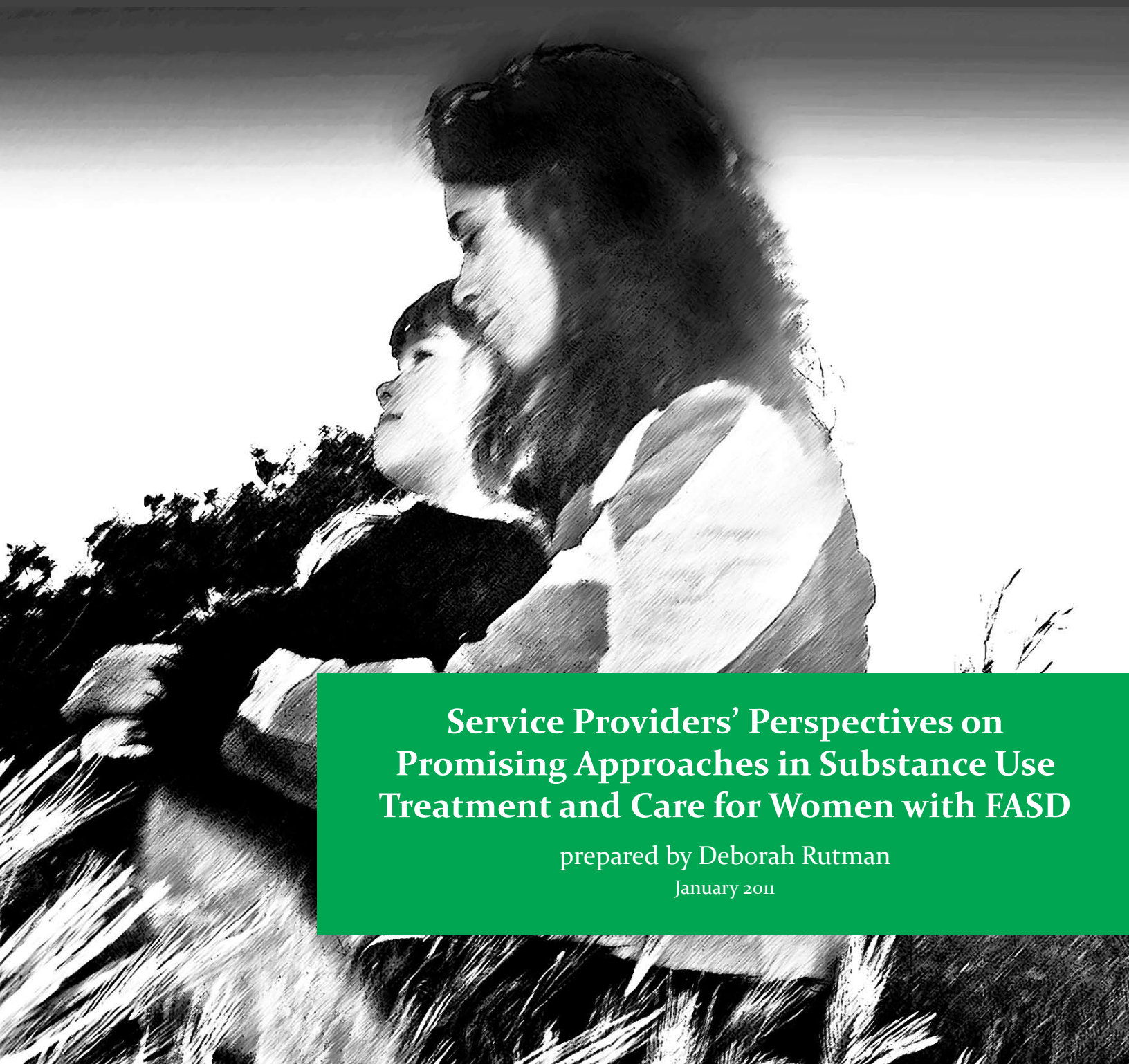
Substance Using Women with FASD and FASD Prevention



Service Providers' Perspectives on 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 Unit
School of Social Work
University of Victoria
Victoria, BC Canada

Contact: drutman@uvic.ca

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.

Service Providers' Perspectives on Promising Approaches in Substance Use Treatment and Care for Women with FASD is the report emerging from the environmental scan component of the project.

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

- *A Literature Review on Promising Approaches in Substance Use Treatment and Care for Women with FASD*, and
- *Voices of Women with FASD: Promising Approaches in Substance Use Treatment and Care.*

For more information, please contact:
Deborah Rutman, PhD
School of Social Work
Box 1700,University of Victoria
Victoria, BC, V8W 2Y2, Canada
drutman@uvic.ca
http://socialwork.uvic.ca/research/projects.php

ISBN 978-1-55058-439-4

Citation:
Rutman, D. (2011). *Substance Using Women with FASD and FASD Prevention: Service Providers' Perspectives on Promising Approaches in Substance Use Treatment and Care for Women with FASD*. Victoria, BC: University of Victoria.

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Preface and Acknowledgements

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

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

This report, *Service Providers' Perspectives on Promising Approaches in Substance Use Treatment and Care for Women with FASD,* emerges from the second component of the project. Separate reports based on findings from the project's *literature review* and from the project's *interviews with women with FASD* also have been produced; each report concludes with a brief synthesis of the findings from all three components of the project.

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

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

Acknowledgements are also gratefully offered to the environmental scan's research team, Lauren Casey, Tracey Fawkes and Barbara Smith, who organized and carried out much of the data collection. 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 are indebted to the service providers and managers who shared their time and knowledge as environmental scan participants. We honour the work you do every day to improve the lives of women through your steadfast support and compassion.

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, giving rise to substantial physiological, cognitive, behavioural and social difficulties. At the same time, the effects of FASD vary considerably amongst those living with the disorder.

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

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."

Despite this, relatively little is known about women with FASD and their experiences, both 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 has 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, Loock, 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.

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. The invisibility of FASD contributes to the many challenges and social and systemic barriers" that people with FASD experience in daily life (Rutman et al. 2005, 2). 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 its 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, and about the individual and 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
- community-based 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

Within the health field, an environmental scan typically involves gathering and synthesizing information to provide a snapshot of current knowledge, policy and/or practice in relation to a given topic; the scan may also yield information regarding good or promising practices and/or policies, in order to inform a blueprint for change. Methods of data collection for environmental scans can include document reviews, face-to-face interviews, phone interviews, or questionnaires with key informants in a sample of communities in a particular jurisdiction.

In this project, with the assistance of our Advisory Group and informed by members of the Network Action Team (NAT) on FASD Prevention from a Women's Health Determinants Perspective[1], we identified communities, organizations and key informants involved in provision of substance use treatment and care, supports and/or services for women with FASD. Wherever possible, we included informants who were: 1) highly knowledgeable about FASD; and 2) who were involved in the delivery of innovative programs in the area of FASD supportive interventions or FASD prevention for women with (suspected) FASD. Thus, our sampling technique for the environmental scan was purposeful, wherein "information-rich cases" were selected as the focus of in-depth study (Morse, 1994; Sandelowski, 1986).

In addition, in undertaking the environmental scan, we were mindful of the importance of strengthening collaborations amongst the project's partners. For example, considerable amount of time was spent in the fall/winter of 2007/2008 building on the existing networks amongst FASD researchers and program delivery staff, in particular those involved in projects funded through the Victoria Foundation's FASD Action Fund and the Canada Northwest FASD Research Network. As well, the project team worked closely with partners at the Canadian National Coalition of Experiential Women (CNCEW)/PEERS who were developing a Task Force and community-based advisory committees to find out what existed in communities in relation to substance use treatment for women with FASD.

We also collaborated closely with partners at the BC Centre of Excellence for Women's Health (BCCEWH), who, concurrent with this project, were carrying out a research project that focused on promising practices in substance use treatment and support for First Nations and Inuit women at risk of having a child affected by FASD. Finally, we were appreciative of assistance provided by project partners from Aurora and the BCCEWH, who convened a group interview for this environmental scan with key informants who were experienced counsellors at the Aurora Centre, regarding their experiences in working with women with FASD.

Informants

A total of 40 individual interviews and one group interview (involving 6 people) were undertaken for the environmental scan component of this project. In order to have overall geographic representation across the province, informants came from 12 communities and all regions of British Columbia.

The environmental scan informants included managers and staff of a variety of organizations offering a range of services/programs, such as:

- Residential treatment facilities
- FASD-focused organizations
- FASD prevention or FASD support-related programs

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

- Sex worker organizations
- Support groups for substance using women or women at risk of having a child with FASD
- Addictions Recovery Support Groups
- Mentoring programs for high risk women

Interview Focus and Process

The majority of the environmental scan interviews were conducted as telephone interviews, although face-to-face interviews were carried out with approximately 10 informants. As well, as noted above, one focus group was carried out with a group of experienced counsellors at a residential treatment facility for women. Interviews ranged from 20-90 minutes in duration, though most were approximately 30-40 minutes. Interviews for the environmental scan were conducted during spring through fall, 2008.

In adherence with ethical protocols, informants completed an informed consent process and consent form prior to taking part in the interview.

The interviews involved a semi-structured format involving open-ended questions. The development of the questions was guided in part by our project advisors/partners; questions focussed on informants' perspectives about:

- the experiences of women with (suspected) FASD in treatment and/or related programming;
- barriers faced by women with (suspected) FASD in accessing and/or in completing treatment;
- effective or promising approaches in working with women with (suspected) FASD;
- approaches that have not worked well for women with (suspected) FASD; and
- what would help improve the design/delivery of programming and care for women with FASD.

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

3. Findings

Barriers for Women with FASD in *Accessing* Substance Use Treatment Programs or Care

Environmental scan informants identified a number of barriers to accessing treatment, care and other needed support for women with FASD. Overall, the barriers identified paralleled those reported in the literature for women, and, as has been described in the literature, the barriers may be categorized as systemic, program-level and personal/social barriers (Network Action Team on FASD Prevention 2007; United Nations Office on Drugs and Crime, 2004).

Moreover, the barriers identified by environmental scan informants spoke to the need to understand women's substance use issues and care-related needs within the context of their life *as mothers*—and as importantly, as mothers living in deep poverty, as mothers fearing the possible removal of their children should they seek treatment (and/or identify as having FASD), and as women who may have co-occurring and often inter-related issues such as mental health problems, violence or abuse in relationships, trauma, as well as problematic substance use.

The barriers also focused on the very limited availability of local resources for women seeking treatment or care, especially comprehensive or holistic resources that are geared to addressing women's multi-faceted needs. Similarly, informants noted that knowledge about what resources existed, even within a person's own community, often wasn't well-known, and thus women who did not have support people or a service navigator faced challenges in accessing care.

Themes of systems-related and program-level barriers to accessing treatment and care identified by informants thus included:

- Fear of children's apprehension and/or concerns about stigmatization
- Presence of co-occurring issues means integrated care is required yet often not available
- Lack of transportation and/or high cost of travel to programs and appointments
- Lack of child care, and/or funding for child care and/or other supports for participation
- Lack of locally available programs for women

In informants' words:

> So many of the women won't go to treatment because they are afraid they will lose their kids.

> Stigmatization—if you are using any services you must be 'crazy'. People know each other, pay attention to gossip or rumours.

> Transportation is the largest barrier, as there is no public transportation. People who need services cannot access them due to not having a vehicle, or if they have one, it is too old. Gas is too expensive and there is no other transportation. As well, the geographic distance to services is quite far.

> More complex / multi-faceted and integrated care is required, yet these holistic or coordinated resources often do not exist in communities.

In addition to these barriers, several informants also identified obstacles that pertained to women with FASD more specifically. These barriers included:

- Challenges in understanding and completing the forms associated with the application process
- Anxiety about a lack of fit with existing programs
- Need for ongoing, hands-on assistance in remembering about and getting to appointments

As described by informants, women with FASD likely needed support in completing the application forms for treatment/care programs, given these women's difficulties with comprehension and literacy.

Moreover, women with FASD likely need support in ensuring that their referral source (e.g. their physician or psychologist) followed up with all the paperwork related to the referral. As a related point, one informant stated that community professionals' lack of understanding of FASD as a *spectrum*, with variable effects or disabilities—and hence, that people with FASD had wide-ranging individual characteristics—was a barrier to accessing service.

> Completing forms is a barrier. They don't understand what is being asked of them. Their cognitive and memory problems make it hard for them to do the forms or to be accurate in their responses.

> Getting the referral completed [is a barrier]. Recently one woman with FASD almost did not get in because her psychologist had not signed off—needed an extra push from us to get all the paperwork in place.

> FASD is very much outside the medical model. One barrier is the community's perception that FASD is a straightforward entity/diagnosis. There is no recognition that it is a spectrum. That recognition would be needed, to think in terms of individuality and individual differences in people.

Informants also identified the structure/format and theoretical approaches used in typical treatment programs as being barriers for women with FASD. For example, several informants pointed out that many women with FASD might have difficulties being in group-based treatment (i.e., therapy groups with a psycho-educational focus).

Informants also noted that rigid rules that often were part of typical treatment programs, such as being on time for all treatment sessions, likely would pose problems for women with FASD unless they had support from someone who could provide reminders and/or assistance with transportation on a regular basis.

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> Women with FASD may have anxiety attached with inability to handle groups.

> The barriers are very significant—getting to an outpatient counsellor, one that has patience and expertise, not missing the appointment.

> Getting people to their appointments or to group meetings is integral. And to do this, you need to build in time to the program's staffing budget.

Barriers for Women with FASD in *Succeeding* in Substance Use Treatment Programs or Care

In addition to barriers in accessing care, informants identified several barriers to completing substance use treatment programs for women who had FASD. In keeping with findings reported above, the primary overarching theme that emerged was that existing programs were a poor fit for women with FASD. More specifically, programs' structure and/or process, programs' content, and programs' physical environment were said to pose barriers for women with FASD.

> Women don't understand and thus can't follow program rules—for example, around time management (e.g. not being late for or missing meetings or sessions).

> The programs all stress compliance, being at appointments on time. And all kinds of inappropriate attributions are made when they aren't on time or don't show up.

These women don't understand the whole process of treatment. Their missing meetings is misunderstood by other clients and by workers as noncompliance. They also can get overwhelmed and act out. They leave the program or are asked to leave.

In addition, many environmental scan informants emphasized the difficulties that women with FASD experience in working in groups or in a group therapy setting: the impulsivity of women with FASD and their poor social, interpersonal and/or communication skills made groups frustrating for them and adversely affected the other women in the group as well.

> Women with FASD can have difficulties with group work. Women's poor social or interpersonal skills impede group process. Other women in the group may not feel safe.

> The group environment is problematic. The behavioural symptoms of FASD may mean that these women don't do well in groups. Other women view them as disruptive and at odds with other women's needs for safety. Other clients get frustrated when the group is disrupted because of FASD-related behaviours. So, if there aren't adequate staffing resources, we're in trouble.

In discussing challenges relating to programs' content, one informant stated that typical treatment programs were problematic for many women with FASD because the curriculum for the psycho-educational and/or therapeutic sessions tended to be abstract and to presuppose that women could be introspective and could identify goals, make plans and be able to execute a series of steps related to their goals.

> The content of programming, especially that which demands women to be self-reflective or to engage in abstract thinking, may be inappropriate.

> They particularly have difficulty with the educational workshops and groups—they don't understand the information being discussed in the workshops.

Too much visual clutter or auditory noise impedes the women's ability to participate successfully in substance use treatment programs.

In addition, several informants identified barriers relating to the physical environment in which typical treatment programs are situated, indicating that too much visual clutter or auditory noise impedes the women's ability to participate successfully in substance use treatment programs.

> Lighting, noise, clutter may be distracting.

> Another thing is how much action is around here—often it keeps the women from accessing our services because of all the people around, the noise, the posters on our walls, the fluorescent lighting. It's too distracting.

Service Providers' Perspectives on the Experiences of Women with FASD in Substance Use Treatment Programs

Environmental scan informants were asked to share their understanding of the experiences of women with FASD in existing treatment programs. Although the question was asked in an open-ended way, informants' answers emphasized the struggles that women experienced, and the themes were very similar to those presented above in response to the preceding question. The main themes included:

- Women with FASD struggle with the group component of programs' structure
- Women with FASD struggle with programs' content, especially material that is abstract
- Women with FASD and concurrent issues (substance use and mental ill health and/or violence/abuse in their relationships) struggle because programs are not set up to address complex needs

In discussing the latter theme, informants noted that for women with FASD, the ramifications of programs not being equipped to address women's complex needs had real implications for women's ability to successfully complete the programs.

> The programs in existence are designed for people who function well mentally. Clients cannot complete treatment because the program is set up for the average 'person'. The programs are not suitable for people suffering concurrent issues —bipolar and addiction and FASD, too complex for treatment centres. Also, those with FASD are sometimes self-medicating because they may have mental illness gone unnoticed.

The issue is not women's motivation to comply, but their ability to behave in keeping with programs' expectations.

In speaking about women's experiences in typical treatment programs, informants were clear that the issue was not women's motivation to comply, but their ability to behave in keeping with programs' expectations. Related challenges were the twin issues that: 1) treatment program staff often lacked training in and understanding about FASD; and 2) women with FASD often hadn't had a formal assessment or diagnosis and/or did not self-identify as having FASD. As informants stated:

> Staff don't understand FASD—they are punitive and see the women as non-compliant.

> A lot of women don't admit to having FASD, or don't know they have it.

> Many women self-identify that they may have FASD—that triggers our knowledge. Others, we may suspect that they may have FASD or a brain injury by their behaviours, by their seeming like they aren't 'getting it'.

> Often we don't have the facts of a client's FASD. We do not diagnose. We go by their behaviour and whether they can adjust to the rules.

Another issue identified as affecting the treatment experience of women with FASD was fact that nearly all residential programs could not accommodate women's children on-site. Again, this was noted above as a key barrier affecting women's access to treatment and care, and is an issue that affects women with and without FASD alike.

> One woman couldn't concentrate on the program because she was worrying about her child and potential child welfare issues, including apprehension.

> One lady, she didn't really concentrate on the treatment program because she didn't have her kids. She could've concentrated more if her kids were there.

Finally, many informants noted that the lack of supported housing in communities for women post-treatment was a serious challenge for women with FASD—and while it was named as a challenge for women overall, the lack of supported housing was viewed as being of heightened importance for women with FASD. As these informants stated:

> It is all the more difficult because these women are very transient, lack stable housing and support people to use as contacts.

> Once women leave our program we try to follow up, but often it is very difficult because of the transient nature of these women's lives.

Further, in commenting on the rate that women with FASD completed substance use programs at her residential treatment facility, one manager stated that many women were able to complete the program, but they struggled, and issues in maintaining gains made during treatment were particularly pressing for them:

> Women with FASD complete the program in essentially the same numbers as other women. However, they struggle more, and concerns regarding lack of after care and follow up are especially pressing for them. ...We do have a fairly high completion rate. We try to be flexible.

Counterbalancing discussion of the difficulties faced by women with FASD, a number of informants spoke of some women having had positive experiences in substance use treatment programs.

Overall, themes in these comments emphasized the importance of a program having capacity to provide particular accommodations in keeping with the needs of clients with FASD. These accommodations included:

- One-to-one support; more intensive support
- Individualized case management
- Relaxation of program requirements/rules regarding attending all group sessions
- Many reminder phone calls and check-ins
- Use of outreach approach to day programs
- Staff's knowledge of FASD and use of an FASD-lens in working with women

In informants' words:

> From a clinical perspective, working with someone who is living with FASD means many reminder phone calls and check-ins. When we do this, the success rate of continued connection increases incredibly.

> If possible, and if resources permit, we try to modify the program to the extent that we can—for example, by having an additional staff person or a student working with them one to one. We also may modify the program expectations—that is, they might not be required to attend every group workshop.

These and similar themes regarding accommodations made to improve treatment experiences and outcomes for women with FASD are described more fully in the discussion that follows.

Working with someone who is living with FASD means many reminder phone calls and check-ins.

Promising Practices—What has Worked Well in Substance Use Treatment Programs or Care for Women with FASD

Care Providers' Understanding of FASD as a Brain-based Lifelong Disability

Implicit in nearly all of informants' responses to questions about both what has worked well and what is needed was a pivotal theme: first and foremost, what was needed was care providers' and program planners' understanding of FASD as a brain-based lifelong disability. This knowledge was central to the development of practices and approaches that worked well for women with (suspected) FASD.

Knowledge about FASD—acquired through professional education and/or ongoing and on-the-job training—was seen as a prime catalyst for change in the way in which programs and staff operated, paving the way for flexibility and potential implementation of a variety of environmental and programmatic accommodations. In addition, program staff's knowledge about FASD led to shifts in their expectations for the women, as well as a more accurate understanding of the women's potentially problematic behaviours.

Further, several informants were quite explicit about the importance of counsellors and managers being knowledgeable about FASD and using an "FASD lens" when working with people who had behaviours and characteristics in keeping with FASD or a similar neuro-developmental disability. Informants also spoke of the importance of care providers' understanding of other relevant issues such as the impact of trauma, residential school, and colonization.

> Professionals need to have a better understanding of women's information processing problems and barriers. It's not that they are unmotivated.

> Staff of treatment program would have to understand FASD. ...Staff need extensive amount of training – not just in FASD, but an understanding of trauma and mental health issues, effects of colonization and residential schools.

Plain, Clear, Concrete Language, as Well as Accommodations for Communication and Memory

In view of difficulties that many people with FASD have with receptive communication, as well as their problems with abstract thinking and memory, a number of communication strategies and/or aids were noted by informants to be effective, including:

- Use of repetition
- Use of plain, concrete language
- Slowing down the pace of conversations and discussions
- Breaking down instructions into small steps
- Providing direction and focus in discussions
- Use of journals and log books
- Tape recording sessions to allow for review
- Using reminders
- Using texting as a way to provide reminders and to stay connected

Informants' comments and stories regarding the importance of making accommodations in keeping with these women's cognitive and communicative needs included:

We use constant repetition—there's recognition of the woman's cognitive limitations and her memory problems.

[We] provide a drop-in and serve a lot of women with FASD. We have changed our language and approach with this population. We have an addictions support group on Thursdays. It isn't specifically for women with FASD, although a lot of the women are affected. So staff facilitate this group in a way that these women can understand. I've noticed that language is a huge barrier, and I have to break the language down.

With [clients who have] FAS or Acquired Brain Injury, I most often have a Supportive Care Worker or another client help them with putting the day's schedule in the cover of their binder every morning, so that they have a concrete simple outline of what they are doing that day. We put in a note that says whether they are in Group A or Group D so that is not a confusing issue, or we highlight all the places they need to be. By Week 3, I ask them to come and do it themselves in my office in the morning and usually by Week 4 or 5, they have mastered the skill and can do it themselves.

Good Practice Tips:
Using Concrete Language and Visual Cues

Care providers at one BC treatment centre for women identified a number of communication strategies that they that had found to be useful with women who may have had prenatal substance exposure, including:

- In group work, using a stop watch or egg timer can help women gauge the length of time they have to talk;
- Asking women to use colours or animals to describe their feelings if it is hard for them to use feeling words;
- Using a concrete representation of things, such as:
  having a basket of rocks to represent all the people in the woman's life that she wants to share her love with.
  having a big blue beach ball to represent the guilt that a woman carries around with her.
  having wool laid out on the floor to show the concept of boundaries.
- Having pictures of the counsellors on the counsellor's office door.

Accommodations in Program Format

A second major theme in relation to "what works" for women with FASD was the notion of making accommodations in the format of the program, in keeping with women's needs. Informants thus spoke of the need for *flexibility* in terms of:

- the timeframe—either in the length of a session, group, or the duration of the program
- the requirement that women attend all sessions of the group
- the requirement for women to sit still during groups
- the requirement that women write a chronology of their alcohol and drug history

In addition, for programs that typically involved clients doing "assignments" and/or written work, several informants noted that allowing women to produce their work in *non-written format* worked well for women with FASD (though by contrast, informants noted that writing and reflecting on their alcohol and drug history worked well for many women without FASD).

As well, informants commented that they found it worked well when a given option or accommodation was made for the whole group, rather than for individual participants—that way, women who may have FASD didn't feel singled out and possibly stigmatized for being different. Elaboration of these ideas is provided in informants' words below:

Good Practice Tips:
Being Flexible and Creative, and Making Accommodations in Format

Care providers at one BC treatment centre for women identified the following strategies that they that had found useful in working with women with FASD:

- Not making the writing of an alcohol & drug history mandatory. Also, allowing the history to not be sequential, or, allowing the woman to include only the highs and lows.
- Instead of requiring women to write their alcohol and drug history, having women with FASD make a collage—cutting out pictures from magazines of things they associate with their substance use or with their healing.
- In goal-setting, helping women with FASD break their goals down into smaller pieces, with concrete steps. And, similar to the above point, allowing women to opt out of writing out their goals; instead, using a shoebox and having women put things that represent recovery in the box, decorate with words like "gratitude" etc.
- In group sessions, allowing women who get restless to get up and walk around. This helps not only those with ADHD or FASD, but also those with back problems.
- Making the adaptations for the whole group and thus not just singling out the woman with FASD. For example, we make it a norm that people are asked to explain what they mean. The counsellor assumes role of Madam Curious—encourages curiosity about the women's own patterns and challenges, making it valued to ask when you don't understand. The difficulty with reading social cues can be the biggest issue for women with FASD in treatment, not the cognitive challenges.

Accommodations to the Physical Environment

Another theme that emerged in relation to "what works" for women with FASD was to be cognizant of the impact of the physical environment on women, and to keep the environment "uncluttered" and calming from a sensory perspective. Along with this was the importance of having visual cues in buildings and in the outdoor environment regarding the location of particular offices and meeting spaces. Informants stated:

> We are watching to see how the environment affects the woman. Lighting makes a difference, as does clutter in the office.

> There needs to be improvements in the physical settings—having a quiet space for interviews or discussions, and making adaptations like having pictures of people on doors.

FASD-informed Theoretical Frameworks, Approaches and Program Components

Informants identified a number of theoretical and/or practice frameworks that they believed worked well in relation to substance use treatment and/or care for women with FASD.

It is interesting to note that nearly all of these theoretical frameworks and/or approaches also have been recognized to be components of effective women-centred substance use treatment/care (irrespective of women being prenatally exposed to alcohol or not), and are included as elements of FASD prevention from a women's health perspective (Network Action Team on FASD Prevention from a Women's Health Determinants Perspective, 2010; Poole, 2008). At the same time, environmental scan informants in this project identified these approaches as working well for women with FASD.

Relational approach

Several informants spoke of the importance of the relationship and connection between the woman and her counsellor and/or with other group members; along with this were comments regarding the need for women to feel safe, respected, welcome, and accepted, and for women to know that someone was committed to go to bat for them and stand by them, i.e. that the counsellor or program wouldn't "give up" on them.

As well, one informant noted that once there was a trusting relationship between the woman and her counsellor, what worked was for the counsellor or program staff to encourage the woman to talk about the day to day impacts of living with FASD, and especially how this might affect the woman's needs for support. In informants' words:

> Building relationships of trust are ways to recruit women into addictions services and/or treatment.

> Stay with people. Don't give up or kick them out of the program. Talk about the disability and how it affects them day to day.

> Most important is to create a safe environment that is accepting of the women. Need to be an advocate and to promote self-advocacy, since these women are often taken advantage of.

Along these lines, staff of one substance use treatment centre for women spoke of the process they used in order to have the group develop connections with and a sense of compassion for one another. Of note, and in keeping with being FASD-informed, was the idea that the program staff used a visual tool with all group members to help the group to elicit and articulate their individual strengths and challenges.

> All of this requires compassion from the group, it can be time consuming, can slow the whole group process down. To elicit compassion from group we try to use a visual tool that has everyone's strengths, challenges and preferences on flip charts on the walls around the group, so that everyone can refer to this easily.

Individualized one-to-one support and case management

In keeping with a relational approach, informants emphasized that what worked for women with FASD was having one-to-one support for the woman that was individually-tailored to her needs and preferences

for support. One-to-one support, provided either by a staff person/counsellor or a mentor, was particularly useful in situations in which women needed to fill out forms, apply for services, identify their goals and create concrete action plans to achieve their goals.

What worked for women with FASD was having one-to-one support for the woman that was individually-tailored to her needs and preferences for support.

This individualized support was similar to the idea of intensive case management, which also was voiced by informants as an approach that worked well for women with FASD. With intensive, individualized case management, a designated staff person/counsellor—i.e., someone with whom the woman had established a trusting relationship—would oversee the woman's care plan on an ongoing basis in order to help ensure that follow up actions had been taken in keeping with the woman's plans and goals.

> There also needs to be an integrated approach—this means that there would be an individualized treatment plan and an individual counsellor of people with FASD. Having this kind of structure would be very beneficial. For example, on intense therapy days (Tuesdays and Thursdays) maybe have an individualized program in the morning, and then a group program in the afternoon. That way the person isn't marginalized or segregated; they participate as they are able. With an individualized plan, together the client and the counsellor come up with personal goals, objectives and a plan. They then have regular follow up meetings to ensure that the client stays on track. The plan must be simple, concrete and relevant.

Another nuance in some informants' comments in relation to individualized care was the idea of "starting where the clients are at" or, in other words, having the treatment or care plan be guided by the woman's readiness to make changes in her life (as determined by the counsellor's use of motivational interviewing, albeit adapted as needed in keeping with the woman's cognitive abilities and needs).

In commenting about the value of one-to-one support, several informants—particularly those affiliated with residential treatment programs—also noted that individualized support generally wasn't available in their program or facility due to funding restrictions. Those who accessed one-to-one support typically were able to do so when this support was covered through the person's insurance. However, one informant stated that in one instance, when the treatment centre's managers became aware that a woman had FASD and would benefit from a more individualized approach which included some one-to-one support, changes in the program's format were made to accommodate the woman's needs. Overall, all comments regarding one-to-one support underscored the notion of individualizing the support, in recognition of women's diversity.

> Having additional support, e.g., a support worker or life skills worker who can provide one to one support for the person. This doesn't currently exist, although people who have a brain injury often have a support worker, which is paid via their insurance.

> Individualize – recognize the diversity of those with FASD.

> Good practice is starting where the clients are: having individual and individualized programming as much as possible, and having an individual treatment plan. Currently, this is done only when something triggers the need, because we don't have the resources to do this for everyone. But it needs to be done for people with FASD. That would be really important.

Along similar lines, another informant spoke of the importance of supporting women with FASD and substance use issues to have a connection to a primary care provider and to community supports, including her physician and support groups:

> The woman needs to create and maintain connections with her doctor, with the community, and with a drop-in group.

Outreach and open door approach, emphasizing safety

Another approach related to one-to-one support that informants believed worked well for women with FASD was to use an outreach approach – that is, what worked was having staff/counsellors and/or mentors be proactive in making contact with women, letting women know they were available to meet in the women's home or at another place of the woman's choosing, and doing phone check-ins, rather than waiting for women to come to them. In addition to being convenient for the woman, having a care provider or mentor come to the home permitted the worker to gain a better understanding of the woman's life in context. As one informant stated:

> There have been times where our staff have been able to gain insight into women's situations (both strengths and challenges) that would be impossible if there was not the opportunity to work at their homes.

An outreach approach also implied that the support provided through a program or resource was available after typical working hours, e.g., at night and/or on weekends. This was deemed important because of the need of women with FASD for crisis-related support (which generally occurred after typical daytime work hours) and ongoing supports.

> There needs to be outreach support that is available outside of normal working hours, e.g., teams of people round the clock.

Other outreach-related supports that were noted as being important and facilitating women's success with programs were offering food or refreshments and providing transportation. Informants further emphasized that program budgets needed to reflect these costs, especially staff time relating to clients' transportation.

Other outreach-related supports that were important and facilitated women's success with programs were offering food or refreshments and providing transportation.

> [What works well] are programs that focus around food. Come and eat and do a workshop.

Harm reduction approach, emphasizing safety

Informants believed that for women with FASD, it was important that programs be guided by a harm reduction approach, so that program staff focused on working with women to address the issues or areas in their life that put them at (highest) risk for harm or danger, rather than to require a goal of abstinence relating to their substance use. In other words, women's safety needed to be of primary concern.

As well, one informant noted that a harm reduction framework was important in that it was non-punitive and recognized that a women's healing journey was a process that most likely involved periodic substance use.

> [What works is] recognizing that relapse happens and working from a harm reduction framework.

Women-centred and gender-specific programming

Along similar lines, two informants indicated that what worked in their organizations was to have women-centred and/or gender-specific treatment programs, in recognition that women's reasons for using substances, their social context and needs, and the realities of their life, including their life as mothers, were different from those of men.

> Gender-specific programs have contributed to our success.

Holistic and comprehensive approach, attending to women's needs in various areas of life

[What works is] a multidisciplinary approach that addresses women's needs in a holistic fashion.

Lastly, a strong, overarching theme in terms of "what works" was for programs to be holistic and developed with an understanding that women with FASD likely

would require long-term or ongoing support in many spheres of their life, including parenting, grief and loss related to parenting, and housing. Thus, women benefitted when programs were multi-faceted in focus and/or were connected to other programs and resources relating to other areas of the woman's life. In one informant's words:

> What works is the use of a collaborative team approach—community of support —support in all aspects of the woman's life, e.g. house cleaning and life skills. ...These women are: raised in poverty; raised in foster care; have substance use issues; need to deal with the multiplicity of issues. ... Working with women with FASD is a long-term commitment. It's such a privilege to see these women raise their children against all odds.

A number of informants specifically noted the importance of ensuring that programs were able to provide or arrange and provide resources for child care and transportation:

> Counsellors have, on occasion, picked women up, and have arranged for babysitting at other organizations.

As well, informants spoke of the value of treatment programs focusing on helping women to develop or improve their life skills (rather than use either insight-oriented or cognitive behaviour therapy):

> Emphasize lifeskills over insight.

Summing up this theme, one informant stated:

> Research [about substance using women and FASD prevention] clearly indicates many women will cease using when their more basic needs are met. Food, clothing, shelter, safety and advocacy, help with custody and legal issues, programs like Structured for Success. [What works is] a multidisciplinary approach that addresses her needs in a holistic fashion.

Good Practice Example:
Making Accommodations to a Program's Structure and Focus

Staff of one BC treatment centre for women made modifications to a residential treatment program upon realizing it wasn't meeting the needs of the women participants whose issues were congruent with those of women with FASD. In one manager's words:

> *Aurora did an innovation on a 5-week residential program. When we realized our criteria were high—we had set the bar too high in terms of our requirements for women's participation—we came up with two 2-week programs.*
>
> *Life skills was the focus of our "Finding Balance" program, [which was for women] in the early stages of recovery, and the second 2-week program was called "Keeping Balance". Though not designed for women with FASD, these programs could be congruent with their needs.*
>
> *The first program was not as intensive from psycho-therapeutic perspective – it wasn't looking at deep issues that require insight (e.g. why they used; what caused them to start using). The early program was practical, focusing on like skills content.*

Examples of Promising Programs for Women Who May Have FASD

Only a handful of informants were able to identify examples of existing programs that they believed were geared to and effective for women with FASD.

Moreover, of the four program examples discussed by informants, three were demonstration programs that had only been created within the previous 1-2 years. All of these were developed based on time-limited (e.g. 3-year) project funding granted by the Victoria Foundation through a special fund established for community-based, FASD-related projects. These projects were in process of being evaluated, but no published evaluation reports were available at the time of conducting interviews with environmental scan informants or when writing this report.

It is also interesting to note that none of these promising programs focused specifically or exclusively on substance use treatment. Indeed, one important element that these programs had in common was that they were guided by holistic frameworks that recognized that people with FASD needed ongoing, coordinated support in multiple areas of life.

Three of the four programs focussed on parenting, with emphasis on life skill development, case advocacy (wherein a one-to-one worker or mentor supported the person in accessing assistance in whatever life domain(s) were needed), and one program was connected to an addictions recovery support group for adults with FASD.

Overall, common features of these examples of promising programs included:

- Programs are FASD-informed
- Programs strive to be holistic, recognizing participants' multiple, inter-connected needs (needs in relation to parenting, substance use, health and mental health)
- Whole family is involved / welcome

Capsule descriptions of these four programs are presented on the following pages.

What is Needed to Improve the Accessibility, Design and Delivery of Substance Use Treatment Programs and Care for Women with FASD

Environmental scan informants were asked two separate yet related questions regarding what would help improve substance use treatment for women with FASD (i.e., What would help improve *access* to programs/care, and What would help improve the *design and delivery* of programs/care). Because of the similarity of the themes that emerged, findings for the two questions have been integrated in the presentation that follows. Themes that focus specifically on accessibility issues are presented first, followed by findings focusing on what is needed to improved the design and delivery of substance use programs and care for women with FASD.

Outreach and one-to-one support for transportation, and enhanced program funding to enable accessibility-related accommodations

The primary theme that informants voiced in relation to what was needed to improve accessibility was the need for programs to have an outreach focus, wherein program staff provided reminder calls before each session, and/or resources existed to provide women with transportation and/or accompaniment.

Informants living in non-urban communities also voiced the importance of having programs located in the community in which the women lived.

Family-accessible treatment programs and/or availability of child care so that women have care for their children while they attend their program

Building on this latter point, another theme was for programs to be accessible for families, in recognition that women typically had children whom they feared could be apprehended should they leave the community in order to attend a treatment program. Thus, informants suggested that what was needed

Promising Practice in Action:
Structured for Success Parenting Program, with linkages to Whitecrow Village's Addictions Recovery Support Group (Prince George, BC)

Description:
Structured for Success is a parenting program designed for parents who themselves may have FASD or have been prenatally exposed to alcohol. The program has been developed using a FASD-lens and provides support, assistance and instruction with daily living and problem solving skills, as well as linkages to mental health services. Similarly, the Addictions Recovery Support Group connected to *Structured for Success* was designed for people with prenatal alcohol exposure.

Key features:
- Families first go into *Structured for Success* and then can access other programs (e.g. the Addictions Recovery Support Group); thus, participants of the Addictions Recovery Support Group are also in *Structured for Success*.
- The Addictions Recovery Support Group is a closed group; this promotes better cohesiveness within the group.
- Discussions about substance use are integrated into *Structured for Success*.
- The whole family is involved in both programs.
- Both programs are guided by a relational approach whereby staff have relationships with the whole family: children, youth, parents, extended family, etc.
- Both programs are trauma-informed, recognizing that participants may have experienced abuse and/or may be survivors of residential schools.
- Support provided through *Structured for Success* may be intensive and ongoing.

As noted by program developers and staff:

> Structured for Success *isn't limited to one hour a day. It's holistic. There's a parenting group and a recovery support group—the programs are integrated.*
>
> *What's different with* Structured for Success' *recovery group is the safety for birth moms.*

Promising Practice in Action:

Supportive Optimistic Advocacy Restorative (SOAR) Mentor Program, Offered Through the Inter-Tribal Health Authority (Vancouver Island First Nations)

Description:
The SOAR Mentor program provides mentoring, support and assistance to women and their families with an aim of maintaining healthy lifestyles and preventing births of babies who are prenatally exposed to alcohol. The program is modelled after the PCAP program developed in Seattle and was adapted for First Nations women who either have used alcohol during pregnancy, who have given birth to a child who may have FASD, and/or who may have FASD themselves. The program was been developed using a FASD-lens and also emphasizes traditional cultural practices.

Key features:

- SOAR uses a relational approach wherein the development of a trusting relationship between staff/mentors and women participants is central to the success of mentoring activities, advocacy and personal growth and change.
- Program provides women with practical support (e.g. transportation), case coordination, and access/advocacy relating to other services.
- An additional primary program activity is to help educate community and other service providers about FASD.
- Advocacy—helping women to find their voice—and to access supports and resources is another key activity for the mentors
- Cultural involvement is key: mentors connect women to their cultural identity using existing supports, elders and family.
- Caseloads for staff are reduced relative to other home visiting or mentoring programs (e.g. caseload = 10-12 women).

As noted by program developers and staff:

[We] remind service providers that FASD is a recognized brain injury and results in limitations beyond the woman's control.

We have found that many women need support to remember to attend and actually get to appointments. Without a support person to facilitate the process, many appointments are missed. …We've learned not to assume that women are literate, and to avoid reliance on written material. Having one to one support in completing these kinds of tasks [is important].

Promising Practice in Action:
Crabtree Corner FASD Peer Support Program, Offered Through the YWCA (Vancouver)

Description:
For many years, Crabtree Corner has been offering community programs to parents and families, including parenting programs, short-term housing, early learning and development programs, and violence prevention programs. Crabtree Corner's FASD prevention program provides multi-faceted support to pregnant and/or parenting women who are at high risk of having a child with prenatal alcohol exposure. This program, like many of Crabtree's other programs, was developed using a FASD-lens.

Key features:
- Emphasis on ensuring that staff have strong understanding of FASD.
- Programs are guided by a relational approach.
- Programs use a holistic and collaborative team approach in order to create a community of support in all aspects of the woman's life.
- Programs are trauma-informed; staff have training in and understanding of trauma and mental health issues.
- Group model works well for women who are not street-entrenched, i.e., for women who are further along in their healing and who are not currently using alcohol and drugs.

As noted by program developers and staff:

We take FASD into account in thinking about parenting. For example, dysmaturity—we think about the need to explain things simply; we provide lots of repetition; we talk about the disability and how it affects them day to day. You're working on so many levels.

We understand women's need for reassurance. We make allowance for missed appointments. We do phone check-ins. We stay with people (don't give up or kick them out of the program). What's most important is to create a safe environment that is accepting of the women.

You need to be an advocate and to promote self-advocacy, since these women are often taken advantage of. …These women are: raised in poverty; raised in foster care; have substance use issues. They need to deal with the multiplicity of issues.

Working with women with FASD is a long-term commitment. It's such a privilege to see these women raise their children against all odds.

Promising Practice in Action:
Whitecrow Village's Addictions Recovery Support Group for Adults With FASD Offered Through Whitecrow Village (Based on Vancouver Island BC)

Description:
Whitecrow Village's programs are based on the strong belief that, "working interdependently with appropriate support, adults with FASD can identify and design their own healthy and stable living requirements." Whitecrow also maintains that the "environment is a major factor in the presence or absence of alcohol and drug abuse and misuse." Thus, in developing Whitecrow's Addictions Recovery Support Group, the program designers focussed on aspects of the environment in the group that could make a positive difference to participants. The Addictions Recovery Support Group was developed using a FASD-lens, and uses a 12-step approach that was adapted to be appropriate for adults living with FASD.

Key features:
- Facilitators of the Addictions Recovery Support Group have a strong understanding of FASD
- The support group is guided by a holistic approach wherein substance use is addressed in the context of the whole person
- Whitecrow's approach to 12-steps is: more concrete; life-skills focused; there are more opportunities for clarifications; more flexibility; more participant-directed; more interactive than the standard 12-step program meetings, with more opportunities for group discussion
- The Addictions Recovery Support Group is strengths-based, with acknowledgement of the strategies that are working.

As noted by program developers and staff:

It's the intangibles of the environment that make a big difference, e.g., respect, use of language—respectful language, concrete, simple language, checking for people's understanding.

The biggest piece of the research with the addictions recovery support group sessions is how to create a sense of refuge and safety, a camplike environment within a weekly session.

were either substance use treatment programs that could accommodate whole families, or programs' provision of respite and/or child care to enable the woman to access a program or resource.

> Support for her whole family. There is always a fear that they are going to get their kids taken away.

Informants clearly appreciated that making these accommodations to improve accessibility had costs attached to them, and moreover, that removing barriers for women who may have FASD was a significant endeavour that required action across multiple sectors of the health and social care system.

> It really will take a system-wide effort to educate and catalyse action about the right to inclusion and the specific steps for women with FASD to access treatment.

Nevertheless, informants strongly believed that these accommodations and accessibility-related policy shifts were what were needed for women with FASD. Without these, women would continue to fall through the cracks, and care providers would miss opportunities to offer support to women who came forward for help.

Mandatory training about FASD for all care providers, and ongoing FASD-focused supervision, mentoring, and support

> *"Education, education education! ...All addictions counselors need mandatory training in FASD."*
>
> *-Interview Informant*

Mandatory training about FASD for care providers was most frequently voiced by informants in relation to the question "What is needed to improve substance use treatment and care for women with FASD?" Indeed, several informants expressed concern regarding the paucity of knowledge that appeared to exist about FASD amongst many staff of substance use treatment facilities or programs, as well as concern about the lack of a requirement that program staff, or service providers in related fields, receive training regarding FASD.

> Education, education education! ...All addictions counselors need mandatory training in FASD. Also, there needs to be a mandatory component on addictions in all BSW and MSW programs.

More specifically, informants spoke of the importance of ensuring that care providers at treatment facilities and programs had a strong understanding of the challenges and issues faced by adults living with FASD, along with knowledge about strategies that were appropriate and effective in working with women with FASD:

> Training should include practical strategies for working with women with FASD.

Care providers' experience with and understanding of FASD was necessary in order to help ensure that they had appropriate expectations for the people they were working with, and would not be "overwhelmed" by clients' life situation and/or needs.

> Support to hire staff with education and experience who will not be overwhelmed by the nature of the population they are working with.

As a related theme, several informants noted the importance of ensuring that care providers were well supported. In view of the intensity and potentially taxing nature of the work, informants emphasized the need for strategies to avoid burn-out, including making regular time to debrief, consult, and share successful approaches and practice tips with colleagues and/or supervisors, ongoing education about FASD, and setting and maintaining personal boundaries.

> Staff need to pay attention to self-care and make time for debriefing. Working with people with FASD can be VERY intense; you need to have boundaries given the women's dependencies. It can be very taxing. Staff need to be able to recognize their triggers.

Using an FASD-Lens in Program Planning and Delivery

Closely linked to the preceding theme was the need for FASD-informed programs—that is, substance use treatment programs and care that were informed by an FASD lens and an understanding of FASD-related accommodations. According to environmental scan informants, FASD-informed and FASD-friendly approaches included:

- Drop in programs
- Flexibility in program rules
- Programs offering food/coffee to help people feel welcome
- Programs that have life-skills focus, rather than psychotherapy focus
- Programs that have a wholistic orientation and/or that can facilitate women's connection to supports and services in various areas of their life
- Programs that are long-term and/or flexible in terms of program duration

In addition, informants noted the value of having "FASD champions" and/or an FASD consultant available to program staff and managers in order to have opportunities to problem-solve using an FASD perspective.

Moreover, in keeping with informants' responses to the question what works for women with FASD, one informant noted the importance of individualized supports and treatment / care plans for women with FASD, given their diverse capabilities and needs.

> Individual support – the four women that currently come to our agency are all so different, with different capacity. What works for one woman does not work for another.

FASD-specific Programs or Groups

Another strong theme in relation to what was needed to improve substance use programming for women with FASD was the idea of having FASD-specific programs or groups for women with FASD and/or women with FASD and mental health issues. Similarly, informants voiced the need for more residential treatment programs for women with special needs.

> I think that women with FASD would benefit from having a small group setting that is geared specifically to them; i.e., a small group residential setting.

That said, in view of the stigma that exists around FASD, informants advised program planners to consider carefully the name given to a program geared to people with FASD.

Post-treatment, Long-term Supportive Housing

A final important theme regarding what was needed with women with FASD, and one that may be linked to the notion of wholistic programming designed with an FASD lens, was the idea of post-treatment, long-term supportive housing.

> Urgent plea for supportive housing options for post-treatment housing, and long term assisted living programs.

As stated previously, this comment reflected the reality that for women with FASD, having a safe and supported place to live must be viewed as the centrepiece to overarching strategies to avoid the use of alcohol and drugs, and thus to facilitate FASD prevention.

4. Discussion and Conclusions

Summary of Findings From the Environmental Scan

This environmental scan on substance use treatment and care for women with FASD was one of three components of the *Substance Using Women with FASD and FASD Prevention* project.

As one component of our effort to expand knowledge regarding effective, appropriate substance use treatment approaches for women living with FASD, we interviewed care providers in British Columbia who were involved in service planning and/or delivery for women, and, where possible, for women with FASD. Our interviews with informants focused on barriers to treatment and care for women with FASD, informants' perspectives on existing promising approaches to substance use treatment for women with FASD, and informants' views about what was needed to improve substance use treatment and care for women with FASD.

Findings revealed that, from informants' perspective, many of the barriers to accessing services for women with FASD were, by and large, the same as those reported for women without FASD. At the same time, informants stressed that women with FASD faced additional barriers, including a lack of fit between the woman and the treatment program, and/or the unavailability of ongoing support to ensure that the woman remembered and got to her program or appointments.

In discussing barriers to successful participation in services, informants identified difficulties experienced by women with FASD in complying with program rules. Informants recognized, however, that for women with FASD, lack of compliance with program rules should not be attributed to lack of motivation or intentional resistance warranting termination of service. Instead, lack of adherence to rules must be understood in terms of compromised capability due to brain damage and thus remedied by program accommodations and program flexibility.

In terms of **promising approaches to substance use treatment**, first and foremost, environmental scan informants stressed the importance of having everyone who was involved in planning and delivering substance use treatment services be 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.

At the same time, given that workers and mentors involved with alcohol and drug services or addictions-focused organizations may themselves have once had substance use issues, it is important to be aware that training about FASD may trigger workers' issues and emotions related to their own past substance use. Sensitivity, cultural safety and non-shaming attitudes in the delivery of FASD training are therefore essential.

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)

Moreover, analysis of the **promising programs** identified by scan informants revealed a key common feature: they were each 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;
- having **smaller caseloads for service providers** given the intensity of women's needs;
- 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 environmental scan 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.

The women with FASD interviewed in this project voiced similar ideas in terms of the approaches and programs that had worked well for them, emphasizing the importance of:

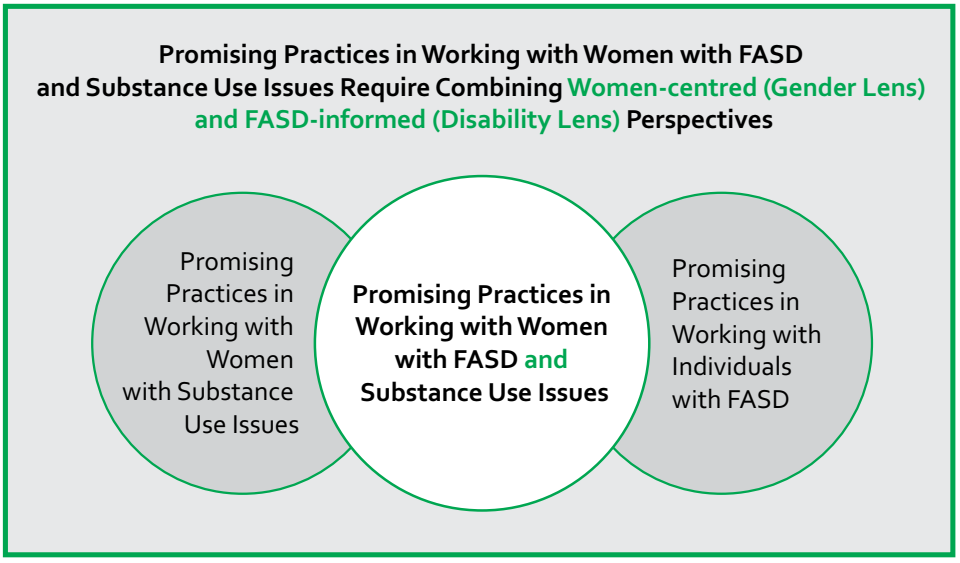
- **being ready for change**—and thus, working with women where they were at, which was often linked to a desire to be involved in their children's care;
- **a relational approach** wherein women had an honest relationship with a counsellor/service provider/group facilitator that was grounded in trust and safety;
- **wholistic, coordinated supports**;
- **one-to-one care from a skilled professional** (e.g., counsellor or physician), ***combined with* women-centred, group-based support and information exchange;**
- **peer-based support**;
- **linkages with FASD-related programs/ organizations**;
- **supportive housing for women**, especially that informed by an FASD-lens; and
- **flexibility** in extending a program's duration and longer-term programs.

In many respects, this project's findings regarding promising approaches in substance use treatment and care for women with FASD closely parallel 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 the 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-related 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 following.

1. As a starting point, training about FASD should be mandatory for *all* involved in alcohol and drug counseling, clinical counseling, social work, child and youth care, mental health, and other related health and social care professions. Training and education should focus on behaviours and characteristics associated with FASD, and should actively and respectfully involve those living with FASD.
2. Training about FASD must be attuned to potential triggers associated with the training and have capacity to address training participants' learning and support needs.
3. In addition, care providers involved in serving women who may have FASD need to be provided with ongoing FASD-focused education, supervision, mentoring and support in recognition of the intensive and taxing nature of the work, and in order to attend to workers' professional development and support needs.
4. In working with women with FASD, care providers must have clear understanding of each woman's life circumstances and her social and cultural context, including:
   - Her readiness for change;
   - Her needs in relation to cultural identity and connectedness;
   - 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	■ Service provider education and training ■ Use of "person-first" language ■ Reframing women's "problem" behaviours and care providers' expectations
Individual Tailoring	■ 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	■ 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	■ 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	■ 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	■ Skilled supervision ■ Smaller case loads ■ Additional staffing

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Appendix A:

Interview Guide For Environmental Scan Participants:

The University of Victoria School of Social Work has partnered with a group of researchers and community organizations to learn about what are effective, appropriate substance use treatment approaches and resources for women living with Fetal Alcohol Spectrum Disorder.

We are interested in finding out how women who may themselves have FASD are being served by substance use programs and resources in your community, and whether there any programs and/or approaches in your community or organization that have been designed specifically to help people with Fetal Alcohol Spectrum Disorder deal with substance use problems.

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1. What types of services and supports are available to women with (suspected) FASD in your community (e.g. housing, health, counselling, alcohol & drug treatment, etc.)?

   Probe: Please describe these programs.

   Probe: Please also describe whether there are any formal or informal linkages between programs.

2. Based on your experience and information, are there women with (suspected) FASD who have attempted to access your organization's or community's services for substance use problems?

3. What barriers exist for women with (suspected) FASD that may prevent them from accessing programs or resources related to substance use treatment?

4. What do you think would help improve access to programs and resources for women with (suspected) FASD?

5. Based on your experience and information, what has been the experience of women with FASD in existing treatment programs?

   Probe: Do women who enter treatment complete the program? If not, what gets in the way?

   Probe: If women drop out, does follow-up or reconnection happen with them in any way?

   Probe: Are there after care programs or supports for women?

6. In your experience, what has worked well in terms of substance use treatment for women with (suspected) FASD?

7. Can you share with us an example of good practice and/or an effective and appropriate substance use treatment program or resource for a woman with FASD? What difference do you think this experience made for her?

8. What do you think would help improve the design or delivery of (substance use treatment) programs and care for women with (suspected) FASD? What needs to be developed?

Thank you for your time!

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Substance Using Women with FASD and FASD Prevention

Service Providers' Perspectives on Promising Approaches in Substance Use Treatment and Care for Women with FASD

prepared by
Deborah Rutman

January 2011

Research Initiatives for Social Change Unit
School of Social Work
University of Victoria
Victoria, BC Canada

Contact: drutman@uvic.ca