

FETAL ALCOHOL SYNDROME IS A FEMINIST ISSUE.  
A FRAMEWORK FOR SERVICES AS ARTICULATED BY AND FOR WOMEN  
WHO HAVE GIVEN BIRTH TO ALCOHOL AFFECTED BABIES.

By

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## ABSTRACT

Since the mid-1980's, the issue of alcohol use during pregnancy has garnered increased social work attention. Women who consume alcohol while pregnant are at risk for giving birth to babies with Fetal Alcohol Syndrome (FAS) and other alcohol related birth defects. Many of the recommendations regarding the prevention and treatment of alcohol use during pregnancy have been written by and for professionals. Absent from these recommendations are the perspectives of the women most closely effected by the issue. Furthermore, the efficacy of treatment and prevention are often measured in terms of fetal outcome without consideration for the woman's health and well being. In an attempt to rectify the eclipsing of women from what is said and done about pregnancy and alcohol use, in-depth interviews were conducted with eight women who have given birth to an alcohol affected baby. The mothers relay their experiences of pregnancy and birth, coping with addiction, and parenting an alcohol affected child. Throughout their trajectories the mothers make efforts to take responsibility for themselves and their children but are continually dismissed or duped by those who are in a position to help. Relationships also figure prominently as adversaries, advocates or enablers. Both pragmatics and philosophy play a role in the day to day ability of the mothers to both make ends meet and to make sense of their lives. Despite these barriers the mothers are able to exert agency and self-advocacy. The stories and recommendations that the mothers offer point to a framework for services that: is holistic and driven by the mothers themselves, provides effective interventions for children and adults who are alcohol affected, offers individualized addiction services, promotes education that is specifically geared towards professionals, and addresses the structural inequities that women face. From the perspectives of the women who have given birth to alcohol affected babies, FAS is a feminist issue.

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## **CHAPTER ONE**

### **MATERNAL ALCOHOL CONSUMPTION:**

#### **A GAP IN KNOWLEDGE – AN ECLIPSING OF WOMEN**

Since the mid-1980's, alcohol use during pregnancy has been viewed as a significant social problem (Anderson, Elk and Andres, 1997: 481; Field, 2000: 5; Janson, Svikis, Lee, Paluzzi, Rutigliano, and Hackerman, 1996: 321). The issue has subsequently garnered increased social work attention (Bowers and Patterson, 1995; Carten, 1996; Cook, 1997: 65; Goldberg, 1995, Whiteford and Vitucci, 1997; Wright, 1981). Women who consume alcohol during pregnancy are at risk for giving birth to alcohol affected babies. These symptoms can manifest as Fetal Alcohol Syndrome (FAS), Fetal Alcohol Effects (FAE), Neonatal Abstinence Syndrome (NAS), or Alcohol Related Birth Defects (ARBD). Fetal Alcohol Syndrome is the leading cause of preventable birth defects in developed countries, and is considered the leading known cause of mental retardation in children (Brynlenson, Conry and Loock, 1998: 14). In Canada, the estimated incidence of FAS and other alcohol related birth defects ranges from 1 in 3000 births to as high as 1 in 500 in certain communities (Brynlenson et al, 1998: 14). In British Columbia, these figures translate to as high as 96 children each year born with alcohol related birth defects (Brynlenson et al, 1998: 14).

The exact amount of alcohol that is considered harmful to the fetus is not yet known. Research suggests a strong link between excessive binge drinking and alcohol related birth defects (Abel 1998, 1999a, 1999b). More recent studies indicate a possible link between small amounts of alcohol and fetal growth retardation, but the association remains inconclusive (Nordstrom-Klee, Delaney-Black, Convington, C., Ager J. and Sokol, R., 2002). Not all women who drink during pregnancy, even to excess, give birth to alcohol affected babies (Abel, 1998, 1999a, 1999b; Jones and Chambers, 1999: 249).

Approximately 20 to 25 per cent of women continue to drink alcohol during pregnancy (Chang, Goetz, Wilkins-Haug, and Berman, 2000: 365), and this figure can reach as high as 60 per cent in certain communities (Anderson, Elk and Andres, 1997: 481 - 482). Alcohol use during pregnancy crosses all socioeconomic groups of women (Bowers and Patterson, 1995; Goldberg, 1995). The use of other substances is often used along with alcohol use, and the choice of substance tends to vary by socioeconomic status. Women from upper-income groups tend to use alcohol and prescription drugs, and women from lower-income groups tend to have higher rates of alcohol and illicit drug use (Bowers and Patterson, 1995: 56). It is still not clear exactly how these substances interact with alcohol, and the subsequent impact they might have on the fetus.

According to Anderson et al., infants of alcohol and substance using mothers are at increased risk for child abuse, neglect, and apprehension (1997: 482). It is also thought that children of alcohol using women do not receive adequate parenting. These correlations are often taken as causal and a woman's social context is rarely factored-in. Often compounding the substance use are problems of poverty, nutrition, lack of adequate housing, and living with an abusive partner (Anderson et al., 1997: 482).

Social workers in medical settings, addiction services and child protection are well situated to assist pregnant women who use alcohol (Bowers and Patterson, 1995; Carten, 1996; Cook, 1997: 65; Goldberg, 1995, Whiteford and Vitucci, 1997: 1377; Wright, 1981). Support and treatment of pregnant women who use alcohol does result in improved outcomes of their offspring (Harrison, 1991: 263; Janson et al, 1996: 327-329). It is unclear the degree to which this positive outcome is due to improved prenatal care or to a decrease in, or abstinence of, alcohol use (Abel, 1999b: 250; Jones and Chambers, 1999: 249). It is presumed that treatment of a pregnant woman also results in improved quality of life for herself. This outcome is, however, rarely referred to in the related literature, which tends to focus on fetal outcome.

I noted a similar eclipsing of mothers within popular and professional discourse about Fetal Alcohol Syndrome during a previous investigation (Northey, 2000). Although the effects of alcohol on the fetus are openly talked about, the perspectives of the mothers who give birth to alcohol affected babies are not. The natural progression would be, then, to uncover these perspectives. These perspectives can, perhaps, inform social workers and other professionals about how we can better support women who use alcohol during pregnancy, improving the health of both the women and their babies.

## **A REVIEW OF THE LITERATURE**

### **The discovery of FAS**

Cautionary tales about the use of alcohol during pregnancy can be found throughout history in the Bible, in artwork and in medical literature (Armstrong, 1998; Neuget, 1981). However, the association between maternal alcohol use and fetal outcome was not confirmed as scientifically valid until 1968, when a French research team

published an empirical study of 127 children born to alcoholic parents (Neugut, 1981: 414). The French team noted that babies born to alcoholic parents presented distinct facial features, low birth weights and size, and mental retardation. The authors did not indicate the way in which they conceptualized or operationalized alcoholic, and the authors did not differentiate the children according to parentage. They did, however, state their reservations about the comparability between those children whose fathers only were alcoholic and others (Neugut, 1981: 415). In 1973, the prestigious British medical journal *The Lancet* published similar findings from a team of researchers in Seattle. Jones, Smith, Ulleland, and Streissguth (1973a) assessed eight unrelated children all born to alcoholic mothers. Later that same year the Seattle team described three more infants with similar abnormalities associated with maternal alcoholism (Jones et al., 1973b). These three studies taken together with two historical reports of a similar association, constituted an observable pattern that the authors labeled Fetal Alcohol Syndrome (FAS) (Jones et al. 1973b). Additional diagnostic categories, such as Fetal Alcohol Effects (FAE), Neonatal Abstinence Syndrome (NAS) and Alcohol Related Birth Defects (ARBD), have been established over the last 30 years (Loock, 1998; Stratton, Howe, and Battaglia, 1996).

What is interesting, if not telling, about the way in which FAS was “discovered” is that despite being labeled a syndrome, which denotes an unknown cause, the etiology of FAS was presumed all along. Furthermore, the list of anomalies found to be associated with the syndrome were not derived through a blind evaluation. The French team first identified alcoholic parents (although the impact of paternal alcohol consumption was not



given serious consideration), the Seattle team identified alcoholic mothers, and thus made their assessments with full knowledge of the history of alcoholism (Neugut, 1981).

The exact amount of maternally consumed alcohol that will result in a baby being born alcohol affected is not yet known. There are also a number of other mitigating factors such as nutrition, gestational age, the influence of other drug use, and the duration and timing of alcohol consumption (Abel, 1998, 1999a). The teratogenic effects of paternal alcohol consumption has only recently been considered despite a suspected association that was recognized since before the French team published their study. Despite the ambiguities and biases inherent in the construction of FAS it is taken as an objective truth that maternal alcohol consumption is bad. The cultural more against drinking during pregnancy is couched in scientific respectability, and this validity serves to reinforce the behaviour as particularly gruesome.

### **Public and professional education.**

Improving both public and professional awareness about FAS and other prenatal alcohol affects has been a key strategy towards prevention (Blume, 1996: 474; Habbick, Nonson, Snyder, Casey and Schulman, 1996: 204 - 207; Little, 2000). The success of educational campaigns is measured in terms of pregnancy outcomes (Murphy-Brennan and Oei, 1999), and not in terms of the impact they have on the lives of women who drink during pregnancy. Educational campaigns have resulted in increased stigma associated with drinking during pregnancy and have not resulted in a decline in the incidence of alcohol affected babies (Clayson, Berkowitz, and Brinidis, 1995; Dufour, Williams, Campbell and Aitken, 1994; Hankin, McCaul and Heussner, 2000; May 1994; Murphy-Brennan and Oei, 1999). In fact, Stratton et al. (1996) noted a substantial

increase in drinking by pregnant women between 1991 and 1995. The lack of a decline in prevalence rates is not surprising given that the issue appears to be one of alcohol addiction (Abel, 1998, 1999a). Knowledge of an issue is rarely a means in itself in curtailing an addiction. In addition, the shift in social mores attached to alcohol and pregnancy has been a noted deterrent to women disclosing honestly their drinking behaviour to those who can help such as social workers, physicians and counselors (Poole and Isaac, 1998; Whiteside-Mansell, Crone and Conners, 1996).

This reluctance may be further impacted by the punitive and litigious trend in responding to alcohol and substance use during pregnancy. As noted by Garcia (1993), as well as by Poole and Isaac (1998), women fear the apprehension of their children and/or their own involuntary incarceration for treatment. The highly publicized case of Ms. G. has played a pivotal role in this regard. In 1996, under the *parens patriae* jurisdiction, the Winnipeg Child and Family Services (WCFS) was successful in apprehending Ms. G., an Aboriginal woman who was four months pregnant and using solvents, placing her into involuntary treatment. The WCFS claimed that Ms. G. “owed a duty of care to herself and to her unborn fetus and [that] her actions violate[d] that duty of care” (BC Centre of Excellence, 1999: 2). The ruling was overturned by the Manitoba Court of Appeal, and then appealed at the Supreme Court of Canada where the “duty of care” argument was thrown out.

Given that women of childbearing age are the target audience of educational campaigns, it is surprising that images of women are largely absent (Northey, 2000). The most popular image is that of the fetus, indicating the extent to which it has entered public consciousness - which also extends to the courtroom. The fetus within these

intersecting contexts appears to overshadow the woman who carries the fetus (Northey, 2000). It is encouraging that recent educational material has elicited input from women who have given birth to alcohol affected babies. The result of one such effort has been the inclusion of actual pregnant women in a television commercial that aired in the Yukon. The message *from* pregnant women who drink *to* pregnant women who drink was that “help is available” (Northey, 2000).

### **The invention of prenatal care.**

The sight of a pregnant woman using alcohol or illicit substances - or even taking a few tablets of mild pain medication for a headache - has not always been a grotesque scene. These pre-natal “don’ts” are tied to the invention of prenatal care that emerged in Canada out of a concern for building a strong Nation and needing a healthy pedigree with which to protect it. Overwhelmed by the high rates of maternal morbidity, the Department of Health set out to instruct mothers in the ways of proper diets, cleanliness, rest and exercise. The hegemonic nature of pre-natal care is laid out in the 1923 *Canadian Mother’s Book* : “the mother is the first servant of the State”, meaning “no baby - no Nation” (McMurchy, 1923: 1, 8). The terms “mother” and “woman” are used interchangeably suggesting women’s ultimate and expected maternal role.

The disciplining project, to borrow a concept from Michel Foucault (1977), of prenatal care continues to advance. Foucault (1977) observes how power and knowledge are linked to create a norm in modern society. Institutions, establishments and procedures, operate as forms of disciplinary power whose aim is to rectify any deviance from the norm. The same mode of operation can be observed within prenatal care: The main goal is to homogenize the pregnancy scene and bring “deviant” mothers in line with

the normal (Boyd, 1999). The knowledge of teratogens has played a significant role in this project, even though much of the science in the area remains ambiguous. Monitoring the fetus itself has become part and parcel of prenatal care. This is due to the growing knowledge of birth defects and the aid of sonography. The personhood of the fetus that sonography suggests presumes motherhood at the point of conception. It also contributes to the idea that anything a pregnant woman does to her body is “doing to the fetus”. The context of the fetus - the woman, her body and her social situation - are disregarded. The woman is reduced to a container for the fetus; whatever happens to the fetus is ultimately her responsibility and her fault.

This plot is exasperated by a relatively new area of business that posits the fetus as a commodity. For example, Viacord’s Cord Blood Banking Service offers, for a fee, to store the blood of the newborn umbilical cord for the family’s future use. The umbilical cord blood contains stem cells that can divide to make new blood and immune cells. By storing the cord blood a precious resource is banked, ready to be withdrawn in the event that it is needed to fight certain cancers and genetic disorders within the family. Business interests market their involvement in the pregnancy scene as a natural “part of the labour and delivery team” (Viacord, 1999). The umbilical cord is presented as a precious resource and the pregnant woman as the container for this resource.

With the commodification of motherhood women and their babies are reduced to objects “subject to quality control” (Schwartz, 1994: 245). The plight of Ms. G. brings into full view the extent to which the State will apply this quality control of the maternal. Ms. G. is reduced to the surrogate of the State which is reminiscent of early twentieth century sentiments: “No Baby - No Nation” (McMurchy, 1923: 1, 8). Although

technology and science have evolved the ideologies tied to motherhood and woman's presumed maternal role have merely solidified.

### **The ideologies tied to motherhood.**

A sizable body of work critiques the ideologies underlying the prescription of motherhood (Bassin, Honey and Kaplan, editors, 1994; Ginsburg and Rapp, 1995; Kline 1995; O'Connor, 1993; Petchesky, 1985; Rapp, 1997; Rich, 1976). A common observation in these inquiries are discourses which posit motherhood as the natural desire of all normal women, that a mother should unselfishly put the child's needs before her own, and that a mother always remain available to her children to support both physically and emotionally (Bassin et al, 1994; Kline, 1995: 119; O'Connor, 1993; Rich, 1976). Abramovitz (1995) demonstrates how women, and in particular mothers, have historically been blamed for social problems. Child rearing has been scrutinized as too passive or too aggressive, too doting or not readily available, and so on, as defined by the psychology and ideologies of the day. These practices, always flawed, are ultimately responsible for the health and well being of the family, as well as all realms of society (Abramovitz, 1995). As Clemmons states, "concern about a woman is focused on what she does rather than who she is. The concern is for her effect on society in a moral arena or a maternal arena; it is not the woman as person who is valued but rather the role she is fulfilling for society" (in Field, 2000: 5).

Unlike the pregnant woman who is fulfilling her normalized role, the addict is seen as deviant. The motherhood discourses intersect with what is said about women and addiction, further ostracizing the "pregnant addict". In analyzing the deliberations made during the Ms. G. case, Callahan (2000) notes that a number of assumptions are made

about women and substance use. She observes that although addiction is recognized as playing a role in substance use during pregnancy, the main impetus is presumed to be the desire to pursue a certain lifestyle. That is, addictions are a lifestyle choice. The pregnant addict, then, is childish, selfish and unable to think of others or of the future (Callahan, 2000: 45).

### **The mother. The fetus.**

In much of the social work, medical and legal discussions about alcohol use and pregnancy, the pregnant woman and fetus are considered two separate entities. Within social work practice the issue is posited as balancing a commitment to “promote client self determination, privacy and access to chosen services, with professional values that support coercive intervention to aid vulnerable people and to protect life” (Bowers and Patterson, 1995: 55; see also Wright, 1981). The systems within which workers operate are identified as contributing to this separation of allegiance (Field, 2000: 19-20). On the one hand, the child protection system aims to assist the woman to become a “good mother” by submitting to a plan as outlined by the worker (Field, 2000: 19-20). Addiction services, on the other hand, aim to assist the pregnant substance using woman to develop and use greater personal power in the process of recovery (Field, 2000: 19- 20). Far from a holistic approach the two seem adversarial: one system values empowerment while the other insists on submission (Field, 2000: 19-20).

A review of the medical literature reveals a similar division between medical specialties. The pediatrician’s primary focus is on the child, whereas the obstetrician’s ultimate concern is for the mother (see Abel, 1999a: 4-6; Abel, 1999b: 250; Jones and Chambers 1999: 249). Rather than contribute to a comprehensive team of care, the

differing perspectives have erupted in a clash between specialties. In the *Joint Statement: Prevention of Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Effects (FAE) in Canada*, (Health Canada 1996) the Society of Obstetrics and Gynecologists of Canada (SOGC) is not listed among the 18 co-signatories. The SOGC refused to sign the document because the statement took the following position:

*there is no definitive information that can be conveyed to women regarding a safe quantity of alcohol use during pregnancy. Consequently, the prudent choice for women who are or may become pregnant is to abstain from alcohol* (emphasis in original) (Health Canada 1996: 3).

The SOGC took offense to the document's emphasis on "*the* prudent choice", which they felt should more appropriately read "*a* prudent choice" for women. The Canadian Pediatric Society coordinated the project and it is their perspective that came through in the final draft. Similar debates between pediatricians and obstetricians have been openly debated within scientific journals (see Abel, 1999a: 4-6; Abel, 1999b: 250; Jones and Chambers, 1999: 250). Rather than ask women what information they would find helpful while drinking during pregnancy, professionals argue amongst themselves about what is best. Such a paternalistic performance contributes to a power imbalance which situates the professional as the expert knower, and the woman who is actually experiencing the phenomenon as incompetent.

In Canada, the unborn fetus is not considered a legal person. Still, the ideologies and values attached to the fetus in this age of reproductive technologies and perfect babies do point to a cultural privileging of the fetus. The case of Ms. G. has sparked a number of deliberations that ponder the legal and philosophical implications of

considering the fetus as a legal entity with rights that need to be protected from the addicted mother (Caulfield and Nelson, 1998; DeCoste, 1998; Diduck, 1998; Shanner, 1998). Daniels (1993) in particular articulates the dilemma posed for feminists, and women in general, when the fetus is privileged. Callahan, similarly notes that during the Ms. G. case women's rights were constructed as primarily concerned with their own right to freedom (2000: 45). This right was seen to be in conflict with a woman's responsibility to care for her children. The fetus was also seen to be in need of protection from willful, selfish mothers like Ms G., and that the state was in a position to offer that protection (Callahan, 2000: 45). A recent study of mothering discourse reveals that the rights of a mother are often seen as secondary in the face of policy, legal and media responses to the concept of "the best interests of the child" (Greeves, Varcoe, Poole, Morrow, Jonhnsen, Pedersen and Irwin, 2002).

### **Screening and identifying women at risk.**

Women report pregnancy as a motivating factor in reducing their in-take of alcohol or abstaining altogether (Bruce and Williams in Field, 2000; Finklestein, in Field, 2000; Chang et al. 2000: 365; Hankin et al., 2000: 1277). Therefore, professionals who can identify a woman who is drinking during pregnancy have a "window of opportunity" to intervene (Anderson, et al, 1997: 481; Chang, et al., 2000; Field, 2000: 5; Hankin et al., 2000: 1277). Even brief interventions have been proven effective in this regard (Anderson, et al, 1997: 481; Chang et al., 2000: 365-369). Consequently, much has been written about the best way to assess and inform pregnant women about personal alcohol use (Anderson and Grant, 1984: 7-10; Handmaker, Miller and Monicke, 1999; Loneck, Garrett and Banks, 1997; Looock and Pool, 1998: 55 - 74; Masis and May 1991; and



Russell 1994). The British Columbia Reproductive Care Program (BCRCP) has adopted the T-ACE questionnaire, which is considered an effective tool in eliciting a disclosure of prenatal alcohol consumption (Chang, Wilkins-Haug, Berman, Goetz, Behr, and Hiley, 1998: 892-98; Sokol, 1989). Despite the fact that screening for prenatal alcohol use is supposed to be standard protocol for all health care providers, research indicates that not all patients are screened (Chang et al. 2000; Hankin, et al., 2000; Northey, 2000). A recent survey of seventy-five family physicians in the Metropolitan Toronto area concludes that none of the physicians were aware of the current screening methods to accurately gauge alcohol use in pregnant and childbearing women (Nevin, Parshuran, Nulman, Koren and Einarson, 2002). The family physicians also did not feel confident in diagnosing FAS (Nevin et al. 2002).

Attempts to construct a profile of 'the woman at risk' have been made in an effort to identify more readily those women who may be at greatest risk. Constructing a profile is also thought to lend insight into why some women who drink during pregnancy do not give birth to alcohol affected babies while others do (Abel, 1982, Clarren, 1998, 2000; Gladstone, Levy, Nulman, and Koren 1997; Golberg 1995; Nanson, 1997; and Sokol, Miller, Sheldon and Reed, 1980). Characteristics associated with pregnant alcohol abusing women include a history of childhood sexual and physical abuse, the use of multiple illicit substances, living with a partner who also uses alcohol and/or other illicit substances, a history of multiple pregnancies, no prenatal care or accessing care late (after the first trimester), a previous birth of an alcohol affected baby, and an untreated mental illness (Abel, 1982, Clarren, 1998, 2000; Dineen, 1994; Gladstone et al., 1997; Goldberg, 1995; Marcenko and Spence, 1995).

Although these findings are sensitive, they are not yet specific enough to create a detectable profile (Abel, 1982; Clarren, 1998). The extent to which such a profile will assist women who use alcohol during pregnancy is also questionable. At best the profile will be able to identify certain correlations. Beyond that, it is difficult to ascertain the nature of the associations; the characteristics, or 'risk variables' do not *explain* a woman's behaviour. A paradigm shift appears to be in order if these 'variables' are to be viewed in terms of a woman's personal strengths or needs. A qualitative approach that elicits the experiences of women would be helpful in this regard as the experiences of these women, more so than their characteristics, is thought to lend insight into how to best approach and support them (Rutman, Callahan, Lundquist, Jackson and Field, 2000: 152). Unfortunately, Rutman et al. note, "there is currently a dearth of knowledge about the life experiences of "those women" who use substances during pregnancy" (2000: 152).

### **Treatment.**

Once a woman has been identified as at risk, a program of treatment is suggested. Research suggests that the most successful programs are comprehensive and participant driven (Anderson and Grant, 1984; Clayson et al., 1995; George 1993; Masis et al. 1991; Streisguth 1994: 60; and Whiteside-Mansell, Crone and Conners 1999). Unfortunately, the majority of treatment programs have assumed what is best rather than ask what is needed and wanted. As Field notes, "there is a large body of literature written by professionals for professionals, ...suggesting how to treat and identify [pregnant women who use alcohol and other substances] (2000: 1). That alcohol addiction has historically

been viewed as a male problem, and that many treatment programs still reflect this presumption, is a case in point (Rhodes, 1997; Whiteside-Mansell et al. 1999).

Developing women-sensitive and women-centered treatment programs is a need identified in recent studies (Murphy and Rosenbaum, 1999; and Poole and Isaac, 1998; Rhodes and Johnson, 1997). These recommendations stem from a feminist philosophy that adopts a concept of empowerment and encourages women to have a say in the conditions of their own lives including treatment for their addictions (Murphy and Rosenbaum, 1999; Poole, 1997: 7; Rhodes and Johnson, 1997; Young, 1994: 48). A feminist proclivity is detected in Poole's (1997) report to the Ministry of Health of British Columbia. Poole suggests that services for women using substances be collaborative in practice between women and their healthcare providers, and that women should be both knowledgeable about, and active participants in their own care (1997: 7).

Given that social work crosses all of the domains discussed in this section, we have ample potential to get caught between conflicting paradigms. We also have the opportunity to advocate for the woman and her baby, together as a unit. The social worker is well situated to put the "fetus back into the uterus, the uterus back into the mother, and the mother back into her social context" (Petchesky, 1985).

### **THE PURPOSE OF THIS STUDY.**

What is largely missing from the research in this area are the voices and experiences of the women most directly affected by this issue. Although the research conducted stems from perceived gaps in knowledge, the assumptions about what is important are not driven by women who consumed alcohol during pregnancy and subsequently gave birth to alcohol affected babies. This absence results in a

marginalization of women who give birth to alcohol affected babies, allowing researchers and other professionals, including social workers, to occupy center stage as the expert knowers. In an effort to rectify this power imbalance, a purpose of primary importance for the present inquiry is to give voice to women who have been marginalized and stigmatized in the literature about pregnancy and alcohol addiction. Given that only some, and not all, women who drink during pregnancy give birth to alcohol affected babies, the investigation chose as its focus biological mothers of affected babies. This particular focus is an attempt to validate the lived experiences of these women, and to also lend insight into their trajectories as set-apart from the generalized “pregnant addict”.

When planning this study, I initially wanted to discover what these women identify as helpful or not during the nine months of pregnancy and through the neonatal period. This purpose was later expanded to uncover the needs of parenting an alcohol affected child, as this was an area that the mothers felt was largely neglected by professionals. The third purpose stems from these identified needs and strengths: to design a framework of support services as articulated by and for women who drink during pregnancy.

The question that the proposed study set out to answer was: What services do biological mothers of alcohol affected babies say they need during the prenatal, birth and neonatal periods? During the interviews the women spoke as much about parenting a special needs child as they did about the struggle with alcohol use. In the spirit of inclusiveness the original research question was then expanded beyond the neonatal period. From their own experiences of drinking during pregnancy and parenting an

alcohol affected child, what formal (medical, social work), and informal (friends, public information) supports have women found helpful and not helpful? What motivated them to seek services? What were the barriers that prevented them from seeking and/or receiving assistance? What was their experience with professionals during pregnancy, delivery and beyond? What was helpful and not helpful during those times?

## CHAPTER TWO

### RESEARCH DESIGN

#### Overview

In order to elicit the experiences of women who have given birth to alcohol affected babies, a methodology that is “sensitive enough to articulate the nuances of human experience and reflection” is needed (Pollio, Henley and Thompson, 1997: vii). A qualitative approach that utilizes open-ended, semi-structured interviews is well suited to this endeavour. The principles guiding this approach stem from the phenomenological tradition of inquiry and incorporate a feminist perspective.

Merleau-Ponty’s brand of phenomenology that concerns a description of the lived body is particularly applicable to this inquiry. Merleau-Ponty’s concept of the “lived body” seeks to overcome the Cartesian mind-body dualism, and to emphasize that human beings both have a body and are bodies (in Pollio et al., 1997: 5). The perspective that Merleau-Ponty attacks is parallel to the tendency to separate the woman from her pregnant body. Given that the phenomenon that the present inquiry is looking at is, at least in part, of an embodied nature, his goal of keeping intact the phenomenon and the body seems relevant.

Consistent with feminist methodology, the women who participate in this inquiry are positioned as experts of their own experiences (Harding, 1997: 166; Thorne and Varcoe, 1998: 481). By contrast, the investigator is positioned as the apprentice who studies under and learns from the participants. Through an interactive and negotiated process the participants were given the opportunity to review for accuracy, transcripts

and interpretations for accuracy. In this way, the investigator worked ethnographically, allowing the phenomenon under investigation to lead her to what is important.

### **Sampling frame.**

As previously stated, not all women who drink alcohol excessively during pregnancy give birth to alcohol affected babies. Therefore women who have given birth to alcohol affected babies are the focus of this investigation, as opposed to women who drank during pregnancy. Such a focus has the advantage of identifying a unique cohort within the generalized “pregnant addicts.” In an effort to make participation inclusive, yet specific, an alcohol affected baby is operationalized both as children who have received a medical diagnosis of Fetal Alcohol Syndrome, Fetal Alcohol Effects, Neonatal Abstinence Syndrome, or Alcohol Related Birth Defects, and those who have not received a formal diagnosis, but who are strongly suspected to have been affected by their mother’s maternal alcohol consumption. A definite diagnosis is difficult to make as few clinicians are sufficiently trained in this area (Nordstrom, et al., 2002; Astley and Clarren, 1999: 1). In order to keep the sample as inclusive as possible, the mother is situated as the expert knower whose own “diagnosis” is considered valid. Although the term Fetal Alcohol Effects has been discontinued as a diagnostic category (Asse, Jones and Clarren, 1995), it is still an active designate within popular and professional discourse about fetal alcohol effects. For that reason, the present study included it as part of the sampling frame during the recruitment of participants.

Other than giving birth to an alcohol affected baby the criteria for sample selection was fairly open. A participant could be the primary parent and caregiver of the affected baby, or the baby could be in temporary or permanent care of someone else. The

respondent may currently be using alcohol or have quit drinking. Participation was limited to women who were nineteen years of age or older when their child was born. The needs of pregnant adolescents are likely different from adult women. In order to ensure some homogeneity of experience, the present investigation focuses on the experiences of adult women.

A total of eight women participated in the study. The choice of sample size is consistent with what others recommend as appropriate for eliciting a thick description of a particular phenomenon. Kvale notes that for the purpose of exploring and describing experience, the number of interviews needed range from five to twenty-five (1996: 102; see also Cresswell, 1998: 113, 122). In short, the goal is not one of attaining a representative sample of some population or domain. Systematic selection of a small sample that is typical and has relative homogeneity, “provides far more confidence that the conclusions adequately represent the average members of the population” than a sample of the same size randomly selected (Maxwell, 1996: 71).

Participants were recruited via third parties - physicians and agency representatives who have contact with women who drink during pregnancy. An introductory letter was sent to the third party explaining the nature of the study, along with a request for their assistance in locating participants. Physicians and agency representatives who agreed to assist were sent posters (“call for research volunteers”) with instructions for distribution. The posters prompted at least two women to respond to the investigator directly. Another four asked an agency to forward their names and contact information to the investigator. The final two participants were recruited through a snowball sampling: one woman referred two of her acquaintances.



At the time of initial contact, and again just prior to the interview, the participants were informed of the focus of the study, of the voluntary nature of participation, of their right to withdraw from the study at any time or refrain from answering any questions. Each participant signed an informed consent form that stipulated this as well. Participants were also informed, both verbally and on the consent form that although their views were held in confidence, the researcher was, however, obligated to report disclosures of abuse or threats of harm to children.

That I hold the title of “social worker” may have negative connotations for some participants. This may contribute to sampling bias in terms of who volunteers to participate. However, to not disclose the academic degree I am undertaking would be a form of deception. Additional bias may derive from my own social location. Although I take an interest in women’s health issues, I have never experienced motherhood. I note at the outset that this phenomenological distance may have assisted me in retaining some professional objectivity, but it could have also prevented me from asking certain questions during the interview, and could possibly cloud my analysis. By openly relaying my location I am attempting to utilize what Sandra Harding refers to as “strong objectivity” (1991: 136 - 162). Harding associates “strong objectivity” with socially situated knowledge, a process that acknowledges the social situatedness, the “historicity”, of the “very best beliefs that any culture has arrived at or “discovered” (1991: 138-162). This is in contrast to a destructive objectivity – one that lacks recognition and insight into the thing. (1991: 138-162).

### **Data collection strategy.**

The form of data collection most appropriate for attaining a thick description of the women's experiences is that of a phenomenological interview, or dialogue as Pollio et al. call it (1997: viii, 28-29). The phenomenological interview is "a rigorous and significant description of the world of everyday human experience as it is lived and described by specific individuals under specific circumstances" (Pollio et al, 1997: 28). During the interview process, or dialogue, the investigator assumes a respectful position vis-à-vis the real expert - participant (Pollio et al. 1997: 29). Whereas a traditional/positivist inquiry may focus on the characteristics of the person discussing a phenomenon as divorced and objectified from their context. By contrast, the phenomenological interview focuses on the phenomenon being discussed; that is, on what is being said and how the speaker is related to the phenomenon.

The interviews with the mothers were semi-structured in the sense that only a few pre-specified questions were used. These questions acted only as a guide to exploring the prenatal, birth and neonatal experiences of the mothers, as well as what they saw as an appropriate framework for services. Consistent with what Pollio et al. (1997) advise, the majority of the questions flowed from the dialogue as it unfolded, rather than being predetermined. The mothers felt compelled to move beyond what I had identified as the primary focus of the interview. Working ethnographically, I allowed the women to lead me to what they felt was important to know. The interviews subsequently took on the appearance of life histories as the women offered context of great depth for their experiences as mothers of alcohol affected children. The process was an iterative one as

all participants were given the opportunity to review verbatim transcripts of the interview(s) in order to suggest changes and/or to clarify meaning.

The interviews were conducted at a mother's home, places of work, or in some cases an agency provided a neutral location for us to meet. Unlike a therapeutic interview, there was no ameliorative concern with the research interview. The interviewer was interested in describing the phenomenon not counselling the discussant (Pollio et al., 1997: viii). That being said, there was a feminist concern for giving voice to the oppressed, and this aim of empowerment encompassed an ameliorative function by nature. This type of interview does pose a potential for emotional strain, and indeed the participants displayed emotion, stress and nervousness during the interviews. The interviews were therefore conducted in such a way as to ensure that the session did not end in an intense state. The interviews ended with a de-briefing and resource information was offered when appropriate.

The choice of data collection may be criticized for relying on subjective experience, which is seen to lack a connection to an objective reality. However, this concern is not valid as what is real "is that which is lived as it is lived" (Pollio et al, 1997: 31). All knowledge, including self-knowledge is constructed in social discourse (Pollio et al., 1997: 31). A study which begins with pre-determined variables enters the "investigation" with a myopic disadvantage: it is looking *for* instead of looking *at*. The advantage of the method employed is that it is flexible enough to move in the directions of what the speaker identifies as important. It is this flexibility that allowed the women to talk as much about the pregnancy experience as their experiences of parenting a special needs child.

That the data collected rely on retrospection may also be criticized for questionable accuracy as memory tends to be selective. However, in actuality, meanings of lived experiences are not static. They change as recollections of the past interact with the present social-historical-political context of the person who experienced the phenomenon. Thus, recollections are fictions in the sense that they are made, not in the sense that they are false.

#### **Data management.**

The interviews were audio-taped, and the tapes transcribed verbatim. Participants were given pseudonyms and no identifying information was included. The tapes and transcripts along with my documented observations constitute the data. For reasons of safety and confidentiality, the data were kept in a locked filing cabinet separate from other study materials, such as signed consent forms.

#### **Data analysis.**

The data were analyzed through both categorizing and contextualizing. Categorizing refers to the identification of dominant themes across the different interviews; contextualizing situates the phenomenon within each individual case. This process of analysis draws from Moustakas' modification of the Van Kaam method of analysis of phenomenological data (1994: 120). It begins by horizontalizing the data by listing from the transcribed interviews every statement, or horizon, relevant to the women's experiences of being a biological mother of an alcohol affected baby. Each horizon is regarded as having equal value (Moustakas, 1994: 118). All horizons referring to an aspect that is necessary to an understanding of a woman's experience of giving birth

to an alcohol affected baby is extracted. These extractions form the invariant constituents of the phenomenon (Moustakas, 1994: 121). All other expressions are eliminated.

The invariant constituents that are in some way related are then clustered into themes. These are the core themes representing the women's experiences.

The invariant constituents and their accompanying themes are checked against the participant's transcribed interview. If the invariant constituents and themes are expressed explicitly, or are compatible if not expressed, they are considered relevant to the woman's experience; all others are discarded.

Using the validated invariant constituents and themes, individual textural descriptions for each woman were constructed (Moustakas, 1994: 121, 133). Thus, the nature and focus of the pregnancy experience, as narrated by each participants was illuminated, including the associated situations, conditions, thoughts, feelings and struggles. From the total textural descriptions a composite textural description of the experience was then composed. Individual structural descriptions were then constructed for each woman's experience. These descriptions provided a vivid account of the underlying dynamics of a woman's trajectory; the themes and qualities that accounted for how and under what conditions feelings and thoughts about her experience were aroused (i.e. fear of having the baby apprehended). A composite structural description was similarly composed. The composite textural and composite structural descriptions were then woven together, providing a synthesis of the meanings and essences of the woman's experience of giving birth to an alcohol affected child.

Moustakas' (1994) model worked well as a systematic, yet not rigid, method for uncovering the lived experience. The participants' stories dictated the "variables" and

outcome of the analysis, and the analysis could begin as soon as the first interview was complete. The model allowed room for reflection and creativity. Through the process of comparisons, and in considering the similarities and differences, a synthesis occurred. Although the model does have the potential to overlook or discard a story that is inconsistent but important nevertheless, the researcher actually found that it allowed for greater inclusivity. The inclusion of a participant who might otherwise be considered an “outlier” is discussed in more detail in the next chapter.

### **Trustworthiness.**

Although efforts to address potential threats to validity have been alluded to throughout this chapter, the issue deserves additional space of its own. The concept of validity here does not refer to some definitively right conclusion. Rather, it refers to the credibility of claims that are being made (Maxwell, 1996: 87). Methods cannot guarantee validity, but they can help generate evidence to rule out threats to validity. In order to determine that the descriptions and interpretations generated through the research process are valid/ credible, the potential threats to validity will first be identified. From there, strategies to address these threats to validity are presented. These strategies are not meant to verify validity, but are rather a means to test the validity of the conclusions I make and the existence of potential threats to those conclusions (Maxwell, 1996: 92).

The goal of the present study is not to arrive at some objective truth. The stories presented here provide useful information about the experiences of women who give birth to alcohol affected babies. This information can and should influence service delivery in ways that better meet the particular wants and needs of these women. The present investigation also points to further questions and additional areas of inquiry. The

process of inquiry into the social world is ongoing - one never gets to the bottom of a matter (Maxwell: 1996: 87).

**Potential threats to validity and strategies to address them.**

Validity threats refer to ways in which my descriptions and interpretations have the potential to be invalid. Invalid, in this context, refers to the potential for alternative explanations to the conclusions that I have drawn about the needs of women who give birth to alcohol affected babies. For example, my assumption, and a well researched assumption, that the women I am concerned about have been oppressed does have the potential to cloud my ability to see that the participants are not oppressed, or that they are themselves oppressors. Similarly, my virtuous goal of “giving voice” to these women does presume a paternalistic agenda, however sincere my intentions. With both these concerns the women’s stories spoke louder and acted to not only reinforce these assumptions, but also revealed the resiliency and agency that the women possess.

Another threat to validity relates to the potential of the descriptions of the women’s experiences to be inaccurate or incomplete. This potential will be largely minimized through the use of audio recordings and by transcribing verbatim the tapes. The descriptions that I constructed are as detailed as possible, which should minimize any tendency to indiscriminately pick and choose data to support some prejudice (Maxwell, 1996: 95). In addition, there is a potential for me to impose my own framework of meaning upon the interpretations, rather than understanding the perspectives of the participants (Maxwell, 1996: 90). To protect against this threat, the participants were given the opportunity to review the transcribed tapes and interpretations for accuracy. Through a process of dialogue and negotiation, the participants’ feedback was

incorporated into the data and analysis. As previously stated, cases that appeared discrepant were not necessarily discarded. All of the women's stories were reported, as so-called discrepancies are still important sites of knowledge that can inform analysis. Finally, my own presence during the interview likely had an influence on how the participants responded. The use of open-ended questions assisted in minimizing this effect, but reactivity, as Maxwell calls it, cannot be completely overcome (1996: 91). I made a conscious effort to be sensitive to when I might have influenced the process. For example, the detecting of a woman's guarded response as a reaction to my title of social worker and/or my obligation to report certain disclosures.



## **CHAPTER THREE**

### **LISTENING TO MOM**

#### **THE MOMS**

It was anticipated at the outset of this project that recruitment of participants would be difficult due to the stigma attached to maternal alcohol consumption. Contrary to this perception, eight women readily volunteered to participate and all were interviewed. The women appreciated the opportunity to tell their stories and felt that they were contributing to research that “needs to be done”. An agency that assisted in third party recruiting offered to send even more women, as interest in the project had heightened. This response to recruitment, and being able to surpass the anticipated number of respondents, reinforced my belief in the necessity for an inquiry focused solely on the experiences of biological mothers of alcohol affected children.

Most of the mothers have used multiple illicit substances in addition to alcohol and were at various stages of sobriety. April and Mytayja were still struggling with their addictions while the others were no longer abusing alcohol and other substances. With one exception, all held to the traditional 12-step Alcoholic Anonymous program to assist them in their sobriety - regardless of whether they were active in their recovery or not. These mothers talked about their addictions within the medical model framework in that the addiction was seen as a “disease” in need of “treatment”. By contrast, Sally has

adopted a form of harm reduction. She continues to drink socially and stated that she is no longer using or abusing alcohol.

Mytayja was somewhat unique and could be considered an “outlier” by other research standards. She did meet the criteria for participation but it was unclear whether or not her daughter was alcohol affected. Mytayja did drink alcohol during her pregnancy and did give birth to a baby with neonatal abstinence syndrome (NAS) – a category that includes babies affected by drugs and/or alcohol. Mytayja believed that the amount of alcohol she consumed while pregnant was minimal - two glasses of wine on one occasion. She contended that her most problematic drug during her pregnancy had been crack cocaine, which she used in significant amounts. She had also been led to believe by medical professionals that her daughter’s symptoms of withdrawal at birth were the result of her cocaine use. Regardless of whether Mytayja’s baby may be drug affected and not alcohol affected I decided to include her in the inquiry for a couple of reasons. First, and most importantly, Mytayja very much wanted to be included in the project. Secondly, I could not rule out for certain that her daughter was not alcohol affected. Finally, Mytayja’s story was very similar to the other mothers’: she has had to navigate the same systems and resources as the others, and has confronted the same cultural mores that shun all mothers who “do that” to their babies.

A brief description of each mom is provided below, followed in the next section by a more in depth account of their experiences.

### *Sally*

Sally is a thirty six- year-old single mother of four children aged thirteen, eleven, nine and six. Her eleven-year-old daughter was diagnosed with Fetal Alcohol Syndrome

at the age of seven. As Sally explained, her “time is really stretched” between caring for her children, attending college to complete a diploma in professional writing, and volunteering as board member for a mental health advocacy group. She does all of this while dealing with a chronic auto-immune disorder that results in severe exhaustion. A very articulate and motivated woman, Sally relayed that for the most part she embraces and copes well with the challenges that this busy lifestyle presents. There was a time, however, when alcohol provided a means of coping with a very unfulfilled existence. Early in her second pregnancy she drank heavily. Working in a bar, Sally found that easy access to alcohol helped her to medicate an undiagnosed mental illness and the scars of past traumas.

### ***Laura***

Laura participated in the inquiry for both personal and professional reasons. She counsels families who have alcohol and/or drug affected children, and is also the mother of an eleven-year-old boy who has FAS. Laura drank only once during her pregnancy, but the amount was excessive: 26 ounces. Binge drinking was Laura’s pattern, a response to life difficulties and painful memories of sexual abuse. Although parenting has been extremely stressful at times, she copes better now having celebrated seven years sobriety. At 30 years of age, Laura enjoys being a mother of three biological sons and has recently become foster mother to a daughter. She presents a calm yet energized disposition and takes pride in her First Nations ancestry.

### ***Julie***

Julie identifies herself as “a birth mom” to a twenty two-year-old son with Fetal Alcohol Syndrome. Julie remained private with respect to some personal details, but

based upon her narrative she is in her early to mid forties. Julie did disclose with much exasperation that her and her son have lived “a horrendous life together”. Her ten years of sobriety and active participation in Alcoholics Anonymous has made parenting alone a special needs child just bearable. She insists that more needs to be done to understand what FAS is and how to best intervene. This poised yet pensive woman has taken this on as a personal task. Julie is presently attending classes to learn how to start a non-profit organization that will raise funds to help her son and others like him.

### *Kay*

A single mother to two daughters, Kay is a soft spoken forty-one year old survivor. She started drinking at twelve having been sexually abused since the age of one and half years. She soon graduated to illicit substances like cocaine and MDA and found it increasingly difficult to “relate to people when straight”. Despite her heavy drug and alcohol use, Kay has managed to achieve several years sobriety. The challenges of parenting a daughter who is alcohol affected has been tempered by the skills she acquired with the help of a family support worker. She plans to expand her knowledge of child and youth development and is currently completing a Bachelor of Arts degree.

### *April*

At forty-five, April is the mother of four adult children aged twenty-six, twenty-three, twenty and eighteen. She is grandmother to three grandchildren, one of whom she is raising. Stress and exasperation were very apparent as April described efforts to parent her grandson as well as two live-in daughters who are alcohol affected. Her current chaotic situation appears relatively calm when compared to the years she spent from age fifteen “working the streets”. Her children were placed in and out of foster care as April

battled heavy alcohol and drug use, prostitution, incarceration and violent relationships. April has made several attempts to stop drinking and using everything from heroin to marijuana to prescription narcotics and benzodiazepines. Although April carries considerable guilt over a recent relapse, she tries to reassure herself that relapse is normal and that things are slowly getting better.

### ***Trish***

Trish is in her early to mid thirties and recently relocated to the Lower Mainland from the interior of the province with her twelve-year-old daughter, ten-year-old son and husband. She needed better access to services for both her multiply handicapped son, who has FAS, and her husband who has a terminal illness. Despite the challenges of her family responsibilities, Trish relays with nervous humour a positive outlook. Smiles mask the pain and guilt that Trish also shares of having used LSD, “dope” and alcohol during her pregnancy. As a way of coping with being sexually abused she turned to drugs and alcohol at the age of fourteen. Trish eventually accessed residential treatment out of fear of losing her children and has been “clean” for almost eight years.

### ***Barb***

At forty-one, Barb is content with her career as a geriatric nurse aide, satisfied with her “dynamite marriage” and is looking forward to becoming a foster mother. Her current lifestyle, she claims, is due primarily to nine years of sobriety through the help of Alcoholics Anonymous. Barb recalls a previous life of heavy drug and alcohol use, violent relationships and trying to cope with a challenging daughter who was in and out of group homes and foster homes. Her daughter eventually went to live with her maternal

grandmother, and at nineteen has just been diagnosed as alcohol affected - as has Barb herself.

### ***Mytayja***

Mytayja, (a pseudonym she created: my-tay-juh) is a twenty-six year old woman who identifies as part "Mulatto and part Metis". At the time of the interview Mytayja was nursing a week old baby boy. With babe at breast she relayed with much emotion her experiences of five pregnancies over the past ten years, one of which resulted in a miscarriage. Mytayja referred to her third baby as a "NAS baby" who, along with Mytayja's other children, has been given into the care of her sister. She has accessed alcohol and drug treatment several times and continues to struggle with cravings and relapses. Mytayja sees her own experience as a mother as directly related to the fact that she is also a drug affected child. She was born to a mother addicted to heroin, was subsequently apprehended as a ward of the courts and eventually adopted into an abusive Caucasian family.

## **THE MOTHERS' EXPERIENCES**

The brief biographies of the mothers reflect a profile that has been identified in the literature (Abel, 1982, Clarren, 1998, 2000; Dineen, 1994; Gladstone et al., 1997; Goldberg, 1995; Marcenko and Spence, 1995). Most of the mothers have had more than one pregnancy, have experienced extreme forms of abuse, had an undiagnosed mental illness and, in the case of Barb and Mytayja, are drug or alcohol affected themselves. That being said, the biographies also challenge stereotypes of just who these mothers are and whether or not categorizing women thus is even helpful. All of these mothers are

sensitive women who love their children and have taken responsible steps to care for them, something the profile described in the literature does not portray.

Constructing a profile may be helpful in identifying risk factors in order to intervene, but it does not indicate exactly what interventions are acceptable to and beneficial for the mothers. The following detailed and often painful accounts that the mothers relay help point to a framework for services as articulated by the mothers. The mothers highlight the stages of pregnancy and birth, coping with addiction and parenting an alcohol affected child. These stages are invariably situated within the broader contexts of their lives. The women talk about their childhood, significant life events and current struggles and successes. A number of themes overlap and intersect throughout the trajectories such as the mothers' efforts to take responsibility for their own lives and the lives of their children. In the face of these efforts the mothers are continually dismissed or duped by those in a position to help. Relationships also figure prominent in the women's stories as adversaries, advocates or enablers. Both pragmatics and philosophy play a role in the day to day ability of the women to make ends meet and make sense of their lives. Finally, the women were able to exert agency despite consistently facing barriers and obstacles. The suggestions offered by the women stem directly from and are consistent with their own experiences as biological mothers of an alcohol affected baby.

### **Pregnancy and Birth**

#### **Taking responsibility**

During their pregnancies all of the mothers at least contemplated ceasing to drink or to smoke or use illicit substances. Each individual mother met this responsible gesture with greater or lesser degrees of success. Julie relays the struggle:

*And when I got pregnant I kind of knew that it probably wasn't a very good idea to drink, uhm, but I did anyway. I could not not drink. I could not not, it had that tight of a grip on me.*

Similarly, Trish had already cut back to using LSD, marijuana, alcohol and “whatever else” only on weekends. When she found out that she was pregnant she stopped using all drugs, including cigarettes.

*Yeah, I stopped because, you know, oh, I've got to, you know. ... I think I might have been about two months pregnant, it was only through the first trimester [that I used], I know it wasn't over three months, for sure, and, uh, that's the effect it had on him, just more or less using only then all weekend and stuff and partying during the weekend.*

Some of the women made efforts to stop drinking and/or using drugs even before they had their pregnancies confirmed. Barb did not “find out” that she was pregnant until the sixth month, but she stopped drinking two months earlier because she “just knew” she was pregnant. Laura had “already cut down on [drinking and especially smoking]” because “there were signs”, even though the doctor kept insisting that she wasn’t pregnant. Both moms would have made these efforts even earlier had they received confirmation of their pregnancy, a process that was surprisingly complicated. Barb recalls how her doctor dismissed and misdiagnosed her when she herself felt that she was pregnant.

*He gave me a test and said that I wasn't pregnant. So, I went away and started jogging and stuff and grapefruit diet and all of that, and I still didn't lose weight. So, I went back to him and I said,” You know,*



*something's up here", and he did an examination and said "You're not pregnant, but you probably have a twenty pound cyst; we need to do an ultrasound so that we can get rid of it". So, I went to the ultrasound and [the technician] said "There's the baby's heart beat!" And there I was, six months pregnant.*

Barb goes on to say that had she "known" she was pregnant earlier she would have had an abortion.

*I would have just had an abortion had I known, because I was a drug addict before that, and I've always drank, so, I was 22 years old and I was a mess. I was in absolutely no place to have a baby, right.*

She holds no grudge against the doctor who misdiagnosed the pregnancy seeing the outcome as "God's way of making sure that [my daughter] came into this world".

Similarly, Laura takes full responsibility for drinking while pregnant, but would have changed her behaviour earlier had she received a proper "diagnosis". She was frustrated with the number of trips she made to a doctor who continued to dismiss her.

*Although the doctor said I wasn't pregnant, I mean there were weird things going on. ...There were signs that prompted me to keep going back to this doctor and say: "You know, I think I'm pregnant". At one point [after several blood and urine tests came back negative] he said "...don't come back here, you're not pregnant". ... And then when I was about 11 weeks or so, I did a home pregnancy test, cuz things just weren't right, and it said that I was pregnant. So, I went back to the doctor...and he said "well **now** you're pregnant". But then he sent me for an ultrasound and I*

*said “well, I was pregnant then too!” [The doctor] felt that the lab must have been mixing up [the results], and I said “Yeah, four times!” I was really hostile by then.*

### **Shame and Denial**

Receiving help to overcome an addiction during pregnancy is a process also overshadowed by shame and denial – on the part of both the mother and/or the helping professionals she confronts. All of the women went to prenatal visits during which time they often remained guarded due to the shame they felt about their drinking. The physicians that they confronted also appeared hesitant. The experiences of Julie and Trish are typical:

*Julie: I went to prenatal, I went to my doctor’s visits regularly. I was never honest. I mean, it’s hard to help somebody when you don’t know exactly what you are dealing with. So, I was never honest about how much I drank, because I was very, very ashamed that I drank the way that I did. ...So, I was just too ashamed to talk to somebody about it - just too afraid. Just the thought of not drinking was terrifying. [Drinking] was what kept me alive, it’s what kept me going, it was my reason to exist. And if somebody would have taken that away from me, I don’t know what I would have done. ...So, no, nobody ever talked to me about it, because I was very secretive about my drinking.*

*Tracy-Anne: During the intake, did the doctor ever ask ...?*

Julie: *I don't remember. I don't remember. I mean I remember going to the doctor and him asking me how much I drank, and I would always lie. I could never be honest about it because of all the shame.*

Trish relays similar shame based anxiety:

Trish: *I didn't say nothing to any doctors like I never brought that up and that was never a question really asked.*

Tracy-Anne: *Nobody asked you about your alcohol use or drug use?*

Trish: *Oh ...I don't remember them asking me and if they did I might, who knows back then if I would have maybe given them an honest answer anyhow, because I didn't want to be in trouble, I didn't want them to think I was a bad mum or a bad person.*

Although Trish and Julie's doctors may not have properly screened them for prenatal alcohol use, their own shame and denial prevented them from reaching out to the doctor. All of the mothers stated that they wished someone would have confronted them gently, and offered help with their drinking. Mytayja felt that her own doctor was simply disinterested.

*So, I'd been seeing this doctor since 1997 and he knew all about my addiction and everything, right, and not once did he ask me when I came, you know, "How are you doing?", you know, "Are you staying clean?", you know, "Are you using dope?" like that, you know, instead he says "hello", and walks in, you know and pats me on the knee and, okay, you know, all chipper cheerful and, you know, okay, "Let's check you out." He'd stay five minutes, that's it, gone, boom.*

Some of the mothers tried to make subtle gestures hoping that their doctors would catch-on and intervene. For example, Kay and her husband arrived at an appointment with the obstetrician while reeking of alcohol. In hindsight she likens her behaviour to that of a teenager who acts out in the hopes that someone will step-in and intervene, yet no one did. She explains:

*We [arrived at the obstetrician's] and we stunk, we stunk [of alcohol]!  
...[yet no one said anything] for fear of, I don't know, somebody getting  
upset or blowing up, or... accusing someone wrongly.*

Laura notes that the way in which the doctor screened her made it difficult for her to disclose:

*Even my family doctor, when he asked me about drugs and alcohol, he  
said "Oh, I know I don't have to ask you about drinking and drugging."  
You know, so, if he would have asked me I would have said, "Oh, no!"  
You know, just from his impression already.*

When the mothers are more direct about their addictions, they report with frustration that they are often dismissed or given misinformation. Barb, for example expressed her concern about the impact of her drinking on the baby, but was "reassured":

*In those days, which was 20 years ago, in those days, the doctors said  
"Oh no, the babies are really strong, and fetuses are strong. Don't worry  
she's going to be fine" and all of that.*

Barb is forgiving of her doctor on the grounds that the medical profession did not yet know how alcohol might impact the baby. In actuality, FAS had been a known diagnostic category and the teratogenic affects of maternal alcohol consumption had entered

prenatal screening for almost ten years at that point. Even if Barb's doctor had not yet caught up to recent knowledge, other doctors continue to offer similar advice in more recent years. Kay recalls:

*I found out that I was pregnant, tried to quit, uhm, talked to my doctor about drinking and uhm, he asked "How much do you drink?", and I said honestly that at the time I was drinking only maybe two or three ciders on a weekend and could I make it on that? And "Oh, no that's fine! In fact a beer a day would never hurt, you know, that keeps you regular." And of course, you say that to an alcoholic and it's like "YES!" You know, I'll go with that. And again like I say, I don't blame him, but it didn't help, let's say.*

Sally's doctor insisted that everything would be fine:

*I had mentioned that I had drank quite a bit [before I found out that I was pregnant], and I was quite worried about that. But, it was shrugged off like "Well, you're not drinking now are you?! ... Well, OK, it's fine. Don't worry about it, it will be fine!" And uhm the doctor didn't ask how much I drank, so I pushed and said ... that I really drank a lot, ... especially on a couple of days.*

Mytaya and April received similar mixed messages about their use of substances.

*I was on valproic acid, that's a mood stabilizer that [the psychiatrist] wanted me to take and I would question it, I would ask them, you know..., right there in that psychiatrist's appointment "Is this going to hurt the baby?" ... We talked about getting my two older kids back and I was*

*crying, telling her, you know, the same thing like, you know, I wanted to parent my kids. [She said] "Oh, you stay clean for a year and you'll get them back", and yeah, you know, but I was concerned about the medication I was on for my baby's sake, so I didn't get any help there. ...And now I find out that in the beginning of a pregnancy, having taken the medication causes, um, the nurse at St. Paul's told me it causes neonatal something, I have to check that out. [Mytayja]*

The drug, valproic acid, that Mytayja was prescribed to stabilize her mood has been assigned a fetal risk factor of D in a pharmaceutical reference guide to the risks of drugs during pregnancy and lactation (Briggs, Freeman and Yaffe, 1994). This level of risk means that there is positive evidence of human fetal risk when taken during pregnancy (Briggs et. al., 1994). The drug is a known teratogen and has been proven to cause major and minor fetal abnormalities, intrauterine growth retardation and fetal/neonatal distress, among other problems (Briggs et. al., 1994). The drug will also intensify the effects of alcohol when consumed. Therefore the effects of the two glasses of wine that Mytayja consumed on one occasion during her pregnancy had an intensified impact on both her and the baby.

April faced a similar dilemma as she was told to cut down on alcohol while at the same time being prescribed her current substance of choice.

*April: Yeah, [my doctor] told me that I needed to quit one or the other - pills or alcohol - because it wasn't healthy for my pregnancies. And of course, I didn't.*

Tracy-Anne: *But he kept prescribing?*

April: *I mean he would beg me to slow down but yes, yeah, he kept prescribing like... back then it was Seconal, Tuinal, Mandrix, you know, all the heavy ones, like I hope they don't have those anymore.*

The barbiturates that April was prescribed are also contraindicated during pregnancy. The baby can become addicted and subsequently experience withdrawal, have bleeding problems, breathing difficulties and birth defects. April's medication is also known to have an intensifying impact on consumed alcohol.

It is difficult to judge whether or not the physicians who the women encounter are incompetent or just trying to reassure the mother in order to maintain a positive rapport. The response to the mothers' concerns may also be due to the ambiguity surrounding alcohol and pregnancy as it is still not clear how much alcohol will result in an alcohol affected baby. But, by not providing clear information the women are left feeling dismissed and misinformed. The women would have preferred an opportunity to talk about their struggles but it seems both their own fears and a lack of willingness on the part of the doctor prevent such a dialogue. Both parties possess elements of denial. In at least one case, the doctor's denial stemmed from his own addictions and manifested in a coercive and dysfunctional relationship with his patient April.

*I used to steal my doctor his alcohol and he would give me any kind of pills I wanted...because he was an alcoholic. And he used to go, his lunch time was from twelve till two and he would go into the Lounge and we'd just meet him there at lunch time and he'd drink and then go back to work and we'd drink with him.*

### **Mistreatment and miscommunication**

For some of the mothers, the birth experience was very traumatic. They relayed the ways in which they were mistreated and/or caught in a web of miscommunication. This was especially true for those mothers who were known addicts at the time of their delivery.

*April: ... then I was in labour, I didn't know what was going on because my addiction had advanced to [the point where] I had forgotten that I was pregnant. And then I'm in the hospital having this baby, just freaked out not knowing what was going on and I remember this old nurse... she finally had me strapped into the bed and brought me right up in front of the nurses' desk.*

*Tracy-Anne: Why did they do that?*

*April: Well because I was really high... and they didn't, I guess, know how to deal with me, and I didn't know what the hell they were doing to me and I was having a baby and just screwed up.*

Whereas April experienced physical restraint, Mytayja was similarly contained through segregation:

*So, she was born and, uh, the hospital that I had her in, as soon as they found out that I was a drug user, um, they really shunned me, they really treated me really bad. I was given like my own chair because like, like with intravenous [drug use], except that I am not even an intravenous [drug] user but, you know, like with the diseases and stuff you can get...I had to have like my own chair, um, and I couldn't use the good, normal*



*washroom that other pregnant women, who wouldn't have had any diseases, used.*

The treatment that both April and Mytayja received reflect how assumptions about who the women are create and reinforce stereotypes and stigma. Mytayja goes on to relay her anxiety at not being able to hold her baby, or being told what was happening with her.

*I worked through the birth and, um, my daughter was born and they took her right into the weighing scale thing, you know, where they weigh the baby and everything and I'm asking them "Is she okay? Is she okay?" And my best friend was there and I was asking her, asking them, if I could hold her and they wouldn't let me hold her for about, oh, I don't know maybe three minutes, three to five minutes and they're washing her up and everything and they...gave her to me for two minutes, not even, and I, I'm just guessing about two minutes and then, uh, took her back.*

The procedures that Mytayja describes are common post delivery of the baby. The lack of communication, however, created stress and anxiety for Mytayja who was unclear about what was happening. Laura was not identified as an addict during her delivery, but she does share Mytayja's feelings of being kept uninformed by those who were treating her very sick baby.

*The ultrasound person was talking and saying, "Oh, there's a double bubble" and I said "Well, what is that?" [and he said] "I'm sorry I can't tell you." Nobody would talk to me. Uhm, the doctor came and said "You know, there's something going on, we need to send you to another hospital." "Well, would somebody tell me what's going on? What's a*

*double bubble?” “Well we can’t talk about that right now.” You know! I was so frustrated. I was just devastated! Here there’s something wrong with my baby. You talk about not inducing stress on a pregnant woman, well withholding information after she’s already heard people mumbling and talking and bringing other people into a room to show them this double bubble thing, and... uhm. ...I think it was two days before somebody finally explained to me what a double bubble was.*

When Laura finally gave birth, she had been in labour for over sixty-nine hours and the baby had to be taken by forceps. From there she recalls a whirlwind of hospitals, specialists, and feeling left behind.

*And the hospital staff were actually really bad. I mean I just felt, like I wasn’t allowed to touch him, I wasn’t allowed to... I mean I was there almost 24 hours a day except for when I would have to leave to, you know, sleep. And... they wouldn’t let me even put my hands into the incubator, it was just REALLY bad. ...and this one nurse, you know, would make me really feel like I wasn’t really competent enough to look after my child. So, by the ninth day I had broke down, and I was crying...*

Even when Laura made her requests and wishes known to the medical personnel, she was ignored:

*...They didn’t respect my wishes. Every time I turned around, you know,... uhm, I had such a hard time in the hospital going to pump milk because I was afraid of what the nurses might do when I was gone. And one of the things that happened was, uhm, I had zero percent tolerance of formula*

*feeding of my child. And ...on one occasion I went down to pump, and uhm, you just know when something's happened to your child, because there was a cold blue going on, and I stopped pumping, ran upstairs and uhm, they were resuscitating my baby, and they didn't want to let me in the room. I just looked at the nurse and said "I brought him in, if he's leaving I'm here." You know, and the doctor just said "Let her in." And they were using the paddles to bring him back. And when all that was done, and he was stabilized again, I looked at the nurses and said "What happened when I was gone?" You know, who knows whether there's actually a connection or not, but they decided that my child was hungry and they fed him formula. And I have no idea if there's a connection or anything, but in my mind at that time, there was a connection, you know. And then after that I didn't trust to leave my room at all; to leave my baby unattended with the nurses - you know the people who are supposed to be good at caring for your children.*

### **Advocacy**

Having access to someone who the mothers felt could act on their behalf was either something they appreciated or found lacking. Both Barb and Kay felt isolated and lonely during their pregnancies and may have benefited from additional support. Due to complications, Kay recalls being "stashed away in the old part of the hospital" after the 19<sup>th</sup> week of gestation. She was separated from her family, friends and community. Her husband visited on weekends and brought "his little care package of ciders and his

alcohol". Barb also relays a sense of loneliness and despair during her pregnancy and birth:

*I was very depressed through the pregnancy, and [after the difficult labour] I didn't even want to see her. I was so depressed I guess, and from the trauma of [the caesarean] ... I was just not thrilled.*

Laura recalls the frustration and isolation at having no one to turn to during her first two hospital stays.

*It would have been nice for someone to actually care; someone who could actually sit with you, you know. I think they need to have counsellors in hospitals, especially when you don't know if your child is going to live or die. ..I didn't meet a social worker until I was in Children's Hospital. So, my stay [in the other two hospitals] there wasn't one. And I think that is just awful.*

When she finally did reach out, Mytayja felt a sense of betrayal by those, in particular social workers, who posed as though they could assist in her dilemma. She had two children previously apprehended by child and family services due to her drug abuse and subsequent inability to parent. During this, her third, pregnancy, she decided to initiate contact with child and family services herself. This was a proactive attempt to determine what their expectations might be and what she needed to do in order to avoid her third child becoming a ward of the court. The outcome was unfortunately not as she had planned:

*I was in the hospital for two days after giving birth. On the second day the nurse and some short guy come into my room and tell me that my daughter*

*is being apprehended because of [my] cocaine use. Later I found out that the Ministry was already in the process of having my daughter removed – because I had contacted them. I had no clue [that was their plan]. They only phoned and visited me once, and then came to the hospital and took away my baby. ...It would have been nice if just once the worker had said “Mytayja, how can we help you?”*

With a subsequent pregnancy, Mytayja found it helpful to have people coming to her aid – both emotionally and physically. With a newborn to care for and no means of transportation in the midst of a city wide bus strike the social worker, health nurse and doula all paid visits to her home.

*...the social worker was here, so she got to see my place already, uh and she says “Mytayja I’m going to give you a chance.” I was in shock, you know, like I’ve been fighting for how long? And that’s why his middle name is Justice.*

*And the health nurse came and that was really cool like with this strike thing, I’m getting all these home visits so it’s a blessing for me, I’m liking it. ...And my doula told me “if you’re out in public and someone asks you to, you know, go [nurse the baby] in the bathroom or to go somewhere private, you tell them to fuck off”, huh huh, plain and simple like.*

Laura experienced similar relief when one of the doctors finally came to her aid.

*I was at [the hospital] ... and I just started crying and said “You know I may as well let you guys keep my baby because, you know, I’m not*

*allowed to be a parent!" ...the doctor was shocked. He didn't know that no one was letting me have contact with my baby, and I was telling him that in my belief children need to be touched, they need to be held and they need that from their parents, because that's what helps them heal. You know, I was really upset because I felt they were starving my baby to death because he was now down to 2 pounds 14 ounces, and uh, they were feeding him TPN and lipids, and I was pumping milk and they weren't giving him any breast milk, and the nurse kept saying that the cardiologist doesn't want him to have food, blah, blah, blah. So, the doctor went and got the cardiologist, brought her in, and uhm, as of that moment he started getting breast milk through the stomach tubes, and the doctor ordered that I be allowed to hold him and that they provide me with the oxygen to hold it on him, and [pointing to photo in album] that was quite the thing after nine days to actually touch your baby.*

## **Addiction**

An important part of the mothers' stories centered on their efforts to achieve sobriety. Throughout this journey it was important for the women to recognize and heal from the impact of violence and abuse in their lives, to garner appropriate and timely services and to develop special relationships.

## **Abuse and violence**

All but one of the mothers identified the impetus for their alcohol and drug use as a means of coping with abuse and violence. Escaping and healing from these traumas was an important part of their efforts towards sobriety. Sally shares:

*I had been sexually abused as a young teenager and then again as an older teenager, uhm, a couple of times. And I had low self esteem and a lot of the issues that go along with how I ended up drinking.*

Laura and Trish made a similar connection:

*That was my sedative. I could go months without thinking about anything about my past, then something would trigger it and I would be at the bar. You know, something would trigger it, and I would be drunk for a day or two. ...And a big part of [my recovery] was just beginning to grieve and heal the childhood abuse.[Laura]*

*I had to look at that part of my life and being sexually abused and all that and living in an ugly lifestyle and it's like, ...I found my release was drinking and I had to look at all those issues too, to accept that they happened. [Trish]*

With Kay, the combination of childhood sexual abuse and an alcoholic family resulted in her drinking from a young age.

*I started drinking at a very very young age, at 12. ...My mom was an alcoholic too. Uhm, there was sexual abuse going on in my family, and with my step father from uhm probably about a year and half old until 12 years old, when my mom finally believed what I was saying. I was taken to a psychiatrist at the age of five or six, when she read my diary. The psychiatrist had the old Freudian belief that a lot of young girls like to believe that, you know.... . So, when I hit 12 I was just angry, just pissed-*

*off at the world, eh. And alcohol was just wonderful for it, eh, you know it helped me to feel bigger than what I was.*

Like Kay, April recalled her extremely abusive upbringing and early drug use. She relayed instances where she was beaten with a horse harness for having a bad report card, thrown against a wall lined with coat hooks because a boy had given her a gift when she was in grade one, tied up and hosed down with hot water by her mother, and of being sexually abused. Not surprisingly, she ran away from home at the age of fifteen and began working the streets. Much of the counselling and recovery work that she has undertaken has helped her to see that her addiction was and remains a way of coping with her abusive childhood and subsequent abusive relationships with men. Even while in jail, drugs (that were secretly provided by the prison guards) helped her to fend off the violent advances from female inmates.

As a child, Mytayja was subjected to her adopted mother's angry outbursts that included being hit with sticks, and forced to conform to religious based schooling where she was punished for cutting her hair and beaten with the paddle for engaging in brawls. At the age of thirteen she was seduced by an older teen from her church and became enmeshed within a cycle of abuse.

*Um, the first time I had a drink was when I was down at the dikes with some guys and girls that I met from school. I passed out after like two coolers, right, and I woke up to this guy, um, he was, he was, whatever, you know, fingers inside me, molested me, assaulted me whatever, you know, and I just froze, I didn't know what to do because like I was coming out of it and, you know, um, I didn't tell my mum or my dad, I didn't have*



*that relationship, I didn't tell anyone, you know, and then the next weekend it got worse and, you know, just the whole cycle started.*

Mytaya goes on to describe how this incident repeated itself several times. The perpetrator eventually introduced her to cocaine, the substance with which she eventually had the most problems with.

For Barb, the connection between the violence and her own behaviour was made after she stopped drinking. When the violent relationships continued, she realized that sobriety is more than just abstaining from alcohol.

*So, I was still getting into violent relationships. I got into one when I was sober, and I thought "OK, I'm sober and I've done the same thing! So, perhaps it's not about the drinking. Perhaps it's about me." So, take away the booze and who's there but you, right. So, then you have to deal with the lifestyle. You have to deal with all of that before you can get recovery. So, that's what I did.*

Even Julie who was not as forthcoming as some of the others insinuated that the reason she drank was to cover up emotional pain.

*People drink and people use because they feel like they've got a huge hole in their soul. They feel like they don't want to live, like they loath themselves, they can't face their life straight, they hurt all the time, they have emotional pain, life is very very overwhelming for people who are addicts and alcoholics and that's the reason we use. So, the recovery process is fixing all of that, healing that part, that broken part inside, and it is a process. ...Recovery is learning how to think differently, and to feel*

*differently, and to heal the broken parts inside. And people who just quit and don't learn how to do that, I mean you can't learn that on your own, people need help to do that.*

The accounts that the women share have similarities that could have possibly been relayed through a few key examples. Portions from all of the mothers' stories are included here in an attempt to validate this important aspect of their trajectories. The emotional scars from past traumas are at the core of the women's dilemma in terms of their addiction. Offering significant space to this particular aspect does risk reducing the mothers to the status of victim. But, as the narratives reveal and their trajectories will continue to show, the mothers exhibit great insight and resiliency.

### **Navigating and Negotiating Services.**

Accessing appropriate services was a relief to mothers, but the process often proved challenging. Both Barb and Julie's narratives above indicate that it is not helpful to simply become a "dry drunk". Sobriety entails a process of engaging and understanding the emotions and patterns that are connected to the addictive behaviour. Not surprising, all of the mothers reported that they needed, and some continue to need, the help of counselling. Through individual or group counselling the mothers are able to connect life events to their addictive behaviour.

Trish felt that it was important to engage in the counselling process regularly: "[A huge help was] being consistent with counselling like not just doing it for six months and then stop but I did mine for like two years straight." Even April, who continues to struggle with her addiction states that her ability to become legal guardian to her grandson is due to the counselling she has undergone. "I thank God for

counselling...[because] now I'm able to love my grandkids!...Before I couldn't get down on the floor and play with my own kids, but now I'm able to do that with my grandson." Sally concludes:

*Now that I've dealt with the emotional issues and why I drank, I don't have a craving to go back to that lifestyle. I have no desire.*

Sally goes on to share that through the help of a therapist she "figured out that I was probably clinically depressed ...from an early teenage stage, and needed medication". She was able to see her drinking as a form of self-medicating because she was not "getting the psychiatric or psychological care that [she] needed". Sally is not alone in her experience. All of the mothers talked about the importance of promoting their own mental health in order to maintain their sobriety. Mytayja still struggles with psychiatric symptoms that have landed her "in the psych ward sixteen times since 1996!" Several of the mothers disclosed that they are now taking medication for such things as chronic depression or extreme mood swings.

Counselling has also helped the mothers to recognize patterns of family dysfunction. Insight into their upbringing and cycles of family violence helps the mothers to connect their own alcohol and drug use to that of their family. Having a parent who drank heavily, or a home environment where alcohol and drug use were encouraged, provided early imprinting for their own addictions. None of the mothers framed this connection in terms of blaming or making excuses for their own behaviour. On the contrary, the mothers were able to see family members as troubled individuals who also need help. As is typical when family norms are scrutinized, some mothers reported that divulging of "family secrets" created family discord. April recalls: "So I got disowned

from my family because I was telling the family secrets when I was getting help, and I told my sister “I don’t care, you guys all need some help!” Laura confronted a similar consequence: “I had pressed charges for childhood abuse. So, I was dissociated from my whole family tree because I was rocking the boat.”

The mothers cite a number of barriers that made it difficult to actually locate a counsellor. Finding a counsellor whose fees were within the mother’s means proved challenging. A mother might subsequently be referred to a psychiatrist, which often proved frustrating because the doctor would simply prescribe and review medications and not provide psychotherapy. A local women’s centre or mental health centre could provide free counselling or charge a sliding scale fee. However, these resources often had long wait lists and tended to be short term. Sally relays the discouraging process that resulted in her drinking again:

*A lot of the places that they referred me to were interim kind of situations where they take you and treat you for a while, and then switch you to someone else - I have a lot of trust issues. And,... somebody who doesn't trust that the world's going to help them out or support them or take care of them, is not going to go easily into a situation where you can't build trust and rapport. I wasn't just going to tell a stranger off the street my life's troubles, and uhm, these counselling situations where you have to go and meet with people to get into counselling, you often have to tell your story,.....after doing that three or four times, and then finding out that that person was only going to see me once or twice then hand me off to the next*

*person, discouraged me so, I stopped looking for help. And uh, I went back to drinking actually.*

Sally eventually found someone with whom she could trust and see over the long term. It is through the help of therapy, she states, that she no longer abuses alcohol. Sally continues to drink, but only on occasion and never as a means to cope. She no longer battles cravings because she has dealt with the underlying emotional issues.

Almost all of the mothers have made Alcoholics Anonymous (AA) a regular part of their lives. It is through AA that they are able to “learn from other addicts”, “tell [their] story”, “get support”, become “more authentic” and “heal wounds”. Even Sally, who for the most part dismisses AA, did find Adult Children of Alcoholics Anonymous (ACOA) helpful. She did not like the concept of AA because she felt that “working the steps and the program becomes your life, your culture...another religious culture.” Through ACOA meetings, however, Sally was able to see “how my family dynamics have been affected by alcohol, because my father was a drinker.”

Some of the mothers underwent supervised detoxification (“detox”) and residential or out patient treatment. Although the mothers appreciate the nurturing and healthy environment of these programs, the rules and terms of participating were often difficult to meet. A common prerequisite to attending an alcohol and drug treatment program was to have at least three months “clean time” – that is, three months with no alcohol or drug use of any kind, licit or not. Kay relays how difficult it was for her to meet the criteria:

*I went to the recovery treatment centre at 6 months clean, and uhm they said, “You can’t come here until you’re off your anti-depressants.” And*

*they said you should be off 30 days, and so that's what I did. That was horrible horrible withdrawal, just horrible withdrawal!*

Some of the mothers felt coerced into treatment, even when they had entered the program voluntarily. Trish, for example, entered out of fear of losing her children.

*And [my counsellor] goes "Well, I'm not going to see you again until you go to the drug and alcohol centre." And by this time it was like God, God, now I've got to do this because they are going to take my kids if I don't do this.*

Being forced into treatment had an adverse affect on April's motivation:

*Like I've been in [residential treatment] because welfare made me go...and I remember people from out of town had come all the way there, but I was only there to please the welfare, I didn't, uh...if you're forced into something it doesn't work and I especially know that.*

Both April and Mytayja have been through treatment several times, and both continue to struggle with their addictions. Mytayja calculates that she has attended thirty weeks of treatment over the past year. She would invariably leave early due to a variety of reasons, most of which related to interpersonal conflict and failing to abide by the rules. On one occasion she was accused of "being in some guy's room", and on another, she was accused of taking antidepressants and subsequently asked to leave. Not conforming to the rules can result in harsh consequences, and to a certain extent the rules penalize a woman for the very reason she is seeking help.

Trish appreciated the rule that she have no contact with friends and family while in residential treatment:

*Going to treatment was the best thing I ever did because I was isolated and removed from everything, everyone and I wasn't able to redirect myself because usually I just redirect, get busy and start doing other things because that's what else I do, forget about me, worry about everyone else.*

On the other hand, Trish expressed how difficult it was to be separated from her children during this “tough time”. She was able to arrange for her children to stay with her mother for two months, but would have preferred if they could have stayed and possibly been a part of the treatment process. Mytaya took matters into her own hands and chose to “break the rules” because access to a telephone was not permitted while in treatment. She needed to contact her family regarding her daughter who was sick in hospital. Sally had similarly declined treatment for very pragmatic reasons. She feared losing her home because she would not be able to pay rent while in treatment.

### **Relationships**

When talking about their efforts to overcome addiction, the mothers refer to the impact of their relationships with others, particularly women and husbands. Meeting and learning from other women provides role modeling and encouragement as well as a sense of accountability. The sense of comfort that the women feel when connecting with other women is reflected in Julie’s narrative:

*I find that when women get together they talk much more openly, and they are a lot more intimate about what’s going on in their lives when there aren’t men around. And that’s a big part of recovery – to be really open*

*and honest about what's going on inside and in your life today. Yeah, ...my preference is to be with women.*

Mytayja appreciated the support of a “buddy” while at a recovery house:

*I'd settled into this home, recovery house, and I'm getting a little understanding [into my addiction]. My roommate was pregnant as well, um, so, you know, we had something to talk about and she was a cocaine user as well, and, uh, and at that time you had to have a buddy system, you know, I mean this is pretty big in recovery, right, and she also came with me to court.*

Meeting someone who had already gone through what the mothers themselves are experiencing was affirming. Kay recalls,

*And in [the support group], there was one of the facilitators who was in recovery herself, who I looked at as my mentor. Uhm, she had been through alcohol addiction and having children affected and what not. And so, by the time my girls started getting older it started to really hit home, you know. I was really able to look at her and how she handled things.*

Barb describes the reciprocity of being sponsored and then becoming a sponsor:

*And it's Alcoholics Anonymous, right. It's not me, it's what I was taught from my sponsor when she took me through the steps, and I have a lot of sponsees that I am taking through the steps.*

The mothers also referred to their relationships with boyfriends and husbands as playing a significant role in their trajectories. Living with a partner who abuses alcohol made it difficult for women to attain their own sobriety, while others found their partners



supportive of their sobriety. Kay's narrative below is reflective of others who felt caught between choosing sobriety and choosing to stay with a partner.

*I went to the drug and alcohol place, and uhm,.. quit. I asked my husband to quit. He already knew, we had talked about this, you know, I wanted to quit, and he didn't really want to. We wanted to save the relationship .... but, I knew he would always hang on to alcohol. So, that was my deterrent. I knew that when I chose to say good-bye to alcohol you're saying good-bye to your husband, right. And so, he tried to quit, and he drank a few times over the year, and then a year came up and he came home drunk and I remember looking at him in the living room, and he was just, he was crying, and I looked at him and said "I guess you made up your mind", and that was that.*

After her marriage dissolved Kay hoped to continue to parent her two daughters.

However, the oldest, who is alcohol affected, opted to live with her father. Kay relays her devastation:

*That was horrible, I think it was my toughest one to deal with. Letting go of the alcohol, you know, I knew that we were going to be really really broke, and struggling really really bad, but I just knew that "Well, I've got the girls", right. And letting go of my daughter was like, "Well what did I do it for?" right.*

In contrast to the above scenario, a partner who was sober contributed to the mother's own ability to "stay clean". Not only were women not tempted by the sight or use of alcohol by a partner, a partner could also act in solidarity with a woman's choice to stop

drinking. Sally recalls: “[My husband] knew that I drank too much, and when I stopped he was very supportive, he just stopped too because drinking was never a problem for him, he was never a heavy drinker.” This same husband helped Sally to get the professional counselling that she needed

*I had tried to find counselling without a lot of success and was getting very discouraged and getting very depressed, very very depressed, and it got to the point where I couldn't look for help any more, so my partner sought out help for me, because he was worried about me. And uhm, ended up out at UBC, and he managed to get me a meeting with the head of the department out there, uhm, and tried to get me some counselling.*

Similarly Trish relays how important it is to have a husband who supports her own efforts towards sobriety.

*Yeah, [my husband's] in the [AA] program too. Like I don't think, I know, I wouldn't be able to live with someone that drank or uses drugs. I wouldn't want my kids around that, even if it was casual or social.*

## **Parenting**

With the exception of Mytayja who is currently not parenting any of her four children, all of the mothers relayed the challenges of parenting their alcohol affected child. The process of receiving a correct diagnosis for their child often proved difficult, as did attaining appropriate treatment and interventions.

## **Diagnosis**

Mytayja was informed that her daughter was “a NAS baby” shortly after she was born. The baby showed signs of withdrawal from narcotics and had to be put in an

incubator. By contrast, some of the other mothers' babies did show signs of withdrawal at birth or shortly after the mother stopped nursing, but these were never recognized as such by doctors. Most of the mothers finally recognized these "indicators" themselves once they became more knowledgeable about Fetal Alcohol Syndrome. However, more so than infantile behaviours that could be excused as colic or allergies, behaviours that began in early childhood contributed to the mother's "knowing" that something was very wrong with her child.

In general the mothers relayed that their child, whether young or adult, lacks any sense of natural consequences. They do not tend to learn from their mistakes and have difficulty thinking ahead to consider the repercussions of their choices. The mothers also shared with exasperation how these children tend to be easily led astray. Julie tells of the "life threatening" situations that her son, now 21, has been involved with.

*Well, like I said, he was in so much trouble all the time. He was having so much trouble in school, so much trouble with the law, and so much trouble with peers, and things just didn't quite fit. Like I had learned that in order for me to get him to do any of the chores around the house, or anything, I would have to write things down because he would forget everything. He had a really hard time being on time for anything. ...It was everyday dealing with either the principal of the school, or an irate landlord, or neighbour, or some lunatic that he met downtown who was calling and leaving death threats on my answering machine; parole officers, probation officers, it was just continual, continual, continual. Him out there on the street, me not knowing where he was, stealing, lying, breaking*

*into other people's homes, just you name it. ...It was really hard, really, really, hard. And to not know why all this is happening and to have no support...*

Laura relays an example of her eleven-year-old son just "not getting it":

*He went to school in the middle of summer wearing gum boots, shorts and a winter parka. And I'm sitting there shaking my head and going "Stand outside and tell me if this is appropriate?" And it was funny, because he couldn't see what was wrong with what he was wearing. And that's when it really kind of hit home that something isn't always working.*

Kay observed her daughter displaying what appeared to be deviant behaviour when she attempted to pinch her sister's fingers in a door. When confronted, it was apparent that her daughter just "didn't make the connection". The alcohol affected children tend to also present as having more insight or attempting to pass as if they understand:

*I would ask him like "Why did you do that?" and he'd kind of look at me and say "Like I don't know." And I kind of knew that he didn't know why he did that. And just things that didn't quite fit. And you know, I've had to explain stuff to him and I'd say, "Do you understand what I mean?", and he'd say "Yeah", but I'd still think, "I don't think he gets it." You know, there was just so much stuff that I just knew he wasn't getting, even though he was pretending that he was. [Julie]*

Given the challenges that their children display, it is not surprising that the mothers feel like an inadequate parent, while at the same time realize that there is something different about their child. Equipped with their experiences as mothers along

with their own research, the women were able to “figure out” the reason for their child’s behaviour. Julie “heard about FAS” and subsequently contacted an agency in Seattle who sent her information. She thought “Wow, this really sounds like he has [FAS]”. Both Laura and Trish made the connection through the work that they were doing. Through supporting families who have alcohol and drug affected children, Laura concluded that her son’s difficulties amounted to more than what the doctors had presumed was “just a fluke of nature”. Trish recognized the signs while attending a conference that would assist her to work with persons who have a developmental disability. Sally happened to read a newspaper article that she felt described not only her daughter, but her husband as well. And so on, the mothers generally made the connection through their own research or serendipitous findings.

The mothers, after realizing that their child is alcohol affected, then set out to have professionals and others confirm and affirm this. Unfortunately, this was a process fraught with disregard for what the mothers felt to be true. Kay, for example, felt dismissed when she approached her daughter’s psychologist: “[The psychologist] either didn’t believe me or didn’t think she was bad enough or whatever....[I felt]not validated and shut down.” Julie’s story is unfortunately typical:

*I didn’t know very much about FAS...., but I inherently knew that that’s what my son had. I had talked to the Principal of the school ... and asked what he knew about FAS and that I suspected that my son might be affected that way, and did he know how I could get a diagnosis. He told me that there was no point in pursuing that because [he felt] nothing*

*could be done, and to just shelve it. And so I did, I just forgot about it [for a while].*

Family members were similarly unwilling to accept that the child was alcohol affected.

Barb relays her mother's response:

*I realized, OK, there's a very good chance that this was what was wrong with my daughter. So, I took the information to my mom, whom my daughter lived with by this time cuz she was in and out of group homes and foster homes since she was 11. So, I took the information to my mom, and my mom said "No way. I don't want you getting into this, I don't want you looking at this. It will give her an excuse to behave badly", although she already was [behaving badly]. So, I dropped it.*

The children themselves were apprehensive about receiving a diagnosis due to preconceived ideas about the syndrome. April had to make several attempts before her daughter would agree to being assessed.

*Every time I'd book an appointment we'd lose [her], she'd be gone because the doctor told her back in '96 that she didn't have FAS: "you can wipe fetal alcohol out, she doesn't look mentally retarded." So, then we couldn't get her to an appointment. [She'd say] "I'm not retarded, I'm not going to no fucking appointment!"*

Several of the mothers utilized the services of a community FAS agency who assisted in connecting the mothers to the appropriate specialists for diagnosis. The support and advocacy that the women received was a welcomed relief. Julie's sentiments were shared by others:

*That was through the help of [the woman at the FAS Agency]. I would not have gotten anywhere without [her]. She is just an angel, an angel, throughout this whole process. She's gotten me the help that I have gotten. Uh, it was through her that I got connected to the pediatrician where I got the diagnosis done.*

Receiving a formal diagnosis was often a double edged sword as the mothers felt both validation and guilt. Sally's feelings were typical of what the other mothers shared:

*Uhm, getting the diagnosis was painful, but I already knew before going in. I already knew, but actually seeing it on paper, hearing it from the doctor, uhm, was very hard, very hard. There's grief and loss issues that I still feel regularly and probably will feel till the day I die. Uhm, I work with my life the best I can, and work forward, cuz I can't change anything that's happened, I can't go back, I can't change it, I can't fix it, it's done. So, we have to deal with what we've got, but it hurts.*

Laura's own anger is apparent:

*Yeah, so it was from my own understanding and making the connections and realizing, wow, you know. And of course then you go through the process again of grieving. You know, like "Was this my fault, and did I hurt my baby?" And you know, then being really angry at the doctors who couldn't tell me I was pregnant, and you know, "How come their labs were making so many mistakes?" You know, you just go through that whole process. First you get really angry.*

For the children who are alcohol affected, receiving a formal diagnosis helps to see themselves as other than bad. Julie explains her son's response:

*And with the diagnosis, it really shifted things for him in the sense that he just always felt so inadequate, so stupid, so, so ... just like such a loser. Like I question what happens to the spirit [voice quivering], you know the human spirit... when all they ever experience is loss? Loss after loss, and rejection after rejection, and failure after failure, and to not have any sense, ...like "Why is that happening?" Because by nature he's a good person. He's got a huge heart, and is really sensitive and then to have all these experiences to keep hitting him his whole life, and then to be able to understand why, has made a big shift for him. It's like "Wow, it's because I think differently, it's because there's something not quite right with my brain. It's not my fault, it wasn't something I did, it was something I was born with, and there's other people like me." Yeah, it's really helped.*

Barb describes how the diagnosis shifted her daughter's self concept:

*When she found out she had FAS she felt like it was for the first time "OK I'll get help." She wouldn't before... uh, I guess it would have admitted there was something wrong with her, but when she realized it was a medical reason she said to me "I always told you there was something wrong with me. Now maybe I can get some help." So, it was quite amazing.*



### Treatment/intervention

Being the parent of an alcohol affected child necessitates contact with an array of professionals from health care providers to social workers to teachers and counsellors. A professional who is perceived as helpful by the mothers is invariably someone with whom the mothers can establish a trusting relationship. The mothers report carrying an enormous amount of “shame” and “guilt”, which often leads to feeling tentative towards professionals. As Kay states: “It’s the guilt and feelings of blame that ultimately holds everybody back.” Similarly, Barb recalls:

*I know what it’s like to deal with school boards... When your child is acting up terribly and you go into a great big boardroom and sit there with all these higher-up people who are looking down at you, you know they treat you terribly. So, I went through that [my daughter’s] whole life.*

By contrast, Laura relays how a nonjudgmental approach can lead to dialogue that transcends feelings of guilt and shame.

*And that was probably the first really helpful health care professionals I had met. And to this day, I just think wonderful things about them. And that’s [the social worker] and [the pediatrician]. Because they didn’t make you feel bad. You know, they just made you feel really supported. They didn’t bullshit you, they told you what they thought, they told you how they saw your child as being affected, and uhm, you know, and it was really helpful because they even gave you some ideas as to what you can do. You know, and not even once, even when we were talking about my pattern of drinking, did I feel threatened or that they were looking at me*

*negatively. I think that's the first time that I felt really supported in this whole process, and by then my son was ... uhm, seven years old?*

One particular support worker, "Anne", was referred to by almost all of the mothers. Anne works for an agency whose focus is to educate and assist with issues pertaining to Fetal Alcohol Syndrome. Julie's narrative captures an opinion shared by the others:

*"Anne" has never ever been judgmental, not once. I've never ever thought that she's judged me for being a birth mom. I mean it's something that's not even in her nature- she's beyond that, you know. And that's really important - to be accepted, that this is like,... like I almost feel like she honours me because of the walk that I'm taking. I know that's a pretty bizarre way to look at it, but that's how I feel. And I really respect her for that. And just, she knows my struggles and she's been able to point me in the right direction. Like you can go here for help, you can go there for help, we're going to try and do this, we're going to try and do that, and yeah. She knows where to go and what's available and what's not available. If I ever need anything she's the one who I call, and she's just always there.*

April recalls a pediatrician whose empathetic response made it easier for her to disclose honestly both her current struggles and past history.

*The [pediatrician who diagnosed the girls when they were adults], said to the both of them, you know and here the doctor's sitting there and she's crying and I'm looking at her thinking what the fuck happened and we*

*were talking about my addiction and she's sitting there and all of a sudden she's crying. And she looked at both the kids and she says, "you know, you girls should be thankful that your mom cares for you", and they both rolled their eyes ...and they don't see that I'm trying to help them and trying to get help for them. So, when the doctor said that and I started to cry and I'm like woah, and [my daughter] goes "Mom, was that ever neat that the doctor was crying.", I said, "Yeah, it goes to show you that she's honest", and she says, "Oh yeah, I guess so."*

The above narratives speak to the pragmatic caring that mothers report as important in relating to a professional. A sympathetic and non-judgmental attitude are valued, but within the context of "really helping" to provide appropriate supports and services. Unfortunately acquiring help for an alcohol affected child has generally been an enormous challenge to the mothers. Trish's experience has been somewhat different in that her son does qualify for services within the school because he is severely physically and mentally handicapped. It should also be noted that both Barb and April's children graduated from high school through a non-academic stream, and do have employment potential. Those experiences noted, there is more generally a lack of appropriate and affordable services. In particular, the mothers report that effective interventions are lacking in the school system. The children rarely qualify for special assistance within the classroom because they do not meet the criteria of what constitutes a "special needs" child. More specifically, the children often do not have an intelligence quotient (IQ) below 70. Consequently, the standard tests that are performed on the children do not adequately reflect their needs. Laura's story is unfortunately typical:

*And my son has had the whole gamut of psycho-educational assessments at school. And of course he doesn't qualify for help, but everyone knows that he would benefit from a full time Special Education Assistant in the classroom. ...And the interesting thing is that when they do these tests, in some of them, he would fit into the category of being severely mentally challenged, and then, on the other end of that scale, he was above average in intelligence. So, they said "Because of this, he doesn't qualify for services." You know, "You guys don't really get it. Just because he can verbally tell you everything, unless you are going to verbally test him on everything, you're failing my son."*

Sally relays a similar sentiment:

*Addressing the criteria for services would be helpful. Uhm, there's these lines that are drawn, these ceilings that are put on. When a person needs help, they need help. And when a person says they want help they should be given it. And when you base your help on either an IQ or a risk factor, you're not helping the people that need and want the help and will be successful when they get help. Uhm, those are big problems.*

She goes on to relay that the teachers subsequently use an inappropriate approach that adversely affects her daughter:

*So, you know her teacher doesn't understand that he pushes her really hard. So, she's more stressed now than she was at the beginning of the year. But she's working really hard and she's really trying. Uhm, she's not stealing anything right now, so I know that it can't be too bad, she's*

*just having the global fits. But, when she gets too stressed, she'll start to find things.*

Julie's son experienced extreme, if not abusive, interventions by teachers, which had a detrimental impact on his behaviour:

*Uhm, his experience in school was really horrific, he was put down a lot. Teachers called him stupid. He was put in the hallway, he had to stand in the corners, he was put down. That was his earliest experience in school. You know, he'd come home from school, ... he failed one of the early grades, he got held back, and that was really humiliating for him. The kids picked on him and they called him stupid, and then as he got older, like when he turned thirteen, it was like oh my God, all hell broke loose. He just rebelled in a really big way. His teachers didn't know how to deal with that. He went to every single high school in Victoria, he got kicked out of every single one of them - including the ones that nobody ever gets kicked out of. He managed to get expelled from all the schools. [He got involved in] lots of drugs, lots of alcohol, hard drugs, crack cocaine, and he's been involved with gangs ... it just goes on and on and on and on.*

All of the mothers attempt to advocate for appropriate services for their children, but tend to be dismissed by those who presume to know better. Laura's attempts to advocate for her son's needs in school is an experience echoed throughout the narratives of other mothers:

*You know I tried having him held back from kindergarten on, you know, saying that he's not ready to move, don't move him on, don't move him.*

*And I was always told "now, now!", you know. And now he sits in grade five, he acts like he should be in grade three, and if they think that holding him back would be emotionally hard on him, I don't think they were anywhere near prepared for a child who is mentally behind his peers and subjected to all the name calling and teasing.*

When Sally's daughter began to leave the school grounds during school hours Sally threatened the school authorities with liability.

*But, I hauled them all into a team meeting and I explained that, you know, "If something happens to her you're going to be liable, because it's your responsibility to keep her safe when I'm not here. You have her for six hours. What are you going to do to keep her safe... and keep her dignity and self esteem intact?!" So, uhm, last year was a nightmare, just a nightmare, she was in a class with forty-five children! It was split, they had two teachers, they were team teaching. It was an experiment, a social experiment that they were doing! She suffered because of it, and she was taking off... disappearing with another girl into the attic of the school. Nobody discovered this for months. And boy, the hullabaloo that came down when I went into have a meeting about that. And it was the grade seven teacher who's her teacher this year. She's one of five grade six [children] in the grade seven class this year, which I was worried about, but it was the only option, cuz the other option was [for her to get] the teacher who had her last year who let her disappear without realizing she was gone, and then said that, you know, it couldn't have happened, the*

*kids must have been lying. So, some teachers have been helpful, others have been useless, and the school won't help unless I'm saying "You could be liable here!"*

The type of services that appear to be most appropriate and effective for alcohol affected children are offered through behaviour psychologists. Unfortunately, these services are often not available in many communities and are costly. Julie relays the dilemma:

*Like he needs psychological services so bad. Even if there was somebody here in [this city] who could help him, there's nobody to pay for it. Like I'm looking at a thousand dollar bill a month to send him to [another city] for psychological services. I can't afford that. None of that's covered because he's "too high functioning" according to the regulations. He just falls between the cracks, he doesn't qualify. If he were to go to jail and into the penitentiary and in that system, then they'd help him. But there's nothing for prevention, it's crazy! It's crazy. ...There's a psychologist who wants to work with him, he wants to work with her, and I can't afford it. If he goes out and murders somebody, then they'd help him, you know.*

*Crazy.*

April was similarly frustrated with the cost of services that were not within her means:

*Here's this [social worker] telling me she can hear the frustration in my voice and for me to calm down and I'm just trying to get her to send me to some places where I can get some help because I still wasn't in contact with [the local FAS agency], and the doctor's office wanted me to pay*

*seventeen hundred dollars for [my daughter] to be tested... I didn't have seventeen hundred dollars to get help for my daughter and the social worker told me they aren't helping me, they ain't giving us no money so I was like "you need to send me to some places, I don't know where to go".*

Not surprising, the mothers feel that it is important that they receive respite from the daily challenges of parenting a special needs child. This much needed break can, however, be difficult to negotiate. Sally relays how she managed to find respite, even though she was not eligible for services.

*She gets respite, uhm we get respite, whichever way you want to look at it, I think it's for all of us, on weekends. I am not eligible for any services unless I were to, I was told by social services that I would have to start certain behaviours, or behave in a certain fashion, uhm, before I could get help for my kids. It would have to be a real serious crisis situation. There needed to be more going on in my family. I wasn't willing to go back and start abusing drugs or alcohol to satisfy some criteria. So [the woman from the FAS community agency] does it out of the kindness of her heart. Uhm, and keeps her for the weekend. Sometimes she just goes overnight, sometimes she goes Friday and doesn't come back until Monday night. And [she] just offered ...because she feels for us and she knows how hard I'm trying and how challenging it is. My mother also has a very difficult time taking care of my daughter. Uhm, so she's kind of the only one I've got who can help me with her right now, and she's not even getting paid to do it.*



Julie and Laura have not been as successful in securing a break away from their challenging children. Julie's story is indicative:

*It was really really hard, [trying to cope with my son's behaviours]. I remember calling social services one day and crying and saying "I can't do this anymore, like send somebody over here and take him! Take him away and have somebody else raise him for a while, I can't do it. I'm going to kill myself, I'm going to kill him, Give us some help!"*

The social worker's response to this mother who was threatening to harm herself and her son was not to place the boy into foster care as requested. Instead the son was deemed not at risk and was assigned a temporary youth care worker, which Julie says "was helpful, but I needed a lot more than that." Laura's experience is similar:

*I kept saying to them "I need a break. Give me a break!" And they never did. They put me on some wait list for respite care, and I think after a year I gave up waiting and moved, and when I moved they said "Well, you lose your spot on the wait list." "Whatever, I'm never going to get a break anyway!!!" You know, and that was just kind of my feeling, that I would just never get a break. I think, looking back, the best thing that they could have done would have been to give me a break. And I didn't ask for much. All I asked for was one weekend. You know, just let me have one weekend to myself, and that would have been the best therapy. And it wasn't just to go out and drink, I could have done that with my kids. It was just to not have to be responsible just for a couple days. Just to uhm give me a chance just to be. And I think that was the most important piece that was*

*missing, was just to be in solitude and know that my children were in a good environment - protected, safe.*

The children of Barb, April and Mytayja went into foster care, either temporarily or permanently. Perhaps if the resources spent on foster care were reallocated to these mothers for respite and other supports, the family may not have been disrupted.

### **Making ends meet and making sense.**

Being able to move forward and transcend their struggles is something that all the mothers are motivated to do. The resiliency that they possess appears to be closely tied to both practical and philosophical needs. More specifically, the mothers require basic material necessities, or the means, to get by, as well as a sense of purpose or meaning within which they can frame their experiences.

### **Means**

The previous narratives indicate that the mothers face financial barriers that prevent them, at least in part, from accessing services for themselves and their children. It is particularly difficult to make ends meet as a single parent, which all of the mothers are or have been. At times the mothers speak more directly about their need for money. Both Julie and Sally openly admit that “money is tight.” For Julie this means that she is “relying on credit” just to get by:

*I'm relying on credit to get by, and I'm almost out of credit. I don't know what's going to happen to my son when I run out of credit. I don't know what's going to happen, that's why I'm scrambling to put something together, cuz, it's expensive to keep somebody out of trouble. It's*

*expensive to keep them entertained, to keep them wanting to live, it costs a lot of money.*

She goes on to explain that although her son is eligible for a disability pension through the government, this is not adequate to pay for his living expenses. Like some of the other moms, Julie's son remains financially dependent upon her well into adulthood. For Sally, a lack of finances has meant that she is unable to afford necessary medication:

*We've found one [medication] that's successful. I've been taking it for a year, uhm, up until a month ago when my medical was no longer covered. I was on income assistance when I was first going to school because I got bursaries, going part time. But now that I'm on student loan going full time, they won't give me any medical coverage and my prescriptions are no longer covered and I didn't have money. So, I was weaning myself off the medication because I needed to stretch it out as long as possible. So, I went to see my doctor today and got a new prescription in the hopes that it's not too expensive. My mother told me that her prescription, which is the same kind as mine, ...[costs] \$104.00! I can't afford that! You know, which child don't I feed this month? Ha Ha! You know, I can't do that.*

Most of the mothers have had to rely upon social assistance at some point, in addition to the help of family members. Kay's experience was shared by the others:

*And when my husband and I did separate I had to collect social assistance, and it was worse than what I thought it would be. You know, I uhm, had to fight for absolutely everything. I had to fight to keep the vehicle, my husband didn't leave me anything else. He left me the vehicle,*

*thank goodness. They were telling me that the payments that he was going to make on the truck would have to be deducted off my measly thousand dollars or eleven hundred dollars I was getting [to support myself and my two daughters], and my mom was already supplying my food, you know, like it was impossible, you know, it's impossible, you can't live off that, much less live it straight.*

While some mothers talked about how difficult it is to make ends meet, others made reference to the stability they felt when they were able to acquire basic living necessities. For example, although Mytayja and her newborn were existing on social assistance, she was much relieved to find an affordable apartment. Similarly, Barb relayed with pride that together with her current husband she now owns a home and a car.

### **Meaning**

Just as necessary as the means to eke out their daily existence, the mothers rely upon a personal belief system that helps to put their life trajectories into perspective. Many of the mothers find this sense of meaning through the twelve-step recovery program, which incorporates a belief in the spiritual realm or a "higher power." Barb explains:

*Ultimately, you have to count on yourself and God - God first, right, a higher power or whatever, I call it God cuz it's easier. I'm not religious at all. Everyday I invite that power into my life and I turn my will over to it.*

Barb now views the fact that her pregnancy was not confirmed until the sixth month as God's will:

*Had I known I was pregnant I would have had an abortion because there's no way I was ready to have a baby. So, I feel like it was sort of God's way of making sure that she came into this world. Because I knew that this child was meant to be born, because she was really heavily involved with my mom and stuff, so I think that it was just meant to be.*

April is adamant that she is not religious or spiritual, but does see God as watching out for her.

*I was raised Roman Catholic, "God is going to punish you", but I knew somebody was watching over me, whether it be that punishing God or not, he was uh, I believed that I was being taken care of all of my life.*

The mothers also feel that it is important to feel like they belonged somewhere. For both Laura and Mytayja, their sense of belonging was facilitated through connecting to their cultural roots. Laura's connection to her First Nation's community has helped in this regard, even though it is not her birthright. She explains:

*And for me, you asked me what brought me around, and it was culture. You know, I started reclaiming roots, finding out where I belong. ...Except that it's not even my birth right background. So, for me, it was finding a place where I belong. Cuz there was so much stuff going on in my own childhood, I was 23 before I found out I wasn't First Nations. So, I spent 23 years of my life believing that that's who I was. And to find out that I wasn't was a huge shock. And I think it was a combination of [things], ...but I think culture plays the biggest role. ...I don't explain it to too many people, but uhm, you know, when I first found out that that wasn't really*

*my culture, I was more lost than I had ever been in my life. So, then I thought, well I can't be here, I can't keep living like this cuz it's not mine, it's just stealing. And several elders, you know, talked to me and said, you know, maybe this wasn't your birthright this time, but you've been here before. And partly because of the abuse and things that I had lived through, there was always elders that came to me in dreams and taught me, you know. I learned a lot of stuff that were things that you might not have learned otherwise. So, they said, you know, "You're welcome to stay here." And that was a real turning point because not only did I belong, you know, I belonged somewhere that wasn't mine originally.*

For Mytayja, discovering her biological family helped her understand "this mysterious puzzle of my life". Pieces of the puzzle include finding out that she is part Metis, and that her biological mother was, like herself, a drug user. She now enjoys participating in First Nations cultural activities, such as an Aboriginal women's arts and crafts circle. Although Mytayja sees the tragedy in her mother's own trajectory, which ended in an overdose, the similarities of their lives have helped her to feel a sense of connection. Similarly, although all of her children have been apprehended, the connection that she maintains still transcends biological ties: "All of my children were born on a Wednesday in the afternoon, and I was born on a Wednesday."

### **Agency**

The narratives indicate that at times the mothers are complacent in terms of the struggles and barriers that they confront. For the most part, however, the women are

continually frustrated at the lack of validation and support that they receive. At other times the mothers attempt to exert agency. Sally recalls:

*The doctor's report had errors in it, mistakes, ...and when I contacted him to have them corrected, he was patronizing, very patronizing. It really pissed me off! So, I wrote down what the problems were, and he said that he would have them fixed. But then, the sneaky bugger sent it back to me saying "revised copy" and word for word it was exactly the same as the previous document. So, there are all these errors that are still there; inaccuracies about what I said to him.*

After feeling shunned and mistreated during the birth of her first baby, Laura took matters into her own hands with subsequent births.

*My experiences in hospitals have not been good ones. Even when I gave birth to my second child, I wouldn't let them take him anywhere, you know. It was like, "No way! I have no trust in you people any more!" And with my third son, I gave birth, I got up, I showered, uhm, you know, signed all the papers, and I was out.*

A number of the mothers have also begun to speak publicly about their experiences. This has enabled them to network with others and to forge alliances. Julie speaks monthly at an alcohol and drug treatment program:

*I tell my story and a big part of my story is my son, because we've had a horrendous life together. ...[through] mentioning the difficulties that we've had... [and people responding] I became aware that there are people out there who were working in the field, and that there were other*

*parents, foster parents, who had children that were affected and who knew what I was going through.*

Some of the mothers exert agency through a litigious process. Kay talks about her ability to “fight” through a tribunal.

*I fought through the tribunal and won – [my husband was made to pay for the vehicle], but other women won't do that. You know, I'm a fighter, because of the sexual abuse I've been a real fighter in my life and that's why I think I made it.*

Laura and April also took pragmatic steps to face past traumas. April sued her ex-husband for sexually abusing her two daughters, and Laura made a criminal injury claim against her own family for the sexual abuse that she had endured. All of these strategies are the mothers' attempts to gain power and control over their lives. Participating in the present inquiry has also been an empowering experience for the mothers. The women appreciated the opportunity to tell their stories, and report that this is the main reason that they agreed to participate.

### **THE MOTHERS' SUGGESTIONS**

Throughout the interviews the mothers made several suggestions in terms of how to respond and support women who have given birth to an alcohol affected baby. Some of these suggestions were elicited through a direct interview question: “If you could develop supports or services for women who drink during pregnancy, what would that look like?” Other suggestions surfaced more naturally during our discussions by way of “they should” or “it would be nice if” or “why don't they”, and so on. The recommendations that follow are consistent with the themes that the women have articulated thus far. These



seven recommendations help point to a framework for services, which is laid out in the concluding chapter.

### **1. Avoid blaming women.**

All of the women talked about wanting to be good mothers and feel a tremendous sense of guilt and responsibility for giving birth to an alcohol affected baby. Responses from professionals and lay persons that reinforce their sense of guilt serve to perpetuate addictive behaviour and deter mothers from seeking help. Education and prevention campaigns whose message is blaming or stigmatizing are also not helpful to women who have some awareness that alcohol and drugs are contraindicated during pregnancy.

### **2. Hold women accountable without shaming.**

All of the women felt that they should be held accountable for their lives as sexually active women, as alcohol and drug users and as mothers. Some of the mothers suggested severe means of accountability, such as mandatory drug testing during pregnancy, refusing to serve alcohol to pregnant women, and preventing women, somehow, from having children if they are using alcohol or drugs or at least ensuring that they are abstinent before they even conceive. These suggestions were always couched with a caveat that means of accountability should not shame women. The caveat does appear moot given what is suggested, but it is also reflective of the women's trajectories. On the one hand, the mothers wished that someone had intervened in order to prevent the birth of an alcohol affected child. On the other hand, the mothers know first hand how difficult it is to admit and expose themselves as being an addict.

### **3. Reduce the stigma attached to addiction.**

Both the public and the professionals need to know that addiction is common in our society. Addiction is not a lifestyle choice, but rather it is a means of coping. Addiction should be understood as a disease that can afflict anyone, even women who are pregnant. The mothers feel that it would be helpful for the women, their children and professionals if addiction was talked about more openly within public and professional discourse.

### **4. Provide more education about what FAS is.**

Social workers, doctors, nurses, teachers and the general public need to be more informed about both the causes and effects of Fetal Alcohol Syndrome and related disorders.

### **5. Offer appropriate and accessible resources.**

The mothers require timely access to services that help women overcome addiction, receive a diagnosis for their child, and get the necessary behaviour, education and vocational training for their children. These services need to reflect expertise in the given area and be both geographically and financially accessible.

### **6. Make crisis intervention available.**

The mothers require somewhere to turn when they are feeling overwhelmed by their addictions and/or by their role as a parent of a special needs child. Some of the mothers felt that they should be able to call a 1-800 number and receive support and expert information at such times.

### **7. Connect with others.**

The mothers felt that it was important that they not be alone in their journey. It would be beneficial to develop a mechanism that can assist women to connect with others in

similar situations. Some mothers suggested a buddy system that could be put in place to help women during pregnancy and through parenting.

## **DISCUSSION AND IMPLICATIONS**

The present inquiry set out to bring the voices of women who have given birth to alcohol affected babies into the discourse of maternal alcohol consumption. The purpose was to provide an opportunity for these mothers to tell their stories and to inform future interventions, services and discourses related to the phenomenon. The findings of this inquiry have implications for theory, practice, policy and future research.

### **Subjugated knowledge.**

It is from the women's stories that we can theorize "why" mothers have been absent from what is said and done about the phenomenon of maternal alcohol consumption. That is, the "non-local determinants of the locally historic or lived orderliness" (Smith, 1990a: 221) can be mapped through what the women say. By exploring the phenomenon of maternal alcohol consumption from the standpoint of those who have felt the full consequences first hand, the social is exposed as something that happens; the social is "not an ensemble of meaning" (Smith, 1999: 75). As Smith points out, the standpoint of women locates us in local, actual and particular bodily sites (1999:75). From the standpoint of women who give birth to alcohol affected babies we can map social relations as coordinated activities, organized within specific places and at certain times connecting people in certain ways that are dependent on certain kinds of relationships. What Smith presents as the standpoints of women denotes plural locations and refers to experience as knowledge (Smith, 1987).

The standpoints of the mothers as illuminated through their stories/texts reveal how the local actualities of their lives are linked to broader processes of power and subjugation. By “working up” (Smith, 1999) from where mothers are located it becomes apparent that the medical, social service and educational professions contribute to a devaluation of women’s experiences. The stories reveal that the mothers’ perspectives are repeatedly dismissed during pregnancy through to parenting. They are “brushed-off”, ignored, not taken seriously, etc., by persons in positions of authority; persons who hold significant power in terms of their ability to enact change. A woman’s own ability to make change also seems to hinge on whether or not her concerns are validated by someone presumed to have more authority than her. The women report similar experiences regardless of whether or not they are identified as someone with an alcohol addiction.

Although working from slightly different paradigms, the pedagogy that informs the various professional practices and discourses stem from one basic message: Drinking during pregnancy can damage the fetus, producing a troublesome and difficult child, and should therefore be avoided. This “text” is taken as truth, rather than a social construction, because it is derived from so-called objective science. It is partly because of what has apparently been “discovered” by medicine that drinking during pregnancy is now discouraged in our society. According to popular, scientific and jurisprudence discourses, the pregnant woman is not supposed to be an addict, and the addict is not supposed to be pregnant.

The pregnant and the addict, then, culminate in an ontological contradiction. Women, with our supposed predisposition to the maternal and to the caring, are meant to

temper society. So, on the one hand the “pregnant addict” is fulfilling the social and cultural expectation that woman’s ultimate role is to have babies. At the same time, her addiction denies the current social prescription of that role. The pregnant addict embodies both what women are supposed to be (the promise of the Nation) and what we are supposed to prevent (the degradation of the Nation). The category of the pregnant woman becomes fused, materially, biologically, with that of a drug addict. The exemplars of each category are normally divorced from each other, when viewed together, they/it pose(s) what Julia Kristeva refers to as an abjection (1982). Abject, according to Kristeva’s theory is a “word which is flush with pleasure and pain” (Kristeva, 1982: 62). The abject is liminal in nature and therefore poses a threat to the process and practice of categorizing in order to make sense of the world. It is this liminal ambiguity that is at the heart of the power of abjection (Kristeva, 1982: 53 - 54).

The concept of the abject appears relevant to the “pregnant addict” and how she is both conceived and perceived. It is apparent from the women’s stories that professionals act paternalistically to “protect” women from pursuing their own suspicions about their pregnancies and about their children. Perhaps the professionals whom the women encounter are afraid to categorize the woman and her child for fear of stigmatizing, or for fear of having to respond to something they would rather not think about.

Although the professionals’ actions are likely in reaction to the mores of the culture surrounding motherhood and addiction, this can only partly explain their dismissive or hesitant conduct. Recall that the women’s perspectives and knowledge were disregarded not only as “those women” (i.e. women who drank while pregnant). Often the “addict” or “alcoholic” aspect of the mothers was not acknowledged or revealed, both

to the mothers themselves and others, until well after the birth of the baby. This would suggest that it is not just the mothers' status as "those women" that is problematic, but their status as *women*. It seems relevant that in all of the scenarios it is the women themselves who initiate the dialogue. It is the women, not the so-called experts and professionals, who are looking for verification, making disclosures, and asking for help. It is the women who are the initial knowers.

The point that I am making is not that the mothers possess some epistemological orientation that is gendered. It is true that what Gilligan (1982) refers to as a "connected knowing" is consistent with the mothers' stories. Gilligan (1982) proposed that women are oriented towards relationships and that this orientation is set apart from and in contrast to a male orientation. Throughout the stages of the mothers trajectories, the women talk about their relationships with others and how these impact their ability to seek out and/or receive help before, during and after their pregnancies. However, from what the mothers have said it is not this way of relating to the world, or *women's ways of knowing*, that is problematic. Rather, it is a mother's claim to know that is dismissed and disregarded. It is women as *the knowers* who are dismissed, not *women's ways of knowing*.

It is well documented that women possess a subordinate status within patriarchal capitalism. In Canada, women head the majority of lone-parent families, and more women than men work part time (28 and 10 percent respectively) (Statistics Canada, 2000). Even when employed, women are still largely responsible for looking after their homes and families. Women employed full-time earn only 73 percent of what men earn, and a disproportionate number of women account for the population of Canadians with

low incomes. In 1997, 56 percent of lone-parent families headed by women had incomes below the low income cut-offs, as did 49 percent of senior women living alone (Statistics Canada, 2000).

The experiences of the mothers speak directly to their marginalized location as women in Canadian society who struggle to make ends meet. The mothers are further marginalized because of their subordinate status vis-à-vis the professionals they encountered. The mothers are patients of doctors, clients of social workers, and parents of children who are doing poorly in school. There is an obvious power imbalance inherent in all of these relationships. The women's stories point to a hierarchy of knowledges with women as knowers occupying the lowest rung. Even the corporeal knowing of the mothers is not valued in its' own right. Despite that nearly all of the women "knew" that they were pregnant, they made what is now a normative response and pursued verification by a doctor. As Martin (1992) observes, pregnancy, which is a normal bodily process and experience for women, is, at least in the Western world, a presumed medical problem requiring medical monitoring and intervention. Relying on medical verification, however, proved problematic as medical knowledge often failed to confirm what some women already knew. The woman's knowledge of being pregnant seems to need the validation of medical expertise and scientific testing, regardless of how many times the tests are wrong.

The shortsighted assumption that a woman confronting an unplanned pregnancy "can just have an abortion" is ignorant of experiences of women like Barb and Laura. These two mothers were continually told that they were not pregnant – despite their own knowing to the contrary. Although the serum and urine tests used to detect pregnancy are

for the most part reliable, false negative and false positive results do occur. A sizable body of literature continues to address the issue and research continues to ensure greater accuracy (Hickey, 2000; O'Connor, Bibrom Peggy and Bouzoukis, 1993; Planet, 1990). Barb openly indicated that she would have had an abortion had she known earlier that she was pregnant. It should be noted that not only is there more risk involved with an abortion performed past the first trimester, but the emotional stakes are often higher as well. Laura indicated that she likely would not have had an abortion. Both women would have changed their behaviour earlier and better prepared themselves for the future had their pregnancies been confirmed.

In theorizing why mothers have been eclipsed from what is said and done about maternal alcohol consumption I would argue that doctors, teachers, social workers and other professionals value science and medicine over what the mothers tell them. The mothers themselves buy into this, in the sense that they feel that their own knowledge needs to be validated by those in position of authority. Mothers are further excluded due to their subordinate status as women within Canadian society, their shunned status as one of "those women", and their lack of power vis-à-vis their position as non-professionals/non-experts. Other influential texts and discourses, such as cultural mores tied to motherhood and to maternal alcohol consumption, continue to drive these processes. The taboo against maternal alcohol consumption is taken as a scientifically verified truth, rather than something that has been constructed at a certain time and in a particular place in response to intersecting social and political agendas. Fortunately, mothers build some resiliency and exercise agency in an attempt to gain autonomy.



### **Counter-hegemonic practice.**

The women's stories remind us that social workers need to continually take stock of our location, and in particular the amount of power inherent in our position. The privilege inherent in this position might be better utilized as advocate rather than as expert knower. In an effort to view maternal alcohol consumption through a critical lens, social workers, and other professionals, should accept as given that social concepts and categories, like "women who give birth to alcohol affected babies" and "Fetal Alcohol Syndrome", are expressions of actual social relations. Karl Marx states in *The German Ideology* that "men [sic] are the producers of their conceptions, ideas, etc. – real, active [people] as they are conditioned by a definite development of their productive forces and of the intercourse corresponding to these..." (1978: 154). Continuing in the tradition of historical materialism, Dorothy Smith asserts that "reason, knowledge and concepts are more than merely attributes of individual consciousness, they are embedded in, organize, and are integral to social relations" (1990a: 160). Social workers are implicated in the social relations that perpetuate what is said and done about maternal alcohol consumption. We are therefore well situated to alter the "abject" status of the pregnant woman who uses substances. This can be done, not by creating another category of what she really is or might be, but by contributing to the counter-hegemony.

If the role of social work is to reduce harmful influences on women, children, the family and broader society, then our work should also be one of challenging oppressive discourses. To do this we must first engage in critical reflection about where and how we are implicated in the practices and discourses, and then set out to disrupt them. The discourses and practices of the status quo are present in our everyday interactions with

clients, colleagues, professionals from other disciplines, in our charting of case files, the letters and recommendations that we draft, as well as the social policies and mandates that we both inscribe and ascribe. These mundane practices can be considered political actions that offer tools with which to draft a counter-hegemony. When social workers adopt a rule of “no jargon allowed”, the woman who is pregnant and drinks alcohol can transcend the “bad mother” label. Through a social worker’s conscious effort to distinguish between the real and the rhetorical the “bad mother” can more appropriately be seen as a woman struggling with addiction, with a special needs child, with poverty, and so on – she is a woman in need of assistance, not blame. Locating the personal lives of those we serve within their larger social and political context will illuminate the oppressiveness of discourses and practices.

### **Women centered policy.**

That a mother’s trajectory hinges on both her specific socio-political location as a woman who drank during pregnancy, as well as her subordinate status as a woman in Canadian society, has implications for policy. Healthcare within Canada now recognizes a population health approach, which emphasizes the social determinants of health. Factors such as income, education and literacy, employment and unemployment, working conditions and factors in the social environment such as housing, violence, hunger, etc. impact directly the health of an individual and broader community (Health Canada, 1999). The move away from a strictly positivist and mechanistic approach to health and medicine is consistent with a shift that the social work profession has previously undergone. Leonard (1970) describes a trend in practice that is less oriented towards “case work” and individual psychology and more concerned with social structures and

how these produce and reproduce inequalities. A policy that embraces a community development approach with a more holistic goal could effectively address the socioeconomic factors related to FAS.

If a policy is to be developed that addresses the social issues as they relate to maternal alcohol use, the women most directly impacted by the phenomenon need to be included in the process. Incorporating the knowledge and concerns of women who have given birth to alcohol affected babies would add legitimacy to the policy development process. It would also validate the mother's experience as a form of legitimate knowledge and thus situate her as the expert. This knowledge could articulate at the policy level more appropriate criteria for services. The mothers reported how frustrating it has been that existing criteria for services continue to disqualify the children who are in need of help.

An inclusive approach to policy development is conducive to a feminist sensibility. Such an approach attempts to flatten hierarchy, is cooperative versus competitive, and moves those who have been relegated to the margins towards the center. The incorporation of what Harding calls "feminist Science" would be beneficial here (1991: 296-312). Harding advocates a feminist epistemology that can direct the production of less partial and distorted beliefs. Like Harding (1991), I see that a poststructuralist predication that 'all is relative' will not likely satisfy policy makers. Instead, Harding's notion of "strong objectivity" seems to hold more integrity. Strong objectivity, as conceived by Harding, reveals and admits up front the historicity of a given phenomenon, like FAS. This is in contrast to a destructive objectivity – one that lacks recognition and insight into the thing (Harding, 1991: 138-162).

Consistent with this feminist approach to policy development is a strategy of harm reduction. A policy rooted in harm reduction “recognizes that there is a continuum of drug use from non-problematic to extremely problematic” (Denning, 2000: 34). The focus of harm reduction is on reducing harm to the person and to those around her by accepting the person for where she is at now and promoting self-efficacy (Denning, 2000: 83). The harm reduction approach to alcohol use during pregnancy does not require abstinence in order for a woman to participate in programs and treatments that help her to cope with her addictions (Denning, 2000: 34). A harm reduction stance recognizes that relapse is common and that traditional programs, such as the 12 step Alcoholics Anonymous model, do not work for a large number of people – as it hasn’t for Mytayja and April (Denning, 2000: 44). The low threshold of such a policy invites health promotion strategies that may include both drug management and abstinence. Thus, a harm reduction approach allows space for those who are unable or unwilling to make the major life change of completely abstaining from alcohol and/or other substances. A policy that embraces a harm reduction framework is amenable to a woman-centered assessment and intervention. Therefore, a woman who is struggling with alcohol use during pregnancy, or at any point in her life, is not handed a prescriptive for her ills. She is instead assisted in making her own choice in terms of level of prevention and intervention.

### **Mothers as researchers.**

The present investigation is one example of creating a venue for women to speak. An improved endeavour might embrace a participant action research model where women can truly occupy the center. It is from the center that participant-researchers hold

more clout with which to question the modernist faith in so-called objective science. The advantage of a PAR model is that the questions that research projects seek to investigate are formulated by the participants themselves. From what the mother's have shared in the present investigation, such questions would likely include: What interventions have parents found effective in parenting an alcohol effected child? What interventions have drug and/or alcohol effected persons found to be helpful to live productive and fulfilling lives? How has a harm reduction approach to addiction impacted a woman's life trajectory including pregnancy, fetal outcome and parenting? What do women feel about specific educational campaigns related to maternal alcohol consumption?

## CHAPTER FOUR

### CONCLUSION: A FRAMEWORK FOR SERVICES

Since the second wave of feminism during the 1960's and 1970's women have made great gains in terms of choices and opportunities afforded to us. The women's health movement in particular was instrumental in women's protesting, chanting, lobbying, organizing and talking openly about our bodies and our health (Ruzek, 1979). We have challenged the established health care system and promoted resources that are accessible to women and that help us make our own health care choices. That women have become more active and vocal about our status as women, mothers and patients, however, does not mean that women and mothers no longer struggle against discrimination, oppression and violence. The mothers who participated in the present study have attested to this throughout their stories. The mothers and their children are at times judged, controlled and kept under surveillance by those who presume to know what is best. At other times, the mothers and their children are completely ignored and shunned. Within both these extremes, the mothers are not considered autonomous agents of their bodies and their babies. From the perspectives of women who give birth to alcohol affected babies then, FAS can be considered a feminist issue. Fortunately, the mothers refuse to remain complacent.

The women who participated in this investigation offer important insights into what is helpful and necessary to assist biological mothers of alcohol affected children. The mothers also articulate what has not been helpful in terms of gaps in service and how services are delivered. Their expressed concerns, experiences and recommendations point to a framework of services that addresses their needs throughout their trajectory as

women, as individuals who struggle with addiction and as mothers of special needs children. The six key aspects of the framework are delineated below.

### **Holistic**

Services should “wrap around” the woman at whatever stage she may be at. This would include services to assist the woman before, during or after pregnancy, and while parenting, which often extends into the adult life of the alcohol affected child. Services should also consider the socio-political context of the mothers’ not only as women who have given birth to an alcohol affected baby, but as women who occupy a subordinate status within Canadian society.

### **By mothers and for mothers.**

Services should be driven by mothers who have experienced the phenomenon first hand and therefore possess important knowledge and relevant expertise. Mothers can act as peer educators, role models and buddies for other mothers at various stages of their trajectory. A forum could be established that affords mothers the opportunity to share their stories and connect with others who have similar experiences. Mothers can act as advocates and agents at both the grassroots and policy levels.

### **Effective interventions for children and adults who are alcohol affected.**

Parenting an alcohol affected child is one of the biggest challenges that the mothers relay. Services need to be developed that can assist the child at home, while in school, and during other social situations. Similar services need to extend into adulthood to assist with life skills and vocational training. The children themselves may play an important role as peer educators. These services need to be effective and accessible to all mothers and their offspring.

**Addiction services that are individualized and accessible.**

That at least one mother, Sally, has successfully managed her addiction outside of the traditional 12 - step model, and that both April and Mytaya have undertaken traditional treatment several times but unsuccessfully speaks to the need for individualized addiction services. A harm reduction model that includes the option of abstinence would keep addiction services inclusive and individualized, while recognizing that sobriety occurs along a continuum. The recent move towards harm reduction within addiction services may help those women for whom the traditional 12-step abstinence model has not been effective. Women need addiction services that are readily accessible both in terms of timing and in terms of not discriminating against women who require medication or need contact with young children and family.

**Education and awareness about Fetal Alcohol Syndrome.**

Education and awareness campaigns need to relay that addiction is a common phenomenon, even during pregnancy. By starting where women are at, rather than where they ought to be, a harm reduction approach to addiction can attain greater acceptance, and FAS can be seen as a disability that is not entirely preventable. Education campaigns need to target professionals such as physicians, nurses, social workers and teachers and reinforce that women who have given birth to alcohol affected babies are not bad mothers.

**Address structural inequities against women.**

Services that seek to assist biological mothers of alcohol affected children, need to address their subordinate status as women in Canadian society. In order for women to succeed, their socio-economic status needs to improve through expanded opportunities



and wages. Such a focus would also concern itself with the violence that women have survived as children and continue to confront as adults. That mothers are continually dismissed as knowers is merely another form of violence that needs to be eradicated. Mothers need to be involved at the policy level where women's equality is articulated.

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