

Substance Using Women with FASD and FASD Prevention



A Literature Review on Promising Approaches in Substance Use Treatment and Care for Women with FASD

prepared by Karen Gelb and Deborah Rutman

January 2011

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Research Initiatives for Social Change (RISC) is the research unit for the School of Social Work at the University of Victoria, Canada. The Research Initiatives for Social Change unit is committed to promoting social change through critical thinking and participatory processes.

Substance Using Women with FASD and FASD Prevention was a research project funded by the Victoria Foundation, through its FASD Action Fund.

The overall purpose of this project was to consolidate and expand knowledge regarding effective, appropriate substance use treatment approaches and resources for women living with Fetal Alcohol Spectrum Disorder (FASD).

The project had three inter-related components:

- a review of literature and practice knowledge;
- an environmental scan to identify promising programs, resources and approaches across BC that relate to substance use care for women with FASD; and
- community-based interviews with women with FASD to identify, from their perspective, “what works” in terms of substance use programs and care.

A Literature Review on Promising Approaches in Substance Use Treatment and Care for Women with FASD is the report emerging from the literature review component of the project.

Two other reports based on findings from this project have been produced and may be accessed electronically or in paper copy:

- *Service Providers’ Perspectives on Promising Approaches in Substance Use Treatment and Care for Women with FASD*, and
- *Voices of Women with FASD: Promising Approaches in Substance Use Treatment and Care*

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Preface and Acknowledgements

Research and practice wisdom tells us that women who themselves have FASD are at high risk of having concurrent substance use, violence and trauma experiences, mental health problems, and of having a baby with FASD. Despite this, there is a dearth of published information that has focused on the support needs of women with FASD who have substance use problems, or on effective practice in providing substance use treatment and care for women with FASD.

Finding respectful, compassionate, and evidence-based ways to better support women with FASD and addictions and/or other concurrent mental health problems is integral to improving women's health and preventing FASD. This three-part project was undertaken to begin to address this gap in knowledge. Our hope is that the knowledge generated through this project will be used to inform policy and program development to better attend to the needs of women with FASD who use substances.

This report, *A Literature Review on Promising Practices in Substance Use Treatment and Care for Women with FASD*, emerges from the first component of the project. Separate reports based on findings from the project's environmental scan and from the project's interviews with women with FASD also have been produced; each report concludes with a brief synthesis of the findings from all three components of the project.

In addition to the generous funding received through the Victoria Foundation, this project has had a large and diverse group of people who recognized its importance and relevance. The project's partners have included: the University of Victoria School of Social Work; the BC Centre of Excellence for Women's Health; the Aurora Centre; the Canadian National Coalition of Experiential Women; the Inter-Tribal Health Authority; PEERS Victoria Resource Society; the Victoria FASD Community Circle; and the Vancouver Island Health Authority.

The project team is extremely appreciative of the project's Advisory Group, whose ongoing support, wisdom and guidance have been invaluable. Over the project's lifetime, Advisory Group members were: Melissa Cailleaux, Lauren Casey, Dana Clifford, Lynda Dechief, Lorraine Greaves, Chris Leischner, Gail Malmo, Lenora Marcellus, Nancy Poole, Amy Salmon, and Marilyn Van Bibber.

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1. Introduction

Fetal Alcohol Spectrum Disorder (FASD) is the term “used to describe various conditions or diagnoses resulting from prenatal alcohol exposure” (George, Masotti, MacLeod, Van Bibber, Looock et al. 2007, 139). FASD is an invisible and lifelong disability, and while its manifestations are varied, they include a range of physiological, cognitive, behavioural and social effects.

Currently, we do not have conclusive, reliable evidence regarding the likelihood that youth or adults with FASD will have problematic substance use issues. However, the literature does suggest that a disproportionate number of people with FASD will have substance use problems (Streissguth, Barr, Kogan, & Bookstein 1996); this includes women with FASD. There is also a high likelihood that women with FASD, like all women, will be sexually active, and at some point may become pregnant. Given the very real possibility of substance use for women with FASD, in conjunction with likely sexual activity, there is a risk that women with FASD may use alcohol or drugs while pregnant. Cumulatively, this suggests that women with FASD are a high-risk group for giving birth to a baby who is prenatally exposed to alcohol.

From the perspective of FASD prevention, women with FASD must therefore be viewed as an important group. Understanding their substance use behaviours, and identifying promising practices in addressing their problem substance use are critical components to FASD prevention. And yet, despite this, relatively little is known about women with FASD and their experiences, both in relation to substance use, and in their attempts to access care related to their substance use.

In order to get at the topic, this literature review covers a scope of information spanning FASD, women’s substance use, women with FASD, available prevention and supports for women, barriers to care, and promising practices, all in relation to

FASD prevention and women with FASD who use substances.

This review, and the larger project of which it is a part, is done in the context of FASD, and therefore the context of alcohol use. However, the material included in this literature review is not always specific to alcohol use as distinct from other substance use. This is largely because the range of literature examined covers the intersection of FASD, alcohol use, women’s substance use, and so forth. Accordingly, there is some flexibility in our use of language referring to alcohol use specifically and substance use as a broader term.

Background and Project Objectives

As well as being at high risk of having problematic substance use, practice wisdom tells us that women with FASD who have substance use problems do not do well in traditional substance use treatment programs: they are often described by practitioners as “very challenging” to work with and have “poorer outcomes.” Nevertheless, we knew of almost no published information on effective practice and substance use treatment programming for women with FASD. Without knowledge about good practice and about the individual and collective needs of this group of women, it is very difficult to offer tailored and responsive services that provide effective prevention and treatment.

This project has aimed to address that gap in knowledge. The overall purpose of this project has been to consolidate and expand knowledge regarding effective, appropriate substance use treatment approaches and resources for women living with Fetal Alcohol Spectrum Disorder.

The project has had three components:

- a review of the literature and practice knowledge regarding promising substance use treatment and care with women with FASD;
- an environmental scan to identify existing and innovative programs, resources, and approaches across British Columbia that are related to substance use treatment for women with FASD; and
- interviews with women living with FASD on their perspectives of their substance use within the context of other issues or challenges in their life—in particular, parenting and their involvement with the child welfare system, their perceived barriers to accessing treatment and care, and their perspectives on useful or promising approaches in relation to addictions/substance use treatment.

This literature review is the product emerging from the first component of the overall project. Our hope is that the knowledge generated through this project will be used to inform policy and program development to better attend to the needs of women with FASD who use substances.

About FASD

Terminology

Fetal Alcohol Spectrum Disorder, FASD, is the term widely used to describe a range of conditions and harms emerging from prenatal exposure to alcohol, and includes several associated terms and conditions. Technically, FASD itself is not a diagnostic term, but rather the umbrella term under which several formal diagnoses are classified (George et al. 2007; Chudley, Conry, Cook, Looock, Rosales et al. 2005; Masotti, George, Szala-Meneok, Morton, Looock et al. 2006; Poole 2008). Classen, Smylie, and Hapke (2008, 1) explain that “diagnoses under the FASD umbrella are Fetal Alcohol Syndrome (FAS), partial FAS (p-FAS) and Alcohol-related Neuro-developmental Disorder (ARND).” Terms such as p-FAS and ARND are “additional diagnostic categories used to describe individuals who have some, but not all, of the characteristics of FAS, and for whom there is

a confirmed history of maternal alcohol exposure” (Motz, Leslie, Pepler, Moore, & Freeman 2006, 16).

In addition to the aforementioned diagnostic terms, many other terms are often associated with the FASD umbrella including Alcohol-Related Birth Defects (ARBD) and Fetal Alcohol Effects (FAE) (George et al. 2007; Motz et al. 2006; Chudley et al. 2005). “While all of the diagnoses encompassed under FASD are caused by prenatal exposure to alcohol, effects vary widely and are influenced by the pattern of alcohol exposure (i.e., threshold amounts of alcohol in the blood, as well as the timing of the exposure), maternal health and nutrition, genetic susceptibility, the use of other substances, and a host of other biological and environmental variables that may have an impact in the prenatal and postnatal periods” (Chudley et al. 2005; see also Dell & Roberts 2006).

Prevalence

FASD is the leading known preventable cause of developmental disability in North America (Poole 2008; Classen et al. 2008; Masotti et al. 2006; Public Health Agency of Canada 2005b). It is widely estimated by a range of sources, including Health Canada, that 9 in every 1000 babies born in Canada have FASD (Motz et al. 2006; AADAC 2004; Umlah & Grant 2003; Public Health Agency of Canada 2005b, A Framework for Action). “This concurs with estimates from the United States of a combined rate of FAS and ARND of 9.1 per 1000 births” (AADAC 2004). Further, “it is estimated that 1 to 3 babies per 1000 births is affected with FAS and that every day, one child with FAS is born in Canada” (AADAC 2004; also Umlah & Grant 2003).

Yet, despite the continually increasing attention to the issue in the past few decades, “estimating the number of children born in Canada with FASD and FAS [remains] difficult, due to inadequate diagnostic availability, and fledgling surveillance initiatives” (Motz et al. 2006, 15).

Effects

The effects of Fetal Alcohol Spectrum Disorder can include “growth deficiency, characteristic facial anomalies, damage to the central nervous system, cardiac problems, skeletal malformations, visual and

auditory deficits, altered immunological function and behavioral problems” (The National Center on Addiction and Substance Abuse at Columbia University 2003, 33). While the hallmark physical characteristics of FAS may be visible in early infancy, the range of social and behavioural characteristics associated with FASD often only become evident as a child ages.

A differentiation between primary and secondary effects of FASD was first made by Ann Streissguth and colleagues in 1996. Primary effects were defined as difficulties or conditions reflecting dysfunctions of the central nervous system, while secondary effects or problems were defined as the characteristics “that arise after birth and presumably could be ameliorated through better understanding and appropriate interventions” (Streissguth, Barr, Kogan, & Bookstein 1997, 27; see also Classen et al. 2008).

Primary effects associated with FASD include conditions such as “lowered IQ with particular deficits in arithmetic; attention deficits; impaired memory; lowered executive functioning (ability to use higher-level cognitive functions to plan and guide behaviour)” (Classen et al. 2008, 2). They also include neurological dysfunction, challenges with memory, conceptualization, abstracting (including understanding abstract concepts such as time and money) and linking concepts (Clarren 2004; Umlah & Grant 2003; Grant, Huggins, Connor, Pedersen, Whitney et al. 2004). Additionally, the primary effects of FASD include a range of social and emotional challenges. These challenges include “difficulties in regulating emotions (i.e., going from being calm to being agitated, as a result of becoming overwhelmed); difficulties reading social cues and in understanding and expressing emotions; lack of social boundaries or sense of ‘personal space’; difficulty showing remorse; and, difficulties in controlling anger” (Rutman, La Berge, & Whewey 2005b, 3).

As a result of these primary effects, “children who grow up with FASD are at high risk of serious secondary problems, such as dropping out of school or getting expelled; getting into trouble with the law; abuse of alcohol and other drugs; inappropriate or risky sexual behavior; inability to maintain employment; and mental health issues such as

clinical depression” (Healthy Child Manitoba n.d.; see also Classen et al. 2008; SAMHSA 2006; and, Dubovsky 2008). These social, behavioural, and psychological challenges are all understood to be the secondary effects of FASD.

All of these primary and secondary effects of FASD interconnect with one another, and with each individual’s environment, and consequently have significant implications in day-to-day life, safety, survival, and capacity to thrive. For example, the Public Health Agency of Canada (2005a, 4) states that “people who are affected by FASD may have special needs that require life-long help—even throughout adulthood.” Practical assistance may be required in areas such as:

- managing time, and being on time for appointments, work, school etc.
- developing daily schedules
- preparing meals and having regular mealtimes
- managing money, such as paying rent and buying food
- learning from experiences and understanding consequences of behaviours, and
- engaging with other people socially

Rutman, La Berge, and Whewey (2005b, 3) explain that the effects and implications of deficits in cognitive processing mean that someone with FASD “may appear to know something or how to do something one day and forget it the next day.” Further, they may have “difficulties with communication, particularly receptive language” which is particularly relevant as it means they may speak quite well, but in actuality understand little. Rutman, La Berge, and Whewey go on to explain that confabulation is often a problem for people with FASD, meaning that a person may make up pieces of information in order to fill in holes in their memory or gaps in their understanding, or simply in an effort to please others. Unfortunately, this type of behaviour is rarely interpreted for what it is and is frequently mistaken for lying (Rutman et al. 2005b; see also Dubovsky 2004).

Perhaps most importantly though, “because FASD is about brain difference, it is an *invisible* disability. Unlike other forms of disability, people can’t see it.” (Rutman et al. 2005b, 2). The invisibility of FASD

contributes to the many challenges and social and systemic barriers that people with FASD experience in daily life. Without an FASD assessment or diagnosis, many if not all of the effects of FASD can be classified as independent problems reflective of a challenging or disruptive personality type or persistent behaviour problems. Such a classification also tends to result in children and adolescents with FASD foundering in school and in other areas of their life, as their disability remains invisible to the majority of people with whom they interact, and they do not receive adequate supports to develop the necessary life skills to thrive.

The invisibility of FASD contributes to the numerous social and systemic challenges and barriers that people with FASD experience in daily life.

Rethinking the Secondary Nature of Secondary Effects

Very recent evidence suggests that some mental health-related issues, including those which have generally been accepted as secondary effects of FASD—such as a person’s response to stress, or their susceptibility/vulnerability to depression—may actually be primary rather than secondary effects of prenatal exposure to alcohol (Weinberg 2009a). Weinberg and colleagues have been researching the stress system in relation to alcohol consumption and prenatal alcohol exposure in animal studies. To date, they have found that “among the physiological abnormalities induced by maternal ethanol intake are marked alterations in both maternal and offspring endocrine function.” This is a pertinent finding, as the “endocrine system influences functions as diverse as reproduction, growth, metabolism, stress responsiveness, and behavior, and is critical in maintaining homeostasis” (Weinberg 2009b, 17).

Weinberg’s research group has been studying the stress system, referred to as the HPA axis—the hypothalamus, pituitary, adrenal axis. Weinberg et al. asked whether the changes to the HPA “induced by prenatal ethanol exposure underlie the increased risk for depression in children with FASD.” While research

in this area is still in its early stages, these hypotheses and associated findings offer a new perspective on the generally accepted primary and secondary effects of FASD. Weinberg and her colleagues’ research may provide evidence that mental health issues—such as depression, anxiety, and heightened responsiveness to stress—that had previously been described as secondary effects of FASD may be better conceptualized as primary characteristics, though again, characteristics that manifest with considerable variability across the population living with FASD.

Strengths

In addition to the lifelong challenges and effects of FASD, it is important to emphasize the strengths and abilities of people with FASD. While these vary markedly from person to person (as do the primary and secondary effects and behavioural characteristics), key strengths often reported in the literature and identified by people living with FASD and their family members include being: artistic, musical, athletic, good at using computers, experiential/kinaesthetic learners, determined, good with animals, friendly and outgoing, creative, and having strong expressive language skills (e.g., storytelling) (Malbin 2002; Better Endings New Beginnings n.d.). Similarly, based on several qualitative research studies with adults with FASD—including a project focusing on parenting with FASD—Rutman and her colleagues reported themes relating to participants’ self-identified accomplishments, which included: raising children and/or getting them back from foster care, graduating from school, maintaining a job, dealing with anger issues, and quitting or reducing substance use (Rutman, La Berge, & Whewey 2002; Rutman et al. 2005b).

Adult Diagnosis

To date, “much of the research on FASD has focused on etiology, prevention and the diagnosis and assessment of children” (Clark, Lutke, Minnes, & Ouellette-Kuntz 2004, 2). While assessment at birth or in early childhood is facilitated by the identification of characteristic facial features, as children mature, these features become less evident. “Diagnosis of FAS or alcohol related effects is most accurately done between ages 2 and 11 years, after puberty growth catch up is common and the facial morphology changes” (Clark et al.

2004, 2). This means that many adolescents and adults with FASD “are hard to identify because the characteristic facial features of the disorder [have] become less pronounced with age and height and growth deficiencies are no longer evident” (Classen et al. 2008, 1). The lessening of these features makes assessment and diagnosis increasingly challenging.

Other challenges with adult diagnosis involve the lack of reliable sources—beyond self-reporting—from which to obtain personal history, and few available professionals working with adults with FASD who are familiar with diagnostic models. Additionally, adult diagnosis often requires a social worker currently working with the individual to act as a detective, seeking out details on personal history, and trying to confirm or validate dated or cryptic records (Down, Gerry, & Horne 2009). And yet, not all adults seeking diagnosis will have access to a social worker, nor will they necessarily have any records or leads to explore. Moreover, in Canada there are currently very few diagnostic clinics or facilities and resources

available for adult diagnosis. And, in many if not most situations, the considerable costs associated with diagnosis are not covered through medical plans, something which can act as a further barrier to adult diagnosis.

Combined, all of these factors make it extremely challenging to access or make a clear FASD diagnosis in adulthood. Indeed, definitive conclusions regarding the feasibility and promising practices/processes in relation to adult diagnosis are very much in the early stages of deliberation by leaders in this area of FASD research. Nevertheless, researchers, policy makers, program developers, service providers, families and those living with FASD are increasingly appreciating the importance of focussing attention on the complex issues surrounding diagnosis. This attention must include awareness of the complex ethical implications of making and assigning a diagnosis, as well as the social and health policy implications as they relate to service development and delivery, and related funding and resource allocation.

2. Literature Review Process

Due to the limited amount of research focusing specifically on FASD prevention and women with FASD who use substances, in order to access the topic, this literature review explored a range of available academic and grey literature that focused on related topics, such as: FASD, women's substance use, women with FASD, available prevention and supports for women, barriers to care, emerging frameworks for understanding the issues, and promising practices, all in relation to FASD prevention.

Key words such as: [Women with FASD] AND ([substance use problems] OR [substance misuse by women]) OR [substance use treatment program for women] OR [interventions]), [Women with brain injury] AND [substance use problems], [Women with mental health issues and substance misuse], [(Cognitive) disability and substance use] were used to complete a comprehensive a review of published literature on these topics. A detailed search strategy, using these key words, was used for the following databases:

- Applied Social Sciences Index and Abstracts (ASSIA)
- Campbell Collaboration)
- CINAHL
- Cochrane Library (CDSR, CENTRAL)
- DARE (accessed via Centre for Reviews and Dissemination (CRD))
- Dissertation Abstracts
- EMBASE
- Health Management Information Consortium Database (HMIC)
- International Bibliography of the Social Sciences (IBSS)
- Medline
- PsycINFO
- Social Care Online (SCO)
- Social Sciences Citation Index

- Social Services Abstracts
- Social Work Abstracts
- System for Information on Grey Literature in Europe (SIGLE)
- Wilson Social Science Abstracts
- ZETOC
- Science Direct
- EBSCOhost

In addition to those research databases listed above, internet-based databases, websites, and other grey literature sources such as conference proceedings specific to the topic were searched and reviewed. The review of grey literature was completed by examining materials found through internet searches using a keyword search. Keywords were used independently and in combination, and included terms such as: "FASD," "Women," "Substance Use," "FASD prevention," "FASD intervention programs" "Support programs for adults with FASD" "Substance use treatment program for parenting women," "Substance use treatment program for women in the justice system" and so forth. The web searches were geared especially towards programming, prevention, and policy related documents that would otherwise not appear in an academic journal search. This component of the literature review turned up a range of content focused on various aspects of women and substance use and FASD, although little specifically on women with FASD, and less so on women with FASD who use substances.

The literature review was geared primarily to Canadian information; however, international literature was included in all phases of this report, partly for greater context on the topic, and also in large part due to the scarcity of information on the topic, Canadian or otherwise.

The major finding from the overall literature review process is that there is indeed very little information

available, academic or grey literature, that covers this topic specifically. As such, FASD prevention for women with FASD who use substances is in many ways understood by focusing on the point of intersection between the many overlapping elements

pertaining to women and substance use more generally. This absence of literature also reinforces the tremendous need for research on this topic, and the importance of this research project to expand the available knowledge base.

3. Women and Substance Use: Issues and Trends

Several Canadian studies have examined alcohol and substance use across the country, disaggregating the data according to age, sex, and region among other variables (that vary to a certain degree by study). To date, there are no epidemiological data that specifically pertain to substance use patterns by women who have FASD. Nevertheless, a review of alcohol use patterns by women is instructive in providing a general frame of reference, and existing data pertaining to particular subsets of women may inform understandings of substance use amongst women with FASD.

This section of the literature review examines recent findings on the prevalence of women’s alcohol use, available data on women’s alcohol use while pregnant, and research findings examining why women drink (i.e., pathways to women’s alcohol use). Available information—albeit limited—regarding substance use, and the context for substance use, amongst women with FASD is also provided.

Canadian Trends in Alcohol Consumption

Data on Prevalence of Women’s Alcohol Use

In 2004, the *Canadian Addiction Survey (CAS)* report was released. The CAS was an extensive study surveying and presenting detailed information on the prevalence of substance use among the Canadian population. Subsequently, in 2008, the *Canadian Addiction Survey (CAS): Focus on Gender* (Ahmad, Flight, Singh, Poole, & Dell 2008) was released, offering valuable insight into specific patterns of Canadian women’s substance use. Drawn from these reports, highlights on Canadian women’s alcohol consumption patterns include the following findings.

The survey found that for women respondents, “frequency of drinking varied with age, province, education and income adequacy” (2008, 14). Among women who reported that they drank in the past year, 36% reported drinking 1-3 times per month, and 31% reported drinking less than once per month; these were the two most frequently reported response categories (Ahmad et al. 2008, 14).

CAS defined heavy drinking for women as 4 or more drinks on any particular occasion. The survey found that “among female past-year drinkers (15 and older), 3% reported heavy drinking at least once a week and 17% reported heavy drinking at least once a month” (Dell & Roberts 2006, 13). Dell and Roberts (2006, 13) reported that in the Canadian Community Health Survey (CCHS), which defined heavy drinking for women as 5 or more drinks per occasion, “8% of women reported heavy drinking at least once a month.” In addition, there was a “higher prevalence of drinking among women with higher incomes and higher ages (over 35 years of age). However, frequency of alcohol intake and amount of alcohol consumed per occasion were both higher among younger women (ages 18-20) and those with low incomes” (The Source n.d.; see also Ahmad et al. 2008).

In keeping with the CAS finding that quantity of alcohol consumed is inversely related to age, the BC Adolescent Health Survey revealed that of “youth who had tried alcohol, 44% reported binge drinking in the past month, a rate that has remained consistent since 1998” (Smith, Stewart, Peled, Poon, Saewye et al. 2009, 34). Meanwhile, Dell and Roberts (2006, 15) reported that “71.1% of females between 15 and 19 years of age used alcohol in the previous 12 months.” Dell and Roberts further reported that while there is limited information “on youth who are out of the mainstream, indications are that the percentage of these females drinking alcohol is higher and their pattern of use is riskier than their high school counterparts” (Dell & Roberts 2006, 15).

In their 2006 report, Dell and Roberts raise the issue that “Canadian studies on women’s use of alcohol during pregnancy, in particular in relation to FAS and FASD, disproportionately focus on Aboriginal women and the geographic areas in which they live” (26). This disproportionate focus can result in heavily skewed data on the prevalence of FASD within both Aboriginal and non-Aboriginal populations (Tait 2003). And yet, despite this disproportionate focus, there are still very little data available on Aboriginal women’s alcohol use; there are few epidemiological studies on the issue, and what data are available are not disaggregated by sex. Accordingly, the nature of substance use—patterns, frequency, and trends—for Aboriginal women remains largely unclear (Tait 2003; Poole, Gelb, & Trainor 2008).

Data on Women’s Alcohol Use While Pregnant

Unfortunately, there is little information in Canada documenting women’s alcohol use while pregnant. Inadequacies in available data stem from limited surveys and significant challenges in data collection, which are currently primarily dependent on self-reporting. “The use of self-report methodologies to collect information about alcohol use in pregnancy is further limited by the associated social stigma, feelings of guilt and shame and/or fear of repercussions (including fear of child welfare involvement and, in some jurisdictions in the US, incarceration)” (Dell & Roberts 2006, 19). Nevertheless, there are some available data on women’s alcohol use while pregnant, and they are detailed here.

Dell and Roberts (2006) state that the 2005 *Report on Maternal and Child Health in Canada* detailed that of mothers in the survey, “roughly 14% reported drinking alcohol (any amount) during pregnancy” (as cited in Dell & Roberts 2006, 21; see also Catherine McCourt, Dana Paquette, Louise Pelletier, & Francesca Reyes 2005). Dell and Roberts further report that the 2000-01 CCHS found that 14% “of all women who reported using alcohol in their lifetime also consumed alcohol during their last pregnancy” (Dell & Roberts 2006, 21; Catherine McCourt et al. 2005). They go on to explain that according to the CCHS findings, those women that did self-report alcohol consumption during pregnancy, for the most

part, drank infrequently: “75.4% drank less than once per month, 9.7% once per month, 6.5% two or three times per month, 5.3% once per week and 1.3% drank every day” (Dell & Roberts 2006, 21).

Illustrating the possible variation in findings depending on the questions asked, the timing of the survey, and the definitions of terms, the CCHS (2000-01) also surveyed heavy drinking during pregnancy with heavy drinking defined as “regularly drinking more than 12 drinks per week” (as opposed to being defined as 5 or more drinks per occasion). With heavy drinking so defined, they found that “6.9% of pregnant women at the time of the survey and 8.6% of non-pregnant women reported heavy drinking. In examining heavy drinking in the week prior to the survey, 0.5% of pregnant and 3.6% of non-pregnant women reported drinking more than 12 drinks” (Dell & Roberts 2006, 23). Furthermore, the survey also found that “of those surveyed, 12.5% of pregnant and 47.7% of non-pregnant women reported consuming between 1 and 9 drinks in the week prior to the survey” (Dell & Roberts 2006, 23).

Current studies suggest that for teens and young adults the combination of drinking behaviour patterns, along with identification of pregnancy later in term, increases the likelihood of binge drinking while pregnant. If adolescent women are binge drinking to the point where they cannot recall their actions, there is increased likelihood of accidental pregnancies—among other potential harms to health—and continued alcohol consumption before becoming aware of the pregnancy. This, in conjunction with adolescent and young adult binge drinking behaviours, increases the chances of significant prenatal alcohol exposure for the fetus. Available data indicate that “seven percent of pregnant teenagers, ages 15 to 17, binge drink compared to 4.8 percent of pregnant women ages 18 to 25 and 3.1 percent of those ages 26 to 44” (The National Center on Addiction and Substance Abuse at Columbia University 2003, 32; Dell & Roberts 2006).

Contextualizing Women's Substance Use

While the literature does not provide evidence that there is one single or common reason why women drink, there are many correlates and contextual factors that have been identified that shed significant light on pathways to women's substance use.

Many women with substance use issues also: have a history of trauma; have come from the child welfare system; and have experienced homelessness and deep poverty. Even more are survivors of domestic or relationship violence, and many have had involvement with the criminal legal system.

Overwhelmingly, women who use substances have had one, if not several, significant traumas in their life. "Women with substance use issues are more likely than their male counterparts to have experienced physical or sexual abuse" (Watkins & Chovanec 2006, 29). Study findings consistently show that there is a strong likelihood that many women with substance use issues are survivors of abuse or sexual exploitation, and some say that "the single greatest predictor for alcohol abuse in women is sexual abuse" (National Women's Health Resource Center Dec 2006, 2). Many women with substance use issues also: have a history of trauma; have come from the child welfare system; and have experienced homelessness and deep poverty. Even more are survivors of domestic or relationship violence, and many have had involvement with the criminal legal system.

A woman with substance use problems most likely has fewer resources (such as employment, income, or education) at her disposal, and she is also likely to be living with a partner who has substance use problems. Furthermore, this woman likely has interconnected mental health challenges. And, in addition to the aforementioned factors that likely need to be viewed as antecedents to her substance

use, it is probable that a woman with substance use problems has dependent children either in her care, or who have been removed from her care by child welfare authorities (United Nations Office on Drugs and Crime August 2004; Carlson 2006; National Women's Health Resource Center Dec 2006; Astley, Bailey, Talbot, & Clarren 2000; Boland 2007; Watkins & Chovanec 2006; Rutman et al. 2002).

Boland (2007) summarizes the key findings from Astley et al.'s 2000 study of 80 women who had children diagnosed with FASD as follows:

A study profiled 80 women who had children diagnosed with FASD. Of these 80 women: 100% had been seriously abused. 90% suffered from depression and phobias. 90% suffered from Post Traumatic Stress Disorder. 80% lived with partners who did not want them to stop using substances. Half had FAS conditions themselves. (Astley et al 2000, as cited in Boland 2007)

Astley et al. (2000, 512) further reported that "while 84% [of women participants] reported they felt they had a problem with alcohol use, 94% reported they did not want to reduce their use because it helped them cope, 72% did not want to reduce because they were in an abusive relationship, and 79% reported they were too depressed to do anything about it." These findings reinforce the notion that women's substance use rarely happens in isolation; it happens within the context of other significant issues in their life, issues that further influence women's readiness and opportunities to access care related to substance use, should they so choose.

In keeping with Astley et al's (2000) research, a study done at Toronto's Breaking the Cycle program examined "the possibility that women drinking in pregnancy were also affected by alcohol use in their mothers."

Women's alcohol use, depression, alcohol use in pregnancy, as well as learning difficulties, and their mother's alcohol consumption were assessed and compared to the general population. ... A substantial proportion of women drinking heavily in pregnancy were born to women who drank heavily. Their characteristics, including rates of

learning, disability, criminality and psychiatric morbidity, suggest that a substantial proportion of them are afflicted by ethanol embryopathy. Further studies should examine these women directly for the diagnosis of FAS. (Rouleau, Levichek, & Koren 2003, 1)

These findings pertain to and support the need for programming tailored to the needs of women with FASD (and hence the aims of this project) and also connect to the discussion below on *Contextualizing substance use for women with FASD*, and to Section 5 of this literature review.

For women, the existence of any co-occurring condition—such as trauma or mental ill health—is directly linked to the accessibility, suitability, and success of treatment programming. For example, the UN states that the presence of PTSD, a co-occurring condition, “has been associated with greater vulnerability to be re-traumatized and generally poorer treatment adherence and outcome” (United Nations Office on Drugs and Crime August 2004, 9). Given the high levels of co-occurring conditions, this finding offers some insight into why some women who are drinking, and perhaps actively accessing services, may continue to drink despite past participation in treatment programs or outreach services.

In understanding why women drink, and how women come to harmful substance use, it is also critical to note the sequence in which concurrent disorders develop, and to recognize that this sequence differs for women and men. “For women, psychiatric disorders, such as depression, panic disorder and PTSD, were more likely to *precede* the onset of a substance use disorder” (United Nations Office on Drugs and Crime August 2004, 9, emphasis added). Further, experiences of abuse typically precede mental ill health, and significantly increase a woman’s risk of addiction due to the resultant emotional pain that leads a woman to “self-medicate with alcohol, illegal drugs and/or prescription drugs” (Carlson 2006, 99; see also National Women’s Health Resource Center Dec 2006; and Ashley, Marsden, & Brady 2003). These findings have important implications for substance use-related treatment and care. Indeed, Finkelstein and colleagues’ pivotal research and

conceptual work have demonstrated the effectiveness and value of a trauma-informed, gender-based service model wherein appreciation of women’s possible experiences of abuse, violence and trauma, and women’s related mental health issues, inform the creation of an integrated service plan (i.e., one that attends to women’s substance use *and* mental health issues) that emphasizes development of healthy coping skills (Finkelstein 2008; Markoff, Reed, Fallot, Elliott, & Bjelajac 2005).

In addition to the influence of personal history and current circumstance, for some women, monumental historical and current political and social factors converge with personal factors to influence substance use. For example, for Aboriginal women, the effects of colonization, residential schools, personal trauma *and* community and cultural trauma cannot be disregarded.

Important re-occurring themes in accounting for substance abuse among Aboriginal groups in Canada are the devastating effects of colonization upon Aboriginal people and the on-going economic and social marginalization experienced by these groups over a number of generations. (Tait 2003, 37)

As in any other cultural or ethnic group, Aboriginal women drink for various reasons; some women may be influenced by the history of colonization and its ongoing effects, while others may not. As such, it is not appropriate to suggest that all Aboriginal women will be equally affected by a collective history of colonization and marginalization. It is, however, critical to understand that for many Aboriginal women, this history will play a pivotal role in their path both in and out of substance use (Tait 2003). “Knowledge of Aboriginal history and experience is especially important for those working in health, justice, and social service sectors” (Chansonneuve 2007, 5).

It is critical to understand that for many Aboriginal women, this history of colonization and marginalization will play a pivotal role in their path both in and out of substance use (Tait 2003).

This knowledge helps to contextualize current use, fosters empathy and understanding, and creates the opportunity for connecting with the Aboriginal healing movement. Accordingly, Rutman and Van Bibber (2010) also emphasize the importance of recognizing the historical context which has led to current health and social conditions for Aboriginal women, and they emphasize the importance of recognizing and attending to this context in discussions about substance use, prevention, and FASD:

Colonization, racism and the deterioration of First Nation political and social institutions, the suppression of traditional spirituality, culture and language, the apprehension of children and loss of traditional lands and economies is the legacy of Canada's settler history... The current health and socio-economic conditions trace their beginnings to these historic events. ...In view of these realities, discussions of FASD in Aboriginal communities cannot take place in a vacuum. (Rutman & Van Bibber 2010, 351)

Contextualizing Substance Use for Women With FASD

There is little available literature exploring the lives of women with FASD, and even less literature specifically examining the substance use patterns of women with FASD. The primary study that speaks to substance use amongst youth and adults with FASD is Streissguth et al.'s (1996) oft-cited research on the occurrence of secondary disabilities. Streissguth et al.'s study found that, based on a sample of 253, for study participants age 12 and over the prevalence of alcohol or drug problems (ADPs) was 35%. Disaggregated by age, the percentage for young adults (age 12-20) with FASD was 30%, and for adults (age 21-51) it was 45%. In this study, "the 57 clients with street drug problems [were] almost entirely 'nested' within the 81 clients with alcohol problems" (Streissguth et al. 1996, 52). Moreover, alcohol use typically began about two years before the use of street drugs. It should be noted, however, that these statistics were not broken down by sex.

While Streissguth's group found no statistically significant differences in the prevalence rates by gender, when the study's findings were disaggregated by sex, age, and FAS diagnosis, highlights included:

- 4% of the 22 young women with FAS age 12-20 had APDs;
- 38% of the 39 young women with FAE age 12-20 had APDs;
- 37% of the 27 women with FAS, age 21-51 had APDs; and
- 70% of the 20 women with FAE, age 21-51 had APDs.

Finally, in examining stages or patterns of substance use, Streissguth et al. (1996) reported that women with FAS had the highest rate of abstinence, relative to men (with FAS or FAE) or to women with FAE.

Although the overall paucity of existing literature about patterns of substance use amongst women with FASD must be acknowledged, the information that does exist regarding the experiences of women with FASD appears to mirror, in many respects, the findings regarding the context for problem substance use amongst women more generally. Correlates such as experiences of abuse, social and economic marginalization, and mental ill health, are consistently reported. In keeping with this, the most prominent risk factors for alcohol or drug problems found in Streissguth et al.'s (1996) study were: living with those who use substances and having been the victim/survivor of violence.

In addition, much like the findings in the previous section on the context of women's substance use, women with FASD cite mental health challenges as a key contextualizing element in their lives, and one that intersects with substance use (Dubovsky 2008). In their 2002 report on adults living with FAS/E, Rutman et al. (2002) state:

Almost every participant spoke at some length about serious mental health issues that they have dealt with at some point in their life. For many people, these issues appear to be either ongoing or recurring. Perhaps no single aspect of one's experience is more ever-present or pervasive than mental health. Mental health issues have reciprocal effects with virtually all areas of a person's life including employment, education,

family and other social relationships. ... The most frequently discussed mental health issues included: sexual, physical and emotional abuse; depression and suicide; alcohol and drug use; anger; and anxiety. (Rutman et al. 2002, 111)

This finding is echoed in the results of a study conducted on the Washington based Parent-Child Assistance Program (PCAP), between 1991 and 2009. The study “compared PCAP clients who were heavily exposed to prenatal alcohol (N=131) versus those who were not exposed to alcohol (N=202)” (Grant, Whitney, Huggins, & O’Malley 2009, slide 6). Of the 131 participants who were heavily exposed to prenatal alcohol, 61% had a childhood history of physical abuse, 70% had a childhood history of sexual abuse, and 48% had been involved in foster care or CPS as child. Furthermore, in assessing participants psychiatric history, 57% had been outpatients, 80% had a history of depression, 61% had trouble concentrating, and 44% had attempted suicide (Grant et al. 2009; see also Grant & Whitney 2007). Significantly, of the 131 women in this study who were heavily exposed to prenatal alcohol, only 15 had an FASD diagnosis. This speaks to points raised in Section 1 of this paper regarding the infrequency with which adults who may have FASD have actually gone through a diagnostic process, and to the invisibility of FASD as a disability. This also suggests that many women seeking or receiving services related to substance use issues and/or other issues in their lives may have been prenatally exposed to alcohol, even though they have not been assessed or do not self-report as having FASD.

In addition to the above, available research focusing on adults with FASD indicates that difficulties in getting and keeping a job are common (Rutman et al. 2002; Rutman, La Berge, & Whewey 2005a); further, stigmatization and marginalization of people with FASD exist in various and numerous spheres of life (e.g., as parents, workers, tenants, students, patients/clients in medical/therapeutic settings and as inmates), which compounds individuals’ risk for social, physical, mentally and spiritual harms, as well as incarceration and institutionalization (Boland 2007).

Adding further depth to our understanding of the experiences of the lives of women with FASD, in her

1997 Master’s thesis, Massey presented the stories of several women with FASD, detailing some of the problems and obstacles that women with FASD face in securing and maintaining safe housing, ongoing medical or health care, adequate high-quality food, and other fundamentals necessary for health and survival. When discussing one participant, “Sherry,” Massey explains:

Sherry’s cognitive and language skills were extremely weak although her spelling was surprisingly well developed. The rest of her academic skills were well below the level required for functional literacy and Sherry could not read well enough to mix baby formula, follow a simple recipe, or find a phone number. She could not read a map or street signs and navigated in the familiar territory of Edmonton’s downtown ‘Drag’, the area where the street prostitutes hang out, by landmarks, not addresses. (Massey 1997, 75)

Massey’s narratives illustrate the interconnection of factors relating to women’s substance use, including the effects of comprehension and literacy, and dimensions such as a history of physical and sexual abuse. In Sherry’s case, she experienced many of the life-history traumas associated with women’s substance use: “In addition to the physical abuse in this foster home, Sherry was raped at age 9 by a 16-year old foster brother and then subjected to ongoing sexual abuse until she was removed from this home at age 11. ... Sherry’s marriage was extremely troubled and characterised by violence, abuse, and alcohol and drug use” (Massey 1997, 71). Unfortunately, Sherry’s story is not unique in this dimension. Massey goes on to detail how other participants in her research also have histories of trauma, sexual assault and abuse, and some have a history of engagement with the justice system.

This common element of a personal history involving trauma or abuse is further reinforced by the more recent research done at the Fetal Alcohol Spectrum Disorders Center for Excellence. In research about adults with FASD, the Centre states:

Given the risk of abuse among persons with an FASD and substance abuse problems, it is likely that clients with an FASD will have a history of

abuse. This abuse can cause long-term damage to mental health and further impair the person’s already compromised ability to form healthy relationships. The counselor working with persons with an FASD needs to be sensitive to the possibility of childhood abuse and other forms of victimization and their impact on the counselor-client relationship. (SAMHSA Fetal Alcohol Spectrum Disorders Center for Excellence 2010, Adults)

A common theme in the lives of all of these women is their often limited ability to comprehend the risks and consequences of their behaviour. Despite their best intentions and the appearance of comprehension, they do not possess the cognitive, social, and life skills necessary to avoid many of the situations they find themselves in. Nor do they always have the skills required to navigate their way out of such situations, once in them.

Candy’s adolescence was marked by a lengthy involvement with the justice system because of incidents of assault, break and enter, theft, and her inability to comply with court and probation orders. She had been in the Edmonton Young Offenders’ Centre and was also placed in a youth detention centre in Calgary. She had committed other crimes, such as driving without a licence and automobile theft, for which she had not been caught. Many of Candy’s arrests were a result of her inability to stand up to her peers. She

was easily persuaded to engage in criminal acts, especially theft. (Massey 1997, 86)

It is the interplay between the effects of FASD and other risk factors that leads to high risk behaviours or situations.

While women with FASD may be at risk for (problematic) substance use because of heightened vulnerability to risk factors resulting from FASD, they are not necessarily at risk of substance use because they are genetically disposed to it. Rather, it is the interplay between the effects of FASD and other risk factors that leads to high risk behaviours or situations. Expanding on this point, in the *Final Evaluation Report* for the With a Little Help from My Friends project, Hume, Rutman, Hubberstey and MacFeeters (2006, v), detail a number of factors as triggers to high risk behaviours. These factors are presented in the chart below, and, based on the current literature review, we have added a few additional triggers, shown in blue.

With the triggers broadly categorized as such, we can endorse the idea that FASD primary effects fall alongside other non-FASD related risk factors to result in triggers to high risk behaviours. It is not the FASD effects alone that make a woman prone to high risk behaviour; it is in addition, or in relation, to these other psychosocial and environmental factors that triggers to high risk behaviours emerge.

| | | |
|---|---|--|
| <p>FASD-Primary Effects Poor impulse control Poor judgement Poor understanding of cause and effect Poor receptive language</p> | <p>Environmental Poverty Homelessness Decreased cultural connection Few healthy role models Experience of abuse/exploitation</p> | <p>Psychosocial Boredom; Loneliness Hopelessness; Low-self esteem “Normalization” of abuse/violence/victimization experiences High stress/anxiety/depression</p> |
|---|---|--|

4. Barriers to Accessing Substance Use Treatment and Care

In the literature on women and substance use, a multitude of barriers to substance use treatment and care have been identified and examined. Some literature on the barriers to treatment and care has taken a woman-centred lens to try and better attend to the gendered nature of barriers to care. Others have taken a cultural lens to their study of barriers, and others still have worked to synthesize both gender and cultural lenses into a more comprehensive analysis on barriers to care.

While attending to these gendered and cultural dimensions is integral to providing responsive care, it must be noted that very little research or discourse has examined barriers as they relate specifically to women with FASD. Accordingly, this section reviews available literature on barriers to treatment and care for women more generally, while identifying and focusing on what literature is available on specific barriers for women with FASD wherever possible.

Barriers to treatment and care for women who use substances have been widely examined (see for example, United Nations Office on Drugs and Crime August 2004; Dell & Roberts 2006; Rutman, Callahan, Lundquist, Jackson, & Field 2000; Watkins & Chovanec 2006; Poole et al. 2008; Currie 2001). “We often place the burden of FASD prevention solely on the shoulders of pregnant women. Yet research and the experiences of women and those who work with them point to the need for multi-level, multi-sectoral responses” (Network Action Team on FASD Prevention 2007, 1). Findings consistently cite barriers to care as a host of obstacles that range from personal to systemic in nature, and cover the scope of practical necessities (such as child care) and systemic factors, such as stigma and judgment so harsh it is a deterrent to treatment. Women consistently identify: fear of child apprehension; contradictions between harm reduction and abstinence based programming; differing views between the addictions and child protection fields; a lack of accessibility (due to

transportation costs, child care, locally provided services, etc.); few services that attend to women’s co-occurring mental health and addictions conditions; feelings of shame, guilt and blame; and a lack of available and appropriate programming as some of the key barriers to treatment (Rutman et al. 2000; Network Action Team on FASD Prevention 2007; United Nations Office on Drugs and Crime August 2004; Poole & Isaac 2001; Poole et al. 2008; Ashley et al. 2003).

Dell and Roberts (2006, 36) state that “those serious about having an impact on the prevalence of prenatal alcohol use must take into account broad factors that have been shown to affect the health of individuals and populations—income, education, quality jobs and social support.” And the evidence regarding barriers to care would support such a statement. Most barriers to care connect to the larger determinants of health and the broader environment of a woman’s life. Without attending to the real-life environment in which a woman lives, we cannot adequately attend to her needs.

Women who seek treatment for substance use are more likely than men to be younger, less educated, of lower economic circumstances, unemployed, have children in their custody, have a partner that uses substances, have been introduced to substance use and injecting-drug use by a partner, have a sex partner who is also an injecting-drug user with whom they inject, have employment and family or social problems, have health problems, have a family history of alcohol or other drug problems, have a drug-only diagnosis as opposed to alcohol and drug diagnoses, and have a shorter period of time between onset of substance use and treatment entry. (Watkins & Chovanec 2006, 25)

Barriers to care are often categorized in levels or categories in order to present the general spectrum

in which barriers limit women's access to care. The categories vary slightly across the literature, but in essence all intend to convey the same concerns; barriers occur (and co-occur) at all levels of a woman's life: at an individual or interpersonal level; at a community level; at a program level (e.g., availability of programming); and at the larger social or systemic level (e.g., city or national views on the issue) (United Nations Office on Drugs and Crime August 2004; Currie 2001).

A brief synthesis of the widely accepted categories of barriers to care appears in Poole et al.'s (2008, 12) report:

1. **Personal and Interpersonal barriers** are directly linked to each woman's personal circumstances including her mental health, attitude to treatment, family context, social and personal relationships, and support networks.
2. **Community or Social barriers** refer to those that occur at a community level and are largely associated with the community's practices, awareness, beliefs, values and norms and have an influence on the broader context of a woman's life.
3. **Structural or Program barriers** pivot around the policies and practices at the service provision level such as program management, type of treatment offered, or organizational regulations.
4. **Systemic barriers** refer to the broader societal practices, municipal to international, that foster or limit the development of services that respond to women's needs—these need not be directly related to substance use treatment, but can be broader health practices, social supports, education programming, child welfare, empowerment, or involvement practices.

This excerpt provides an overview of the framework used to categorize barriers to care within the literature. The levels of barriers are helpful in conceptualizing and targeting responses that address the multi-levelled barriers to a woman's care, and in developing specific and responsive policy initiatives.

However, while we can tease apart the levels in which barriers occur for the purposes of academic review, or clarity in conceptualization, it is paramount to understand that **all of these levels are hugely intertwined**. A women's experience does not happen

in isolation, so despite the classification of barriers on paper, at any given time she will be influenced by the (untidy) interplay of all of these levels. As Watkins and Chovanec (2006, 3) state, "Women with substance use issues lead complex lives and substance abuse is only one factor in their lives." Whether we conceptually organize the barriers to treatment or not, what is important to understand is that there are a host of obstacles in all areas of women's life that have a bearing on their capacity to seek treatment.

A common barrier to the accessibility of services is the degree to which services meet the realities of women's lives. For example, treatment services and child welfare services are often tremendously out of sync. Carlson (2006, 104) explains,

Different timelines characterize work in the child welfare and substance abuse fields. ...Differing perceptions of significance of relapse can also be an issue. Whereas relapse is often seen as treatment failure by child welfare authorities, an indicator that the woman is not sufficiently motivated to be a good parent and grounds for child removal or not returning a child to a parent's care, relapse is viewed as a common, even normative albeit not positive, part of the recovery process by staff in substance abuse treatment programs.

Differing views and differing expectations between involved support or supervisory agencies can be a tremendous challenge for women seeking treatment. This also applies to the different prevailing philosophical orientations of the many systems in which women are involved: child welfare/protection typically, or at least historically, has worked from an abstinence perspective, while (women-centred) substance use treatment and care service sectors operate from a harm reduction model (Rutman et al. 2000). Additionally, the conflicting or extensive attendance and participation requirements of various services can in itself be an additional barrier. Poole (2000, 40) calls for increased interagency coordination, and explains that such coordination "serves to alleviate the problems associated with elements of programming being in different locations, programs having separate regulations, long waitlists for services, differing intake procedures

and eligibility requirements—all of which serve as significant barriers to treatment.”

Further consideration on the influence of differing views between agencies reveals that many women are faced with prioritization of their own needs with the possible risks of accessing care. For example, “in conjunction with their substance use concerns, many women face custody issues concerning their children, including the possibility of losing custody. Child protection agencies have equated substance use with abuse or neglect of children, making women wary of disclosing their substance use for fear of intervention or loss of custody” (Watkins & Chovanec 2006, 29). For those women that do seek treatment, many still carry with them the concerns of mothering, be it separation anxiety serving as a distraction from treatment programming, or having to navigate the parallel requests of addictions services and child protection services in order to “complete” recovery and regain custody of her children. All of these variables serve as barriers to care, and barriers to successful treatment.

Women who “identify themselves as belonging to non-dominant ethnic backgrounds may be hesitant to seek services from programs that do not support or reflect their experiences, values, and beliefs (Moses et al., 2004). Language barriers may also prevent some from fully participating in treatment services” (Watkins & Chovanec 2006, 29). An inability to locate treatment services that align with personal values and world views, that respect cultural history, and that are accessible in a language that a woman is comfortable speaking is a clear barrier to care. Unfortunately, it is all too common. Moreover, for some women, the effects of identifying themselves as someone who uses substances comes with risks of exclusion or isolation from within the community:

Aboriginal women whose lives have included substance use and FASD repeatedly identify the consequences of disclosure as a barrier to accessing support services for themselves and their children. Given the high degree of stigma associated with maternal substance use and the negative consequences for Aboriginal women and families linked to disclosure of such use, this comes as no surprise. (Salmon 2007b, 229).

The stigma surrounding substance use and mothering is intense, at best. The media consistently reinforces the simplistic and inaccurate notion that mothers who use substances are bad parents, selfish and uncaring (The “Mothering Under Duress” Research Team 2007; Rutman et al. 2000). “Through the interplay of powerful discourses, mothers-to-be are transformed into ‘pregnant addicts’ who are considered at best sick and at worst criminal. They are identified as ‘those bad mothers’ who do not adhere to the predominant ideologies of motherhood, and as such are caught up in discursive practices that seek to ‘treat’ or ‘punish’ them” (Rutman et al. 2000, 6). This harsh view of women who use substances fosters intense shame and guilt in women themselves, and serves as a barrier for many women to face their substance use, reach out for services, disclose their situation to anyone in their community, or believe that they can change their circumstances.

Many participants in our focus groups spoke of their tremendous, relentless feelings of guilt and shame regarding their substance use during pregnancy. ... Women’s feelings of guilt and shame about their substance use seemed to come from within. At the same time, they spoke about how their feelings were fueled and heightened by their perception that society was shaming and blaming. (Rutman et al. 2000, 76-77)

Barriers for Women with FASD

There is very little literature that specifically examines barriers to treatment and care for women with FASD. However, to the extent that researchers and practitioners have discussed the importance of attending to the needs of women with FASD, there is some acknowledgement—either implicitly or explicitly—that these women’s experiences are different relative to those of other women. Although a comprehensive understanding of how their experiences are different is not widely documented, we will briefly examine the issues here.

It is becoming increasingly understood that a woman with FASD will have specific barriers to care beyond the more generalized barriers experienced

by women. For example, women with FASD who are parenting have reported feeling highly stigmatized and scrutinized by both child welfare authorities and the public because they have chosen to be mothers; in view of this, they have reported experiencing heightened reluctance to seek help for substance use issues because they believe that admission of substance use problems would further confirm the authorities' perception of their inadequacies as mothers and the removal of their children from their care (Rutman et al. 2005b).

Behaviour “problems,” comprehension difficulties, and poor capacity to recall or follow abstinence requirements may impede adherence to program rules, resulting in women with FASD facing further obstacles to their participation in treatment services.

Moreover, in addition to experiencing all of the barriers that other women experience when trying to access treatment, women with FASD will also face barriers to accessing care and to participating successfully in programs into which they enter. For women with FASD it is often the case that “what makes them eligible for programs are the same issues that have them terminated” (Debolt 2008, 13). For example, behaviour “problems,” comprehension difficulties, and poor capacity to recall or follow abstinence requirements, may impede adherence to program rules, resulting in women with FASD facing further obstacles to their participation in treatment services.

Susan Opie, a therapist in private practice in Manitoba, says people with FASD face particular

challenges when aiming to access mental health or alcohol and drug treatment services.

“A lot of people with FASD have severe memory impairment and difficulties with executive functioning, following goals and following up on plans,” she says. “All those things have huge implications if you’re providing mental health services.”

Behavioural problems may exclude individuals with FASD from residential or inpatient programs, while learning and cognitive disabilities make it difficult for them to succeed in mental health and addiction programs designed for people without such disabilities, Opie says. ...

Gaps in mental health services can be exacerbated by gaps in supported living. Adults with FASD usually require supported housing, but are excluded from many programs intended for people with developmental disabilities, whose criteria they may not meet. Although most adults with FASD have normal IQs, their other impairments make it difficult for them to live independently. “If they also have significant mental health needs that require additional treatment and follow-up with medication or self-care, it’s very difficult,” says Opie. (Nicholson Winter 2008/09, 3)

If we are not attentive to the dynamics that FASD brings to the substance use treatment setting, then we are missing the full treatment and prevention picture. Service providers at all levels—from front line to management and policy level—need to be informed about the experience and effects of FASD so that programming and individual level responses can attend to women with FASD who use substances.

5. Promising Practices in Relation to Substance Use Treatment and Care

Prior to examining the literature on promising practices in substance use treatment and care, it is important to briefly clarify the terminology in use. *Knowledge for Health*, a Johns Hopkins website designed to facilitate the dissemination of up-to-date health information, describes “promising practices” as a term “often used to indicate practices or approaches that have not been evaluated as rigorously as ‘best practices’, but that still offer ideas about what works best in a given situation.” (Johns Hopkins Bloomberg School of Public Health n.d.). In keeping with the Knowledge for Health conceptualization, in this paper promising practices are understood to be the theoretical frameworks, practices, and approaches underlying good/better practice in the provision of substance use treatment and care for women living with FASD.

While some best practice or promising practice reviews include examples of services or programming currently exemplifying the practice in action, this report presents the underlying approaches and conceptual/theoretical frameworks free from program examples. The intent is to ensure that the promising practices are discernible regardless of changes to particular, existing programs, and the underlying practice remains clearly understandable regardless of familiarity with the program itself.

Of the promising practices presented here, some have been extensively evaluated, while others emerge from the grey literature and stem from program reviews, research, and/or practice-based and experiential knowledge shared through conference presentations. Specifically, in the case of promising practices for women with FASD, the cited promising practices have emerged predominantly from a synthesis of available literature on: a) promising practices for women; and b) promising practices for adults with FASD.

It must be noted that the existing literature on promising practices for substance use treatment for

women far surpasses that which exists in relation to adults with FASD. As discussed previously, the published literature on FASD intervention or support-related programming for adults, and hence, on related promising practices, is still in its infancy. Nevertheless, based on the burgeoning interest and activity in programs, practitioner training and continuing education focusing on adults with FASD, it is anticipated that more published literature from which to extract promising practices will be forthcoming. Until then, the following discussion serves as a starting point to improve programming for women with FASD.

Using a Gender Lens

Much of the currently available information on promising practices and recommended strategies for working with people with FASD focuses on an abstracted or generic gender-neutral person with FASD. While these promising practices are tremendously useful and are an excellent start, the literature indicates that any substance use treatment or FASD prevention approach that does not include a gender lens is fundamentally limited in that it is bound to overlook many of the women-centred considerations pertinent to women with FASD.

Women-centred Prevention, Treatment, and Care

The Network Action Team on FASD Prevention from a Women’s Health Determinants Perspective¹ developed a consensus document based on a range of evidence sources—women’s experiences, current research, published articles, as well as expert evidence—that offers a clear perspective on what

¹ This NAT is one of five Network Action Teams operating as part of the Canada Northwest FASD Research Network, which was created in 2005 as a partnership involving four Canadian provinces (Manitoba, Saskatchewan, Alberta and British Columbia) and all three Canadian territories (Nunavut, Northwest Territories and the Yukon).

needs to be involved in successful FASD prevention/programming from a women's health determinants perspective.

Although not specific to women with FASD, the "fundamental components of FASD prevention" are applicable to all women, therefore offering a solid basis from which to develop promising practices in

substance use treatment programming for women with FASD. While women with FASD may have specific needs in relation to substance use treatment, it is critical to recognize that, first and foremost, they are women.

A summary of this consensus document is highlighted in the following text box.

Consensus on 10 Fundamental Components of FASD Prevention From a Women's Health Determinants Perspective

Respectful Respect is paramount to successful FASD prevention and treatment. It is a vital tool in the elimination of discrimination and stigma in prevention initiatives, and it is pivotal to creating an environment where women can address their health care needs.

Relational Throughout life the process of building relationships and connecting with other people can be extremely important. It is vital to FASD prevention to acknowledge that the process of growth, change, healing, and prevention does not happen in isolation.

Self-determining Women have the right to both determine and lead their own paths of growth and change.

Women-centered Women-centred FASD prevention and care recognizes that, in addition to being inextricably linked to fetal and child health, family health, and community health, women's health is important in and of itself.

Harm-reduction-oriented Preventing FASD involves understanding substance use and addictions, including the full range of patterns of alcohol and other substance use, influences on use, consequences of use, pathways to and from use, and readiness to change.

Trauma-informed Multiple and complex links exist between experiences of violence, experiences of trauma, substance use, addictions, and mental health.

Health promoting Promoting women's health involves attending to how the social determinants of health affect overall health. In the context of FASD prevention, health promotion approaches draw the lens back so that FASD can be understood in its broader context.

Culturally safe Women who seek help from service agencies need to feel respected, safe, and accepted for who they are, with regard to both their cultural identity and personal behaviours.

Supportive of mothering FASD prevention must recognize the importance of supporting women's choices and roles as mothers, as well as the possible short- and long-term influences that a loss of custody may have on a woman.

Uses a disability lens Women with substance use and mental health problems may also have disabilities, including FASD. Women need care and prevention responses that fit with what we know about the spectrum of disabilities related to FASD.

(Network Action Team on FASD Prevention from a Women's Health Determinants Perspective 2010a)

Attending to Women’s Real-Life Context

Time and again, women speak about the reality that substance use and healing do not happen in isolation; they happen within the real life context of women’s lives. And the real life context—the personal, familial, social, political, cultural, and economic context—of women’s lives is as varied as the women themselves.

In a recent study on substance use treatment and support for First Nations and Inuit women, “focus group participants emphasized that no one model will ever address the differences in women’s needs, thus reinforcing, particularly as it relates to mothering and treatment, the need for a continuum of services that attend to mothers’ needs” (Poole et al. 2008, 19). The need to tailor service options to a woman’s particular needs and context was similarly emphasized by Parkes and her colleagues:

One of the main critiques of the studies we reviewed is the lack of explicit attention paid to tailoring alcohol interventions to particular subgroups and subpopulations of women. There is clearly no profile of a woman who drinks in pregnancy that can be used by health care professionals, despite the interest in research that tries to map such risk factors. (Parkes, Poole, Salmon, Greaves, & Urquhart 2008, 62)

The importance of attending to women’s life context cannot be overstated, a point reaffirmed by the current literature review. It extends well beyond the need to offer a range of services and a continuum of care; it also speaks to the need to acknowledge the community that women live in and the other services they may be negotiating (Poole, Gelb, & Trainor 2009, Poole 2000). “The *context* of the lives of girls and women is critically important, as this context determines how girls and women seek services or whether they are able to access services at all” (Poole et al. 2008, 6).

For example, the effect of social stigma and punitive organizational philosophies can deter woman from treatment or diminish their chances of success. In Rutman et al.’s study (2000, iv), research participants “spoke of three major ideological shifts that are critical [in order to] to ensure effective policy and program development. These ideological shifts are:

- from a moralizing/medical model to a harm-reduction/health promotion philosophy;
- from child welfare mandate as protection-focused to one that emphasizes supporting families; and
- from viewing child apprehension as the failure on the mother’s part to a failure of the system/community to provide what is needed.”

In the report *Fetal Alcohol Spectrum Disorder (FASD) Prevention: Canadian Perspectives*, Poole (2008) details how “Canadian prevention specialists have identified four mutually reinforcing prevention approaches as effective in delivering FASD prevention. The four levels of prevention span general and specific practices that assist women to improve their health and the health of their babies, with support from family, support networks, services and community.” In this four-part model of prevention, prevention strategies range from broad community-wide initiative (e.g., community awareness campaigns) to specialized holistic treatment programs. Notably though, all of these levels of prevention are situated within the larger context of women’s lives.

Cultural Safety

Included in the aforementioned “10 Fundamental Components of FASD Prevention from a Women’s Health Determinants Perspective” is the notion of ensuring that programming is culturally safe. In the context of FASD prevention for Aboriginal women, central to promising practices is recognition of the differing roots of Aboriginal women’s drinking (as discussed in Section 3: Women and Substance Use). Accordingly, promising practices need to acknowledge and attend to these factors as best as possible.

When attending to gender and culture, and their interaction, it is important to recognise that there is no generic First Nations woman, or Inuit woman, and therefore no one-size-fits-all answer to what treatment and other systemic responses are needed. Aboriginal women are diverse in many dimensions, as First Nations and Inuit women, in their rural, urban or remote location, in their acculturation and interest in traditional healing approaches, in their identification with

women-centred and family-centred approaches, and many other dimensions. (Poole et al. 2008, 5)

Echoing the idea that there is no generic Indigenous woman, no generic level of acculturation amongst Indigenous women, and thus no one-size-fits-all culturally appropriate response, Salmon (2007a, p.269) emphasizes the importance of “culturally appropriate” FASD-related programming that “creat[es] conditions that enable Aboriginal women to connect with traditional knowledge of their cultures in ways that are meaningful and welcoming *to them*” (emphasis added). Individualized meaning-making processes are important, Salmon (2007a, p.269) suggests, given the reality that many Aboriginal women may feel disconnected from their culture due to “contemporary legacies of state-sponsored activities designed to dismantle Aboriginal cultures, languages, spiritualities, families and social and political institutions.”

In her 2007 report, Chansonneuve states that there is more than sufficient evidence supporting the notion that promising treatment practices for Aboriginal women who use substances is rooted in a “shared understanding of the origins of the addictions epidemic, a multidisciplinary approach to addressing the multiple interrelated factors underlying addictive behaviours, and healing strategies that align with the impacts of residential school abuse” (Chansonneuve 2007, 59). Accordingly, Chansonneuve (2007, 60) goes on to detail 10 characteristics “that define a uniquely Aboriginal approach to addictions prevention and intervention.” These characteristics are summarized as follows:

1. An Aboriginal approach identifies and addresses the underlying causes of addictive behaviours unique to the historical experiences of Aboriginal people in Canada.
2. The wisdom of Aboriginal cultures and spirituality is at the very heart of healing and recovery.
3. The relationship among suffering, resilience, experiential knowledge, and spiritual growth is acknowledged and honoured.
4. The interconnectedness among individuals, families, and communities is strengthened.
5. The differing pace at which individuals, families, and communities move through the stages of healing is understood and respected.

6. Healing encompasses a range of traditional and contemporary activities with an equally valued role for everyone in the circle of care.
7. Community health and community development are inseparable.
8. Culture is healing.
9. Legacy education is healing.
10. Healing is a lifelong journey of growth and change.

Beyond these 10 characteristics, Chansonneuve (2007, 62) reaffirms that for all women, promising practices must “include a range of activities aimed at reducing social isolation, strengthening parenting skills, fostering healthy identity, and teaching children to express emotions in healthy ways.”

Promising Practices for Women with FASD

Fundamental to any promising practice in program development for people with FASD is recognition of the presence of FASD and all of its associated effects. This point relates to and underscores the final element of the 10 Components of FASD Prevention from a Women’s Health Determinants perspective— i.e. the critical importance of using a disability lens in developing and implementing all FASD prevention and support-related activities and programming.

Substance use treatment and care for people with FASD needs to be different... This is in large part due to the primary effects of FASD, including issues such as poor attentional capacity, poor abstract reasoning, short-term memory deficits, impulsivity, and difficulties in reading social cues and with social boundaries.

Although the published literature is still minimal, there is agreement within the existing literature and among professionals that substance use treatment and care for people with FASD needs to be different from that created for and implemented with people

without FASD. This is in large part due to the primary effects of FASD, including issues such as poor attentional capacity, poor abstract reasoning, short-term memory deficits, impulsivity, and difficulties in reading social cues and with social boundaries.

As is discussed in more detail below, promising practices for practitioners and programs working with women with FASD include treatment models that involve strategies such as staff training and support, environmental accommodations, and understanding and respecting that “non-compliance” and “poor follow through” with care plans may not be deliberate or wilful, but instead an effect of FASD.

Mandatory Staff Education and Training on FASD

A core theme that underlies the spectrum of promising practices discussed in the literature is seemingly simple yet profoundly important: it comes down to having a solid base of knowledge about FASD, and keeping this knowledge ever-present in informing all aspects of program design and implementation.

Illustrating the importance of staff knowledge about FASD, Grant et al. (2004, 501) conducted a pilot community intervention for young women with FASD. The pilot “consisted of delivery of the standard PCAP model, enhanced in two ways: (1) by modifying PCAP in order to accommodate enrollment of clients with FASD; (2) by educating community service providers to accommodate clients with FASD.” In order to achieve this education programming, “an FAS expert and author trained staff on the day to day management of individuals with FASD, and facilitated a staffing session on management issues advocates had encountered in working with clients with FASD who were among their PCAP clients” (Grant et al. 2004, 501).

The program demonstrated success with adapted programming: “advocates’ assistance resulted in clients’ increased use of services. By combining education with follow-up hands-on experience, we demystified the FASD disability for the providers, who were then able to deliver services appropriately tailored to the specific needs of FASD patients” (Grant et al. 2004, 507). Similarly, Grant & Whitney

(2007, slide 49) reinforced the value of education in demystifying FASD in their presentation entitled “Working Effectively with Mothers who have Fetal Alcohol Spectrum Disorders: The Parent-Child Assistance Program (PCAP) Experience.” In this presentation, Grant and Whitney presented the simple equation: “Education + Hands-on experience = FASD demystified. Providers learned to deliver services appropriately tailored to specific needs of FASD patients.”

This raises a very important consideration: education and training need to address the ways in which FASD will factor into day-to-day life. Accordingly, practitioners need to be trained in both the behavioural and cognitive components of FASD, and in motivational approaches.

The available, relevant literature thus suggests that all levels of staff need to understand FASD, and all treatment program managers and staff should participate in mandatory training and education on FASD. FASD awareness is critical, since women who may have FASD will rarely self-identify—indeed, chances are, they will not have a diagnosis.

Fundamentally, then, this promising practice underlies all other ones, as practitioners need to understand how and when to start working differently (i.e., to change their own practice and programming) in order to work effectively with the women they are trying to serve.

Removing Stigma and Using Person-First Language

As part of education and training relating to FASD, recognizing, confronting and erasing stigma are critical.

Stigma is a major issue with FASD. A counselor needs to be aware of this stigma and approach the issue carefully and sensitively if he or she suspects a client has an FASD. Given their cognitive, social, and emotional deficits, persons with an FASD may feel powerless to change and stuck with the stigma forever. It is important to work through this issue with clients with an FASD. They need to understand that they are not responsible for their disability and that they deserve respect. They also

need to know that change is possible. (SAMHSA Fetal Alcohol Spectrum Disorders Center for Excellence n.d., Adults)

Using person-first language helps reduce stigma surrounding FASD.

Using person-first language helps reduce stigma surrounding FASD. “A fetal alcohol spectrum disorder may be part of who a person is, but it is not the person’s entire identity. Someone can ‘have fetal alcohol syndrome (FAS)’ but nobody ‘is FAS’” (SAMHSA Fetal Alcohol Spectrum Disorders Center for Excellence n.d., Adults; Dubovsky 2004). Similarly, speaking to the importance of person-first language, Dubovsky (2004) urges us to speak of “a mother with FAS”, not “an FAS mom.” Additionally, at a community level, promoting person-first language helps stigma reduction and FASD awareness more broadly, supporting prevention within the community.

For women with children, the stigma of having FASD is often further exacerbated. The fear and judgement that surrounds women with FASD is a strong silencer, and can create an environment of shame and secrecy around a woman. Thus, fostering non-judgmental attitudes within services (as discussed in the following section on *Using a Relational Approach*) is vital to enabling successful programming:

I was attending a pregnancy program, and one week was about fetal alcohol. I had been tested as a kid and I knew that I was affected by fetal alcohol.... One of the staff in the program asked me if I would speak at a conference. I agreed. ... It was the first time I had actually talked about it. I cried all the way through. I really felt that, because I had come out with it, I was going to lose my kids. That was my biggest concern—they’re going to take my kids. (Rutman et al. 2002, 25)

Using a Comprehensive, Woman-centred Approach

As discussed earlier in this section, recognizing the inter-connectedness of different facets of a woman’s life, and the real life context in which she lives, is paramount to success. Just as there is no

generic woman who uses substances, there is also no generic woman with FASD; she may have a history of trauma and abuse, or she may have been raised in a supportive and safe home environment. Indeed, time and again FASD researchers have emphasized that a hallmark of FASD is the individual differences in abilities and challenges that people with FASD possess (i.e., their specific primary disabilities) as well as their lived experiences and personal histories, giving rise to particular secondary effects and vulnerabilities. Accordingly, in the case of women with FASD we need to look at each situation individually, and we need to tailor interventions specifically to each woman’s needs and circumstances, embracing a comprehensive approach to service provision.

It is crucial to recognize that women with FASD can be, and often are, mothers. Moreover, the woman’s care and health cannot be attended to independent of her life as a mother.

One component of a comprehensive approach involves linking women with a host of services and supports that they may need in different areas of their life. Staff involved with a pilot PCAP program that was adapted to serve women who likely had FASD found that a key focus of the program needed to be on facilitating linkages with other community resources:

In 2001 we undertook the 12-month pilot study reported here with the aims of assessing and better understanding specifically how women with FASD could be helped within the existing framework of PCAP. In consideration of the special cognitive deficits associated with FASD, we realized that to meet the needs of these women we would have to develop specific strategies to increase connection to community services and improve quality of services delivered. (Grant et al. 2004, 501)

Further, lessons learned from this PCAP program included the importance of: a women-only treatment setting; treatment settings that permitted children to stay with women or to visit; and programs that

arranged for post-treatment, transitional housing for women (Grant & Whitney 2007, slide 59).

Using a Relational Approach: Fostering a Trust-based Relationship

Positive, trusting relationships are crucial. The quality of interpersonal relationships may determine whether or not a person remains in an intervention, and may be more important than the concrete services received (Grant et al, 2009).

As indicated in the Consensus document noted above, the literature on treatment, care and healing for women who use substances emphasizes the importance of a relational approach, wherein the relationship and connection between the woman and her service provider(s) is key to fostering growth and change. Further to this point, the Network Action Team on FASD Prevention from a Women's Health perspective published a separate document that speaks to the importance of a relational approach (Network Action Team on FASD Prevention from a Women's Health Determinants Perspective 2010b). In speaking about the critical value of the relationship between the woman and her service/care provider(s), the authors stated:

Women reveal that the support of a caring, respectful, accepting, patient, encouraging, inspiring, and empathetic service provider is pivotal in determining the course of their treatment choices ... Growth-promoting relationships such as this allow women to regain or establish trust in service providers and ultimately result in positive engagement with services. (Network Action Team on FASD Prevention from a Women's Health Determinants Perspective 2010b, 2)

In keeping with this discussion, the emerging literature on support-related interventions for women with FASD has also articulated the importance of a relational approach. For example, the Parent-Child Assistance Program (PCAP) model, which was

developed by University of Washington researchers, implemented in numerous sites across Canada and the US, and specifically modified for women with FASD, is, at its core, a relationally based approach. Therese Grant, one of the architects of the PCAP model, stated in a recent presentation focussing on the use of this model with women who were heavily prenatally exposed to alcohol, that:

Positive, trusting relationships are crucial. The quality of interpersonal relationships may determine whether or not a person remains in an intervention, and may be more important than the concrete services received. [Therefore], don't make promises you can't keep or that are unrealistic, and do uphold promises that you make to clients (Grant et al. 2009, slide 25).

In addition to being a relational approach, the PCAP model adheres to a harm reduction philosophy wherein "the goal is to reduce harmful consequences" of using substances for both the woman and the child, and services providers work to "reinforce every step in the right direction", working with women where they are at in their readiness for change process (Grant et al. 2009, slide 43). Aligned with this, the PCAP model uses motivational interviewing, which can be modified for people with FASD (see section on *Program or Service Accommodations and Modifications*, following).

In Canada, McFarlane and her team in northern Alberta have reported on their use of a PCAP approach, given its efficacy as good practice, with women with FASD at the Lakeland Centre for FASD (McFarlane, Fries, Ring, & Sanregret 2010). Moreover, strategies that were reported to work well at the Lakeland Centre in engaging people with FASD and in fostering positive relationships in the interest of supporting the woman or client to reach her goals, were:

- Building a relationship at the beginning
- Being non-judgemental about the woman's decisions
- Never kicking a woman out of the program

Schrivens, Wilson, White and Marshall (2010) similarly described the importance of relationship and trust building in working in a mentorship-based

parenting program in British Columbia, modeled after PCAP, for Aboriginal mothers who may have FASD themselves. Speaking to the question of “what works” with women with (possible) FASD, Schrivens et al. (2010) reported that a “relationship-based, strengths-based orientation” was good practice for the Aboriginal women in their programs. Along similar lines, Rutman, Hubberstey and Hume’s (2010) evaluation of the BC Key Worker program (a program designed to support families with a child or youth with FASD or similar neuro-developmental conditions) found that Key Workers’ use of relational and family-centred approaches were key to families’ satisfaction with the program, families’ sense of being supported, and other positive outcomes.

Lastly, in describing the promising practices associated with the Manitoba-based FASD Life’s Journey’s programs for adults with FASD, Bennett and Woodward (2010) spoke of the importance of a relational approach. Further, for FASD Life’s Journey’s programs, the service model has been guided by a harm reduction framework; additional components of this model, again congruent with a relational approach, were a strengths-based approach, along with recognition of the lifespan nature of FASD as a disability (Bennett & Woodward 2010).

One-to-One Support

One-to-one care has been identified as a promising practice in that it enables tailored and responsive strategies to suit each woman’s needs as they vary by circumstance and personal development.

Treating adults with an FASD is extremely complex and little has been written about it. However, promising strategies that have been proposed for working with clients with an FASD reflect some of the successful approaches used in advocacy programs, including mentoring and family involvement. Persons with an FASD seem to respond well to mentoring, one-on-one relationships where they feel a personal bond with a person who acts as an advocate. (SAMHSA Fetal Alcohol Spectrum Disorders Center for Excellence n.d., Adults)

One-to-one support helps in the development of trust-based relationships by creating space and

allowing time for interpersonal relationships to grow between the client and the support person. These direct relationships can be nurtured in one-to-one interactions and activities in ways that are very hard to accomplish in group settings. This type of approach also enables flexible and responsive support that can be ideally tailored to each woman’s needs (Middleton, Rumbold, Crowther, & Robinson 2009). This type of tailored approach is also at the crux of the tiered model of supports and services discussed in the *Systems Approach to Substance Use in Canada* report by the National Treatment Strategies Working Group (2008), wherein both one-to-one support and case management support (see following section) were included as useful supports for people with multiple issues and complex needs.

Intensive or Enhanced Case Management

Intensive case management allows a practitioner to be involved in a woman’s situation, following her needs across services. As an approach, it shares important features with a relational approach to care and one-to-one support. A number of FASD researchers and managers involved in program development and delivery have identified intensive or enhanced case management as a promising practice or core component of their service model (May, Miller, Goodhart, Maestas, Buckley et al. 2008; Bennett & Woodward 2010; Grant & Whitney 2007; McFarlane et al. 2010). In these programs, which are geared to people with (suspected) FASD, case management involves:

- Establishing a trusting relationship with the client
- Establishing close and frequent communication with the client (e.g. check-ins and regularly scheduled meetings)
- Developing a care plan based on the client’s goals, strengths and needs
- Providing/facilitating transportation for important appointments
- Liaising with other service providers
- Assisting/supporting the development of life skills and/or the client’s participation in healthy, safe activities
- Establish close communications with supportive significant others in the client’s life

- Advocating for improved communication among service providers, continuity of care, and access to care/services (May et al. 2008; Bennett & Woodward 2010)

Though placed as the final bullet in the list above, researchers, program managers, and service providers have all emphasized the importance of advocacy as a component of case management, since FASD-informed case managers are typically involved in educating other service providers about FASD, and in helping to ensure that women access and receive the services and supports that they need (McFarlane et al. 2010). In addition, Grant and Whitney (2007, slide 55) have noted that a case management approach is particularly valuable in assisting women “secure stable housing” and “a measure of financial stability for the future.”

In keeping with the aforementioned, in their evaluation of an enhanced case management program for high risk women in the Northern Plains States in the US, May et al. (2008) found that case management was:

A key intervention in preventing FASD and also as a major force within the community that provides needed and specific FASD prevention services for those identified as high risk. Furthermore, CM [case management] is a tangible element of commitment to all citizens of the community, especially those with greatest need and who also represent great challenges to local health and social services. ...Since only 2 of 119 children born thus far may have an FASD (2%) substantial medical, educational, and social service costs have been avoided. Our ongoing work has given us clear indications that enhanced CM [case management] can be an efficacious intervention for women at high risk for births of children with an FASD. (May et al. 2008, 757)

Indeed, in reporting positive outcomes associated with this enhanced case management program, May and his colleagues stated:

In addition to the targeted prevention of FASD, other benefits may have been facilitated by the CM [case management] engagement. Additional

reported measures of success include enrolling in school, regaining custody of children, completing substance abuse treatment and probation, maintaining substantially long periods of abstinence, enrolling in programs to improve life skills, and gaining employment. (May et al. 2008, 756)

FASD-informed Accommodations and Program or Practice Modifications

We begin by reframing what we would typically think of as “problematic behaviours,” and recognize that behaviours are often a symptom of the presenting neuropsychological impairment (Boyd et al, 2008).

A number of researchers and practice experts have discussed the importance of implementing a range of environmental accommodations and adjustments within treatment settings and programs. Along these lines, the US Fetal Alcohol Spectrum Disorders Center for Excellence has stated:

The emphasis needs to be on adapting the environment because people [with FASD] cannot change how their brains work. The environment is taken in its broadest sense and includes personal, physical, social, cultural, and institutional components (SAMHSA Fetal Alcohol Spectrum Disorders Center for Excellence n.d., Adults; see also, Nicholson Winter 2008/09).

Similarly, Boyd, Sesk and McCormick (2008) have stressed the need for FASD-informed accommodations, grounded in practitioners’ deep understanding of FASD and their re-interpretation of clients’ “difficult behaviours” in keeping with this knowledge:

We begin by reframing what we would typically think of as “problematic behaviours,” and recognize that behaviours are often a symptom of the presenting neuropsychological impairment. ... As support workers and interventionists, CSG [Community Support Group] volunteers focus

their energies not on the individual but rather on accommodations in the environment that can be made to better address the unique needs of those living with FASD to reduce challenges and improve outcomes. (Boyd, Sesk, & McCormick 2008)

As well as being necessary from a 'best practice perspective', there also is a legal duty to accommodate people with FASD (or with any disability) so that they are enabled to access and use public services. This duty derives from the Canadian Charter of Rights and Freedoms, and the point is increasingly being raised by legal professionals, scholars, disability rights advocates and families (Boulding 2007; Mitten 2005; Rutman, La Berge, & Wheway 2007). Boulding (2007, p.2), a lawyer who has written extensively about his own journey in shifting practice to make appropriate accommodations for clients with FASD, has emphasized:

Because this is a brain-based physical disability, we have a legal duty to accommodate witnesses with FASD. Accommodation takes many forms; a one-size-fits-all approach is not appropriate.

Program modifications could include establishing goals that are realistic, outcome oriented, and time specific.

In addition, the Fetal Alcohol Spectrum Disorders Center for Excellence has offered the following suggestions for program modifications:

- Setting consistent appointment days and times
- Scheduling short, more frequent sessions and limiting the number of meetings
- Ensuring that the physical space for services is not cluttered or distracting
- Arranging for someone to get the client to appointments or meetings
- Limiting the number of treatment plans or steps involved in the treatment plan
- Establishing goals that are realistic, outcome oriented, and time specific
- Talking to the individual and family about their goals

- Breaking steps down and working on one step at a time

Susan Opie (Nicholson Winter 2008/09, 4) has further explained that:

- Treatment must address neurodevelopmental challenges, such as memory and language impairments. Identify and use the client's strengths or interests, such as music or art.
- Clients with FASD may need longer-term supports to avoid reverting to previous behaviours.

Spend part of client time moving, walking, or going outside.

Opie (2008) also suggests that practitioners start to think differently about interventions, and consider the following challenges and suggestions:

- Attention span, distractability – Use movement based activities, objects for fidgeting with, spend part of client time moving, walking, or going outside.
- Utilize tactile strengths – Have soft blanket, plush animal, or other items that client likes to touch (Whale)
- Calming activities, coping skills, mindfulness – May be helpful, client may enjoy learning, [but] May be very difficult for client to utilize when highly distressed
- Utilize activities client enjoys that may be designed for younger developmental age, e.g. calming CDs, playful activities. Be mindful of also teaching appropriate behaviour for chronological age.
- Some clients with FASD will be set with whatever routine was set in initial sessions.
- Some clients with FASD will need a consistent shift of activities to maintain interest.

As another important illustration of how to think differently about key interventions, Grant and colleagues (Grant et al. 2009) and Dubovsky (2009) have written about ways that motivational interviewing can be adapted and used effectively with people with FASD. Motivational interviewing “teaches people to examine their behaviour, think about ways in which they are uncomfortable with what they are

doing, and get motivated to make changes” (Grant et al. 2009, slide 27); the approach typically relies on a person’s having intact receptive language and abstract thinking capabilities—capabilities that are likely impaired with prenatal alcohol exposure. Thus, to modify motivational interviewing when working with people with FASD, Grant et al (2009) and Dubovsky (2009) both recommend service providers being more active in their role in helping the person examine her behaviour, as well as using more closed-ended questions and concrete language, working with the person’s step by step goals and “offering solutions and having the client choose the best option possible” (Grant et al. 2009, slide 28-29).

In addition, Grant and Whitney (2007, slide 51) have emphasized that practitioners should, “Teach generalization: don’t assume a lesson learned in one context will transfer to another”. This point has been emphasized as being key when working with women with FASD.

Ongoing Checks for Comprehension

Due to learning differences and varying levels of comprehension, it is important to check in regularly with a woman with FASD to ensure she understands the information communicated to her. It is then important to follow-up and check in again at a later date to ensure that she still recalls, and understands, the same information.

Women with an FASD may appear to understand when they do not. They can often repeat information without understanding it. It is important to provide consistency and recheck the retention of information often. Ask the client to summarize what you have said. Review written material, such as rules, at each session. Do not assume that the client is familiar with a concept or can apply it because you have reviewed it multiple times. Remember, the only consistent thing about FASD is inconsistency. A client can know something on Monday and forget it on Tuesday. *Repeat, repeat, repeat* [emphasis added]. (SAMHSA Fetal Alcohol Spectrum Disorders Center for Excellence n.d., Adults)

Other researchers and care providers have emphasized similar practices relating to

communication, including:

- Ask the client to demonstrate skills, rather than on their reporting that they do the skill (Grant et al. 2009)
- Assess feeling vocabulary early on; many adults with FASD need to be taught words to discuss emotions (Opie 2008)
- Reviewing what happens at meetings and processing the information (SAMHSA Fetal Alcohol Spectrum Disorders Center for Excellence n.d., Adults)

Thus, checking in regularly and implementing a range of strategies to ensure that the woman both recalls and understands the information communicated to her are key practices for women with FASD.

Screening and Assessment

Finally, in the context of promising practices, FASD screening and assessments can be seen as a double-edged sword. On the positive side, identifying the presence or possibility of FASD in women who may not have had a diagnosis before entering treatment or accessing services can help improve the quality of services and can enable more personalized care. Along these lines, Dubovsky (2004) has noted that the benefits of identification/diagnosis of FASD are that:

- the individual is recognized as having a disability;
- the individual may feel relieved that he/she is not ‘lazy’ or a ‘bad’ person;
- we can focus on why the person is not succeeding in a program and how we can help them succeed; and
- if we recognize FASD, we can improve treatment outcomes.

Similarly, Classen et al. (2008, 1) have stated:

Women seeking treatment for substance abuse may be at a heightened risk of Fetal Alcohol Spectrum Disorder (FASD). By screening to identify women for indicators of FASD at the onset of treatment, a program can provide or arrange specialized interventions that may increase women’s likelihood of achieving abstinence and/or improving their quality of life. (Classen et al. 2008, 1)

Nevertheless, it must be recognized that there are many possible implications and ramifications associated with adult diagnosis, including some which may not be health-promoting for the woman (e.g., a potentially greater possibility of child apprehension due to stigma associated with FASD, or restricted social services or supports). Accordingly, we need to be cautious as to how we are implementing various components of screening and assessment, how screening and assessment is undertaken in relation to other supportive interventions such as substance use treatment and healing-related processes, and how, and for what purpose, the information pertaining to the assessments is used. As an overarching key point in this regard, Parkes et al. (2008) have urged that it is essential that the process of identifying women who use alcohol during pregnancy, (including women who themselves may have FASD), is connected to supportive action for the women.

In many ways, screening and assessments are their own emerging sub-fields, still in their infancy. As discussed in Section 1, conducting FASD assessments and diagnosis for adults is extremely complex, involving difficult, nuanced and highly labour intensive processes.

In terms of screening, the following issues have been raised:

While the need to screen adult populations for FASD is clear, the challenge lies in determining how to screen in an effective, efficient and inexpensive way. Screening and diagnosing adults with FASD is difficult because adults lack the physical stigmata of the disorder and the

behavioural manifestations can vary widely in form and severity. Compounding this problem is the lack of a gold standard for the diagnosis of FASD in children or adults. (Classen et al. 2008, 2)

In terms of FASD assessment, the literature shows that treatment programs and facilities are not typically equipped to have the staffing expertise and resources to do assessments, especially given that assessment is best conceptualized as involving a multi-disciplinary team and as a process that occurs over time. “Counselors need to use developmentally appropriate assessment tools to assist in identifying needs and planning support. The assessment process should identify skills, areas of vulnerability, and stresses” (SAMHSA Fetal Alcohol Spectrum Disorders Center for Excellence n.d., Adults).

Furthermore and most importantly, assessments should be characterized by sensitive, safe, non-judgemental, non-stigmatizing interactions with those doing the screening and intake, along with support and follow-up during and after the screening process. This is particularly important in light of the myriad ramifications that assessment can have for a woman and her children.

Thus, although screening and assessments have been discussed in the literature as comprising elements of promising practice in that they would allow practitioners to know whether a woman may have FASD and also to pave the way for a more individualized treatment plan, we believe that these components of promising practice merit further, careful consideration by researchers and practitioners alike.

6. Discussion and Conclusions

Summary of Findings from the Literature Review

This literature review on substance use treatment and care for women with FASD was one of three components of the *Substance Using Women with FASD and FASD Prevention* project. In reviewing available literature on this topic, it is evident that there is little research that specifically examines substance use, treatment, and care for women with FASD. While there is some available grey literature based on emerging studies and practice wisdom, fundamentally, this body of literature is in a very early stage.

In our attempt to consolidate and expand knowledge regarding effective and appropriate substance use treatment approaches for women living with FASD, we pulled together literature and content from several intersecting areas. Drawing content from research on FASD, women's substance use, women with FASD, barriers to care, and promising practices in substance use treatment and FASD prevention, we created a solid base from which to explore this topic. We emphasized the importance of applying a gender lens to the topic, so as to better understand the distinct needs of *women* living with FASD, as opposed to generically examining the needs of adults with FASD.

We also drew on promising practices in the fields of substance use treatment, and linked them together with promising practices in the care and treatment of women living with FASD.

Promising practices in substance use treatment for women that were identified in this literature review include the following practices:

- Applying a gender lens;
- Offering women-centred prevention, treatment, and care;
- Attending to women's real-life context;

- Applying a women's health determinants perspective; and
- Being culturally safe.

Specific promising practices for programs and practitioners working with women living with FASD were identified as:

- Mandatory staff education and training on FASD;
- Providing a range of environmental accommodations;
- Removing stigma and using person-first language;
- Providing a comprehensive woman-centred approach;
- Using a relational approach (fostering a trust-based relationship);
- Offering one-to-one support;
- Providing intensive or enhanced case management; and
- Considering the benefits and implications of screening and assessment.

These promising practices, generated based on available evidence from the literature, offer a starting point for treatment services.

Synthesis of Findings Across Project Components

The promising practices identified through this literature review are also highly congruent with our findings from the other components of this project, that is, our findings relating to promising practices based on an environmental scan involving BC service providers, and our findings about "what works well" from the perspective of women with FASD.

For example, environmental scan informants stressed the pivotal importance of having everyone involved in planning and delivering substance use treatment

services be fully grounded in knowledge about FASD. Indeed, informants voiced the need for mandatory training in FASD for students, service providers and managers involved in alcohol and drug counselling, clinical counselling, mental health services, social work and child welfare, and other human service professions. Significantly, none of these fields currently have such a knowledge requirement.

Following from this “first principle” recommendation for care providers to have a **strong understanding of FASD**, environmental scan informants identified additional promising approaches and needed program/policy-related shifts, including:

- **Care providers receiving ongoing FASD-focused** education, supervision, mentoring and support
- **Programs making FASD-informed accommodations** to their format and content, and to the physical space in which the programs were delivered
- **Care providers using clear and plain language**, and using accommodations related to communication and memory
- **Programs being grounded in FASD-informed and women-centred** theoretical frameworks that featured:
 - a relational approach;
 - individualized support and case management;
 - gender-specific programming;
 - FASD-specific programming;
 - an outreach and “open door” approach;
 - a harm reduction approach;
 - wholistic and collaborative approaches, attending to women’s needs in various areas of their life; and
 - mothering-informed approaches (i.e., sensitive to the centrality of mothering-related issues and needs within women’s life)

In addition, women with FASD voiced similar ideas in terms of the approaches and programs that had worked well for them, emphasizing the importance of:

- **being ready for change**, and thus, working with women where they were at, which often was linked to a desire to be involved in their children’s care;

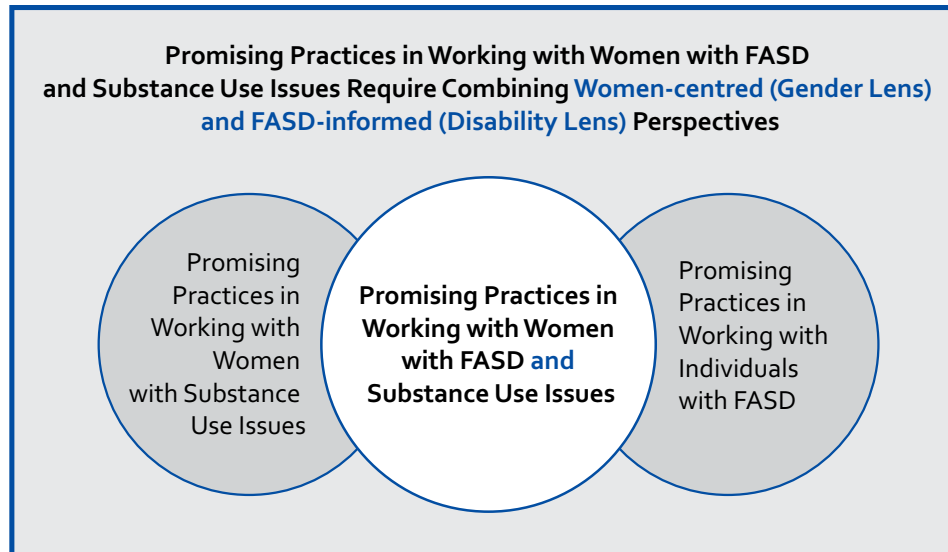
- **a relational approach** wherein women had an honest relationship with a counsellor/service provider/group facilitator that was grounded in trust and safety;
- **wholistic, coordinated supports**;
- **one-to-one care from a skilled professional** (e.g., counsellor or physician), **combined with women-centred, group-based support and information exchange**;
- **peer-based support**;
- **linkages with FASD-related programs/ organizations**;
- **supportive housing for women**, especially that informed by an FASD-lens; and
- **flexibility** in extending a program’s duration and longer-term programs.

In many respects, this project’s findings regarding promising approaches in substance use treatment and care for women with FASD closely parallels the existing body of knowledge surrounding promising practices in substance use care for women overall. Given these findings, it may be easy to overlook the knowledge generated through the project that speaks specifically to its FASD focus.

However, a key message of this project is the critical importance of **marrying what is known about promising practices for women with what is known about promising practices for adults with FASD**, and ensuring that all programming is developed and delivered based on both women-centred and FASD lenses. This message is depicted in graphic form in the following figure.

Without FASD-informed accommodations, even women-centred approaches to group programming likely will not work well for women with FASD.

As an illustration of this message and based on synthesizing information from all three project components, this project found that if group-based programming or support is to work well for women with FASD, it needs to be provided by a facilitator who has a deep understanding of the types of issues



that women with FASD may have experienced. Additionally, it must be delivered in ways that attend to women’s multi-faceted and yet individual needs—including their particular communication needs, (e.g., for concrete language and use of physical objects in describing their emotions or life stories), and needs in relation to the timing and timeframe of the program (e.g., need for reminder calls and/or transportation to enable program access, need for flexibility in terms of lateness or missing sessions, need for options to extend the duration of the program, etc.), physical setting of the program (e.g., need for a calming physical space), linkages to other programs as well as advocacy and support in accessing these resources, and ongoing one-to-one support from a care provider/care manager. Without FASD-informed, skilled facilitation and FASD-related accommodations to the group—accommodations that necessitate additional staffing and resourcing of the groups—even women-centred approaches to group programming likely will not work well for women with FASD.

As a second example, we learned from the interviews with women with FASD that being ready to make changes in their life was key to their process of reducing or quitting using drugs or alcohol, and readiness also influenced their having a good experience with services. In tandem with this, we learned from the literature that a readiness for change approach was a promising approach with women

with FASD. However, in using this approach, it was important to make FASD-informed accommodations, including having care providers be more active in helping the woman examine her behaviour, as well as using more concrete language and breaking the woman’s goals into small, discrete steps. Thus, care providers’ use of motivational interviewing techniques, albeit practiced in keeping with FASD-informed adaptations, is recommended.

Moreover, since women with FASD do not necessarily disclose that they have FASD due to stigma and/or lack of a diagnosis or self-understanding regarding FASD, women who have been prenatally exposed to alcohol may not be able to articulate their needs or name FASD-focused or FASD-informed services as ones that have been helpful to them. For this reason, skilled care providers or mentors who are highly knowledgeable about FASD and who bring this knowledge into their practice are best able to be successful in working with women who have FASD. Policy makers’ and care providers’ application of a “goodness of fit” approach in tailoring the way they work to the needs of women with FASD is a key component of wise practice and better programming (Malbin, 2002).

Without doubt, additional research is needed to further inform suitable treatment and care programming. There is a serious need for service providers, program developers, and managers to

truly understand FASD, and ideally have experience working with people who live with FASD. Moreover, there is a driving need for greater understanding and awareness about FASD and its implications, so that we can better attend to the needs of women with FASD who use substances, improve our treatment services, and inform prevention initiatives.

Conclusions and Directions for Change

By way of conclusion and based on a synthesis of key promising approaches identified through this project, we offer the following directions for practice, programming and policy action. A summary of these directions for change is also presented in the table following.

1. As a starting point, training about FASD should be mandatory for all involved in alcohol and drug counseling, clinical counseling, social work, child and youth care, mental health, and other related health and social care professions. Training and education should focus on behaviours and characteristics associated with FASD, and should actively and respectfully involve those living with FASD.
 2. Training about FASD must be attuned to potential triggers associated with the training and have capacity to address training participants' learning and support needs.
 3. In addition, care providers involved in serving women who may have FASD need to be provided with *ongoing* FASD-focused education, supervision, mentoring and support in recognition of the intensive and taxing nature of the work, and in order to attend to workers' professional development and support needs.
 4. In working with women with FASD, care providers must have clear understanding of each woman's life circumstances and her social and cultural context, including:
 - Her readiness for change;
 - Her needs in relation to cultural identity and connectedness;
 5. Her needs and issues as a mother—and potentially as a mother of a substance-exposed child—including issues of shame, guilt, grief, and involvement with the child protection system;
 - Her needs in relation to communication, memory, and cognition;
 - Her needs in relation to safe housing, income and food security, health, mental well-being and social support; and
 - Barriers she may have faced in accessing or participating in services.
5. Substance use treatment programs and care serving women need to be designed and implemented using both *FASD-informed* and *women-centred* theoretical frameworks, featuring, in particular:
- a relational approach;
 - one to one support and care management, combined with group-based support;
 - gender-specific and mothering-informed programming;
 - FASD-specific programming; and
 - wholistic, collaborative and culturally safe approaches.

It is the braiding together of the FASD-lens and the gender-lens that gives rise to promising and appropriate approaches for women who have FASD.

6. In keeping with FASD-informed practice, care providers need to: ensure their use of clear and concrete language; pay attention to communication pace; break goal setting and other activities into small, do-able steps; and continually check to ensure women's comprehension.
7. In keeping with FASD-informed approaches, programs need to make accommodations to their format, content, and physical space, including:
 - Sensory aspects of the environment such as reducing noise level and visual clutter
 - Consistency in time of day; length of time per session to prevent fatigue or hunger.
8. In keeping with FASD-informed and women-centred approaches, there needs to be enhanced availability of family-accessible treatment programs and/or resources available for child care to enable women's participation in programming.

Directions for Practice and Policy Change to Improve Substance Use Treatment and Care for Women with FASD

| Area of Change | Examples |
|--|---|
| FASD Training and Education | <ul style="list-style-type: none"> ■ Service provider education and training ■ Use of “person-first” language ■ Reframing women’s “problem” behaviours and care providers’ expectations |
| Individual Tailoring | <ul style="list-style-type: none"> ■ Assess readiness for change and work where women are at ■ Attend to each woman’s life circumstances ■ Attend to cultural identity and connectedness ■ Attend to mothering-related needs ■ One-to-one support and care (combined with group programming) |
| Practice Accommodations | <ul style="list-style-type: none"> ■ Communication accommodations (e.g., concrete language; concrete objects to represent feelings or goals) ■ Adapting motivational interviewing techniques ■ Adapting history-writing or goal-setting activities |
| Program and Environmental Accommodations | <ul style="list-style-type: none"> ■ Reminder calls and transportation assistance ■ Consistency in program timing ■ Flexibility for late arrivals or missed appointments ■ Extended timeframes for program duration ■ Flexibility and/or adaptations in group programming and process ■ Reducing noise levels or visual clutter |
| Wholistic, Collaborative Programming and Advocacy | <ul style="list-style-type: none"> ■ Peer-based support and/or mentoring ■ Intensive case management ■ Supportive housing ■ Collaborating with child welfare services to address issues related to child protection |
| Service Provider Support | <ul style="list-style-type: none"> ■ Skilled supervision ■ Smaller case loads ■ Additional staffing |

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Substance Using Women with FASD and FASD Prevention

**A Literature Review on Promising
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Treatment and Care for Women
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prepared by Karen Gelb and
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