Fetal Alcohol Spectrum Disorder Awareness Campaign Project

Literature Review

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Abstract

Approximately 23,000 Albertans currently live with Fetal Alcohol Spectrum Disorder (FASD) and each year more than 360 babies are born in Alberta with this disorder. This literature review examines the most recent and important literature on FASD prevention, the economic and social costs of FASD, the level of FASD awareness, who is at risk of having an FASD-affected child, and the barriers women face to get the assistance they need to help them stop drinking.

The research suggests that women who wish to stop drinking while pregnant can be helped if they are aware of the relationship between consuming alcohol and FASD and if they are aware of and have access to appropriate and meaningful resources to help them stop. FASD prevention services and programs need to address the unique and often very complex lives of the women they serve in a social- and culturally-sensitive manner at the community level. Currently, FASD prevention programs and services are fragmented and underfunded.

Because it is much more cost-effective to invest in FASD prevention and intervention programs and services than it is to raise an FASD-affected child, the Government of Alberta, through their *FASD 10-year Strategic Plan* proposes to increase FASD awareness and prevention by providing support to promote a coordinated approach to FASD prevention activities; to encourage community-based early intervention and harm reduction programs to high-risk populations, including specifically designed Aboriginal programs; and to continue to research and inform Albertans about the complex nature and causes of FASD.

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Introduction

The Government of Alberta (2008) estimates that approximately 23,000 Albertans currently live with Fetal Alcohol Spectrum Disorder (FASD) and that each year more than 360 babies are born in Alberta with this disorder. FASD occurs when the mother consumes alcohol during pregnancy and results in irreversible brain damage in the developing fetus. There is no cure. FASD-affected individuals have to cope with the manifestations of brain damage for the rest of their lives. No-one knows definitively when or how much alcohol can affect the fetus, so the message to women who plan on becoming pregnant or who are pregnant is that no amount of alcohol is safe. FASD has a significant impact on individuals and families and its costly effects are realized in many social systems, such as criminal justice, child protection, education, health and other social systems (Government of Alberta, 2008). All Albertans bear, either directly or indirectly, the social and economic effects of FASD (Government of Alberta, 2008).

FASD is a public health issue and as such requires comprehensive public awareness campaigns and integrated prevention programs and services. Because we are all affected in some way by FASD, it is important that the development and delivery of solutions are community-based and supported by government policy and funding. In this way, solutions are tailored to the unique needs of every community (Government of Alberta, 2008).

This document contains a comprehensive review of the most recent and important literature on FASD. We will define FASD, look at the prevalence of FASD, and examine the economic and social costs of having an FASD-affected child. We will also explore at-risk populations and issues around why women continue to drink during pregnancy, barriers to seeking assistance, and what the literature has to say about screening women who are, or wish to become, pregnant. This paper also takes a look at FASD in Aboriginal communities and issues around awareness. We will consider recent research into prevention and intervention strategies and present a case study of intervention and prevention strategies from the point of view of service providers and recipients of services in Manitoba. The final section of this paper examines evidence to support best practices and related policy considerations.

One of the most important messages of this overview is that FASD does not occur in isolation and is not solely a medical or a woman's issue. Rather, FASD impacts individuals, families, communities and many facets of society (PFASDP, 2007). The effects of FASD are often inter-generational, and for many individuals, are only understood in a complexity of living conditions that cannot be isolated from their socio-political, historical contexts. FASD is a public health, social, political and economic issue that involves the federal, territorial and provincial levels of government, communities, and various organizations and groups (Government of Canada, 2007b).

What is FASD?

Fetal Alcohol Spectrum Disorder (FASD) is the leading non-genetic cause of intellectual and developmental disability in the western world. The Public Health Agency of Canada (2005) estimates FASD affects one percent of the Canadian population. FASD is an "umbrella" term (not a diagnostic term) that encompasses the following disorders: Fetal Alcohol Syndrome (FAS), the severest form of FASD characterized by abnormal facial features, growth deficiencies, and problems with the central nervous system; Partial FAS; Alcohol-Related Neurological Disorder (ARND), where there is a range of neurological impairments but no evident growth deficiency or facial characteristics; and Alcohol Related Birth Defects (ARBD), which refers to defects in other organs, skeletal abnormalities and vision and hearing problems (Thanh and Jonsson, 2009; Rasmussen et al., 2008; Thurmeier, 2007; and Public Health Agency of Canada, 2005).

FASD-affected children may be born with physical characteristics such as microcephaly, which is an abnormally small head due to the failure of brain growth. Microcephaly may not be obvious at birth but it might develop in the first few years of life as the head fails to grow while the face continues to develop at a normal rate. In the end, the child presents with a small head, a relatively large face, and a receding forehead (MedicineNet.com, 2009). Other physical characteristics of FAS include a flat elongated philtrum,[1] thin upper lip, small eye slits and height and weight below the 10th percentile (Rasmussen et al., 2008).

Most often FASD is an invisible disability (Rasmussen et al., 2008). Many FASD-affected children spend a lifetime dealing with delayed and disordered speech and language development, impaired memory and reasoning skills, learning disabilities, attention deficit with or without hyperactivity disorder, impairment of large muscle coordination and small muscle control, and because of their lack of reasoning skills may engage in inappropriate behaviours (Rasmussen et al., 2008; Health Canada, 2001). Furthermore, they often experience secondary disabilities, such as "mental health problems, disrupted school experience, involvement with crime, substance abuse, dependent living and employment difficulties" (Health Canada, 2001, p. 3). Other secondary disabilities develop over time as a result of negative life experiences and include depression, anxiety, and attachment disorder. Because secondary symptoms present when individuals are in their teens or as adults, they are not immediately associated with FASD. Therefore, affected individuals, because they have not been diagnosed with FASD, are expected to cope with their mental health issues, in spite of their disability, but lack the appropriate supports to do so (Rasmussen et al., 2008).

Unfortunately, FASD symptoms cannot be reversed (BCCEWH, c. 2002). Although alcohol consumption during pregnancy is a necessary cause of FASD, it is not the only contributing factor. Other factors that come into play include: "the amount of alcohol consumed, the pattern and timing of drinking, maternal age, the mother's ability to metabolize alcohol and the genetic susceptibility of the fetus" (Roberts and Nanson, 2001, as cited in Dzakpasu, 2003, p.6). Additional impediments that impact the health of the fetus are limited use of pre- and post-natal care and services, inadequate nutrition and a poor social environment (e.g. stress, abuse, neglect)

[1] The midline groove in the upper lip

(Bingol et al., 1987, as cited in Abel, 1995). Many of these factors are directly related to those who are considered to be socially vulnerable, especially women living in poverty.

According to Health Canada (2006), the severity of disability depends on how much alcohol is consumed during pregnancy and the stage at which it is consumed. The degree to which an unborn baby is affected by prenatal alcohol exposure is related to timing and duration of alcohol exposure, the pattern or intensity of maternal drinking, maternal metabolism and fetal genetics (Health Canada, 1996). Heavy or binge drinking (five or more drinks per occasion) and frequent drinking (seven or more drinks per week) are both associated with an increased likelihood of a woman having a child affected by FASD (Motz et al., 2006).

Motz et al. (2006) describe how the fetus is placed at risk for FASD when the mother consumes alcohol. Alcohol crosses the placenta into the fetus' circulatory system. The fetus cannot eliminate alcohol at the same rate as the mother because it is small and has an underdeveloped liver and enzyme system. Thus the fetus is exposed to alcohol longer than the mother and is forced to focus its energy on metabolizing the alcohol. This diverts energy that is needed to grow healthy tissues and cells. Alcohol is a toxic agent and if the fetus is exposed to it for long periods, cells in developing organs may be permanently damaged. The brain is particularly susceptible because brain development occurs throughout pregnancy.

Estimates of Prevalence

No-one knows with any degree of certainty what the real incidence and prevalence of FASD is (Basford, et. al., 2004). According to Motz et. al. (2006) the lack of precise information on incidence and prevalence is "due to inadequate diagnostic availability" and "fledgling surveillance initiatives" (p. 15). There are currently no official statistics on the prevalence of FASD in Canada because there is no comprehensive approach to diagnosing the disorder (AADAC, 2004). Health Canada estimates that approximately nine out of every 1,000 babies are born with FASD (Health Canada, 2006, p. 1). Researchers estimate that over 3,000 babies are born each year with FASD in Canada and over 300,000 Canadians are currently living with this condition (Health Canada, 2006, p.1). Researchers have found that the incidence of FASD is higher among heavy drinkers (i.e. those who have two or more drinks a day or five or more drinks per occasion) at 43.1 per 1000 live births (Tough et al., 2005a, p. 2). Recent international data suggests that current estimates may be higher than suspected (Institute of Health Economics, 2009). Canadian data indicates that prevalence is higher in rural communities, foster care systems and juvenile justice systems (Institute of Health Economics, 2009). The Government of Alberta estimates that 23,000 individuals are living with FASD and an additional 360 babies are born with FASD each year in the province (Government of Alberta, 2008, p. 3). In light of these statistics, it is essential that awareness and prevention campaigns identify at-risk populations so that appropriate interventions can help to minimize the incidence of FASD. Accurate data that details regional and local prevalence will enhance prevention and intervention efforts of targeted populations (Institute of Health Economics, 2009). Perhaps the most important starting point of accurate data collection is to determine the level of pre-natal exposure to alcohol (Institute of Health Economics, 2009).

Economic Costs

Estimates of the costs of FASD vary. A recent study by the Government of Canada (2007d) showed that the cost for families with a FASD-affected child for medical and other treatments

was approximately $24,000 a year. According to Than and Jonsson (2009), the total annual costs for all Canadian FASD-affected individuals between the ages of zero and 21 years can potentially reach $571 million. The authors also estimate that the annual cost per person with FASD in Canada for 2008 is $15,812 which includes "medical, education, social services, direct costs to the patient /family, productivity losses, and externalizing behaviours" (p. 84).[2] Further, they estimate that the annual long-term economic costs[3] of FASD in Alberta is more than $400 million each year. They estimate that the annual short-term economic costs[4] range between $48 and $143 million each year. They also estimate that total daily cost of FASD in Alberta is between $105 to $316 thousand (p. 85).[5] To put the costs of FASD in perspective, Alberta spent $124 million in 2008 on diabetes, heart disease and chronic obstructive pulmonary disease (COPD) combined in contrast to approximately $400 million on FASD (p. 88). According to the Institute of Health Economics (2009, p. 6) the total annual FASD cost breakdown for Alberta is: educational and medical costs (including addictions and drug treatments) - 60%; costs to the family - 20%;, and "social services, supportive housing, lost productivity costs and other services … such as the justice system" account for the remaining 20%.

According to Than and Jonsson (2009), the costs borne by the province for the treatment of FASD have a significant impact on the economy. The authors conclude that funding prevention programs would save the Alberta economy the equivalent of the life time costs of FASD for each case prevented. An American study, outlined in the Public Health Agency of Canada's 2005 report (p. 6), estimated that the cost of providing effective pre-pregnancy prevention programs to mothers who already have an FASD child would be 30 times less than the cost of raising another FASD child.

Social Costs

FASD manifests itself in multiple ways. The behavioural, mental and physical deficits of an FASD-affected child require extensive support and services from the health system, social services, education and training, justice, addictions and family supports (Rasmussen et al., 2008). The impact of FASD on individuals and communities is both socially and economically substantial (PFASDP, 2007). Further, as children with FASD reach adolescence they have more social and behavioural problems, such as an increase in mental illness, substance abuse, school failure, and trouble with the law (Public Health Agency of Canada, 2005). As adults, FASD-affected individuals are more likely to experience psychosocial problems that increase their chances of incarceration in prisons or jails or psychiatric or addiction facilities. They are also

[2] It appears that externalizing behaviours are not consistently defined in the literature. Keil and Price (2006) suggest that there is general consensus that externalizing behaviours are "overt, disruptive, and often involve the violation of societal norms, the destruction of property, and harm towards others" (p.763). Liu (2004) argues that the behaviours include aggression both verbal and physical that harm or threaten to harm children, adults and animals; delinquency (e.g., theft, vandalism) excluding violent acts, and hyperactivity. It is important to note that the authors agree that these behaviours are most likely to worsen as the child develops into adolescence and adulthood.

[3] The projected amount of money incurred by a cohort of children born with FASD each year.

[4] The amount of money incurred by FASD-affected individuals each year.

[5] Thanh and Jonsson (2009) suggest these costs are an underestimate as they do not include costs incurred by individuals in institutions such as facilities for disabled children or the judicial system or those who are homeless.

much less likely to live independently and hold down jobs (Public Health Agency of Canada, 2005).

Supports and services for families are essential. Rasmussen et al.'s (2008) review of recent research on parents and caregivers of children with FASD shows that parents' and caregivers' perceived needs include "social support; material support; structured home environment; organization skills; understanding from others; collaboration with school, health care and social services; child management skills and recognition that each child is unique" (p. 188). Additionally, this research shows that childhood externalizing behaviours increases maternal stress and the child's difficulty with performing daily tasks causes parental stress. Adoptive and foster parents of FASD-affected children reported higher levels of stress than biological parents (Rasmussen, et. el., 2008). Foster and adoptive parents require support and guidance, an understanding of their child's family history, and a firm grounding of the neurological disorder and potential behavioural problems (Health Canada, 2001).Biological parents of an FASD-affected child require long-term support to cope with their feelings of guilt, shame, depression and anger as they come to terms with their grief (Health Canada, 2001). Indeed, regardless of whether a biological mother keeps her FASD-affected child or not, her emotional and social state may increase the likelihood of continued drinking putting her at a higher risk for having another FASD child (Institute of Health Economics, 2009). Parents may need counselling and respite care as part of their long-term support. This may be especially necessary for women whose partners drink heavily as their partners are less likely to provide the emotional support and nurturing environment necessary to raise an FASD-affected child (Health Canada, 2001).

Children with FASD have poorer health-related quality of life scores, especially on cognitive and emotional indicators (Rasmussen et al., 2008). FASD-affected infants are more likely to require hospitalization for illnesses related to major organs and they are at increased risk of infection. They require intense supervision in the early years and more supervision in their youth than unaffected children (Rasmussen et al., 2008). Parents must live with the prospect that their child may not have the skills and knowledge to live on their own. As a result, the primary caregiver might have to leave his or her job thereby reducing the family income. All members of the family are impacted by the emotional, financial and social burden of raising an FASD-affected child. This burden can result in family disruption without proper supports (Institute of Health Economics, 2009). More research is required to understand the specific and direct impact FASD has on daily living to ensure that FASD-affected families receive the appropriate resources and services they need to cope with the stress of raising an FASD-affected child (Rasmussen et al., 2008).

Children with FASD are particularly disadvantaged when they enter the child welfare system (Burnside, 2009). According to the author, it is too often the case that these children are moved from one foster family to another as they grow older and their behaviours become more difficult for foster parents to cope with. Once they reach the age of majority, they are no longer considered permanent wards, and without continuing support, are left to fend for themselves. For children with FASD, the age of majority is an arbitrary number and most often does not reflect their functional abilities. Releasing an 18 year-old FASD adult who has a functional age of eight or nine into the community is fraught with danger because these individuals are so vulnerable. Without ongoing support, they face immense challenges that affect their physical and mental health, education and employment choices, and life stability.

Who is at Risk of Having an FASD-Affected Child?

While all women who consume alcohol before pregnancy recognition and during the rest of their pregnancy are at risk of having an FASD-affected child, those who are most likely to drink alcohol while pregnant tend to be young women, women with low education and income, and women with high education and income (Basford et al., 2004). A lot of FASD research and initiatives have focused on socially and economically disadvantaged groups, while little is known about women who do not fall into these sub-groups (Motz et al., 2006; Basford et al., 2004).

Socially Disadvantaged Populations

Some groups of women are at higher risk than others of consuming alcohol during pregnancy. In particular, women in rural, remote, Aboriginal and inner-city communities and other socially disadvantaged groups consume more alcohol during pregnancy and thus are at greater risk of having an FASD-affected child (Masotti, et al., 2006; AADAC, 2004).

A multi-disciplinary team at the University of Calgary (Government of Alberta, 2007) studied pregnant women who accessed programs to help support them during pregnancy to minimize the risk of giving birth to children with FASD. The majority of these women were in their mid-20s, smoked, had less than a high school education, were single, unemployed and socially isolated. Most reported a history of abuse, time in foster care, and had childhood exposure to alcohol and alcoholism. The majority of their pregnancies were unplanned. As well, less than half of these women abstained from alcohol by their second trimester and the majority reported using cocaine and engaged in binge drinking. Moreover, one-quarter of these women were in abusive relationships. In many cases their partners were addicted to either drugs or alcohol and many of the women found themselves in precarious or unstable relationships. Over 30% of the women interviewed had received medical treatment for issues surrounding alcohol ingestion in the past and over half of them had at least one prior arrest for alcohol-related offences. The message of abstinence from alcohol during pregnancy was not salient for this population as 65% of the participants reported that treatment for alcohol addiction was not important (p. 1).

Other social circumstances can also prevent women from seeking assistance, such as, “exposure to violence or abuse, poverty, homelessness, trauma, mother’s stress level, access to prenatal care, mother’s overall health, genetics, experience of loss, [and] racial discrimination” (AADAC, 2008, p. 2). Further, if the father drinks, this puts additional pressure on women who drink with their partners to continue drinking (Health Canada, 2001).

High Education and Income Groups

Although higher educated women were more likely than their counterparts to be aware of the risks of alcohol use during pregnancy (Environics, 2002), Burgoyne et al. (2006, p. 2) found that older mothers (aged 35 and older) were more likely to consume alcohol during pregnancy than younger mothers (aged 25 and under) (21.6% and 14.1%, respectively).The results of the 2000/01 Canadian Community Health Survey for Alberta also showed a relationship between drinking alcohol during pregnancy and income levels. Specifically, among women who consumed alcohol during pregnancy, 40.5% of them had an income of more than $80,000 per year compared to only 9.9% who had an income of less than $29,999 per year (Public Health Agency, 2006 as cited in Thurmeier, 2007, p. 7).

Although it is well-established that FASD cuts across all social strata, most programs continue to target women who are socially and economically disadvantaged even though women who are older, well-educated and have higher incomes face a similar risk of having FASD-affected children (Dell and Roberts, 2005). This may be because these women have misconceptions about their risks and may think this is just an issue for the "typically identified" high risk women who are younger and have lower levels of education and income. As a result, current prevention strategies may need to be adapted to this target population (Thurmeier, 2007).

Interestingly, Astley et al. (2000) found that some women who gave birth to an FASD-affected child were more likely than others to achieve abstinence. Compared to women who did not achieve abstinence, those who were successful "had significantly higher IQs, higher household incomes, larger more satisfactory social support networks, were more likely to report a religious affiliation, and were more likely to be receiving mental health treatment for their mental health disorders" (p. 513).

Family Planning and Prenatal Education

Since most FASD-affected babies are the result of unplanned pregnancies, family planning is a key prevention measure. Reaching out to women of childbearing years prior to conception to inform and educate them about the dangers associated with prenatal alcohol consumption is crucial. A study by Environics (1999) found that 98% of Canadians believed that the more alcohol a pregnant woman drank, the more likely it was the baby would be harmed. Women who binge drink are more likely than others to experience an unintended pregnancy and thereby increase the likelihood of exposing their fetus to alcohol (Tough et al., 2005b). Although the majority of women reduce alcohol consumption when they realize they are pregnant, this may not occur until well into the first trimester when vital fetal development is at its peak (Kesmodel, 2001). In a recent survey of urban Alberta women, 50% of respondents reported consuming alcohol until they recognized they were pregnant, at an average of five weeks gestation, and 80% reported pre-conception alcohol consumption (Tough, et al., 2006, p.97). In a family planning study of 80 women who gave birth to an FASD-affected child, social circumstances such as "maternal alcohol and drug use, lack of access to birth control and lack of support by their partner to use birth control" (Astley et al., 2000, p. 509) contributed to a lack of effective family planning.

Mixed Messages

A substantial number of people, including some medical doctors, still believe that the effects of alcohol on the baby's development is unclear and that it is safe to drink in moderation (PFASDP, 2007). Tough et al. (2005b) reported that in Canada moderate drinking guidelines are defined as no more than two drinks per occasion or no more than nine standard drinks per week. In their study of various health care providers' definitions of moderate consumption, Tough et al. (2005b) found that definitions of moderate drinking varied by health care provider. About 90% of providers defined moderate alcohol consumption among preconception women as one or two drinks per occasion, but fewer than half of providers frequently defined moderation for their patients. Health care providers who defined moderation as four or more occasions a week were more likely to recommend abstinence during pregnancy. Family physicians were more likely than obstetricians or midwives to recommend abstinence from alcohol during pregnancy and

12% of all health care providers recommended a “glass in moderation, abstinence only in the first trimester, no recommendation or some combination of consumption patterns” (p. 294).

According to Dr. Vyta Senikas, a spokeswoman for the Society of Obstetricians and Gynecologists, “The advice [about drinking alcohol during pregnancy] is extremely inconsistent, the advice is downright wrong and the perception on the part of the public is extremely wide and varied” (Rynor, 2009, p. A5). Senikas says there are no Canadian guidelines for doctors about alcohol and pregnancy so the advice varies from province to province and physician to physician. To that end, based on international and national research, the Society of Obstetricians and Gynecologists are expecting to have a new set of guidelines in the near future that will provide recommendations for physicians to give to their patients (Rynor, 2009).

Why Women Consume Alcohol During Pregnancy

According to AADAC (2008), all women want a safe and healthy pregnancy that ends in a safe and healthy baby. However, some women continue to consume alcohol after pregnancy is recognized. There are a number of beliefs associated with alcohol use that may put certain groups of women at increased risk of exposing their fetus to alcohol. For example, some women may continue to drink alcohol during pregnancy if they believe there is minimal risk or little harm done to the baby (AADAC, 2008). Some women who have an established drinking pattern might find it difficult to stop. For example, a recent survey on insomnia in Quebec (60% female respondents) found that eight percent of the sample used alcohol as a sleep aid and for those with insomnia, 28% reported they self-medicated with alcohol (Kirkey, 2009). Some women are unaware of the negative effects that alcohol, drug use and smoking may have on a developing fetus because of inaccurate or incomplete information (AADAC, 2008). It might be difficult for some women to stop consuming alcohol on their own because they feel powerless against their addiction even when they are aware of the consequences (AADAC, 2008).

Barriers to Seeking Treatment

Current prevention approaches that focus on a singular determinant, namely alcohol use and the impact on the baby, may actually be creating barriers to women who need help to deal with their substance use during pregnancy (BCCEWH, c. 2002). There are a wide range of contributing factors that go well beyond the use of alcohol and pregnancy (BCCEWH, c. 2002) and if they are ignored, many women may “fall through the cracks.” Barriers to treatment are more pronounced for women with multiple social issues. For example, many women feel stigmatized and feel guilt and shame because of negative attitudes towards them and what they are doing to their baby (AADAC, 2008). Some face a lack of child care while in treatment or fear losing custody of their children. Women may lack support from their family and friends; experience emotional barriers such as fear, denial, low self-esteem or a sense of powerlessness; have negative past experiences with treatment programs; or experience access issues related to transportation, finances, distance and geographical isolation (AADAC, 2008). Many mothers of FASD- affected children have “co-morbid histories of serious violence and trauma, serious mental health problems, and difficult relationships in which partners often control their substance use and access to services” (Astley et al., 2000 as cited in BCCEWH, c. 2002, p. 2).

Screening Women at Risk of FASD

There are a number of approaches to screening for alcohol use that could help to prevent FASD. Tough et al. (2005, pp 1199-1200) suggests that the first step to FASD prevention is for primary health care providers to engage in *preconception counselling*. In a study of women attending maternity clinics for prenatal care, 54% said they had a discussion about alcohol use during pregnancy (Public Health Agency of Canada, 2005). Early pregnancy is a critical time for fetal development and at that time certain behaviours can impact the fetus' health. Ideally, family physicians could assess preconception women for risk of alcohol exposure during pregnancy. This would require taking a detailed history of alcohol and drug use, sexual or emotional abuse and family history of addictions. Depending on the answers to the questions, physicians would then probe for current alcohol use and make referrals where necessary (Tough et al., 2005). One study found that fewer than 15% of health care professionals obtain patient histories (Public Health Agency of Canada, 2005).

A second prevention approach is *diagnosing children with FASD* (Tough et al., 2005). This would identify women who are at risk for consuming alcohol during a subsequent pregnancy and making appropriate referrals.

Thirdly, when a woman's pregnancy is confirmed, she could be screened at her first prenatal visit with a *standard alcohol screening tool* such as CAGE (cut down, annoyed, guilty, eye opener) (HealthLink, 2003) or T-ACE (tolerance, annoyed, cut down, eye opener) combined with a discussion about current alcohol consumption (Tough et al., 2005). The Alberta Partnership on Fetal Alcohol Syndrome recommends that physicians use T-ACE instead of CAGE because it has "higher sensitivity and specificity when used to assess periconceptual heavy drinking" (2003, p. 88).

There is a need for primary health care providers to become educated about, and increase the use of, standard screening tools for alcohol as a matter of practice (Clarke and Tough, 2003). By not using such tools, Clarke and Tough (2003) argue that the opportunity to identify women at risk can be missed. In particular, those who are at the highest risk of not being identified are women over the age of 35, those who are highly educated, those with a history of emotional and sexual abuse, and those of high socio-economic status.

Tough et al. (2005a) conducted a study to examine Canadian health care providers' attitudes and knowledge of FASD and pre-conception counselling to identify the number of missed opportunities for health care providers to identify women at-risk.[6] The study found that overall 94% of providers agreed that FASD was an identifiable syndrome. Pediatricians were the most likely of the various health care providers to agree that FASD was an identifiable syndrome at 96% while mid-wives were the least likely to agree at 90% (p. 7). While the majority of health care providers were aware that alcohol was a significant risk factor for brain damage in the fetus, approximately 25% still felt that the effects of alcohol on the fetus remained unclear (p. 7). Eighty-six percent of health care providers felt that discussing alcohol use would not deter patients from treatment (p. 7).Only 54% of respondents felt prepared to care for pregnant women or birth mothers in the area of alcohol use or dependency (p. 7), while 70% were prepared to

[6] Providers included pediatricians, psychiatrists, midwives, family physicians, and obstetricians.

access resources for these patients (p. 5). As well, 86% of providers asked women about their alcohol consumption prior to knowing about the pregnancy (p. 9). Family physicians were the most likely to recommend abstinence during pregnancy (90%) and 72% reported they always counselled women to abstain from further alcohol use when women reported moderate alcohol consumption or binge drinking (pp. 9-10). The majority of health care providers indicated that they would like to have a registry of specialists for consultation about FAS/FAE (62%), clinical practice guidelines (61%), and referral resources for women of childbearing age with substance abuse problems (63%) as a support to their clinical practices (pp. 10-11). However, fewer than 26% were interested in training on addiction counselling or Telemedicine to improve their own skills (p.10).

Clarke and Tough (2003) argue for improvements in implementing the existing Clinical Practice Guidelines which recommend abstinence from alcohol during pregnancy. Great variation in implementing the Guidelines exists across Canadian regions (75% in Quebec versus 90% in the Prairies) (Clarke and Tough, p. 2). Better efforts need to be made to improve professional preparedness to care for alcohol-dependent pregnant women and individuals already affected with FASD as fewer than 60% health care practitioners indicated they were prepared to do so (Clarke and Tough, p. 3).

In 1999, Health Canada conducted a national survey of women. Almost half of those surveyed identified a doctor or doctor's office as the best information source about the effects of alcohol during pregnancy (Clarke and Tough, 2003). This suggests that women are willing to receive information from their physician or health care provider. However, as discussed, there is a concern about physicians' ability, willingness or capacity to discuss alcohol consumption or addictions with pregnant women. For example, Tough et al. (2005) found that while 85% of doctors discuss issues of birth control with patients, less than half of the family physicians frequently discussed the risks of alcohol use, drug use, or smoking during pregnancy with women of childbearing years. However, according to the authors, almost half of all providers felt that existing information was not in a useful form for clients, which may explain the limited discussion of these topics between doctors and patients.

Another national study of Canadian health care providers (Public Health Agency of Canada, 2005) revealed similar results. This study, which also included pediatricians and midwives, found that while most health care professionals have a basic understanding of FASD, there were regional and professional differences in their knowledge and attitudes toward alcohol consumption during pregnancy. Although the report discussed a number of key findings and recommendations, the most salient of these were that while less than 60% of health care providers were prepared to deal with high risk clients, 70% were willing to access resources for them. Largely due to time constraints:

> …professionals were generally not interested in receiving training in addiction counselling, preferring instead to use a registry of consultation specialists, clinical practice guidelines for diagnosis of FAS, referral resources for women with alcohol problems and/or materials or training on FAS (p. ii).

Physicians are in an ideal situation to discuss alcohol-related issues aimed at women and teens of child-bearing age. A study conducted by the Physicians for FASD Prevention (2007) sought to determine the degree to which Alberta physicians (primary or obstetrical) provided screening,

prevention and intervention activities to females regarding the use of alcohol. While three-quarters of physicians claimed they routinely screened female patients for alcohol use, the majority reported that they were unlikely to discuss it in relation to pregnancy and contraception unless the patient raised the issue themselves. By and large, physicians felt that they had the expertise and resources to manage women at risk of having an FASD child, but claimed very few of these patients presented at their practices. Physicians believed that women at high risk rarely seek primary care and those that do underreport their consumption. However, physicians in the study expressed low interest in FASD prevention due to the amount of time they would have to spend with the patient given other competing priorities. The authors concluded that while physicians view alcohol use as a significant social and health issue, FASD was not a high priority.

These studies suggest that health care providers would benefit from more education and training to care for women at risk of having an FASD-affected child and for individuals with FASD and their families. Additionally, there is a need for training, education and support for health care providers to make accurate and timely diagnoses and referrals. Further research and action is required to address health care providers' perceptions that they do not have enough time; that "user-friendly" information is not available; that drinking in moderation while pregnant is okay and that clients already know about alcohol abuse. However, given the presence of these issues and the realities of primary care physicians' clinical practices, having them screen for FASD and provide prevention services may not be the best approach (PFASDP, 2007).

FASD and Aboriginal Communities

The Royal Commission on Aboriginal Peoples (1996) described First Nations and Inuit people as living in "Third World socioeconomic conditions within the boundaries of a wealthy, industrialized, First World nation" (as cited in Health Canada, 2001, p. 3). The Royal Commission stated that colonialism has left Aboriginal people operating at lower levels of self-sufficiency and unable to develop their traditional knowledge and skills, especially in the area of parenting (Health Canada, 2001). As a result, addictions, alcoholism, substance abuse and violence have become prevalent in their communities and pose a threat to their very survival. Prevention of FASD in these communities needs to be placed in the context and reality of Aboriginal life, namely, "discrimination, poverty, domestic violence, solvent and drug abuse, and residential school syndrome" (Health Canada, 2001, p. 5).

"It Takes a Community" (Health Canada, 2001) is a national initiative that provides a framework within which issues around FASD in Aboriginal communities can be addressed in a culturally meaningful way. The community-based approach attempts to engage community members and caregivers to understand the "nature and far-reaching effects of FAS/E on individuals and communities" (p. 79). The guiding principles of this initiative are: respect, caring, hope, humility, compassion, patience and cooperation. According to this initiative, empowerment is crucial:

> A key element of community healing is the understanding within the community that social and cultural wellness and progress depends on taking immediate action to prevent further cases of FAS/E and support those already afflicted….The Community Healing and Intervention Program (CHIP) uses a health promotion approach that empowers people to understand the health, cultural, social and

> economic complexities of FAS/E and to do so with respect and compassion for all concerned (pp. 79-80).

Under this initiative, one of the key prevention measures is to educate the community about how to bring about disclosure, using an informed and caring support network; to train facilitators in communication skills and ensure they have an in-depth knowledge of FAS/E so they can present information with respect, care and hope; to increase knowledge around traditional practices of conception, pregnancy and birth; and to revisit the notion of traditional parenting targeted at young Aboriginal women, pregnant women at risk, women who do not access prenatal care, Aboriginal men who are engaged in risk behaviours, male parents and future fathers (Health Canada, 2001)

Tait (2003), has argued that the pervasive impact of the residential school system and other forms of colonialism were not the same for every student and some fared better than others. As a result, Aboriginal alcohol abuse should be considered as a problem for certain individuals and sub-populations rather than for *all* Aboriginal people, *per se*. Therefore, FASD programs and services should be tailored and targeted to at-risk Aboriginal populations as opposed to all Aboriginal populations. Tait (2003) suggests that the cultural characteristics of specific communities as well as local factors such as community integration or dysfunction should be considered in the development of appropriate assessment tools. She claims that there are methodological problems in studies that have concluded that Aboriginality *per se* is a risk factor for FASD. Instead, she states that chronic poverty and social marginalization are more important indicators than ethnicity. Because Aboriginal women are the poorest and most marginalized group in Canada, it is these factors that place them as women at risk. Unfortunately, there is little research that compares how alcohol consumption varies across Aboriginal communities (May, 1994 cited in BCCEWH, c. 2002). Basford et al. (2004) noticed that while Aboriginal women appear to be at greater risk of bearing children with FASD, they are also more likely to have been assessed for alcohol consumption than Non-aboriginal women (Basford et al., 2004).

According to Tait (2003) best FASD prevention practices in Aboriginal communities FASD are those that engage members of the community to coordinate services at the local level (Tait, 2003). In this way, the focus is greater than just preventing pregnant women from consuming alcohol, but rather it "involves whole communities to gain control over their lives through the development of community-based institutions in areas of culture, education, health, economies and justice" (p. 201).

Masotti et al., (2006) recognized the importance of community involvement in preventing FASD in Aboriginal communities. They discovered that there were two important issues to overcome to assist communities in the prevention of FASD. The first was a lack of resources and research capacity in some communities. Secondly, they had to find a way to overcome the cynicism Aboriginal communities had about "university-based investigators conducting research *on* people and their communities" (p. 0001). In response to these observations, Masotti et al., (2006) developed a partnership approach between the researchers and the community. This approach facilitated a sense of community ownership with the goal of developing community research capacity. In order to offer methodological expertise and consultative support without obstructing community ownership, the researchers did not enter the communities. Rather, they recruited research facilitators from the community who were trained about FASD, FASD interventions, and screening instruments. The research facilitators were solely responsible for conducting

research in their respective communities. Local opinion leaders participated in the development of a community-specific intervention and a community advisory committee helped with the operationalization and evaluation of the intervention. Masotti et al.'s ongoing project indicates that a community-based, participatory research approach is both effective and portable.

Researchers have attempted to develop a culturally-appropriate model in an attempt to prevent FASD in Aboriginal communities. The Aboriginal Healing Foundation (AHF) funded a project that examined five case studies of Aboriginal healing programs in rural, remote, and urban regions of Canada. The major goal of this research was to compare each of the programs so that they could generate a model of best practices for Aboriginal healing; a common understanding of the meanings and processes of healing in Aboriginal communities; and, ultimately, develop research methodologies to study the process of healing (Aboriginal Healing Foundation, 2008). The study found that while very few of the research participants had experienced the residential school system, the legacy of the residential school system had a deep impact on the social, cultural and psychological characteristics of the participants.

When these models of healing were examined, they showed that Aboriginal clients were unique and their experiences were culturally, socially, and spiritually diverse. However, there were some common threads. Most clients had issues with "alcohol and substance abuse, interpersonal violence, homelessness, physical illness, criminality" and disrupted social relationships as a result of their behaviours (Aboriginal Healing Foundation, 2008, p. 4). Consequently, while the research showed that there was a need for flexible and diverse treatment regimes, various forms of Aboriginal spirituality were thought to be an integral part of all programs. Clients commonly preferred to have Aboriginal therapists, but of greater importance to them was the therapist's ability to empathize. Clients felt more comfortable with their therapists if they shared similar experiences to themselves. It was also important for clients to believe that treatment staff were knowledgeable and experienced. Because of the diversity of client-centred approaches to treatment, efficacy of treatment could not be compared to a "gold standard" but rather researchers felt that treatment approaches needed to be qualitatively assessed on a case-by-case basis (Aboriginal Healing Foundation, 2008).

For AHF, the concept of healing was difficult to pin down and was perceived, more likely than not, as an active, life-long process that a person "does." Healing required a commitment from the individual and was perceived as an "on-going process of self-transformation" that was about repairing damaged and disordered relationships. Ultimately, healing was about hope for the "individual, the family, the community, and the future" (Aboriginal Healing Foundation, 2008, pp. 6-7).

FASD Awareness

There are three levels of preventative programs: primary, secondary, and tertiary (Thurmeier, 2007). Primary prevention involves actions taken at the community level that concentrate on personal efforts to protect health by increasing knowledge among individuals about a particular health issue. Primary prevention uses marketing strategies and public awareness campaigns. The goal of these strategies is "individual, systems and environmental behaviour change through population health promotion, alcohol control measures," and other education and awareness approaches (Ott et al., 2004, p. 2). Secondary prevention programs are aimed at people who are at risk of a particular health problem and include early detection and effective intervention

(Thurmeier, 2007). Tertiary prevention is targeted at individuals who are already affected by a health problem with the goal of minimizing long-term effects or disabilities (Thurmeier, 2007).

The most common primary prevention strategy is public awareness campaigns. The role of awareness campaigns is to raise concern about the issue and encourage individuals to change their behaviours (Burgoyne, 2006). Awareness strategies have the potential to influence people's levels of awareness, knowledge and attitudes, as well as encourage information-seeking behaviours. In this way, awareness campaigns are there to clarify, remind, reinforce and encourage people who already know a fair amount about the topic (Burgoyne et. al., 2006).To make public FASD awareness campaigns more effective, they must be linked with other services that are currently available to, or needed by, pregnant women and families who are affected by, or are at risk of, FASD (Burgoyne et. al., 2006).

Awareness is the first step towards behaviour change (Burgoyne, 2006). Burgoyne outlines Prochaska and DiClemente's (1982;1995) Model of Change Theory (see pp. 14-15). There are six stages of change:

1. **Precontemplation**: before an individual thinks of making a change
2. **Contemplation**: thinking about making a change
3. **Preparation**: serious commitment to change
4. **Action**: begins to make specific changes
5. **Maintenance**: support needed to maintain the change
6. **Termination**: change successfully completed.

Burgoyne (2006) suggests that awareness campaigns are most often designed for individuals in the first three stages of change and different messages are needed for each stage. For example, in the precontemplation stage, the key message is to inform the public about the relationship between alcohol use and pregnancy. The contemplation stage outlines the benefits of change while the preparation stage provides information to populations at risk on how to access resources and supports to help individuals to stop drinking.

How messages are conveyed can influence whether or not an individual will use the information to change their behaviour (Thurmeier, 2007). For Thurmeier (2007), campaigns about alcohol and pregnancy have two main components: threat and efficacy. The key message in threat raises the questions: is it serious or severe and can it happen to me? With efficacy the questions raised are: does the response work and can I do the response? For messages to be effective, efficacy must be higher than the threat. Specifically, when self-efficacy is high, messages with a higher level of threat can be employed as a means of prevention. On the other hand, when self-efficacy is low, the message must focus primarily on links to services and support (Burgoyne, 2006, p. 15). Burgoyne (2006), suggests that because pregnancy is such a sensitive issue, one should avoid strong fear-based approaches to avoid possible negative consequences.

FASD awareness campaign messages are well understood in general populations – for example, 92% of Canadians are aware that alcohol use in pregnancy can cause long-term disabilities in the

child (Thurmeier, 2007). However, according to Thurmeier (2007), the effectiveness of these types of programs for specific sub-populations is debatable as they require the individual to be aware of the campaign and have the capability to self-initiate behavioural changes. Future awareness campaigns need to be tailored toward smaller sub-populations and should contain images, messages, resources and approaches that are respectful and positive (Thurmeier, 2007).

According to a report produced by the Canada Northwest FASD Research Network (2006), FASD awareness campaigns are neither "systematically delivered or evaluated for reach and effectiveness" (p. 11). Therefore, their effectiveness may not be universal. For the authors:

> The messaging and imagery used in prevention campaigns tends to oversimplify the issue of alcohol use in pregnancy. There is [a] need to reach a range of audiences (community, partners, friends, extended families, women at various levels of risk, culturally diverse women, young women of childbearing years, etc. (p. 11).

Unfortunately, there does not appear to be any method that can evaluate the relationship between public awareness campaigns and actual change in behaviour. For example, Burgoyne et al. (2006) conducted a multi-level public awareness campaign in Ontario in 2004 entitled, *Be Safe*. The year-long campaign led to an increase in public knowledge of the risks of alcohol consumption for women of child-bearing age as measured by pre- and post-campaign surveys. However, there were no observed differences in the number of times the public called the resource contact number or accessed the website before or after the awareness campaign. The researchers concluded that there was no evidence to suggest that people had demonstrated a willingness to change their behaviour.

Due to the many contributing factors that influence women's consumption of alcohol while pregnant, it is important that awareness campaigns address a wide variety of needs. Perhaps the largest obstacle for women with substance use issues is to overcome the stigma and judgemental attitudes that surround alcohol consumption during pregnancy. Poole and Isaac (2001, as cited in Burgoyne, 2006), suggested that pregnant women who consume alcohol may find it difficult to access services due to the judgemental attitudes of service providers, feelings of depression, shame, and low self-esteem in addition to the threat of losing their children. Awareness campaigns must address the potential risks associated with alcohol consumption while avoiding judgemental attitudes about pregnant women struggling with alcohol use.

As discussed, it is essential that researchers or public interest groups tailor their awareness campaigns when they target particular sub-populations if they are to be effective. Particular groups of women, such as those at higher risk, young women, and women of specific cultural backgrounds, such as Aboriginal women, will have different information needs and will arguably respond differently to various approaches (Burgoyne, 2006). Therefore, carefully defining and learning about a particular population of interest is an important component in developing an effective awareness campaign. The most common populations targeted within Canada include the community (38%), youth (30%), the general public (28%), women of childbearing age (21%), service providers (19%), partners and family members of pregnant women (15%), the Aboriginal community (13%), and pregnant women (11%) (p. 36).

As our knowledge of FASD increases, we find that FASD is not solely the responsibility of women but rather, it is a public health, political, social, economic, and environmental issue that involves a concerted effort on the part of individuals, families, communities, health practitioners, and all levels of government (Health Canada, 2001; Motz et al., 2006). Partnerships and collaborations have been set up across the country in order to share expertise, resources and best practices for preventing and treating FASD. For example, the Canada Northwest FASD Partnership was created in 1998 in western Canada and the territories to prevent FASD and provide support to those living with this disorder (Government of Canada, 2007b). The scope and size of these programs and their ability to effectively deliver services to those in need varies across the country.

The Public Health Agency of Canada's (PHAC) Fetal Alcohol Spectrum Disorder Initiative, established in 1999, has worked to reduce the number of babies exposed to prenatal alcohol and to improve the quality of their lives. The FASD Initiative has focused on public awareness, building an evidence base, promoting information exchange by polling public health professionals, and developing and distributing information publications about FASD (Government of Canada, 2007c). One such initiative includes increasing knowledge on the life conditions that affect the health and well-being of those living with FASD; what works to support their special needs; the causes that lead women to drink during pregnancy; and the long-term impact of alcohol exposure on the developing fetus (Government of Canada, 2007c).

Results from a primary prevention forum conducted by the Canada Northwest FASD Research Network (2006), outlined the need to describe and study various program models that include: "obstetrical, outreach, drop-in, mentoring, home visitation, and peer support services" (Canada Northwest FASD Research Network, 2006, p. 12). Members of the forum suggested that qualitative research needs to be done to help understand programs that work with high-risk women to determine their needs at the time the child is diagnosed, barriers to accessing services and programs, and women's individual preferences for services and support (Canada Northwest FASD Research Network, 2006). Members also felt that more information was needed to gain a better understanding of how women's substance abuse connects with mental health problems, historical issues such as colonization, residential schools, childhood sexual abuse, and family and community violence. Finally, the participants asked how program and service providers can work with child protection services to help women and their families who want to retain custody of their children to get the additional supports they need to provide a nurturing environment (Canada Northwest FASD Research Network, 2006).

Prevention and Intervention Strategies

Secondary prevention strategies include measures of early detection and effective interventions with respect to a particular health problem (Thurmeier, 2007). The target population is often those who are at risk of a particular health issue. For FASD this level of prevention attempts to reduce the duration and severity of maternal drinking.

Typically, FASD prevention efforts have focussed on women's alcohol use during pregnancy and its impact on children's health (BCCEWH, c. 2002). Recent evidence suggests that this focus is too narrow and may actually present barriers to women at risk of having an FASD child (BCCEWH, c. 2002). There is a call in the literature for "an alternative, multiple-determinants approaches to FASD prevention" that are more effective, humane and cost-effective (ibid., p. 1).

To be more effective in preventing FASD, we need to move away from focusing just on women's alcohol use to an increased understanding of the underlying socioeconomic factors and broader determinants of health to understand FASD (BCCEWH, c. 2002).This approach offers supports beyond just dealing with alcohol use during pregnancy to assistance where needed in all areas of life (Van Den Broek, 2007). Because FASD affects people from all walks of life, prevention strategies need to be accessible and meaningful to various groups in the community including, for example, "women of high and low economic status, cultural groups, health professionals, educators, youth and men" (Thurmeier, 2007, p. 41). Among other things, prevention strategies "should be comprehensive, collaborative, community-based, culturally appropriate, and non-judgemental" (Thurmeier, 2007, p. 46). Roberts and Nanson (2001) conclude that there is strong evidence to support an:

> …intensive case management or coordination [of] services that advocate for women [as they are] effective in promoting family planning, access to substance abuse treatment, retention in treatment, reduced consumption and connections to community services for high-risk pregnant women (p. 46).

In 2003, Health Canada released the report, "FASD: A Framework for Action" to help guide the development of collaborative efforts to address the issues associated with FASD. In 2005, the Canadian Medical Association Journal, with support from the Public Health Agency of Canada and the First Nations and Inuit Branch of Health Canada (as cited in Health Canada, 2006 – no citation given) published *Fetal alcohol spectrum disorder: Canadian guidelines for diagnosis*. These guidelines provided community-based programming to reduce FASD births and improve the quality of life for those living with FASD (Health Canada, 2006). Such programs included training for community health workers and early childhood educators to increase community awareness; help for communities to develop local plans to reduce FASD; and support mentoring projects that paired pregnant at-risk women with community members who had similar experiences (Health Canada, 2006).

A Case Study of the Service Needs of Pregnant Addicted Women and the Types of Programs and Services Available in Manitoba

The following study showcases the types of FASD prevention and intervention strategies employed in Manitoba in 2000. This study presents the perspectives of both the recipients and providers of services to FASD at-risk pregnant mothers. It offers a unique perspective on what is working and the needs and gaps in services for clients and service providers.

In 2000, Caroline Tait wrote a seminal report on her study of the service needs of pregnant addicted women in Manitoba. Her study involved qualitative interviews with 74 women who had children and/or were pregnant. Participants reported having current or past problems with various substances, drugs and/or alcohol. Additionally, the project conducted 85 interviews with service providers. The study examined and described the service needs and experiences of pregnant women who were misusing substances; the range of programs and services offered in Manitoba at the time; the challenges of meeting the needs of Aboriginal participants; the barriers and gaps to meeting consumers' needs; and effective programs and services for pregnant addicted women. What follows is a discussion of Tait's findings as they relate to the women who accessed programs and services in Winnipeg, Thompson and The Pas and the providers of these services and programs.

Primary Prevention Strategies

Mentor Programs

Child and Family Services(CFS), public health nurses and outreach workers have used "quasi-mentors" who are typically support workers who go to women's homes to assist with home care, infant and child care. Quasi-mentors can be viewed as very supportive as long as the client does not perceive they are involved with a CFS-related agency. Many respondents felt that the mentor had been sent by CSF to spy on them with the intent of having their children apprehended by CSF. Aboriginal women and women who had been in foster care as children were more likely to perceive CFS as a threat to their families and tended to avoid any involvement with CFS-related agencies. As a result, many women missed out on support programs. Social workers often interpreted this behaviour as either non-compliant or as a woman's unwillingness to look after themselves and their children.

" STOP FAS" programs provided long-term support to women who were at risk of having an FASD-affected child. These programs focused on the well-being of both the mother and her children. The service provider assisted women to access services deemed necessary by the client. According to service providers and consumers, the program has been very successful. Unfortunately, service providers reported systemic barriers within the system of care. One of the main problems was a lack of communication and flexibility among service providers regarding the types of services and programs that were available. Service providers were often viewed by clients as friends rather than service providers. While service providers had a mandate to work with the client and her children, lack of support from partners or other family members sometimes put the service provider in an adversarial position.

Community Wellness

Community wellness programs, the majority of which occur in rural and urban Aboriginal communities, attempted to understand substance misuse as a health and wellness issue caused by historical and social factors that affected the well-being of the community. The success of community wellness programs depended on the health and capacity of the community. Communities that have extremely high rates of alcoholism do not have the resources and support to help women to stop consuming alcohol. Tait argues that while First Nation reserve communities have the means to influence and control services delivered on reserve, services and programs for Métis, off-reserve status and non-status First Nation people do not have adequate funding to deliver culturally-appropriate services. However, federal and provincial programs are beginning to target these groups.

Secondary Prevention Programs

Pregnancy Programs

Pregnancy programs did not typically target pregnant women with substance misuse problems, however they did try to offer education and support to help women with this issue. Generally, pregnancy programs offered a weekly special group service but most had an open-door policy that allowed women to gather outside of meeting times. Some programs offered pre- and post-partum home visits and the majority provided food, parenting classes, nutritional education, information about healthy choices and general support and information. In addition, these

programs advocated on the client's behalf to enter addiction treatment programs or to help with other social issues. Both providers and clients felt that these programs provided invaluable support and information but also offered women an opportunity to engage with others who were in similar situations. Pregnancy programs have the potential to provide outreach services to pregnant women at risk but funding was often an issue.

Residential homes for pregnant women who have issues with alcohol were available as an alternative to residential addiction treatment. Their purpose was to provide a safe and nurturing environment for pregnant women and to help them access outpatient or day addiction treatment services or self-help groups by supplying them with transportation to these services and childcare for their newborns. Unfortunately, many of these residential homes did not provide childcare for pregnant mothers.

Community Services for Women

There is a wide variety of community services for women, especially in the larger urban areas. While these services are not strictly focused on women with substance misuse during pregnancy, they had experience with this type of client. Services included "women's resource centres, shelters, transition housing, youth programs and services, support and self-help groups, and outreach centres" (p.23). The majority of these organizations provided information and referral services to women who needed addiction treatment and support during their pregnancies. Service providers were key contacts for women, and in some cases the only contact, when additional care and support was required. There was a concern amongst service providers that the types of addiction services available did not cater to women's needs and lacked flexibility and coordination of related services. This was especially the case for women with substance misuse issues who were caring for their children.

Place versus Program

There were a few services for women and their children that operated as outreach or drop-in centres. Clients accessed services on a drop-in basis without having to attend specific programs. *Street Connections* in Winnipeg is a good example of this type of service. Women would access these services knowing that they would meet other women who were facing similar challenges. *Street Connections* allowed women to build positive support networks in a non-judgemental or non-threatening environment. The program had nurses, counsellors and social workers who were available on a daily basis to mix with clients. Clients using these services felt comfortable discussing their situations because they knew their conversations were confidential; they respected the worker's opinions and they felt that they were not being judged or pushed into programs they did not want. Clients felt that *Street Connections* left them with a sense of community and accomplishment in addition to providing them with on-going assistance and support.

Health Care Providers

Tait (2000) found, according to the service providers and clients who participated in the project, that physicians did not typically collect patient information on possible alcohol abuse or make referrals to addiction treatment programs. Physicians tended to trivialize alcohol use among middle-income women even though these women had serious substance abuse problems. Middle-income women felt that physicians were unable to see them as addicted. Women also

reported that they were rushed through physician visits and even though nurses were in a better position to raise the subject of alcohol consumption during pregnancy, they too were limited by time constraints.

Community health clinics, on the other hand, were more receptive and supportive to women at risk. Physicians and other health care providers in this setting gave out information about substance use during pregnancy and were more prepared to deal with other health and social issues. The study found that public health nurses and midwives were better situated to provide the services and support necessary for pregnant women with substance use issues in both urban and rural settings.

Child and Family Services

As previously mentioned, the relationship between pregnant women who abuse alcohol and CFS was widely viewed as negative by clients, largely because of the fear that children of at-risk mothers would be apprehended. A common practice for many CFS agencies in Manitoba was the use of "birth alerts" that were placed on women who were pregnant and misusing substances. Birth alerts were perceived as a threat to women who feared their newly-born child would be removed unless they entered an addiction treatment program and sufficiently demonstrated to CFS that they were committed to the well-being of their baby. Social workers and others who worked for CFS did not feel this was the best response for these clients. Instead, they felt that "birth alerts" was a punitive sanction that women interpreted as a form of force or coercion. As a result, birth alerts were more likely to prevent women from going into treatment. Women who were in the program would try to hide from CFS or eventually drop out, which was often interpreted by CFS as a lack of personal commitment. Ironically, the study found that this type of practice increased women's anxiety and the risk of clients going back to abusing substances once their children were apprehended.

Poverty and Service Delivery

Service providers felt that unless clients' larger issues were addressed, women would continue to move in and out of addiction treatment programs with little success. Women substantiated this claim. They reported that their social environment was the main contributor to their substance misuse.

Detoxification and Treatment Programs

Pregnant women could access all addiction services offered to non-pregnant women but in some cases they were only admitted if they could complete the program prior to giving birth. These services did not usually include special services for pregnant women. In addition, these residential programs did not allow women to bring their children or newborns with them to treatment. Outpatient or day programs typically did not provide child care but there were some programs that treated the whole family. Women-centred treatment programs were typically offered only in large urban centres.

Detoxification and Outpatient Withdrawal Units

At the time the project was conducted, there were no detoxification and outpatient withdrawal units specifically designed for women. There were secondary detoxification units located in Winnipeg. Women who accessed withdrawal services stayed for about four or five days and then

were referred to other addiction services. There was only one site in Winnipeg that allowed intoxicated clients. Lack of shelter for intoxicated women was prevalent throughout the province because shelters were not equipped to deal with them.

Outpatient and Day Treatment

Outpatient and day treatment programs could be short- or long-term and were sometimes a prerequisite for residential treatment. They were often used by women who were on a waiting list for residential treatment for temporary support. Gender-specific treatment programs typically had long waiting lists (some up to a year and a half). Addiction workers argued that the best time for treatment was when clients were ready to address their issue. Many women fell through the cracks because they were unsuccessful in accessing treatment when they needed it. The fact that there were long waiting lists suggested that women believed the service was appropriate and meaningful to them and that they were committed to participate. Outpatient/day programs enabled women to stay with their families while they received treatment. Service providers reported that the success of these programs depended on the social environments in which clients lived. Clients with supportive networks were more likely to succeed than clients who lived in a community where substance abuse was rife. Unfortunately, attendance in these programs was hampered by the lack of childcare and the need for women to attend to other responsibilities like prenatal appointments. Again, lack of child care and transportation were barriers for some clients.

Residential Treatment

Residential addiction treatment programs were found in all regions of Manitoba. There were a few women-centred residential programs but most were gender-mixed. For the most part, pregnant women were a treatment priority as long as they could complete the program before giving birth. Some residential programs allowed children who were placed in day care or school while the mother was in treatment. Non-Aboriginal residential programs included: “life skills programs, self-help and empowerment approaches, behavioural therapies, harm reduction approaches, therapeutic communities, gender-sensitive treatment, and relapse prevention” (p. 34). First Nation treatment centres were most often based on traditional models of healing in combination with other treatment methods.

Aftercare

Most addiction treatment programs also provided aftercare programs that helped clients make the transition from treatment back to living in their communities. These programs were typically comprised of several meetings in a group setting or one-on-one counselling and required the client to return to the treatment centre. Some aftercare programs were available in the region where the client lived. Again, as with other programs, the client had to make the effort to attend but sometimes were impeded by child care and transportation issues.

Self-help and Support Groups

Several self-help and support groups existed for individuals with addiction problems, the most notable of which was Alcoholics Anonymous. There were a few women-centred groups, but they were only available in Winnipeg. Tait (2000) believed that this type of service was instrumental in assisting women to address their substance misuse and recovery. Typically, these services “provide[d] awareness about the nature of alcohol and drug misuse, support people before and

after addiction treatment, and provide long-term community support" (p. 34). Unfortunately, these types of services were limited in regions other than Winnipeg and child care and transportation issues often prevented women from attending.

Service providers said they were prevented from achieving their service goals for women who were pregnant and consumed alcohol due to several barriers. The main ones cited in Tait's (2000, p. 25) study were:

- Narrow mandates that limited their ability to support the whole woman and all of her problems simultaneously
- Being under pressure to report substance abuse to CFS that could erode the trust established between the client and service provider
- Being located, for example, in the same building as CFS which might discourage woman from attending programs for fear of child apprehension
- Not having enough funding or staff to offer individual counselling, outreach services or follow-up programs
- Lack of transportation or childcare to enable clients to access services.

In conclusion, Tait (2000) noted that any single service or program would not adequately address all the needs of pregnant women striving to deal with their substance misuse problems. Attempts to address the needs of these women required a collaborative effort among service providers. The women in this study reported that the most important contribution a service provided was a supportive and non-judgemental environment where women felt uninhibited to work with service providers to address their needs. For treatment programs to work they must take into account individual needs, which requires an increase in communication and service and program flexibility. Finally, service providers must develop a continuity of care. In her report, Tait made 49 recommendations to Manitoba Health to support the goal of providing at-risk women with the best possible programs and services to meet their needs.

Towards Best Practices

Much work has been done at the national, provincial, regional and community levels on improving programs and services related to FASD awareness, prevention, intervention, diagnosis and treatment.

According to Health Canada's (2006a) study which conducted interviews with key informants (experts who provided outreach and early intervention services or facilitated community linkages for women with substance use problems) and focus groups of women who had been in need of early intervention and outreach services for treatment related to substance abuse, best practices were comprised of three major domains: early intervention, outreach and community linkages. The results of the study indicated that early intervention required "an understanding of the unique circumstances of each client and adapting services to facilitate timely access to needed treatment" (p. 2). A variety of outreach services and places to provide these services were identified by study participants with the aim of reaching "women with substance use problems … in their own environments to engage them in treatment or assist them in accessing other

needed services" (p. 2). Finally, the report concluded that "community linkages need[ed] to be considered at both the client and systemic level" (p.3). For the client, community linkages needed to address addictions issues and related health and basic needs by ensuring referral to agencies that could address these issues (p.3). Specific recommendations on best practices were outlined in the report as emerging guidelines that were to be considered as part of ongoing research. Research should be informed by current evidence in the literature, key experts in the area and women who have experienced the process of accessing substance abuse treatment services.

Government of Alberta *FASD 10-year Strategic Plan*

The Government of Alberta is engaged in a provincial initiative, *FASD 10-year Strategic Plan* (2008) in part to develop appropriate strategies to increase awareness and prevention of FASD. The Government of Alberta acknowledges that current programs and services are still in the developmental stages which might be limited in scope and require evaluation to determine their effectiveness. However, the Government is committed to providing a coordinated approach to address FASD that is unique to Alberta. This "Made-in-Alberta" multi-level approach is focused on developing and delivering community-based solutions that are supported by government funding and policy. The guiding principles for the *Strategic Plan* (p.8)included:

- Reflect that needs exist across the lifespan
- Develop a cross-government approach (cross-ministerial, cross-jurisdictional, other levels of government)
- Recognize that services are needed across the continuum (prevention, diagnosis and support)
- Align planning efforts with other government initiatives (complementarity and synergy)
- Include a wide range of perspectives
- Recognize that collaboration with stakeholders is critical
- Understand and utilize appropriate terminology.

With respect to particular awareness and prevention initiatives, the Government of Alberta's *FASD 10-year Strategic Plan* is designed to provide services and activities in several areas: information, universal prevention, targeted prevention, indicated prevention, and treatment (p. 13). The services and activities they support aim to educate and inform people about the risks associated with pregnancy and alcohol consumption, the effects of FASD and to ensure that awareness and prevention services are culturally-appropriate. The goals of these services and activities are 1) to ensure that "Albertans understand that alcohol use during pregnancy can lead to FASD, that FASD can be prevented and that FASD prevention is a shared responsibility" (p. 14) and 2) "Alcohol use during pregnancy is eliminated" (p. 15).

The Government of Alberta proposes three major strategies to realize their goal of FASD awareness and prevention:

1. Promote a coordinated approach to FASD prevention activities.

2. Encourage regional bodies and communities to provide early intervention and harm reduction programming to high-risk populations, including services designed for Aboriginal communities.

3. Continue to inform Albertans across government regarding the complex nature of FASD and its cause (p 14).

The Alberta *FASD 10-year Strategic Plan* is an ambitious undertaking given that FASD is a complex problem requiring multi-level and multi-faceted solutions. As we have seen in this literature review, prevention requires that we have a complete understanding of the life circumstances that pregnant women at risk experience. To eradicate FASD, issues of poverty, violence, sexual abuse, dysfunctional communities and other complex contributing factors need to be addressed by the Government of Alberta. These issues are compounded in Aboriginal communities where the legacy of residential schools affects even those who were not part of that system. Eradicating FASD also involves breaking the cycle for those who are affected by it. Most important for these individuals is early diagnosis and assessment so that coherent and integrated interventions and support programs can be implemented as soon as possible.

Conclusion

Successful approaches to prevention start with compassionate service providers who offer a warm, hopeful and non-judgmental environment. Services providers are aware of and understand the root causes, or social determinants, of alcohol abuse and realize that women do not intentionally want to harm their unborn child. Many women who use substances while pregnant want to quit or cut down, but face multiple barriers to treatment. The stigma associated with their disclosure often prevents women from seeking help as does the fear of losing custody of their children (AADAC, 2008). Other barriers such as transportation, childcare, family and community dysfunction, poverty, and geographical and social isolation prevent women from obtaining the services they may want to reduce the harm to their babies. Appropriate funding of prevention and intervention programs and individually-based approaches will significantly enhance the effectiveness of treatment for mothers at risk. Finally, we must be mindful that FASD cuts across all social strata and appropriate and integrated prevention and intervention programs and services need to address this fact.

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