

Substance Using Women with FASD and FASD Prevention



**Voices of Women with FASD: Promising
Approaches in Substance Use Treatment and
Care for Women with FASD**

prepared by 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.

Voices of Women with FASD: Promising Approaches in Substance Use Treatment and Care is the report emerging from the community-based interviews with women.

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

- *A Literature Review on Promising Approaches in Substance Use Treatment and Care for Women with FASD*, and
- *Service Providers’ Perspectives on Promising Approaches in Substance Use Treatment and Care for Women with FASD*.

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ISBN 978-1-55058-440-0

Citation

Rutman, D. (2011). *Substance Using Women with FASD and FASD Prevention. Voices of Women with FASD: Promising Approaches in Substance Use Treatment and Care*. Victoria, BC: University of Victoria.

Cover photograph by Nick Kenrick

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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 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, *Voices of Women with FASD: Promising Approaches in Substance Use Treatment and Care*, emerges from the third component of the project. Separate reports based on findings from the project's literature review and from the project's environmental scan with BC service providers also have been produced; each report concludes with a brief synthesis of the findings from all 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 included: the University of Victoria School of Social Work; the BC Centre of Excellence for Women's Health; the Aurora Centre; 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.

Acknowledgements are also gratefully offered to the community research team, Lauren Casey, Tracey Fawkes and Barbara Smith, who organized and carried out many of the interviews with women. As well, heartfelt thanks are given to the following report reviewers who provided extremely useful feedback on earlier drafts of this report: Janet Christie, Karen Gelb, Liza Miles, Tasnim Nathoo, Tracy Pawson, Betty Poag and Hanna Schrivens.

Lastly, we respectfully thank the women interviewed for this project who shared their time and insights with us. We honour your wisdom about what has worked well for you, and greatly appreciate your sharing your knowledge to help improve the lives of other women.

1. Introduction

Fetal Alcohol Spectrum Disorder (FASD) is the term widely used to describe a range of conditions and harms emerging from prenatal exposure to alcohol. FASD is an invisible and lifelong disability. It gives rise to substantial physiological, cognitive, behavioural and social difficulties, although the effects of FASD vary considerably amongst those living with the disorder.

Currently, we do not have conclusive evidence regarding the likelihood that people who have 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). 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 possible reality of substance use for women with FASD, in conjunction with likely sexual activity, there is a strong risk that women with FASD may use alcohol or drugs while pregnant. Thus, from the perspective of FASD prevention, women with FASD need to be viewed as a group warranting particular attention.

As well as being at high risk of having problem 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 “very challenging” to work with and have “poorer outcomes.”

From the perspective of FASD prevention, women with FASD need to be viewed as a group warranting particular attention.

Despite this, relatively little is known about women with FASD and their experiences in relation to substance use, in their attempts to access care related

to their substance use, and in terms of what is good practice and promising substance use treatment programming for women with FASD. This project aimed to address this gap in knowledge.

Background

About FASD

Technically, FASD itself is not a diagnostic term, but rather the umbrella term under which several formal diagnoses are classified, including Fetal Alcohol Syndrome (FAS), partial FAS (p-FAS) and Alcohol-related Neuro-developmental Disorder (ARND) (Chudley, Conry, Cook, Looock, Rosales et al. 2005; Poole 2008).

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 are visible at birth, the range of social and behavioural characteristics associated with FASD often only become visible as a child develops.

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).

Primary effects associated with FASD include “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, Smylie & Hapke, 2008, 2). They also include challenges with memory, conceptualization, abstracting, and linking concepts (Clarren 2004; Umlah & Grant 2003; Grant, Huggins, Connor, Pedersen, Whitney et al. 2004). In addition, Rutman, La Berge, & Wheway (2005, 3) explain that people 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. As well, 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. 2005).

Additionally, the primary effects of FASD also include a range of social and emotional challenges such as “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 et al 2005, 3).

As a result of these primary effects, people with FASD are at high risk of serious secondary problems, such as: having mental health issues including clinical depression; getting into trouble with the law; misusing alcohol or other drugs; not finishing high school (due to dropping out or getting expelled); being victimized or being vulnerable to abuse; and having difficulties with employment. These social, behavioural, and psychological challenges are all understood to be *secondary* effects of FASD. All of these primary and secondary effects of FASD interconnect with one another, and consequently have significant implications in day-to-day life, safety, survival, and capacity to thrive.

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

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. 2005, 2). The invisibility of FASD contributes to the numerous social and systemic challenges and 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.

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 2009). While studies in this area are still in their early stages, 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.

Project Objectives

Without knowledge about good practice for the individual and about the collective needs of women with FASD, it is very difficult to offer tailored and responsive services that provide effective prevention and treatment. Thus, 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.

In view of its aims and components, this project may be viewed as lying at the intersection of FASD prevention and supportive interventions for women with FASD.

2. Research Process

In keeping with research exploring people's lived experiences, this component of the project employed a qualitative research design (Barnsley & Ellis, 1992).

Face to face interviews were conducted with 13 substance-using women who had or were suspected of having FASD. The interviews took place in four communities in BC: a medium sized city on Vancouver Island, a small city on Vancouver Island, a medium sized city in the BC Interior, and a medium sized city in Northern BC.

Participants

In keeping with a number of qualitative methodologies, purposeful sampling techniques were used for this component of the project, wherein “information-rich cases” were selected as the focus of in-depth study (Morse, 1994; Sandelowski, 1986).

Eligibility criteria for participation in the interviews, developed collaboratively by the project team and Advisory Committee, were that participants were women who:

- had a substance use problem, *or*
- were birth mothers of a substance-exposed child or were at high risk of having a substance-exposed child, *and*
 - self-reported having been prenatally exposed to alcohol or that their birth mother had alcohol use problems, *or*
 - were assessed/diagnosed and/or self-identified as having FASD, *or*
 - were raised by someone other than their birth parents, *and*
 - were identified by service providers or support people as having behaviours or characteristics in keeping with FASD.

Our project advisors—in particular, those who were managers or staff of programs and organizations serving women with substance use problems—provided key assistance in identifying a potential sample of interview participants. The women identified were participants of FASD-related projects or programs serving women with current or past substance use issues.

As another strategy for identifying and recruiting interview participants, staff of a community-based action research project working with sex workers with FASD in several communities in BC were engaged as research assistants for this project. These researchers invited several of the participants of their action research project who met the above criteria to take part in an interview for this project.

In keeping with other studies focusing on issues for adults living with FASD, we did not require women to have had a diagnosis/assessment of FASD as a criterion for their participation in an interview. This is because the majority of adults living with FASD have not had a formal diagnosis. To ignore those who lack a diagnosis would be to further marginalize and dismiss the experiences of those living with FASD.

Nevertheless, during the timeframe of this project, two of the interview participants in fact were involved as clients of an adult FASD diagnostic clinic. One woman received a diagnosis of Alcohol-Related Neurodevelopmental Disorder (ARND), and the other woman received a diagnosis of partial-Fetal Alcohol Syndrome (p-FAS). A third interview participant attempted but was not able to obtain an FASD assessment because the woman's mother was deceased and maternal confirmation of alcohol consumption could not be confirmed; nevertheless, she was viewed as having “suspected FASD” by the FASD-focused organization that referred her to this research project.

In addition, all prospective participants needed to either self-report having been prenatally exposed to alcohol, self-identify as having FASD, or identify with receiving services or care related to adults or families living with FASD. Further, service providers who were knowledgeable about FASD and who worked with the women indicated that they displayed behaviours in keeping with FASD, including impulsivity, problems with memory or comprehension, social vulnerability, and difficulties with adaptive functioning.

The 13 women participating in the interviews ranged in age from their mid 20s to their early 50s; more specifically:

- 2 were in their 20s;
- 7 were in their 30s;
- 2 were in their 40s; and
- 2 were in their 50s.

Four of the women identified as being of Aboriginal heritage, and nine women were Caucasian.

Interview Focus and Process

Potential participants were told that the interview would focus on their experiences in accessing and receiving services, support, and care particularly (but not necessarily exclusively) in relation to substance use.

The interviews used a semi-structured format involving open-ended questions. The interviews were carried out as guided conversations, using a general

interview guide (Patton, 1990). The development of the questions was guided in part by our project advisors/partners. Interview questions focussed on:

- women's life "story" from their own perspective, including their family and their involvement in raising their children, their current living situation, and the things they liked to do;
- women's use of and/or difficulties with drugs or alcohol;
- women's experiences in getting help—or their decisions not to try to get help—in dealing with alcohol or drug use;
- women's positive experiences in substance use treatment and care, and/or what had worked well and/or been helpful in relation to problem alcohol or drug use;
- what hadn't worked well;
- what would help improve substance use treatment programs and care; and
- any other areas in the women's life in which they needed help or support.

A copy of the Interview Guide for informants is provided in Appendix A.

Interviews with the women were conducted during spring through fall, 2008. Interviews ranged from 30-90 minutes in duration, though most were approximately 30-60 minutes. Interviews took place either in the women's homes or in a private location of the woman's choice. In adherence with ethical protocols, informants completed an informed consent process and consent form prior to taking part in the interview.

3. Findings

Women’s Lives: Situating Substance Use and ‘What Helps’

Women as Mothers

Twelve of the 13 women interviewed for this project were mothers. Beyond this common experience, however, there was variability: the women’s number of children and the children’s ages varied considerably (e.g., four of the women had one child; three women had five children; several women had toddlers; and one woman’s children were all grown, although she was actively involved in the day to day care of her grandchildren).

Similarly, the health, developmental and behavioural issues experienced by the women’s children varied. Although some women’s children were healthy and “typical” from a neuro-developmental perspective, a number of women had at least one child who had a disability requiring special and often complex care. For example, several of the women reported that at least one of their children had either FASD, NAS or another neuro-developmental disability such as Autism Spectrum Disorder or Tourette Syndrome.

All of the mothers interviewed for this project had involvement with child welfare authorities, and all had their child or children removed from their care for at least some period of time. Many women had attempted to, or were in the process of trying to, regain custody or improve their access to at least one of their children. However, the degree to which the women were raising and/or were in contact with their children varied—both across the sample of women and within an individual woman’s family of children. At the time of the interviews, six of the 12 mothers interviewed were caring for at least one of their children.

All of the mothers interviewed for this project had involvement with child welfare authorities, and all had their child or children removed from their care for at least some period of time.

At the same time, several women had complex relationships with their children— relationships that the women negotiated amidst other stressful issues and dynamics in their life:

[After having two children,] I had two more kids. All were removed. I got heavy into drugs and crime. I’m clean now and have a baby. Some of my kids visit me; my daughter won’t speak to me. ...I live with my baby and my oldest son—he gives me a bit of a worry. I have a restraining order on my baby’s father. He drinks all the time. I just moved into low rental housing, and now I might get kicked out because of him.

Overall, however, it was apparent in the women’s stories that their roles, work, and relationships as mothers were central to their self-identities and a predominant force in their life journeys, regardless of whether their child(ren) were currently in their care.

Women’s Experience of Abuse, Trauma, and Related Mental Health Issues

Nine of the 13 women interviewed for this project shared information indicating that they were survivors of abuse, violence and/or trauma. (It should be noted, however, that women were not expressly asked whether they had these types of experiences; thus, it is possible that other participants were violence or trauma survivors but did not volunteer this information as part of the interview.)

The women shared information relating to violence, abuse or trauma in response to an open-ended invitation to talk about themselves (“tell their story”) at the beginning of the interview and/or as part of talking about their living situation or their needs in broad areas of their life. For some women, mention of violence, abuse and/or trauma came about in speaking about their family and childhood experiences; others spoke of abusive or violent relationships with a former partner; and for others, the experience of violence or trauma was noted in conjunction with their many years of survival sex work and life on the street. At the same time, violence and abuse were likely part of many of the women’s experiences in both their childhood and adult life. As one woman stated:

Had the Ministry [of Children and Family Development] done their job, I may not have spent 30 years out there. I never was able to access services as a kid. I’m now five years clean and sober. I’m a survivor of sexual abuse—was a sex worker for 30 years.

In addition, all 13 of the women interviewed for this project reported having serious mental ill-health issues, including depression and post-traumatic stress disorder, which they linked to abuse experienced in childhood or as an adult, residential school experiences and related disconnection from family, community and culture, and/or to violence associated with sex work or living on the street.

Moreover, many of the women made connections between their experiences of violence, abuse and other issues that triggered their mental ill-health and their heavy substance use. That is, they used substances and ultimately experienced substance use problems as a means to self-medicate and to numb or mitigate pain.

“They wanted to go back to foster care and that hurt me. I ended up relapsing so badly that I died a couple of times. Slept in instant bank places, whatever.”
-Interview Informant

Further, several women described how the removal of their children by child welfare authorities and/or the return of their children without adequate supports, triggered feelings of rage, depression, and hopelessness that in turn led to their increased substance use.

I hardly raised them. They were all taken away from me. I got clean for two years. They were going up for adoption and I fought for them. I got them all back at once. I was living in a bachelor apartment. I couldn’t get any support for shoes, clothes or living. They wanted to go back to foster care and that hurt me. I ended up relapsing so badly that I died a couple of times. Slept in instant bank places, whatever.

Women’s Self-Identification as Having FASD

Ten of the 13 women shared information about their mother drinking heavily in pregnancy or their family’s generational substance use. Four of these women also volunteered that they thought that they had FASD themselves, even though they had not been formally assessed or diagnosed. For example, one woman said:

I grew up with my mom and she drank a lot. She drank with all of us when she was pregnant, and that was a big issue. ...I was always told I had severe learning disabilities. I didn’t know why, and I think that that (having FASD) was part of my struggle.

Similarly, another woman shared that she believed she had FASD. For this woman, self-identification was based on her experience of hallmark characteristics and behaviours associated with FASD, which she learned about as a result of her children having had a formal assessment for FASD and her “reading everything she could” about FASD as a follow-up to the assessment, coupled with her knowledge of her mother’s heavy consumption of alcohol during pregnancy. She said of her own experiences with services:

I couldn’t get anyone to understand my needs. ... We’re misunderstood a lot for how we behave.

Nevertheless, it must be noted that *none of the women interviewed volunteered information regarding having been formally assessed or diagnosed*. This was the case even though service providers on the project's Advisory Committee had knowledge that several participants had in fact been assessed as having FASD.

Context for Women's Substance Use

In the course of sharing information about themselves (e.g., initially telling their story, talking about their family, their living situation, and so on) as well as their use of and difficulties with drugs or alcohol, the women provided an important context for their substance use. A discussion of several overall themes follows, although it is also important to emphasize that the specific context for each woman's substance use and her individual healing path was as unique as the women themselves.

As noted above, a strong theme in women's discussion of their substance use and what gave rise to problematic substance use was their feelings of depression, loss and disconnection. For example, one woman talked about how moving from a community in which she felt socially, physically and spiritually connected to another community in which she felt disconnected and isolated "brought her soul down" and led to heavy alcohol use.

I wasn't prepared for [that community]. It brought my soul down. I need ocean. And alcohol became heavier, and I started to lose my identity and family.

A strong theme in women's discussion of their substance use and what gave rise to problematic substance use was their feelings of depression, loss and disconnection.

This woman also linked her ongoing substance use to trauma related to residential school experiences:

Residential was part of that in my life also. I found out later, when I did treatment, that that was, at core, why the behaviour continued.

Another theme in several women's interviews was that alcohol and drug use was "what everyone did" and thus was viewed as normal within the women's families and communities. These women's substance use began in their early teens or earlier, and they reported being introduced to alcohol and drugs at a young age by family members.

I started drinking at 14. My dad was a big drinker. I never thought there anything was wrong with drinking. My mom was partying with my dad and drank while she was pregnant. I believe I am affected with FASD, although I've never had an official diagnosis.

Women commented that they didn't realize their substance use was problematic until they were pregnant or parenting, and/or when they fell within the radar of service providers or child welfare authorities.

A few of these women also spent parts of their childhood living in foster care and/or on the street, and abuse and trauma were inter-mingled with these experiences. Moreover, women commented that they didn't realize their substance use was problematic until they were pregnant or parenting, and/or when they fell within the radar of service providers or child welfare authorities. In the words of one woman:

My family was abusive. My mom was in the closet about her drinking—lots of denial. By the time I was 14, I was on the street. Got into drugs at 12 when my grandma died. I had my first drink at 3 years old. Went into foster home at 16. I was always drinking. ...Then I got introduced to cocaine, which let me drink more. I never thought about it—no one ever told me to stop—until I started having my kids.

An additional theme relating to the context of women's substance use was the influence of the woman's partner in her use. For example, several women stated that their partner had introduced them to a particular drug (e.g., cocaine, heroin, crystal

methamphetamine), which led to their addiction or problematic substance use.

Alcohol didn't come into my life until I was 21, but marijuana was age 11, and coke came into my life two years ago. And that was with a spouse that introduced me to it.

Women also shared stories of how their partner's lack of support for their efforts to obtain services, or conversely a partner's commitment to quitting, made a difference in the women's own efforts to get or stay clean.

When I first tried to get straight, my ex-husband hemmed and hawed. My ex-husband wouldn't take time off work to look after the kids. ...One year later, I went into treatment. They said, "Don't hook up with someone when you're finished." I did and got into trouble. I lost my kids.

Women's Needs

Toward the end of each interview, following discussion of their positive and negative experiences in accessing services related to problem substance use, women were asked whether there were other areas in their life in which they needed help. Themes emerging from their answers to this question follow (listed in order of the strength of the theme) and are presented in this section of the findings in order to provide additional contextual information about the women's life experiences, day-to-day struggles, substance use and healing.

- **Affordable, safe and/or supported housing** was identified most frequently as an ongoing need for interview participants. Along these lines, women spoke about their safety concerns for themselves and their children in their current housing.
- **Income** was named as a pressing need by more than half of the women interviewed. Many noted that they needed additional income given the high costs of raising children. As well, one woman added that she needed help in managing money, since she struggled with "spending whatever money [she] had, which [wasn't] much".
- **Mothering-related support** needs were identified by many participants, including the need for assistance with: advocating for their

children, especially in terms of accessing resources; understanding the needs of their children, particularly those with neuro-developmental disabilities; finding and being able to pay for quality child care; accessing respite care; and having mentoring and peer support in relation to caring for children and/or dealing with mothering-related grief and loss issues.

- **Greater availability of mental health and trauma-related services and counseling** was another strong theme in women's discussions of their needs. Several women identified that they wished they had more time with an existing counselor, while another woman reported wanting to access care for "some past traumas, some situations ranging from when I was little to past abusive relationships that I've never actually dealt with."
- **Employment readiness, job search, and life skills** assistance were named as needs by several women.

In sum, most women had needs for assistance in multiple areas of their life, and they described their needs in ways that reflected these inter-connections. In women's words:

I need help!! I need my support group back. I need continued respite. I have a bus pass. Housing is always an issue—I can't afford to pay so I'm stuck in this low-rental bad news neighbourhood.

I need permanent housing and finances to raise children. I need help with providing my son with medication. I would like more help with parenting. I would like help obtaining employment.

I need food in my fridge because my kid is giving our food to the homeless. ...There's always something that comes up that I need help with: parenting two boys with FASD, not to mention my own stuff, is extremely challenging. ...I'm going to need help with advocating, for others and for myself. I need individual help with the education system badly.

Good Experiences in Receiving Service or Care Related to Substance Use

All of the women participating in an interview for this project identified at least one good experience that they had had in receiving support or care related to their substance use. Some women described a program or programs in which they participated; others talked about the care or support they received from a health care provider or counsellor; and others discussed support they received from family, their partner, or peers.

Notably, a number of the programs reported to have been helpful were not actual substance use treatment programs. Rather, they were mothering or personal development/employability programs guided by a holistic philosophy that recognized that women seeking support often had multiple issues that needed to be addressed in an integrated way.

Overall, key themes in women's discussion of their positive experiences in relation to substance use treatment and care included:

- **Readiness for change** is crucial; thus, *immediacy of support* is important
- **Relational approach** is key; having an *honest* relationship with a counsellor/service provider/group facilitator that is grounded in *trust, safety, non-judgement and steadfast commitment* is foundational to change
- **Wholistic, coordinated supports** are most useful
- **One-to-one care** from a skilled professional (e.g., counsellor or physician) is important, *combined with women-centred, group-based support and information exchange*
- **Peer-based support** is important, wherein mentors and peers have empathy or lived experience of the women's issues

- **Linkages with FASD-related programs/ organizations** and/or with *service providers who are knowledgeable about FASD* is very important
- **Supportive housing for women**, especially that which is *informed by an FASD-lens*, is central to helping women take steps toward healing and change
- **Flexibility in extending a program's duration and longer-term programs** are helpful (e.g., 6 months or more); similarly, regular sessions with a support worker/counsellor is important (e.g., weekly or bi-weekly)
- Support from family and/or partner

Additional discussion of these themes follows.

Readiness for Change

In speaking about positive experiences, nearly all of the women interviewed emphasized the importance of being ready to make a change in their life in relation to their substance use. Indeed, several indicated that once they decided that they were ready to reduce or quit drinking or using drugs, then their experience in accessing care was positive and successful. In women's words:

For myself, I feel that you have to be ready. You have to be ready. And if you're not ready for it, it's a waste of people's time and your time. Because you just get to the point where you need to do something. Court orders just don't do it.

Once I knew I wanted to quit, it wasn't so hard. I went to alcohol and drug programs. I was in a group and saw a counsellor one on one. It was good.

Further to this, from women's perspective, their readiness for change was what differentiated their successful experiences in reducing or quitting their drinking or drug use from their previous, less positive experiences with treatment or other types of programs.

Regarding my drinking, it was me that was difficult: "I did not have a problem". I drank, I got drunk, I fell down—I had no problem. ...For me, there were things out there, but always in the background. I had no idea that what I was doing

was hurting myself and others. Once I decided to get help, there was help available. I got into a recovery house right away. I kept close to [my] drug and alcohol counsellors.

From women’s perspective, their readiness for change was what differentiated their successful experiences in reducing or quitting their drinking or drug use from their previous, less positive experiences with treatment or other types of programs.

Moreover, two women reported that once they decided that they were ready and motivated to quit using, they stopped or cut back through their own efforts and without participating in formal substance use treatment programming.

I found out I was pregnant. From there I just did it myself. I’ve seen kids taken away, and I wasn’t going to get that.

Readiness for change linked to pregnancy or mothering—wanting to be involved in child(ren)’s care.

As illustrated by the preceding quote, for the majority of the women participating in interviews for this project, readiness for change and for reducing their substance use was related to their life and role as a mother. For some, pregnancy and the desire for their baby’s good health triggered their realization that they were ready to quit using. Along these lines, several women stated that prior to their pregnancy, they weren’t ready to address their substance use issues; once they learned they were pregnant, however, they knew they wanted their life to change. Participants stated:

I couldn’t stop—I didn’t want to stop. Well, I did, but I didn’t know how to want to stop. I knew people cared about me, but what can they do? If I won’t show up or try—it has to come from within. Getting pregnant was a huge reason why I quit.

Not great experiences with getting help? I looked into stuff but I never did it because I wasn’t ready until I found out I was pregnant.

Several other participants stated that their desire to ensure the safety of their child(ren) or their hope to keep custody and/or stay involved in their child(ren)’s care prompted them to want to change and to seek help in reducing their drinking or drug use. Women also believed that unless they quit or reduced their substance use, they likely would have their child(ren) removed by authorities.

Once my children were taken away, I was in fear for their safety. That’s when I started to buckle down.

The program, the day program that my social worker is forcing me to do, it’s called Elements. ‘Cause I’d never actually completed anything. I think [it’s] really helped me. You know, the first month or two, it’s a little hard, it’s kind of hard to grasp. But my focus has always been my, getting custody of my son back. So that’s, that was kind of an incentive in a way.

Finally, several women’s comments illustrated understanding of ramifications of the concept of “readiness” in terms of resource allocation and effective approaches in working with women. Specifically, programs and care needed to be readily available and easily accessible, and care providers were urged to work with women “where they were at”, in their individual place of change.

Relational Approach, Emphasizing Non-Judgement, Trust, Safety, and Hope

A strong theme in the women’s discussion of their positive experiences in accessing treatment and care had to do with the importance of having a respectful, honest and trusting relationship with a care provider, such as a counsellor, doctor or program/group facilitator. Indeed, for many of the women, this relationship with a trusted support person or service provider was the anchor on which everything else rested in terms of programming and was more important than their program having a particular focus.

For many women, their relationship with a trusted support person or service provider is the anchor on which everything else rests in terms of programming and is more important than their program having a particular focus.

Further to this, some women commented that they sought to make changes in their life in part because of the inspiration or commitments they felt, based on their relationship with this person or group. Women also noted that having someone express confidence that they could be successful in making changes in their life and in reducing or quitting their substance use meant a great deal to them and strengthened their own self-confidence and sense of self-worth.

I was lucky to have met some people who believed in me.

He had faith in me. I kept screwing up, but he kept supporting me. Even though he was tough, I have a lot of respect for him.

PEERS¹ respected me; I felt self-esteem. As a result, I worked really hard to please them.

Along these lines, two women specifically highlighted the positive relationship they had with their Ministry of Children and Family Development social worker, who they identified as a support person whose confidence in them boosted their motivation to stay on track.

Also, I mean everybody wants to ‘diss’ the child and families (Ministry of Children and Family Development), but I love my child and families worker. ...I have an awesome, an awesome relationship with my social worker. So I think that a lot of my success has to do with her.

¹ PEERS Victoria Resource Society is non-profit society established by former sex workers and community supporters and is dedicated to the empowerment, education and support of sex workers (see text box on page 22).

Women identified a number of characteristics that mattered to them in the person from whom they received care/support, including being respectful, honest, and appreciative of their needs— that is, someone with whom women felt safe, who challenged them from a place of caring and support, and who conveyed that he or she would not give up on them.

Drug and alcohol counsellors were also knowledgeable and made me feel safe. I had support from Metis Services². A man who worked there was awesome. He really cared about me.

“[The counsellor] has had a big impact on my life. Just the way she talks to me—she’s real—you can’t bullshit her. She calls you on your shit; she cares. She goes the extra mile. I like her honesty.”

-Interview Informant

Similarly, in speaking about the importance of relationships borne out of understanding and empathy, several women emphasized the value of having a service provider recognize—and even anticipate—their financial and day-to-day needs and thus provide instrumental support in whatever ways were possible.

We need ways to get to meetings—bus fare, day care. I couldn’t get to AA meetings. [The Moms Mentoring Moms facilitator] got me day care and took me to a meeting and even bought a cake and a pin for my AA birthday. They went the extra mile because they know from a deep place— understanding and so much support and care.

Service providers’ understanding of the kinds of practical supports that women with FASD likely would need was also important and was potentially suggested by this woman’s comment, even though the woman didn’t articulate this point explicitly.

² Metis Community Services is a non-profit agency providing human service programs for Métis children and families in the Vancouver Island region (see <http://metis.ca>).

Finally, women emphasized that their counsellor's or service provider's use of a non-judgemental and non-shaming approach was critical to helping them. First and foremost, these approaches created a sense of trust and safety, which paved the way for women to engage and keep coming. In addition, these approaches facilitated the women to think about and make sense of their own personal stories, including the triggers to their substance use, along with their strengths and accomplishments as people.

Aurora Centre³ didn't shame me. Took me though my history and helped me to understand why. Try to build your self-esteem along the way.

I saw a therapist, a wonderful woman. She said she couldn't do anything for me, but she did. She introduced me to a way of introspecting—looking inside. We did 'on a scale of 1-10...' a lot. She also introduced me to other women. Spiritually, I've been growing a lot.

Wholistic, Coordinated Supports that Consider Women's Needs in an Integrated Way

Another key theme emerging from the interviews with women was the importance of having support and services that approached them and their family wholistically, in recognition that women's needs in different areas of their life were inter-connected, and that women's issues were also inextricably connected to their children's well-being and safety. For example, one woman was particularly positive about the outreach support workers at a transition house who assisted in ensuring that supports were in place so that she could keep custody of her child.

In a similar vein, a number of women spoke appreciatively of care providers or programs that provided them with assistance in more than one area of their life and/or that provided hands-on help in linking with other resources in the community. Women said:

³ Aurora Centre is a women-only treatment centre, providing both residential and day treatment services (see <http://www.bcwomens.ca/Services/HealthServices/AuroraCentre/default.htm>).

Then I started up with the Moms Mentoring Moms group, through the FASD Community Circle. That program pretty much changed my life. They got my debt cleared with BC Housing. They got me to PEERS, introduced me to PEERS. I'm in my fifth month of a six-month day program called Elements.

Support, support, support from non-government people who understand how important practical support is. Getting a phone bill paid, a grocery voucher, daycare so we can go to meetings. Help in raising kids with FASD—or any kids; having FASD is tough. My house is filthy—I don't know how to clean. I barely get my kids to school. [The Moms Mentoring Moms facilitator] used to get me a housekeeper and someone to help me manage my life.

I had support from a counsellor from Metis Services, the Moms Mentoring Moms program, the FASD Key Worker program⁴, and Whitecrow camps for my kids who have FASD⁵.

Implicit in all of these comments is the importance of programs and service providers employing a women-centred approach, wherein the focus provided can be flexible and is directed by a woman's individual goals and needs. Also noteworthy was that the multi-faceted and flexible programs viewed positively by women were ones informed by a strong understanding of FASD and the needs of people living with FASD.

⁴ The Key Worker and Parent Support program is a province-wide program of the BC Ministry of Children and Family Development. Key Workers provide families and service providers with information/education about FASD, support, and advocacy in facilitating access to services and/or devising environmental accommodations that are appropriate for the child and supportive for the family (see http://www.mcf.gov.bc.ca/fasd/kw_support.htm).

⁵ Whitecrow village is a non-profit organization dedicated to providing families and communities with an understanding of FASD. Whitecrow "camps" are typically week-long camping sessions that offer families and others a "unique opportunity to work, learn and play together" as an FASD community (see <http://www.whitecrowvillage.org/programs.html>)

“Support, support, support from non-government people who understand how important practical support is. Getting a phone bill paid, a grocery voucher, daycare so we can go to meetings. Help in raising kids with FASD—or any kids; having FASD is tough.”

-Interview Informant

One-to-One Care, Combined with Women-Centred, Group-Based Support and Information Exchange

A number of women reported that what had been helpful to them was having both a supportive care provider whom they saw on a one-to-one basis, and also participating in a women-centred, peer-based group or program. Through these supports and programs, women worked through various personal issues which helped make them feel better about themselves and improve their sense of self-worth. In women’s words:

I see a psychologist, and am working with that person, and it has made me a better person. To be able to have someone to help me, to guide me through a lot of the substance use. Also, PEERS having workshops.

My doctor made me get outside help. I went to the Sexual Assault Centre’s “How to Love Yourself” program, which was really helpful.

Several women specifically identified their physician as being instrumental in helping them during the course of their healing; having a doctor who was supportive, who understood the inter-connections between issues in women’s life, and who empowered women to direct their own plan of care was deemed to be of great importance.

And to be connected with my doctor, that was a big thing, to get medication. Because depression did step in when children were gone, so I lost myself for awhile. I’m happy I have this medication—I am now feeling well.

My methadone doctor has helped me through it all the way.

Having a really good drug and alcohol doctor. He really cared, was supportive, included me in the care.

As well, in elaborating about what they liked about the combination of individual counselling/medical care and group-based peer-support, a couple of women noted that they valued knowing that they could contact and seek help from the members of their peer group on an as-needed basis, which bridged a gap in time between appointments with their professional care provider.

My counsellor at Mental Health, her appointment—it is about every 6 weeks to book appointments with her. I need more availability for counselling based on addictions—is once every week or once every two weeks. That’s why I like the Moms Mentoring Moms: they have all had addictions, and gone through things themselves.

Peer-Based, Women-Centred Support Programs

A strong theme in women’s discussion of their positive experiences was the power of women’s peer-based support programs in promoting personal change and healing.

My only good experience [in getting help for substance use] has been this group—Moms Mentoring Moms. That’s one I have been happy and comfortable coming to, and it’s ending. It’s sad because it’s our connection to each other. And there’s some of us who live for our Wednesday group. My boyfriend notices the difference when he comes home from work and I am smiling. I’m chipper, hanging with the girls, just chit-chatting about whatever. Not some formal setting, where it’s “Here’s the pamphlets” and everyone goes around in circles.

PEERS Elements program—being with women who have been through the same experiences. Not talking to some straight-edge person who has never had a drug problem.

Clearly, interview participants' positive regard for exemplary peer-based programs for women is evidenced in many of the comments excerpted previously. The following pages provide additional

information about these programs, as well as women's perspectives on what has been helpful and why the program or approach worked well for them.

Promising Program Example from Women’s Perspective: Moms Mentoring Moms Support Group (Victoria BC)

The Moms Mentoring Moms (MMM) Support Group operated through the FASD Community Circle–Victoria⁶. The overall aim of Moms Mentoring Moms was “to develop a model of support for high risk women” including birth mothers of children prenatally exposed to alcohol “where addiction was identified as a barrier” to parenting⁷. It was anticipated that many of the women participating in the group would have been prenatally exposed to alcohol themselves.

Key objectives of the Moms Mentoring Moms group were to:

- Support moms to develop effective wellness strategies and social supports
- Support moms to develop appropriate parenting strategies and life skills
- Support women to decrease their intake during pregnancy
- Build positive working relationships within the community
- Build the capacity of women to mentor other women

The Moms Mentoring Moms group was co-facilitated by two women who had extensive knowledge about FASD and experience working with women with an addiction issue. One woman had an adult son with FASD and the other was an art therapist. In addition to leading the weekly groups, the co-facilitators made referrals to and connected women with other organizations, and provided practical support, information and advocacy. As well, the MMM team included two mentors from Prostitutes Empowerment Education and Resources Society (PEERS), who similarly supported participants by engaging in outreach and by providing practical and emotional support, advocacy, and information.

Without exception, the women interviewed in the current research project who had participated in Moms Mentoring Moms were extremely positive about their experience. In their words:

The FASD Community Circle’s Moms Mentoring Moms has been incredible. Individual support and peer support. Workshops, people would come in from the community. We had art therapy. Lots of laughs, lots of information sessions on FASD. They were there for all of us, 24/7. I know that if I’m ever struggling I could call them or the women in my group. Helping other women in the group was fantastic—it is good for my recovery.

Moms Mentoring Moms was a unique program—women came because they felt safe; they would not have gone to a child protection officer. We learned so much and felt so safe. These women learned to trust, and it was fantastic.

I used to hear nothing but negative, but now that I’m in the Moms group, there’s positive. There were no support groups like the Moms group.

⁶ At the time that women were interviewed for this project, the FASD Community Circle was a non-governmental organization dedicated to FASD prevention and to the provision of quality education, ongoing support, and services for people with FASD. The FASD Community Circle is now a program operated through Beacon Community Services in Victoria.

⁷ Additional information about Moms Mentoring Moms is available in the project’s Final Evaluation Report: Shepherd, Blythe. n.d. Moms Mentoring Moms Evaluation Program Final Report. Available from http://www.hcip-bc.org/readings/documents/Moms_Mentoring_Moms_FinalReport.pdf

Promising Program Example from Women's Perspective: PEERS Victoria Resource Society's Elements program (Victoria BC)

As outlined in its website, PEERS is dedicated to the empowerment, education and support of sex workers by working to improve their safety and working conditions, assisting those who desire to leave the sex industry, increasing public understanding and awareness of these issues, and promoting the experiential voice (see: www.peers.bc.ca). As a peer-based organization, PEERS' programs are developed and implemented by sex workers in collaboration with non-sex workers who are committed to PEERS' core values.

PEERS' Elements Program is a six-month program designed for those wanting to transition from the sex trade toward mainstream employment and/or education. Participants attend groups four days a week. In addition, they can access one-to-one counseling once a week and receive individualized support to help address specific needs.

The curriculum for the Elements groups is continually evolving based on participant input. Core components include: mental health and addiction issues, understanding trauma and its connections to addiction, family connections, healing, personal growth, communication, and employability skills, including basic computer literacy. In the last two months of the program, participants are supported to prepare for mainstream work, secondary or post-secondary training; program activities include volunteer placement.

Nearly all of the women interviewed in the current research project who had participated in Elements voiced their appreciation of the program. They particularly valued the combination of practical, one-to-one, client-directed support and the peer-based group work.

The people at PEERS treated me well. They brought me money for food when I had none. That's what kept me sober. I didn't want to let them down. That's why I did service work and volunteered. It felt good to be helping others and not to be so selfish.

Well, through PEERS I've gained a lot of knowledge and support and strength. And you know, they helped me with my housing. ... Elements touches a lot of stuff, so you're still working on your stuff, etc. And that was a 6-month course.

PEERS did a "Freeing the Heart" weekend workshop. We learned amazing techniques for letting go of anger, and for releasing all that I had been holding on to. We'd blow up balloons. We wrote on them all the things that we had wanted to say to people. We had 60 balloons each. I felt so light afterwards. I felt like a miracle had happened.

I went to PEERS groups. They were very supportive. They did what I thought I needed—not what they thought I needed.

Linkages with FASD-focused Programs and/or with Service Providers who have Strong Understanding of FASD

A number of the women spoke of the positive experiences they had had with programs and organizations designed for and/or run by people with FASD. Some of these programs were geared to adults with FASD and others were geared to supporting children with FASD and their families. Even though not all of the women interviewed shared in their interview that they had FASD or had been prenatally exposed to alcohol, all but a couple disclosed having a personal or family connection with FASD. Moreover, several women revealed that one or more of their children had FASD, and that they sought specialized services or assistance in caring for their children and addressing their needs.

A strong theme relating to the importance of FASD-informed or FASD-focused programs and organizations was that the women appreciated that the care providers or group facilitators understood FASD at a deep level. Because of this understanding, the program or approach was aligned with the needs of the women, children or families affected by FASD. Women also stated that they learned a lot about FASD through these programs, and that they applied this new information to their interactions with their children and/or to their understanding of themselves and their own behaviours or challenges. In women's words:

I have been part of the Cowichan Valley [FASD Action Team Society's] 'Towards Inclusion' program, and I learned a lot through that in ways to manage with my own anger as well. [In the program] you teach other people about living with FASD. And it was really helpful to recognize why lights are always bright for me, and that. I learned a lot from that, and from the Moms group.

A child care social worker was also very helpful—he really understood FAS. I also met a Key Worker when my kids did the [FASD] diagnosis. I hooked up with her and her organization. I don't think I would be nearly where I'm at if it wasn't for them. They genuinely cared. They had a lot of knowledge, compassion and personal experience.

The biggest thing is that [the Key Worker] had had an FASD child.

Camp Whitecrow is unbelievable—we've been there 5 times out of the last 4 years. It is very structured, which neither I nor my children are used to. There are lots of activities for the kids. Everyone there really gets FASD. I always learn from these camps. They are really supportive and kind.

I also liked the FAS program. That kind of opened up the whole floodgates for everything else.

Women learned a lot about FASD through these programs, and they applied this new information to their interactions with their children and/or to their understanding of themselves and their own behaviours or challenges.

Echoing this theme but speaking to it from the perspective of having poor experiences when care providers or programs did *not* appreciate FASD, one woman said:

It seemed as though no one recognized the FASD part. They'd struggle to help. I'd have a hard time to say what I'd want.

Supportive Housing, Especially Housing for Women Informed by an FASD-lens

"I'm now in a program—it's like a foster home, but instead of just taking in children, they take, like, a mother with a child. The family is really nice."

-Interview Informant

Many of the women interviewed for this project reported very precarious housing situations such that they would have a home and then lose their home with great regularity, resulting ultimately in homelessness and a return to their former pattern of

drug use in keeping with life on the streets. For these women, accessing stable and supportive housing was often the lynch pin of personal change and growth:

More than anything, I mean, what I found is that having a consistent stable home is definitely a factor [in terms of substance use]. Like, I would find a place and be in a place for a month or two and then, you know, I'd look for something else. And so I'd leave that place thinking I'm going into something better and wind up somewhere, and then it didn't work out and I'd get kicked out, and then I'd be back on the streets. What's the first thing that you're going to do being around on the streets, staying in shelters, being around drug addicts? Like, you know, I wound up using.

As well, three women spoke of having very positive experiences living in supportive housing geared to women with FASD and their children, wherein women and their children were fostered in a family home setting; in addition to the housing, a worker affiliated with the home was available to provide assistance and/or support in keeping with women's needs, including acting as a liaison with child welfare workers. (This supportive housing resource was a demonstration project for women with FASD and their children; see text box, following). The women learned about the supportive housing resource through their involvement with other programs for women parenting children with FASD and/or who were at high risk of having a child with FASD, or who were seeking to transition from sex work. One woman stated:

I'm now in a program called the Collaborative Care Homes, and the way I would describe it would be: it's like a foster home, but instead of just taking in children, they take, like, a mother with a child. The family is really nice.

All three women spoke about the value of this home to them: the home provided stability and security, as well as support from service providers who understood FASD and the types of issues that the women likely were dealing with. As discussed previously (see section on *Wholistic, coordinated supports*), from women's perspective, these programs/resources and their inter-connections

were extremely important and led to women feeling supported in different facets of life, including in relation to their substance use issues.

Flexibility in Extending a Program's Duration and Having Longer Timeframes for Program Participation

For women with FASD, timeframes for supportive services need to be elastic in recognition on their ongoing needs.

Another theme emerging from women's discussion of their positive experiences was the importance of having timeframes for services be flexible, and specifically, be expandable in recognition of women's needs for long-term support. For example, one woman spoke of the value of staying in detox for longer than the standard program timeframe. This woman was also able to live in supportive housing for an extended time period relative to what was standard policy. She stated:

I was kept in detox longer. I stayed in second stage housing for 8 months, with programming and supports. This made a huge difference. Now, I am employed and going to school to be a resident care worker. ...The stay at supportive housing wasn't long enough. I could have used at least 3-5 years.

Noteworthy in this woman's comments was the point that she would have benefitted from additional time in a supported housing environment (i.e., years rather than months). This speaks to the theme of safe housing being so crucial to women's healing and wellness, and also to the idea that for women with FASD, timeframes for supportive services need to be elastic in recognition on their ongoing needs.

Support from Family and/or Partner

Several women voiced their appreciation for the support they received from family members (e.g., their mother or a sister) or from their partner, which they believed helped them to reduce or quit using substances and/or to benefit from their participation

Promising Program Example from Women's Perspective: FASD Collaborative Family Care Homes Project (Victoria BC)

The FASD Collaborative Family Care Homes project was created in 2007 as a three-year demonstration project sponsored by PEERS Victoria Resources Society in partnership with the Victoria FASD Community Circle and funded by the Victoria Foundation's FASD Action Fund.

As stated in the project's webpage⁸, key objectives of the project included:

- To provide support to mothers who have FASD and their children by housing them in a family home environment
- To support mothers whose children would otherwise be apprehended with the opportunity to raise their children
- To create a stabilized, structured environment where women and children will have better opportunities to access informal and formal resources in the community
- To provide parenting role models and support for moms and their newborns/children

A total of six homes operated during the course of the project. The partnership approach to running the project was viewed as being beneficial for both the women and their families receiving support, and for the agencies involved. The collaborations enabled inter-agency training and referrals to the organizations' other programs, as well as referrals and connections to other resources and supports in the community, which in turn helped to ensure that women's multiple needs were being addressed.

As discussed previously, the women interviewed in the current research project who had been involved with the FASD Collaborative Family Care Homes project were positive about their experience. In their words:

[I needed] housing, definitely. If it wasn't for the Collaborative Care Homes, I wouldn't be where I'm at. I know that for sure. I think there needs to be more programs like that. ...So to kind of look at us as a family and deal with us and make sure that both of our needs are met, or all of our needs [are met], including our son's.

I was on the streets for a year and I didn't enjoy it. But with [the emergency shelter for women], PEERS' support, and Human Exchange⁹ support, then the Collaboration [Family Care] Home fell into place.

Consistently, like I've had housing, lost housing, had housing, lost housing, had housing. ...I'm now in another program through PEERS...called the Collaborative Care Home. And so I've been able to get into a home. Starting today I'll be having my son Thursday through Saturday. So, everything is looking really good.

8 Additional information about the FASD Collaborative Family Care Homes project is available through the PEERS Victoria Resource Society website: http://www.peers.bc.ca/images/FASD-CFCareHomes_news09.pdf

9 The Victoria Human Exchange Society is a "grass roots group providing support and advocacy to people working hard to solve their own problems". Additional Information is available through the Society's website: <http://www.humanx.org/mission.htm>

Promising Program Example from Women's Perspective: Phoenix Transition Society's Phoenix House (Prince George, BC)

The Phoenix Transition Society "operates a shelter with a supportive environment for women and their children who are in crisis"¹⁰. In addition to temporary shelter for women and their children, additional supportive services include: short term supportive counseling, referral to appropriate agencies, assistance in attending appointments and in finding housing, and follow-up support for women after they leave the Transition House.

The women interviewed in this research project who had received shelter and support from the transition house were positive about their experience. What stood out for women were:

- the outreach-oriented, individualized support (e.g., accompaniment to appointments, assistance with obtaining employment and/or accessing education or training programs);
- the wholistic focus on both the women's well-being and safety and the child's well-being and safety; and
- flexibility in extending the duration of service, in keeping with the woman's needs.

In one woman's words:

Phoenix House was [especially helpful] because of the supports put in place, and with helping me keep custody of my child.

in services or treatment. Women's comments signified the importance of being amidst people who could encourage them from a place of understanding. Women who were in a healthy and respectful relationship with a caring, non-abusive partner also spoke of the importance of this relationship. For some, the experience was profoundly different from previous experiences in which violence in relationships was the norm.

My mom, who is now clean, supported me all the way.

I'm feeling pretty good, I'm into a new relationship with a man who truly loves me unconditionally, the first non-abusive emotionally and physical, and I am 38 years old. ... He's the best thing that ever happened to me, and truly, he's the one who got me off crack. I would be dead or in an institution right now if not for him.

Ongoing Drug Testing

Finally, two women stated that, for them, having regular urine testing was helpful and contributed

to their success in staying away from drugs and alcohol. Interestingly, however, the women's comments indicated that the drug testing happened within the context of other supports and services (e.g., for one of these women, ongoing care from a supportive physician along with access to community-based programs). Nevertheless, their comments also suggested that they appreciated the concrete feedback that drug testing provided, which reinforced their efforts to remain clean.

Also I was getting drug tested for about six months. And I said to my social worker later on, I said, 'You know, that was the most clean I've ever been besides now.' And my social worker said, 'Well, you know, we can't put you on drug testing for the rest of your life just as a means of keeping you clean.' But then I was talking to somebody about that a couple of days ago, and they were saying, 'You know, like, why not, if it works?' ...I found it works.

¹⁰ Additional information about Phoenix House is available through the Phoenix Transition Society's website: <http://www.phoenixhouse.ca/index.php>

Barriers to Care and Bad Experiences with Substance Use Programs

In addition to discussing their positive experiences, women interviewed for this project were asked both about any challenges or barriers they experienced in trying to access treatment/care, as well as about any negative experiences they had with the care they received related to their substance use. Following is discussion of the themes relating to these questions.

Barriers to Accessing Substance Use-Related Services and Care

Women identified a number of barriers that hindered them in accessing care for substance use issues, including:

- Inadequate availability of services, such that women could not access help at the immediate point that they were ready;
- Homelessness;
- Inability to access substance use-related care when trying to enter through the ‘emergency psychiatric care’ door; and
- Concerns about having a child apprehended if the need for care is revealed.

Several women spoke of their frustration when they reached a point of readiness for services and they were told they had to wait because the type of service or program they sought was not available immediately. Along these lines, one woman reported that she was told by staff of a Methadone clinic that she needed to continue to use drugs for several weeks—living on the street throughout this period—because there was no space in the Methadone program available for her. Another woman similarly reported having to wait to get into a detox program in her community.

Trying to get on the Methadone program was hard. I had to wait 4 weeks—they told me to keep using drugs until 4 weeks. This kept me on the street because I was so sick. They actually told me to keep on using. ...Waiting when you’re so sick is

horrible, and they actually had these stupid rules about who can get it, when, and for how long.

Another two women reported that homelessness, poverty, and for one of the women, concomitant health problems created serious barriers to their accessing services relating to substance use. In one woman’s words:

Yes, in an immediate situation with no housing, it’s awful—that’s how I ended up in a transition house. If you’re homeless and you want immediate rehabilitation, it’s impossible. You have to jump through so many hoops with no money.

Linking to the idea that substance use and mental health services for women needed to be better coordinated such that “every door is the right door”, one woman reported being thwarted in her efforts to access substance use-related care when she went to psychiatric emergency services at an acute care hospital and was discharged without receiving substance use-related support or follow-up because her mental health needs were not perceived to be sufficiently high-risk. This woman stated:

My mom took me to the psych ward at the hospital. They couldn’t do anything because I wasn’t suicidal or in any manic episode. I don’t have any mental health issues, other than depression that comes from boredom.

Finally, one woman shared that she felt she could never be completely honest with care providers and substance use-related programs because of her concerns that child welfare authorities would remove her child if they were apprised of her problems with alcohol and/or drugs.

I’ve been through numerous counselling sessions and types, for a variety of reasons from alcohol and drugs to being involved with social services. I didn’t feel I could ever be truly honest because I knew everything I said would go back to social services. So I wasted their time and money and jumped through the hoops like a trick pony ...

Negative Experiences with Service or Care Relating to Substance Use

The women participating in this project had less to say about negative or bad experiences that they had had with substance use-related services relative to the number and depth of comments made about positive experiences and what worked well for them. Along these lines, three women said that they did not have any bad experiences with services or care related to substance use.

In addition, themes emerging from women's comments about their poor experiences can be viewed as the converse of the themes emerging from women's discussion of their positive experiences. For example, linking to the theme of the importance of readiness for change, three women stated that when they were *not ready*, their experience in a substance use treatment program did *not* go well and their substance use intensified.

I went to treatment, but I wasn't ready for that then. I just got the addiction, the addiction just got heavier.

Key themes in women's discussion of their negative experiences with services and care included:

- Experiences felt negative when women's trust and sense of safety were violated, and/or when women felt judged or felt de-personalized
- Experiences felt negative when services and care were not informed by an understanding of FASD-related challenges and/or behaviours (being fidgety, difficulties with attention and with receptive communication, etc.)
- Experiences felt negative when services and care were not wholistic, for example, not taking into consideration women's inter-related experiences of violence and trauma, and/or their mental health issues.

Abrogated Trust and Sense of Safety

Several women spoke of situations in which they felt that the trust they had developed with a service provider or organization was broken. In each of the examples provided, the service provider shared information about the woman's substance use (i.e., her relapsing) with child welfare authorities, which

in turn jeopardized the woman's efforts to maintain or regain the care of her children. In these situations, after the women felt that they could not continue to trust the service provider, they stopped using the service or program. Further, their disillusionment and sense of not being supported potentially increased their wariness about having involvement with services in the future.

They kept an eye on me, and then if I relapsed, they would tell the Ministry. This came up in court. And these people I thought I could trust, and in the process they burnt me.

The women won't come to the group anymore. [The new group facilitator] is intrusive and asks women what the other women are doing, i.e., Are they working? Are they doing any criminal activity? He says some of the women don't belong.... The women participated, they loved the group, but now they won't go. I don't feel comfortable anymore or feel like I am being supported.

Feeling Judged

Two women stated that a negative experience was when they felt judged by care providers. Again, at least one of these women ended her involvement with the program because she did not feel accepted for who she was, and because her relationships with those affiliated with the program did not feel safe.

I left the treatment centre because of homophobia.

Judgements at the hospital. There were lots of stereotypes, and the nurses were so rude.

Feeling De-personalized

One woman commented that a bad experience for her was when she felt as though she was not treated as an individual—in other words, when she did not have a relationship with a care provider, or when staff at the program or group did not engage with her as a person with unique experiences, goals, and needs.

Being treated like a number, being dehumanized.

Program Not Informed by an FASD-lens: Getting Kicked Out for Being Fidgety

One woman shared what she deemed a bad experience with a treatment program in which she was asked to leave the group-based program because she was agitated, and her fidgetiness was deemed to be “triggering” and disruptive to the other group participants. Further, the woman’s antsy behaviour was attributed to her using substances, rather than to her difficulties with attention and maintaining focus. By contrast, the woman herself attributed her need to move around to her neuro-behavioural conditions (ADHD and FASD), and she expressed frustration that the service providers and program managers did not believe her explanation, recognize her needs, and adapt the program to enable her to participate.

So I got asked to leave. And then also I was diagnosed with ADHD when I was 10. Now that I’m looking into it, that’s part of my FAS, I’m not too sure. ...I usually say right off the bat that, you know, “you have to excuse me”, but being a... you know, maybe, facilitators could recognize that that’s a part of me. But with the fidgeting and stuff, I was asked to leave ‘cause I was told I was being a trigger to other members in that group.

Program Not Informed by an FASD-lens: Not Understanding what Counsellor is Saying

Rushed communication with a counsellor resulted in one woman feeling “more screwed up in her head” than before she sought help.

As another example of how not being informed by an FASD lens related to a bad experience with services, one woman described a situation in which her alcohol and drug counsellor spoke to her in ways that felt rushed, and provided her with applications for other programs that the woman found confusing. The counsellor, in other words, did not check for the woman’s comprehension of what was being said or recommended in terms of programming. As a result,

the woman felt “more screwed up in her head” than before she sought help. The woman also felt stressed because of the pace—again, likely because the counsellor spoke too quickly and/or used language that was too complex or abstract—and also reported feeling distracted by the busy-ness of the office environment.

I also had a drug counsellor there. She was nice enough, but it seemed like every time I went in her office, her office was so busy. Like, once a month, you know, we’d start talking about things and then she’d throw another application for some kind of treatment centre in my lap. So I had like six or seven different application forms. A little bit of information and no, kind of, like, resolution to it. You know? Starting to fill some stuff out, and just, you know, like more screwed up in my head than before.

Not Having Mental Health Issues Recognized

Finally, one woman commented that, for her, a bad experience with services happened when the care providers did not appreciate the inter-connections between her substance use and her mental health issues:

Not having mental health issues recognized or minimized.

Women’s Tips and Parting Messages for Ways that Substance Use Treatment Programs and Services Could Be Improved

Finally, in addition to being asked to describe positive experiences they had had with services and care, women were asked whether they had any tips for dealing with their substance use problems and/or suggestions for ways that services and programs could be improved in order to better meet their needs. Similarly, they were asked if they had any parting messages for those planning and delivering programs and services for women.

Key themes and women's messages, in their own words, follow.

Women's Tips for Dealing with Drugs or Alcohol Problems:

Themes:

- Be honest with yourself about the need for support
- Reach out for help when help is needed
- Keep in mind your reasons for wanting to stay clean
- Use self-talk, be positive, and have hope

In women's words:

Admit that you have a problem.

Phone someone who cares. ... Always remember to talk to someone about your problems.

When I feel really bad I stay home and realize why I want to stay clean, or I'll go to a meeting.

Self-talk is huge. It works wonders. If it wasn't for that, I wouldn't be able to push myself and at least get out of the house once a day. Be positive, try to be as positive as you can.

Women's Parting Messages:

Meet women where they're at...period.

Longer detox and program stays.

Walk a mile in my shoes and don't judge.

I truly do not believe that anyone can develop these programs unless they have walked in these shoes. ...Strictly textbook, we will see right through. We will have no respect, and the validity will not be there.

Be aware of the power that you wield as service providers.

We need recovery housing that women can take their kids to, with them.

I think they need more programs to help people understand FASD—I don't even understand it. People shouldn't be mistreated just because they are different.

4. Discussion and Conclusions

Summary of Interview Findings

This set of community-based interviews, carried out with women with FASD, was one of three components of the *Substance Using Women with FASD and FASD Prevention* project, an endeavour aiming to expand knowledge regarding effective, appropriate substance use treatment approaches for women living with FASD.

In this component of the project, we interviewed 13 substance-using women who had or were suspected of having FASD; the interviews took place in four geographically diverse communities in British Columbia. Our qualitative interviews with women enabled them to tell their story in their own words. The interviews focused on: women's positive experiences in substance use treatment and/or other types of programming, and/or what had been helpful in relation to problem alcohol or drug use; what hadn't worked well; what would help improve substance use treatment programs and care; and any other areas in the women's life in which they needed help or support.

Findings revealed a number of common themes that were braided together in the women's descriptions of themselves, most notably: being mothers and being entangled with the child welfare system; living in deep, intractable poverty; struggling to find stable, safe housing for themselves and their children; being survivors of abuse and trauma, and living in highly fragile domestic relationships in which they were vulnerable physically, emotionally and financially; having mental health issues and needs related to their experiences of abuse and trauma; and having problem substance use which typically exacerbated their involvement with child welfare authorities. Also notably, having FASD was not typically prominent or even visible in women's descriptions of themselves. Lessons for policy makers, service planners and care providers, emerging from women's self-descriptions,

are multi-fold. First, because women don't compartmentalize their substance use from other aspects of their life, those providing care to women must consider all aspects of a woman's life, i.e., must see the whole woman and place her substance use within the context of day to day realities. Second, women with FASD or other invisible disabilities likely will not announce themselves as having been prenatally exposed to substances. For this reason, those planning and providing services and care to women must anticipate the possibility of substance exposure amongst the women they serve, and accommodate their needs accordingly.

In terms of **promising approaches to substance use treatment**, the themes emerging from women's stories of their positive experiences of services and care, their self-care strategies and tips, and their parting messages to improve services for women with FASD were highly congruent. These themes may be summarized as follows:

- **Focus on women's readiness** and work with women where they're at;
- **Ensure that services are available** for women when they are ready to access help;
- **Employ a relational approach** and develop and maintain a respectful relationship with women wherein women feel safe, and not judged, blamed or shamed;
- **Develop and deliver wholistic, women-centred, integrated programs** that support women in the areas of housing, mothering, substance use issues, mental wellness, life skills, and employment, and that offer women both one-to-one care and peer-based group support;
- **Ensure the availability of one-to-one care** from a skilled professional (e.g., counsellor or physician), combined with women-centred, **group-based support** and information exchange;
- **Plan and deliver services based on compassion** for women's experiences;

- **Employ collaborative approaches**, highlighting linkages with FASD-related programs/organizations;
- **Ensure the availability of supportive housing** for women, especially that informed by an FASD-lens; and
- **Offer flexibility in extending a program's duration** as well as longer-term programs.

As a final but extremely important theme, women's voices spoke to the critical need to ensure that **all programs for women with substance use problems are planned and delivered based on a deep understanding of FASD**, along with appreciation of the myriad implications of FASD in terms of the women's stigmatization, marginalization, life challenges, and probable involvement with multiple child/social welfare and other service systems.

Along these lines, analysis of the useful **programs** identified by women revealed a key common feature: nearly all were designed and implemented using an FASD-lens; that is, with the issues and needs of women with FASD foremost in mind. This meant that attention was given to:

- providing **ample one-to-one support**, and allocating resources toward this support;
- providing **flexibility in how, when and where** the woman met with her worker;
- appreciating, without judgement, **women's struggles as highly stigmatized mothers**, parenting with FASD and, potentially, having substance exposed children as well;
- **working collaboratively and making connections with other programs/resources** in different spheres of the woman's life (e.g. parenting/mothering, substance use, life skills and employability-related skills, safe and supportive housing).

Synthesis of Findings Across Project Components

The promising approaches that emerged from the interviews with women with FASD were

highly congruent with our findings from the other components of this project.

For example, in the literature review, promising practices in the fields of substance use treatment for women were identified and then linked with promising practices in the care and treatment of women living with FASD. Based on the literature, 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.

Similarly, environmental scan informants (BC service providers working with substance using women) 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

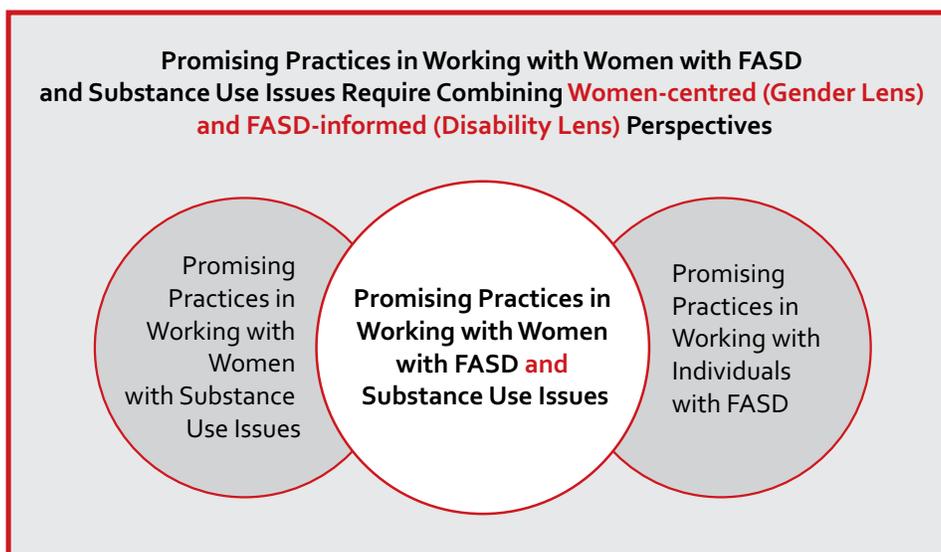
- **Programs making FASD-informed accommodations** to their format and content, and to the physical space in which the programs were delivered
- **Care providers using clear and plain language**, and using accommodations related to communication and memory
- **Programs being grounded in FASD-informed 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 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 figure at the bottom of this page.

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).

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 on page 35.

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;
 - 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

References

- Barnsley, J. and D. Ellis. 1992. *Research for Change: Participatory Action Research for Community Groups*. Vancouver: The Women's Research Centre.
- Chudley, A. E., J. Conry, J. L. Cook, C. Loock, T. Rosales, and N. LeBlanc. 2005. Fetal alcohol spectrum disorder: Canadian guidelines for diagnosis. *CMAJ* 172(5_suppl):S1-21.
- Clarren, S. G. B. 2004. Teaching Students with Fetal Alcohol Spectrum Disorder: Building Strengths, Creating Hope, edited by A. Learning: Alberta Learning, Special Programs Branch: Learning and Teaching Resources Branch.
- Classen, C., D. Smylie, and E. Hapke. 2008. Screening for FASD in Women Seeking Treatment for Substance Abuse. In *Gender Matters Conference*. Toronto, ON.
- Grant, T., J. Huggins, P. Connor, J. Y. Pedersen, N. Whitney, and A. Streissguth. 2004. A Pilot Community Intervention for Young Women with Fetal Alcohol Spectrum Disorders *Community Mental Health Journal* 40(6):499-511.
- Malbin, D. 2002. *Trying Differently Rather Than Harder*, 2nd Ed. Portland, OR: FASCETS Inc.
- Morse, J. 1994. Designing funded qualitative research. In N.K. Denzin and Y.S. Lincoln (Eds.) *Handbook of Qualitative Research*. Thousand Oaks, California: Sage Publications.
- Patton, M. 1990. *Qualitative Evaluation and Research Methods*. Newbury Park, California: Sage.
- Poole, N. A. 2008. *Fetal Alcohol Spectrum Disorder (FASD) Prevention: Canadian Perspectives*. Ottawa, ON: Public Health Agency of Canada.
- Rutman, D., C. La Berge, and D. Wheway. 2005. *Parenting with FASD. Challenges, Strategies and Supports: A research and video production project*. Victoria, BC: School of Social Work, University of Victoria.
- Sandelowski, M. 1986. The problem with rigor in qualitative research. *Advances in Nursing Science*, 8(3), 27-37.
- Shepherd, Blythe. n.d. *Moms Mentoring Moms Evaluation Program Final Report*. Available from http://www.hcip-bc.org/readings/documents/Moms_Mentoring_Moms_FinalReport.pdf
- Streissguth, A., H. Barr, J. Kogan, and F. Bookstein. 1996. *Understanding the occurrence of secondary disabilities in clients with Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Effects (FAE)*. Edited by A. Streissguth. Seattle: University of Washington, School of Medicine.
- Streissguth, A. P., H. M. Barr, J. Kogan, and F. L. Bookstein. 1997. Primary and Secondary Disabilities in Fetal Alcohol Syndrome. In *The Challenge of fetal alcohol syndrome: overcoming secondary disabilities*, edited by A. P. Streissguth and J. Kanter. Seattle, WA: University of Washington Press.
- The National Center on Addiction and Substance Abuse at Columbia University. 2003. *The Formative Years: Pathways to Substance Abuse Among Girls and Young Women Ages 8-22*. New York, NY: CASA.
- Umlah, C., and T. Grant. 2003. Intervening to prevent prenatal alcohol and drug exposure: The Manitoba experience in replicating a paraprofessional model. *Envision: The Manitoba Journal of Child Welfare* 2(1): 12.
- Weinberg, J. 2009. Direct and indirect mechanisms for alcohol damage to the brain; Presentation slides. In *IHE Consensus Development Conference on Fetal Alcohol Spectrum Disorder (FASD) – Across the Lifespan*. Edmonton, Alberta.

Appendix A

Interview Guide for Women with FASD

Preamble: As you know, the main purpose of doing these interviews is to find out what it has been like for you to try to get help for problems you may have had with drugs or alcohol, and also to find out what works for you—what you find supportive or helpful—when it comes to helping you with substance use problems or other issues in your life.

Introduction

1. Tell me about yourself—tell me your story...
 2. What kinds of things do you like to do?
 3. Tell me about your living situation—who are you living with? How is this working out for you?
 4. Tell me about your family—do you have children? If so, how are you involved in raising them?
-

Substance Use Issues

5. Have you ever had difficulties with drugs or alcohol?
6. Have you ever tried to get help in dealing with drug or alcohol use?

If so, tell me more about that. What was your experience in trying to get help for drug or alcohol problems?

If not, can you tell me why did you not try to get help?

7. Can you think of a good experience you had (regarding substance use treatment/care)?
What made it good or helpful/supportive?
Probe: Has there been a person who has been especially helpful or supportive? If so, what made this person helpful?

Was there a program that was especially helpful? If so, what made it helpful?

8. Have you had not so good (or bad) experiences or any difficulties in trying to get help for a drug or alcohol problem? If so, what made it bad or difficult for you?
9. Do you have any suggestions about ways that the substance use treatment programs could be done differently, to work better for you?
Probe: How can treatment programs meet your needs?
10. Are there other areas of your life that you need help with? If so, what are these?
Probe: Housing; work; money/finances; health; child care; parenting; legal system, etc.
11. Overall, what kinds of tips have you developed that's worked for you in dealing with problems with drugs or alcohol, or in dealing with your day-to-day life, that you think other people with fetal alcohol might also find useful?
12. What would you like to tell people who develop programs, or the professionals who work in these programs, about what's helpful for women?
Probe: What is the most important message that this research should tell?

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Substance Using Women with FASD and FASD Prevention

**Voices of Women with FASD:
Promising Approaches in
Substance Use Treatment and
Care for Women with FASD**

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January 2011

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