

Fetal Alcohol Spectrum Disorder Increasing our Understanding

Nancy Poole

**Director, BC Centre of Excellence for Women's Health,
Vancouver, Canada**

**Lead, Prevention Team, Canada FASD Research
Network**



Values to Guide our Work on FAS

Respect

Understanding

Compassion

Hope



What does FASD look like?

WHAT IS FASD?

What is FASD?

- **FASD** is an umbrella term describing the range of effects that can occur in an individual whose mother drank alcohol during pregnancy.
- These effects may include physical, mental, behavioral, and/or learning disabilities with possible lifelong implications.
- The term FASD is not intended for use as a clinical diagnosis. Diagnoses like FAS, partial FAS and ARND fall under the umbrella of FASD.

Alcohol affects every area of the brain

- Brain stem **Regulation of state**
- Cerebellum **Motor Skills** coordination /balance
- Limbic system **Attention**
- Cerebrum (left temporal lobe **Speech and language**
- Frontal lobes **Executive functioning**
- Multiple locations **Learning, memory, cognition**
- Whole brain **Adaptive skills and applications**

ALARMMERS

- **A**daptation
- **L**earning
- **A**ttentions
- **R**easoning
- **M**emory
- **M**otor
- **E**xecutive function
- **R**egulation of state
- **S**peech /language

The diagnoses related to alcohol and other drug use in pregnancy

- Fetal Alcohol Syndrome includes
 1. A pattern of facial anomalies
 2. Growth deficiencies
 3. Brain damage
- Partial FAS
- Alcohol-related neurodevelopmental disorder (ARND)
- Alcohol-related Birth Defects (ARBD)

Key factors that contribute to FASD

- Alcohol - There is no known safe time during the pregnancy or safe amount that a woman can drink
- Other factors increase the risk of FAS
 - BMI, genetics, age, length of drinking history, nutrition, environmental stressors
 - Influence of broad determinants of health such as violence, social support
- The risk is higher for those who already have a child affected by FASD

FASD Diagnosis

Assessment and diagnosis is complex and relies on:

- A multidisciplinary assessment
- A comprehensive battery of cognitive and performance testing examining many domains of brain function

Canadian Guidelines for Diagnosis

Suggested Domains for Neurobehavioral Measurement

1. Hard and Soft Neurological Signs
2. Brain Structure
3. Cognition
4. Communication
5. Academic Achievement
6. Memory
7. Executive Functioning and Abstract Reasoning
8. Attention Deficit/Hyperactivity Disorder
9. Adaptive Behavior/Social Skills/Social Communication

Chudley, A.E., Conry, J., Cook, J.L., Looock, C., Rosales, T., LeBlanc, N. (2005). Fetal alcohol spectrum disorder: Canadian guidelines for diagnosis. CMAJ 172 (5_suppl).

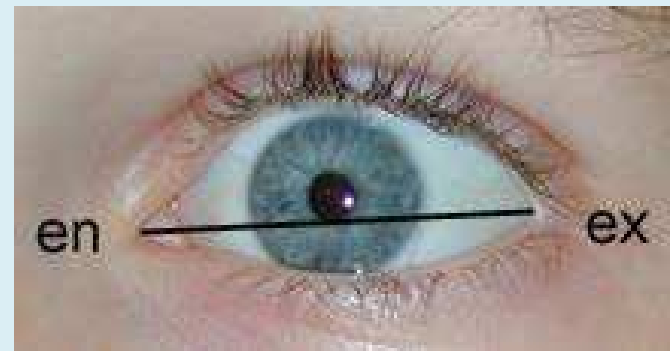
<http://www.phac-aspc.gc.ca/hp-ps/dca-dea/prog-ini/fasd-etcaf/publications/can-gu-ld-eng.php>

Currently . . .

Current diagnostic methods are being standardized across diagnostic clinics in Canada

- Canadian Standards for normal values in key physical indicators of FASD (*Eye Slits*)
- Common cognitive and psychometric test batteries used in all clinics
- Common collection of historical data, physical and cognitive findings and diagnosis and recommendations

Palpebral fissures measured using computerized method developed by Astley, et.al.



Summary of the cognitive and behavioural problems associated with FAS

- Easily distracted by sounds and movement
- Impulsive
- Hyperactive
- Short attention span and concentration abilities
- Difficulty incorporating change in routine
- Limitations in problem solving
- Limitations in ability to generalize information, form links, learn from their experience, understand consequences & take instruction
- Trouble expressing feelings and understanding feelings of others
- Problems adapting to the normal stresses of day-to-day living.

While it is easy to focus only on the difficulties,
individuals with FAS also exhibit positive
characteristics such as being...



Action for inclusion

STRATEGIES FOR WORKING WITH INDIVIDUALS WITH FASD

Get Started

Get to know FASD across the lifespan and
learn about interventions

Begin by choosing a gender:



Male



Female

Select a development stage ▼

Start



Strategies



- Keep it simple
- Slow it down
- Modify environment
- Identify strengths
- Check for understanding
- Support success!

Some Canadian links on intervention

- KnowFASD <http://knowfasd.ca>
- Blog <http://fasdintervention.wordpress.com/>
- For educators -
www.fasdoutreach.ca/
- Whitecrow
www.whitecrowvillage.org/

Challenges for health promotion, prevention and treatment providers

ISSUES UNDERLYING FASD PREVENTION STRATEGIES

Issue: Barriers to discussing alcohol use with pregnant women

- Women report that guilt, shame and fears of losing their children to child welfare authorities prevent them from getting the help they need with alcohol problems

Poole, N., & Isaac, B. (2001). *Apprehensions: Barriers to Treatment for Substance-Using Mothers*. Vancouver, BC: British Columbia Centre of Excellence for Women's Health

- Physicians report that they don't feel fully prepared to discuss substance use with women

Tough, S. C., Clarke, M. E., Hicks, M., & Clarren, S. (2005). *Attitudes and approaches of Canadian providers to preconception counselling and the prevention of Fetal Alcohol Spectrum Disorders*. *Journal of FAS International*, 3, e3.



Issue: Lack of recognition and tailored support

- Problem alcohol use in women is often not recognized or treated.
 - Often health care providers use confrontational, proscriptive or substance-focused approaches, which can be ineffective in supporting paced and achievable change in substance use by women
- 1% of mothers identified with risky alcohol use in antenatal records in BC at start of ActNow HCIP initiative

Arrests of and Forced Interventions on Pregnant Women in the United States, 1973–2005 (Paltrow and Flavin, 2013)



Ferguson v. City of Charleston, 99-936.

For five years, a state hospital in Charleston, South Carolina, collaborated with the local police department to search pregnant women and new mothers for evidence of drug use without a warrant or their consent. Medical staff gave this information to police who arrested women right out of their hospital beds.

Source: <http://advocatesforpregnantwomen.org>

- 413 cases between 1973 and 2005
- 41 (10%) involved alcohol
- Low-income women (71%) and women of color (59%), especially African American women (52%), overrepresented
- In all but three states, such prosecutions have been declared unconstitutional or the resulting convictions have been overturned

A recent study of US **state level policies** regarding **alcohol use during pregnancy** revealed substantial variability in characteristics of policies as of January 2012 (19 primarily supportive, 12 primarily punitive, 12 with a mixed approach, and 8 with no policies)

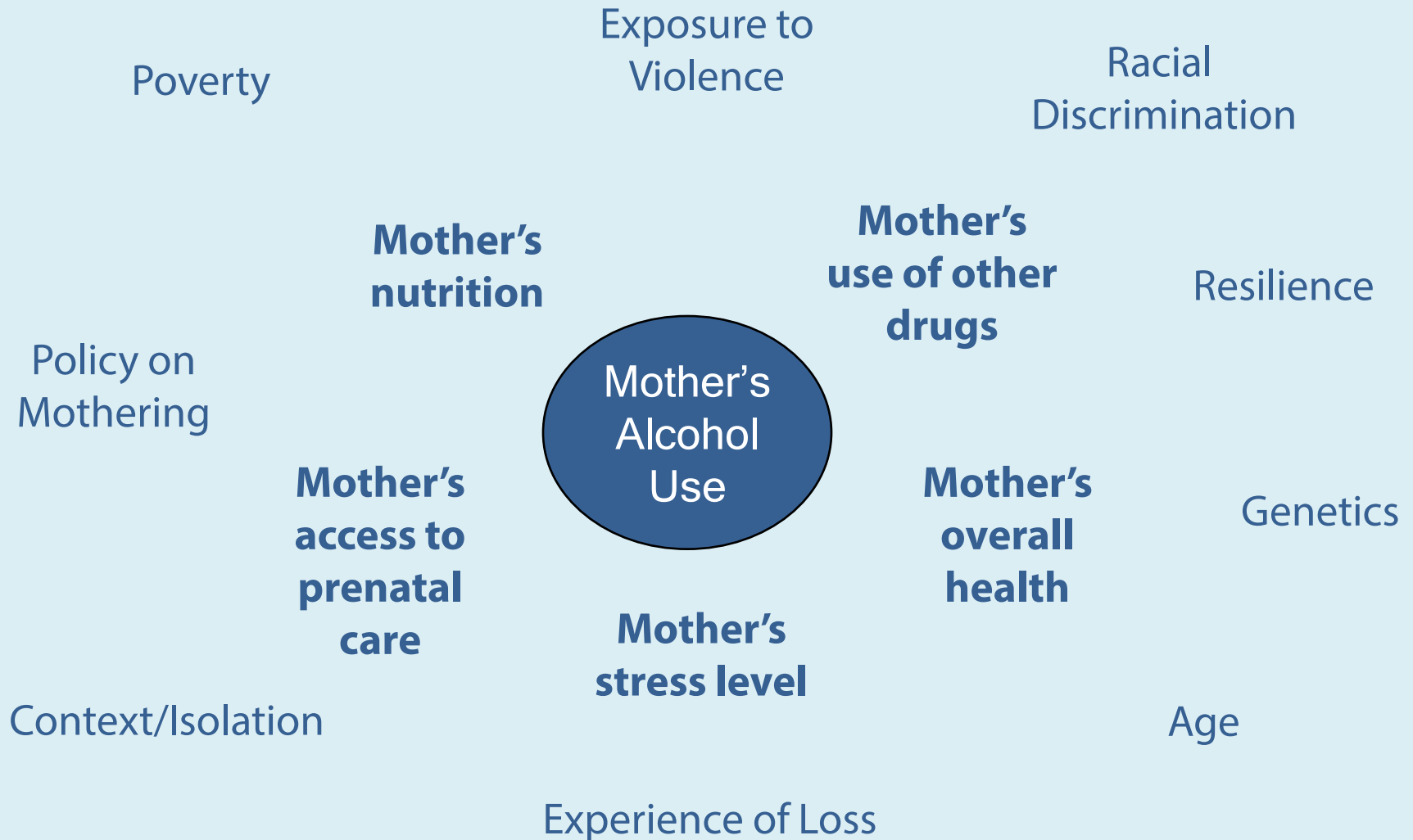
Poor Public Health Policy



April 2012 – The chemical endangerment law in Alabama was created in 2006 to protect children from explosive meth labs. It has now been used to prosecute 60 women for exposing their children to substances during pregnancy.

- In addition to being a violation of the constitutional rights of pregnant women, the evidence shows that **these arrests and detentions have not resulted in prompt or appropriate prenatal and/or substance use treatment, care and support**
- Hundreds of medical and public health groups have advocated against these measures as **the threat of arrest deters women from seeking prenatal care, accessing addictions treatment or speaking openly about their alcohol and drug use with health and social service providers - counter-productive**

It's Not Only About Alcohol



Reasons Why Women May Drink During Pregnancy

1. Women are unaware they are pregnant.
2. Women are unaware of the extent of damage alcohol can cause the fetus.
3. Women underestimate the harms alcohol consumption can cause because they know other women who drank during pregnancy and their children appear healthy.
4. Alcohol use is the norm in their social group and abstaining may therefore be difficult.
5. Women may be using alcohol to cope with difficult life situations such as violence, depression, poverty, or isolation.
6. Women may struggle with alcohol addiction.

(Cismaru et al., 2010)

Why do girls and women drink alcohol during pregnancy?
Information for Service Providers

"It is safest not to drink alcohol during pregnancy." Yet, 11% of Canadian women continue to drink after learning they are pregnant. Many service providers struggle to understand why a woman drinks during pregnancy.

6 Reasons Why Girls & Women May Drink During Pregnancy

- 1. Women are unaware they are pregnant.**
Approximately 50% of pregnancies are unplanned. Most women will stop drinking when they learn they are pregnant. It is important to have conversations with women about alcohol use before they become pregnant.
- 2. Women are unaware of the extent of damage alcohol can cause the fetus.**
While Fetal Alcohol Spectrum Disorder is the leading known cause of developmental disability, the range of harms of alcohol during pregnancy is still debated in the media and science has yet to determine all the factors that affect how alcohol can affect a developing fetus.
- 3. Women underestimate the harms alcohol consumption can cause because they know other women who drank during pregnancy and their children appear healthy.**
While many women are aware of the possible harms of alcohol, tobacco and other drugs, the effects can be varied, invisible, and only apparent years down the road.
- 4. Alcohol use is the norm in their social group and abstaining may therefore be difficult.**
For some women, it can be hard to abstain when it's expected that they drink, especially if people don't yet know they are pregnant. Alcohol use is often an integral part of business networking, socializing, and relationships.
- 5. Women may be using alcohol to cope with difficult life situations such as violence, depression, poverty, or isolation.**
Many women can find it difficult to stop drinking when their life circumstances remain challenging during pregnancy or if they have few alternatives for finding support and treatment.
- 6. Women may struggle with alcohol addiction.**
Addiction spans all segments of society and can be a concern long before pregnancy. In some cases, pregnancy can be an opportunity to address addiction issues, but in other cases, harm reduction approaches should be considered until a woman is ready to address her addiction.

Research shows that drinking alcohol during pregnancy is most consistently predicted by: 1) how much women drank before they were pregnant; and 2) being in an abusive relationship.

References
1. Cismaru, M., et al., Preventing fetal alcohol spectrum disorders: the role of protection motivation theory. *Health Marketing Quarterly*, 2010, 27(1): p. 66-85.
2. Skagerström, J., G. Chang, and P. Nilsson, Predictors of Drinking During Pregnancy: A Systematic Review. *Journal of Women's Health* (15405956), 2011, 20(9): p. 901-913.
3. Walker, M., Al-Sabah, B., Islam, F., & Tamim, H. (2011). The epidemiology of alcohol utilization during pregnancy: an analysis of the Canadian Maternity Experiences Survey (MES). *BMC Pregnancy and Childbirth*, 11(1), 52. doi:10.1186/1471-2333-11-52

Coalescing on Women and Substance Use • www.coalescing-vc.org

www.coalescing-vc.org

Recent research and media attention

Is there a safe amount of alcohol consumption during pregnancy?

Clear risk at moderate-high levels of alcohol consumption

- Women who report having consumed 7–14 drinks per week when pregnant are more likely to have a baby with birth defects or complications
- 5 or more drinks per occasion places the fetus at greatest risk of Fetal Alcohol Syndrome, one of the diagnoses that fall under the umbrella of Fetal Alcohol Spectrum Disorder (FASD)

Studies of women drinking low-moderate amounts of alcohol show both adverse effects and no effects.

Basic science (in lab) shows alcohol is a teratogen and has dose dependent and exist on a continuum



“Light” drinking during pregnancy remains a hot media topic

So what is our message?

Better safe than sorry?

- While the risk from "light" consumption during pregnancy appears very low, there is no known threshold of alcohol use in pregnancy that has been definitively proven to be safe.
- Individual-level factors such as nutrition, genetics, and other substance use can interact to affect outcomes.
- Potential for misunderstanding drink sizes and actual alcohol content of various types of drinks
- Compelling evidence from research on animals that even low doses of alcohol at any time during pregnancy can affect fetus



Research to Practice

- No safe time
- No known safe amount
- No safe kind

Discussing ambiguity with women – Helpful or not?

Public health guidelines: "The safest choice is to not drink at all while pregnant, planning to become pregnant or before breastfeeding"

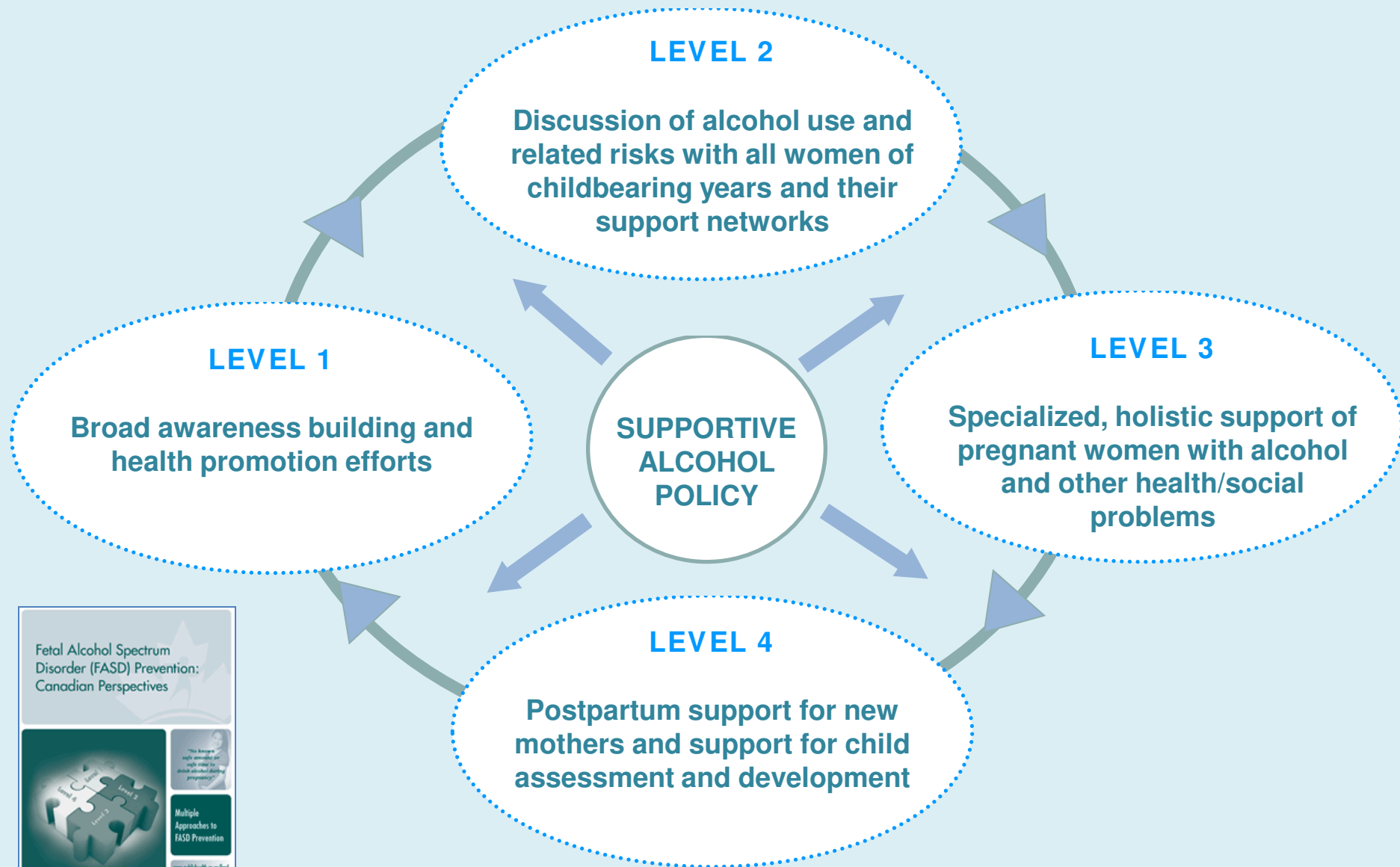
Importance of being honest and factual about the limits of research on alcohol during pregnancy suggested by some studies

"Credibility ... was enhanced by acknowledging uncertainty about the risk to the fetus with low to moderate alcohol exposure. Rather than undermine an abstinence-based message, this information served as a clear rationale for the recommendation. An honest and scientific framing of the message and delivery by an expert source were also shown to minimize counterargument and strengthen the message's persuasiveness." (France et al., 2013, p.8)

Linking women's health promotion and child wellbeing, 4 levels of prevention

PROMISING PRACTICES IN PREVENTION

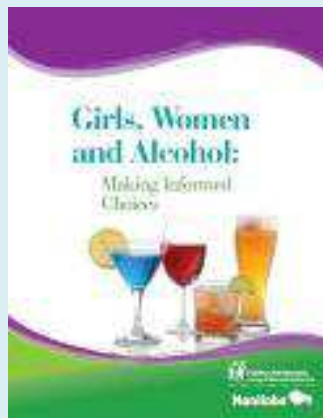
4 Levels of FASD Prevention



Level 1 - Broad awareness building and health promotion efforts

Examples:

- Development of health education materials (pamphlets, posters)
- Awareness campaigns
- Low risk drinking guidelines
- Materials for facilitators of girls' empowerment groups
- Warning labels



www.gov.mb.ca/healthchild



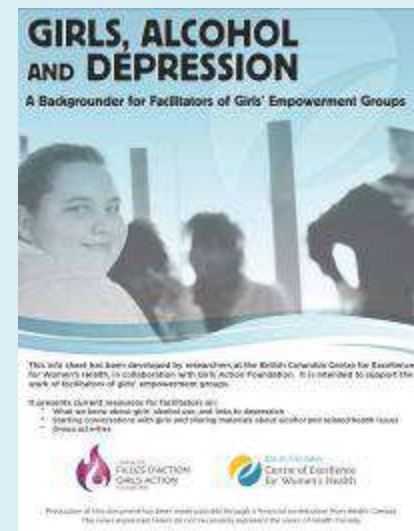
<http://www.ccsa.ca>



<http://educalcoool.qc.ca>



www.bcliquorstores.com



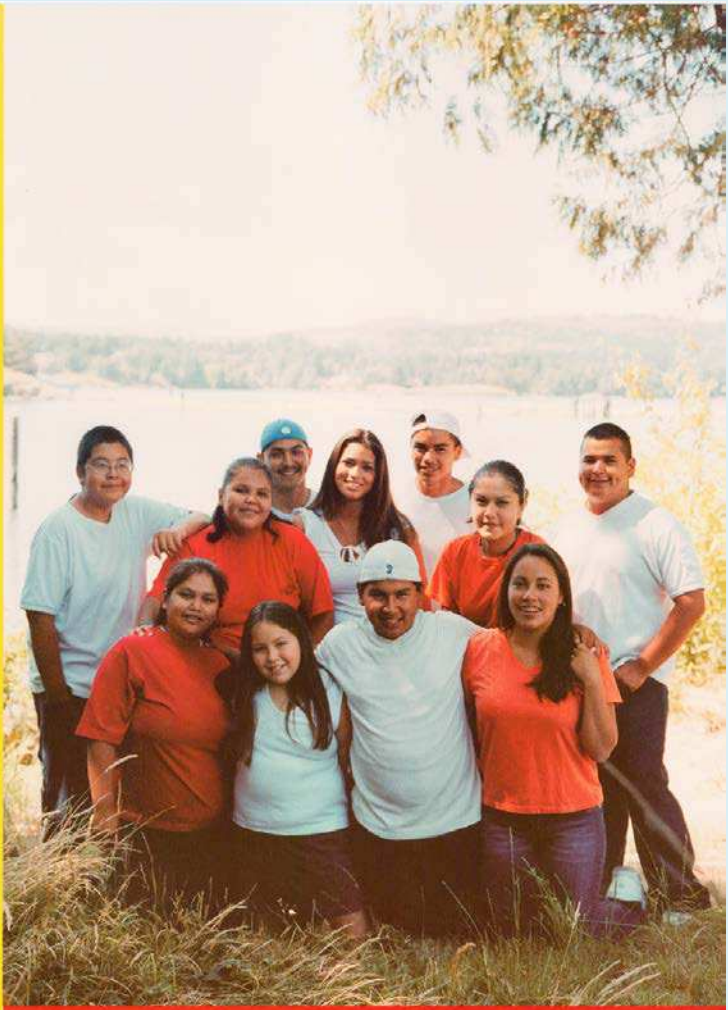
<http://girlsactionfoundation.ca>

Recommended approach

Shares the weight of change between young men and women

Links the outcome to broader community health.

Friends
help
friends
choose a
healthy
lifestyle.
Please don't
drink
alcohol
during
pregnancy.



For information on Fetal Alcohol Syndrome
talk to your health care provider or contact:
BC Aboriginal Network
on Disability Society
1-888-615-4511
www.bcanadbc.ca

© 2011 Health Canada
Healthy Canada
Healthy Youth Plan

**Healthy pregnancy.
Healthy baby. Healthy Nation.**

Key element for campaign effectiveness

Level of Threat

Efficacy Response

Threat is low	<i>No response</i> – individuals do not feel concerned
Threat is higher than efficacy	<i>Defensive response</i> – individuals respond with avoidance, denial, anger, rationalizing (it won't happen to me)
Efficacy is higher than threat	<i>Positive response</i> – increases in awareness, etc.

Alcohol and pregnancy awareness campaigns

Awareness campaigns have the potential to:

- Influence levels of awareness about prenatal alcohol exposure
- Encourage information-seeking (e.g., link to a website)
- Indicate what services are available and how to access them
- Change behaviour (maybe....)

Research evidence suggests that alcohol and pregnancy awareness campaigns **increase knowledge** of the risks of drinking during pregnancy but have **little impact on women's behaviours**.

→ Most likely to have an influence on 'low-risk' drinkers and little to no effect on those who drink heavily or binge drink during pregnancy.

Level 2 – Discussion of alcohol by and with professionals

There is evidence for a wide range of tools and interventions related to identification and brief support by physicians and related health professionals

- Education about drink size and “alcohol literacy”
- Routine screening (embedding it in larger screening efforts)
- Screening for polydrug use (e.g., alcohol and tobacco)
- Tools: CAGE, AUDIT, T-ACE, TWEAK, TLFB
- Web- and computer-based screening, telephone screening
- Medical school training and continuing education (e.g., MDcme.ca online modules)



But can we make these screening efforts safe, given the stigma and the fear women have about losing custody of their children

Might we use the Low Risk Drinking Guidelines to help?

What do the guidelines say about pregnancy and breastfeeding?

“The safest choice is to not drink at all while pregnant, planning to become pregnant or before breastfeeding.”

Canada's low risk drinking guidelines and related resources are available for download from www.ccsa.ca.

Canada's Low-Risk Alcohol Drinking Guidelines

Drinking is a personal choice. If you choose to drink, these guidelines can help you decide when, where, why and how.

For these guidelines, “a drink” means:



Your limits

Reduce your long-term health risks by drinking no more than:

- 10 drinks a week for women, with no more than 2 drinks a day most days
- 15 drinks a week for men, with no more than 3 drinks a day most days

Plan non-drinking days every week to avoid developing a habit.

Special occasions

Reduce your risk of injury and harm by drinking no more than 3 drinks (for women) or 4 drinks (for men) on any single occasion.

Plan to drink in a safe environment. Stay within the weekly limits outlined above in **Your limits**.

Safer drinking tips

- Set limits for yourself and stick to them.
- Drink slowly. Have no more than 2 drinks in any 3 hours.
- For every drink of alcohol, have one non-alcoholic drink.
- Eat before and while you are drinking.
- Always consider your age, body weight and health problems that might suggest lower limits.
- While drinking may provide health benefits for certain groups of people, do not start to drink or increase your drinking for health benefits.

Low-risk drinking helps to promote a culture of moderation. Low-risk drinking supports healthy lifestyles.

When zero's the limit

Do not drink when you are:

- driving a vehicle or using machinery and tools
- taking medicine or other drugs that interact with alcohol
- doing any kind of dangerous physical activity
- living with mental or physical health problems
- living with alcohol dependence
- pregnant or planning to be pregnant
- responsible for the safety of others
- making important decisions

Pregnant? Zero is safest

If you are pregnant or planning to become pregnant, or about to breastfeed, the safest choice is to drink no alcohol at all.

Delay your drinking

Alcohol can harm the way the body and brain develop. Teens should speak with their parents about drinking. If they choose to drink, they should do so under parental guidance, never more than 1–2 drinks at a time, and never more than 1–2 times per week. They should plan ahead, follow local alcohol laws and consider the **Safer drinking tips** listed in this brochure.

Youth in their late teens to age 24 years should never exceed the daily and weekly limits outlined in **Your limits**.



The Canadian Centre on Substance Abuse changes lives by bringing people and knowledge together to reduce the harm of alcohol and other drugs on society. We partner with public, private and non-governmental organizations to improve the health and safety of Canadians.

CCSA wishes to thank the partners who supported development of Canada's Low-Risk Alcohol Drinking Guidelines. For a complete list of the organizations supporting the guidelines, please visit www.ccsa.ca/Eng/Priorities/Alcohol/Canada-Low-Risk-Alcohol-Drinking-Guidelines/Pages/default.aspx

References:
B.A. F. Bennett, D. O'Brien, L. Fawcett, C. L. Mitchell, J. 2011. Alcohol and health in Canada: a summary of evidence and public health drinking guidelines. The Canadian Alcohol Guidelines Review.

200-76 Albert Street, Ottawa, ON K1R 8Z7
Tel: 613-993-4000 | Fax: 613-993-2101
Ottawa's main contact: 613-993-2101
Toll-free (Canada only): 1-877-337-2667
National Alcohol Drinking Advisory Committee
© Canadian Centre on Substance Abuse 2015
Collection of all rights reserved in English



Visit our website to find out more!
www.ccsa.ca

Discussing alcohol with pregnant women

Key Resource

The Society of Obstetricians and Gynaecologists of Canada (SOGC)'s Alcohol Use in Pregnancy Consensus Clinical Guideline (2010)

- Chapter on Counselling and Communication With Women About Alcohol Use
- Brief interventions from pre-conception to pregnancy, scenarios, documentation, tools
- Focus is on supportive dialogue and motivational interviewing approaches



Use of Motivational Interviewing (MI)

“A person-centred, goal directed counselling method for resolving ambivalence and promoting positive change by eliciting and strengthening the person’s own motivation for change.”

W.R. Miller. Plenary presentation, International Conference on Motivational Interviewing. Interlaken, Switzerland, June 7, 2008.

Obstacles to Guiding

Motivational Interviewing

- Righting Reflex
- Roadblocks
 - Ordering
 - Warning, threatening
 - Giving advice, providing solutions
 - Telling people what they should do
 - Disagreeing
 - Approving, praising
 - Shaming
 - Interpreting
 - Questioning
 - Reassuring

Research on Motivational Interviewing

Motivational Interviewing

Effective in brief interactions

Shown to outperform traditional advice giving

Effect not necessarily related to the practitioner's educational background

This can be a helpful stance for all types of professionals who work with women of childbearing years – not only physicians

5 Methods for building motivation for change

Motivational Interviewing

OARS

1. O = Ask **open** questions
2. A = **Affirm**
3. R = **Reflective** listening
4. S = **Summarize**
5. **Elicit change talk**

Example of counsellor using OARS – on BCCEWH youtube site in Part 3.3 Scenarios, making the links

General guidelines for discussing alcohol with pregnant women

- Be non-judgmental and empathetic
- Ask her what she knows; dispel myths
- Work to understand the benefits of substance use for her
- Encourage all small steps for change
- Keep asking, keep encouraging
- Talk about the benefits for both her and the baby

Resources

Coalescing on Women and Substance Use - Alcohol and Pregnancy

- BC Ministry of Health in collaboration with the BC Centre of Excellence for Women's Health
- Resources to support service providers to successfully engage with women and their partners on alcohol use, pregnancy, and prevention of Fetal Alcohol Spectrum Disorder (FASD)
- Infographics, resources and tools, self-assessment questions, tips for health care providers

www.coalescing-vc.org

Alcohol, Pregnancy and Partner Support

Information for Service Providers

Many women are more likely to avoid alcohol during pregnancy if their partners support them in doing so. Conversely, women find it more difficult to reduce their drinking when their partners oppose that decision or take steps to undermine their efforts. If a woman's partner is supportive of her decision regarding reducing alcohol use during pregnancy, service providers can involve partners in supporting healthy alcohol-free pregnancies.

5 Ways Partners Can Support Women

Service providers can talk to women about what they would find supportive. Some of the things women might find helpful include having their partner:

1. Take a pause¹ from alcohol during the pregnancy by quitting or cutting down. Avoid drinking around her and in social situations when they are together.
2. Tell family, friends and anyone offering her alcohol that there is no known safe time to drink alcohol during pregnancy and no known safe amount.
3. Offer her non-alcoholic drinks (e.g., mocktails) and bring non-alcoholic drinks to social events.
4. Take part in social and recreational activities with her that don't involve alcohol.
5. Help reduce the stress in her life. (You can ask her for specific details of how you might do this.)

Many partners want to support their pregnant partners. Service providers can involve partners, directly and indirectly, by:

- ▶ Including information about how partners can support women in both preconception and prenatal materials
- ▶ Asking women if they would like to invite their partner or a close family member or friend to their next appointment to discuss how they can support them in achieving an alcohol free pregnancy, as well as making healthy choices overall.
- ▶ Sharing suggestions of how soon-to-be parents can be supportive of their pregnant partners. Encourage partners to ask pregnant women what kind of support she needs to avoid alcohol, reduce stress, and still have fun.

Remember, a partner can be male or female and that some women may not have the support of a partner and may rely on family or friends.

Many partners are interested in thinking about or changing their own alcohol and drug use as they prepare for parenthood. Service providers can provide information and connect partners with community resources. (It's best to do this separately from a woman's care and treatment).

References

1. van der Wal, N.Y., C. Hoog, and H. de Vries. A qualitative investigation of alcohol use advice during pregnancy: Experiences of Dutch midwives, pregnant women and their partners. *Midwifery*. 2013. In Press.
2. Gearing, R.E., T. McNeil, and F.A. Loeber. Father involvement and fetal alcohol spectrum disorder: Developing best practices. *Fetal Alcohol Research*. 2005. 3, p. e14.
3. Mellgren, S., T. Torstein, and F. Thuen. Changes in alcohol use and relationship satisfaction in Norwegian couples during pregnancy. *Substance Abuse Treatment, Prevention & Policy*. 2013. 8(1), p. 1-11.
4. Everett, K.D., et al. Maternal tobacco and alcohol use during and after pregnancy. *American Journal of Maternal Health*. 2007. 14(1), p. 317-325.
5. Chang, G., et al. Brief intervention for Prenatal Alcohol Use: A Randomized Trial. *Obstet Gynecol*. 2005. 105(5 Pt 1), p. 991-998.

British Columbia
Centre of Excellence
for Women's Health

Coalescing on Women and Substance Use • www.coalescing-vc.org

Level 3 – Holistic care and advocacy

Realities of the lives of birth mothers with children with FASD

Study of birth mothers of 160 children with FAS

Of the 80 who were able to be interviewed:

- 100% seriously sexually, physically or emotionally abused
- 80% had a major mental illness
- 80% lived with men who did not want them to quit drinking

Astley, S. J., Bailey, D., Talbot, C., & Clarren, S. K. (2000). Fetal Alcohol Syndrome (FAS) Primary Prevention through FASD Diagnosis II: A comprehensive profile of 80 birth mothers of children with FAS. *Alcohol and Alcoholism*, 35(5), 509-519.

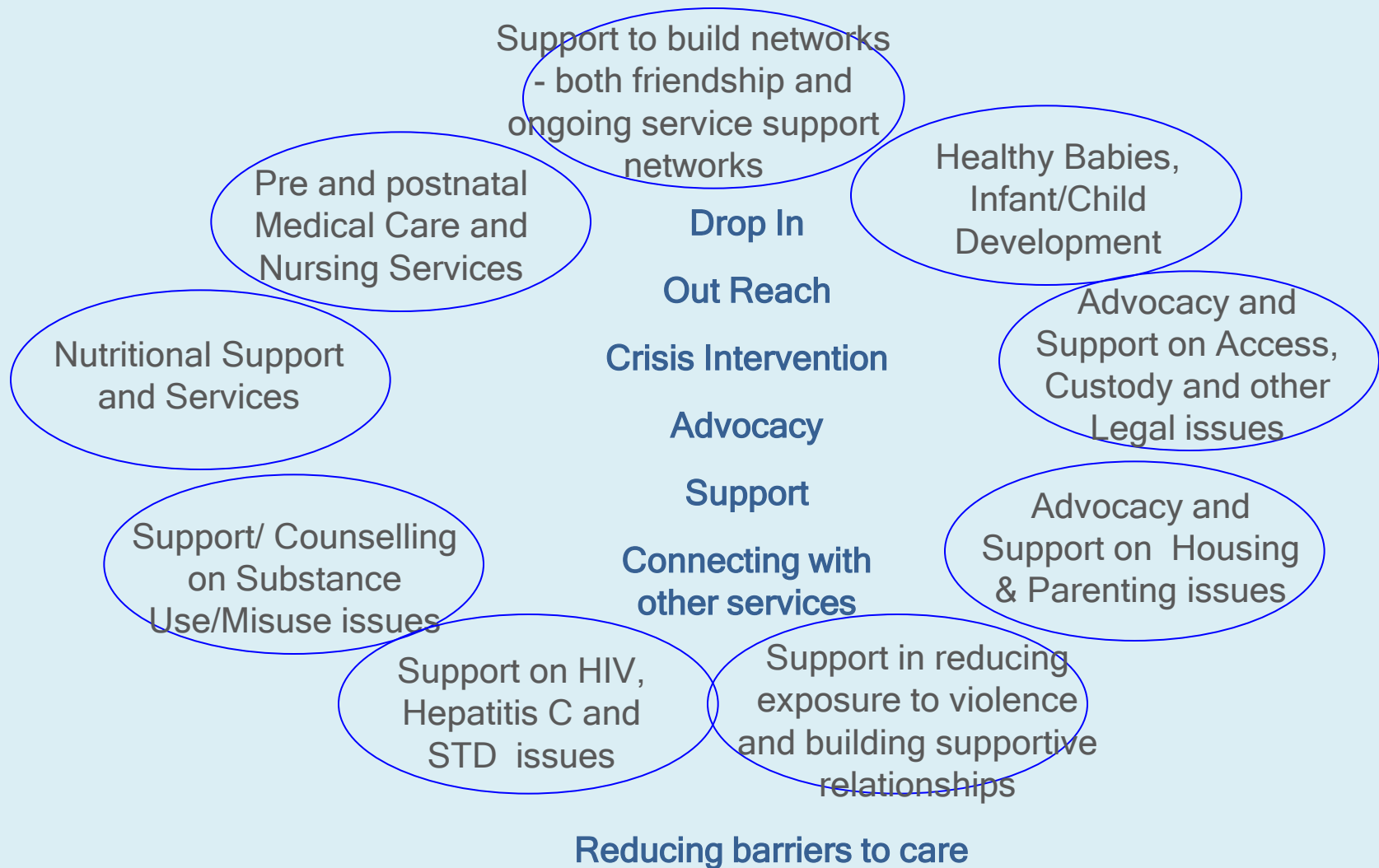
Level 3 – Holistic care and advocacy

Based on the recognition that the health of women and their children is linked to the conditions of their lives and their ability to influence these conditions

Sheway Program

- Provides services in a flexible, welcoming, non-judgmental, nurturing and accepting way
- Supports women's self determination, choices and empowerment
- Offers respect and understanding of First Nations culture, history and tradition
- Takes a harm reduction approach to substance use
- Links women and their families into a network of health-related, social, emotional, cultural & practical support

Sheway's holistic & transdisciplinary care



Specialized prenatal programs

20 years of evaluation research has shown that:

- Early engagement of pregnant women who use substances has been shown to affect a range of outcomes related to maternal, fetal, and child outcomes
- Women who participate in these programs are more likely to keep custody of their child and have higher rates of accessing addictions treatment.
- Children who are involved with their mothers in a comprehensive program of support have been shown to have enhanced developmental outcomes.



**Sheway -
Vancouver**



**Breaking the Cycle
Toronto**

Fir Square Combined Care Unit, at BC Women's Hospital

Mother-centred care that in turn supports positive outcomes for infants

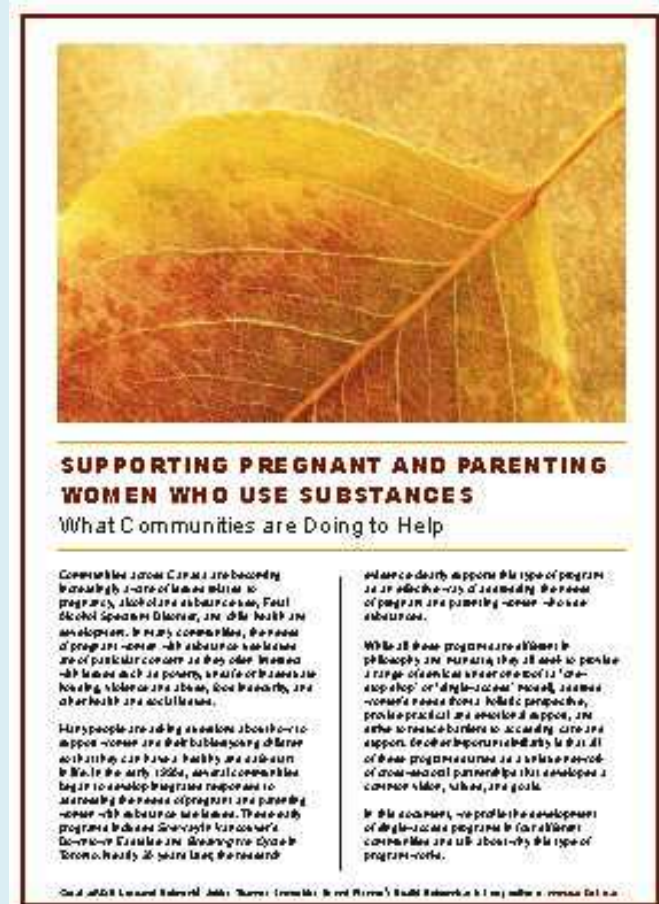
- Care centred on the mother child unit
- Shift from expectation that mothers adapt to systems - to reorganization of providers
- Continuity of care between community and hospital
- Work to support child protection and enhanced mothering capacity



Resource on community support programs working on FASD prevention

This and related materials have been developed by a network of service providers, researchers, policy analysts and birth mothers connected to the CanFASD Research Network

For more info see blog
<http://fasdprevention.wordpress.com/>



Download from
www.canfasd.ca

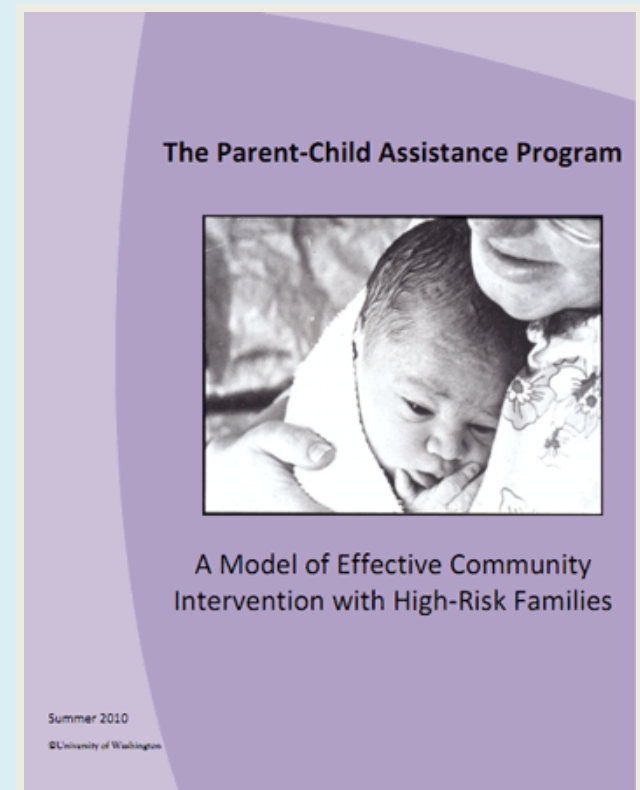
Level 4 Postpartum initiatives and support for new mothers and fathers

- 1. Home visitation** by nurses postpartum
- 2. Stop FASD, PCAP and other mentoring programs**
 - lay advocates work with women who have had a child affected for 3 years post partum – helping her negotiate the service system to improve her health and the health and wellbeing of her children
- 3. Key Worker & Parent Support Services**
 - Two services are available to assist families of children and youth with confirmed or suspected FASD.

P-CAP and other mentoring programs

Parent–Child Assistance Program (PCAP) - began in 1991 at the University of Washington.

- Intensive three-year one-on-one mentoring program for women at high risk for giving birth to a baby exposed to prenatal alcohol
- Addresses history of complex background factors, including trauma, childhood abuse, mental illness, violence, and poverty
- Aim of the program is to prevent future alcohol and drug exposed births among high-risk mothers who have already delivered at least one exposed child



Source: <http://depts.washington.edu/pcapuw/>

Effectiveness of home visiting programs

Studies look at the impact of home visiting on a range of outcomes - substance use, parenting skills, parent-child relationship and reproductive health.

Recent study: RCT - prenatal and infancy home visits among African American women in an urban setting

By the time the firstborn child was 12 years old, nurse-visited mothers compared with control subjects reported less role impairment owing to alcohol and other drug use (0.0% vs 2.5%, $P = .04$)

During this 12-year period, government spent less per year on food stamps, Medicaid, and Aid to Families with Dependent Children and Temporary Assistance for Needy Families for nurse-visited than control families



Olds,, et al. (2010).

Effectiveness of women-specific integrated substance use treatment – focus on attachment, mothering, and prevention of retraumatization

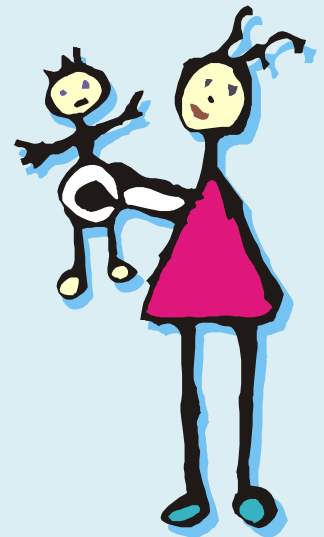
Examples

Jean Tweed Centre
Toronto

Family Treatment
Program, Prince Albert

Moms and Kids Too

- Less intensive time commitment
7 weeks, 3 days per week, shorter days (10-3)
- Breakfast
- Play group – Mother Goose
- Healthy Parenting Program
- Women's Health
- Relapse Prevention
- Group Therapy



Perspectives of women with alcohol and drug problems and addictions

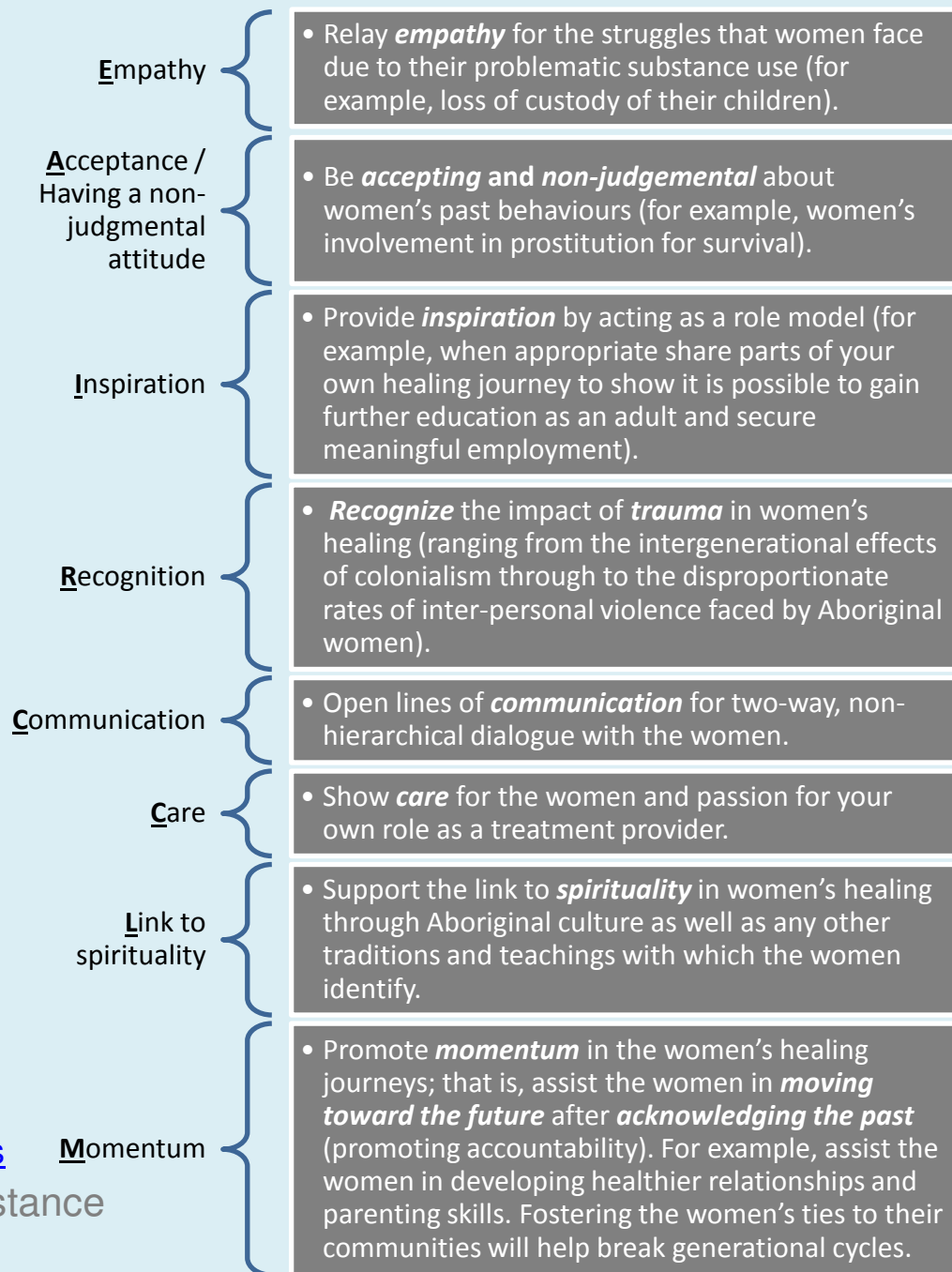
- ❖ In a recent study, Aboriginal women participating in treatment identified the RECLAIM principles as important for treatment providers to understand and apply when supporting Aboriginal women's healing from illicit drug abuse.

From Stilletos to Mocassins

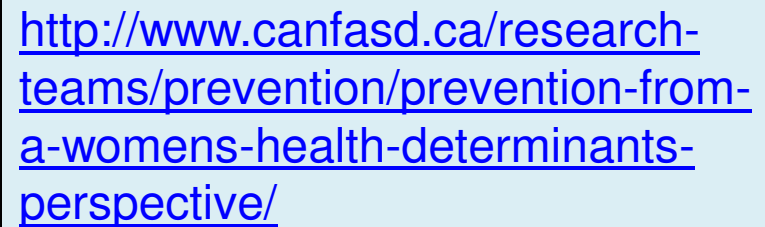
<http://www.youtube.com/watch?v=1QRb8wA2iHs>

Colleen Anne Dell, Research Chair in Substance Abuse, University of Saskatchewan

www.addictionresearchchair.ca



- Respectful
- Relational
- Self-Determining
- Woman-Centered
- Harm Reduction Oriented
- Trauma Informed
- Health Promoting
- Culturally Safe
- Supportive of Mothering
- Uses a Disability Lens



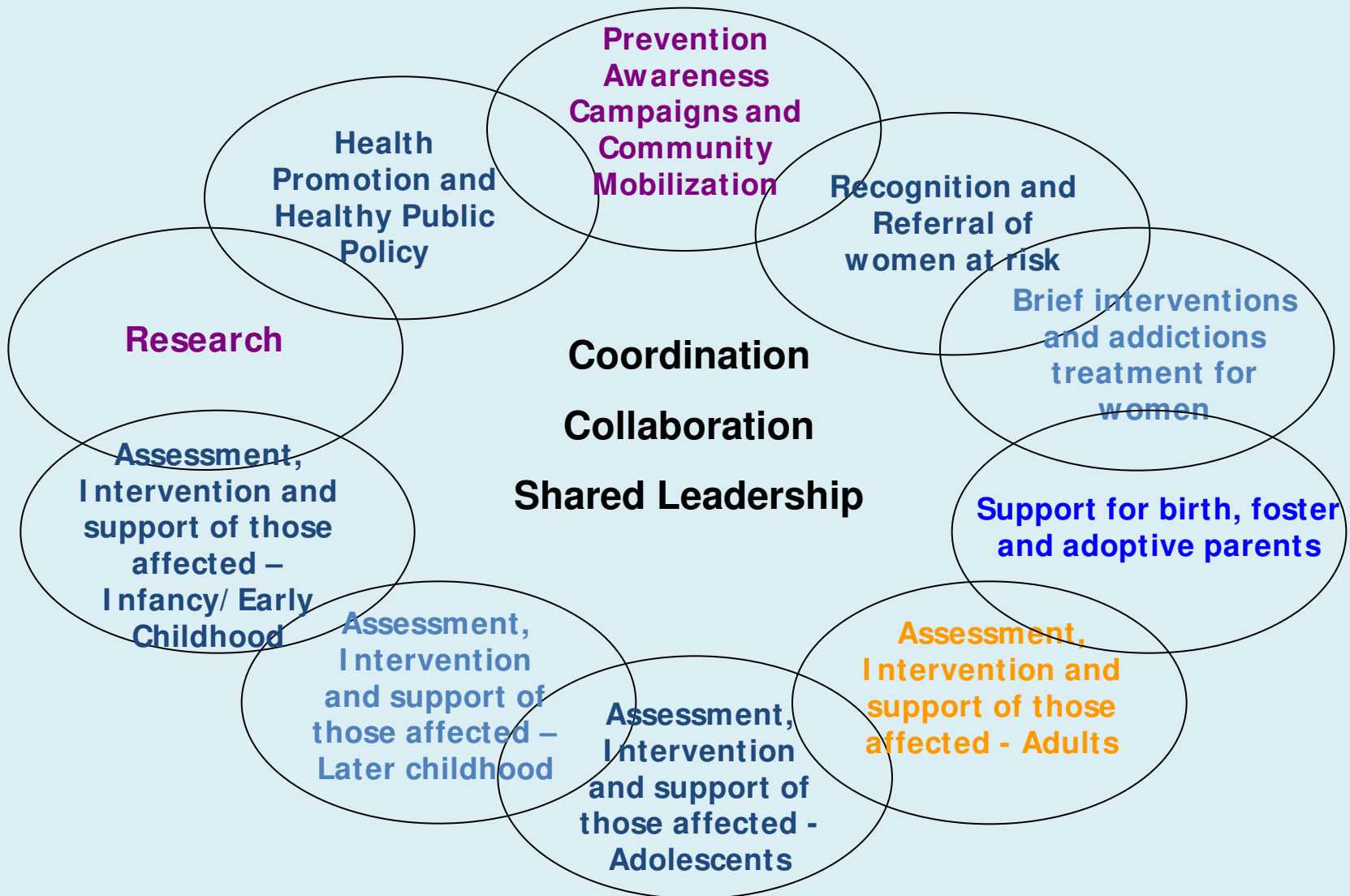
Foundations

FASD Strategic Plan (BC)

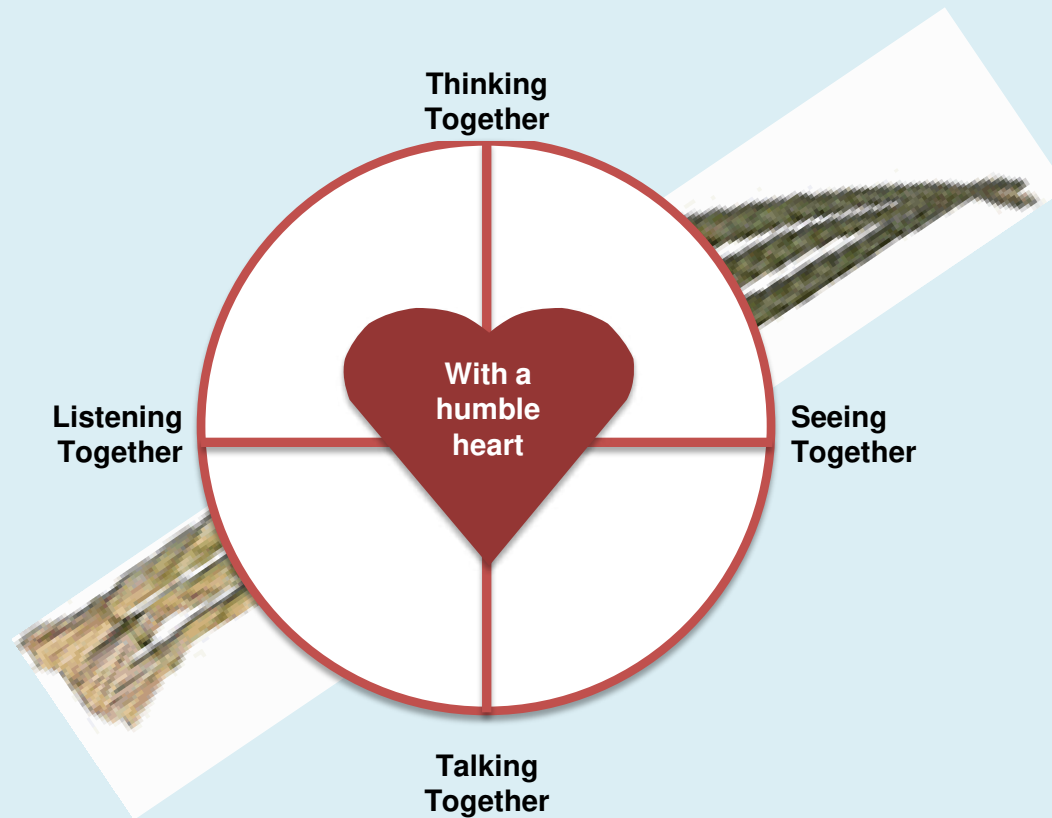
Principles:

- 1. Respect, Compassion and Cultural Sensitivity***
- 2. Comprehensiveness***
- 3. Collaboration, Inclusion and Capacity Building***
- 4. Balance*** – Efforts are directed equally to FASD *prevention* through provision of support to women, and to *intervention* through provision of support to those affected and their families.
- 5. Evidence based***

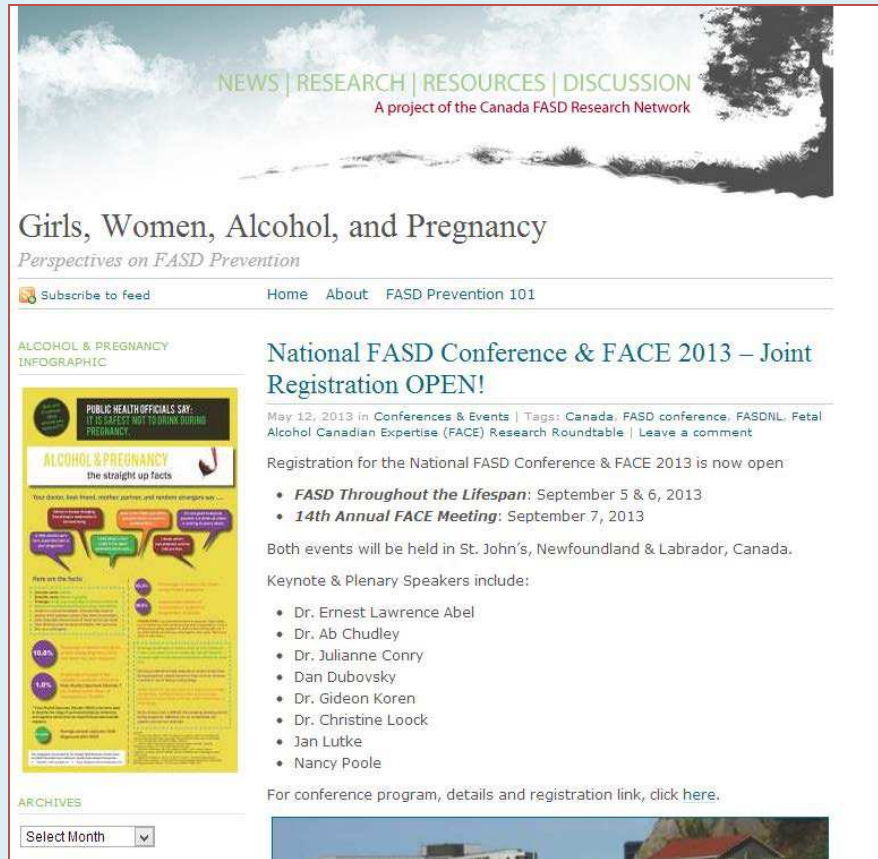
Working Together



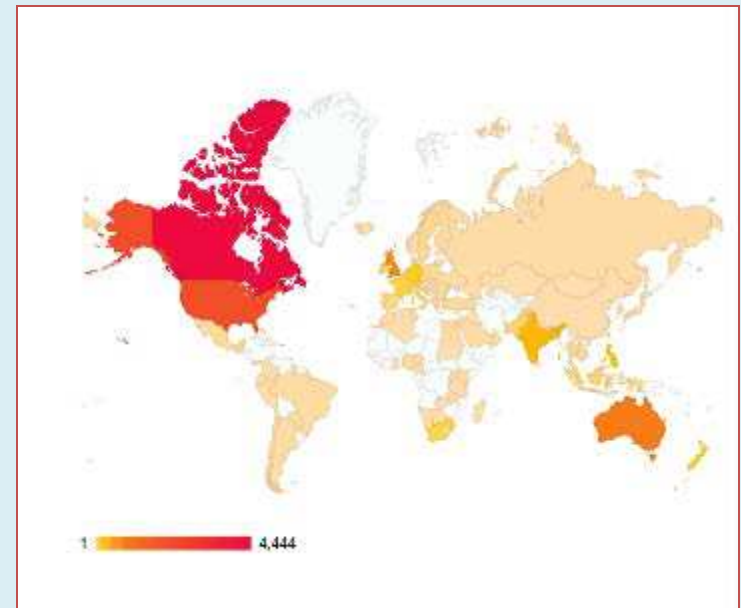
TRANSFORMING RELATIONSHIPS: a prerequisite for accommodating complexity and fostering collaboration



Girls, Women, Alcohol, and Pregnancy Blog



Started in July 2010
Approx. 3000 visitors a month



www.fasdprevention.wordpress.com



ALCOHOL, PREGNANCY AND PREVENTION OF FETAL ALCOHOL SPECTRUM DISORDER WHAT MEN CAN DO TO HELP

Fetal Alcohol Spectrum Disorder (FASD) is the leading known cause of developmental disability. FASD is the result of exposure to alcohol in utero and is believed to affect 1% of the population. While men's alcohol use is not a direct contributor to FASD, there are many ways that men can help to prevent FASD.

Preventing FASD is about more than telling women not to drink alcohol during pregnancy – in fact, this approach can often lead to more harm than good. Researchers and service providers who are part of the Canada FASD Research Network have some suggestions for men who want to make a difference.

1 Take a 'pregnant pause'. If your partner, friend, sister, co-worker or another woman you know is pregnant, you may want to consider taking a pause from drinking as a way of showing support. Whether it's for a month, three months or the entire pregnancy, remaining alcohol-free can be helpful and encouraging for many women.

2 Be a good host. When entertaining friends or family or having a night out, offer non-alcoholic beverages and avoid pressuring women to drink (pregnant or not). Some women continue to drink alcohol during pregnancy because they have a hard time saying 'no' when it is expected that they drink in certain social situations or when they haven't told others about their pregnancy. As a host offer 'mocktails' and other non-alcoholic options for drinks, and make sure that everyone feels part of the fun whether or not they are drinking alcohol.

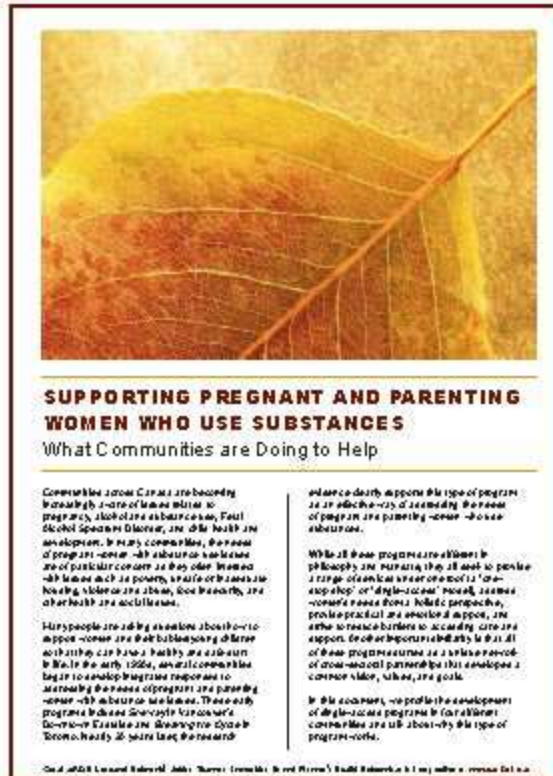
3 Minimize harms. Most of us don't drink on our own – our drinking habits are shaped by those around us. Support a 'culture of moderation' by taking a look at your own drinking and working to minimize any harmful effects that your own drinking might have on yourself or others. Taking a look at Canada's Low Risk Drinking Guidelines is a good place to start (www.ccsa.ca).



Evaluation of FASD Prevention and FASD Support Programs
An Introductory Guide

www.fasd-evaluation.ca

Selected Publications from the CanFASD Prevention Network Action Team



Communities across Canada are becoming increasingly aware of the need to support pregnant, alcohol and substance use, Fetal Alcohol Spectrum Disorder, and the health and well-being of their communities. The need for support is not only for women who use substances, but also for their families and the communities they live in. This report provides a look at what communities are doing to help pregnant and parenting women who use substances, and what communities can do to help.

Many people are asking questions about how to support women who use substances during pregnancy. This report provides a look at what communities are doing to help pregnant and parenting women who use substances, and what communities can do to help.

Evidence clearly supports the type of programs that are needed to support pregnant and parenting women who use substances.

While all these programs are different, they all share the same goal: to provide a safe and supportive environment for pregnant and parenting women who use substances. This report provides a look at what communities are doing to help pregnant and parenting women who use substances, and what communities can do to help.

In the community, the profile of the population of pregnant and parenting women who use substances is changing. This report provides a look at what communities are doing to help pregnant and parenting women who use substances, and what communities can do to help.

CanFASD Research Network Action Team. (2010). Supporting Pregnant and Parenting Women Who Use Substances: What Communities are Doing to Help. Ottawa, ON: CanFASD Research Network.



FASD PREVENTION: AN ANNOTATED BIBLIOGRAPHY, 2013
Prepared by Rose Schmidt, Clary Gossman and Nancy Poole
BC Centre of Excellence for Women's Health
January 2014

CanFASD Northwest
CANADA NORTHWEST FASD RESEARCH NETWORK

February 2010

Consensus on

10 Fundamental components of FASD prevention from a women's health determinants perspective

The following ten fundamental components of FASD prevention emerged from a working session of the Network Action Team on FASD prevention. This session was held in Victoria, B.C., in March 2009, and was funded by the Canadian Institutes for Health Research. This consensus document weaves together a range of sources – women's experiences, peer-reviewed research, published articles, as well as expert evidence – to create a clear message regarding the importance of FASD prevention from a women's health determinants perspective.

1. Respectful

Respect is paramount to successful FASD prevention and treatment. It is a vital tool in the elimination of discrimination and stigma in prevention initiatives, and it is pivotal to creating an environment where women can address their health care needs. In FASD prevention, the implementation of respect as a fundamental principle involves creating conditions for women to discuss their experiences, identifying coping strategies and healing processes to promote women's wellness, and supporting the inclusion and full participation of women in their own health, care, and well-being.

References

Canadian Centre on Substance Abuse. 2001. Respect is Key: A conversation with Pam Woodworth. Ottawa, ON: CCSSA.
Four Worlds Centre for Development Learning. July 2003. Making the Path by Walking In: A Comprehensive Evaluation of the Women and Children's Healing and Recovery Program Pilot, Yellowknife, Northwest Territories, Cochrane, A.L.
Poole, N. 2000. Evaluation Report of the Sheway Project for High-risk Pregnant and Parenting Women. Vancouver, BC: SCCWH.

2. Relational

Throughout life the process of building relationships and connecting with other people can be extremely important. Women who are most at risk for having a child at risk of FASD experience some form of social disconnection, whether that be from their friends or family, the larger community, or other types of relational engagement. It is vital to FASD prevention

to acknowledge that the process of growth, change, healing, and prevention does not happen in isolation. It moves forward through interactions with others in long-term, supportive, trust-based relationships. Therefore, paying attention to the relational dynamics of interpersonal connections in day-to-day life, as well as in comprehensive treatment settings, can enhance the success of FASD prevention initiatives.

References

Hartling, L.M. 2003. Prevention Through Connection: A Collaborative approach to women's substance abuse. Stone Centre, Wellesley College, Wellesley, MA.
The Breaking the Cycle Compendium: Volume 1: The Roots of Relationship. Edited by M. Leslie. 2007. Mohrhardt Press.
Marshall, L. (2004). The ethics of relation: Public health nurses and child protection clients. Journal of Advanced Nursing, 50(4), 414-420.

3. Self-Determining

Women have the right to both determine and lead their own paths of growth and change. Although it may run contrary to many prevailing beliefs in substance use treatment and prevention approaches, self-determination is fundamental to successful FASD prevention. As such, the role of health care and other support systems in FASD prevention should be to support women's autonomy, decision making, and control of resources, so as to facilitate self-determined care. In order to provide this support, most effective health systems should involve women in designing models of care, and individually, women should be able to determine their own process of care.

CanFASD
CANADA FASD RESEARCH NETWORK

www.canfasd.ca

CONTACT

BC Centre of Excellence for Women's Health www.bccewh.bc.ca

Coalescing on Women and Substance Use www.coalescing-vc.org

Canada FASD Research Network www.canfasd.ca

FASD Evaluation www.fasdevaluation.ca

Know FASD www.knowfasd.ca

Girls, Women, Alcohol, and Pregnancy Blog
<http://fasdprevention.wordpress.com>