




FASD | ONE
Fetal Alcohol Spectrum Disorder
Ontario Network of Expertise

Mary Mueller and Jody Kroeplin
FASD ONE Prevention Action Group
February 9, 2017

Objectives:

- Increase knowledge about FASD ONE
- To review best practices to prevent FASD
- To explore your role in prevention of FASD
- To become familiar with prevention activities that are occurring across the province



FASD | ONE
Fetal Alcohol Spectrum Disorder
Ontario Network of Expertise

FASD Ontario Network of Expertise

- Formerly called FASD Stakeholders of Ontario
- Developed with funding from the Public Health Agency of Canada



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FASD ONE

A volunteer collaborative of:

- parents/caregivers
- practitioners
- service providers




Goals

- Prevention of FASD
- Better outcomes for individuals living with the disability by advancing the development and dissemination of best practices



Five Working Groups

- Diagnostic
- Education
- Intervention and Support
- Prevention
- Justice



FASD ONE Accomplishments

- Organized FASD summer camp 2007
- Inaugural FASD diagnostic services meeting 2007
- Commissioned 3 research papers on effective practices, education and respite 2009
- Produced a semi-annual newsletters (2010-2013)




FASD ONE Accomplishments (cont'd)

- Developed a website www.fasdontario.ca
- FASD Justice reports in 2013 and 2015
- Facilitated many parent/caregiver workshops
- Hosted FASD symposia - 2011, 2013 and 2016
- Developed a *Call to Action in Ontario* 2014

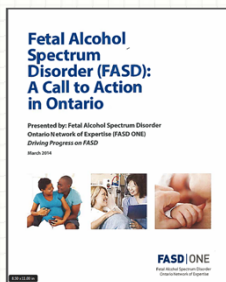


A Call to Action

- Informed by stakeholders from across the province including individuals with FASD, caregivers and a wide spectrum of service providers.
- Reflected the growing understanding that a multi-sector, coordinated and collaborative response is required to address the complex issues of FASD prevention and effective intervention.



FASD ONE Call To Action in Ontario



A Call to Action

Proposed recommendations for a strategy to:

1. Prevent FASD by providing evidence-based information and accessible, comprehensive services to pregnant women and all women of childbearing age;
2. Ensure timely access to assessment and diagnostic services to children, youth and adults who may be affected by FASD;
3. Support children, youth and adults who are affected with the disability through evidence-based interventions that stabilize home life and maximize potential.



A Call to Action

Provided recommendations in the following areas:

- Awareness and Prevention
- Assessment and Diagnosis
- Intervention and Support
- Knowledge Transfer
- Research and Evaluation



FASD ONE Call To Action Prevention Recommendations

Objective:

Ontarians will receive accurate information regarding the risks of alcohol use during pregnancy along with timely access to the services they require to abstain from or limit alcohol use in pregnancy



FASD ONE Call To Action Prevention Recommendations

1.1 Ensure that all Ontarians receive ongoing evidence based information about the effects of alcohol use in pregnancy using broad based, community driven, linguistically and culturally appropriate communication channels, resources and materials

1.2 Ensure that all pregnant women and women of childbearing age have the opportunity to discuss their alcohol use, the risk of alcohol exposed pregnancy, and pregnancy planning in a safe environment with well-informed practitioners



FASD ONE Call To Action Prevention Recommendations

1.3 Ensure that all pregnant women who are using alcohol or are at higher risk of alcohol use in pregnancy have priority access to holistic, culturally appropriate women centred services that reflect the social determinants – addiction treatment, mental health services, prenatal care, safe housing, income stability, food security

1.4 Ensure that new mothers receive postpartum support to assist them to maintain healthy changes made during pregnancy to prevent future alcohol exposed pregnancies to support the development of their children and to prevent secondary disabilities related to prenatal alcohol exposure



Prevention of FASD

Is It As Easy As Telling Women Not To Drink?

Mary Mueller, Region of Waterloo Public Health, R.N., B.Sc.N.
Waterloo Region FASD Community of Practice
Wednesday May 13, 2015

What is FASD?

- Fetal Alcohol Spectrum Disorder (older terms - FAS, FAE, ARND)
- Caused by Alcohol Use in Pregnancy
- Presentation varies depending on:
 - Amount of alcohol consumed
 - When it was consumed
 - Frequency of consumption

Damage Makes Learning and Life More Difficult

- Alcohol crosses the placenta
- Primary damage to brain and central nervous system
- Damage can occur whenever alcohol is consumed in pregnancy
- Invisible disability as we cannot see brain damage



What is the Cost to Society?

- FASD affects 1% of the Canadian population
- Many experts feel that the prevalence of FASD is much higher due to a lack of awareness about FASD in the medical community and a shortage of diagnostic services
- Public Health Agency of Canada estimates 5.3 billion dollars are spent annually to support those with FASD (birth to age 53)
- CanFASD a Canadian research network estimates the annual cost to be 7.6 billion (Thanh and Jonsson)
- 800,000 - 1.4 million dollars/individual is the estimated cost to support those affected with FASD over a life time
- The rate of FASD in Canada's prisons is estimated to be ten times higher than the general population



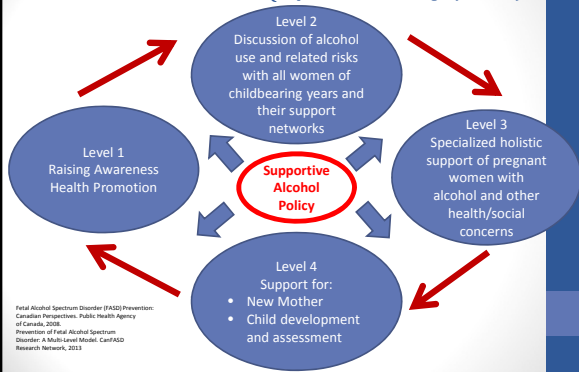
What is the Cost to Society?

- 60% of people with FASD 12 years and older have been charged with/or convicted of a crime
- 95% of those with FASD have a mental illness
- CanFASD estimates that Canada would benefit greatly if we were to devote resources to the prevention of FASD
- If we spent \$150,000 to prevent FASD we would save \$1.6 million (CanFASD, 2013)

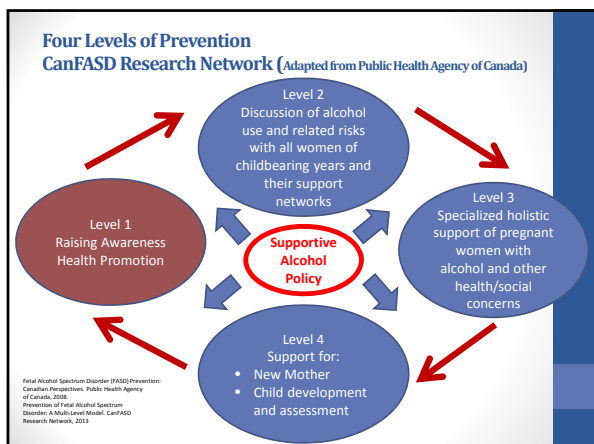
John Howard Society, FASD Factsheet, 2010



Four Levels of Prevention CanFASD Research Network (Adapted from Public Health Agency of Canada)



Fetal Alcohol Spectrum Disorder (FASD) Prevention: Canadian Perspectives. Public Health Agency of Canada, 2008. Prevention of Fetal Alcohol Spectrum Disorder: A Multi-Level Model. CanFASD Research Network, 2013.

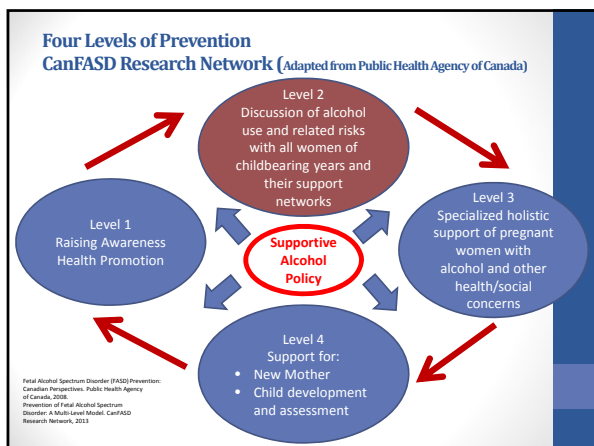


LEVEL 1 - RAISING AWARENESS/HEALTH PROMOTION

- Important component of a comprehensive health promotion approach
- Changing alcohol consumption patterns is complex
- This level is the foundation for the other 3 levels of prevention
- Provincial and local campaigns
- On it's own is not very effective

Level 1 - What is Your Role?

- Support local efforts on FASD Awareness Month
- Increase knowledge with your own colleagues and agency staff
- Help to challenge, present evidence and dispel ever prevalent myths
- Post information on your website, your facebook page, twitter account etc.



LEVEL 2 Discussion of alcohol use and related risks with all women of childbearing years and their support networks

- Evidence indicates this is one of the most effective strategies to reduce alcohol exposed pregnancies (FASD ONE - Call to Action)
- Health and social service providers (HCP) are seen as a credible source of information and their advice is likely to lead to behaviour change (SOGC - 2010)
- 2009 – 43% of women and 32% of women planning a pregnancy in the next 2 years did not recall receiving any information about alcohol and pregnancy from their doctor (Best Start – 2009)
- Need to shift the reproductive health lens to include preconception

Why Focus on Women and Alcohol Use?

*Ontario:
Past Year Alcohol Consumption for Women

- 74.6% - 2010
- 78.9% in 2011
- 76.7% in 2015

- 17.1% reported exceeding the LRADG^ for women
- Daily drinking rates for women increased from 2.6% of women in 2001 to 5.8% in 2015
- Hazardous/harmful drinking for women increased from 4.8% in 1998 to 8.4% in 2015 (Based on AUDIT Screen Score of 8+)
- Binge drinking rates for young women have increased in the last decade but have recently show some decline(5 or more drinks on a single occasion)

*Addiction and Mental Health Indicators Among Ontario Adults 1997-2011, CAMH
*CAMH Emonitor 2015
**LRADG – Low Risk Alcohol Drinking Guidelines

Why Focus on Women and Alcohol Use?

- Alcohol affects women differently than men
- If women consume alcohol above LRADG may increase their risk of chronic disease*, violence and injuries
- Risky use of substances before pregnancy puts a woman at higher risk of alcohol use in pregnancy
- Fetal Alcohol Spectrum Disorder (FASD) is caused by alcohol use in pregnancy



*Chronic diseases – cancer, heart disease and stroke

National and Local Statistics

Waiting to Prevent FASD in Pregnancy is Too Late!

- Rate of unintended pregnancy in Canada is estimated to be 40% (PHAC)
- Women at highest risk of binge drinking 15 to 19 years of age, followed closely by those 20-24 years of age
- Highest rates of unintended pregnancy in 15-19 year olds (82% of pregnancies in this age group did not intend to get pregnant)
- 2009 Canadian Maternity Experiences Survey found 62.4% of women drank 3 months preceding pregnancy, 10.5% reported drinking in pregnancy

Canada's Low Risk Alcohol Drinking Guidelines

What is a Standard Drink?

Beer	341 ml, 12 oz, 5% alcohol
Wine	142ml, 5 oz, 12% alcohol
Liquor or Spirits	43 ml, 1.5 oz, 40% alcohol

- Women -2/day, 10 /week
- Men -3/day,15/week
- 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)

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.

<http://www.ccsa.ca>



Target Groups That Require Different Approaches

All Women/Men in their Childbearing Years



- ▶ Women struggling with Social Determinants of Health (lack of income, lack of education, lack of appropriate social support, in violent relationships, women with mental health issues, women who have had past trauma)
- ▶ Women who are working, more established career, waited until their career was more established to begin a family
- ▶ Important to address partner's substance use

Strategies to Reduce Substance Use Women of Childbearing Age Independent Practice



Women of Childbearing Years: Screening, Brief Intervention, Referral

- ▶ Begin Before Pregnancy
- ▶ Screen all women for substance/alcohol use issues
- ▶ Be aware of the current research regarding substances used and their related health risks
- ▶ Provide key messages to all women on Canada's LRADG* (2 drinks/day, 10 drinks/week, 3 drinks/special occasion, no alcohol if pregnant, planning a pregnancy)
- ▶ Add in no alcohol if you suspect you are pregnant
- ▶ <http://www.rethinkyourdrinking.ca>
- ▶ Emphasize that LRADG* are upper limits - if do not drink even better

* LRADG - Low Risk Alcohol Drinking Guidelines

Strategies to Reduce Substance Use Women of Childbearing Age Independent Practice

- Screening Tools:
- Assess if following/aware of LRADG
- Substance Abuse Screen
- T-ACE
- CAGE
- TWEAK



One Open Ended Question

How does alcohol fit into your life?

Strategies to Reduce Substance Use Childbearing Age Independent Practice



Women of Childbearing Years:

- ▶ If above LRADG* or screen positive on screen advise to cut back – offer referral to local service or online/phone support
- ▶ If using alcohol/substances assess how often, how much, reason for use, self perception of use
- ▶ Drug and Alcohol Helpline - <http://www.drugandalcoholhelpline.ca/> 1-800-565-8603
- ▶ Centre for Addiction and Mental Health http://www.camh.ca/en/hospital/health_information/finding_help/Pages/finding_help.aspx
- ▶ Discuss use of reliable birth control that is easy to use to prevent alcohol/substance exposed pregnancy
- ▶ Multi-vitamin recommended for all women of childbearing age

* LRADG – Low Risk Alcohol Drinking Guidelines



Do You See Women in Their Childbearing Years?

Do You Discuss Alcohol Use With All Women?

Asking About Alcohol and Birth Control Use Together Can Decrease the Risk of FASO

- The risk of Fetal Alcohol Spectrum Disorder (FASD) can be decreased by 50% or more by talking about alcohol and birth control use before pregnancy
- 24.7% of women in Ontario drank alcohol in 2013
- 50% of all pregnancies are unplanned
- Women drinking alcohol daily has increased from 2.6% in 2000 to 5.6% in 2013
- 50% of women 15 years and over report binge drinking in 2013 compared to 46% in 2004

Things to Discuss at Each Visit

- How does alcohol fit in your life?
- If you drink alcohol do you use reliable birth control every time?
- Are you aware of Canada's Low Risk Alcohol Drinking Guidelines?

You Can Prevent FASO by Screening for Alcohol and Birth Control Use Before Pregnancy

Strategies to Reduce Substance Use **10** Women of Childbearing Age

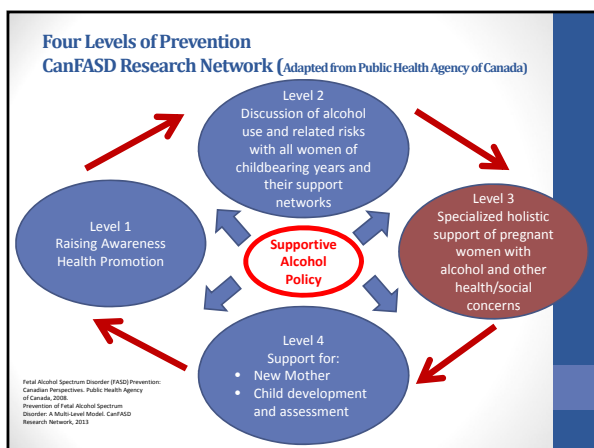
Consensus on 10 Fundamental Components of FASD Prevention from a Women's Health Determinants Perspective. CanFASD originally Canada NorthWest FASD Research Network - February 2010

1. Respectful
2. Relational
3. Self-Determining
4. Women Centred
5. Harm Reduction Oriented
6. Trauma Informed
7. Health Promoting
8. Culturally Safe
9. Supportive of Mothering
10. Use a Disability Lens

LEVEL 2 - WHAT IS YOUR ROLE?

Discussion of alcohol use and related risks with all women of childbearing years and their support networks

- Screen for risky alcohol use with all women of childbearing age
- Provide key messages regarding safer alcohol use
- Discuss the importance of being on a reliable form of birth control if you are using any alcohol/substances
- Link to services if needed



Level 3
Specialized Holistic Support of Pregnant Women with Alcohol and Other Health/Social Concerns

- Addiction Programs specializing in services for Pregnant and Parenting Women
- Regular Addiction Services
- Healthy Babies, Healthy Children
- Often Family and Children's Services are involved
- Canadian Prenatal Nutrition Programs
- Places providing housing/support with SDOH
- Motherisk - 1-877-327-4636
- Women may want to go outside of region for treatment

OUTCOME OF PRENATAL SUBSTANCE USE EXPOSURE ON BABIES/CHILDREN

Impact of alcohol on baby depends on:

- When alcohol is consumed
- How much is consumed
- How often it is consumed

May also depend on:

- Age
- Nutrition
- Determinants of health
- Genetic factors

Risk Factors for Alcohol Use in Pregnancy

- Women who drink above the low risk drinking guidelines before pregnancy
2 standard drinks/day or no more than 10 standard drinks/week
- Pre-pregnancy binge drinking - binge drinking defined as 4+ drinks in 2 hours for an average sized female
- Women using birth control unreliably
- Women 35 years of age and older who work and drink socially
- Having a partner who drinks
- Low socioeconomic status – low income, low paying job, lower education, unstable housing, low social support

Saskatchewan Prevention Institute, 2013

Risk Factors for Alcohol Use in Pregnancy

- Mother with cognitive impairments – consider she may have undiagnosed FASD
- Mental Health Issues
- Mothers using tobacco or other substance more at risk of alcohol exposed fetus
- Having a previous child who was exposed to alcohol in pregnancy

Saskatchewan Prevention Institute, 2013

Prevalence of Substance Use in Pregnancy



- Alcohol - 11% of women consumed alcohol
- Alcohol use in pregnancy is more commonly reported in older women
- Tobacco - 13% of women smoked cigarettes
- Tobacco use in pregnancy is more common in younger women
- Illicit Drug Use - 5% of women reported illicit drug use
- Under-reporting issue in pregnancy - social stigma - prevalence rates likely higher
- Assume if using illicit drugs - also use alcohol and may have poorer eating habits

Canadian Perinatal Health Report, 2008

Substance Use in Pregnancy? Not Simple

- 2/3 with substance use problems also have mental health issues
- Many women with substance use issues, also experience physical/sexual abuse
- Not as easy as just telling women don't use alcohol/substances in pregnancy
- Assess and provide treatment/support for substance use, mental health issues, and abuse
- Advising women to stop using substances in pregnancy may help lighter users
- Those using substances to cope not as likely to be helpful, and may be harmful?



Strategies to Reduce Substance Use Pregnancy

- ▶ Practice asking and referring, the more you do it the easier it becomes
- ▶ Ask/advise all women multiple times about alcohol/substance use in pregnancy
- ▶ Encourage all women to abstain from alcohol/substance use throughout pregnancy
- ▶ Approach in a non-judgemental gentle way – may be the first time she has shared with anyone
- ▶ Discuss effects of alcohol/substance use on the developing baby with all women
- ▶ Refer to Motherisk if more information is needed 1-877-327-4636
- ▶ Acknowledge many pregnancies are unplanned – alcohol/substance use may have been consumed before knowing about pregnancy
- ▶ Emphasize can't change the past but do have control over their future behaviour

Strategies to Reduce Substance Use Pregnancy

- ▶ Offer to provide further support/referrals if the woman wants –addiction treatment
- ▶ Support can take many forms – addiction counselling, listening, a trusting relationship, help with determinants of health(give prenatal vitamins), relationship counselling – assess for abuse
- ▶ Tell her that she and her baby deserve a life free of alcohol/substances – she is worth it!
- ▶ Sometimes role may be harm reduction – alcohol (? crystal meth) are the substances that we are aware of that causes the most permanent harm to the developing baby
- ▶ If a women has consumed alcohol or substances in pregnancy, document in her file **after she leaves** Why? - Must be confirmed alcohol use to diagnose FASD in the future
- ▶ Thank her for sharing and encourage her to come back and talk again

Strategies to Reduce Substance Use in Pregnancy Working With Someone Who May Have FASD

- FASD-informed approach to practice
- Trauma-informed
- Harm reduction
- Cultural safety and FASD

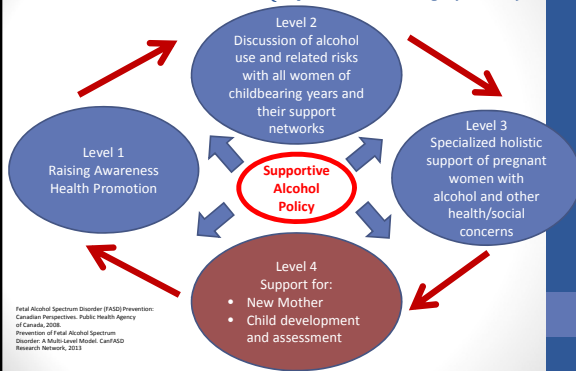


Level 3 – What is Your Role?

- Ensure women at risk of using alcohol/substances in pregnancy are connected with supportive services (addictions, support around determinants of health)
- Provide key messages regarding alcohol/substance use to all pregnant women
- Be prepared to take a harm reduction approach if the woman is not ready for abstinence
- Be aware of the role of a woman's support network



Four Levels of Prevention CanFASD Research Network (Adapted from Public Health Agency of Canada)



Level 4 : Support for the new mother and child development and assessment

- **Birth Control** - Postpartum women become preconception and may be at risk of future alcohol exposed pregnancies
- **Infant and Child Development Programs, HBHC, other developmental services**
- **Ontario Early Years Centres, Community programs**
- **Programs through community centres etc.**
- **Family & Children's Services can be helpful and are often involved**



Level 4 – What is Your Role?

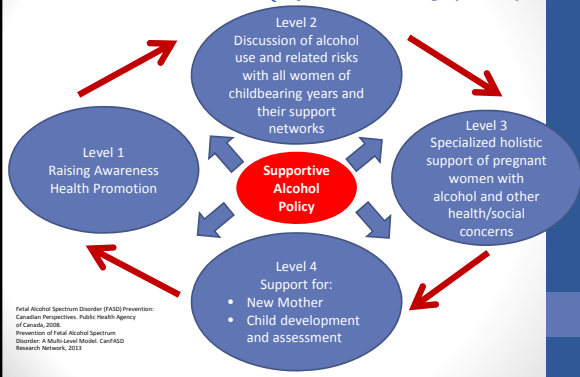
Support for: New Mother, Child Development and Assessment

- Ensure the baby is being followed by appropriate services for assessment and stimulation due to risk factor of substance use in utero
- Ensure the new mother has supportive parenting services
- Support the new mother to remain alcohol/substance free
- Discuss the effects of alcohol/substance use on breastfeeding
- Ensure the new mother has access to reliable birth control



Four Levels of Prevention

CanFASD Research Network (Adapted from Public Health Agency of Canada)



Policies That Affect Alcohol Use/Distribution


Levels of Influence - Where Can You Make a Difference?

Alcohol policy is:

- ▶ A benefit to all sectors of society
- ▶ Especially relevant to those who drink in an unsafe manner
- ▶ Effective in reducing the overall harm from alcohol which may reduce the incidence of FASD



Policies That Affect Alcohol Use/Distribution



Alcohol Policy Approach	Theoretical Assumption
1. Regulating physical availability of alcohol	Reducing supply by restricting physical availability will increase effort to obtain alcohol and thereby reduce total volume consumed and alcohol-related problems
2. Controlling affordability (alcohol taxes and other price controls)	Increasing the economic cost of alcohol (i.e., the price to the consumer) relative to alternative commodities will reduce demand
3. Placing restrictions on marketing	Reducing exposure to marketing will slow recruitment of drinkers and reduce heavier drinking by young persons
4. Developing drinking and driving prevention and countermeasures	Deterrence, punishment and social pressure will reduce drinking and driving
5. Modifying the drinking context	Creating environmental and social constraints will limit alcohol consumption and reduce alcohol-related violence
6. Developing education and persuasion strategies	Health information that increases knowledge and changes attitudes will prevent drinking problems
7. Providing treatment and early intervention services	Alcohol dependence will be prevented by motivating heavy drinkers to drink moderately; various therapeutic interventions will increase abstinence among persons who have developed a dependence on alcohol

Policies That Affect Alcohol Use/Distribution




- Legal drinking age
- Universal screening, brief interventions and referrals
- Availability of alcohol – alcohol in grocery/convenience stores
- Limiting of alcohol marketing youth and women of childbearing age
- Warning labels and signs – Sandy’s Law
- Provincial Alcohol Strategy- Ontario does not have one

Working with Pregnant Women Better Practices – Provincial Practice/Policy

Levels of Influence – Where Can You Make a Difference

- Working alone – moderately effective
- Working together – effective and wise use of resources
- Evaluating success of strategy – more effective
- **Developing policy** across the province to ensure all women of childbearing age screened for alcohol use – **most effective**
- **Developing alcohol policy** that limits availability of alcohol and changes societal attitudes towards alcohol - **most effective**



Thank You!
Questions
Or
Comments

Applying Knowledge to Practice
FASD prevention strategies and activities
In Ontario

Activity – Showcasing Your Region’s Work in FASD Prevention

- Each table should have five different piles of cards.
- Piles will be titled:
 - Level 1: Awareness Raising/Health Promotion
 - Level 2: Discussion of Alcohol Use and Related Risks with Women of Childbearing Years and Their Support Networks
 - Level 3: Specialized Holistic Support of Pregnant Women with Alcohol and other Health/Social Concerns
 - Level 4: Support for: New Mother/Child Development and Assessment
 - Supportive Alcohol Polic

Activity

Introductions in Small Groups

- Introductions:
 - Introduce yourselves and the sector that you work in.
 - Share how long you have worked in FASD prevention, or other areas of FASD (i.e. justice, education, client/ family support).
 - Share what geographic area or region you represent.

Activity – Showcasing and

Networking

- Showcase your work:
 - Discuss with the group activities that have been done, or you have been involved with, based on FASD Levels of Prevention or Alcohol Policy development.
 - For each activity, document your:
 - Challenges – What didn't work well? What were your road blocks?
 - Successes – What did work well?
 - Supporters/influencers – Who did you need to gain support from? (High Level Supporters/Low Level Supporters)
 - Audience – What group(s) of people did you want to target with your strategy/activity?
 - Work plan – What was the progression of activities to reach the final goal.
 - Practice Change/Outcomes – Did your strategy/activities result in your desired outcome and practice change?

Activity – Sharing

- Determine a spokesperson for your group to report to the larger group on activities that were discussed.
- FASD ONE presenter will collect cards following session and add to FASD ONE 2017 work plan to collate and share
 - Please provide your contact information and geographic area if you would like to be acknowledged on the environmental scan.
- Questions?
