# FASD Informed Practice for Community Based Programs



© 2013 College of New Caledonia All rights reserved Printed in Canada

ISBN: 978-0-921087-76-2 College of New Caledonia Press: <u>http://www.cnc.bc.ca/visiting/cnc\_press.htm</u>

Additional copies available from:

College of New Caledonia Lakes District Campus Box 5000 Burns Lake, BC V0J 1E0

Toll-free: 1-866-692-1943 Email: lksdist@cnc.bc.ca The views expressed herein do not necessarily represent the views of the

Public Health Agency of Canada.

# Acknowledgements

**To the women** who access our programs; by sharing their experiences and graciously allowing us into their lives they continue to provide insight to help increase our knowledge and understanding of the challenges and barriers they face.

*The Advisory Committee* was comprised of committed individuals who have rich and varied backgrounds and experience.

Anne Fuller, Ministry of Children and Family Development Carolyn Solomon, BC Ministry of Health Chi Cejalvo, BC Association of Pregnancy Outreach Programs Colleen Wickenheiser, Public Health Agency of Canada Deborah Rutman, Note Bene Consulting & University of Victoria Ellen Garvie, CAPC Coordinator Joan Conlon, College of New Caledonia Nancy Poole, BC Centre of Excellence for Women's Health Pat Chisholm, Pregnancy and Family Resource Programs, Cranbrook, BC

#### Colleagues:

Linda Schmidt, Barb Durban, Melissa Mills, Kim Campbell, Andrea Currie, Cathy Ashurst and Julie Daum for their support and contributions.

Sharon Davidson, for her expertise and attention to detail and proofreading.

Joan Ragsdale, CNC Lakes District Campus Regional Director, for the leadership to remain steadfast in providing programs and services that offer high quality care based on research, frontline experience and best practice.

A special thanks to Joan Conlon for her insight and thoughtful contributions.

**The Public Health Agency of Canada** and Colleen Wickenheiser for the foresight and commitment to fund this project in a continuing effort to better support programs in their work with vulnerable families.

Writer: Anne Guarasci

# Table of Contents

FASD Informed Practice

a)	Introduction	5
b)	Fetal Alcohol Spectrum Disorder (FASD)	5
c)	What is FASD informed practice?	
d)	Benefits of FASD informed practice	9
e)	Barriers to FASD informed practice	10
f)	FASD – Promoting Dialogue	10
g)	Promoting dialogue about alcohol/substance use during pregnancy	12
Ageno	cy Policies that Support FASD Informed Practice	13
a.	Internal Policies	13
b.	Collaborating and Partnering with Agencies and Services	14
Partic	ipant Recruitment/Retention	15
Traum	na Informed Practice	
a)	Key Principles of Trauma Informed Practice	17
b)	Trauma and Debriefing for Workers	18
c)	Trauma and FASD	18
Cultur	rally Appropriate Practice	
Harm	reduction	
a)	Seven Principles of Harm Reduction	21
Contra	aception	23
Indivio	dual Support and FASD Prevention	24
a)	Time Requirements	24
b)	Informed Consent	24
c)	Individualized Assistance	24
d)	Relationships	25
e)	Communication	25
f)	Parenting Support	25
g)	Meeting Preparation	25
h)	Reflective Practice and FASD	

Group Facilitation

Facilitating Effective Group Sessions	
a) Ensure Participants Feel Safe/Supported	
b) Group Facilitation Tips/Recommendations	

Group	Exercises	30
a)	Group Guidelines	31
b)	Icebreaker – Guess Who?	32
c)	Parenting – Coping Skills for New Mothers	33
d)	Nutrition – High Density Baby Food	35
e)	Healthy Communication – More Than Words	36
f)	Health Relationships and Mental Health –	
	Expression – Healthy Communication	37
g)	Budgeting – Budget Your Life	38
h)	Nutrition – Tried It	39
i)	FASD Awareness – Spot the Knot Scavenger Hunt	40
j)	Health Relationships and Mental Health – My Life Brochure	42
k)	Child Safety Collage	43
I)	Self-Care – Relaxation Activity	44
Appen	dix A: Related Resources	46
Appen	dix B: FASD Behaviours/Characteristics	47
Refere	nces	51

#### Introduction

This resource was developed as a result of recommendations from an FASD Consultation meeting in Vancouver in March 2012. Representatives from Canada Prenatal Nutrition Program (CPNP), Community Action Plan for Children (CAPC) and Aboriginal Headstart Program (AHS) frontline workers and coordinators recognized the need for practical information and steps that support FASD informed practice.

Supporting marginalized families who live with FASD presents complex challenges. Families live with multiple issues including poverty, current or past trauma, violence, abuse, previous childhood experiences, dependency, and addiction issues. It's very difficult to compartmentalize strategies and approaches because issues and challenges are intertwined. In depth knowledge about FASD is vital to an effective FASD informed practice.

How a service provider approaches working with this participant group is significantly influenced by his/her own values, beliefs and world view. It is essential that staff are aware of their own feelings about the emotionally charged issues that surface when working in this field, for example, abortion, gender issues, violence/abuse, and women and alcohol or other substances. Part of informed practice is self-awareness and an understanding as to how personal values and beliefs influence practice.

# Fetal Alcohol Spectrum Disorder (FASD)

FASD is an umbrella term describing a number of diagnoses including: Alcohol Related Neurodevelopment Disorder; Partial FAS; and Fetal Alcohol Syndrome. FASD can include a variety of physical anomalies, characteristic facial features and brain injury. FASD is caused by prenatal alcohol exposure.

The effects of prenatal alcohol exposure occur on a continuum and range in severity from mild to severe. The degree of severity is influenced by the amount of alcohol consumed, the frequency and timing of alcohol consumption, genetic makeup and the overall health of the pregnant woman. Different parts of the body and brain develop at different times during pregnancy. The brain is developing from conception to birth, so it is vulnerable throughout pregnancy.

Although there are approaches and strategies that can assist people who have FASD to live a fulfilling life, the brain injury that is caused by prenatal alcohol exposure is permanent. Individuals who have FASD face many challenges, and their need for support varies depending on the severity of brain injury incurred. *It is not known if there is a safe level of alcohol consumption during pregnancy, therefore it is recommended not to drink alcohol during pregnancy* (Carson et al., 2010). Good nutrition may help mitigate the effects of alcohol during pregnancy (Thomas, Abou, & Dominguez, 2009; Keen et al., 2010).

This table illustrates how participant profiles mirror outcomes of a longitudinal Secondary Disability Study conducted at the University of Washington. The most common outcomes for the 415 individuals who participated in the study, and are diagnosed under the fetal alcohol spectrum, are listed on the right.

AHS/CAPC/CPNP Participant Profile	Secondary Disabilities Study	
Poverty	Unemployment	
Unemployment	Early School Drop Out (Low Education)	
Lack of Transportation	Dependent Living	
Low Education	Mental Health Issues	
Crowded and/or Unstable Living	Alcohol Drug Problems	
Childhood Trauma	Trouble with the Law	
Domestic Violence	Inappropriate Sexual Behaviour	
Depression/Low Self Esteem	Confinement	
Dependency Issues		
nvolvement with Justice System Striessguth, A., Barr, H., Kogan,		
(Child Protection/Criminal)	Bookstein. F. (1996)	

Many participants live in poverty, have unstable and/or unsafe housing, are socially isolated, experience domestic violence, live with addiction, have low education and employment and have experienced trauma. These factors are further complicated by psychosocial issues including "boredom; loneliness; hopelessness; low self-esteem, normalization of abuse/violence/victimization experiences and high stress/anxiety/depression." (Gelb & Rutman, 2011, p. 18). Typically these individuals do not experience success in programs that have stringent rules/boundaries. FASD diagnosis is relatively rare for adults;

however, it is a commonly accepted notion that marginalized, high risk families can be over represented by individuals who have FASD.

The following information and recommendations are designed to assist programs in providing FASD informed services/supports when working with marginalized women and their families who may be living with FASD. These approaches have been developed as a result of evidence-based research and practical experience.

"One percent (Prevalence of FASD) is a profound epidemic, and it's likely higher." Dr. Sterling Clarren Johnston, A.C. (2011)

# What is FASD informed practice?

FASD informed practice includes:

- an awareness that FASD (diagnosed and undiagnosed) is a reality for some participants
- a strong theoretical and practical understanding of the traits, characteristics, barriers and needs of those affected by FASD
- a willingness on the part of all staff including administration, reception and frontline workers, to participate in ongoing FASD education and training initiatives
- agency policies that accommodate the unique needs of individuals who live with FASD in an effort to make the program fit for participants
- reflective practice whereby staff are encouraged to work as a team to debrief and problem solve
- service providers' use of an "FASD lens" to develop strategies and supports on an individual basis according to each participant's presenting behaviours and assets
- trusting relationships between participants and service providers, and a respectful and individualized approach to service delivery that recognizes participants' strengths

It's everyone's responsibility to ensure participants feel welcome and supported. It's especially important that the first person a participant comes into contact with is respectful, empathetic, nonjudgemental and welcoming - recognizing that this can be challenging due to the fact that individuals who have FASD often have difficulty reading and responding appropriately to social cues. This initial contact person's formal role may have to do with registration and/or reception and s/he is often perceived as a gatekeeper to services. This first encounter sets a tone for participants and is integral to a positive ongoing relationship.

For information about resources that provide more information around strategies and supports for individuals who live with FASD, refer to Appendix A.

# **Benefits of FASD Informed Practice**

Among other challenges, organic brain injury associated with FASD inhibits participants' ability to:

- Follow through
- Control impulses and
- Understand directions/expectations

See Appendix B for more information on possible FASD behaviours and characteristics.

Given these challenges, there are obvious benefits for participants who have FASD if service and supports are designed to ensure that participants' individual strengths and challenges are considered. In a nonjudgmental environment where workers demonstrate acceptance, participants are able to engage freely. With adequate and appropriate supports, participants can experience success, meet expectations of other agencies (for example child welfare), and experience a sense of belonging.

When staff members understand the challenges associated with FASD, have built trusting relationships, and are able to make observations of behaviours they can:

- avoid negative judgements and feelings of frustration
- adjust approaches to create a better fit with participants' abilities
- adjust their expectations so they are more realistic
- think creatively and develop positive solutions/strategies
- experience a higher degree of job satisfaction

Program coordinators/managers are able to support workers more effectively if they have a clear understanding of the participant group and the demands on workers. They can reflect challenges and successes in reports and evaluations and ideally utilize the information to encourage community support for the program and possibly secure additional/relevant funding.

As programs are better able to modify their practices to accommodate participants who live with FASD they have more capacity to support other agencies in the community to do the same. Information about working effectively with families who live with FASD is relevant for service providers in human services fields including health, justice, social services and education.

# **Barriers to FASD Informed Practice**

Most often barriers to FASD informed practice can be addressed through education and awareness. Stigma and taboos around alcohol present somewhat more complex challenges. As understanding about the potential for harm with prenatal alcohol exposure increases, harsh judgements toward women who use substances during pregnancy can also increase. In some cultures women are strictly forbidden to use alcohol making it an extremely difficult topic to address, hence it is essential to create a safe environment where participants and staff are able to communicate freely without fear of judgement or reprisal.

The most prevalent barriers to FASD informed practice include:

- the lack of understanding of the pervasiveness of FASD especially in marginalized and high risk populations including intergenerational FASD
- the lack of comprehensive FASD training at all levels (administrative and operational)
- insufficient resources to accommodate the needs of women who have FASD
- the misconception that it is too difficult and complicated for workers to have a positive impact on women's lives when FASD is a factor
- stigma and taboos around alcohol use and FASD that can impact staff at all levels
- reluctance on the part of staff to participate in dialogue about FASD when there are unresolved personal issues related to FASD

# **FASD - Promoting Dialogue**

FASD can be an extremely sensitive issue. It is important to be cognizant of the stigma around FASD (diagnosed and undiagnosed) and the fact that because it is connected to a woman's alcohol use there may be a great deal of shame and guilt attached to this topic. Using a woman centred approach, service providers need to work to create a trusting relationship and a safe environment for discussion.

If a participant indicates or wonders whether she and/or her children may have FASD, it may be helpful to offer support in exploring that possibility. It's very important to remain strengths-based by reaffirming the participant's abilities and personal qualities and reminding her that everyone's brain works differently. No one has a perfect brain. Staff can respectfully offer observation, for example, "I noticed that it was difficult for you to remember your appointment. Sometimes I have a hard time

remembering appointments too. I know a couple of good ways to remind myself. Would you like to know what they are?" In this case self-disclosure can be used to help normalize difficulty with memory and build relationship. Asking permission is respectful and helps to reinforce the concept of self-determination.

At this point it's appropriate to offer solutions/supports; for example, demonstrate how to enter reminders in a cell phone, offer to phone and remind her of appointments, and/or support her to ask for reminder phone calls from dentists, doctors, social workers etc.

Note: Diagnosis and assessment can lead to increased self-understanding and a more positive selfimage. Diagnosis, however; may not be a realistic option, and although staff cannot confirm that a woman and/or her children have FASD they can connect families to relevant professionals – i.e. paediatrician and early intervention therapy. Staff can offer assistance in building supports and developing strategies so as to enhance daily functioning.

In a group setting the topic of FASD can be discussed in the context of healthy pregnancies and the importance of avoiding alcohol during pregnancy. Including a discussion around the importance of good nutrition and a supportive living environment in promoting healthy pregnancy helps support a harm reduction approach. This script can be used to introduce FASD to groups.

People used to believe that the placenta could filter out toxins so the developing fetus would not be harmed. What we now know is that alcohol crosses the placenta freely and can cause FASD. Many women who drank during pregnancy were unaware of the harm alcohol can cause. About half the pregnancies in Canada are unplanned, and most women don't know they are pregnant until at least six weeks into their pregnancy and often longer – so they may not know they are pregnant and could be drinking.

Even if a woman has consumed alcohol early in pregnancy there are still lots of opportunities to enhance her health and the health of her infant for the duration of her pregnancy. These include rest, nutrition and regular medical check-ups.

It is essential to recognize that no woman sets out to harm her baby and many people, from all walks of life, have FASD and each of these individuals is unique and has strengths and potential!

11

# Promoting dialogue about alcohol/substance use during pregnancy

Stigma, harsh judgements and cultural taboos about women and substance use create barriers to open dialogue. Along with accurate information about alcohol/substance use during pregnancy, participants need a safe, non-judgemental environment in order to engage in dialogue about alcohol and substance use.

When attempting to promote discussion about the role that alcohol and other substances play in a woman's life, it's important to be sensitive to a participant's situation and ensure that she:

- feels comfortable and is ready to talk about her relationship with alcohol and other substances
- knows that her confidence will be protected
- is confident that she will not be harshly judged
- feels a sense of control

It's essential to allow time for participants to talk about what they see as being important – for example if a participant is particularly worried about food/housing and/or safety, a discussion about alcohol use may need to wait.

If engaging in a discussion about a participant's alcohol use, it is imperative that staff is capable and prepared to advocate for and connect women to appropriate services and offer adequate supports. For example, if a woman discloses that she lives in a place where she is under tremendous pressure to consume alcohol the staff member needs to have the capacity to assist her in acquiring a stable living environment. It will not suffice to simply reiterate the importance of avoiding alcohol. This only serves to reinforce feelings of guilt and shame.

Many women are aware of the potential harm alcohol can have during pregnancy. If attempting to administer a screen to determine alcohol dependency and/or risk it may be easier for a woman to answer questions about alcohol use before she knew she was pregnant.

"Walk with Women on their Journey." Sarah Payne 2010

# Agency Policies that Support FASD Informed Practice Internal Policies

As an agency it's essential to educate and support staff to:

- Engage in reflective practice
- Work from an FASD informed approach
- Employ a trauma informed approach and
- Focus on harm reduction

By avoiding the expectation that participants will adjust to agency policies/practices and asking the question "How can we make our services work for families?" agencies can create an environment that fits with participants' unique needs. Agency policies need to support innovative/creative practice and allow experiences and learning to influence policies so as to meet the evolving needs of families. This is a fundamental philosophical shift that requires active involvement from administration as well as frontline staff and includes:

- Recognition and action around basic needs (food, housing, safety)
- Connection to other resources (If possible include one on one support to connect participants to other services including assistance with transportation, filling out forms and interpreting expectations.)
- Advocacy and support to navigate systems
- Creative and flexible programming that is responsive to the unique needs of participants
- Internal expectations for employees and systems whereby responses are adaptive to the needs of the participants rather than the needs of the agency

Organizations that demonstrate FASD informed practice refrain from limits to service based on:

- Missed appointments
- Discomfort with formal institutions
- Lack of transportation
- Location of residence
- Inability to understand or meet expectations

Avoid a punitive approach - for example, fines for late or missed appointments and/or attitudes that convey disappointment. Rather recognize that women are often overcoming challenges/ barriers and demonstrating commitment by showing up to a program and provide a welcoming experience!

# **Collaborating and Partnering with Agencies and Services:**

Taking a strength based approach to working within the community with other agencies can enhance relationships by encouraging openness and sharing of information – and taking a "we're all in this together" approach. Coordinate short training sessions around FASD, trauma and harm reduction to encourage a deeper understanding of marginalized women who live with FASD and the issues they face.

Workers need to be supported to have diplomatic and meaningful discussions on an individual basis with other practitioners (from health, social services, justice and education) in the community who work with the same participant group. Cultivate empathy and understanding for other practitioners in the human services field by recognizing the challenges they face both systemically and within their participant groups. This may require internal collaboration to problem solve and strategize as to how to positively impact practice. Inviting practitioners to come together for a roundtable session over lunch and providing a mini presentation to spur discussion can encourage thought and reflection and help build relationships.

> "Insanity: Doing the same thing over and over again and expecting different results." Albert Einstein

# Participant Recruitment/Retention

Women who have FASD or other related disabilities require support to participate in a program including reminders, transportation, and hands on assistance with organization. This level of support can be perceived as enabling and viewed negatively, however; when considered within the context of a disability it becomes clear that in fact intensive support is required. In addition they may not understand what a program is about and/or be hesitant to walk through the doors of an unfamiliar building.

In the case of referral, ideally, the referee can obtain permission from the participant for the service provider to make contact. This way the proverbial ball is in the service provider's court and s/he can be sure to follow up on the referral by arranging to make a home-visit or inviting the participant for coffee. Recruitment efforts can be enhanced by encouraging informal recruitment among peers, allowing participants to bring support people to the program and by creating collaborative community connections.

Integrating practices and strategies associated with FASD, trauma informed practice, and harm reduction enhances and encourages retention. This participant group benefits immensely from a safe, non-judgmental, welcoming atmosphere combined with practical supports such as reminders, transportation, assistance with organization and food.

#### **Trauma Informed Practice**

"Trauma describes experiences that may overwhelm a person's capacity to cope. Traumatic events experienced early in life, such as abuse, neglect, witnessing violence and disrupted attachment can be devastating. Equally challenging can be later life experiences that are out of one's control, such as violence, accidents, natural disaster, war, incarceration or sudden unexpected loss. These events can undermine or damage people's sense of safety, self and selfefficacy as well as the ability to regulate emotions and navigate relationships. " (Poole & Greaves, 2012 p. xi)

There is a well-established connection between trauma and substance use. Women who have endured traumatic experiences may tend to self-medicate in an effort to cope with the mental and physical reactions they experience from trauma including anxiety, fear, shame and hopelessness. (Poole, & Greaves, 2012 p. xi)

Trauma impacts an individual's ability to function and regulate emotions. Service providers observe that many participants have not only experienced trauma in the past – they continue to experience trauma and live with violence and abuse. Women who have FASD are at greater risk of having their boundaries violated and can become victims of abuse due to difficulty with impulse control and appropriate decision making good judgment among other FASD related characteristics. See Appendix 1 for a brief outline of FASD behaviours and characteristics.

Studies indicate that trauma informed practice is effective in supporting women to make positive changes. It is not necessary or even expected that staff will encourage women to disclose or discuss traumatic events, rather it is important to recognize that trauma is likely part of what underlies some behaviours and substance use.

Hughes and Hyman found there is evidence to support physical exercise including laughter yoga and Brain Gym as non-threatening methods to support recovery from trauma. (Poole & Greaves, 2012). Hughes, Hyman – page 89 Poole, Greaves (Eds. 2012). These activities help to release tension, and when performed together, they help build relationships between staff and participants.

#### Key Principles of Trauma Informed Practice:

- 1. **Trauma awareness and training** at each level of service delivery is fundamental. It's important to build awareness among staff and clients as to how common trauma is; how its impact can be central to one's development; the range of adaptations people make to cope and survive; and the relationship between trauma and substance use, physical health and mental health.
- 2. Emphasis on safety and trustworthiness: Trauma survivors often feel unsafe as they are likely to have experienced violations of boundaries and abuse of power. Physical and emotional safety is paramount. Safety and trustworthiness are established through welcoming intake procedures; adapting physical space; providing clear information about services; ensuring informed consent; creating safety plans; demonstrating predictability; establishing consistent appointments; and maintaining utmost respect for participant confidentiality.
- 3. Opportunity for choice, collaboration and connection: Participants need safe environments that foster a sense of efficacy, self-determination, dignity and personal control. This includes: open communication, equal power where women have control over, and input into, the services they receive. Participants feel free to express themselves without fear of judgment. Practitioners collaborate with women to determine the best course of action.
- 4. Strength-based and skill building: Participants are encouraged to identify their strengths and develop resiliency and coping skills. Workers acknowledge participants' strengths, creativity, determination and abilities. Emphasis is placed on supporting, teaching and modelling skills to recognize and cope with triggers so as to remain calm and centred.

Adapted from "Essentials of Trauma informed Care" Poole (2012) Canadian Centre on Substance Abuse 2012

#### **Trauma and Debriefing for Workers**

Marginalized women who live with FASD commonly live with past and present abuse and violence. The severity of abuse that they share with workers can be incredibly disturbing and in fact cause vicarious trauma. Ensuring ample opportunity for supportive debriefing and supervision for workers as well as access to professional counselling are optimum.

FASD presents differently and each individual is unique. Behaviours can be confusing and so, while protecting confidentiality, it's important to support teams to collaborate, brainstorm and problem solve together. Workers can mentor and support each other to develop creative approaches to better support women who have FASD.

## Trauma and FASD

Observations from service providers who work with women who live in high risk conditions indicate that most participants have experienced trauma. Many participants also have FASD (diagnosed and undiagnosed). Supporting individuals who have experienced trauma, and have FASD, poses unique challenges. At times, strategies to support this participant group may seem counter intuitive.

A woman who has FASD and has experienced trauma may disclose inappropriately – i.e. in a public or group setting. In this case the support worker or facilitator needs to gently guide her out of the setting – for her own safety and the safety of others. For example, if she is disclosing information about sexual abuse or violence her story may impact and trigger the people around her. It's very important to recognize what she has experienced; however, she may also perseverate – see Appendix B. In this case a support worker needs to offer a diversion to assist the participant to move on and focus on something that does not feed negative emotions and feelings.

Staff can validate an individual's state of mind or feelings about a situation but, if that person is living with FASD, it may not be in her best interest to encourage more discussion/or perpetuate the issue. Rather, staff can offer to connect the individual to a counsellor and respectfully support the person to move on to something else.

Difficulty with reality and confabulation can make it challenging for staff to determine whether or not the information they are hearing is accurate. This behaviour is exacerbated by stressful situations and participants may be in a sense searching for the right story so it appears that they have several different stories about one incident. It's very important not to act on a particular story or accusation before confirming that it's true – if that's possible.

Although it's not possible to offer definitive solutions for each situation that may arise, there are considerations that will assist staff in providing effective services and supports. In order to effectively support this participant group, staff requires education and training in: FASD; trauma informed practice (including information about domestic violence); relationship based service delivery; and reflective practice.

#### **Culturally Appropriate Practice**

Culturally appropriate practice is a philosophical approach to service delivery that promotes respect and openness to ongoing learning about diverse cultures. Service providers are encouraged to read, discuss and participate in information sessions about the culture within which they work. They need to be aware of their own culture and cultural values. Understanding personal cultural values helps build respect for the values that are the foundation of another culture.

Culture has been compared to an iceberg in that what underlies cultural practices is much larger and deeper than it appears. Culture can be rooted in hundreds or thousands of years of history and has an extremely important and profound influence on the lives of individuals and families. It's helpful to arrange to have people from within the culture provide training, information and guidance and hire staff from within the culture when possible. Talking about culture can be enjoyable for participants. Staff can encourage discussion through curiosity and respectfully asking questions. Listening to a participant's perceptions, reflections and beliefs can enhance mutual understanding and strengthen relationship.

#### Harm Reduction and FASD

The underlying philosophy to harm reduction is an acceptance that substance use may always be a reality for some individuals and that abstinence from substance use is not necessarily the ultimate goal. It is possible to mitigate the harm from substances and work toward healthier outcomes.

When working with Individuals who live with FASD, a harm reduction approach includes consideration of the behaviours and characteristics associated with the disability. For example a participant who has FASD may have resolved to reduce or abstain from alcohol; however, she may be easily misled by her peers. A creative approach is helpful to support participants in avoiding the company of people who will encourage substance use. At times this may be as simple as supporting her to recall positive supports in her life or reminding her that she decided not to hang out with someone who has a negative influence. An illustration or picture may be helpful. A participant may want to post a no drinking and/or smoking sign in her apartment as a reminder that she wants to avoid a party atmosphere and/or secondary smoke in her home.

#### **Seven Principles of Harm Reduction**

FASD strategies in combination with the following principles are critical components of effective, respectful practice.

- Individualized service delivery. Each participant is unique and has a unique history, personality, strengths and challenges. There is no one size fits all approach to supporting participants who have alcohol/drug dependency or addiction issues.
- 2. Allow participants to determine priorities and the direction of service delivery. For some this will involve a plan with tangible steps and goals; others may need time to explore their substance use; for others the goals may have nothing to do with substance use.
- Assume participants have strengths. Participants who access services demonstrate initiative and commitment to improving their lives. They have developed resourcefulness necessary to survive adversity such as poverty, violence and stigmatization.
- Recognize and accept small steps forward. Cutting down on substance use and/or increasing good nutrition, attending programs and connecting with staff and peers are all positive steps forward.
- 5. Avoid expectations for abstinence and work together with participants to set realistic goals in regard to substance use. Participants may not be able to cut down and/or abstain from all the substances they use. In this case staff can support participants to use less harmful substances.
- 6. Develop a collaborative relationship and empower participants. By building a trusting relationship staff can open dialogue and learn about a participant's reality, culture and history so that rather than working at a participant, staff is working in partnership alongside/with the participant.
- 7. Avoid stigmatizing participants for their substance use and maintain a respectful approach to service delivery to ensure participants feel valued.

Adapted from Harm Reduction Philosophy, Tatarsky (2002) Harm Reduction – Pragmatic Strategies for Managing High Risk Behaviors A common goal for programs is to improve the health and wellbeing of pregnant women, new mothers, babies and young children who are facing challenging life circumstances. Even though staff is aware of the importance of avoiding alcohol and substances, it's important to recognize participants' right to choose whether or not to use substances and /or engage in risky behaviours.

By building respectful and trusting relationships, service providers can help increase the quality of life for families through harm reduction and a focus on social determinants of health including stable/safe housing, nutrition, income and personal/social supports. Evidence supports harm reduction as an effective method to reduce behaviours that put individuals at risk, and promote positive change.

Support for individuals who have FASD includes reminders, assistance with paper work, transportation and advocacy. Examples of harm reduction strategies/techniques are listed below:

- Reduce isolation: nonjudgmental and supportive programs can provide a safe place for participants to go even if they are currently using.
- Provide access to and support for good nutrition: have fruit juice and healthy snacks available for participants who drop into the program
- Support access to needle exchange programs, if available: this can lead to other positive connections in the community and even a willingness to consider treatment and/or drug maintenance programs
- Support access to birth control see section below.
- Reduce the risk of contracting HIV/AIDS, Hepatitis C and other sexually transmitted infections by supporting the use of condoms.
- Support participants to ensure their children are safe if/when they decide to use and/or go out by helping them identify people with whom their children will be safe.
- Assist participants to recognize and remember who in their circles is supportive and who is nonsupportive.

We have one participant who comes to the centre to take a breath from her chaotic life. She won't necessarily need anything concrete – just a warm welcome, a cup of tea and safe place to sit down.

Family Support Worker

# Contraception

Marginalized women who live with FASD often have difficulty understanding and communicating what they need and/or want in order to prevent pregnancy. Medical professionals may not be sensitive to the individual learning and behaviour needs of participants hence they do not take the time necessary to ensure women understand their options. Women who live with FASD will likely have difficulty remembering to take a pill each day. They need support to understand and access other options for reliable birth control. Support workers can assist participants in preventing future unwanted pregnancies and sexually transmitted infections (STI) by:

- Providing a safe non-judgemental opportunity for women to discuss personal preferences in terms of family planning
- Providing education and support around the use of condoms for women and their partners
- Supporting women to address issues that their partners and/or family members may have in terms of family planning and contraception
- Providing reminders and accompanying/advocating for women during medical appointments especially if they display a slow cognitive pace and/or difficulty with receptive language processing
- Interpreting what's been discussed in terms of birth control options, including potential side effects, cost and directions
- Dispelling myths about birth control
- Supporting women to follow through i.e. fill prescriptions, arrange for follow up appointments for an IUD, Depo-Provera, tubal ligation etc.
- Providing information and supporting access to the Emergency Contraceptive Pill
- Helping women to keep track of their menstrual cycles.

# Individual Support and FASD Prevention

Outlined below are brief strategies for a number of key components required for effective individualized support.

# **Time Requirements**

Marginalized participants who live with FASD are often in crisis and chaos and require a significant time commitment. One to one outreach services that include advocacy and support dramatically increase potential for success. Marginalized women who struggle with substance use issues can benefit immensely when staff assist with meeting basic needs including: housing; income; accessing relevant resources; and organization/daily living. (Rutman, 2011). In the event that staff are unable to offer this level of support, hopefully, they can refer/connect participants to other agencies and/or informal support systems that have the necessary capacity.

## **Informed Consent**

Obtaining informed consent, to exchange information and work on behalf of a participant, may be challenging depending on her cognitive ability to comprehend what informed consent means. Staff can assist participants to understand what informed consent means and when disclosure is necessary by providing specific examples. Before speaking on a participant's behalf it is good practice to double check that the participant still gives consent as circumstances often change.

## Individualized Assistance

Through individualized outreach services support workers can:

- assist participants in generalizing information from group or parenting sessions to home
- connect and advocate for participants with other agencies
- provide transportation to and advocacy for appointments with other agencies/service providers
- interpret dialogue and/or written material that is exchanged during appointments/meetings
- accompany participants to grocery shop on a low budget
- assist participants to organize their daily lives by developing supportive strategies in the home

Over the years the women we work with have developed so many coping mechanisms that people assume they are fully functioning adults when in fact they may be functioning at a 12 year old level.

Family Support Worker

## **Relationships**

It is essential that individual support is based on a trusting relationship between the worker and the participant. In order to build trust workers need to be accepting of participants through a nonjudgmental approach and:

- Allow participants to determine the direction of services
- Protect participants' confidentiality
- Provide solution focused services
- Acknowledge and accentuate participant strengths
- Assist with securing basic needs

#### Communication

When communicating with a participant, avoid intellectualizing and ensure that she is ready and willing to engage in a discussion. Before engaging in discussion about a specific topic area, for example breastfeeding, ensure the participant is interested. If she is under a great deal of stress, hungry and/or preoccupied with another issue it's best to wait until another time to talk. Mirroring is a communication style where the worker observes and matches the pace and complexity of language used by the participant. Most of the time it's best to use simple language and try to make information sharing fun!

## **Parenting Support**

Staff can support healthy parenting by:

- Reaffirming the connection between mother and child
- Accentuating positive parenting behaviours
- Modelling healthy interactions with children
- Assisting parents in identifying age appropriate toys and activities for their children
- Supporting parents to attend parenting groups by providing reminders, transportation and assistance with organization

#### **Meeting Preparation**

Role playing possible interactions with professionals is an effective strategy to help prepare participants for meetings. The goal of this type of role playing is to model assertive behaviour and communication and promote self-efficacy. A trusting relationship allows for interactions and observation so that staff can gauge participants' abilities with some degree of accuracy so as to maintain realistic expectations.

# **Reflective practice and FASD**

Reflective practice is a process whereby the service provider continually learns from experiences in the field and adapts and modifies practices in an effort to provide effective interventions and supports to participants. This is tremendously important for programs that work with women who are considered at risk and have FASD because of the complexity of disabilities associated with FASD. There is likelihood that challenges are further compounded by dependency issues, trauma, violence and poverty.

Service providers need to retain the characteristics of FASD (refer to Appendix 1) in their frame of reference and:

- Be aware of their own unique set of thoughts, values and beliefs; and examine how these impact practices as they are what underlie interpretations, judgments and decisions.
- Question assumptions, preconceptions and biases. This is essential when working with marginalized individuals who may have FASD.
- Approach their work with participants from a curious, non-judgmental perspective.
- Be willing to learn from participants through observation.
- Ask questions! Participants can be surprisingly insightful as to what they need and what works for them.
- Pursue ongoing professional development to enhance awareness and understanding of FASD and other related issues.

To be engaged in reflective practice, service providers need to be willing and able to make changes to practice when participant behaviours or patterns indicate modifications are needed. A simple example - it becomes apparent that a significant number of participants have difficulty arriving to group sessions in the morning; it may be best to reschedule group sessions to the afternoon.

"Often what you see and/or hear is not what you get!" Family support worker

# **Group Facilitation**

# **Facilitating Effective Group Sessions**

Group sessions have proven to be an excellent way to connect with participants impacted by FASD, hence the following section includes a number of activities that can enhance group sessions focused on parenting and personal growth.

FASD often includes difficulty functioning in a traditional classroom setting for a number of different reasons. Typically, facilitators depend on participants' ability to learn using receptive language processing i.e. connecting words to the ideas they represent – this can be particularly difficult for individuals who have FASD. Traditional teaching methods also rely on participants' ability to:

- recall information
- generalize information from one setting to another
- understand abstract concepts
- pay attention

In addition, individuals who have FASD are often developmentally younger than their chronological age. The following group exercises are designed to address challenges with learning, hence they are activity based, enjoyable and provide concrete learning opportunities.

# **Ensure Participants Feel Safe/Supported**

Avoid discussions or videos that depict or describe abuse and violence. Women who have similar experiences can be re-traumatized. If someone begins disclosing such events, offer a distraction or if necessary politely stop the conversation and ask to speak to her outside of the room. Check to ensure that everyone is okay before continuing on and in the event that a woman is re-experiencing a traumatic event offer support and if possible connect her to a counsellor.

Conduct a formal briefing session with outside speakers before they present to the group to ensure they are aware of the unique learning needs of the group as well as the need to avoid subject matter that might traumatize participants.

Facilitating groups for participants who may have FASD presents unique challenges. Facilitators need to have a comprehensive understanding of the behaviours and characteristics of FASD as well as the ability to intervene in a timely and effective manner to ensure the safety of all the participants in the group.

# **Group Facilitation Tips/Recommendations**

Preplanning as well as site and equipment preparation are critical elements to establishing an environment where participants can concentrate and become engaged in learning. Noted below are some of the important features to consider when acquiring and setting up group sessions.

- Ensure the room is set up beforehand and audio visual equipment, flip charts, materials and supplies are organized and ready to go.
- Anticipate that participants may resist new activities and/or move through an activity quickly and have <u>at least</u> one back up plan for group activities.
- Write the day's agenda, in simple language, on a whiteboard or flipchart.
- Avoid changing facilitators and forewarn participants if there are going to be changes.
- Reduce distractions and noises as much as possible, lower the stimulation and limit clutter. It
  may be helpful to hang curtains over cluttered open cupboards. Participants may be
  hypersensitive and can be distracted by environmental noises such as traffic, heating systems, or
  the hum of fluorescent lights. Where possible, these factors need to be eliminated or reduced
  by relocation or replacement for example by acquiring silent "no hum" lighting.
- Avoid exercises, games and activities that require reading lengthy instructions. If written instructions are necessary, rewrite them in simple language and read together with the group.
- Participants may be fidgety and/or need to move provide the opportunity to move, doodle or manipulate something such as a piece of silly putty.
- Physically walk around and gather participants back to group after a break.
- Have at least two facilitators for groups of eight or more.
- Use a variety of modalities such as videos, pictures and models (for example models of the uterus, fetus, baby food, dolls and diapers).
- Provide a quiet place of retreat for participants if they appear overwhelmed either by what's happening in group or what's happening in their lives.
- Participants may have a developmental age much younger than their chronological age be sure to include fun activities to help participants remain engaged.
- Avoid taking behaviours personally. If a participant shuts down and becomes nonresponsive she can appear disrespectful but it's more likely that she is overwhelmed and needs time to regroup.
- Accentuate each participant's strengths to encourage active participation.
- Support participants to generalize information from group to home with: low literacy handouts; step-by-step instructions; and picture cues. It's helpful to provide fridge magnets or sticky tack so participants can easily display an activity sheet at home, on a wall or the fridge.
- Prepare participants for guest speakers in advance
- Provide guest speakers with guidelines for presentations to the group and ensure they have a clear understanding of the group dynamics.

# **Group Exercises**

Group sessions: reduce isolation; encourage peer support; and connect participants to professionals from other services/agencies in the community. Participants also experience positive social interaction that doesn't involve drugs and alcohol.

The following is a compilation of group exercises focused on maternal and infant/child health, selfesteem, and parenting. Individuals who have FASD often have difficulty with abstract concepts and receptive language processing. The following activities have been developed to meet some of the unique learning needs of individuals who may have FASD so as to support learning through interactive exercises and concrete learning opportunities. They have also been designed to help create a safe group environment where participants can have fun, learn new skills and develop healthy relationships.

# **Group Guidelines**

#### Purpose

Create group safety and boundaries in a concrete and collaborative manner.

#### **Materials**

White board or flip chart Felt pens Post it notes Poster board

#### Instructions

- Introduce this exercise as an opportunity to develop group guidelines together. Ask participants to think back on other experiences they have had with groups. Ask what they liked or disliked.
- 2. Facilitate a discussion/brainstorming session about group guidelines.
- 3. Talk through and act out rules and expectations.
- Give participants post-it notes to write responses to phrases such as, "What I want from the facilitator and fellow participants". Encourage participants to post these on the board or flipchart.
- 5. Transfer the guidelines to a poster board and laminate if possible.
- 6. Post guidelines in a prominent place in the room and refer back to the guidelines in the event that boundaries and roles become confused.

Note: Create an atmosphere of safety in the group. Inclusive guidelines based on respect are most effective. When referring back to the guidelines remind participants that they designed the guidelines to reflect their values.

This exercise is best done in the spirit of respect, not from an authoritarian perspective. Introduce the activity as a chance to discuss, in a healthy way, what participants expect from each other and from facilitators in terms of respect and support.

Mention there are some aspects of group that are negotiable and some that are nonnegotiable. Outline these at the beginning of the discussion. For example: people need to be respectful towards each other—no name calling.

Adapted from Establish the Connection – Groups for At -risk Youth Hennig, M. (2012)

#### Helpful Hints

Difficulty with time and organization may hamper a participant's ability to arrive to group at the usual start time. Encourage participants to arrive at the regular start time but if they don't, avoid negative or punitive reactions.

One guideline might be to ensure cell phones are off or on vibrate. This may be a good area for discussion.

At a later date, help the participants find pictures to use as visuals for the guidelines they developed.

#### Ice Breaker **Guess Who? Helpful Hints** Purpose To assist with communication and problem solving On a white board or flip chart, write out specific examples of **Materials** identifiers participants can Paper choose to write. Pencils Flip Chart/White Board Feathers Let participants copy word for word if they need to. Instructions 1. Hand out blank pieces of paper and a pencil to each participant. 2. Ask participants to find a private area in the room and write down one *If the chaos of* thing that the group may not know about them. (i.e. I like playing guitar; throwing papers my favourite colour is purple; I love country music) around the room is 3. Once they are finished, ask participants to scrunch up their papers and too much for thrown them around the room. After the papers are totally mixed up, participants put each person picks one up. them in a hat or 4. Ask participants to stand or sit in a circle. box. 5. Choose a participant to start by reading her paper. They then try to guess whose paper it is from the description. 6. Once a participant's identity has been guessed, they are given a symbol to Don't give up! Be hold (e.g. a feather) to show that they can no longer be chosen. aware that you need lots of energy and *motivating tactics to* Debrief get participants Ask the participants: what happened? What did you like about the activity? What started with these games but once they did you not like? Was it difficult to write something about yourself? Did you learn are involved, the anything new about your fellow participants? game will gain momentum.

	Parenting		
Coping Skills for New Mothers			
Purpose		Helpful Hints	
To enhance parent child interaction, open discussion about challenges associated with new parenthood and encourage peer support and access to community supports/services.		Very important to ensure the group is cohesive and has established positive	
Materials	Preparation	relationships.	
Two or three dice 4 – 5 small gifts/person Markers	Purchase and wrap gifts Ideas for gifts include: lip gloss, gum,	Encourage participants to	
Whiteboard and/or flipchart	hand lotion, hair elastics, facial masks, earrings, head bands etc.	provide support to their fellow participants if they	
Instructions		become frustrated.	
Create a safe environment by reminding participants about the group guidelines with emphasis on confidentiality. Ensure participants are aware that you will provide an opportunity to debrief individually if necessary. Having access to mental health supports/counsellor is optimum. Have participants sit in a circle around the table and/or on the floor.		Assist participants to identify ways they can connect with each other when they are tired or stressed.	
Facilitate a list building exercise where participants are encouraged to list some of the feelings and emotions (negative or positive) they experience with the early stages of parenthood. List these on a whiteboard or flipchart. Note that it is very normal and even expected to feel stress as a new mother.		Remind participants of some community agencies that may be able to offer support.	
Ask: Who here has felt stressed as a pare happens when you feel stressed? How d	o you handle it?		
Discuss healthy and unhealthy ways to de of stress relievers, calming techniques, sa the whiteboard.	•		
Reframe negative activities/solutions. For screaming at children the facilitator can remoment to collect oneself.			

Parenting	
Coping Skills for New Mothers	
Continued The Frustration Game 1. Set the timer for 15 minutes 2. Each player takes a turn rolling the dice. 3. If a player rolls doubles she can choose a gift from the gift bag	Examples of Calming Techniques: • Count backwards from 10 • Think of a place you'd like to be.
<ol> <li>Continue this exercise until the timer runs out</li> <li>When the timer goes off – set it again for 15 minutes</li> </ol>	<ul> <li>Take three deep breaths.</li> </ul>
But the rules change!!!	• Go for a two
6. When a player shakes doubles they can choose from the bag or take a gift from another participant	minute walk down the hall
This is when the game can get frustrating. If parents are disappointed and/or frustrated use this as an opportunity to revisit the stress relieving/calming techniques list.	<ul> <li>Try to remember a funny joke</li> </ul>
<ol> <li>If a player loses a gift to another player she can choose another gift from the gift bag</li> </ol>	If you need the game to move faster – use three dice.
Debrief	
Compliment the group for being good sports. Ask the group how they felt about the exercise and the game and briefly review the stress relievers, calming techniques and safety plans.	Use humour to provide support and remind participants of the stress relievers
Adapted from Establish the Connection – Groups for At -risk Youth Hennig, M. (2012)	and calming techniques on the board.

	Nutrition		
High [	Density Baby Food		
Durness		Helpful Hints	
<b>Purpose</b> To enhance skills in preparing and understanding the benefits of high density first foods for babies		Allow time for parents to try new	
Materials	Preparation	food too!	
Equipped Kitchen Pots Vegetable peelers, chopping knives Plates, cutlery Baby food grinder, food processor, or blender	Purchase meat, vegetables and/or fruit in quantities large enough to provide participants with samples. Purchase comparable jarred baby food.	Discuss the importance of trying to offer new foods more than once!	
Meat and or assorted vegetables and fruit		Understand that	
<ol> <li>Instructions</li> <li>Have participants cook meats, vegetables, or fruit separately - soft enough to mash. While cooking, add small amounts of water as necessary so food does not dry out.</li> </ol>		participants may have difficulty with trying new tastes and textures.	
2. Mash the food in order to show the variety of textures, (9-12 months is barely mashed, 7-9 months is mashed but has visible chunks and a variety of textures, for a baby 6 months the texture is mashed smooth).		Refer to foods as high nutrient foods vs. low nutrient foods and avoid	
<ol><li>Use a jar of baby food for a variety of texture.</li></ol>	age groups to look at and compare	referring to food as good or bad.	
<ol> <li>Discuss the importance of following g foods.</li> </ol>	uidelines when introducing new		
5. Explain the importance of food storage	ge and the consequences of spoilage.		
Debrief			
Ask participants if they would like to try the h store bought food. Ask them what they like be			
Look at the nutrient list and ingredients on th in terms of importance.	e jarred baby food. Discuss additives		
Compare costs for homemade baby food com food.	pared to the store bought jarred		

Healthy Communication	
More Than Words	
<b>Purpose</b> To enhance communication, and build self-awareness <i>Note: This exercise is similar to the telephone game and can be used as an</i> <i>icebreaker.</i>	<i>Helpful Hints</i> <i>Provide fun</i> <i>incentives for</i> <i>participating</i> .
Materials Felt Pens Paper White board or flip chart	Have a facilitator demonstrate the activity.
<ol> <li>Instructions         <ol> <li>Divide participants into two lines with each person facing the back of the person in front of them. The first person in each line faces the whiteboard or flipchart.</li> <li>Ask participants to refrain from talking as soon as the exercise begins.</li> <li>Give the last participants in each line a simple drawing on a sheet of paper.</li> <li>Have the last person in each row draw the picture on the back of the person ahead of them with her finger.</li> <li>One by one each participant then draws what she felt on her back on the back of the person in front of her.</li> <li>This continues until the person at the front, facing the wall draws what she felt on her back on the white board or flipchart.</li> <li>Show everyone the drawing from the start of the line and compare it to the one drawn at the end of the line.</li> </ol> </li> <li>Debrief         Ask the participants what happened? What did they like about the activity? What did they not like? Is it hard communicating without speaking? How do we communicate with others, without words? Why is it important to understand this?         </li> </ol>	Participants enjoy this activity, so have plenty of drawings in case they want to play again. Allow participants to debrief in their own way after this activity. Create the opportunity for discussion with open ended questions.

#### **Healthy Relationships and Mental Health Expression – Healthy Communication Helpful Hints** Purpose To talk about expression and emotions, promote healthy expression, and assist Keep the atmosphere in recognizing emotions in others, including children. *light – this is meant* to be fun **Materials** Preparation Be prepared to play along especially if 10-15 blank cards Label each card with an emotion and a body part i.e. participants appear White board and Emotion - Happy, Body Part - Arms to have difficulty markers understanding the 2 Minute Timer Have enough room for everyone to stand and see their game. team member act out the emotion on the card Instructions If a participant is unwilling to play – 1. Facilitate a discussion about communication styles to lead into "emotional avoid taking it charades". personally; allow for her to observe or 2. Ask the group the following questions. How can you tell how another engage in another person is feeling? How do you express your emotions? activity. 3. Have participants form two teams, each team will take turns. 4. Instruct "team A" to have a player take a card and keep it hidden from teammates. She then acts out the emotion written on the card using only the body part listed. 5. Team A then guesses the correct emotion. If the timer has not gone off the player can pick another card and continue acting out emotions. 6. Assign a point for each correct guess. 7. Repeat steps for team B 8. Continue the game until all the cards have been used. 9. Tally the points to determine the winning team. Debrief Encourage participants to discuss how this game made them feel. Did this help you understand more about communication and body language? How can parents use this game to encourage children to express themselves? Adapted from Establish the Connection – Groups for At -risk Youth Hennig, M. (2012)

#### Budgeting **Budget Your Life Helpful Hints** Purpose To assist with budgeting and financial planning Have a list of services **Materials** Preparation that support food security in your Medium sized room with Create a board game with 31 squares to represent community. tables and chairs the days of the month. A pair of dice Board game Each square has a different status – for example Offer to read cards Play money (This can be free day, pay day, incidentals, bills, lucky, or out in order to avoid purchased at department shopping. Ensure there are only two to four pay day singling out players or dollar stores) squares on the board and six to eight free day who may have squares. difficulty with literacy. Create cards with comments for the participants to pick up depending on the square they land on. For example, a comment on an incidental card could Create cards that read "A friend asked you to lend them \$50. You can reflect realistic choose to say yes or no. If you say yes, give \$50 to a challenges that player of your choice." participants experience. This is a great opportunity to Instructions talk about specific challenges without Note: This exercise is meant to be a light, easy way to discuss budgeting and the singling anyone out. challenges of living with a limited income. 1. Instruct the class that this exercise is to see which player can budget Create cards that his/her money most effectively to make it to the end of the game. As require players to soon as a player is in debt, he or she is out of the game. make a choice. E.g. shopping card could 2. Each player takes a turn by shaking dice and moving around the board. read "You have pop, The player who makes it to day 31 with the most money wins the game. oranges, milk and candles on your list. Expenses You have little food in Note: This can be a brainstorming session where participants help make the house. You have the cards and determine costs together. Examples of expenses include: to put something groceries; hydro; telephone; heat; clothing; bus fare; and entertainment. back. Which items will you purchase?" Adapted from Establish the Connection – Groups for At -risk Youth List prices on the Hennig, M. (2012)

card.

	Nutrition	
	Tried It	
Purpose		Helpful Hints
To encourage and create opportunities	s to support good nutrition	It's important to
Materials	Preparation	empower women when it comes to food
4 ropes – skipping rope length 4 pieces of paper	Create four signs that read: Tried It and Like It; Would Like to Try It; No	choices.
Felt markers Stack of food magazines	Thanks; and Don't know.	Allow participants the opportunity to share
20 – 40 Blank index cards Glue sticks	Note: Participants can be part of the preparation, see below.	negative and positive experiences with foods.
Instructions		It may be difficult for some participants to experience new foods
<ol> <li>Have participants browse through the magazines provided, choose and cut out pictures of nutritious foods. This is an opportunity for the facilitator to discuss nutrient dense foods.</li> </ol>		due to sensitivities – with taste, texture and smell.
2. Have participants glue their pio	ctures onto the index cards.	Participants are often reluctant to purchase
3. Collect the cards and mix them up in a stack.		new foods due to limited budgets. It
	on the floor. Place one sign inside each ng back tables to create space.)	might be helpful to identify foods that are affordable and if
	ime and encourage all participants to nd, representing how they feel about	opportunities to experience other foods during group.
Debrief		This exercise can be
Allow time after each one for comments from participants in regard to their choices. This is an opportunity for the instructor to elaborate about the food in terms of taste, nutritional value etc.		modified to include participants' children.
Note: If the group appears interested i plan to have it included in a future acti		
Adapted from Establish th	e Connection – Groups for At -risk Youth Hennig, M. (2012)	

FASD Awareness Spot the Knot Scavenger Hunt		

## FASD Awareness continued.....

## Instructions

- 1. Before the exercise begins place FASD knots/facts around the room and/or building.
- 2. Explain this exercise is like a scavenger hunt, but instead of items, participants bring back FASD facts that are hidden around the building.
- 3. Explain that this is a timed activity, set the timer for 45 minutes, and have a loud whistle to call participants back to the group.
- 4. Check each participant's FASD facts as they return to group. When the group is reassembled award each team with prizes for participating.

#### Debrief

Review group guidelines (i.e. confidentiality, positive and supportive language). As a group debrief and share the FASD Facts. Ensure that comments are framed in a positive and supportive manner.

## Sample FASD Facts

There is no known safe amount of alcohol use during pregnancy.

FASD can cause birth defects and problems with learning.

Individuals with FASD have brain injury.

FASD can affect everyone, no matter what race, religion, or how much money they have. Everyone is at risk!

FASD is preventable. We can support pregnant women to make healthy choices.

People who have FASD can have trouble living on their own.

The effects of prenatal alcohol exposure last a lifetime.

FASD was recognized as a medical disorder in 1973.

FASD is considered to be an invisible disability, because most people who have FASD look the same as everyone else.

Individuals with FASD can have difficulty getting to places on time.

People with FASD have many strengths – artistic, funny, imaginative

Ensure there is enough support staff to walk around the area and provide individual support.

Pair participants up so they can support each other (i.e. pair a participant who struggles with literacy with someone who has strong literacy skills).

	Healthy Relationships and Mental Health	
	My Life Brochure	Helpful Hints
Purpose		neipjurnints
To enhance self-esteer	n, self-awareness and team build	It's very important
Materials	Preparation	to ensure the group is cohesive and has
		established positive
8.5 x 11 paper	Have participants fold the paper twice to make it into a	relationships.
Colourful markers	brochure with three panels.	
Paper Clips		Remind participants
	Tri fold	to frame comments
		in a positive and
Instructions		supportive manner.
Have participants refle	ct on a positive aspect of their family history (e.g. clan,	
	s etc) Have them consider their strengths and think about	Let participants
what they would like for their children to know	or their children in the future. Ask what they would like	know they can choose to keep their
		brochure private if
	articipants sit next to each other around a table. Explain meant to be fun and positive. Instruct participants to:	they like.
	nes on the front cover and decorate anyway they like	
	ide panel write/illustrate where they come from (family	If participants have
history)		difficulty with
	inside panel have them describe their strengths	literacy they can
	side panel have them describe what they would like to see en in the future.	focus more on drawing pictures.
	e – have each participant fold and paperclip their brochure	
and pass it to t		
	ng the brochures, have each participant write a positive ut the person whose pamphlet they have, on the back panel	Once participants complete the inside
	the next person.	panel encourage
	exercise until the brochures have gone around the table and	them to decorate
been returned	to the original owners.	the front of the
Debrief		brochure until everyone is done.
Ask narticinants: if the	y would like to share their brochure and talk about what	everyone is done.
	n; and how they felt when other participants said nice things	
	ipants know they can keep this brochure for reflection.	
ļ A	Adapted from 'Brochure About Me' Debbie Cook, CTRS, CLP of	
	New Hampshire Hospital 1999	

Child Safety Collage	
Purpose	Helpful Hints
To discuss methods to keep children safe	Maintain safety in
Materials	the group!
Pens	
Flipchart or whiteboard Small pieces of paper	<i>Be sensitive to the fact that there may</i>
Bristol board	be parents in the
Felt markers	group who have
Glue sticks Scissors	children in care of child welfare services.
5(155015	crina werjare services.
<ul> <li>Instructions <ol> <li>Facilitate a brainstorming session focused on ways in which adults keep children safe. Record ideas on the flipchart or whiteboard.</li> <li>Encourage participants to choose two or three concepts and work individually to draw and/or cut and paste pictures illustrating safety ideas onto small pieces</li> <li>Have the group collaborate and create a collage by gluing their illustrations on the Bristol board. This can then be posted on the wall.</li> </ol> During the brainstorming session encourage participants to think about: different age groups; different types of safety for example emotional safety</li></ul>	Be aware that participants and/or their children may have experienced childhood sexual abuse. If a participant appears uncomfortable and/or needs to talk about her personal experiences take her aside so she can talk and/or let her know
(children need to feel safe to express their feelings), physical safety (car seat,	that you are available
food, bicycle, playground).	after group. Connect participants to a
Debrief	mental health
Review the Bristol board collage highlighting participants' attention to safety and creative ideas and abilities. This exercise may be helpful in identifying areas where more information and/or community connections are needed. For example you may want to invite a speaker on car seat safety, infant safety etc.	counsellor if available.

	Self-Care		
	Relaxation Activity		
		Helpful Hints	
Purpo	<b>se</b> vide relaxation and grounding techniques		
io pio			
Mater	ials	Some participants	
νοσα Ν	1ats/gym mats	may not feel comfortable lying	
-	for body awareness	down, provide a	
		chair, be creative in allowing others to	
Inctru	ctions	participate in a	
		different way. Be	
1.	Start the activity with a short discussion about stress and ask participants:	flexible!	
	<ul><li>What causes you stress?</li><li>What can it do to your body?</li></ul>		
	When is stress good?	Invite a mental health counsellor to	
	<ul> <li>When was the last time you shut your phone off and didn't answer a text message?</li> </ul>	come relax with the	
	<ul> <li>Do you remember the last time you were able to sit in silence?</li> </ul>	group. This will	
_		provide an opportunity for the	
2.	Before beginning the relaxation exercise ask participants to take note as to	participants to	
З	how they are feeling. Explain the importance of breathing and reflecting. Explain that taking	create a personal connection to other	
5.	even one minute out of each day to relax and breathe can make a	connection to other	
	difference in a person's stress level.	members.	
4.	Ask participants to take off their shoes, lie down on a matt, and close their		
_	eyes.	Talk in a calm, slow	
5. 6	Turn the lights down low.	quiet voice	
6.	Ask participants to take a deep breath in, hold for three seconds and then breathe all the air out. Repeat three times.	encouraging participants to ente	
7.	To start the relaxation exercise, ask participants to think only about what	into a calm mood.	
	you are saying.		
	Script		
	• This exercise is meant to help you relax your body from the tip of		
	your toes to the top of your head.		
	<ul> <li>Focus on your feet. Keeping your eyes closed; bring your feet forward and as you take a breath relax them</li> </ul>		
	<ul> <li>forward and as you take a breath relax them.</li> <li>Now move gradually up your body flexing and relaxing your legs –</li> </ul>		
	- Now move bradding up your body nexing and relaxing your legs -		

breathing in and out each time you relax your muscles. Move up to your midsection - gently press your lower back to the • floor – breathe and relax. Move up to your shoulders - gently push your shoulders together -breathe in deep and as you breathe out relax them. Now move to your face. Scrunch up your face muscles and then • relax them. Take a deep breath and as you breathe out soften your eyes and relax your jaw. Now breathe consciously deeply in and out all the while relaxing • your whole body. Allow participants to relax for a few minutes in silence. When you're ready to wind up the exercise let them know they are going to be asked to do a little energizing exercise. Ask them to rub the bottom of their feet together vigorously, and then have them rub their hands together vigorously and when they are ready they can slowly sit up. Turn the lights up if necessary. **Debrief:** Ask the group to reflect back on how they felt before the exercise. Ask them how they feel after having done the relaxation exercise.

## Appendix A: Related Resources

*Empowering Front-Line Staff and Families Through a Collection of Lived Experiences* was developed as a resource for programs that focus on working with marginalized women who are pregnant and parenting and live with FASD.

College of New Caledonia PO Box 5000 Burns Lake, BC VOJ 1E0

http://www.cnc.bc.ca/ shared/assets/Empowering Front-Line Staff and Families Through a Collection of Lived Experiences20638.pdf

Supporting Success for Adults with Fetal Alcohol Spectrum Disorder (FASD) was developed by Community Living British Columbia. This document provides a brief overview and history of FASD as well as a compilation of potential supports and strategies to assist individuals who have FASD with daily living and work life.

Community Living British Columbia Airport Square – 7<sup>th</sup> Floor 1200 West 73<sup>rd</sup> Avenue Vancouver, British Columbia Canada V6P 6G5

http://www.communitylivingbc.ca/wp-content/uploads/Supporting-Success-for-Adults-with-FASD.pdf

## Appendix B

# **FASD Behaviours/Characteristics**

Following are descriptions of some of the challenges associated with FASD and some of the characteristics/behaviours that are common to individuals who have FASD. These traits have been observed and researched over the last three decades and are described in numerous publications including those by Streisguth (1997), Malbin (2002), and PHAC (2005). Under each description is an example as to how behaviours/characteristics can manifest. These examples are based on observations and were contributed by educators, frontline workers and caregivers.

**Impulse control:** This behaviour can look irrational, as the individual acts out impulsively, may become angry without warning, or may inappropriately hug, laugh or yell. A typical brain can function somewhat like a filter, allowing people to monitor and control impulses – a person who has FASD may not have that capacity.

**Abstract Concepts:** People who have FASD often take jargon literally and misunderstand abstract concepts involving money, time, responsibility, value, safety and friendship.

**Memory:** Short term memory challenges may require the individual to be reminded about the same thing every day. Memory can also be spotty - the individual may remember something day after day and then all of a sudden the information is gone. He or she may be unable to retrieve information she just heard. Impaired working memory affects an individual's ability to consider all the elements of a situation. Once long term memory is activated, this learning may become rigid and difficult to change when new learning is required.

**Understanding cause and effect:** For every personal action there is a reaction that a typical individual can usually predict. Individuals who have FASD however; have difficulty recognizing the link between their behaviours and outcomes. They do not learn from consequences.

**Difficulty with Change:** It can be very difficult for individuals who have FASD to adjust to changes whether they are environmental or related to rules, times and procedures.

**Attention/Hyperactivity:** An individual who has FASD may struggle to pay attention –she may be easily distracted, become overwhelmed and mentally fatigued within a relatively short period of time. In addition she may have difficulty sitting still.

**Chronology:** The individual may not have a clear sense of her own history. We carry a chronology of our lives along with us – so we usually have our memories sorted and anchored in the order in which they occurred. We know when key events happened in our lives such as when someone close to us passed away.

**Good Judgment:** An individual who has FASD may be unable to make good choices because of an inability to reason out consequences or she may decide without using information from the past.

**Difficulty Generalizing Information:** An individual may learn a skill or a rule in one place but not be able to transfer that information to another place. Similarly she may be able to complete a task with one set of materials but not another.

**Organization:** The ability to plan daily tasks is compromised for people who have FASD and they may have a reactionary response and difficulty determining the necessary sequence of events to complete a task, and the time each task requires.

**Following Through:** An individual may be unable to carry information forward and act appropriately even though she appears to understand, and states, what needs to be done. This is a person who can "talk the talk" but has difficulty "walking the talk".

**Reality:** This is often referred to as confabulation. The individual seems to be lying when in fact she is trying to fill in memory gaps and piece together different chunks of information. Something she has seen or was told can become part of her own reality.

**Motivation:** A person may appear disengaged, tired or lazy when in reality she may be overwhelmed and may not know how to get started. She may be mentally fatigued by the events and in essence "shut down".

**Social Interaction:** Like everyone, people who have FASD want friends, but may be easily misled because of their need to belong. They will take the blame for something if they think it's what a person wants to hear and they are easily manipulated to take blame. They will participate in an activity because they have been asked and give no regard to the level of safety.

**Communication Issues:** A person who has FASD may not understand what another is saying if that person talks too quickly. Complex language might be unmanageable; also, she may not understand the different applications/meanings of one word or the abstract meaning of idiomatic expressions such as "just grow up," "hit the road," "you need to take responsibility," or "when you are ready."

**Cognitive Pace:** People who have FASD have been referred to as 10 second people in a two-second world. This can be both embarrassing and intimidating causing the individual to withdraw and seem disengaged. The person may need extra time to answer questions. Silent pauses allow time to process information more efficiently.

**Perseveration:** People who have FASD may get "stuck" and need support to let things go such as strongly held beliefs, emotions, fascination or something they have heard.

**Sensitivity:** Some people can be hyper sensitive while others are hypo sensitive. Sensory issues have a significant impact on an individual's ability to function in a typical fashion.

**Developmentally Younger:** Individuals who have FASD are often developmentally younger than their chronological age.

Adapted from Empowering Frontline Staff and Families through a Collection of Lived Experiences Anne Guarasci It is hoped that this resource can inspire and support programs and agencies to practice from an

FASD informed perspective.

There is no greater disability in society, than the inability to see a person as more

Robert M. Hensel

#### References

- Carson G., Cox L.V., Crane J., Croteau P., Graves L., Kluka S., ... & Society of Obstetricians and Gynaecologists of Canada. (2010). Alcohol Use and Pregnancy Consensus Clinical Guidelines. *Journal of Obstetrics and Gynaecology Canada*, 32(8 Suppl 3). Retrieved from <u>http://www.sogc.org/guidelines/documents/gui245CPG1008E.pdf</u>
- Clarren, S. K., & Salmon A. (2010). Prevention of fetal alcohol spectrum disorder: Proposal for a comprehensive approach. *Expert Reviews of Obstetrics & Gynecology*. 5(1).
   DOI 10.1586/eog.09.72
- Gelb, K., & Rutman, D. (2011). Substance using women with FASD and FASD prevention: A literature review on promising approaches in substance use treatment and care for women with FASD. Victoria, BC: University of Victoria.
- Guarasci, A. (2011). *Empowering front-line staff and families through a collection of lived experiences.* Burns Lake, BC: College of New Caledonia.
- Guarasci, A. (2012, March 7). BC regional fetal alcohol spectrum disorder (FASD) consultation meeting *Public Health Agency: Vancouver Meeting Summary Report*. Burns Lake, BC: College of New Caledonia
- Hennig, M. (2012). *Establish the connection: Groups for at-risk you*th. Burns Lake, BC: College of New Caledonia.
- Hughes, S. &Hyman, P. Trauma-Informed Body-Centred Interventions. In Poole, N., & Greaves,L. (Eds.). (2012) *Becoming trauma informed*. Toronto, ON: Centre for Addiction andMental Health.

- Johnston, A.D., (2011, November 22). Better testing needed to diagnose fetal alcohol spectrum disorder, Canadian expert Sterling Clarren says. *Toronto Star*. Retrieved from <a href="http://speakyourmind.thestar.com/thestar/atkinson-series/better-testing-needed-to-diagnose-fetal-alcohol-spectrum-disorder-canadian-expert-sterling-clarren-says/">http://speakyourmind.thestar.com/thestar/atkinson-series/better-testing-needed-to-diagnose-fetal-alcohol-spectrum-disorder-canadian-expert-sterling-clarren-says/</a>
- Keen, C.L., Uriu-Adams, J.Y., Skalny, A., Grabeklis, A., & Grabeklis, S., Green, K., Yevtushok, L., Wertelecki, W.W., & Chambers, C.D. (2010). The Plausibility of Maternal Nutritional Status Being a Contributing Factor to the Risk for Fetal Alcohol Spectrum Disorders: the Potential Influence of Zinc Status as an Example. *Biofactors*, *36*(2). Retrieved from <a href="http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2927848">http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2927848</a>
- Malbin, D. (2002). *Fetal Alcohol Spectrum Disorders: Trying Differently Rather Than Harder, Second Edition*. Portland, Oregon: Tectrice, Inc.
- Public Health Agency of Canada (2005). *FASD: A Framework for Action*. Retrieved from http://www.phac-aspc.gc.ca/publicat/fasd-fw-etcaf-ca/index-eng.php
- Poole, N. (2012). Essentials of trauma-informed care. Ottawa, ON: Canadian Centre on Substance Abuse. Retrieved from <u>http://www.cnsaap.ca/SiteCollectionDocuments/PT-</u> <u>Trauma-informed-Care-2012-01-en.pdf</u>
- Rutman, D. (2011b). Substance using women with FASD and FASD prevention: Voices of women with FASD: Promising approaches in substance use treatment and care for women with FASD. Victoria, BC: University of Victoria
- Streissguth, A., H. Barr, J. K., & F. Bookstein. (1996). Understanding the occurrence of secondary disabilities in clients with Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Effects (FAE). Edited by A. Streissguth. Seattle: University of Washington School of Medicine.

- Tatarsky (2002). Harm Reduction Philosophy. In Marlatt, G.A., Larimer, M.E., & Witkiewitz,K. (Eds.) (2012). *Harm reduction pragmatic strategies for managing high risk behaviors*.New York, NY: The Guilford Press
- Thomas, J.D., Abou, E.J., & Dominguez, H.D. (2009). Prenatal choline supplementation mitigates the adverse effects of prenatal alcohol exposure on development in rats. *Neurotoxicology and Teratology*, 31(5), 303-311. Retrieved from http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2952280



**CNC** Press