. He had low birth weight. During the delivery there were complications but just last year I finally talked to his father and he said that he was in the washroom smoking a hit of coke. And I didn't know this. I thought he just couldn't handle seeing me in so much pain and that's why he left."

"You said that you cut down your use during the pregnancy."

"A lot because I was very conscious. I was very guilty. You know, but there was still a lot of bad influences around me. My friends were all partying and I wanted to go and party with them."

"Were you able to see a doctor regularly?"

"Yah, when I first found out. And then I don't know. I was suppose to go to some kind of classes but I never attended those. I kept a couple doctor's appointments in between."

"Did the doctor ask if you were using?"

"No."

"When did you tell social services that you were pregnant?"

"I think it was the sixth month when I finally told them that I was pregnant. And my boyfriend and I were constantly fighting about the partying and the dope, you know. And then he'd say "well do you want some?" and I'd say "No!" and then he'd do it right in front of me and I'd be tempted to do some…It was that I liked it a lot. That's all…I didn't know of any resources in the city where I could go and what I could do to help me or somebody to talk to or whatever…and I was very paranoid about getting caught cause I was living with a man. I'm supposed to be single. After I had the baby I kicked him out. I was very stressed out and trying to pretend that everything is okay. And I've got everything under control. I'm doing fine with the baby, 'cause I didn't want CFS involved. I was just terrified of them getting involved."

"After you had the baby did a social worker come to see you at the hospital?"

"No. No. I had the baby and he came home with me. My cousin is a nurse and she did some talking and got me this woman to come home with me just to make sure I was okay. She thought I was just alone, period. So I can remember every time she had an appointment to come over I would just clean that house spotless. And make sure my son was fed and changed. I made sure he had a bath and he was clean and I was clean and presentable. I was very worried about what she might think or discover that I'm a lousy person or you know."

"Were you afraid they might take your child away from you?"

"No, that I didn't know how to parent. Maybe I was doing something wrong. 'Cause I really didn't know. This was my first kid. I have no support. Didn't know of anywhere that I could get help. I was too shy and even if I attempted to ask for help they'd be in there and say you're an unfit parent and take the baby away. And I guess more or less I was also stubborn and thinking I can do this by myself worse comes to worse."

A few weeks after Jennifer took her son home he became ill and was admitted to the hospital. Although her son was admitted for a health problem unrelated to symptoms of FAS, it was during this hospital stay that he was diagnosed with FAS. Alone and depressed about her son's illness and the diagnosis, Jennifer met up with some old friends and began to drink again.

"So I felt really guilty. I guess I couldn't live with that guilt. He was in the hospital and I went to see him and I started drinking because I didn't know how to deal with it. Who to talk to, where to go."

"Did the hospital offer you support or did they refer you to a counselor when they told you your son had FAS?"

"I was just dulled. I didn't know. I was too shy or too afraid to ask for help. Who do I talk to? I didn't know what kind of support was out there. Anyway, I didn't come in for a visit. I was out drinking and I guess that's when, because I didn't come in for a day or something like that when he was in intensive care. They ended up calling CFS and said that I had abandoned him at the hospital."

"Which in your opinion you hadn't."

"No. No. I was out drinking and I was being irresponsible, right. And then the next day I went and found that he was in the custody of CFS and there was nothing I could do. I couldn't take him home. Somebody stole my baby away from me without me even knowing. I have no say in it. I have no rights. So when that happened just, boom! I left the hospital and that's when I really started drinking and I didn't stop. I kept drinking everyday…That's it. I went right down."

In the months after Jennifer's son was taken into care by CFS she attended supervised visits with him but the visits did not go well. The baby appeared sick to her on most visits and cried most of the time. Before her son's first birthday Jennifer was pregnant again.

"And then I became pregnant with my daughter. I was really messed up, drinking, drugs. Yah, drinking and drugs during my pregnancy. I was too scared to even think about an abortion. I was already too far along to get one done. So it was I have no choice now. I was so messed up on the alcohol but I couldn't stop drinking. So anyway, she turned out to be fine when I had her. Maybe it was her father's genes in her that are very strong. I don't know but I did drink and she turned out fine. Healthy and she's a bit hyper. Well I don't know that's probably from her father because he seems full of energy all the time. He has custody of her."

Three years after becoming pregnant with her first child, Jennifer found herself alone, drinking daily, and pregnant for the third time. She had been kicked out of her apartment, the second time in the past three years, and was homeless, relying on friends to let her stay with them. With assistance from a local Aboriginal women's center, Jennifer entered a six week addiction treatment program in the fourth month of her pregnancy; however, she started drinking again after successfully completing the program and returning to her neighborhood. Her third child, a boy, was apprehended by CFS at birth. Jennifer was told that he had FAE.

"When he was born they automatically apprehended him. They put a birth alert on him. When I couldn't take my baby home I still came for visits in the hospital regularly. And then this one day, it was pouring rain and I slept all afternoon and I missed, you know, to come in to see him. And they whisked him away. I came to the hospital with a toy and a new sleeper for him and they said he was gone, Child and Family came and took him. And when I left the hospital I went to do whatever I've always gone to do in the past. It's to go get drunk, 'cause I don't know how to deal with it."

“Did anyone try to help you at the hospital?”

‘No.”

Jennifer spent the next year trying to convince CFS to return her son to her care. During this period CFS gained a court order which stipulated that Jennifer was required to complete an addiction treatment program and parenting classes in order to gain custody of her son.

“So we went to court and I agreed. I guess it was a big relief because I didn’t know how to parent. I had not really gotten a chance to parent with my other kids. I went to one parenting class. The reason I didn’t go back was everyone still had their kids with them. Mine were taken away. Everybody else had their kids with them. I felt very uncomfortable there and I never went back. And they [CFS] asked me how come I didn’t finish the class. I tried to explain to them and they said, “well that’s not good enough. You should have kept up with it. You would have been closer to getting your son back.” …All they said was that I had to do this, this, this and this and if I didn’t do it I wouldn’t get my kid. And they didn’t give me support as far as somebody to talk to when I was upset about not being able to take my son home…I was so intimidated by them to begin with…they had a hold of my life and they could do what they want. They have my life in the palm of their hand and they could have squished me or thrown me away or taken my son forever for all I know. I didn’t dare contradict what they said or stand up to them because they had my son…If CFS gets involved you can pretty much kiss your kids goodbye.”

As Jennifer and I concluded our discussion of her life and the difficulties she faced in trying to gain custody of her son, she revealed the circumstances around a fourth pregnancy that had occurred earlier that year. While she had not mentioned this pregnancy earlier, she decided that I needed to know about the pregnancy in order to understand her ongoing battle with alcohol abuse, poverty, and CFS. Six months prior to our meeting, Jennifer had found out that she was pregnant with her fourth child. Faced with the reality that she was still drinking and with the inevitability that CFS would apprehend the child at birth, she decided to terminate the pregnancy, a decision that emotionally she was still struggling with.

“I could give a thousand reasons why I had an abortion, guilt, being ashamed of myself.”

“Were you afraid that something was going to happen to the baby?”

“It was just like when I had my first son. I didn’t even know I was until, um. I had a test and I found out. Okay, yes I am. And I had been using a lot of drugs at the time and I was drinking. I was still partying and stuff. I think a lot of it also had to do with maybe,

> um, I don't deserve another child. I guess it has a lot to do with guilt over having three children, giving birth to three children and I don't have any of them in my custody. You know what I mean. Maybe not wanting to go through that again with CFS because I know he or she would be apprehended right at birth. Um, I wasn't ready emotionally, physically or spiritually. I was too wrapped up in my drugs and drinking. And just being on the street and that. The father was very understanding at the time because he was incarcerated he said it was my choice…
>
> I tried to keep it quiet, hush, hush. I felt very alone when it happened and then afterwards I'm waiting to be released and my ride didn't show up so I got anxious, oh my god I have to get out of here! And I was just crying, what the hell am I dong here to begin with? Where's my boyfriend? Oh it was just a very scary experience for me and I didn't think I was going to get out of the hospital. They weren't going to release me…
>
> And even to this day I still feel guilt about it. 'Cause I should have been more responsible with my body and with my boyfriend. So what if it feels good. It can still feel good but still be safe, well, with birth control. I know myself I wasn't ready to have another baby. It would have been nice, just being filled with it, trying to get that feeling of happiness again. Like you know, you have a baby and it's suppose to be a happy time. You're family is suppose to be around you and your boyfriend, your husband or your lover or whoever. That's how I picture it. It didn't happen that way. It wasn't going to happen that way and I wasn't ready…I don't know maybe it's a fantasy world 'cause I still wonder what it could have been like if I had gotten my shit together."

By the age of twenty-six Jennifer had successfully completed five addiction treatment programs each lasting between 3-6 weeks. After completing each of the programs, she returned to her old neighborhood in Winnipeg and began drinking within days or weeks. Despite her many relapses and struggle with alcohol abuse, Jennifer said she found it difficult to think of herself as an alcoholic even though she knew that her health care and social service providers saw her this way. In explaining her alcohol abuse, Jennifer emphasized that it stemmed from her feelings of insecurity, loss, and depression that escalated during her adolescence, particularly after she was raped, and continued into her adult years with the circumstances surrounding her relationships with men, her increased drug and alcohol abuse, her unplanned pregnancies and the apprehension by CFS of her children. Although Jennifer was struggling with her alcohol abuse problem when we met, she had recently started to explore her Aboriginal identity and heritage, and was finding significant support from a local Aboriginal healing circles and from outreach addiction counseling.

The "Perfect Family"

I first met Libby when she showed up unannounced at my hotel room in a small city in Manitoba. I had spent part of the same day with a friend of hers who suggested to Libby that she come and speak to me about my research. Libby was thirty-four years old, Caucasian, and a single mother of three children. She had grown up in a very violent and abusive home situation and both of her parents were alcoholics. At the time we met, she had just started working as a full time clerk at a local department store. Libby had completed her fifth addiction treatment program three months prior to our meeting and was expecting to have her three children returned to her care by CFS in the next month. While in treatment she met her boyfriend, Peter, who was attending the same treatment program because of a drug addiction. Both Libby and Peter had abstained from using drugs or alcohol since leaving the program and Peter was training to become an addiction counselor.

Libby began drinking alcohol at the age of twelve and by her fifteenth birthday was drinking and using marijuana on a daily basis. She attributes her decision to drop out of high school to her disruptive home and her increased drinking. Libby's decision to leave school resulted in an estrangement between her and her father and to her moving out of her family's home. Shortly after leaving her parents' home, she moved to Winnipeg and met a man with whom she lived for five years.

Libby was twenty when she became aware that she was two months pregnant with her first child. The pregnancy was unplanned and throughout it she drank heavily, used cocaine and hallucinogens, and on occasion sniffed gasoline. Her relationship with the child's father was very violent and abusive, mirroring her upbringing with an abusive father. During her pregnancy, her partner's violence escalated, and he became even more violent after the birth of their daughter.

> "Everything was okay until my baby started walking. Before that I didn't drink as much. Then when she was walking she broke a glass vase and her father got really mad. He was drunk and he was really, really mad. I was trying so hard to defend her because she's just a little baby and everything. I stood in front of her and he pushed me out of the way and he grabbed the baby and he started shaking her. I said, "What are you doing? You don't shake her like that!" Then he threw her. Broke her arm here [indicating to a spot on her lower arm]. So she had a little cast right there. I had to take her to the hospital and they asked what happened and of course I lied cause he [the father] said, "If you tell them what happened then I'm going to kill you." So I said to myself, "O.K. he's serious." And

I didn’t want to be threatened because I remembered my dad with his gun and everything. And so I took her [to the doctor] and I told them that she fell down the stairs. Meanwhile we didn’t have any stairs in our apartment. I was trying to keep a straight face but I couldn’t look at the doctor because I knew I was lying. And so the doctor just wrote it up as falling down the stairs. He said, “If this continues or if she comes back in then we will have to investigate.” I said, “Oh, no you don’t have to investigate.” That’s what happened. I felt so awful because I had lied and that. So I took her back home and he [the father] was really drunk and I said, “Well, I just got you out of hot water. I told him [the doctor] that she fell down the stairs.” He goes, “Well that’s good and blah, blah, blah.” I said, “O.K.” And then I got pregnant again.”

“I was drinking, smoking cigarettes, smoking drugs with that pregnancy, ‘cause I was raped and got pregnant with my second and I thought well I don’t want this one because it wasn’t planned. Well actually my partner, my first child’s father was the one that had the party and said, “Well if you [to the man who raped her] don’t go sleep with her I’m going to kill you and kill her and kill the kid.” So I was just looking at him and I thought, “What is he doing!” And so he [the man who raped her] went for it and I was crying all the way through and what not. I found out later that I was pregnant. He [her partner] forced another man on me and said, “Well if you don’t go sleep with her then I’m going to kill you, kill her, and kill the baby.”

“Were you still living with him when this happened?”

“We were still together but he was drunk when he said all this. And so he stood there and made sure that it happened. I don’t know why he did that and I didn’t stick around to find out. Because after that I said forget this. I grabbed my kid and I didn’t have no shoes on. It was in the middle of the winter and I just got a blanket around her and I just ran out with my baby and I had my pants on and what not and I ran out and called the cops. I said, “I want to go to a women’s shelter. I want to go now.” So I went there. He found me [a few weeks later]. He said, “Oh, I’m sorry, I won’t do it again.” You hear sorry a lot. Of course me, I was a sucker, I fell for it. And then I told him that I was pregnant. I told him that I just found out that morning and he said, “O.K. we’ll handle this.”

“And did you know at the time that the pregnancy was a result of the rape?”

“No, I didn’t. I thought at first that it was going to be his [her partner’s] child. So he was pampering me all through the pregnancy.”

“Did you use during the pregnancy?”

“Yup, ‘cause I just had this gut feeling that something was wrong and it’s going to be trouble and what not. So when I was in the shower I was pounding on my stomach ‘cause I didn’t want this child. It didn’t feel right.”

“Can I ask you why you didn’t have an abortion?”

“I don’t believe in abortion.”

“Why don’t you believe in abortion? Is it a religious belief?”

“I believe that if you’re foolish enough to play with fire you’re going to get burned. And if you don’t want it then there’s either giving it up to a family or else giving it to child and family services. I don’t believe in abortion. I thought the drugs would slowly kill it, that’s what I thought. If I do enough drugs it will slowly kill it. If I inject myself with needles it will kill it in some form, but she survived everything I tried. I thought, “O.K., that’s O.K. I will just learn to live with it.” And then when I gave birth and he [her partner] looked at it, he goes, “That black bastard is not coming home.” I looked at him, I said, “This is my child, how dare you.” And I just picked her up and I said, “You know, if she’s not going home then I’m not going home. You have to learn to accept her.” So he said, “O.K.” and I brought the baby home and I thought this is going to be a perfect family even though she is different, she’s still going to be my daughter.”

“When I brought her home, my baby, I though everything is going to be fine. But whenever he [her partner] got mad he always took it out on the baby. There was one time, I felt so sorry because he [her partner] held her up, her feet were in this hand and her head was in this hand and she was only a week old. She was starting to roll over already and hold up her head and everything at a week old. I guess he didn’t’ like that because she was so strong and my older daughter didn’t do that when she was born. So he said, “This is it. This is where I draw the line.” I was looking at him and I was watching the baby and she was crying. He said, “If you take one step I could snap this kid’s head.” The baby was crying and then he said, “I can snap this kid’s head like it was an accident.” I said, “No!” So instead of taking two steps forward, I took two steps back and I just sat there. I wasn’t going to risk having her neck snapped so I just sat back and I said, “Well if it is going to make you feel like a man go ahead, but just remember I know the cops’ number.” So I sat down and he just threw her down on the couch. And she was crying and everything. I picked her up. I was nursing her, so I picked her up. I said, “You’re nothing but a bastard.” I was really pissed off and everything.”

“There was another time when he was drunk also. He took everything out on the baby ‘cause she was a black child. There’s one time when he was drunk and you know those small cans of soup. He warmed it up on the stove with the lid off and he said, “go get me that can of soup.” So I brought it to him with my oven mitts on and I brought him a cup. And he threw the cup and smashed it. I looked at it and next thing I know my daughter was crying and he [her partner] was pouring the soup all over her. I yelled, “oh, you are nothing but a bastard!” I was so mad and I took off and I left. I left out of that situation when she was a year old. Well not exactly a year old yet. I guess in a couple months she would of been a year old. And then I found out I was pregnant with the third one. I said forget this I’m going back home [to her parent’s home] and that’s it and he’s not going to have no contact or anything with me. And so I gave birth here. He doesn’t know he has another child. That’s one thing I don’t really care about ‘cause just when I promised myself after I got clean and sober that my kids weren’t going to go through that anymore.

Before I really became a mother it took me five treatments. Five times before I really actually straightened out."

"And how did you feel about the third pregnancy?"

"I wanted the baby, I thought I could change just a little bit, like be there as a parent. Have a more stable home. Try and lean off the drug abuse and the alcohol abuse and start doing things right, that a normal person would do. When I was carrying my third I was thinking, "well this happened and this happened to these kids. If I don't want this to happen then I got to quit doing this and this." But it wasn't all at once. I had to do it little by little. And if I'd get urges or anything I used to eat fruit or something or keep myself busy and then after a while I took up some kind of, what do you call that? Prenatal, and I thought, "Well O.K. this one has a chance. This one is not going to turn out like the other ones." He didn't. He's a smart kid. He's really smart. He started reading when he was six and a half. And he's really starting to read chapter books. Just from me slowly, gradually getting off the pot and everything else."

"With him I used drugs once every month, every two months. Like I was trying to break the habit. Like I didn't want that lifestyle but I still wanted it. So I gave myself an ultimatum, I said to myself, "well if you want this child and you want this child to be happy then you have to cut this out. But if you don't want this child, you don't want a normal child then go ahead and do it." The more I said it the more I didn't want it 'cause I'd figure well if I was stupid enough to play with fire and get burnt then I have to be smart and responsible for this child that's not even born yet."

Shortly after Libby returned to her home community, her two children were apprehended by social services because of her substance abuse. By becoming a single mother and applying for social assistance, Libby became visible to CFS. Even though she had been living in a much more violent situation both for herself and her children, the violence and substance abuse characteristic of her life in Winnipeg was hidden by her partner's employment.

As a requirement to regain custody of her children, a judge ordered Libby to complete an addiction treatment program. This order began a five year cycle in which Libby entered treatment, would either relapse during or after completing the program, and then after a few months of using return to treatment. On the occasions when she completed a treatment program, her child would be returned to her care only to be apprehended weeks or months later when social service workers learnt that she was using again.

The lives of Libby's children have been filled with disruption, violence and neglect. Regularly while in her care they have gone without food, milk, diapers, clean clothes, and supervision, mirroring the circumstances in Libby's own childhood. Days or weeks of relative stability followed by drunken chaos have characterized the children's relationship with their mother. Libby describes her children as being withdrawn, "like they are in their own shell." The two older children have experienced learning and behavioral problems in school, which Libby partially attributes to her alcohol and drug abuse when she was pregnant with them. However, neither of the children have been diagnosed with a learning disability or with a prenatal alcohol or drug exposure related illness.

> "When I first got my apartment I decided to throw a house warming party, but I wasn't going to drink. But I was fooling myself because I was setting myself up for a drunk. And I just got all my furniture and everything, and I was so proud of myself but I wasn't thinking. Like I promised my kids, I said, "O.K. mom is not going to drink anymore but mom is going to have a party but mom is not going to drink." And they must of knew something because they barricaded their door with their dresser. As the people came in my oldest pushed the dresser. Well she thought that she barricaded it but she just put the dresser in front of it so when I got drunk I could push the dresser. And the kids were under their bed. They were in the corner and they were just shaking. And I felt sorry and I just said, "Well, see this is what you brought on me." I remember saying that. That hits me all the time and I said, "See what you've done, you've brought this onto me." It wasn't the kids it was me that brought it onto myself. 'Cause I was the one that had the party. I guess the more that I drank was to somehow relieve all the pain and the guilt I did when the kids were little and that. I didn't know how to express myself."

> "It took me three years just to get on my feet and be ready to be a mom. When I would get them back [from CFS] they say, "Mom," every time I went to an AA meeting, they said, "Mom, are you coming back tonight?" I said, "No, I'm not going to get drunk, I'm going to be back." Ya, right. It was just like they were putting me to the test that I was going to go out and get drunk or what not. There was part of me that said, "Go and get drunk, show them that they're pushing your buttons. Show them that you can handle it." But there was another part of me saying, "No, you got to put your foot down, tell them that you're going to be home and come home instead. You got to leave this part behind and just go forward."

During her life Libby had no one that she felt she could turn to for support. While she was still estranged from her father she had rebuilt a relationship with her mother, who was now divorced from her father. Libby struggled throughout the years with feelings of guilt about the difficult life her children had endured, and providing them with a good home remained the central motivator for her to cut down her alcohol or drug use. By the time she was thirty years old, she had been abusing alcohol and drugs for over fifteen years and her children had been in and out of multiple foster homes.

"I cut down quite a bit but I still had the cravings. You do a lot of sweating, you do a lot of hallucinating but it gets better as times goes by. I did a lot of hallucinating. I did lots. There were times when I'd just lay in bed and I'd be sweating. I'd be shaking. I'd go into DTs [delirium tremens] and everything. It was so bad, the DTs that I was hospitalized because my body required that drug and suddenly it wasn't there and so my body was withdrawing through all that. It takes a lot out of your body. Once you go through DTs the longer you stay sober and clean, the more it comes. And I found that they don't last as long but they shorten up as the period goes by that you're straight and sober."

"My kids were in care and I felt I was missing something. I had just got off the phone with them one day and said, "I'm going to do it this time, but not for them but for me. I've got to do it for me." I had just talked to them on the phone and I had occasional visitations with them. And so I put my mind to it and I said, "Well this is it. I can't take it anymore. One of these days I'm going to die and then who are they going to have?" So I made an appointment with the treatment center and I went there and I did my three weeks. And it was just like the sky was so blue, the birds were singing, it was just like a whole different meaning. But then it came to discharge day. It was just like, it felt like I was getting kicked out of my own home, the only place I felt safe. I said, "I don't want to go, I want to stay here. I feel safe and secure in this place." Because I didn't know how it was out there after I've been in there [treatment]. They told me to come back for, what do you call it?"

"Aftercare?"

"Ya, aftercare. Oh I felt so relieved when I walked back into that place 'cause that's where I sobered up. That's where I made a difference in myself. And my kids were so much happier."

"What was your relationship with Child and Family Services like?"

"It gave me some space that I needed 'cause it's been so long since I had the kids and that I need to take little baby steps to giant steps and that."

"Do you feel that they have supported you over the years?"

"Oh ya, they were there from the time that I needed them to the time I didn't and they're still there for me."

"So, when they apprehended your children they made the right decision?"

> "Oh ya, I think they did. 'Cause if they didn't my kids might have not been alive today, you know. It would be hard to say but one of them probably wouldn't have been here, maybe none of them would have been if they didn't step in and do what they had to do."

Child and family services

Libby's description of her relationship with CFS is similar to that of other non-Aboriginal women and markedly different from the descriptions given by Aboriginal women. On the one hand, Libby assumes that once she has successfully completed a treatment program her children will be returned to her care for as long as she remains sober and she sees her substance abuse as a legitimate reason for CFS to remove her children from her care. Libby's belief that her children will be returned to her care is also supported by her experiences with CFS, as on several previous occasions CFS has returned all three of her children to her.

In contrast, Aboriginal women, such as Jennifer, express significant concern that once their children are in the custody of CFS they will never be returned to them, even if they successfully complete an addiction treatment program. Typically, Aboriginal women describe their relationship with CFS as being one of antagonism, and most have little trust in the promises or agreements social workers make with them. The experience of Aboriginal women supported their perceptions of CFS, as many of the women had lost permanent custody of all their children and had no hope of regaining custody of them—a situation that the women firmly blamed themselves for creating.

The role of men in the lives of women such as Jennifer and Libby is both disturbing and, unfortunately, too common. However, despite the violence that is experienced by women and their children, CFS marginalizes men within their provision of services and surveillance of clients. The category "parent" is equated with "mother," and it is women who are coerced into addiction treatment and parenting classes, and who have their children apprehended from them. Further, within a violent situation, CFS takes measures to ensure the safety of the children by removing them from the home, leaving the woman to either stay in the home to endure ongoing violence, or to make her own way to a women's shelter without her children. In this context, the woman is punished for the man's violence by having her children removed from her care.

In discussions with social service providers, they often comment on the bad judgement that many of their clients have in relation to choosing male partners. I recall one addiction counselor expressing his disbelief at a client whom he described as "being unable to leave them [men] alone." For most social service providers, the men who become partners of their clients are "problems" that contribute to the women not being "good mothers." It many instances it is as if the service providers believe that the women should give up completely any relationships that they have with men. However, as expressed in all the narratives of women I spoke with, women and their children do not live apart, but with men. To deny the central role that men play in the lives of this group of women and their children is to ignore an important part of their lives. It is also to ignore a link between cognitive and behavioral dysfunction in children arising from physical forms of violence meted against them, and the impact upon children of having to live in a violent home situation for an extended period of time. As I reviewed the transcripts of the interviews with the women from Manitoba and Montreal, the amount of physical violence that they and their children experience is remarkable, and sadly much of it goes unreported to authorities and unacknowledged by the larger society.

Conclusion

The narrative pieced together by Jennifer and Libby highlight the importance of CFS in the lives of these women, and how their identities, partially because of their relationship with CFS, is largely based on how they and others see them as mothers. However, their narratives also reveal that despite their shared experience of substance addiction, Jennifer's children are diagnosed or labeled, one as having FAS, and another as having FAE, while the possibility of FAS/ARBEs is never raised as a health issue by service providers in relation to Libby's children. While Jennifer was uncertain when I asked her if her children had in fact been medically assessed for FAS/E because the information of their diagnosis had been conveyed to her by her social worker, she nevertheless carried this added burden of guilt, shame and worry about her children. Further, one would expect that the diagnosis or label was a consideration in decisions made by CFS about returning her children to her care, a consideration that did not arise in relation to assessment of Libby as a parent.

Although Jennifer and Libby share common life experiences, as do other women living in similar social circumstances, the attachment of the category FAS to Aboriginal women and their children marks differing experiences for Aboriginal and non-Aboriginal women. While I spoke with several non-Aboriginal women during my field research, none of them had children who had been diagnosed or labeled with FAS/ARBEs. Further, while some of the non-Aboriginal women did see their alcohol abuse during pregnancy as causing harm to their children, the perception that this made them "bad mothers" was expressed to a far lesser degree than it was by Aboriginal women.

Chapter Eleven
OUTRAGE, SILENCE AND THE TRICKSTER

Introduction

Belly stretched taut in a bulge
Breasts swelling as you guzzle beer, who wants Nirvana?
Here is water, wine, beer
Enough books for a week
A mess of afterbirth
A smell of hot earth, a warm mist
Steams from the crotch

"You can't be killers all your life
"The people are coming—"
        —and when Magpie
Revived him, limp rag of fur in the river
Drowned and drifting, fish-food in the shallows,
"Up yours! sang Coyote
                and ran[1].

Over the past year, the Canadian public has watched as the Vancouver police search for bodies of women missing from Vancouver's Downtown East Side on a former pig farm on the outskirts of the nearby suburb of Port Coquitlam. Sadly, one of the women who are being looked for is the sister of Ernie Crey, a co-author of *Stolen from our embrace: the abduction of First Nations children and the restoration of Aboriginal communities* (Fournier & Crey 1997). In their text, Fournier and Crey interweave archival, scientific and historical texts with personal accounts from Aboriginal people to discuss the links between colonial acculturation strategies, specifically the residential school and child welfare systems, and intergenerational problems experienced by Aboriginal peoples, such as sexual abuse, relationship and family dysfunction, alcohol abuse and FAS. Their analysis is the first to look at intergenerational links between the residential schools and FAS/ARBEs, and they point to a legacy of child physical and sexual abuse at residential schools, in foster and adoption homes, and most recently within Aboriginal families and communities, that has been tied to alcohol abuse by Aboriginal women and to FAS among their children.

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[1] "A Berry Feast" by Gary Snyder in Bright 1993:14).

One of the most striking personal narratives in *Stolen from our embrace* is Ernie Crey's recounting of his growing up in British Columbia during the 1950s and 60s. Mr. Crey tells of four generations of his Sto:lo family, beginning with the lives of his great-grandparents who live "amid a thriving aboriginal populace, at the peak of the Fraser River civilization" (1997:21). His life story is moving and powerful, illustrating first hand the experience of many Aboriginal families in Canada. Mr. Crey writes,

> As a child, I was forcibly removed from Sto:lo culture by social welfare authorities. Our family life was shattered after seven of my eight siblings and I were split apart into separate foster homes. We were never again to reunite as a family. My grandparents were proud, independent people who had lived through the deliberate dismantling of Sto:lo culture by priests who probed and pried into every corner of our lives. I had seen my father's spirit dimmed by the residential school where his culture was choked out of him, so that he held his Halq'emeylem language and spiritual knowledge in check, depriving us, his children, of our most precious birthright (1997:20).

Ernie Crey's story is not just one of loss, trauma and suffering, but also tells of resistance, resilience and his rediscovery of his Sto:lo culture: strengths that one assumes he is drawing upon as he watches police search the property of the farm in Port Conquitlam for his sister's body.

The women, now determined to number well over the fifty hypothesized when the investigation began, have disappeared from one of the poorest neighborhoods in Canada. The women have been collectively described as "street involved," "prostitutes" and "drug addicts," and most are Aboriginal. What is shocking about this story is that fifty women from one neighborhood disappeared over a number of years without anyone ever being properly investigated or implicated in their disappearance—despite families and friends giving police several leads, including identifying the farm in Port Coquitlam. A lingering question is, had these women disappeared from an upscale neighborhood in West Vancouver, would it have take so long to make an arrest, and would the number of missing women ever have been allowed to reach as many as fifty before public outcry demanded that something be done? Had these women been the wives, mothers, and daughters of some of Vancouver's most prominent families, would the police have waited so long to create a special task force to investigate the disappearances, and commit the resources needed to investigate the farm?

The lack of public outcry and the silence around the disappearance of fifty women from a poor inner-city neighborhood is indicative of other issues related to women who are street involved and who have substance addictions. These women are the "undeserving poor," unlike their children, who are Canada's "deserving poor," as reflected in government programs to address "child poverty" rather than "poverty" in general (see, Swift 1995). When a woman who is street-involved becomes pregnant, she challenges this distinction and become the "trickster." The "trickster" is a common character found in some indigenous oral traditions (Bright 1993, Ricketts 1965). The vulgar but sacred trickster assumes many forms, and alternately scandalizes, disgusts, amuses, disrupts and humiliates. The trickster is also a creative force, ultimately transforming the world around her in outrageous and shocking ways. However, the trickster does not always act as original creator: rather, she "changes things into the forms they have retained ever since"—she is the creator of "the world-as-it-is" (Ricketts 1965:327, 341).

When the trickster appears as an impoverished pregnant alcoholic or addict, she simultaneously conjures up outrage and anxiety, indignation and concern. She is viewed as both vulgar and sacred, disgusting and hallowed. Her power lies within her ability to be pregnant, and in her ability to disrupt the ideas that others have of her, and instead to define herself as a "mother" and "deserving." No longer invisible, she demands our attention, she forces us to see her. The trickster's power, her new visibility, rallies those around her; suddenly she is worthy of attention, care, support and concern, as we becomes self-consciously aware that somehow, as a society, we are implicated in her addiction.

While a pregnant woman who abuses substances may be a powerful trickster, eventually, like most tricksters, she becomes the victim of her own tricks (Bright 1993:21). Whereas the pregnant alcoholic/addict conjures up outrage, the outrage quickly turns to silence and indifference as her baby is apprehended and she returns to the streets. The deterioration of her health, the acts of violence committed against her, and the pain she feels from experiencing multiple losses are met with further silence, as is her disappearance and death.

In this chapter I present the narratives of two Aboriginal women, both of whom are "street-involved." The first is of Emma, a young women, who, despite her enormous personal loss and pain, continues to challenge and resist the authority of CFS through her repeated pregnancies and desire and demands to be allowed to parent to her children. The second narrative is of Janet, an Aboriginal woman who at the age of thirty-four is suffering from a range of serious health problems, including an ongoing struggle with alcohol and inhalant abuse. With all four of her children removed from her care, and it being impossible because of a tubal legation for her to become pregnant, Janet has increasingly become more marginalized, vulnerable to violence and premature death. An important question is raised by the experiences of these two women: why, when so much societal outrage over pregnant women abusing alcohol exists—both directed at times toward pregnant women and at other times toward the lack of services to support them from drinking, are we not equally outraged by young women, many of whom are Aboriginal, dying premature deaths from alcohol and drug-related illness, accidents, and violence?

Lucky Trickster

I met Emma, or as she refers to herself on the street, Lucky Trickster, on a cold fall afternoon at her apartment in Winnipeg. She had contacted me through a friend of hers whom I had met a few days earlier. On the telephone Emma said that she was interested in speaking to me because she felt she could provide important insight into the lives of single mothers with addictions. Emma was twenty-two years old, of First Nation and Scottish ancestry, and the mother of six children. None of the children were in her care and she was pregnant for the tenth time. Her youngest child, a seven month old girl, had died a few months prior to our meeting while in Emma's care. Emma had been caring for her two youngest daughters when the death occurred, and despite the death being the result of natural causes, her other daughter was apprehended by CFS. Emma was devastated by her daughter's death and the events surrounding the investigation by police, as they initially believed that she was somehow implicated in the death. She was also very angry and frustrated with the decision of CFS to remove her other daughter from her care, and believed that CFS was using the death of her older daughter to unjustly support their actions. Emma was hoping that with the education and job training classes that she had agreed to attend, CFS would recognize her efforts and decide to return her daughter to her care.

Emma grew up in a poor working class neighborhood of Vancouver, British Columbia, with her mother and stepfather. Both her biological parents and stepfather were alcoholics, and her childhood was characterized by physical abuse, neglect, and multiple moves with her younger sister, from her parents' home to foster care and then back again. At the age of ten she was sexually assaulted by a neighbor who was attending a party at her home. The abuse by the neighbor continued undetected by her parents for a year, at which time her mother found out and reported the abuse to the police. The man was convicted and sent to prison.

When Emma was eleven years old, she was removed once again from her parent's care and placed in a juvenile youth detention facility. Two months prior to her being taken into care by CFS, three men had raped her after she had agreed to go with one of them to his house to smoke marijuana. Emma kept the rape a secret and while at the youth facility, had a miscarriage. On several occasions Emma attempted to run away from the youth facility, something she had done on previous occasions from several other foster and group homes, but was unsuccessful. Emma said she always ran away so that she could be with her family because she felt that no one at the homes really cared for her the way she needed to be cared for. She was also very concerned about her younger sister's well-being whenever they were apart.

From the age of three, Emma had been allowed to drink small amounts of beer and by age eleven she was drinking beer whenever she could gain access to it. At the age of nine, she started getting in trouble with the law and at the age of fourteen ran away from her parent's home after being beaten by her stepfather. She never returned to live with them, but kept in touch with her mother. Emma had hoped to go and live with her father on his reserve, but instead ended up living on the streets of Winnipeg as one of a growing number of "street kids." As with other young girls in similar situations, Emma began working as a prostitute. Her drug and alcohol abuse increased and she was introduced to a range of harder drugs, including hallucinogens and cocaine.

"When I was a child all I had was myself in the beginning. I was the one who had showed myself the roots to life. I had to show myself the roots to the streets, the roots to drugs. I showed myself the way past that. I showed myself prostitution. Believe it or not, I don't remember half the things. I don't remember how I got into doing prostitution. Part of it was sexual abuse, the other part I don't understand. I knew I had to lose my virginity, that was the first thing."

Emma was fifteen years old when she went to the doctor because of abdominal pains and found out that she was pregnant again. The father of the baby promised to marry her when she turned sixteen, but left Winnipeg shortly after he found out about the pregnancy.

"I was still doing acid and I still hadn't had my period. I did mesc [mescaline]. I was drinking and then I went in and had pregnancy tests done and I was pregnant. I cried. It was like a cry of happiness knowing that I was pregnant but I was already addicted to acid. They say you can't get addicted to acid. That's B.S. because you can get addicted. The baby is addicted to that high. You have to keep going and you have to slowly wean yourself off. And that's actually what I did. But by then I got into doing the mesc. It's a…I can't remember exactly. It's a powder. It is mainly snorted. What it is, you take one capsule, you snort that, and then you go and have one beer and its like you're totally pissed drunk. Well, I did half a capsule the first time but I was all high on acid. And I didn't understand what the high was. So when I was sober, I did two and a half capsules. Big mistake. I was trying to vomit. Nothing would come out but foam. And I thought the T.V. was speaking French and I thought I could understand it. And I had this harsh French accent happening. It was totally driving me nuts. So I wanted to go over to the bar and I wanted to go drink some more over there. Somebody gave me a beer or I bought it, I can't remember but I was drinking out of this jug. I was drinking this beer and I was already gone. It was pretty weird."

"I was working the streets constantly and I was four months pregnant. CFS wanted to take my baby from me because I was a drug user and a prostitute. They were using all this against me, as well as they were using my past against me, the sexual abuse. They were saying that they thought I was the one who is going to do this [sexually abuse] to my kids. I quit doing acid when I was in between seven and eight months. When he was born they said I couldn't breast feed, I was denied. He was seven pounds and was really healthy. CFS apprehended him at the hospital and they said I could come and see him everyday as long as he was in the hospital, but I never did."

Emma became pregnant again a few weeks after giving birth but miscarried early on in the pregnancy. She attributes the miscarriage to the violent relationship she had with her partner.

"When I met the father of my next baby I was pregnant with my first baby. We'd constantly argue, argue, argue. One time he picked me up and threw me against the doors, the stove, everything. But meanwhile I would beat on him. And it was like we always like the making up part. Always in the bed, right. That's how I kept getting pregnant. I wanted to get custody of my son [her first child] but he took me away and that's when I had my miscarriage. I was panhandling in Edmonton and my boyfriend would take my money and spend it on drugs."

"After I miscarried I got pregnant right away again. I was drinking and I did acid once during that pregnancy. I think that was Valentine's Day. Valentine's Day I did acid because I was so depressed and I wanted to be happy. And that was like my happy drug. It made me happy go lucky and that. What happened is that I was suicidal, I got very suicidal. I wanted to do something to die. That's how I felt. My boyfriend and I were smoking weed and I was always drinking with him. Like he was pretty shocked to see how I drank. 'Cause I don't look Aboriginal. But he was pretty shocked. What do you expect from a Winnipeg girl?"

Emma gave birth to twin girls in an Edmonton hospital later that year. Social services placed the twins in temporary care at the hospital because Emma had no permanent residence. In the next three months she tried to find an apartment so she could gain custody of the twins. During this time she was arrested on drug and prostitute-related charges and was afraid that if she was convicted, she would be sent to jail. Emma decided to return to Winnipeg to avoid the charges, and before leaving agreed to place the twins up for adoption. Since placing the twins for adoption, and despite recent efforts to gain information through CFS, she has had no information about the twins. Emma has two pictures that had been taken of the twins at the hospital shortly after they were born.

Emma returned to Winnipeg and began working as a prostitute in order to support herself. She was no longer with her partner and because of the drug charges in Edmonton wanted to avoid social service agencies because she feared they would report her to the police. During this period, Emma saw her biological father on and off, but because of the difficulties in his life, including his addiction to alcohol, he was unable to offer help to her. Emma had cut off her contact with her mother because of an argument they had had about her sister.

"When you were working the streets did you use condoms? With your boyfriends did you use birth control?"

"I couldn't take birth control. I tried to take birth control pills but I get sick from it and I can't take the shot [DepoProvera] either now because they say I have some kind of condition."

"Do you use condoms?"

"With my partner?"

"Yes."

"Occasionally, but not really."

"Is that generally your choice or his?"

"It is mutual. In the beginning part of the relationship, ya, we use condoms. But you know, if I feel I know enough about somebody I won't use. Depends on who the person is as well…You see the very, very first time I had worked I had heard nothing about condoms. Like I had never heard about STDs or anything like that when I was little. Nobody would talk to me about that."

Similar to other women, Emma's practice has been to use condoms with the men she has as clients and not with her boyfriends. Although she is aware about the risks of contracting a STD, including HIV, she, like other women who are "street involved," associate the use of condoms with a loss of intimacy between them and their boyfriends. The use, or non-use, of a condom effectively drew a line between the men who were "clients" and men who were "boyfriends." As with other women, it is important to Emma that she never becomes pregnant with the child of one of her clients, and all pregnancies are attributed by her and other women to sexual relations with boyfriend further marking the separation between personal and work relationships.

In Emma's self-perception, both her attractiveness to men and her ability to easily become pregnant are personal characteristics that she emphasizes and uses to contrast the image that she feels social services has of her as a mother. In our discussion she often associated her pregnancies with a seductive power over men, both boyfriends and clients, blurring the boundaries between "purity," "sacredness" and "motherhood" with "profanity," "seduction," and "prostitution."

" There are a lot of guys that are infatuated with girls that are pregnant[2]. I know when I was pregnant with my son I had a really good date. He was my regular. He just loved pregnant women. He loved the natural beauty of the belly. And its like we didn't have to have sex or I didn't have to give him a blow job or any like that. Just to see the female naked body. The natural beauty of the curve of the belly is what had turned him on. And I think that's so neat. Because there's so many guys out there that are not attracted to pregnant women. And they go out and look for something that isn't pregnant. And when

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[2] In a recent presentation given by a front-line worker who advocates for the rights of women who are street-involved, she discussed a group of women who have clients that pay them substantially more when they are pregnant. She suggested that these women commonly have multiple pregnancies in a short period resulting in children being born who they are never able to parent.

you know that a guy is attracted to you, the natural beauty of the pregnancy. I've had a lot of guys that are so attracted to me, pregnant or not. I've got that glow to me that attracts all these males. Its like I'm a magnet. It just makes me feel so good inside. And its just so remarkable because there are still those guys out there that are very turned on by pregnant women. I don't see nothing wrong with it. It's because of the milk in the breast. And the guys are curious because they have never tasted breast milk before or they want to see if you're tighter or if a little bit looser after having a baby."

"After I had my first born I told them [CFS], "you know what? I'm going to keep having kids until you let me keep one. That's what I told them, and it's like they actually took me serious. But it was actually kind of amusing in a way. But what had happened, I realized that I'm a very fertile female and I've had my problems and that, but I've never believed in abortion. If I can give birth to a child and I can look after a child, if I'm capable of looking after a child, I will look after my child. But I do not believe in abortion."

"After you had a few children already, you can actually feel the fluttering around two months. And I can feel fluttering but it's not as frequent as when you actually feel a baby kick. A baby kicks more but I do feel fluttering in my belly but mainly its right at that time."

"It's like if you didn't care for your first born, this one will be your first born. So this is your gift child. Just like mine was my gift child. After every baby you have, every time you give birth, it is not the same no more. The first time is the first experience of life. Ya you give life every other time but it's not the same feeling. Like when I had my first son he was right on my chest and it was just a wonderful feeling. And just to think that I had harmed him in that way of doing all those drugs and that, it made me feel like so bad. I just felt so guilty inside of me. It's also like every mother's day or on their birthdays I get really emotional and alone feeling. It's like I feel like it's not worth living anymore."

"And CFS has taken my daughter. I've never neglected her, I've always gotten her everything she's wanted. She's always been fed, clothed, everything. And CFS has taken my daughter on the grounds of some rumors and me supposedly selling my breast milk. And me supposedly being suicidal, and me supposedly jeopardizing my children's lives. It wouldn't actually be any of their business but see the way I look at it is that I was breast feeding my little girl that passed away as well as my other daughter. They thought I was selling it to Johns to make money."

"And then they had this thing about me working the streets. I'm sorry if I'm not getting child tax or things like that, I'm going to provide for my family. And the only way I know how at that, that's the only way I know how to make money because this is how I was raised. I raised myself to know, to survive on the streets. Like it wasn't for pleasure and it wasn't for money. It wasn't really for the money. It was for my kids. Like my kids are my drugs. You know. They are my natural way of being happy. Getting bursts of energy to do everything. That's what my kids are. They are my high. It might be the wrong way to look at it but you know it's a good way to put a point across."

"There's a difference between child and family services and all the other services. Child and family services they tell you that you have to do this if you want your kids back. Actually you do not have to do as they say. They push it against you and they make you believe in it. But if you actually do some research, CFS does not have any authorization to threaten you with your child. It's the situation I'm in now. With my daughter passed away and they have taken my other daughter. For what actual reason? Because of some rumors that were spread around?"

"You see at the age of sixteen I was one of those kind of spiteful kids that you know, I don't care what you say. I'm still going to have a kid. That's the kind of head I had on my shoulders at that time. I was very pigheaded. If it didn't go my way, hit the road sort of thing. But that's the way my attitude was and I had a pretty big head. And I just told CFS point blank, "You know I'll just keep having kids until you let me keep them. Keep at least one of them." And I've kept that theory. And then I was just like I'll go somewhere else. And it actually pretty much did work. It was to the point where people were letting me try parenting my kids. And people did after a while see that I was a good mom. And no matter if I was abused, that I didn't have the love and affection and that, but I was still able to provide for my family. For my kids, to provide a good loving home for them. And it's like all my kids. I loved all my children. Yes, sometimes in the beginning I wasn't ready, like I was still a child. Happy go luck little girl. It's like I was still trying to find within myself who I was."

"This baby (pointing to her abdomen) is a gift for the guy I'm with. The guy I plan to stay with for the rest of my life. I'm giving him the chance to be able to have one child with me. But some of them don't care [other women]. They say, well I'm not keeping the baby anyway, so I'm going to do all the drugs I want and when they do that they are harming that human being inside of them. Like ya, if they don't want it, stay clean until the baby is born so the baby will have half a chance to live."

Emma had attended a number of programs for single mothers, women with addictions, and counseling sessions for the abuse she experienced as a child. In some cases she decided to go to the programs on her own, but in most cases she was sent to the program by social services as a requirement for regaining custody of one of her children.

"When I was younger, about twelve or thirteen and I was in CFS I went to a substance abuse and anger management program. They give you a piece of paper and they say, 'Well, which drugs do you do?' Well I know I do these drugs and what does this help me. The same with anger management. They get you to point out your anger problems. And they don't work on them. They just point them out to you and say, 'O.K. this is why you're angry.' And they expect you to look at the papers and say, 'Oh, I'm not angry anymore.' They never gave me counseling for any of it. The sexual abuse. I went through sexual abuse programs. CFS had technically forced me to go because I was a child and I didn't know. And they sent me to the sexual abuse program and if they would have never sent me to these program, um I think I would have probably left it in my past and never remembered. Most of my past, like the bad things that have happened to me like I've forgotten about most of them. But a lot of them are there because CFS had hounded me with my feelings. They had toyed with them so now its like I can see it as if it's happening at this moment."

"Do you feel it helped you in anyway to resolve things?"

"No, it didn't. It just showed me that I have to do things in my own way. My way of seeing it is that, like I told you yesterday about that man sexually abusing me. For me to find a cure for it is for him to come up and say, 'hey, yes I did it to you. I'm sorry.' That there, is my cure. Everybody's cure is all inside of them. It isn't a metaphor by saying you have to go to see somebody to get the help you need. The help is inside of you. It is up to you if you want to find that help inside of yourself. To help yourself deal with reality."

In order to regain custody of her daughter, Emma was told by CFS that she had to be evaluated by a psychiatrist.

"Because my baby had passed away people were spreading rumors around about me saying that I was selling my breast milk, saying that I was jeopardizing my children's lives, saying that I was suicidal. People were saying a lot of things about me and they were not true. And they did not take a little bit of time to come and ask me the questions. But they were still on the files [reports to CFS from her neighbors] that these questions were brought up. And they had to take it further, saying that we have to take your daughter because these things were said, and we have to make sure that this is not true. But I have to go through a whole assessment with this shrink that I'm normal. And meanwhile the shrink, every time I had seen him he had made me cry. And I had asked him, 'What? Do you get off on seeing me cry or something?' Like I'm a very blunt person. If I don't like you I'm going to tell you. And ya, I've lashed out in certain ways because of my past childhood and that, but I would never lash out at a child. 'Cause a child doesn't know any better. But I do."

Emma was seeing her daughter several times a day because her daughter's foster home was close to Emma's school. While her daughter's foster care placement allowed them to see each other often, Emma said that her daughter was very upset each time she left her, which upset Emma and made her feel guilty because her daughter did not understand why Emma could not stay with her. When we spoke, Emma did not know if CFS had plans to apprehend the child she was pregnant with, but hoped that by the time of the birth, she would have her daughter back in her care and CFS would agree to let her parent her newborn.

After spending two afternoons together, Emma introduced me to an older woman who she referred to as her “mother.” The woman, a retired social worker who had known Emma for several years, offered a broader perspective on Emma’s situation.

> “And I think some women and Emma absolutely included, mature and settle down. And they’re not living on the streets. And so they come to a place that they can parent. You know if you can’t at sixteen that doesn’t mean you can’t at twenty-two. And I think another thing for you, Emma, is that you love being pregnant. Parenting isn’t easy but, Emma, I’ve got to say I take my hat off to her. She did incredibly well with her last two children. She’s very nurturing. There’s a difference too between Emma and some of the other women because I don’t think that you’ve ever been an addict. You did a lot of drugs and you did some sniffing during your first pregnancy but, you weren’t addicted in the same way as a lot of the women I’ve dealt with are. And you’re right, there are some women who the motivation to be able to get off the drugs is the pregnancy. There’s a lot of women I know that have been motivated because they got pregnant and they just found ways to stop. They’re done with the drugs. Now I have to be an adult and I have to stop. And there’s other women, who I have met, one woman in particular had eight children and with her eighth she asked me to be at the hospital. She knew that she couldn’t keep the baby but I saw her all the way through. She would talk about using less, trying to use less to provide for her baby. At the same time her emotional pain was so huge and so dominant that she couldn’t quit all together. It would be just too overwhelming. She felt like she had to die. So I see people struggling with their addictions around their pregnancies and I don’t think that anybody wants to hurt their baby. I don’t thing it is because they don’t care. I can’t imagine anything more painful that carrying a baby knowing you’re going to lose that child. And there are certainly some women that look at it as a gift to the world. And even if they can’t raise it doesn’t mean they don’t love it. And again, so much loss in your life makes so much pain.”

Silence

Janet is a thirty-four year old First Nation woman who has lived on the streets of Winnipeg for several years. She is the mother of four children. Her oldest daughter has been adopted into a non-Aboriginal family, her next two daughters live with their biological father, and her youngest child, her son, is in foster care.

Janet is the sixth child of two former residential schools students and was raised for the first four years of her live in a northern Manitoba reserve. She spent the rest of her childhood being moved in and out of foster and group homes run by non-Aboriginal parents. In two of the homes the foster fathers sexually and physically abused her, and in both cases the abuse went undetected by social service agencies.

Janet was fourteen years old when she started drinking alcohol and sniffing substances such as glue and gasoline with other children in the foster homes. Her alcohol and inhalant use continued throughout her adolescence and into adulthood, with periodic breaks. Janet could remember going to at least seven addiction treatment programs, mostly at the request of social services in order to regain custody of her children.

"Well they put me in River House and St Norbert. I went to a lot of treatment centers. They made me go."

"And what was it like?"

"It was O.K. I worked, I was getting paid, my kids were going to school when I was at St Norbet. They were with me in there. It was good but I only stayed for a month."

"Why did you leave the program?"

"I decided to leave 'cause it was a kind of strict place. The rules and that were hard. You had to sit on the seat if you were bad in the hallway. You had to be careful about your kids. Watch them closely. I was on the hot seat a lot of times."

"Because you weren't supervising your kids?"

"Ya, but I had to work too and my kids were small."

"And what about this hot seat, how did you feel about it?"

"You have to sit in a circle and everybody [the other clients] yell at you. You've got to sit down and you can't say nothing. But I started yelling back at them. I had my two girls with me but then I eventually lost them [to CFS] 'cause I couldn't stay in the program and I started drinking again. I was stupid."

Janet's first pregnancy was at the age of eighteen. Confirmation of her pregnancy came around the third month after seeing a doctor at a community clinic. At the time, Janet was homeless and living in the Downtown East Side of Vancouver. She describes this as a very difficult and depressing time for her. Janet was drinking alcohol and sniffing solvents on a daily basis, while working as a prostitute to support herself. After the birth of her daughter, she tried to parent her child but struggled with poverty, her addiction, and her social context, as she was surrounded by friends who were themselves all addicted. Within a short period after giving birth, CFS apprehended her daughter, who was later placed for adoption with an non-Aboriginal family. Janet has no contact with her daughter and worries about her safety and well-being because of her own experiences in foster care.

Janet’s next two children were from a relationship she had with a man in Edmonton. This was a relatively stable time in her life and, even though she separated from the man after the birth of their second daughter because he was having affairs with other women, she was able for a few years to parent her children and keep her substance use under control. During her second and third pregnancies, she attended an outreach program for pregnant women. The workers gave her milk, food and vitamins and helped her to prepare for the arrival of her babies by providing her with a crib, clothes and a stroller. Janet emphasized the importance of the program and how central the support of the outreach workers was in her life. She said it was the first time in her life that someone had taken the time to sit and talk to her about how she was feeling.

“Well I did [quit using substances] when my girls were small and living with me. Well, I did it with them [used substances when she was pregnant] but then after that I didn’t do it for about two or three years. And then I was living with this abusive man. He used to beat me up all the time and I started doing everything again. Then I phoned my sister up and she came and got me and I came to Winnipeg and I started using and I lost them [her children to CFS].”

In describing her life, the only happiness that Janet can recall is when she had her children with her.

“Well my three girls I didn’t do too much damage to them. Well my second one has asthma now from that. I was using glue. And my boy he was in the hospital ever since he was born because I did needles too with him. I did drinking and sniffing, I did all the damage to that one. He’s on special medication. I feel bad and hurt. I feel real bad what I did to them.”

“Did you have any opportunity to parent your children?”

“With my girls yes. With my boy no. They took him right at birth. At the hospital they just took him right at birth.”

“So when they took him at birth did you know that they were going to take him?”

“No, they didn’t even let me hold him…they just took him away.”

“And what did they do for you? Who was there to help you, to comfort you because of the loss?”

“Nobody, I went to my sister’s place and then I went to court and everything but I didn’t get him back. He can think and all that, but he’s got to be on medication and all that, ‘cause I did lots with him, I drank, I did needles. I sniffed. With my girls I just drank.

With my first one I drank a little and sniffed. With my second one I drank lots and I sniffed lots. But with my boy I had no support 'cause I left my husband. I was even working the street with him. I was pregnant with him, I was working on the street with him. I was using drugs."

Janet worries a lot about her oldest daughter and son being in foster care and less about her other two daughters who are living with their biological father.

" How does it make you feel to have your daughters living with their father?"

"I feel a little more relief. I don't worry as much. I used to worry lots 'cause one night I slept over night at this foster home. That man didn't know I was sleeping there and he walked in the room, in my daughters' room and I heard him say, 'Why didn't you tell me the woman was here?' I got them out of that foster home right away. I told child and family service, I say, 'Why is that man walking in that room when my girls are sleeping and he didn't know I was there?' And I got them out of that foster home right away, 'cause maybe he was sexually abusing them or something."

"Do you think that you will have more children?"

"Not after what I did with my little boy. What I put him through. I got my tubes tied 'cause I didn't want to put more pain on my kids. I really punished my boy a lot. I put him through a lot. I told them to do it. When I seen what I did to my boy, I said, 'Tie my tubes 'cause I caused him lots of pain.'"

When I met Janet she was in a wheelchair because she had been hit by a car a year and a half earlier. It was very difficult for her to get around in the chair because it was not electric and because of the limited services and accessibility for wheelchairs in the area she lives. After the accident, Janet was confined to the wheelchair but through physiotherapy had regain the ability to walk for short distances. Five months after her accident, she quit going to physiotherapy because of her increased abuse of alcohol and glue sniffing. As with other women, Janet felt her health care providers would harshly condemn her substance use, and therefore she began avoiding the services she needed to continue her recovery. However, Janet did want to contact her physiotherapist to begin treatments again as her legs were getting worse and she was now unable to walk.

In general, Janet's health has deteriorated since the accident and she lives with severe chronic pain. Her daily life is full of multiple challenges, including finding ways to get around in her wheelchair, living on a small disability allowance, and negotiating the harsh streets of Winnipeg's North End. Because she is unable to get pregnant, it is unlikely that social service providers will encourage her to any great extent to seek help for her addiction or other health problems. Janet describes feeling depressed most of the time, and throughout our conversation broke down in tears several times.

> "It's a battle. I try to stop [using substances] but I sit down sometimes and everything just builds up inside me. All my problems are coming and I just do that to forget."

Conclusion

As stated previously, research has shown that women with chronic substance abuse problems are at high risk of dying prematurely if they continue to abuse substances. The narrative accounts of Emma's and Janet's experiences illustrate the central role that CFS plays in the lives of impoverished Aboriginal women, whose family histories are interwoven within a broader context characterized by colonization, poverty, sexism and racism. Within their narratives, however, both Emma and Janet situate their ongoing difficulties within the context of their relationship with CFS and within the deficits that they believe to exist in their own personal characters.

Emma's repeated pregnancies, however, act as a source of power and resistance for her, in a world that has been largely dictated by CFS workers. Both her sexuality and repeated pregnancies challenge the prescribed social roles that she is to embrace as a "woman in need." However, despite her resistance, she cannot situate herself and her children outside of the surveillance and decision-making of CFS. In contrast, Janet is largely invisible in a social service milieu that prioritizes young pregnant women and children. No longer parenting her children and unable to get pregnant, Janet becomes even more marginalized within the social context in which the most marginalized people in Canada live. In common with the other women discussed in this section, Janet's needs reach far beyond basic outreach services and addiction treatment programs, and the benefits that she would gain from reuniting with her children sit in opposition to the perceived needs of her children. However, unless some form of intense psychiatric and addiction treatment is provided to Janet in a place that she feels safe to begin to rebuild her life, and unless this support is extended to her as she integrates back into the larger society, it is likely that her life will end on the streets of Winnipeg within the next few years. Unfortunately even with this type of support, there are no guarantees women such as Janet will fare better in neighborhoods, where poverty is endemic and only limited options exist for them to transform their lives into something other than what they are.

Chapter Twelve

AN EMPTY SIGN: SYSTEMATIC PREDETECTION AND FETAL ALCOHOL SYNDROME

Introduction

> *As an adult, Jane told me of being sexually abused by her foster parent's son, who was never charged and is now a Christian missionary in Africa. In her late teens, Jane gave birth to a son who was adopted by the same parents and continues to live there. It hurts me to see my nieces and nephews repeat our history as foster kids in white, ultra-Christian homes. Jane now spends most of her time on Vancouver's meanest streets, on a methadone-maintenance program but receiving no psychiatric care or counseling to help her cope with the immense losses in her life…The trouble my siblings and I have suffered can only truly be understood in a cultural context, not just as a series of traumatic life events but as a deep spiritual estrangement from the complex Sto:lo beliefs. As Sto:lo, we believe that our ancestors continue to play a role in our daily lives. In our society, when you are ill or feeling discomfort, you are described as being "Indian sick," which means that spiritual forces are at work in your life. In order to understand these forces, you must return to spiritual teachers. The elders believe the voices and spirits that non-native medical experts might diagnose as a profound mental illness are in fact an expression of the cultural estrangement so many of us have suffered.*
>
> Ernie Crey
> "Stolen from our embrace: the abduction of First Nations children and the restoration of Aboriginal communities"

> *FAS is implicated in most adoptions that go bad. Virtually every native child adopted over the past 20 years has some degree of alcohol damage. It is that, and not the pain of alienation from white society, that accounts for their frequent estrangement from their adoptive families and their terrible problems in life. The failure of cross-cultural adoptions is one of the most tragically misunderstood stories of recent years. It has wreaked havoc in some of Canada's most prominent families…And yet adoptive families everywhere are still being told their children were ruined by a cultural identity crisis.*
>
> Margaret Wente
> "Our poor ruined babies: the hidden epidemic"
> *Globe and Mail,* Saturday, October 2000

In this chapter I explore various representations of persons with FAS/ARBEs, particularly adolescents and adults, and how these images reinforce the perception that large numbers of Aboriginal people have FAS. I specifically explore the association of FAS/ARBEs with a broad set of behavioral and social problems that have been labeled "secondary disabilities" of FAS. In this discussion I illustrate how fluid the category FAS has become as it is applied within local contexts, through government funding initiatives, within the media, and by educators[1] in workshops targeting social service providers.

Creating "risk" and "pathology" at national and local levels

The identification in the 1980s of elevated rates of FAS in Aboriginal communities drew the attention of the federal, territorial and some provincial governments. Researchers, especially pediatricians and child psychologists from the University of British Columbia argued that Aboriginal peoples were at significantly greater risk for FAS/ARBEs than any other group, with rates reaching in some communities as high as two out of every ten children being alcohol-affected (Robinson et. al. 1987, see, also Robinson & Armstrong 1988). The suggestion that large numbers of Aboriginal children suffered from chronic brain damage and that the cause was alcohol consumption by pregnant women led to FAS prevention program funding being offered by the federal, western provincial, and territorial governments to Aboriginal communities, particularly reserves.

To justify funding for FAS/ARBEs prevention, governments first required Aboriginal communities to describe the extent of their "FAS problem" in order to qualify for funding. In effect, this placed the communities in a position of having to create a "FAS problem" because so few individuals had been assessed or diagnosed, making it unclear if a problem even existed. For example, when FAS funding first became available in the 1980s and 1990s, Aboriginal communities had limited knowledge about FAS/ARBEs, few or no individuals in their communities had been assessed or diagnosed, and alcohol use patterns and levels varied among women from community to community, and, even within sub-populations of women. Further, given the short time frame in which communities were given to produce proposals to qualify for government funding

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[1] I use the term educators to refer to individual who provide community-based training on FAS. The background training and experience of this group of individuals is varied and includes nurses, social workers, and community outreach workers.

(sometimes a matter of weeks), governments could not have reasonably expected the communities to make any kind of meaningful and definitive evaluation upon which to base their proposals.

The emphasis on FAS-related programs and services for Aboriginal communities has continued over the past twenty years, particularly in western and northern regions, and in reserve communities. For example, in 1998, out of twenty community development initiatives funded by the Saskatchewan provincial government and sponsored by the Saskatchewan Institute on Prevention of Handicaps, sixteen were located in reserve communities, and the other four urban and prison based initiatives were run by Aboriginal organizations or had a strong Aboriginal component. However, while the federal, provincial and territorial governments continue to allocate millions of dollars to address FAS/ARBEs in Aboriginal communities today, they still do not have an evaluation that determines the extent of the "FAS problem" in Aboriginal or non-Aboriginal populations. This is not to suggest, however, that the funding allocated by governments is wasted. In fact, communities have been very resourceful with this money, which, when divided between communities is actually quite limited. Further, the benefits of the funding have reached beyond the limited scope outlined by governments and is applied in ways that span a broad spectrum of issues for women and their children.

The local context

At various government levels, Aboriginal leaders have identified FAS/ARBEs as a health and social concern for their people. As knowledge of FAS and the dangers associated with prenatal alcohol use entered public health discourse, Aboriginal peoples associated FAS as a further outcome of alcohol abuse problems found in some of their communities. The announcement of government funding for FAS also meant that they could access financial resources to improve community support programs for families. However, not all Aboriginal people were convinced that FAS was a problem in their communities. For example, in a preliminary field trip to Saskatchewan in 1997, two First Nations health care providers from different reserve communities expressed dissimilar views on FAS. One suggested that I make my portrayal of FAS a "worse case scenario" in order to prompt governments to allocate sufficient funding for communities to deal with the myriad of health and social problems that they have, FAS being only one. The second health care provider said that in general, her community, including their leaders saw FAS as yet another ploy by the federal government to discredit Aboriginal peoples. While the community wanted to access the funding attached to FAS, they were worried about the long-term impact of telling the government that they had a "FAS problem."

However, by the late 1990s a sense of urgency about preventing prenatal alcohol exposure and FAS/ARBEs was entrenched in many urban and reserve contexts and was added to a range of other "problems" that Aboriginal peoples saw as requiring their immediate attention. Significantly more funding however, was made available to reserve than to urban Aboriginal populations, partially because of jurisdictional issues between the federal and provincial governments over their respective responsibilities for First Nations people living off reserve.

The identification of FAS as a serious public health crisis by some Aboriginal peoples also added to the growing distinction within and between Aboriginal communities of those who abstained from alcohol use and those who did not. FAS reconfirmed for those who abstained that alcohol was a very dangerous substance that had found yet another way to impose itself negatively upon their communities, and was further justification that alcohol use of any kind should be rejected collectively by Aboriginal peoples. The growing class divisions among Aboriginal peoples strengthen further this perception, because it was clear for many that alcohol use held individuals and communities back from achieving wellness and prosperity. Emerging class divisions mirrored divisions between those individuals and communities who abstained from alcohol use and those who did not[2].

Many reserve and urban Aboriginal communities took "ownership" of the "FAS problem" by creating "culturally meaningful" services for their people (see, for example, Assembly of Manitoba Chiefs 1997, Ontario Federation of Indian Friendship Centres 2002). This has occurred in much the same way as Aboriginal groups have chosen to address other health and wellness issues, such as addiction, family violence, and

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[2] It should be pointed out that many Aboriginal people who are perceived to fall within the category of "abstainers" actually drink alcohol and would be considered to be "social" drinkers. However, their alcohol use is perceived by them and others as benign. In many instances the lines between abstainers and users is blurred, as are class and social divisions. Generally as someone is perceived to cross that distinction from abstainer to user it is accompanied by some type of personal loss such as a job, community respect, family relationships etc. that can influence their position within the social structure.

"community healing." The focus has been on "community wellness" and a holistic approach that simultaneously addresses the health and wellness of the individual, family and community (Adelson 2000). The success of FAS programs in reducing prenatal alcohol exposure and in supporting individuals diagnosed with FAS/ARBEs appears to be directly linked to a broader community wellness program existing, as well as lower frequency and levels of alcohol use/abuse in the general population.

In examining published profiles of community support programs for persons who are alcohol-affected, I found that the programs all share in common the fact that very few of the individuals in the programs who are identified as having FAS have been medically assessed or diagnosed (in some cases none of the clients are diagnosed). The outcome of this is twofold: (1) as more individuals identify themselves or their children as being alcohol affected, the greater the "FAS problem" appears to be in Aboriginal communities. In local contexts, prenatal alcohol exposure potentially becomes an explanation for an array of behavioral problems, learning difficulties, and individual and family "dysfunction" of which FAS/ARBEs may, or may not be a contributing factor. (2) As people increasingly take on the label of FAS/E in local community contexts, they influence the profile of the "typical" person with FAS. For example, in the early 1990s, the Ktunaxa Nation and Kinbasket people of British Columbia surveyed their population and "identified factors suggesting high rates of FAS and FAE" (Anderson & Wemigwans 2002:6). They engaged in a "participatory action research project" to examine how people experience FAS and FAE at the community level, and as part of this developed a FAS/E prevention program and community support project for children between the ages of six to thirteen years. A profile of the Community Healing and Intervention Program (CHIP) is given in a recent publication by the Ontario Federation of Indian Friendship Centers (2002), and outlines the many local successes that the program has achieved for children and their families.

An important aspect of this program is that it challenges the negative stereotypes of persons who are alcohol-affected. For example, John Barnes, the youth worker for the program who has partial FAS (self-identified) has two university degrees, a Bachelor of Arts and a Bachelor of Social Work. After experiencing learning difficulties in University, John learnt about the symptoms of FAE and "realized that many of the symptoms fit him—such as memory glitches, difficulty understanding consequences and time, and abnormally high pain threshold" (Anderson & Wemigwans 2002:7). Barnes' self-education about FAS/E, according to journalists Doug Andersen and Jennifer Wemigwans, "helped him to see what worked for both him and his clients. Just the fact that he has FAE, helps his clients" (2002:7). Discussing the negative stereotypes, Barnes states:

> They see that I'm an intelligent person. I have my own life. I work around my disabilities; I don't deny them. It's important for [the clients to see]. A lot of people won't talk about it, 'cause they think it means that you're stupid, but it has nothing to do with that. Everyone that knows me knows that I'm not (quoted in Anderson & Wemigwans 2002:7).

In reading the profile of the program, especially about the support that it has received from the community, it is evident that it has significant meaning in this local context and is helping to build strong support networks for families around a shared common interest of preventing alcohol use by pregnant women, and supporting children who are "alcohol-affected." It also indicates that in a situation where referral for diagnostic assessments for FAS is difficult to obtain, or in some cases not prioritized by certain community members, that the community has still found meaningful ways to come together around the issue of "FAS."

The Ktunaza Nation project, however, raises a number of questions about the practice of non-medical labeling and how this feeds into local perceptions about prevalence rates and the identification of "alcohol-affected persons." For example, in discussing prevalence rates in the community with Jason Louie, the Community Support Worker for CHIP, Anderson and Wemigwans write,

> Jason isn't sure how prevalent FAS/E is in the community, since no detailed formal studies have been done, but it's safe to say it's significant. A lot of the kids he works with have not been diagnosed, and many don't seek out diagnosis, although CHIP does make referrals for FAS diagnostic assessments. However, CHIP staff can see the patterns with clients in the community. Sometimes the birth mother shares that she consumed alcohol during her pregnancy. Because CHIP is community based, the workers may also know or hear through the grapevine that a mother drank during pregnancy. They also know that if a child was adopted there's also a good chance that alcohol was involved (Anderson & Wemigwans 2002:8).

In this local context, prenatal alcohol exposure and not necessarily abuse, is believed to be sufficient to cause FAS/ARBEs, and as evident by the statement above, the behavior of pregnant women in the community has come under increasingly greater surveillance. How the mothers in the community are responding to the "realization" that their alcohol use has "damaged" their child(ren) is unclear in the report, and in many ways does not appear to be an issue that receives must attention in the community. Further, unlike the debates within medical circles about the challenges of applying a diagnosis of FAS and, more specifically FAE, appropriately and consistently from patient to patient, the "FAS problem" in this local context—both its prevalence and its manifestation in individual behavior and appearance—appears obvious and straight forward to community workers. The suggestion that "a pattern" exists that can be mapped onto individual behavior indicates that community workers and others have very clear ideas of who is or is not "alcohol affected" in the community. This begs the question of who is in the positions of authority to "diagnosis" individuals, who receives the label, and who does not, and why.

The broader context

> *Underfunded First Nations health care systems, both on reserve and in the inner city, have difficulty getting and allocating funding to take care of their own fetal-alcohol-damaged children and adults. Yet when a native child is taken into care, it appears that funding suddenly kicks in to take him or her on the round of medical appointments that the child will need for the rest of his or her life. Diagnosis and visits to a psychologist can be more readily organized and reimbursed when a child is in government care. Birth parents struggling to take care of their own alcohol-affected children may feel discouraged and ultimately be defeated by the lack of diagnosis, counseling, tutoring, respite care, and by the need for ceaseless advocacy to achieve services for their child and to keep the family intact. On an isolated reserve, access to good health care and diagnosis is a challenge, unless the First Nations has specifically developed programs for alcohol-affected children. Frustrated aboriginal parents may surrender a child to government care so that he or she can get the medical and social help needed. Rather than stimulating a flow of funding to help First Nations take care of their own, FAS/FAE is too frequently used as another justification for separating aboriginal children from their parents and extended family.*
>
> Suzanne Fournier & Ernie Crey[3]

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[3] Fournier & Crey 1997:178-180.

The initial creation in the 1980s and 1990s by federal and some provincial governments of a "need" for FAS prevention programming targeting Aboriginal women, implied that a percentage of the children born to these women had FAS/ARBEs. Because very few children living on or off-reserve had been diagnosed it was also implied that under-diagnosis was a common problem. Aboriginal children living in impoverished families and those who are placed in foster care emerged as obvious "at-risk" groups and increasingly they have been targeted across Canada for screening and assessment for FAS/ARBEs. As indicated in the statement above by Fournier and Crey, the identification of FAS as a health problem has specific implications for Aboriginal families, and raises concern about how the needs of children with FAS can be met within local contexts where few, if any, resources exist.

As money flowed into Aboriginal communities for FAS prevention, certain community workers and parents began to demand medical assessments for children with perceived developmental or behavioral problems, and funding and supports to assist children, adolescents and adults who were alcohol-affected. A service provider from a hospital in northern Manitoba, for example, explains how diagnostic assessment generally come about with their tele-link diagnostic service[4]:

> You know they've been to a workshop [the parents] or something like that and they think that sounds like my child and they call in. And then we go through just gathering the information about their history and stuff. The doctor sees the children before they go on the tele-link and then it's determined whether it's appropriate for the link or not. We found some of the parents want the children diagnosed but there are some of the kids that are 15, 16 years old and they want no part of it. They don't have an issue with going to see the doctor but they want no part of the tele-link. Which is fine you know we can still go through the material. There's a psychologist that's involved in it and with the schools we can still do all the assessments and all of that, we just may not have the diagnosis.

Service providers in Manitoba expressed differing points of view about why so much attention is given to FAS prevention when the population of individuals diagnosed with FAS is relatively small and diagnostic assessment are difficult to obtain. An Aboriginal outreach worker suggested that FAS is a new way for non-Aboriginal social service providers to make Aboriginal women feel guilty and to undermine the women's

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[4] The tele-link is a video link to a team of FAS experts (pediatricians, geneticist) in Winnipeg who in conjunction with the physician in the northern community make the assessment.

abilities to parent their children. In discussing a client who feared that her baby was going to be apprehended by CFS, the worker stated:

> And having that threat [of having your child apprehended] hang over your head, how are you suppose to feel comfortable enough to look after your child if you know that the first move that you make, wrong move, that they're going to come and take your child away from you? But, the baby itself is, to me she's normal. But it's almost like they're looking for something to be wrong with the baby.

In a discussion with two non-Aboriginal family outreach workers who work with Aboriginal women living on and off reserve, a different type of concern was expressed about diagnostic assessments. They suggest that a high level of denial and apathy exists among Aboriginal women in northern Manitoba, especially younger mothers, about FAS and this is the reason that "affected" children are not being assessed.

Worker I: I find that a lot of the moms when they have their babies, especially when they start to get a little bit older and I really notice some facial features. They don't see it and I won't bring it up with them that they should have their child checked for FAS or FAE because they don't see that there is a problem, whereas I see real delays.

Worker II: We're seeing that in the hospital too and with some of the families that we've been working with, yes they have been diagnosed and then there's outright denial. There is nothing wrong with my child. You guys are lying.

Worker I: Ya that's what I've seen a lot of too.

Worker II: A lot of denial

Worker I: Where as I say wow is that ever a FAS face but mom doesn't see there's a problem and she doesn't bring it to anybody's attention. She's quite happy with the baby the way it is. Well what can you do then?

Worker II: Sometimes I wonder about delays. Like they're nine months old and they're not sitting yet. And they're not attempting to, or just starting to, sit and they're falling back and doing it all the time. Well, a nine month old should be able to be sitting. If that's the first step, they've rolled over already at six months or seven months is when they first roll over. Well they should be doing that at 3 or 4 months. So I see these delays. Whereas I as a parent would be bringing a child to a doctor saying, "what's wrong? Why is my child so delayed?" Whereas they're quite happy with the progress their baby is making.

Worker I: A lot of it has to do with having a first child and being very young. Not having a hot clue what developmental levels or stages are and remember the baby's there to feed the mother's need. We had one that was two years old and still not walking. Wasn't talking and the mother was force bottle feeding this child in an effort to not allow the child to grow. And her excuse was "well we just baby the baby, you know too much." And we did the developmental assessment on it and that child was more than six to nine months delayed in her major gross and fine motor development, language skills, and the mother still denies. Just begrudgingly now and again she'll say, "well yes I used during the pregnancy" or "I didn't use that much." The child has gone into care.

The type of criticism levied against mothers by the two outreach workers is characteristics of service providers—most specifically non-Aboriginal—who believe that a significant number of Aboriginal children have FAS/ARBEs and that this "fact" is masked by a lack of diagnostic assessments. As illustrated in the narrative of the two-year old child, the mother and the service provider have very different perceptions of the child's development. The service provider blames the mother's age and "poor parenting skills" and stresses the importance of pressuring the mother to "admit" that she drank during her pregnancy. The narrative also demonstrates the type of informal screening assessment for FAS that occurs, and although many service providers deny that this information is passed onto CFS, it was confirmed to me that in at least some cases, information is shared regularly back and forth between CFS and outreach agencies about particular clients.

As both the number of diagnosed, and perceived number of undiagnosed Aboriginal children with FAS/ARBEs grew, Aboriginal leaders and community workers, especially in the western and northern regions of Canada called for increased funding and services for the emerging "FAS-problem" in their communities. The federal government, western provinces and territories responded by creating several initiatives. For example, the four western provinces and three territories organized in the late 1990s into a consortium called the Prairie Northern FAS Partnership designed to support coordinated strategic action on FAS issues. Health Canada began a three-year, eleven million dollar "Fetal Alcohol Syndrome/Fetal Alcohol Effects (FAS/FAE) Initiative" in January 2001 that allocated funding for public awareness and education, training and capacity development, early identification and diagnosis, coordination, surveillance, and a strategic project fund for the creation of FAS programming where no previous activity or capacity existed. The 2001 federal budget included $25 million dollars in new funding for FAS prevention efforts on reserves.

Primary and "secondary" disabilities

In Canada, as elsewhere, the individuals typically diagnosed with FAS/ARBEs or involved as subjects in FAS research are infants and children. Only in the past five years in Canada have studies involving cohorts of adolescents and adults been completed (see, for example, Fast et al. 1999), and diagnostic assessments extended to include these patients populations. In a review of FAS research, Abel points out that there are few scientific studies, but many anecdotal observations of adolescent and adult patients with FAS/ARBEs, most of which is contradictory in its content (1998a:131). He cautions that for any age group, anecdotal evidence should be viewed critically, because, as he states, "*the plural of anecdote is not data*" (1998a:131 emphasis in text). Discussing the commonly held perceptions about FAS, Abel states:

> Adolescents with FAS have been described as irresponsible, learning impaired, impulsive, having poor judgement, lacking in inhibition and remorse, and unable to appreciate the consequences of their actions. They are also said to be prone to lying, cheating, and stealing. They continue to be garrulous, socially winsome, and often convincing, insisting that they can control their own lives. However, their conversation is often unresponsive, their winsome behavior may make them easily manipulated and victimized, and they may require constant supervision.
>
> Adolescents with FAS/ARBE are also described as being gullible and having poor problem-solving abilities. Abstract reasoning is difficult for them. Consequently, their mathematical skills are poorly developed. Related problems involve management of time and money. Keeping appointments is difficult because they do not equate clock time with the need to do something or be somewhere. Saving money for a future purchase is too abstract a concept for them to understand it well. Normal functioning is said to be possible for them only in highly structured situations (Morse & Weiner 1996).
>
> Although there is little doubt that intellectual functioning continues to be impaired in people with FAS…conduct disorder should not be taken for granted as characteristic of in utero alcohol exposure. People with FAS/ARBE are more likely to be victims than victimizers. There is much stronger evidence that conduct disorders are related to early postnatal neglect and abuse rather than prenatal neglect and abuse…and there is still reason to expect that cognitive functioning improves with age, depending on the initial cognitive damage…the chances of improvement depend on a combination of the extent of neurological damage and home environment. The potential influence of the latter also depends on the age at which a child is placed into an enriching environment (1998a:131-132).

Recently, signs of alcohol-related pathology have been closely associated in adolescent and adult populations to what are termed “secondary disabilities” (see for example, Conry & Fast 2000, Fast et al. 1999, Streissguth et al. 1997). “Secondary disabilities” include, mental health problems, disrupted school experience (suspended, expelled, or dropped out), trouble with the law, confinement (inpatient treatment for mental health, addiction problems or incarceration), inappropriate sexual behavior, and alcohol/drug problems (Streissguth et al 1997:34). This set of “disabilities” are believed to arise from the interaction between primary disabilities, especially neurodevelopmental anomalies, and negative environmental influences. Living in an unstable home environment, multiple foster placements, being a victim of child abuse/neglect, not being diagnosed before six years of age, and not receiving special health, social and educational services are identified as risk factors that magnify the severity of primary disabilities in alcohol-affected persons (Streissguth et al. 1997).

In the past five years, the correlation between the diagnosis FAS/ARBEs (primary disabilities) and a number of “secondary disabilities” has gained significant prominence in FAS research and intervention programming (Streissguth & Kanter 1997 Szabo 2000). For the most part, concerns such as those raised by Abel, have been ignored and instead researchers, medical and social service professionals, and the general public have found the argument that FAS/ARBEs is a root cause that contributes significantly to a number of social problems, not only compelling, but very convincing.

The rate of “secondary disabilities” found among persons with FAS/ARBEs is believed to be high and especially exaggerated in the population of alcohol-affected individuals who have not been medically assessed and targeted for support services (Streissguth et al. 1997). Not surprisingly, FAS researchers such as pediatrician, Christine Loock and child psychologists Julianne Conry and Diane Fast turned their attention to juvenile detention centers, prison populations and to marginalized women, especially those who are “street-involved,” to find populations of alcohol-affected adolescents and adults (see, for example Fast et al. 1999, see also, Chapter Thirteen). As they and others anticipated, an over-representation of Aboriginal people who fit into the emerging adolescent and adult FAS/ARBE profile were found.

As stated earlier, a general consensus exists that most people with FAS/ARBEs are not diagnosed and the actual prevalence rate of FAS/ARBEs is much higher than currently estimated. What this suggests to some, is that if more individuals with FAS/ARBEs are diagnosed then significantly more of our social problems, especially those among Aboriginal groups, would be explained by prenatal alcohol exposure. It also implies that interventions, particularly preventative strategies, could be designed for affected individuals and populations in order to diminish their aberrant behavior.

However, despite a consensus among some scientific researchers and lay advocacy groups that FAS/ARBEs is a root cause that significantly contributes to social problems in our society, only a few studies have actually examined "secondary disabilities" (see, for example, LaDue et al. 1992, Streissguth et al. 1997). Of those that have, each has failed to use control groups to factor in variables such as the stability of home environments, and ethnic and socioeconomic backgrounds (Abel 1998a:134).

The most commonly cited research on "secondary disabilities" is part of a longitudinal study by Streissguth and colleagues (1997). They found that in a cohort (n=415[5]) of individuals diagnosed with FAS or FAE, 94% (n=415) experienced mental health problems[6], 60% (n=253[7]) had been in trouble with the law, 60% (n=253) had a disruptive school experience, 50% had been confined[8], 50% (n=253) had exhibited inappropriate sexual behavior[9], and 30% (n=253) had drug or alcohol problems[10]. Although the study raises several important issues about the life experiences of persons with FAS/ARBEs, the results are based on a single cohort of individuals and lacks a comparative control group. The researchers also point out that the correlation between FAS/FAE and "secondary disabilities" reported in the study, "may or may not be

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[5] ages ranged from 6 to 51 years of age

[6] Mental health problems were defined as "ever having gone to a psychotherapist or counselor for a mental health problem or having any one of a long list of mental health problems" (Streissguth et al. 1997:33).

[7] Ages ranged from 12-51 years of age.

[8] Confinement included "inpatient treatment for mental health problems or alcohol/drug problems, or ever having been incarcerated for a crime" (Streissguth et al 1997:34). The authors indicate that this is also an approximate percentage.

[9] Inappropriate sexual behavior included "having been reported to have repeated problems with one or more of 10 inappropriate sexual behaviors or ever having been sentenced to a sexual offenders' treatment program" (Streissguth 1997:34).

[10] Drug/Alcohol problems were defined as having been in treatment for an alcohol or drug problem or as having alcohol and/or drug problems" (self-identified) (Streissguth et al 1997:34).

causative" (Streissguth et al. 1997:37).

"**Secondary disabilities" and public health campaigns**

> *I don't know about you, but, I get really angry when I think about the fact that we are sacrificing kids to a life of anger and maladjustment, to potential violence, to potential criminal conduct and a life of incarceration—in and out of jails—when in fact, fetal alcohol syndrome is completely preventable.*
>
> The Honourable Anne McLellan,
> Minister of Justice[11], October 16, 1999

Despite the methodological problems inherent in Streissguth's study, it is commonly referred to in public health information as a typical profile of adolescents and adults who are alcohol-affected. Referral to the study in public health education is largely for the purpose of emphasizing to pregnant women the causative relationship between their alcohol use and a set of health and social problems in alcohol-exposed offspring, and to draw attention to the lack of specialized services for persons who are alcohol-affected.

An example of how Streissguth's study is used as a reference point in Canadian FAS prevention campaigns is illustrated in information that is included in the "Drink Smart Canada" poster prevention program (see Table 12.1). The creator of the campaign is Member of Parliament, Paul Szabo. In his monograph, "Fetal Alcohol Syndrome—The Real Brain Drain," Szabo emphasizes the problem of "secondary disabilities," particularly among populations where under-diagnosis is believed to be common such as adolescents and adults, and among affected persons who do not have the full-blown syndrome. For example, he states that twenty-percent more men with FAE experience trouble with the law as compared to men with FAS (2000:25-26). Szabo also refers in his monograph to a Saskatchewan study that found "nearly 50% of young offenders had been born with FAS," and to a Manitoba study that found "over 50% of the young people in detention suffer from some degree of FAS" (Szabo 2000:26). In both cases, Szabo does not provide the names of the study's author(s), nor the study's citation[12]. In a library

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[11] Quoted in Szabo (2000.) Anne McLellan is currently Minister of Health for the Federal Canadian government.

[12] It is likely that Szabo is not referring to a study but to a statement made by Jo Nanson, a Saskatchewan researcher in which she tells a journalist that she thinks half the young offenders in Saskatchewan are alcohol-affected.

search of the FAS literature, I could not locate either of the studies nor corresponding statistics[13]. Research findings that are so startling, especially in light of virtually no research existing on "secondary disabilities" in Canada, would, without doubt, draw the attention of FAS researchers and the medical community. However, during my extensive search of the FAS literature—published and non-published—I did not come across either study, nor did I hear any comments made about the study findings, for example at FAS conferences, workshops or meetings.

The "Drink Smart Canada" campaign is an example of the ways in which a limited body of research—in this case, a single study—is exaggerated to the level of being representative of all persons with FAS/ARBEs. Further, within a context where adolescents and adults are generally not assessed medically for FAS/ARBEs, a situation arises whereby the existence of a population is assumed, and because those who belong to this population are also conceptualized as being largely undiagnosed, the population is also perceived to be at greater risk for "secondary disabilities." As indicated in Table 12.1 public health information is purposely exaggerated in some cases in order to impress upon the audience the seriousness of the problem. For example, rather than FAS being identified by Szabo as the leading known cause of preventable mental retardation as is suggested by some scientific researchers, FAS is presented as the leading cause of all mental retardation, and the "characteristic facial features" are described as "facial malformations" indicating that they are easily recognizable and that they add to the person's disability in some way.

Table 12.1
CANADIAN STATISTICS[14]

Consumption of alcohol during pregnancy is the leading known cause of mental retardation.

For every 10,000 child births, 20 have Fetal Alcohol Syndrome (FAS) and 100 have other alcohol-related birth defects.

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[13] I contacted Mr. Szabo's office by e-mail for the references but did not receive a response to my request.

[14] The "Drink Smart Canada" education and awareness campaign was created by Paul Szabo who is the Member of Parliament for Mississauga South and involved the creation of two posters, a monograph, "Fetal Alcohol Syndrome—The Real Brain Drain" (2000), and website information. The information above, came from one of the posters in the campaign and was reprinted in a 2001 calendar agenda created by the Commission de la santé et des services sociaux des premières nations du québec et du labrador as a education and awareness tool to inform Aboriginal communities in Quebec about FAS/ARBEs.

FAS includes, brain and facial malformations, behaviour dysfunction and learning disabilities.

FAS is incurable and tragic for its victims:

- 60% will be suspended or drop out of school
- 60% will get in trouble with the law
- 50% will go to jail or be put in an institution
- 30% will become abusers of drugs and alcohol
- 80% will never be able to live independently
- 80% will have problems with employment

Alcohol can harm an unborn child at any time with the first trimester being the most vulnerable.

"Binge" drinking (more than 4 drinks on one occasion) causes the most devastating effects.

Facial features are substantially formed between days 15 and 22 of pregnancy.

There is no recommended safe level of alcohol consumption during pregnancy.

Creating individuals and populations

In Canada, medical practitioners and social service providers will generally describe the "typical" adolescent or adult with FAS/E along the lines of the anecdotal descriptions discussed above by Abel. As Abel observes, the descriptions are not necessarily consistent and at times are even contradictory. There is, however, a general consensus that prenatal alcohol-affected individuals "typically" experience most, if not all, of the "secondary disabilities" listed above. Gender differences related to "primary" and "secondary" disabilities are increasingly factored into the profile of the "typical" adolescent and adult with FAS/E, with males being associated with violent and criminal behavior (see, for example, Szabo 2000) and females with promiscuity and multiple pregnancies (see, for example, Streissguth 1997, see, also Chapter Thirteen). While the Canadian perception of the "typical" adolescent or adult with FAS is not unlike that found in the Unites States, there is, however, one significant difference. The "typical" adolescent or adult who is alcohol-affected is, in Canada, believed to be someone who is also "typically" Aboriginal[15].

"Speaking Plainly" about " harsh realities"

To further examine understandings in Canada of "secondary disabilities," I return to Abel's description of the "typical" characteristics that are associated with adolescents with FAS. I compare the characteristic profile to two newspaper accounts, one that focuses on First Nation reserve populations and the other that focuses on persons with FAS.

In a newspaper article by journalist Ric Dophin published in the Calgary Herald, June 11, 2002, entitled, "No Simple Solutions to Native Problems," he describes First Nation reserves in Canada as "nests of hopelessness." Dophin writes,

> Treaty Indians receive billions of dollars a year in aid; their food, housing, university, college and medicine is free; they pay no taxes; they can hunt and fish whenever they want to: and they are accorded special treatment by the courts, the schools and employers. Despite all of this largesse—okay, probably because of it—their society is a shambles. Rates of addiction to alcohol, cocaine, gambling, glue are eight to 10 times the norm. Birthrates, encouraged by child welfare benefits, are three times the non-Indian level and the progeny are typically fathered by several men, usually absent. A disproportionate number of native children are born with fetal alcohol syndrome, a condition that predisposes them to not working or to the drug-oriented criminal world. The number of Indian youth in criminal gangs, at least in the gang-central city of Winnipeg, increases by 20 per cent a year. Unemployment in the native population everywhere hovers between 60 and 80 per cent. And although they constitute only six percent of the general population, Indians account for 43 per cent of the social work caseload and 50 per cent of the prison population…A Chinese-Canadian friend of mine in Edmonton, whose parents suffered discrimination similar to that of their native contemporaries, nonetheless managed to rise from dishwasher to multimillionaire restauranteur. He hunts and fishes with some of his friends from the nearby Enoch band, a once oil-rich community that squandered its royalties and now believes that a subsidized casino is its ticket to prosperity. The restauranteur has been approached to invest, but says he would never do business with the natives. "They have no concept of what money is," he says. "It's always been something that they've had given to them, with no risk or effort. Getting it, losing it, what does it matter? They're not getting any of my money" (2002).

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[15] I am not suggesting that only persons who are Aboriginal are diagnosed with FAS/ARBEs in Canada as non-Aboriginal people have also been diagnosed. Rather, I am arguing that the "typical" profile of the person with FAS/ARBEs and of populations where FAS is widespread, has been strongly associated in Canada with a number of factors, including social problems, that are commonly found in Aboriginal populations.

The second article is written by award winning journalist, Margaret Wente, entitled "Finally, we're talking about FAS," which was published in *The Globe and Mail*, one of Canada's two national newspapers, on February 1, 2001. Wente writes:

> There were plenty of good intentions expressed in Adrienne Clarkson's Speech from the Throne. There was one that nobody with a heart should forget. "This syndrome" is fetal alcohol syndrome, the most devastating childhood epidemic in Canada today. FAS (and its less visible companion, fetal alcohol effect) cause significant, irreversible brain damage. Thousands of babies every year are poisoned in the womb by alcohol, and far too many of them are native. They're born without a chance.
>
> You've seen lots of kids with FAS and FAE. They are the giggling, howling, glue-sniffing ghost children from Sheshatshiu who so shocked the nation that the Governor-General herself paid a visit to their ruined community. Some of them, sadly, may grow up to be like David Trott, whose picture you may have also seen. He's awaiting trial for impulsively strangling a nine-year-old girl in B.C.….FAS and FAE are six times more common in Canada than AIDS. They are the leading known cause of mental retardation. And they are the common denominator for many of the plagues of native communities. Alcohol-damaged kids have poor impulse control, significant learning disabilities, and impaired judgement. Under the best of circumstances, they have terrible trouble in school. Even if they never drink themselves, their difficulties are lifelong. As they get older, their sexual behaviour is also impulsive. Among native communities, rates of child sexual abuse and teenage pregnancy are very high. Heavy drinking (and its effects) are responsible…FAS and FAE are the main reason there are so many native men in jail. Even if they don't drink themselves, they're brain damaged because their mothers drank. (Some experts say that up to half the prison population is so afflicted.) Another of the Throne Speech's worthy goals is to reduce the high rate of native incarceration. That won't happen until the connection between criminal behaviour and FAS is far better recognized…But the facts about our most vulnerable citizens ought to break your heart. There are around 300,000 aboriginal kids in Canada under the age of 15 (and high birth rates mean the numbers are soaring). The guesses about the prevalence of FAS and FAE in native communities go as high as 40 per cent. At one Ojibwa school in Manitoba, the teachers found that 30 per cent of the mothers there admitted to drinking heavily during their pregnancies. FAS is a national tragedy. It can't be cured, only prevented. No matter how painful it may be to speak about it, we must speak plainly until it is.

In comparing the two articles, what emerges is a circular argument in which the "typical" reserve community resembles the "typical" population of persons with FAS/ARBEs, and vice versa. For example, themes of irresponsibility and poor judgment similarly thread their way through the two articles and mirror Abel's discussion of profiles describing the "typical" adolescent with FAS. References to poor problem-solving abilities, difficulties with abstract reasoning, money and time management, an inability to appreciate the consequences of one's actions, and a "misperceived" notion on the part of Aboriginal leaders/communities and of persons with FAS, that they can successfully control their own lives, are made in the articles. Typical "secondary disabilities"—trouble with the law, drug and alcohol problems, incarceration, difficulties in school, and inappropriate sexual behavior such as promiscuity—are also themes raised in both articles, as are other "social problems/secondary disabilities," such as chronic unemployment, teen pregnancies, high birth rates, and violent behavior.

An added dimension in the articles is the way in which both journalists imply that they are writing from a position of social responsibility. By claiming to "speak plainly" they use their positions as journalists to spew a diatribe of racist stereotypes that suggests that the contribution of Aboriginal peoples to Canadian society, both now and in the past, has been negligible, and in fact, Aboriginal peoples are nothing more than a bio-underclass who mistakenly believe they can direct their own futures.

Our "Native Son:" an ethnographic account of "secondary disabilities"

> *[FAS] has wreaked havoc in some of Canada's most prominent families, including Jean Chrétien, whose adopted son, Michel, has been in and out of prison. Michel's history of assault, learning problems, and addiction is textbook illustration of fetal alcohol damage. And yet adoptive families everywhere are still being told their children were ruined by a cultural identity crisis.*
>
> Margaret Wente
> "Our poor ruined babies: the hidden epidemic"
> *The Globe and Mail*, Saturday, October 7, 2000

> *Prime Minister Chrétien's official statements have never used the words "fetal alcohol" as a possible factor in his son's lifelong problems. But Michel's aboriginal background, the fact that he was adopted from an orphanage, and his history of addiction and trouble with the law are factors associated with FASD [fetal alcohol spectrum disorder]. We hope that his lawyer will insist he see an expert diagnostician. If Michel Chrétien is found guilty, and is indeed struggling with fetal-alcohol damage, this could result in more appropriate sentencing and ways of helping him control his impulses.*
>
> Bonnie Buxton
> Co-founder of International FAS Awareness Day (September 9th)
> "Coping with fetal-alcohol disorder"
> *The Gazette*, Montreal, Sunday August 11, 2002

Michel Chrétien, for no other reasons than the fact that he is Aboriginal, the adoptive son of the Prime Minister, and has developed a pattern of recidivism, has become the person Canadians most associate with the diagnosis FAS. His "diagnosis," made by journalists, particularly Margaret Wente, and supported by parent advocates such as Bonnie Buxton, has little to do with Chrétien himself, and more with illustrating to Canadians that when present, FAS can defy the love and support found even in the most "prominent" families and environmental conditions. Newspaper articles generally praise the Prime Minister and his wife, Aline for their commitment to their son, even in light of his ongoing problems with drug and alcohol abuse and violent behavior. Newspaper articles consistently stress how differently Michel has turned out in comparison to the Chrétien's biological children, and use this as further "diagnostic" evidence that Michel is alcohol-affected.

In the remainder of this chapter I explore how recidivism, and more broadly, adult profiles such as the one typically given of Michel Chrétien by newspaper journalists are increasingly invoked as a sign of undiagnosed alcohol-related pathology. I do so in order to illustrate the fluidity of the category FAS, especially the ways in which perceptions of it are manipulated in order to imply high prevalence rates in a context where prevalence rates are unknown.

The workshop

During a workshop in February 2001, entitled, *Fetal Alcohol Syndrome and the Legal System*, Christine Loock presented a slide of two autopsied infant brains to an audience in Vancouver made up of health and social service providers, and government and community representatives from across Canada. The much larger "normal" brain, full of detail conspicuously overshadowed the smaller smooth mass beside it. The photograph, one commonly shown at presentations on FAS, was believed by Loock to need no explanation. The pathology was clear. The crowd stared at the image as she announced: "this *is* FAS".

However, as quickly as the powerful image taught the audience what FAS *is*, we were told that patients with FAS do not actually have brains like this, they do not die as infants, but instead their brains can, and most often are, structurally indistinct from the "normal" brain. So where then, according to Loock does the pathology lie? The pathology lies, she explains, not necessarily in the structure of the brain but in the way it functions. Pathology is not identified by seeing, that being why CT (computed tomography) scans and MR (magnetic resonance) images have been relatively unsuccessful in identifying individuals with FAS. Rather, she explains, pathology is performed, and it is the interpretation of this performance, of the "brain in action" (Dumont 2000:219), which directs clinicians like herself to FAS.

Later in her presentation, Loock tells the audience that people who suffer from brain damage caused by prenatal alcohol exposure are common in our society. FAS knows no boundaries, it effects everyone because, "whether we realize it or not, we all know someone who is effected." Loock explains that the person with FAS could be a friend, our own child, or even ourselves, however, the majority of affected individuals, she states, go about their lives undetected by the medical field. This, she quickly adds, does not mean that persons with FAS do not show up in other places. In fact, the complete opposite is true. They show up throughout society, in foster care after being apprehended from their alcoholic mothers, in our school systems when they disrupt classrooms and cannot learn, in our homes when they cannot remember to follow the rules, and in our criminal justice system when they break the law.

Earlier I suggested medical researchers and clinicians are increasingly re-conceptualizing brain damage caused by prenatal alcohol exposure as performative in nature. This refers to a belief that functional brain abnormalities produce certain behaviors which when undiagnosed would be viewed by society as inappropriate, and in some cases deviant or criminal. Performance in this regard has a dual meaning. One, it refers to how well the brain is perceived to be functioning, how well it is or is not performing the tasks it is meant to perform. Second, it refers to a belief by researchers and others, that individuals who have brain damage caused by prenatal alcohol exposure are scripted very stringently into a unique pattern of behaviors that *are* FAS/E.

Primary impairments as discussed previously, include impulsiveness, attention deficits, trouble understanding consequences, difficulty sorting out cause and effect, short and long term memory problems, and poor judgement (Streissguth 1997). While individually none of these are unique to FAS, it is how they collectively manifest in an individual's behavior that is believed to be important. Some clinicians, such as Loock, argue that this collective manifestations of pathology specifically places individuals with FAS/E at increased risk of getting in trouble with the law, which is now medicalized as a "secondary disabilities" of FAS/E. For example, Streissguth writes,

> Criminality is not a typical behavior profile for people with Down syndrome…and intentional premeditated criminal activity is not characteristic of people with FAS/FAE…despite their high rates of trouble with the law. Many seem to slip into trouble with the law as a result of their maladaptive behaviors…When they have time on their hands due to unstructured days, disrupted schooling, poor family supervision, and unhealthy peer groups, and compound their problems with judgement with the use of alcohol and other drugs, they are more likely to get into trouble with the law (1997:239).

Loock and her colleagues at the University of British Columbia argue that the pathology of FAS "performs" throughout a person's lifetime, and clinicians experienced in interpreting this performance can easily identify who is or is not FAS. For example during the workshop, Julianne Conry, a colleague of Loock's suggested that by picking clues out of newspaper accounts of specific criminal acts, she could distinguish if the criminal had FAS/E. However exaggerated, this claim reflects a perception that certain FAS experts want service providers and the general public to internalize—that despite general diagnostic inconsistency, some clinicians have developed a level of expertise that has allowed them to analyze diagnosed cases of FAS/E—in all their complexity and difference—and come up with a "natural script" that is unique to alcohol-related pathology (see, also Streissguth 1997).

In the case of criminal behavior, this claim also hinges on professionals such as judges, lawyers, prison officials, and guards, "correctly" re-interpreting criminal behavior and rehabilitation of individuals believed to "suffer" from FAS/E in a medical-disability, rather than social, framework. While other factors, such as the physical phenotype and confirmed maternal alcohol exposure remain important, they are no longer necessary to identify all cases of FAS/E. This is important given the growing belief that persons with FAE who have IQs close to or within the "normal" range, and not the facial phenotype—those affected individuals who appear to be "normal"—are at far greater risk of getting in trouble with the law than those with the full-blown syndrome (Conry & Fast 2000, Fast et al. 1999, Streissguth 1997)

Criminal behavior in Canada is increasingly linked to maternal alcohol exposure. In an interview for *The Fifth Estate*, Judge Barry Stuart of the Yukon Territorial Court stated: “however pervasive it is now, as generations and new generations of FAS children come through the system, it’s going to become worse to the point that I think that we won’t be able to function effectively.” Recidivism is a central theme in this growing concern as later stated by Judge Stuart: “We have very high criminal statistics in the Yukon and one wonders why. Most of them are recidivists. And so, despite the heroic efforts of many people in the system to try to get these people back into a positive style of life, they keep coming back before the Court” (quoted in Conry & Fast 2000:94).

FAS as an explanatory framework for recidivism fills in a gap where no explanation previously existed, that being the overrepresentation of Aboriginal men in Canadian jails and prisons. Despite the deterrent of incarceration, recidivism is high among these offenders (Motiuk & Nafekh 2000:14), an indication that some believe is typical of persons with FAS. For example, UBC psychologists Julianne Conry and Diane Fast write,

> …traditional jail sentences have been found to be counter-productive as a means of rehabilitation or reduction of recidivism. Those with FAS/FAE do not understand or anticipate the consequences of their actions, and do not learn the expected lessons from custodial or other sentences (Conry & Fast 2000:104).

Similar sentiments were expressed by Jo Nanson, a Saskatchewan clinician, who predicted half the young offenders, the large majority of whom are Aboriginal, appearing in Saskatchewan provincial court are there because of alcohol-related pathology. She argues that FAS is common, and many individuals move undiagnosed through the criminal justice system. Given the “nature” of their affliction, she states, they often re-offend: “They are very impulsive and do things that are not well thought out, and they get into significant difficulty from that…The malicious intent is seldom there. I find they’re exploited by more talented criminals to do some of the running, if you like, and they’re more likely to get caught” (Nanson quoted in Zakreski 1998).

Risk of recidivism among adults has been directly linked to behavioral problems that are associated with children who have FAS such as impulsiveness and trouble understanding consequences. In arguments claiming that recidivism is a “secondary disability” of FAS, a contrived context of child-parent interaction in which the child receives support, understanding, and love—a context without risk—but where pathology nonetheless manifests in behavioral problems is invoked. This is then compared to problems that these children are believed to have later in life with the law in which perceived alcohol-related pathology becomes the common denominator of both childhood and adult misbehavior; Michel Chrétien being the most commonly used example. Chrétien is portrayed as being raised in a risk-free environment but nevertheless had behavioral problems as a child, and the circumstances leading up to his adoption are minimized. Despite the benefits he gains from being the Prime Minister's son, he is portrayed as failing to take advantage of this because of alcohol-related pathology, and his violent behavior and recidivism is attributed to his biological mother's presumed abuse of alcohol.

The argument that is made is that while the context changes and the person ages the pathology continues to perform over the life-span. For example, in her presentation to workshop participants, Conry stated:

> Many children as they grow-up respond to adult approval and praise. FAS children…don't seem to respond in the same way…they are seen as stubborn and non-compliant. The result is that as they get older they may not respond to social sanctions in the same way, they are not worried about breaking the law, so this becomes problematic when trying to change their behavior. They ignore verbal limit setting and they are very impulsive. This decreases the effectiveness of social sanctions, such as being held in youth protection, as they come out and do the same thing, therefore the sanctions do not seem to work in the same way (2001 presentation).

As stated earlier by Abel, many characteristics attributed to adolescents and adults with FAS come from anecdotal accounts based on a very small number of persons who are diagnosed, many of whom were raised in very disruptive home environments. This is also true about accounts of recidivism found among persons diagnosed or labeled with FAS.

In explaining recidivism, researchers invoke prenatal alcohol effects to explain behavior that on the surface appears to be illogical and undesirable to a "normal" person. Recidivism is then used as a marker of FAS pathology not only of individual offenders, but for a particular population of offenders, Aboriginal men. While most of us would agree that returning to jail is an undesirable fate, to decontexualize this behavior and to individualize and pathologize it as simply a consequence of FAS, fails to give any weight and consideration to other mitigating factors (Lock 1998:12). It is with this in mind that I introduce James.

James

When I met James he was in his late twenties, and had just completed a six-month prison term. James is of First Nation ancestry, and told me that as a child he was diagnosed with FAS. He currently lacks any of the physical phenotypic features, and does not remember ever accessing specialized services or taking medication because of his diagnosis. James' childhood was very tumultuous and he spent most of it being moved in and out of different group and foster homes. He dropped out of school in the ninth grade after being placed in a special education class. By this time he was already using drugs and alcohol on a daily basis.

As with most foster children, once James reached legal age he was not allowed to stay with his foster family. He had no transitional support out of foster care and basically was left to fend for himself. He started getting in trouble with the law before leaving foster care and since then has been in and out of jail for minor offences. This he links to a number of factors.

> “When you’re locked up I guess you become a better criminal because you’re surrounded by it, you get ideas, you hear other people talk about how they did their stuff and that…but I guess for a lot of people like us Indians it becomes, like part of our lives because you have uncles, aunts, cousins locked up in there, and then you go and you have family among you, it becomes part of your life…like my younger brother, before I got sentenced he said ‘well, its about time you went back to jail.’ For them it is kind of like respectable to go to jail.”

James was living with his girlfriend, Marie, in a run-down hotel room in a region of Winnipeg that is known for drugs, prostitution, violence, and poverty. Neither could conceive of how their situation would improve in the near future. When I asked James about what he planned to do now that he was out of prison, he explained:

> “When I got released they said, ‘here’s your money. There’ll always be a place when you decide to come back.’ That was it. Getting a job because I have a criminal record is pretty hard. Getting welfare is hard because I’ve been incarcerated…They expect I won’t be out too long and I’ll be back in.”

James was supporting himself by “scheming,” which basically meant stealing money and other things he could pawn or sell on the street. He had no other income and felt his best strategy was to stay out of the vision of the police, or anyone who could report him. However, he fully expected to end up back in jail in the next year or two unless he and Marie could find a way to move to her home reserve. Outside of his relationship with Marie, all his friends and relatives were heavily involved in drinking alcohol or sniffing inhalants. Even though he had been to a number of addiction treatment programs, once back in his neighborhood he quickly fell back into using.

Kleinman, Das and Lock argue that "what we represent and how we represent it prefigures what we will, or will not, do to intervene. What is not pictured is not real. Much of routinized misery is invisible; much that is made visible is not ordinary or routine" (1997:xiii). In Canada, Aboriginal inmates, in general, experience the "secondary disabilities" attributed to FAS/E such as mental health problems, disrupted school experiences, trouble with the law, confinement, inappropriate sexual behavior, drug and alcohol problems, and victimization at alarming rates (Tait 2003). Further, Aboriginal inmates, in general, have fewer childhood "protective factors" that are believed to prevent individuals, whether they have FAS/E or not, from coming in contact with the criminal justice system such as: living in a stable and nurturing home environment, not having frequent changes of household, and not being a victim of violence. Because of this, it has been relatively easy for FAS experts such as Loock and Conry, to re-conceptualize this complex array of factors in terms of a medical framework of primary and secondary disabilities influenced by risk and protective factors. In this circular argument these factors then become warning signs of the performance of an underlying pathology, creating a population of FAS/E persons without confirmation of individual diagnostic assessments. As stated previously, this re-conceptualization has entered more public arenas, particularly the media, where eager journalists are willing to take leaps of faith where little evidence exists.

Conclusion

The challenges faced by Aboriginal and non-Aboriginal service providers in trying to address the needs of communities and individuals who live in chronic poverty, endemic social and family dysfunction, and who experience a myriad of health and social problems is enormous. As discussed in Section Three, processes of colonization systematically undermined the social and family structures in Aboriginal communities, marginalized Aboriginal peoples within the larger society, and left a legacy of poor health and educational training within the general Aboriginal population. It is of no surprise given this context, that a great deal of time and resources are needed to rebuild Aboriginal families and communities. Central to this is a necessary commitment on the part of the larger society to the full and equal participation of Aboriginal peoples in Canadian society.

In this context, the diagnostic category FAS not only provides a medicalized framework to explain undesirable behavior by individuals and collective dysfunction in Aboriginal communities, but it also provides hope for a better future that is perceived to be obtainable through straightforward changes in behavior—that being the refraining by pregnant women from alcohol use. Significant gains will be made, according to many Aboriginal and non-Aboriginal health and social service providers involved in FAS prevention, specifically a reduction in the range of social problems/”secondary disabilities” attributed to alcohol-related pathology. This is supported by a general perception that prevalence rate of one in five individuals being alcohol-affected is common in many Aboriginal communities.

However, as FAS becomes an explanatory framework to account for social dysfunction, past colonial and neo-colonial processes, and on-going systemic racism and marginalization of Aboriginal peoples is masked, and the source of “Indian problems” to an increasing degree is situated on the backs of Aboriginal women who are led to believe that they have physiologically damaged the brains of large numbers of their children due to their alcohol use. Further, although certain Aboriginal communities may have higher prevalence rates of FAS due to endemic alcohol abuse, the rates that are commonly attributed to Aboriginal populations are unsubstantiated by scientific research.

Chapter Thirteen
SIMMERING OUTRAGE DURING AN "EPIDEMIC" OF FETAL ALCOHOL SYNDROME

Introduction

Within Canada, especially in the western and northern regions, non-medical labeling (by ones self or by someone else) of persons with FAS/ARBEs has become a common practice in some local settings, as has the identification of "high risk" local populations. As stated previously, community workers have been much quicker than physicians to embrace the category of FAS/ARBEs as an explanation for certain realities they see among the lives of the clients or communities they serve (see for example, Continuing Education in the Health Sciences 1998). Their willingness to do so is supported by the creation of government prevention programs, as the creation of these programs implies that a population of affected individuals exists. Further, the information that has been given to community workers by governments and educators in areas of FAS diagnostic assessment and outreach training, such as a language of "epidemic" prevalence rates and "secondary" disabilities, is easily mapped onto the bodies and behavior of marginalized groups, most particularly Aboriginal communities.

In this chapter I present a narrative account that describes a workshop that I attended in Vancouver, British Columbia, at the end of my field research. In this narrative I examine how the perception of an "epidemic" of FAS/ARBEs in Aboriginal communities is mapped onto knowledge and practices attached to "risk" and "prevention," and to the surveillance and "predetection" of "at-risk" populations of Aboriginal women. Central within this account is the practice of non-medical labeling of Aboriginal women with FAS/ARBEs, and how, with the creation of this new population of "FAS persons," prevention strategies targeting Aboriginal women have expanded beyond simply preventing pregnant women from drinking alcohol.

As a hypothesis emerged in the late 1990s within medical and lay arenas that high numbers of Aboriginal women with FAS/ARBEs were giving birth to epidemic numbers of babies with FAS/ARBEs, so too, did arguments grounded in moral, medical, and social justification for "preventing" these women from giving birth to more babies. Underlying these strategies, as will be illustrated in the following discussion, is the belief that to successfully prevent FAS/ARBEs in Aboriginal populations, fertility rates in reserve and urban ghetto communities need to be dramatically curbed. As illustrated in previous chapters, older women with chronic alcohol addictions are the women who are at highest risk for having an alcohol-affected child, and teenagers and young adult women are groups whose risk has been determined to be minimal, especially in the absence of chronic binge drinking patterns. Despite this, Aboriginal teenagers and young adult women are the central target groups where contraception is introduced as a form of FAS prevention.

Anthropologists Faye Ginsburg and Rayna Rapp argue that local reproductive relations are both constituted by and resistant to more global forms of power. They see the “politics of reproduction” as “synthesizing these two perspectives—the local and the global—by examining the multiple levels on which reproductive practices, policies, and politics, so often depend” (1991:313). Ginsburg and Rapp employ the concept “stratified reproduction”—the critical examination of the means by which some categories of people are empowered to nurture and reproduce, while others are not. To this end, they ask, “Who defines the body of the nation into which the next generation is recruited? Who is considered to be in that national body, who is out of it?” (Ginsburg & Rapp 1995b:3). The concept of stratified reproduction helps to illuminate these arrangements “by which some reproductive futures are valued while others are despised” (Ginsburg & Rapp 1995b:3).

In the this chapter I further examine how the practice of non-medical labeling of persons as having FAS is not limited to the local context but has entered into the arena of research. I refer specifically to a study that one of the workshop participants refers to as a project that will add to knowledge about the lives of persons with FAS/ARBEs, even though none of the study participants are diagnosed and all are Aboriginal. As will be illustrated by the example of the Vancouver workshop, various competing understandings of FAS exist, including my own, all of which contribute to the discursive arena in Canada attached to diagnostic category FAS.

Garden Therapy

Looking out of the plane window at the lights of Montreal, I felt relieved to be coming home. Even though I had only been away from home for a week it felt much longer and I looked forward to seeing my husband, Adil, and our son, Skender. I also hoped that returning home would lessen the unease that I felt as a result of the meeting I had just attended in Vancouver that aimed to provide direction for research initiatives concerning pregnancy and substance abuse to the newly formed Canadian Institute for Gender and Health Research (IGH). This latest trip to Vancouver also marked the end of my doctoral field research on FAS and I felt a sense of urgency in light of the past few days to reexamine some of my writing, and as quickly as possible produce a written critique of what I now saw to be a blanket acceptance across Canada, that in many Aboriginal communities, FAS is a health and social problem of epidemic proportions. It was with this in mind that I arrived at Dorval airport, hopped in a taxi and headed home.

The next morning I was awoken by Skender jumping on the bed shouting "mommy, mommy!" The night before he was sound asleep when I gave him a hug and kiss, and it was only after Adil placed him on our bed the next morning that he realized that I was home. We had breakfast together and by 7:30, Adil was on his way to drop Skender off at daycare before going to work. Still feeling the effects of the Vancouver meeting I decided to retreat to the garden for the morning to see if that would help me to reconcile my thoughts on what had transpired during the two-day workshop.

"Garden therapy," as I have come to call it, has served me well, as it is in the garden that I am often able to piece together and analyze my work on FAS and to sort through my own personal biases, assumptions, and concerns that arise as I straddle my role as researcher/academic and my ingrained tendencies as a community activist to be critical of everything that is said and written about Canadian Aboriginal peoples. However, unlike other days of digging and pulling weeds while deep in thought, today I felt particularly worried, concerned and even alone. Why did it feel as though I was the only one at the meeting who felt outraged by the lack of critical reflection by the provincial and federal governments who pour thousands, sometimes millions, of dollars into programs for FAS,[1] when very few individuals have actually been assessed or diagnosed with the illness, and so much uncertainty remains as to the actual rates of

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[1] The use of the term fetal alcohol syndrome (FAS) in relation to the Vancouver workshop should be understood to include FAS and other alcohol-related birth effects. At the beginning of the workshop the organizers announced that the use of the term FAS would imply both FAS and FAE, which would make it easier for workshop discussants.

effected individuals? Why was it that my outrage appeared to be met, at best, by limited concern, and, at worst, dismissed out of hand by other participants? How was I to interpret the silence by some participants whom I knew had knowledge of the research literature on FAS, including the gaps and the numerous methodological problems associated with it, but who chose to stay silent rather than to support my concerns? Why did they not at least support my call for critical evaluation of government programming and for an examination of non-medical labeling by service providers of Aboriginal mothers and their offspring as being alcohol-affected[2]?

As these questions occupied my thoughts, I could not help but think how lucky it was that Lucille Bruce had attended the meeting. Lucille, a fellow Métis, is someone I had met during my field research in Manitoba, and had been sent to the Vancouver workshop to represent the Canadian Women's Health Network. My guess was that Madeline Boscoe, the network's Executive Director, had specifically chosen Lucille because she is a community activist who works daily with Aboriginal women who experience multiple problems such as poverty, racism, substance abuse and violence. Lucille's attendance was also significant for me because it meant that I was not the only Aboriginal person at the meeting. However, two Métis people do not represent an "Aboriginal presence," which is a common mistake made by non-Aboriginal people, and Lucille and I expressed concern to one another after the first day about the absence of First Nations and Inuit participants, particularly given the direction of the day's discussion[3].

As we entered the second day of the meeting, it felt as though Lucille and I were a quasi tag team, with her drawing on experience from her work at a transition house for Aboriginal women in Winnipeg, and me introducing critiques of why the current direction of FAS research, prevention, and intervention services are problematic in relation to Aboriginal women, their children and their communities. Thinking about Lucille's support at the meeting, I felt much better. Maybe it had not been as bad as I had

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[2] This chapter was written immediately after returning from the workshop. In later conversations with other participants who attended the workshop they expressed similar concerns, but said they were afraid or reluctant for various reasons to express them at the workshop.

[3] In an e-mail to the organizing committee later that week, I expressed my concern about the lack of Aboriginal representation at the meeting. I was told that two participants who were First Nations had been

remembered it the night before. Maybe I was just feeling tired from the week of traveling and meetings. However, as I surveyed the garden for weeds, the feeling of outrage brought on by the meeting continued to simmer in my thoughts.

The Workshop

The workshop, “FAS and Women’s Health: Setting a Women-Centered Research Agenda,” was organized by the British Columbia Centre of Excellence for Women’s Health. It is not surprising that such a meeting would take place in Vancouver given the significant amount of attention that FAS receives in health care and social service discourse in British Columbia. My role in the workshop was as a researcher who had examined barriers that prevent pregnant women, particularly Aboriginal women, from accessing addiction, prenatal, and other support services. The session in which I was assigned to be the “discussion starter” was scheduled for the second day and was described in the agenda as “bringing a women-centered and culturally competent approach to FAS prevention focused on pregnant, substance using Aboriginal women.”

As I sat in my garden in Lachine thinking about how the session had gone, I was sure that my presentation, which focused not so much on Aboriginal women, but on the dominant social service and health systems that serve this group, and on representations of Aboriginal women within the FAS research literature, had been less than satisfying for the workshop organizers. While I felt the organizers recognized the logic of my presentation given the previous day’s focus on Aboriginal peoples, I was also aware that at least some of the participants identified me more as an “angry Indian” than a productive “discussion starter.” Even though this was somewhat true, this was not the reason I was feeling such unease; I have known many “angry Indians” who, because of their anger and insistence on holding their ground on important issues, have individually and collectively transformed Aboriginal and non-Aboriginal relations in Canada in productive and positive ways. In this way I felt I was in good company. Rather, what weighed so heavily on my mind, and what I could not shake off as I sat in the sun admiring the beauty of the spring garden, was the overwhelming presence of the “white man’s burden,” which had hung like a thick cloud over the workshop.

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invited but declined to attend the meeting. The organizers were unsure why these individuals had decided to decline the invitation.

In Canada, according to many Aboriginal people, the companion of “the white man’s burden” is the “Indian problem,” and it is this that best describes the ways in which federal and provincial governments have approached, past and present, the socioeconomic, historical, and cultural/traditional realities of First Nations, Inuit, and Métis peoples. If looked at from a historical perspective, one could readily argue that colonialist governments, with the support of their constituents, have ideologically framed Aboriginal and non-Aboriginal relations in Canada using this dichotomy: Aboriginal peoples have problems, and the dominant non-Aboriginal society carries the burden of identifying, describing, and intervening in the lives of Aboriginal peoples in connection with those problems (see Section Three).

A case in point, which was discussed in greater detail in Section Three, is the residential school system, which was based on the perceived “burden” held by the colonialist government and churches who believed that it was necessary for them to “civilize,” “christianize” and “assimilate” Aboriginal children. This was based on the contention that by removing Aboriginal children from the care of their parents and, therefore, the “immorality” of indigenous traditions and cultures, these children could be imbued with European values and culture and thus become productive members of society. Decades later at the Vancouver meeting, it was evident although not so obviously stated, that “the white man’s burden” and the “Indian problem” were front and center. In this context, the “problem” was reconceptualized as large numbers of Aboriginal women with FAS/ARBEs who abuse alcohol, drugs and other substances, having multiple pregnancies and thereby giving to birth to “epidemic” numbers of children with FAS/ARBEs. It was the “white man’s burden” to come up with solutions in the form of research, interventions, and services to address this problem.

Approximately twenty-five people attended the workshop, and all came to the meeting with expertise and resolution to provide direction on research aimed at pregnant women with substance abuse problems. The organizers had intentionally brought together a diverse group that included researchers, front line workers, physicians, policy makers and government representatives with the goal in mind that this diversity would best address the complexity of the issues to be discussed. The workshop started with a presentation by one of the workshop organizers, Dr. Lorraine Greaves from the British

Columbia Centre of Excellence in Women's Health. Greaves outlined the ways in which FAS prevention research, interventions, and services in Canada overwhelmingly focus on the fetus, and therefore the goal of the workshop was to advocate for a shift in focus away from what she called the "uterine tradition" to a "women-centered approach," that addressed the mother and fetus as a single unit.

A presentation by Dr. Norma Finkelstein from the Institute for Health and Recovery in Boston followed the one by Lorraine Greaves, and outlined an American attempt at addressing substance use during pregnancy, including programming, coalition work, policy, and research. By mid-morning, it seemed evident that the workshop would prove to be productive and informative, and that the final report intended for the IGH would be a positive contribution toward gender-sensitive research on pregnancy and substance abuse.

My optimism was short lived, however, as I felt increasingly concerned during the discussion period and the second half of the morning about the direction the workshop was taking. At first, workshop participants collectively struggled with the shift in focus outlined by Greaves, and much of the discussion remained concerned with the risk to the developing fetus posed by substance abuse. Confusion also occurred around the diagnostic criteria for FAS after a pediatrician, who commonly assesses patients, most of whom are Aboriginal, for FAS in northern British Columbia argued that CNS dysfunction was not a necessary criterion for diagnosis of the syndrome. Others, such as a Vancouver physician and myself, disagreed with her, arguing that CNS dysfunction was clearly listed as a necessary criterion in all the diagnostic literature discussing the full blown syndrome, and including FAE. When the discussion did focus on women at risk of producing children with FAS, it was mainly about Aboriginal women, and there appeared to be an uncritical perception by most participants that Aboriginal women were not only at high risk, but basically they constituted the entire risk group itself[4].

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[4] Some of the participants in the workshop did not contribute to the discussion during the two-day workshop except to submit written suggestions at the end of the workshop to the organizers. It is unclear why they did not verbalize their opinions, as there was sufficient opportunity for them to do so. Therefore, it is unclear if their silence meant that they concurred with the identification of Aboriginal women as basically defining the risk group.

Christine Loock who was also in attendance, was the first to draw the attention of the workshop participants to the link between risk and being Aboriginal. During an open discussion early the first morning, she suggested that FAS was not an issue about all women, but that the women who were at risk were "different:" these women, she stated, had "disabilities," they were women who themselves were FAS, and, she added, they were First Nations. Loock also told the participants that "FAS means you have trouble making choices," and that "the babies [being born to the women at risk] are *our* future mothers."

Loock went on to tell the workshop participants that the women she sees in her clinical practice who are at risk of giving birth to a child with FAS/ARBEs, live mostly in the Downtown East Side of Vancouver. While she linked having FAS/ARBEs and giving birth to a child with FAS/ARBEs to poverty and being First Nations, she did not make the same argument for non-Aboriginal women with alcohol abuse problems who live in the same neighborhood[5].

In her comments, Loock referred to her own pregnancy several years previously and how, even though she is a Harvard medical graduate, she had unwittingly placed her unborn child at "risk" because she did not know of the "dangers" associated with alcohol use during pregnancy. However, in previous meetings or conferences when I had heard Loock refer to her own experience, she had done so to illustrate that *all* women are at risk if they do not know or follow the public health message. Fortunately for her, she stated, her alcohol use did not result in a child who was alcohol-affected. However, on this occasion, Loock's remarks illustrated a shift in the FAS discourse that would become more apparent over the next day and a half of the workshop. Impressing upon the audience that all women are at risk was no longer the basis for giving an account of her own pregnancy, but rather the point that she wanted to make was that she and the women in her clinical practice were, in fact, different from one another.

Based on the research literature discussing biological mothers of children with FAS, one could assume that the difference that Loock would highlight would be

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[5] In a recent conversation with Christine Loock she stated something very different, suggesting that Aboriginal identity was not found to be correlated with having a child with FAS. She referred to an unpublished B.C. study in which this was found.

grounded in a discussion of social inequality. As stated previously, risk factors associated with socioeconomically disadvantaged women, such as poor nutrition, tobacco use, and lack of prenatal care, have been found to interact with risk factors associated with chronic alcohol abuse, such as cirrhosis of the liver, to impact negatively upon the physiological processes of pregnancy and fetal development (see, Abel 1998a). Given her identification of First Nations women as the women "at-risk," one would also expect Loock to explain what specifically places impoverished First Nations women at greater risk than other groups of impoverished women.

Much to my surprise, however, Loock suggested that the women "at-risk" of giving birth to a child with FAS are women who themselves have FAS. While she acknowledged their impoverished circumstances as a contributing risk factor, she emphasized that the women at risk for producing a child with prenatal alcohol effects suffer from FAS/ARBEs, unlike herself, and thus have difficulty making good choices. This, I inferred from her discussion of the women in her clinical practice, referred especially to having unprotected sex, not using contraception, working as prostitutes, and having difficulty not drinking alcohol.

As I watched Loock very passionately tell the workshop participants that "after years of work on FAS we have not done our job properly, we have let these women and their children down," I could feel myself becoming agitated at the unstated implications of her statements. Suggesting that the women who are giving birth to children with FAS are themselves both individuals with FAS and First Nations meant that alcohol-related birth effects were now being characterized as an "intergenerational" phenomenon among Aboriginal peoples. The urban ghettos of Aboriginal families that have emerged in the past forty years in major Canadian cities are, according to this line of thinking, made up partially of a bio-underclass who suffers from permanent brain damage and alcohol addiction/abuse that over several generations, have given birth to similarly alcohol-affected offspring.

In this argument, the "risk factors" specific to Aboriginal women that, rightly or wrongly, were invoked by earlier researchers such as "race," ethnicity, cultural practices, or collective history, are usurped as the underlying factors that place Aboriginal women and their offspring at risk, and instead the primary and overarching risk factor is having widespread alcohol-related pathology. This shift in thinking implies that, despite First Nations women being the women "at-risk," their Aboriginal identity becomes relatively unimportant apart from helping to identifying them. This argument echoes the argument made by Streissguth that was discussed in the Introduction of this dissertation. Streissguth suggests that if the frequency of FAS is high, it becomes a "community catastrophe that threatens to wipe out any culture in just a few generations" (1997:9). In this context, the focus is no longer on "risk factors" in Aboriginal communities and neighborhoods, but rather the argument contends that in some local contexts, such as the Downtown East Side of Vancouver, a culture of pathology has arisen from widespread alcohol-related pathology among Aboriginal women, which places the next generation at risk of being similarly affected.

In concluding her remarks, Loock announced that she would not be staying at the workshop because she had to teach a class on the effects of prenatal substance use to a group of medical students, among whom I knew there would be few Aboriginal students. As she left the meeting, I could feel my agitation growing as I began to think about how she had redefined our task. The "Indian problem" and the "white man's burden" were now front and center as we began the second half of the morning.

The "making" of an epidemic of FAS

Agitation is often difficult to deal with in a setting where a certain amount of decorum is required if one is to be heard. However, as I listened to a presentation later that morning by a front-line worker, Anne Price, who works for a government funded FAS prevention program in the Burns Lake region of northern British Columbia, called *Healthier Babies, Brighter Futures,* I found myself thinking that too much decorum was stifling in such an ill-conceived meeting. Price's session was described in the workshop agenda as "bringing a women-centered approach to broad publicly focused FAS prevention strategies" such as raising public awareness, and community and policy development. In her introduction, she stated that Burns Lake[6] is located near several First Nation reserve communities and that even though the program targets all women, the large majority of women that her program serves are Aboriginal.

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[6] Approximately 40 per cent of the total population of 6,000 living in Burns Lake are Aboriginal. Several First Nation reserve communities are located nearby.

The program described by Price provides public health education on FAS and appears to bring a level of support and outreach services to women, their children and the community that is generally welcomed by the people of Burns Lake, and, to a lesser degree, according to Price, by the surrounding reserves. During the presentation, she stated that "most of the moms [that they provide services to] have had prenatal exposure to alcohol." She also referred at different times to FAS being a serious health problem in the area, thereby confirming to the workshop participants that government funding and focus on FAS prevention and intervention services had hit its mark in the case of the Burns Lake area.

The Burns Lake *Healthier Babies, Brighter Futures* program was featured in a February 2001 report entitled, *Fetal Alcohol Syndrome: A Call for Action in B.C.*, which was published by the Children's Commission of the B.C. Ministry for Children and Families. Under the subtitle "Innovation," the program in Burns Lake is described as a "successful prevention project" that "clearly shows that spending money on prevention and early intervention more than pays off" (The Children's Commission 2001:24). In the document, Price describes the Burns Lake program as follows:

> The program has managed to connect with very hard-to-reach families. Client profiles at intake show that 83 percent of women display FAS characteristics and behaviors. When the program began, 100 percent of the clients who came to the program were not on birth control, as it is difficult for people with FAS to remember to take a daily pill (The Children's Commission 2001:25)[7].

In the report the program's success is discussed in relation to increased birth control and pregnancy prevention, "healthier" pregnancies (abstinence or decrease in maternal substance use), birth outcomes such as "healthy birth weights," and women maintaining custody of their children. What is notable about the characteristics of the program that are believed to make it successful, is that success is not measured in anyway in terms of improved health and wellness of women (clients), and actually the emphasis on birth control and pregnancy prevention suggests that success is measured, at least partially, by making the alcohol abuse of "at-risk" women less visible. More simply stated, when the women are not pregnant their substance use/abuse, and all the problems associated with

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[7] The exact number of women in the program is not given in the publication.

it, lie outside of the range of “prevention” provided by this program and others like it. Furthermore, increased use of contraception means that fewer babies will be born, which is perceived as a desirable “preventive” measure.

The simple question “How do you know that?” is an essential research tool for anthropologists, and even more so for one who is Aboriginal in a context such as this, as it queries what appears to be most obvious to the presenter. When I posed the question to Price about how she knew that there were so many people with FAS in the Burns Lake region, and that I was unclear what she was trying to convey to the workshop members by saying “most of the moms have had prenatal exposure to alcohol,” she looked surprised. However, the surprise quickly shifted back to me, and I speculate to others in the room, when she announced that actually none of the mothers or their offspring in the Burns Lake region, that she knew of, had been medically assessed for or diagnosed with FAS/ARBEs. Adding further to my surprise was that she appeared to be absolutely untroubled by this fact in relation to her earlier statements.

I then decided to press Price for information on how she and her colleagues knew that a specific individual had FAS by asking, “was it their facial features, growth retardation, or cognitive problems?” and, if not, how did they know that prenatal alcohol exposure had resulted in harm to a specific woman? At this point, Price became very defensive, stating that because there was so much alcohol abuse in the Aboriginal communities in the Burns Lake area, high rates of FAS were present. She and her colleagues, she stated, did not go around labeling people because of how they looked or acted, because the problem of FAS in the area was self-evident.

As indicated in Price’s discussion of the Burns Lake prevention program published in the report by The Children’s Commission, there is some type of in-take screening process undertaken when clients access the program. This is indicated by her statement that “83 per cent of the women display FAS characteristics and behaviors” (Price in The Children’s Commission 2001:25). What the screening process entails, however, is unclear, as indicated by Price’s response to my question about how she knew the women were alcohol-affected.

Price’s emphasis on the women having “prenatal exposure to alcohol” becomes even more troublesome when considered in relation to the statement she makes in the report about contraception and it being “difficult for people with FAS to remember to take a daily pill.” In this statement, she suggests that failing to remember to take a daily birth control pill is an indication of FAS. Therefore, when she states “100 per cent of the clients who came to the program were not on birth control,” she is actually implying that they are not taking birth control pills due to alcohol-related pathology. This implies that the babies the women are giving birth to are actually the outcome of FAS pathology, indicating that a more “appropriate” intervention in the form of contraception is warranted for this group of women in order to prevent pregnancy, and in turn, FAS/ARBEs.

During my field research, I found that the use of contraception as a preventative strategy for FAS/ARBEs was mainly prescribed by physicians and community clinics who had high concentrations of adolescent and young adult Aboriginal clients. In some local and regional contexts in Manitoba, one of the “preventative” responses to FAS/ARBEs is the prescribing of Depo-Provera®[8] to women, including adolescent girls, some as young as 13 years of age. This form of contraception, I was told by some outreach and social workers, eliminated the need for women and girls to remember to take a pill every day or to negotiate condom use with male partners (Tait 2000:14-15). However, public health nurses were quick to point out that Depo-Provera® was not designed for young adolescent girls whose bodies are still developing, nor does it address the negative health and wellness consequences of alcohol addiction/abuse or the problem of sexually transmitted diseases. Women who use Depo-Provera® also end up falling outside of the scope of many FAS prevention programs and support services because they are not “at risk” of becoming pregnant.

My fieldwork experience suggests that the individuals most commonly labeled as having prenatal alcohol effects in the absence of a medical assessment or diagnosis are First Nations. Generally, non-medical labeling involves an “assessment” based on the opinion of one or more persons, and involves consideration of the person’s body, specifically their facial characteristics, possibly consideration of their height and weight, and an “assessment” of their intelligence, cognitive abilities, and behavior. For example,

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[8] A prescription of DepoProvera® lasts for three months and is given to women through injection.

memory problems reported by clients are interpreted as symptomatic of FAS/ARBEs. However, as we see by Price's statement about birth control pills and FAS, certain actions, or in this case, non-actions (not taking birth control pills) by the person under consideration, maybe interpreted as pathology (poor memory) resulting from prenatal alcohol exposure, apart from the person ever reporting that they experienced such a memory problem. The question remains as to whether or not the client population belonging to the Burns Lake program may in fact refrain from using birth control pills for a whole range of reasons other than poor memory, such as an exercise of personal choice, a desire to become pregnant, or concerns about health risks and side effects of different forms of contraception.

In prevention and intervention program training for community workers, information conveyed to trainees tends toward simplification and the adoption of very basic understanding of FAS and the "typical" person with FAS. In discussions with various individuals who have attended training sessions for community and front-line workers about FAS/ARBEs, they generally report coming away from a one- or two-day training session with the impression that prevalence rates of FAS/ARBEs are high, especially among Aboriginal peoples. They also report that persons with FAS/ARBEs are easy to identify, and some felt that after their training they were able to identify at least some persons with FAS. Trainees generally come away with a core understanding of the "typical" person with FAS, including a perception about the "FAS behavioral profile." In this profile, persons with FAS generally are described as being unable to distinguish between right and wrong, no clear understanding of the consequences that can result from their actions, trouble following instructions and rules, and poor short and long-term memory. They are also believed to be hyperactive, gullible, and easily victimized.

In Canada, medical assessments for FAS/ARBEs involve long waiting lists, and for people living in rural settings, assessments require travel to an urban centre, which can be lengthy and expensive. It is also very difficult for adolescents and adults to receive an assessment; therefore, many front-line workers, are forced to use non-medical labeling or "screening" in order to define their target population. Further, based on the public health message that implies that low threshold levels of alcohol exposure are dangerous to the fetus, high prevalence rates of FAS/ARBEs are assumed to exist. In the example of the Burns Lake prevention program, “screening” for FAS becomes part of the client in-take process for a prevention program, even though the program is not specifically targeting persons with FAS/ARBEs but rather pregnant women who drink alcohol.

Returning to Price’s response to my question about identifying persons with FAS, she suggests that “seeing” FAS is simply a matter of “seeing,” or at least perceiving, widespread alcohol use[9]. However, her response also suggests that she is “seeing” particular cohorts of Aboriginal people with FAS, as indicated in her statement that “most of the moms have had prenatal exposure to alcohol.” This claim reinforces an image of an “epidemic” situation as it implies that the “FAS problem” is compounded generationally by women with FAS, during the course of their childbearing years, giving birth on multiple occasions to babies with FAS.

Price’s response further suggests that community workers, like herself, and possibly members of the community at large, will consider most of the women who attend the program to have FAS/ARBEs. Because of this, one can speculate that these women will be treated as having a chronic brain dysfunction, which could be used to justify actions such as increased surveillance, apprehension of their children, and justification to pressure them not to have any more children. In this context, the women themselves may adopt some form of identity associated with FAS that will influence both positively and negatively their self-perception, including the ways in which they engage in, and are perceived by the communities in which they live.

Important to the representation developed by Price is the identification of the Aboriginal population in the Burns Lake region as a “population in crisis,” an image that was further reinforced during the workshop by the Chief of Pediatrics from the Prince George Regional Hospital, Marie Hay. In order to impress upon the workshop participants the level of dysfunction in Aboriginal communities in northern British Columbia, Hay stated that in recent generations in some Aboriginal communities, a one-hundred percent rate of sexual abuse of children has occurred. While it was unclear how

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[9] Known or perceived in-utero alcohol exposure is sometimes enough for a person to be labeled as having FAS/E, and alcohol abuse by the mother is not seen to be necessary. In some cases, just the fact that the child is Aboriginal is enough for non-medical persons to perceive prenatal alcohol exposure had occurred, especially if the child has been in foster or adoptive care.

she knew this, and because there was no one at the meeting from the communities in question who could challenge or confirm her assertion, the image of Aboriginal people in this area of British Columbia as being in a state of chaos was reinforced. She painted a picture of adults as drunkards and sexual predators, of parents, particularly mothers, as incapable—because of their own alcohol-related pathology—of caring for their children or for themselves while pregnant and, of epidemic numbers of children with FAS/ARBEs being victimized and neglected.

Once again, Streissguth's image of the culture-less society of pathology emerged, as Hay explained to the workshop participants how hard it was for her as a medical doctor to watch Aboriginal children growing up in such circumstances. Because of this, she stated, it was difficult for her to focus on the needs of the mothers when the damage they were causing to the children was so obvious and preventable.

By the end of the first day of the workshop I was significantly concerned and agitated by the assumed association being repeatedly made by workshop participants between Aboriginal peoples, particularly First Nations women and their children, and a perceived widespread problem of FAS in Aboriginal communities across Canada. I was equally concerned that hardly any of the workshop participants were trained as researchers and that few appeared to have a solid knowledge base of the research literature on FAS, despite this meeting being an initiative specifically undertaken to influence the direction of gender-based research in this area.

Over dinner that evening, Lucille Bruce and I discussed some of the implications of the day's discussion. We were both concerned about the negative picture that was being painted of Aboriginal mothers and their children, especially in the Burns Lake region. Of equal concern was the inability of workshop participants to stay focused on the women, and how time and time again the discussion shifted toward "protection" of the fetus. A final concern was the position that we were placed in as the only two Aboriginal people at the meeting, especially because it meant that organizers could claim that the workshop had "representation" from the Aboriginal community. This is especially troublesome given the fact that Lucille was at the meeting at the request of Madeline Boscoe and the CWHN, and was not specifically chosen by the organizers. With the workshop's portrayal of an "epidemic" problem of FAS among Aboriginal people, and the lack of critical reflection about this stance, Lucille and I both felt uneasy with the kind of report that would come out of the workshop and that our names would be attached to it.

Later that evening I found myself struggling with how best to constructively critique the first day's discussion in my presentation that was scheduled for the next morning. In the end I decided against presenting the paper that I had prepared which outlined and critiqued the continuum of health and social services for Aboriginal women struggling with substance addiction/abuse problems, and instead I reworked a paper I had given two days earlier at the Canadian Anthropology Association meetings. The paper analyzed the ways in which Aboriginal women are represented in the FAS research literature, and in poorly conceived mainstream and medical discussions of women at risk for giving birth to an alcohol-affected child. This, I hoped, would generate some critical reflection on the perceived scope of the FAS problem, and shift the group's focus to the health and wellbeing of women with substance addictions.

Day two

At the conclusion of my presentation the next morning, I was uncertain as to how the different participants viewed my analysis; however, I felt somewhat encouraged by the direction of the discussion that followed as there appeared to be some critical reflection about the non-medical labeling of Aboriginal peoples with FAS. Lucille Bruce also spoke about the growing number of Aboriginal women she sees in Winnipeg who are labeling themselves and their children as having FAS. As the discussion around my presentation concluded, I hoped that the next presenter, Dr. Deborah Rutman, a research associate with the Research Initiatives for Social Change Unit in the School of Social Work at the University of Victoria, would continue to focus the group's attention on women with substance addictions, as she was scheduled to speak on "supports for mothers with substance abuse problems" and on ways to bring "the voices of mothers into both policy and practice."

As I anticipated, Rutman's discussion supported much of what had been said by Lorraine Greaves, myself and others during the workshop about the need to focus on women as well as their offspring. However, in concluding her presentation, Rutman turned her attention to a research project she and her colleagues are currently working on that involves "persons with FAS." She pointed out that this project involves both Aboriginal and non-Aboriginal researchers, which she said was an important characteristic of the study team since most of their study cohort are Aboriginal people. Because of the previous day's heated discussion of labeling that had been sparked by Price's account of Burns Lake and the lack of diagnostic assessments for FAS, Rutman was careful to point out that the cohort of persons with FAS in their study were "self-identified persons with FAS." In this way, she stated, individuals were not being labeled by others but were identifying themselves as having FAS.

The question of why someone would self-identify as having FAS, and why the individuals who mostly do so are Aboriginal, are important questions in relation to those issues of inequality and social change that are researched by Rutman's unit. In connection with their research focus one could ask, "Upon what basis do individuals decide to identify themselves as having FAS?" For example, "Does someone else first label them? Or, do they hear or read about FAS and then apply this knowledge to their own lives? Does assuming the label give them access to certain supports or benefits?"

However, while these are important research questions in this context, they are not questions being considered by Rutman and her team. Neither is the question of why a diagnostic assessment for FAS is so difficult for patients to access in Canada and elsewhere. When some of the workshop participants, including myself, raised the methodological problems associated with her research, Rutman defended her study by stating that the research would be impossible if they had to rely on finding individuals who were actually diagnosed with FAS, as this population is very small. "Why," she queried, "should the research be prevented by the lack of diagnostic assessments?"

Rutman's statement generated a significant degree of discussion including some workshop participants questioning the scientific validity and ethics of a study based on this type of research design. However, what is important about this study is that it serves as an example of the widespread assumption among professional and lay persons that FAS is under-diagnosed and that the prevalence rates are high, especially among Aboriginal peoples. While Rutman's study may fail to maintain certain scientific standards, it is an unsettling example of non-medical labeling that has significant potential to enter into the discursive arena associated with FAS in Canada and further define the “typical” person with FAS. For example, the expected outcome of this study, according to Rutman, is to produce a “profile” or “accurate” account of a cohort of “persons with FAS.” Whether or not it will be made explicit in published papers and reports that the persons are not medically diagnosed, but rather have self-identified, is unclear. However, it is unlikely that a peer-reviewed scientific journal will publish this type of study. Nevertheless, as the events of the Vancouver workshop show, certain activities in Canada, such as clinical practice, prevention programs, and research have significant potential to contribute to national constructions of the category FAS, and a perceived epidemic that reaches far beyond what is substantiated by scientific research and believed to exist in comparable contexts in other countries such as United States.

Hacking (1999) argues that activities such as these can be central in the emergence of categories of people, as it is through an association with these activities that populations are created. Li and colleagues suggest that research, for example, generates more experts, generating more cases, generating more research (1990:177). In this way, a positive feed-forward cycle or “looping” effect comes into operation. The research of Li and colleagues on child abuse draws attention to a central belief that is also present in FAS research, which is that higher prevalence rates indicate that one is getting closer to the truth.

In discussing two papers (Wyatt and Peters 1986a, 1986b) written on how to conduct child-abuse surveys, Li and colleagues write:

> Although not explicitly stated, the aim is to produce more “accurate,” i.e. higher prevalence rates—the assumption is that, since child abuse is ubiquitous, only higher rates are truly indicative of the magnitude of the problem. The possibility that a survey interview may become a process of persuasion is simply ignored…” (Li et al. 1990:179 in Hacking 1999:160-161).

Similarly, the screening process used by Price in Burns Lake and the self-identification process used by Rutman and her colleagues assume that prevalence rates of FAS are widespread, which in turn allows them to take rudimentary screening assessments and self-identification as strong indicators of high FAS prevalence rates. In the example of self-identification, two necessary factors of prenatal alcohol effects, maternal alcohol exposure (based on the participant’s self-report) and “dysfunction” that can be related in some way to “secondary disabilities” are easily “confirmed.” The possibility that participants for various reasons may accept the label or self-identify as being FAS is ignored entirely.

Retrospective thoughts

In retrospect, the Vancouver workshop confirmed much of what I already knew through my field research about the knowledge production and practices in Canada associated with the diagnostic category FAS. However, while the workshop serves as a micro example of a larger phenomenon, my description suggests that the category FAS has been created and used by the dominant non-Aboriginal society to label Aboriginal peoples. As anthropologists know, things are never that simple. Within Canada, Aboriginal peoples in general, including leaders, academics, front-line and community workers, social workers, and teachers, are as vocal and insistent as the larger society—and in some cases even more so—that FAS is a serious health and social problem found in their communities.

An important question about the Vancouver meeting, one which will go unanswered, is whether, if there had been better representation of First Nations, Métis and Inuit front-line workers and leaders, they would have supported my concerns about the lack of diagnostic assessments and the labeling of significant numbers of Aboriginal people as having FAS. The research that I have conducted and discussed in this thesis suggests that Aboriginal people generally are concerned about diagnostic assessments being difficult to obtain, but they do not necessarily share my concerns, that based on the lack of medical assessments and insufficient clinical and epidemiological data, the scope of the "FAS problem" in their communities is being overstated by the federal and provincial governments, and by service providers who target Aboriginal peoples. Aboriginal communities have "taken ownership" of the "FAS problem," a situation that has resulted not in a critique of the scope of the problem, but in demands to all levels of government to direct more funding, programming, and human resources toward addressing the "tragedy of FAS" in their communities.

In relation to the outcome of the workshop, there exists a certain irony between what happened over the two-day meeting and the report that was produced as a result. In the weeks following the workshop, a report was produced and delivered to the IGH and to all of the workshop participants (Greaves, Poole & Cormier 2002). While I gave a small amount of feedback in the weeks after the workshop to Nancy Poole, Lorraine Greaves and Renée Cormier, the report authors, I could not at the time imagine how any kind of meaningful research recommendations could come out of what felt like two very disjointed days of debate and discussion. However, much to my surprise and appreciation, I received a report in which the three authors carefully describe and analyze the information given over the two days, and in which they produce a set of research recommendations that challenge the assumptions and questionable practices attached to the category FAS and the treatment of pregnant women, especially Aboriginal women, in Canada. After having reviewed the report I not only feel that it stands as a successful representation of the ideas expressed and debated at the two-day workshop, but it also attempts to redefine, at least to some degree, the ways in which research questions attached to alcohol use by pregnant women and FAS/ARBEs should be framed and researched in the Canadian context.

Conclusion

In this chapter I discussed some of the assumptions that are built into FAS prevention strategies that target Aboriginal women. I argue that in conjunction with understandings of adolescent and adult populations and “secondary disabilities,” there has emerged images of a culture-less pathological society existing in many urban and reserve Aboriginal communities. These images have been invoked, for example, to reinforce a narrative of difference which suggests that a bio-underclass of Aboriginal women exists who, over the generations have given birth to epidemic numbers of FAS/ARBE children. This narrative serves to justify preventative strategies including interventions to curb fertility rates in Aboriginal communities, and acts as a reference point asserting that self-identification can be used as an acceptable marker of FAS/ARBEs when clinical diagnostic assessments are difficult to obtain.

Chapter Fourteen
CONCLUSION

In this dissertation I examine the diagnostic category "fetal alcohol syndrome" from various vantage points, specifically as it is applied to the lives of Aboriginal peoples in Canada. Following the "G" case in 1997 an explosion of federal and provincial government interest resulted in FAS being identified as a serious health and social problem in Canada that was especially prevalent among Aboriginal communities. As the research and writing of this dissertation was undertaken, in various public and professional arenas the knowledge and practices associated with the category continued to transform understanding of alcohol use by pregnant women and persons with FAS. During this period, particularly in western regions, alcohol use by pregnant women was transformed from a public health issue to an issue of morality and what it means to be a "good" mother.

Increasingly, those at the center of FAS research, clinical practice, and prevention set their sites on identifying new risk groups of women and children, within a growing consensus that all alcohol exposure is potentially damaging to the fetus. However, despite attention being paid to other groups, Aboriginal women and their children remain the central target group in Canada for FAS prevention, reinforcing views that they are the population who are most "at risk," and that in their communities prevalence rates are extremely elevated.

Are Aboriginal women at increased risk?

Aboriginal women in North America are collectively very diverse in culture, language, geographical location, *and* alcohol consumption. Within Canada and North America more generally, debate has occurred as to whether Aboriginal women are at greater risk than their non-Aboriginal counterparts for having children with FAS/ARBEs. In the appraisal of the epidemiology of FAS among Canadian Aboriginal peoples, Bray and Anderson argue that despite Aboriginal women and children being over-represented in epidemiological studies, the research has not yet established whether any Aboriginal population is a high risk group for FAS (1989:44). In 1989, Bray and Anderson cautioned against the assumption that Aboriginal women are more likely than non-Aboriginal women to be alcohol abusers. They point out that no conclusive data regarding typical and excessive alcohol consumption patterns and drinking styles of Aboriginal women of childbearing ages exists in Canada (1989:44). This observation appears to hold true today. Epidemiological research continues to be inconclusive in its assessment of the level of risk Aboriginal women face in relation to alcohol abuse and adverse pregnancy outcomes.

However, despite methodological problems such as detection bias accounting for at least some of the inflated prevalence rates of FAS found among Aboriginal children, the studies also signal that risk maybe higher in certain Aboriginal populations (Bray & Anderson 1989). Bray and Anderson suggest that if the studies are signaling increased risk then a new question should be asked: "*What are the factors that could put Canadian Native women at risk for producing children with FAS?*" (1989:44). Based upon this question, Bray and Anderson recommend that community-specific data be collected regarding the alcohol consumption patterns of Aboriginal women. This, they argue, would "contribute to a solid data base to assess whether a targeted alcohol abuse prevention program is needed and whether an investigation into the prevalence of FAS is worthwhile" (Bray & Anderson 1989:44).

A Reversal of Time

The most common way that FAS researchers in Canada have identified Aboriginal women as being the largest "at risk" group for having children affected by in utero alcohol exposure is through a reversal of time. The high prevalence rates of FAS found among Aboriginal children in FAS studies have been used as evidence to support arguments that pregnant Aboriginal women are more likely than pregnant women of other ethnic groups to drink alcohol. This type of reversal of time is not however, specific to Canadian studies. In writing about American research, Armstrong states:

> Indeed, the literature contains several examples of how FAS was and is used to label affected women and children as medical and social problems. Most commonly, the diagnosis of FAS in a child was used to diagnose the mother as an alcoholic retrospectively (e.g. Hanson et al. 1976, Smith 1979, Davis and Lipson 1984). As Smith noted, "Clinicians familiar with FAS have been alerted to previously unrecognized alcoholism in a mother simply because her child had a distinctively 'FAS' face (Smith 1979: p, 124). Erb and Andersen (1978: p 644) likewise noted in *Clinical Pediatrics* that "many children will be identified as displaying FAS and their mothers can be identified as alcohol abusers." Since alcoholism in the mother was one of the original criteria for a diagnosis of FAS, this tautology seems particularly insidious, reasoning as it goes that

> since the child has FAS, the mother is an alcoholic, therefore, the child has FAS. Indeed the power of FAS as a morally stigmatizing category helps to explain the rapid embrace of this new diagnosis in the medical and lay world alike (1998:2035).

As stated previously, most early Canadian FAS studies (Asante 1981, Asante & Nelms-Matzke 1985, Asante & Robinson 1990, Robinson et al. 1985a, 1985b, Smith et al. 1981) were conducted by researchers who were developmental pediatricians, therefore, the objective of their research was to identify the children within a study cohort who had FAS/ARBEs. Not all studies required confirmation of gestational exposure to alcohol as part of the diagnostic criteria, and even in the studies that required confirmed prenatal alcohol exposure, there was virtually no information collected about the patterns and level of alcohol use by the biological mothers. As illustrated in the study by Asante, researcher confirmed "high rates" of maternal alcohol abuse among Aboriginal women based on the high prevalence rate of FAS/FAE that they found among Aboriginal children that they diagnosed (1981).

This reversal of time, while common to early North American studies is especially significant in Canadian studies because of the extraordinarily high prevalence rates that were being reported by the researchers. To date no other studies outside of Canada have produced similar prevalence rates in a study cohort that are comparable to those found among Canadian Aboriginal populations. As was discussed in this dissertation, the diagnosis of Aboriginal children with FAS/ARBEs, especially when alcohol abuse has not been confirmed and when a minimalist paradigm is used, raises significant concern about misclassification and over diagnosis.

The full implication of the reversal of time in early FAS studies is especially significant when placed in the context of the explosion of FAS research and, prevention and intervention programs that began to occur in the late 1980s and 1990s. During this period, researchers and those involved in FAS programs and services began to expand their interests beyond infants and children to adolescent and adult groups. With this came a new set of "risk" factors and a new language of "secondary disabilities" that further implicated Aboriginal women and their offspring as being at significantly greater risk than any other social group. Because for various reasons, the availability of diagnostic assessments has not been forthcoming, a practice of non-medical labeling of persons with FAS has become increasingly common in Aboriginal communities which has the potential to further stigmatize Aboriginal women in their role as mothers.

While this dissertation attempts to challenge assumptions that are made within North America about alcohol use by pregnant women and FAS/ARBEs, it is not meant to suggest that prenatal alcohol-related pathology does not exist. Having had the opportunity to meet and speak with persons who are diagnosed with FAS/FAE, as well as their families, it is clear that as with other similar illnesses which affect cognition and behavior, the challenges for those individuals who are affected and their families are significant. It is also evident that despite the focus on prevention and alarmist descriptions of the extent of the "FAS problem," supports and services for the small population of diagnosed individuals in Canada is inadequate[1].

In concluding this dissertation I am reminded of a Cree woman in Winnipeg who encouraged my research because of her fear that more and more Aboriginal children were being falsely labeled as having FAS. It was from her statement; "not all of our children are FAS" and from my own fear upon first hearing the predictions about the high prevalence rates of FAS among Aboriginal peoples, that I decided to focus on the diagnostic category and not solely on substance abuse and pregnancy as I originally planned. As has been illustrated by the previous discussion, the knowledge production attached to the category FAS in Canada is embedded within understandings of alcohol use, the "reproductive body," and the lives of Aboriginal peoples. This dissertation directly challenges claims that are made about "risk" and prevalence rates, in an attempt to bring critical reflection upon what are now entrenched understandings of alcohol use by pregnant women and FAS.

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[1] The associated costs of providing support for persons with FAS is estimated to be approximately 1.4 million dollars per person (Health Canada website).

BIBLIOGRAPHY

Aase, J. M. (1981). “The Fetal Alcohol Syndrome in American Indians: A High Risk Group.” Neurobehavioral Toxicology and Teratology 3: 153-156.

Aase, J. M. (1994). “Clinical Recognition of FAS: Difficulties of Detection and Diagnosis.” Alcohol Health and Research World 18: 5-9.

Aase, J. M., K.L. Jones & S.K. Clarren (1995). “Do We Need the Term 'FAE'?” Pediatrics 95: 428-430.

Abel, E. L. (1982). “Characteristics of Mothers of Fetal Alcohol Syndrome Children.” Neurobehavioral Toxicology 4: 3-4.

Abel, E. L. (1984). Fetal Alcohol Syndrome and Fetal Alcohol Effects. New York, Plenum Press.

Abel, E. L. (1988). “Fetal Alcohol Syndrome in Families.” Neurotoxicology and Teratology 10: 1-2.

Abel, E. L. (1995). “An Update on Incidence of FAS: FAS Is Not an Equal Opportunity Birth Defect.” Neurotoxicology and Teratology 17(4): 437-443.

Abel, E. L. (1997). “Maternal Alcohol Consumption and Spontaneous Abortion.” Alcohol & Alcoholism 32(3): 211-219.

Abel, E. L. (1997). “Was the Fetal Alcohol Syndrome Recognized in the Ancient Near East?” Alcohol & Alcoholism 32(1): 3-7.

Abel, E. L. (1998). Fetal Alcohol Abuse Syndrome. New York, Plenum Press.

Abel, E. L. (1998). “Prevention of Alcohol Abuse-Related Birth Effects - I. Public Education Efforts.” Alcohol & Alcoholism 33(4): 411-416.

Abel, E. L. (1999). “What Really Causes FAS?” Teratology 59: 4-6.

Abel, E. L. (1999). “Was Fetal Alcohol Syndrome Recognized by the Greeks and Romans?” Alcohol & Alcoholism 34(6): 868-872.

Abel, E. L. (2001). “Gin Lane: Did Hogarth Know About Fetal Alcohol Syndrome?” Alcohol & Alcoholism 36(2): 131-134.

Abel, E. L. and B. A. Dintcheff (1984). “Factors Affecting the Outcome of Maternal Alcohol Exposure: I Parity.” Neurobehavioral Toxicology and Teratology 6: 373-377.

Abel, E. L. and B. A. Dintcheff (1985). “Factors Affecting the Outcome of Maternal Alcohol Exposure: II Maternal age.” Neurobehavioral Toxicology and Teratology 7: 263-266.

Abel, E. L. and J. H. Hannigan (1995). “Maternal Risk Factors in Fetal Alcohol Syndrome: Provocative and Permissive Influences.” Neurotoxicology and Teratology 17(4): 445-462.

Abel, E. L. and M. L. Kruger (1995). “Hon v.Stroh Brewery Co.: What do we mean by "moderate" and "heavy" drinking.” Alcoholism: Clinical and Experimental Research 19: 1024-1031.

Addition Research Foundation of Ontario (1996). The Hidden Majority, a guidebook on alcohol and other drug issues for counselors who work with women. Toronto, Ontario.

Adelson, N. (2000). 'Being Alive Well' : Health and the Politics of Cree Well-Being. Toronto, University of Toronto Press.

Anderson, D. and J. Wemigwans (2002). “Healing with a deep heart: a community-based approach to living with FAS/E.” Aboriginal Approaches to fetal alcohol syndrome/effects. Toronto: Ontario Federation of Friendship Centres:6-12.

Armitage, A. (1995). Comparing the policy of Aboriginal Assimilation: Australia, Canada, New Zealand. Vancouver, University of British Columbia Press.

Armstrong, E. M. (1998). “Diagnosing Moral Disorder: The Discovery and Evolution of Fetal Alcohol Syndrome.” Soc. Sci. Med. 47(12): 2025-2042.

Armstrong, E. M. and E. L. Abel (2000). “Fetal Alcohol Syndrome: The Origins of a Moral Panic.” Alcohol & Alcoholism 35(3): 276-282.

Armstrong, J. (2000). Fetal alcohol syndrome carrier a life sentence. The Globe and Mail. Toronto: A6.

Aronson, J. E. (2000). Alcohol-Related Disorders and Children Adopted from Abroad. Adoption and Prenatal Alcohol and Drug Exposure. R.P. Barth, M. Freundlich &. D. Brodzinsky (eds.). Washington, D.C., Child Welfare League of America: 147-169.

Asante, K. O. (1981). “FAS in northwest BC and the Yukon.” BC Medical Journal 23(7): 331-335.

Asante, K. O. and J. Nelms-Matzke (1985). Survey of Children with Chronic Handicaps and Fetal Alcohol Syndrome in Yukon and British Columbia. Ottawa, National Native Advisory Council on Alcohol and Drug Abuse, Health and Welfare Canada.

Asante, K. O. and G. Robinson (1990). “Pregnancy Outreach Program in British Columbia: The Prevention of Alcohol-Related Birth Defects.” Canadian Journal of Public Health 81: 76-77.

Ashley, M. J., J.S. Olin, W.H. le Richie, A. Kornaczewski, W. Schmidt, et al. (1977). “Morbidity in Alcoholics: Evidence for Accelerated Development of Physical Disease in Women.” Archives of Internal Medicine 137: 883-887.

Assembly of Manitoba Chiefs (1997). Certified Resolution: Fetal Alcohol Syndrome/Effects Resolution, Chief's Health Assembly.

Astley, S. J., D. Bailey, et al. (2000). “Fetal Alcohol Syndrome (FAS) Primary Prevention Through FAS Diagnosis: II. A Comprehensive Profile of 80 Birth Mothers of Children With FAS.” Alcohol & Alcoholism 35(5): 509-519.

Astley, S. J., D. Bailey, et al. (2000). “Fetal Alcohol Syndrome (FAS) Primary Prevention Through FAS Diagnosis: I. Identification of High-Risk Birth Mothers Through the Diagnosis of Their Children.” Alcohol & Alcoholism 35(5): 499-508.

Astley, S. J. and S. K. Clarren (2000). “Diagnosing The Full Spectrum of Fetal Alcohol-Exposed Individuals: Introducing the 4-Digit Diagnostic Code.” Alcohol & Alcoholism 35(4): 400-410.

Astley, S. J. and S. K. Clarren (2001). “Measuring the Facial Phenotype of Individuals with Prenatal Alcohol Exposure : Correlations with Brain Dysfunction.” Alcohol & Alcoholism 36(2): 147-159.

Astley, S. J., S. I. Magnuson, et al. (1999). “Fetal Alcohol Syndrome: Changes in Craniofacial Form With Age, Cognition, and Timing of Ethanol Exposure in the Macaque.” Teratology 59: 163-172.

Astley, S. J. S. K. C. (1999). Diagnostic Guide for Fetal Alcohol Syndrome (FAS) and Related Conditions: The 4-digit diagnostic code. Seattle, WA, University of Washington.

Bagley, C. and R. Ramsay (1986). “Sexual Abuse in Childhood: Psychosocial Outcomes and Implications for Social Work Practice.” Journal of Social Work and Human Sexuality 4: 33-47.

Barnett, C. C. (1997). A Judicial Perspective on FAS: Memories of the making of Nanook of the north. The Challenges of fetal alcohol syndrome: overcoming secondary disabilities. A. P. Streissguth and J. Kanter. Seattle, University of Washington Press: 134-145.

Barr, H. M. and A. P. Streissguth (2001). “Identifying Maternal Self-Reported Alcohol Use Associated With Fetal Alcohol Spectrum Disorders.” Alcoholism: Clinical and Experimental Research 25(2): 283-287.

BC FAS Resource Society (1998). Community Action Guide: Working together for the prevention of Fetal Alcohol Syndrome. Victoria, British Columbia Ministry for Children and Families.

Bennion, L. and T. K. Li (1976). “Alcohol Metabolism in American Indians and Whites.” New England Journal of Medicine 284: 251-254.

Benoit, C. and D. Carroll (2001). Marginalized Voices From the Downtown Eastside: Aboriginal Women Speak About their Health Experiences. Vancouver, The National Network on Environments and Women's Health.

Bernard, H. R., D. (1988). Research Methods in Cultural Anthropology. Newbury Park, Sage Publications.

Bessner, R. (1993). State Intervention in Pregnancy. Misconceptions: The social construction of choice and the new reproductive and genetic technologies. G. Basen, M. Eichler and A. Lippman (eds). Hull, Voyageur Publishing. 2: 170-182.

Bingol, N., C. Schuster, et al. (1987). “Influences of socio-economic factors on the occurrence of fetal alcohol syndrome.” Adv. Alcohol Substance Abuse 6: 105-118.

Bledsoe, C. (1990). The Politics of Children: Fosterage and the Social Management of Fertility among the Mende of Sierra Leone. Births and Power. W. Penn Handwerker (ed.). Boulder, Colorado: Westview Press: 81-100.

Boland, F. J., R. Burrill, et al. (1998). Fetal Alcohol Syndrome: Implications for Correctional Service. Ottawa, Correctional Service Canada.

Boland, F. J., M. Duwyn, et al. (2000). “Fetal Alcohol Syndrome: Understanding its Impact.” Forum on Correctional Research 12(1): 16-18.

Boney-McCoy, S. and D. Finkelhor (1995). “Prior Victimization: A Risk Factor for Child Sexual Abuse and for PTSD-related Symptomatology Among Sexually Abused Youth.” Child Abuse and Neglect 19(1401-1421).

Boyd, S. C. (1999). Mothers and Illicit Drugs: Transcending the Myths. Toronto, University of Toronto Press.

Brady, M. (2000). “Alcohol Policy Issues for Indigenous People in the United States, Canada, Australia and New Zealand.” Contemporary Drug Problems 27(Fall 2000): 435-509.

Bray, D. L. and P. D. Anderson (1989). “Appraisal of the Epidemiology of Fetal Alcohol Syndrome Among Canadian Native Peoples.” Canadian Journal of Public Health 80: 42-45.

Brody, H. (1988). Maps and Dreams: Indians and the British Columbia Frontier. Vancouver, Douglas & McIntyre.

Browne, A. J. and J. Fiske (2001). “First Nations Women's Encounters With Mainstream Health Care Services.” Western Journal of Nursing Research 23(2): 126-147.

Bull, L. (1991). “Native Residential Schooling: The Native Perspective.” Canadian Journal of Native Education 18(Supplement): 3-63.

Burd, L. and M. E. K. Moffatt (1994). “Epidemiology of Fetal Alcohol Syndrome in American Indians, Alaskan Natives, and Canadian Aboriginal Peoples: a Review of the Literature.” Public Health Reports 109(5): 688-693.

Buxton, B. (2002). Coping with fetal-alcohol disorder. The Gazette. Montreal: A17.

Castel, R., Arthur C. (1991). From Dangerous to Risk. The Foucault effect: studies in governmentality. G. Burchell, C. Gordon and P. Miller. Chicago, University of Chicago Press.

Chavez, G. F., J.F. Cordero & J.E. Becerrant (1988). “Leading Major Congenital Malformations Among Minority Groups in the United States 1981-1986.” MMWR Morb Mortal Wkly Rep 37(SS-3): 17-25.

Chisholm, P. (1996). Does a Fetus have Rights. Maclean's. August 19, 1996: 16-19.

Chrisjohn, R. D. and S. Young (1997). The Circle Game: Shadows and Substance in the Indian Residential School Experience in Canada. British Columbia, Theytus Books Ltd.

Chudley, A. E., et al. (1999). Pitfalls in Diagnosis of FAS in a Manitoba Native School-Aged Population, Concurrent Session 4A. Prairie Province Conference on Fetal Alcohol Syndrome, Together let's find a solution, Calgary, Alberta, University of Calgary.

Clarren, S. K. (1978). “The Fetal Alcohol Syndrome.” The New England Journal of Medicine 298(19): 1063-1067.

Clarren, S. K. (1981). “Recognition of Fetal Alcohol Syndrome.” JAMA 245(23): 2436-2439.

Clarren, S. K., P.D. Sampson, J. Larsen, D.J. Donnell, H.M. Barr et al. (1987). “Facial Effects of Fetal Alcohol Exposure: Assessment by Photographs and Morphometric Analysis.” American Journal of Medical Genetics 26: 651-666.

Clarren, S. K. (1998). FAS: A Diagnosis for Two. Finding common ground: Working together for the future, UBC, Vancouver, B.C., Continuing Education in the Health Sciences.

Clarren, S. K. and S. J. Astley (1997). Development of the FAS Diagnostic and Prevention Network in Washington State. The Challenge of Fetal Alcohol Syndrome: Overcoming Secondary Disabilities. A. P. Streissguth and J. Kanter. Seattle, University of Washington Press.

Clarren, S. K., S. J. Astley, et al. (1988). “Physical Anomalies and Developmental Delays in Nonhuman Primate Infants Exposed to Weekly Doses of Ethanol During Gestation.” Teratology 37: 561-569.

Clarren, S. K., S. J. Astley, et al. (1990). “Neuroanatomic and Neurochemical Abnormalities in Non-human Primate Infants Exposed to Weekly Doses of Ethanol during Gestation.” Alcoholism: Clinical and Experimental Research 14(5): 674-683.

Clarren, S. K. and D. W. Smith (1978). “The Fetal Alcohol Syndrome.” The New England Journal of Medicine 298(19): 1063-1067.

Clarren, S. K. and D. W. Smith (1999). The Development of the FAS-Diagnostic and Prevention Network: A Practical Approach to FAS Identification, Treatment and Primary Prevention. Forum on Fetal Alcohol Syndrome, Government Conference Centre, Ottawa, Ontario.

Cohen, N. A., Ed. (1992). Child Welfare: A multicultural focus. Boston, Allyn and Bacon.

Coles, C. D., K. A. Platzman, et al. (1997). “A Comparison of Children Affected by Prenatal Alcohol Exposure and Attention Deficit, Hyperactivity Disorder.” Alcoholism: Clinical and Experimental Research 21(1): 150-161.

Coles, C. D., I. E. Smith, et al. (1985). “Neonatal neurobehavioral characteristics as correlates of maternal alcohol use during gestation.” Alcoholism: Clinical and Experimental Research 9: 454-460.

Colmant, S. A. (2000). “U.S. and Canadian Boarding Schools: A Review, Past and Present.” Native American Hemispheric Journal of Indigenous Issues 17(4): 24-32.

Conry, J. (1990). “Neuropsychological Deficits in Fetal Alcohol Syndrome and Fetal Alcohol Effects.” Alcoholism: Clinical and Experimental Research 14(5): 650-655.

Conry, J. and D. K. Fast (2000). Fetal Alcohol Syndrome and the Criminal Justice System. Vancouver, B.C. Fetal Alcohol Syndrome Resource Society & Law Foundation of British Columbia.

Continuing Education in the Health Science, UBC (1998). Finding Common Ground: working together for the future, Conference proceedings. Vancouver, B.C.

Corrigan, G. E. (1976). “The fetal alcohol syndrome.” Texam Medicine 72: 72-74.

Coyne, A. (1997). Court's conundrum. The Gazette. Montreal. Tuesday, Nov. 4, 1997.

Dahaene, P. and A. P. Streissguth (1994). “Quel est votre diagnostic? Le voir en peinture [What is your diagnosis? Look at the picture].” Le Concours Medical 115(15): 1271-1273.

Daschele, T. and B. Nighthorse Campbell (1994). Disaster on the reservation. Born Hooked: Poisoned in the Womb. G. E. McCuen. Hudson, Wisconsin, Gem Publications Inc.: 58-64.

Davis-Floyd, R. E. (1992). “The technocratic body and the organic body: culture models for women's birth choices.” Knowledge and Society: the anthropology of science and technology 9: 59-93.

Davis-Floyd, R. E. (1992). Birth as an American rite of passage. Berkeley, University of California Press.

Dehaene, P., G. Crepin, et al. (1981). “Aspects epidemiologiques du syndrome d'alcoholisme foetal.” La Nouvelle Presse Medicale 10(3): 2639-2643.

Deiter, C. (1999). From Our Mothers' Arms: The Intergenerational Impact of Residential Schools in Saskatchewan. Toronto, United Church Publishing House.

Dophin, R. (2002). No Simple Solutions to Native Problems. Calgary Herald. June 11, 2002.

Dorris, M. (1989). The Broken Cord. New York, HarperCollins.

Douglas, M. (1992). Risk and Blame: Essays in cultural theory. New York, Routledge.

Dreyfus, H.L. and P. Rabinow (1983). Michel Foucault: Beyond structuralism and hermeneutics. Chicago, University of Chicago Press.

Duden, B. (1993). Disembodying women: perspectives on pregnancy and the unborn. Cambridge, Harvard University Press.

Duimstra, C., D. Johnson, et al. (1993). “A Fetal Alcohol Syndrome Surveillance Pilot Project in American Indian Communities in the Northern Plains.” Public Health Reports 108(2): 225-229.

Dumont, J. (2000). When explanations rest: “good-enough” brain science and the new socio-medical disorders. Living and working with the new medical technologies. M. Lock, A. Young & A. Cambrosio (eds). Cambridge: Cambridge University Press.

Edwards, J., S. Franklin, et al., Eds. (1993). Technologies of procreation: kinship in the age of assisted conception. Manchester, Manchester University Press.

Egeland, G. M., K. A. Perham-Hester, et al. (1998). “Fetal Alcohol Syndrome in Alaska, 1977 through 1992: An Administrative Prevalence Derived from Multiple Data Sources.” American Journal of Public Health 88(5): 781-786.

Epstein, L. (1999). The culture of social work. Reading Foucault for social work. A. S. Chambon, A. Irving and L. Epstein. New York, Columbia University Press: 3-26.

Ernhart, C. B., T. Greene, et al. (1995). “Neonatal Diagnosis of Fetal Alcohol Syndrome: Not Necessarily a Hopeless Prognosis.” Alcoholism: Clinical and Experimental Research 19(6): 1550-1557.

Ernhart, C. B., M. Morrow-Tlucak, et al. (1988). “Underreporting of Alcohol Use in Pregnancy.” Alcoholism: Clinical and Experimental Research 12(4): 506-511.

Escobar, A. (1995). Encountering development: The making and unmaking of the Third World. Princeton, Princeton University Press.

Fast, D. K., J. Conry, et al. (1999). “Identifying Fetal Alcohol Syndrome Among Youth in the Criminal Justice System.” Developmental and Behavioral Pediatrics 20(5): 370-372.

Federal Provincial & Territorial Advisory Committee on Population Health (1999). Statistical Report on the Health of Canadians, Meeting of Ministers of Health. Charlottetown, PEI, Minister of Public Works and Government Services Canada.

Feehan, T. M. (1996). Stories of Healing from a First Nations Perspective. M.A. Thesis, University of Victoria.

Fenna, D., L. Mix, O. Schaefer & J.A. Gilbert (1971). “Ethanol Metabolism in Various Racial Groups.” Canadian Medical Association Journal 105: 472-475.

Fisher, A. D. (1987). “Alcoholism and race: the misapplication of both concepts to North American Indians.” Canadian Review of Sociology & Anthropology 24: 81-98.

Fiske, J. (1996). Gender and the Paradox of Residential Education in Carrier Society. Women of the First Nations: Power, Wisdom, and Strength. C. Miller & P. Chuchryk (eds). Winnipeg, University of Manitoba Press.

Foucault, M. (1975). The Birth of the Clinic: An archaeology of medical perception. New York, Vintage Books.

Foucault, M. (1979). Discipline and Punish: The Birth of the Prison. New York, Vintage Books.

Foucault, M. (1990). The History of Sexuality: An introduction. New York, Vintage Books.

Fournier, S. and E. Crey (1997). Stolen From Our Embrace: The Abduction of First Nations Children and the Restoration of Aboriginal Communities. Toronto, Douglas & McIntyre.

Frank, J. W., R. S. Moore, et al. (2000). “Historical and Cultural Roots of Drinking Problems Among American Indians.” American Journal of Public Health 90(3): 344-351.

Frisby, D. (1986). Fragments of Modernity. Cambridge, Mass, MIT Press.

Funkhouser, J. E. and R. W. Denniston (1985). “Preventing Alcohol-Related Birth Defects.” Alcohol Health and Research World 10: 54-59.

Gal, S. (1997). Gender in the Post-Socialist Transition: The Abortion Debate in Hungary. The Gender Sexuality Reader: Culture, History, Political Economy. R.N. Lancaster & M. di Leonardo (eds.). New York: Routledge: 122-133.

Gigerenzer, G., Z. Swijtink, et al. (1989). The empire of chance: how probability changed science and everyday life. Cambridge, Cambridge University Press.

Ginsburg, F. D. (1989). Contested Lives: abortion debate in an American community. Berkeley, University of California Press.

Ginsburg, F. D. (1990). The "word-made" flesh: the disembodiment of gender in the abortion debate. Uncertain terms: negotiating gender in American culture. F. D. Ginsburg and A. L. Tsing. Boston, Beacon Press: 59-75.

Ginsburg, F. D. and R. Rapp (1991). “The politics of reproduction.” Annual Review of Anthropology 20: 311-343.

Ginsburg, F. D. and R. Rapp, Eds. (1995). Conceiving the New World Order: The Global Politics of Reproduction. Berkeley, University of California Press.

Ginsburg, F. D. and R. Rapp, Eds. (1995). Conceiving the new world order: the global politics of reproduction. Berkeley, University of California Press.

Ginsburg, F. D. and R. Rapp (1995). Introduction. Conceiving the new world order: the global politics of reproduction. F. D. Ginsburg and R. Rapp. Berkeley, University of California Press: 1-17.

Godel, J. C., et al. (2000). “Exposure to Alcohol in utero: Influence on Cognitive Function and Learning in a Northern Elementary School Population.” Paediatric Child Health 5(2): 93-100.

Godel, J. C., H. F. Pabst, et al. (1992). “Smoking and caffeine and alcohol intake during pregnancy in a northern population: effect on fetal growth.” Canadian Medical Association Journal 147(2): 181-188.

Goffman, E. (1961). Asylums: essays on the social situations of mental patients and other inmates. New York, Doubleday & company inc.

Golden, J. (1999). “"An Argument That Goes Back to the Womb": The Demedicalization of Fetal Alcohol Syndrome, 1973-1992.” Journal of Social History winter: 269-298.

Goody, E.N. (1982). Parenthood and Social Reproduction. New York: Cambridge University Press.

Graham, E. (1997). The Mush Hole Life at Two Indian Residential Schools. Waterloo, Heffle Publishing.

Grant, A. (1996). No End of Grief: Indian Residential Schools in Canada. Winnipeg, Pemmican Publishing Inc.

Greaves, L., N. Poole, et al. (2002). Fetal Alcohol Syndrome and Women's health: setting a women-centred research agenda. Vancouver, The British Columbia Centre of Excellence in Women's Health.

Gresko, J. (1986). Creating Little Dominions within the Dominion: Early Catholic Indian Schools in Saskatchewan and British Columbia. Indian Education in Canada. J. Barman, Y Herbert (eds). Vancouver, University of British Columbia. 1:The Legacy.

Habbick, B. F., J. L. Nanson, et al. (1997). “Mortality in Foetal Alcohol Syndrome.” Canadian Journal of Public Health 88(3): 181-183.

Habbick, B. F., J. L. Nanson, et al. (1996). “Foetal Alcohol Syndrome in Saskatchewan: Unchanged Incidence in a 20-year Period.” Canadian Journal of Public Health 87(3): 204-207.

Habbick, B. F., W. A. Zaleski, et al. (1979). “Liver Abnormalities in Three Patients with Fetal Alcohol Syndrome.” The Lancet: 580-581.

Hacking, I. (1983). Representing and intervening: Introductory topics in the philosophy of natural science. New York, Cambridge University Press.

Hacking, I. (1986). Making Up People. Reconstructing Individualism. T. Heller, M. Sosna and D. E. Wellberry. Stanford, Stanford University Press.

Hacking, I. (1992). The self-vindication of the laboratory sciences. Science, Practice and Culture. A. Pickering. Chicago, University of Chicago Press: 29-64.

Hacking, I. (1999). The Social Construction of What? Cambridge, Mass., Harvard University Press.

Haig-Brown, C. (1988). Resistance and Renewal: Surviving the Indian Residential School. Vancouver, Tillacum Library.

Handwerker, L. (1994). “Medical Risk: Implicating Poor Pregnant Women.” Soc. Sci. Med. 38(5): 665-675.

Hanson, J. W., A. P. Streissguth, et al. (1978). “The effects of moderate alcohol consumption during pregnancy on fetal growth and morphogenesis.” The Journal of Pediatrics 92(3): 457-460.

Haraway, D. (1997). Modest_Witness@second_millennium.femaleman©_meets_oncomouse©. New York, Routledge.

Hard, M. L., T. R. Einarson, et al. (2001). “The role of acetaldehyde in pregnancy outcome after prenatal alcohol exposure.” Therapeutic Drug Monitoring 23(4): 427-434.

Hay, M., S. Olech, et al. (1998). FAS/E Children in Northern BC: A Study of 148 Children in one Pediatrician's Practice. Finding common ground: Working together for the future, UBC, Vancouver, B.C., Continuing Education in the Health Sciences.

Heriot, M. Jean (1996). Fetal Rights Versus the Female Body: Contested Domains. Medical Anthropology Quarterly. Vol. 10(2):176-194.

Hingson, R., J.J. Alpert, N. Day, E. Dooling, H. Kayne, et al. (1982). “Effects of Maternal Drinking and Marijuana Use on Fetal Growth and Development.” Pediatrics 70: 539-546.

Hogue, C. J. R., J.W. Buehler, L.T. Strauss & J.C. Smith (1987). “Overview of the National Infant Mortality Surveillance (NIMS) project-design, methods, results.” Public Health Reports 102: 126-138.

Ing, N. R. (1991). “The Effects of Residential Schools on Native Child-Rearing Practices.” Canadian Journal of Native Education 18(Supplement): 67-116.

Irwin, S. & B. Jordan (1987). Knowledge, Practice, and Power: Court-Ordered Cesarean Sections. Medical Anthropology Quarterly. Vol. 1, no. 3:319-334.

Jacobs, K. and K. Gill (2002). “Substance Abuse in an Urban Aboriginal Population: Social, Legal and Psychological Consequences.” Journal of Ethnicity in Substance Abuse 1(1): 7-25.

Jacobson, J. L., S.W. Jacobson & R.J. Sokol (1996). “Increased Vulnerability to Alcohol-Related Birth Defects in the Offspring of Mothers Over 30.” Alcoholism: Clinical and Experimental Research 20: 359-363.

Johansen, B. (2000). “Education - The Nightmare and The Dream: A Shared National Tragedy, A Shared National Disgrace.” Native American Hemispheric Journal of Indigenous Issues 17(4): 10-20.

Johnson, K. C. and J. Rouleau (1997). “Temporal Trends in Canadian Birth Defects Birth Prevalences, 1979-1993.” Canadian Journal of Public Health 88(3): 169-176.

Jones, K. L., D.W. Smith, C.N. Ulleland & A.P. Streissguth (1973). “Pattern of Malformation in Offspring of Chronic Alcoholic Mothers.” Lancet 1: 1267-1271.

Jones, K. L. (1975). “The fetal alcohol syndrome.” Addictive Diseases: An International Journal 2: 79-88.

Jones, K. L. and D. F. Smith (1973). “Recognition of the Fetal Alcohol Syndrome in Early Infancy.” The Lancet: 999-1001.

Jones, K. L., D. F. Smith, et al. (1974). “Outcome in offspring of chronic alcoholic women.” The Lancet 1: 1076-1078.

Jones, K. L., D. F. Smith, et al. (1973). “Pattern of Malformation in Offspring of Chronic Alcoholic Mothers.” The Lancet: 1267-1271.

Jones, K. L. and D. W. Smith (1975). “The fetal alcohol syndrome.” Teratology 12: 1-10.

Kalter, H. (1968). Teratology of the Central Nervous System. Chicago, University of Chicago Press.

Kamien, M. (1978). “The Measurement of Alcohol Consumption in Australian Aborigines.” Community Health Studies II(3): 149-151.

Kaminski, M., M. Franc, M. Lebouvier, D. Du Mazubrun & C. Rumeau-Rouquette (1981). “Moderate Alcohol Use and Pregnancy Outcome.” Neurobehavioral Toxicology and Teratology 3: 173-181.

Kan, S. (1989). Symbolic Immorality: the Tlingit Potlatch of the nineteenth century. Washington, Smithsonian Institution Press.

Keesing, R. M. (1992). Custom and Confrontation: The Kwaio Struggle for Cultural Autonomy. Chicago, University of Chicago Press.

Kelm, M. (1996). “'A Scandalous Procession': Residential Schooling and the Reformation of Aboriginal Bodies, 1900-1950.” Native Studies Review 11(2): 51-89.

Kelm, M. (1998). Colonizing Bodies: Aboriginal Health and Healing in British Columbia 1900-50. Vancouver, UBC Press.

Kleinman, A. (1995). Writing at the Margin: Discourse Between Anthropology and Medicine. Berkeley, University of California Press.

Kleinman, A., Veena Das & Margaret Lock (1997). Introduction. Social Suffering. A. Kleinman, Veena Das & Margaret Lock. Berkeley, University of California Press.

Kleinman, A., V. Das, et al., Eds. (1997). Social Suffering. Berkeley, University of California Press.

Kleinman, A. and J. Kleinman (1997). The appeal of experience, the dismay of images: cultural appropriation of suffering in our times. Social Suffering. A. Kleinman, V. Das and M. Lock. Berkeley, University of California Press.

Knockwood, I. and G. Thomas (1992). Out of the Depths the Experience of Mi'Kmaw Children at the Indian Residential School at Shubenacadie, Nova Scotia. Nova Scotia, Roseway Publishing.

Knupfer, G. (1987). “Drinking for Health: The Daily Light Drinker's Fiction.” British Journal of Addiction 82: 547-555.

Krous, H. F. (1981). “Fetal alcohol syndrome: a dilemma of maternal alcoholism.” Pathology Annual 16: 295-311.

LaDue, R. and T. Dunne (1997). Legal Issues and FAS. The Challenge of Fetal Alcohol Syndrome: Overcoming Secondary Disabilities. A. P. Streissguth and J. Kanter. Seattle, University of Washington Press.

Law Commission of Canada (2000). Institutional Child Abuse-Restoring Dignity: Responding to Child Abuse in Canadian Institutions. Ottawa, Minister of Public Works and Government Services.

Legge, C., Gary Roberts & Mollie Butler (2000). Situational Analysis: Fetal Alcohol Syndrome/Fetal Alcohol Effects and the Effects of Other Substance Use During Pregnancy. Ottawa, Canada's Drug Strategy, Health Canada.

Lemoine, P., et al. (1968). “Les enfants de parents alcooliques: Anomalies observees a propos de 127 cas [The Children of alcoholic parents: Anomalies observed in 127 cases].” Quest Medicale 2: 476-482.

Lemoine, P. and H. Lemoine (1992). “Avenir des enfants de meres alcoliques (etude de 105 das retrouves a l'age adulte) et qelques constatations d'interet prophalactique.” Annales de Pediatrie 39: 226-235.

Leslie, M. and G. Roberts (2001). Enhancing Fetal Alcohol Syndrome (FAS)-related Intervention at the Prenatal and Early Childhood Stages in Canada. Ottawa, Canadian Centre on Substance Abuse.

Lewin, E. (1990). Claims to Motherhood: Custody Disputes and Maternal Strategies. Uncertain Terms: Negotiating Gender in American Culture. F. Ginsburg & A. Lowenhaupt Tsing (eds.). Boston: Beacon Press. 199-214.

Lewin, E. (1995). On the Outside Looking In: The Politics of Lesbian Motherhood. Conceiving the New World Order: The Global Politics of Reproduction. F. Ginsburg & R. Rapp (eds.). Berkeley: University of California Press.

Lewin, E. (1998). Wives, Mothers, and Lesbians: Rethinking Resistance in the U.S.. Pragmatic Women and Body Politicss. M. Lock & P. Kaufert (eds). Cambridge: University Press. 164-177.

Li, C.K., D.J. West & T.J. Woodhouse (1990). Children's Sexual Encounters with Adults. London: Duckworth.

Lindor, E., A. McCarthy, et al. (1980). "Fetal alcohol syndrome: a review and case presentation." Journal of Obstetrics, Gynecology and Neonatal Nursing 9: 222-228.

Lipman, E. L., D. R. Offord, et al. (1993). "Follow-up of Psychiatric and Educational Morbidity among Adopted Children." J. Am. Acad. Child Adolesc. Psychiatry 32(5): 1007-1012.

Little, B. B., L. M. Snell, et al. (1990). "Failure to Recognize Fetal Alcohol Syndrome in Newborn Infants." American Journal of Diseases in Childhood 144: 1142-1146.

Little, R. E., F.A. Schultz & W. Mandell (1976). "Drinking During Pregnancy." Journal of Studies on Alcohol 37: 375-379.

Little, R. E. (1977). "Moderate alcohol use drinking pregnancy and decreased infant birth weight." American Journal of Public Health 38: 176-180.

Little, R. E., R.L. Asker, P.D. Sampson & J.H. Renwick (1986). "Fetal Growth and Moderate Drinking in Early Pregnancy." American Journal of Epidemiology 123: 270-278.

Little, R. E. and A. P. Streissguth (1978). "Drinking During Pregnancy in Alcoholic Women." Alcoholism: Clinical and Experimental Research 2: 179-183.

Little, R. E. and A. P. Streissguth (1981). "Effects of alcohol on the fetus: impact and prevention." Canadian Medical Association Journal 125(159-164).

Lock, M. (1993). Encounters with Aging: Mythologies of Menopause in Japan and North America. Berkeley, University of California Press.

Lock, M. (1997). “Decentering the natural body: making difference matter.” Configurations 5: 267-292.

Lock, M. and P. A. Kaufert, Eds. (1998). Pragmatic women and body politics. Cambridge Studies in Medical Anthropology. Cambridge, Cambridge University Press.

Lock, M. and P. A. Kaufert (1998). Introduction. Pragmatic Women and Body Politics. M. Lock and P. A. Kaufert. Cambridge, Cambridge University Press: 1-27.

Loock, C. A. (1998). Poly Drug Use. Finding common ground: Working together for the future, UBC, Vancouver, B.C., Continuing Education in the Health Sciences.

Lux, M. K. (2001). Medicine that walks: disease, medicine, and Canadian plains native peoples 1880-1940. Toronto, University of Toronto Press.

MacDonald, J. A. (1995). The Program of the Spallumcheen Indian Band in British Columbia as a Model of Indian Child Welfare. Social Welfare Policy in Canada. R. B. B. J. Keshen. Toronto, Copp Clark Ltd.: 380-391.

Majewski, F. (1981). “Alcohol Embryopathy: Some Facts and Speculations About Pathogenesis.” Neurobehavioral Toxicology and Teratology 3: 129-144.

Majewski, F. (1993). “Alcohol Embryopathy: Experience in 200 Patients.” Development Brain Dysfunction 6: 248-265.

Manuel, G. and M. Poslums (1974). The Fourth World: An Indian Reality. Don Mills, Collier-Macmillan Canada Ltd.

Maracle, B. (1993). Crazywater: Native Voices on Addiction Recovery. Toronto, Penguin Books.

Marinovich, N., O. Larsson & K. Barber (1976). “Comparative Metabolism Rates of Ethanol in Adults of Aboriginal and European Descent.” Medical Journal of Australia 1(Special Supplement): 44-46.

Martin, E. (1987). The woman in the body: a cultural analysis of reproduction. Boston, Beacon Press.

Martin, E. (1990). The ideology of reproduction: the reproduction of ideology. Uncertain Terms: negotiating gender in American culture. F. D. Ginsburg and A. L. Tsing. Boston, Beacon Press: 300-314.

Martin, E. (1997). The egg and the sperm: how science has constructed a romance based on stereotypical male-female roles. Situated lives: gender and culture in everyday life. L. Lamphere, H. Ragone and P. Zavella. New York, Routledge: 85-98.

Mattson, S. N. and E. P. Riley (1997). Neurobehavioral and Neuroanatomical Effects of Heavy Prenatal Exposure to Alcohol. The Challenge of Fetal Alcohol Syndrome: Overcoming Secondary Disabilities. A. P. Streissguth and J. Kanter. Seattle, University of Washington Press.

May, P. A., K.J. Hymbaugh, M. Aase & J.J. Samet (1983). “Epidemiology of Fetal Alcohol Syndrome Among American Indians of the Southwest.” Social Biology 30: 374-387.

May, P. A. (1984). Explanation of Native American Drinking: A Literature Review. Mni Wakan and the Sioux: Respite, Release and Recreation. R. Hornby & R. Dana (eds). Brandon, Justin Publishing: 13-27.

May, P. A. (1991). “Fetal Alcohol Effects Among North American Indians: Evidence and Implications for Society.” Alcohol Health and Research World 15(3): 239-248.

May, P. A. (1992). “Alcohol Policy Considerations for Indian Reservations and Bordertown Communities.” American Indian and Alaska Native Mental Health Research 4(3): 5-59.

May, P. A. (1995). “A Multiple-Level, Comprehensive Approach to the Prevention of Fetal Alcohol Syndrome (FAS) and Other Alcohol-Related Birth Defects (ARBD).” International Journal of the Addictions 30(12): 1549-1602.

May, P. A. (1998). The Challenges and Beauty of a Comprehensive Approach to the Prevention of FAS. Finding Common Ground: Working Together for the Future, Vancouver.

May, P. A., L. Brooke, et al. (2000). “Epidemiology of Fetal Alcohol Syndrome in a South African Community in the Western Cape Province.” American Journal of Public Health 90(12): 1905-1912.

May, P. A. and K. J. Hymbaugh (1983). “A Pilot Project on Fetal Alcohol Syndrome Among American Indians.” Alcohol Health and Research World 7(2): 3-9.

May, P. A. and K. J. Hymbaugh (1989). “A Macro-level Fetal Alcohol Syndrome Prevention Program for Native Americans and Alaska Natives: Description and Evaluation.” Journal of Studies on Alcohol 30(6): 508-518.

May, P. A. and M. B. Smith (1988). “Some Navajo Indian Opinions About Alcohol Abuse and Prohibition: A Survey and Recommendations for Policy.” Journal of Studies on Alcohol 49(4): 324-334.

McCuen, G. E. (1994). Born Hooked: Poisoned in the Womb. Hudson, Gary E. McCuen Publications, Inc.

Miller, J. R. (1987). “The Irony of Residential Schooling.” Canadian Journal of Native Education 14(2).

Miller, J. R. (1989). Skyscrapers Hide the Heavens: A History of Indian-White Relations in Canada. Toronto, University of Toronto Press.

Miller, J. R., Ed. (1991). Sweet Promises: A Reader on Indian-White Relations in Canada. Toronto, University of Toronto Press.

Miller, J. R. (1991). “Denominational Rivalry in Indian Residential Education.” Western Oblate Studies 2.

Miller, J. R. (1996). Shingwauk's Vision: A History of Native Residential Schools. Toronto, University of Toronto Press.

Miller, M., J. Israel & J. Cuttone (1981). “Fetal Alcohol Syndrome.” Journal of Pediatric Ophthalmology and Strabismus 18: 6-15.

Million, D. (2000). “Telling Secrets Sex, Power and Narratives in Indian Residential School Histories.” Canadian Woman Studies 20(2): 92-104.

Milloy, J. S. (1999). A National Crime: The Canadian Government and the Residential School System 1879-1986. Winnipeg, University of Manitoba Press.

Mitchell, L. and E. Georges (1998). Baby's First Picture: The Cyborg Fetus of Ultrasound Imaging. Cyborg Babies: From Techno-Sex to Techno-Tots. R. Davis-Floyd and J. Dumit. New York, Routledge: 105-124.

Modell, J. (1998). Rights to the Children: Foster Care and Social Reproduction in Hawai’i. Reproducing Reproduction: Kinship, Power and Technological Innovation. S. Franklin & H. Ragone (eds.). Philadelphia: University of Pennsylvania Press. 156-172.

Moffatt, K. (1999). Surveillance and government welfare recipients. Reading Foucault for social work. A. S. Chambon, A. Irving and L. Epstein. New York, Columbia University Press: 219-246.

Moffatt, M. E. K., A. E. Chudley, et al. (1996). Fetal Alcohol Syndrome, Fetal Alcohol Effects and the Impact of Alcohol Exposure during Pregnancy on School Performance and Behavior in School-Age Children in a First Nation Community. Winnipeg.

Motiuk, L. and M. Nafekh (2000). “Aboriginal Offenders in Federal Corrections: A Profile.” Forum on Correctional Research 12(1): 10-15.

Nader, L. (1972). Up the Anthropologist: Perspectives Gained from Studying Up. Reinventing Anthropology. D. Hymes. New York, Pantheon Press: 285-311.

Nandy, A. (1989). The intimate enemy: loss and recovery of self under colonialism. Delphi, Oxford University Press.

Nanson, J. L. (1997). “Binge drinking women during pregnancy: Who are the women at risk?” Canadian Medical Association Journal 156(6): 807-8.

Nanson, J. L., R. Bolaria, et al. (1995). “Physician Awareness of Fetal Alcohol Syndrome: A Survey of Pediatricians and General Practitioners.” Canadian Medical Association Journal 152(7): 1071-1076.

Nanson, J. L. and M. Hiscock (1990). “Attention Deficits in Children Exposed to Alcohol Prenatally.” Alcoholism: Clinical and Experimental Research 14(5): 656-661.

Nordstrom, M. L., S. Cnattingius & B. Haglund (1993). “Social Difference in Swedish Infant Mortality By Cause of Death, 1983 to 1986.” American Journal of Public Health 83: 26-30.

O'Neil, J. D. (1986). “The Politics of Health in the Fourth World: A Northern Canadian Example.” Human Organisation 45(2): 119-128.

O'Neil, J. D. (1988). Self-determination, Medical Ideology and Health Services in Inuit Communities. Northern Communities: The Prospects for Empowerment. G. Dack & K. Coates (eds). Edmonton, Boreal Institution for Northern Studies, University of Alberta.

O'Neil, J. D. (1991). Aboriginal Health Policy for the Next Century. The Path to Healing: Report of the National Roundtable on Aboriginal Health and Social Issues. Ottawa, Royal Commission on Aboriginal Peoples.

O'Neil, J. D. (1993). Aboriginal Health Policy for the Next Century. The Path of Healing. Royal Commission on Aboriginal Peoples. Ottawa, Minister of Supply and Services Canada:27-48.

O'Neil, J. D. and P. L. Kaufert (1990). The Politics of Obstetric Care: The Inuit Experience. Birth and Power: Social Change and the Politics of Reproduction. W. Handwerker. Boulder, Westview Press: 53-68.

O'Neil, J. D., J. Reading, et al. (1998). “Changing the relations of surveillance: the development of a discourse of resistance in Aboriginal epidemiology.” Human Organisation 57(2): 230-237.

Olegard, R., K.G. Sabel, M. Aronsson et al. (1979). "Effects on the Child of Alcohol Abuse During Pregnancy. Retrospective and Prospective Studies." Acta Paediatr Scand (Suppl) 275: 112-121.

Olegard, R. and K. Sabel (1979). "Effects on the Child of Alcohol Abuse During Pregnancy." Acta Paediatr Scand 275: 112-121.

Ouellett, B. (1988). Conference presentation. Alcohol and Child/Family Health, Vancouver, British Columbia.

Pauley, P. J. (1996). "How Did the Effects of Alcohol on Reproduction Become Scientifically Uninteresting?" Journal of the History of Biology 29: 1-28.

Pelton, L., Ed. (1981). The social context of child abuse and neglect. New York, Human Sciences Press.

Petchesky, R. P. (1994). Fetal Images: the power of visual culture in the politics of reproduction. Theorizing Feminism: parallel trends in the humanities and social sciences. A. C. Herrmann and A. J. Stewart. Boulder, Westview Press: 401-423.

Piatote, B. H. (2000). "Boarding Schools and the Future: The Trend Toward Meeting Specialized Needs." Native American Hemispheric Journal of Indigenous Issues 17(4): 32-37.

Polednak, A. P. (1991). "Black-White Differences in Infant Mortality in 38 Standard Metropolitan Statistical Areas." American Journal of Public Health 81: 1480-1482.

Poole, N. (1997). Alcohol and Other Drug Problems and BC Women: A Report to the Minister of Health from the Minister's Advisory Council on Women's Health. Victoria, British Columbia Ministry of Health and Ministry Responsible for Seniors.

Pukui, M.K., E.W. Haertig & C.A. Lee (1972). Nana I Ke Kumu (Look to the Source). Honolulu: Queen Lili'uokalani Children's Centre.

Rapp, R. (1988). "Chromosomes and communication: the discourse of genetic counseling." Medical Anthropology Quarterly 2: 143-157.

Rapp, R. (1990). Constructing amniocentesis: maternal and medical discourses. Uncertain terms: negotiating gender in American culture. F. D. Ginsburg and A. L. Tsing. Boston, Beacon Press: 28-42.

Rapp, R. (1991). Moral pioneers: women, men, and fetuses on a frontier of reproductive technology. Gender at the crossroads of knowledge: feminist anthropology in the postmodern era. M. di Leonardo. Berkeley, University of California Press: 383-395.

Rapp, R. (1993). Accounting for amniocentesis. Knowledge, power and practice: the anthropology of medicine and everyday life. S. Lindenbaum and M. Lock. Berkeley, University of California Press: 55-76.

Rapp, R. (1995). Risky business: genetic counseling in a shifting world. Articulating hidden histories: exploring the influence of Eric R. Wolf. J. Schneider and R. Rapp. Berkeley, University of California Press: 175-189.

Ray, A. J. (1974). Indians in the Fur Trade: Their Role as Hunters, Trappers and Middlemen in the Lands Southwest of Hudson Bay, 1660-1870. Toronto, University of Toronto Press.

Remkes, T. (1993). “Saying No - Completely.” The Canadian Nurse June: 25-28.

Ricketts, M. L. (1965). “The North American Indian Trickster.” History of Religion 5: 327-350.

Roberts, D. (1998). Native murder rate in Manitoba alarming, study shows. The Globe and Mail. Toronto: A3.

Roberts, G. and J. Nanson (2000). Best Practices: Fetal Alcohol Syndrome/Fetal Alcohol Effects and the Effects of Other Substances Use During Pregnancy. Ottawa, Canada's Drug Strategy Division, Health Canada.

Roberts, G. and A. Ogborne (1999). Best Practices: Substance Abuse Treatment and Rehabilitation. Ottawa, Office of Alcohol, Drugs and Dependency Issues, Health Canada.

Roberts, G. and A. Ogborne (1999). Profile: Substance Abuse Treatment and Rehabilitation in Canada. Ottawa, Office of Alcohol, Drugs and Dependency Issues, Health Canada.

Roberts, G., A. Ogborne, et al. (1999). Best Practices: Substance Abuse Treatment and Rehabilitation. Ottawa, Office of Alcohol, Drugs and Dependency Issues - Health Canada.

Robinson, G., J. Conry, et al. (1987). “Clinical profile and prevalence of fetal alcohol syndrome in an isolated community in British Columbia.” Canadian Medical Association Journal 137: 203-207.

Robinson, G. C. (1988). Opening Remarks. Alcohol & Child/Family Health, Vancouver, B.C. FAS Resource Group.

Robinson, G. C. and R. W. Armstrong (1988). Alcohol and Child/Family Health, Vancouver, British Columbia, B.C. FAS Resource Group.

Robles, N. and N. L. Day (1990). “Recall of Alcohol Consumption during Pregnancy.” Journal of Studies on Alcohol 51(5): 403-407.

Rosett, H. L. and L. Weiner (1980). “Clinical and Experimental Perspectives on Prevention of the Fetal Alcohol Syndrome.” Neurobehavioral Toxicology 2: 267-270.

Rosett, H. L. and L. Weiner (1984). Alcohol and the Fetus. New York, Oxford.

Rosett, H. L., L. Weiner, et al. (1983). “Treatment experience with problem drinkers.” J. Am. Med. Ass. 249: 2029-2033.

Rossett, H. L. (1980). “A clinical perspective of the fetal alcohol syndrome.” Alcoholism: Clinical and Experimental Research 4: 119-122.

Royal Commission on Aboriginal Peoples (1995). Choosing Life: Special Report on Suicide Among Aboriginal Peoples. Ottawa, Supply and Services.

Royal Commission on Aboriginal Peoples (1996). Gathering Strength: Report of the Royal Commission on Aboriginal Peoples. Ottawa, Minister of Supply and Services Canada.

Royal Commission on Aboriginal Peoples (1996). Looking Forward Looking Back: Report of the Royal Commission on Aboriginal Peoples. Ottawa, Minister of Supply and Services Canada.

Royal Commission on New Reproductive Technologies (1993). Proceed With Care: Final Report of the Royal Commission on New Reproductive Technologies. vol. 2. Ottawa, Minister of Government Services.

Salaspuro, M. (1993). “Nutrient Intake and Nutritional Status in Alcoholics.” Alcohol and Alcoholism 28: 85-88.

Sampson, P. D., A. P. Streissguth, et al. (1997). “Incidence of Fetal Alcohol Syndrome and Prevalence of Alcohol-Related Neurodevelopmental Disorder.” Teratology 56: 317-326.

Satzewich, V. and L. Mahood (1995). “Indian Agents and the Residential School System in Canada, 1946-1970.” Historical Studies in Education 7(1): 45-69.

Sawicki, J. (1991). Disciplining Foucault: Feminism, Power, and the Body. New York, Routledge.

Scarry, E. (1985). The Body in Pain: The Making and Unmaking of the World. Oxford, Oxford University Press.

Serdula, M., D. F. Williamson, et al. (1991). “Trends in Alcohol Consumption by Pregnant Women: 1985 through 1988.” JAMA 265(7): 876-879.

Shiono, P. H., M.A. Klebanoff & G.G. Rhoads (1986). “Smoking and Drinking During Pregnancy: Their effects on preterm birth.” Journal of the American Medical Association 225: 82-84.

Smith, D. F., G. G. Sandor, et al. (1981). “Intrinsic Defects in the Fetal Alcohol Syndrome: Studies on 76 Cases from British Columbia and the Yukon Territory.” Neurobehavioral Toxicology and Teratology 3: 145-152.

Smith, D. W. (1979). “The fetal alcohol syndrome.” Hospital Practice 14: 121-128.

Snakeskin, D. (1998). Fetal alcohol syndrome linked to crime. The Saskatoon Star Phoenix. Saskatoon: 5C.

Sokol, R. J. (1981). “Alcohol and abnormal outcomes of pregnancy.” Canadian Medical Association Journal 125: 143-148.

Sokol, R. J., J. Ager, S. Martier, S. Debanne, C. Ernhart et al. (1986). “Significant Determinants of Susceptibility to Alcohol Teratogenicity.” Annals New York Academy of Sciences 477: 87-102.

Sokol, R. J. and S. K. Clarren (1989). “Guidelines for Use of Terminology Describing the Impact of Prenatal Alcohol on the Offspring.” Alcoholism: Clinical and Experimental Research 13(4): 597-598.

Spohr, H. L., J. Willms & H.C. Steinhausen (1983). “Prenatal Exposure and Long-Term Developmental Consequences.” Lancet 341: 907=910.

Spohr, H. L., J. Willms & H.C. Steinhausen (1984). Discussion. Range of Alcohol-Induced Damage in the Developing Central Nervous System. O. E. Pratt & R. Doshik (eds). London, Pitman: 153.

Spohr, H. L., J. Willms & H.C. Steinhausen (1993). “Prenatal Exposure and Long-term Developmental Consequences.” Lancet 341: 907-910.

Spohr, H. L., J. Willms & H.C. Steinhausen (1994). “The Fetal Alcohol Syndrome in Adolescents.” Acta Paediatrica 404: 19-26.

Square, D. (1997). “Fetal alcohol syndrome epidemic on Manitoba reserve.” Canadian Medical Association Journal 157(1): 59-60.

Square, D. (1999). “Fetal alcohol syndrome diagnosed by telelink in Manitoba.” Canadian Medical Association Journal 160(5): 627.

Statistics Canada (1993). Language, Tradition, Health, Lifestyle and Social Issues. 1991, Aboriginal Peoples Survey.

Steckley, J. L. and B. Cummins (2001). Full Circle. Canada's First Nations. Toronto, Prentice Hall.

Sterling, C. (2002). Keynote address. Yukon 2002 Prairie Northern Conference on Fetal Alcohol Syndrome, Yukon.

Strathern, M. (1992). Reproducing the future: anthropology, kinship and the new reproductive technologies. New York, Routledge.

Stratton, K., C. Howe, et al., Eds. (1996). Fetal Alcohol Syndrome: Diagnosis, Epidemiology, Prevention, and Treatment. Washington, D.C., National Academy Press.

Streissguth, A. P. (1977). “Maternal drinking and the outcome of pregnancy: implications of child mental health.” American Journal of Orthopsychiatry 47: 422-431.

Streissguth, A. P. (1978). “Fetal alcohol syndrome: an epidemiological perspective.” American Journal of Epidemiology 107: 467-478.

Streissguth, A. P., H.M. Barr, D.C. Martin & C.S. Harman (1980). “Effects of Maternal Alcohol, Nicotine and Caffeine Use During Pregnancy on Infant and Motor Development at Eight Months.” Alcoholism: Clinical and Experimental Research 4: 152-164.

Streissguth, A. P., D.C. Martin, H.M. Barr, B.M. Sandman, G.L. Kirchner & B.L. Darby (1984). “Intrauterine Alcohol and Nicotine Exposure: Attention and Reaction Time in 4-year-old Children.” Developmental Psychology 20: 533-541.

Streissguth, A. P., R.A. LaDue & S.P. Randels (1987). “Indian Adolescents and Adults with Fetal Alcohol Syndrome: Findings and Recommendations.” IHS Primary Care Provider 12: 89-91.

Streissguth, A. P., R.A. LaDue & S.P. Randels (1988). A Manual on Adolescent and Adults with Fetal Alcohol Syndrome with Special Reference to American Indians. Rockville, MD, The Indian Health Services.

Streissguth, A. P. (1990). “Prenatal Alcohol-Induced Brain Damage and Long-Term Postnatal Consequences: Introduction to the Symposium.” Alcoholism: Clinical and Experimental Research 14(5): 648-649.

Streissguth, A. P., F.L. Bookstein, P.C. Sampson, H.M. Barr (1993). The Enduring Effects of Prenatal Alcohol Exposure on Child Development: Birth Through Seven Years, a Partial Least Square Solution. Ann Arbor, MI, University of Michigan Press.

Streissguth, A. P. (1994). Fetal alcohol syndrome: the ten common misconceptions. Born hooked: poisoned in the womb. G. E. McCuen. Hudson, Wisconsin, GEM publications, inc.

Streissguth, A. P., et al. (1996). Understanding the Occurrence of Secondary Disabilities in Clients with Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Effects (FAE). Seattle, WA, University of Washington School of Medicine.

Streissguth, A. P. (1997). Fetal Alcohol Syndrome: A Guide for Families and Communities. Toronto, Paul H. Brooks Publishing Co.

Streissguth, A. P., J. M. Aase, et al. (1991). "Fetal Alcohol Syndrome in Adolescents and Adults." JAMA 265(15): 1961-1967.

Streissguth, A. P., H. M. Barr, et al. (1997). Primary and Secondary Disabilities in Fetal Alcohol Syndrome. The Challenge of Fetal Alcohol Syndrome: Overcoming Secondary Disabilities. A. P. Streissguth and J. Kanter. Seattle, University of Washington Press.

Streissguth, A. P., H. M. Barr, et al. (1990). "Moderate Prenatal Alcohol Exposure: Effects on Child IQ and Learning Problems at Age 7 1/2 Years." Alcoholism: Clinical and Experimental Research 14(5): 662-669.

Streissguth, A. P., S. K. Clarren, et al. (1985). "Natural History of the Fetal Alcohol Syndrome: A 10-Year Follow-up of Eleven Patients." The Lancet July: 85-91.

Streissguth, A. P., B. L. Darby, et al. (1983). "Comparison of drinking and smoking patterns during pregnancy over a six-year interval." American Journal of Obstetrics and Gynecology 145(6): 716-724.

Streissguth, A. P. and P. Dehaene (1993). "Fetal Alcohol Syndrome in Twins of Alcoholic Women = Concordance of Diagnosis and IQ." American Journal of Medical Genetics 47: 857-861.

Streissguth, A. P. and C. T. Giunta (1988). "Mental Health and Health Needs of Infants and Preschool Children with Fetal Alcohol Syndrome: Symposium on Addiction and the Family." International Journal of Family Psychiatry 9(1): 29-47.

Streissguth, A. P. and J. Kanter, Eds. (1997). The Challenges of Fetal Alcohol Syndrome: Overcoming Secondary Disabilities. Seattle, University of Washington Press.

Streissguth, A. P. and R. A. LaDue (1985). "Psychological and Behavioral Effects in Children Prenatally Exposed to Alcohol." Alcohol Health and Research World Fall: 6-12.

Streissguth, A. P. and J. C. Martin (1983). Prenatal Effects of Alcohol Abuse in Humans and Laboratory Animals. The Pathogenesis of Alcoholism. B. Kissen & H. Begleiter (eds). New York, Plenum Publishing. 7: 539-589.

Streissguth, A. P. and K. O'Malley (2000). “Neuropsychiatric Implications and Long-term consequences of Fetal Alcohol Spectrum Disorders.” Semin Clin Neuropsych 5: 177-190.

Streissguth, A. P. and S. P. Randels (1989). Long Term Effects of Fetal Alcohol Syndrome. Child/Family Health. G. Robinson. Vancouver, University of British Columbia Press.

Streissguth, A. P., P. D. Sampson, et al. (1989). “Neurobehavioral Dose-Response Effects in Humans from Infancy to Adulthood.” Annals New York Academy of Sciences 562: 145-158.

Streissguth, A. P., P. D. Sampson, et al. (1994). “Maternal Drinking During Pregnancy: Attention and Short-Term Memory in 14-Year-Old Offspring - A Longitudinal Prospective Study.” Alcoholism: Clinical and Experimental Research 18(1): 202-217.

Stromland, K. (1985). “Ocular Abnormalities in the Fetal Alcohol Syndrome.” Acta Ophthalmologica 171: 63.

Swift, K. J. (1991). Contradictions in Child Welfare: Neglect and Responsibility. Women's Caring: Feminist Perspectives on Social Welfare. C. T. Baines, P. M. Evans & S. M. Neysmith (eds). Toronto, McClelland and Stewart: 234-271.

Swift, K. J. (1995). Manufacturing 'Bad Mothers': A Critical Perspective on Child Neglect. Toronto, University of Toronto.

Szabo, P. (2000). Fetal Alcohol Syndrome. Ottawa.

Tait, C. L. (2000). A Study of the Service Needs of Pregnant Addicted Women in Manitoba. Winnipeg, Prairie Women's Health Centre of Excellence.

Tait, C. L. (2003). Fetal Alcohol Syndrome among Canadian Aboriginal peoples: review and analysis of the Intergenerational links to residential schools. Ottawa, Aboriginal Healing Foundation.

Taylor, J. S. (1998). Image of contradiction: obstetrical ultrasound in American culture. Reproducing Reproduction: Kinship, Power and Technological Innovation. S. Franklin and H. Ragone. Philadelphia, University of Pennsylvania Press: 13-45.

Tsing, Anna Lownhaupt (1990). Monster Stories: Women Charged with Perinatal Endangerment. Uncertain Terms: Negotiating Gender in American Culture. F. Gingsburg & A.L. Tsing (eds). Boston: Beacon Press. 282-299.

U.S. Department of Health and Human Services, Centre for Disease Control and Prevention (1993). “Advance Report of Final Natality Statistics, 1990.” Monthly Vital Statistics Report 41(1-51).

Van Bibber, M. (1997). It Takes A Community: A Resource Manual for Community-based Prevention of Fetal Alcohol Syndrome and Fetal Alcohol Effects. Ottawa, Aboriginal Nurses Association of Canada.

Van Kirk, S. (1980). 'Many Tender Ties': Women in Fur-Trade Society, 1670-1870. Winnipeg, Watson and Dwyer.

Van Kirk, S. (1991). The Impact of White Women on Fur Trade Society. Sweet Promises: A Reader on Indian-White Relations in Canada. J. R. Miller. Toronto, University of Toronto Press: 180-204.

Viadero, D. (1994). Little Lasting Harm for Crack Children. Born Hooked: Poisoned in the Womb. G. E. McGuen. Hudson, Wisconsin, Gary McCuen Publications Inc.: 85-90.

Virji, S. K. (1991). “The Relationship Between Alcohol Consumption During Pregnancy and Infant Birth Weight.” Acta Obstetricia et Gynecologica Scandinavica 70: 303-308.

Vitez, M., G. Koranyi, et al. (1984). “A Semiquantitative Score System For Epidemiologic Studies of Fetal Alcohol Syndrome.” American Journal of Epidemiology 119(3): 301-308.

Vohees, C. V., S. Rauch & R. Hitzermaun (1988). “Effects of Short-Term Prenatal Alcohol Exposure on Neuronal Membrane Order in Rats.” Developmental Brain Research 38: 161-166.

Volkan, V. D. (2002). The Third Reich in the unconscious: transgenerational transmission and its consequences. New York, Brunner-Routledge.

Waldman, H. B. (1989). “Fetal alcohol syndrome and the realities of our time.” Journal of Dentistry for Children 56(6): 435-437.

Waldram, J. B., D. Ann Herring & T. Kue Young (1995). Aboriginal Health in Canada: Historical, Cultural, and Epidemiological Perspectives. Toronto, University of Toronto Press.

Walpole, I., S. Zubrick, et al. (1990). “Is there a fetal effect with low to moderate alcohol use before and during pregnancy?” Journal of Epidemiology and Community Health 44: 297-301.

Ward, M. C. (1995). Early childbearing: what is the problem and who owns it? Conceiving the new world order: the global politics of reproduction. F. D. Ginsburg and R. Rapp. Berkeley, University of California Press: 140-158.

Wente, M. (2000). Our poor ruined babies: the hidden epidemic. The Globe and Mail. Toronto.

Wente, M. (2001). Finally, we're talking about FAS. The Globe and Mail. Toronto. February 1, 2001.

Wheeler, S. F. (1993). "Substance Abuse During Pregnancy." Primary Care 20(1): 191-207.

Whiteford, L. M. and J. Vitucci (1997). "Pregnancy and Addiction: Translating Research into Practice." Soc. Sci. Med. 44(9): 1371-1380.

Williams, R. J. and S. P. Gloster (1999). "Knowledge of Fetal Alcohol Syndrome (FAS) among Natives in Northern Manitoba." Journal of Studies on Alcohol 60(6): 833-836.

Women's Health Rights Coalition (1997). Factum of the Intervenor. Supreme Court of Canada. Ottawa.

Women's Legal Education and Action Fund (1997). Factum of the Intervenor, Supreme Court of Canada. Court File No. 25508.

Wood, C. (1996). Beyond Abortion. Maclean's. August 19, 1996:14-15.

Young, A. (1995). The Harmony of Illusions: Inventing Post-Traumatic Stress Disorder. Princeton, New Jersey, Princeton University Press.

Young, A. (up.). Trauma, memory, and history. Conference Paper. Wissenschaftskoleg zu Berlin. June 2002.

Zakreski, D. (1998). Fetal Alcohol Syndrome Linked to Crime. The Saskatoon Star Phoenix. Tuesday, March 10, 1998.