FASD Prevention: Women and Pregnancy

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Date: June 16, 2009

Government of Alberta

The FASD Learning Series is part of the Alberta government's commitment to programs and services for people affected by FASD and those who support them.

Session Goals

- What are we trying to prevent and why?
- Who is responsible for prevention?
- What are the strategies for prevention?
- Do the strategies work (evaluation and outcomes) and are they sustainable?

Safest not to drink in pregnancy or planning pregnancy

No known safe amount or time to drink in pregnancy

Need to address why women drink, not just the drinking

What are we Trying to Prevent and Why?

- Preventing FASD
- Diagnosis of FASD
- Impact of Alcohol use from a Woman's Perspective

Preventing FASD

Prenatal exposure puts fetus at risk for brain damage but not diagnostic of FASD

- Complex interaction between maternal alcohol use pattern, maternal biology, fetal susceptibility, non-linear relationship
- Impact of postnatal factors (Perry)
- Incidence 9.1 per 1000 live births, higher in high risk populations
- Economic burden: $344 million annual cost in Canada for individuals under 21 years (Stade)

Diagnosis of FASD

- Multidisciplinary team to determine evidence of organic brain damage and strengths deficits functional profile to link to resources
- Confirmed alcohol is key but birth mothers may not disclose due to stigma
- FASD impacts function across the lifespan with different supports needed at different ages
- Preventing secondary disabilities by interventions
- Lack of diagnostic services for adults with FASD

Impact of Alcohol Use from a Woman's Perspective

- Who is Drinking Alcohol?
- Addictions in Pregnancy
- Impact on Woman Herself
- Listen to Her Story

Who is Drinking Alcohol?

- 76.8% Canadian women drink
- 15% younger women 18-19 age group are heavy drinkers
- 11% 20-24 age group are heavy drinkers

(2004 Canadian Addictions Survey)

Who is Drinking Alcohol?

- 12-14% of Canadian mothers indicated alcohol use in their last pregnancy
- >90% knew alcohol not recommended in pregnancy

(Dell and Roberts 2006)

Who is Drinking Alcohol?

- 11.6% of pregnant women reported alcohol use currently
- 3.7% binge pattern and 0.7% heavy drinking

(CDC US data 2004)

Who is Drinking Alcohol?

- >90% of women in Alberta aware that no alcohol is best in pregnancy
- 20% admitted to alcohol use during pregnancy
- Knowledge does not equal actions – Why?

(Alberta data Tough 2006)

Who is Drinking Alcohol?

- Older women 30+ years of age, college educated, higher income, consuming alcohol before pregnancy
- Risk by occupation
- Unplanned pregnancy, low self esteem, smoking
- Intergenerational: family history of substance abuse

Who is Drinking Alcohol?

- Less than high school education (80%)
- Poverty (45%) and unemployment (75%)
- Current partner uses substances (25%)
- Currently experiences domestic violence (46%)
- Poor social networks (20-35%)

Addictions in Pregnancy

Recent history:

- Arrested on alcohol related charges 50%
- Had mental health problems 58%
- Involved with child protection in past 3 years 65%

Childhood history:

- In foster care as child 60%
- Abused as a child 88%
- Had a parent with substance abuse issues 88%

Impact on Woman Herself

- Susceptibility to health issues
- Ability to parent
- Risk for subsequent pregnancies with prenatal alcohol exposure
- Life choice decision making
- "Diagnosis for Two": diagnosis of child with FASD should link back to the birth mother with supports

Listen to Her Story

- Abuse in childhood, in foster care
- Domestic violence, partner substance abuse
- Mental health
- Poverty, housing
- Education lack
- Loss of connection to culture
- No positive support systems

Prevention

- Who is Responsible for Prevention?
- What are the Strategies for Prevention?

Who is Responsible for Prevention?

- Physicians, Health Care Providers, Psychosocial Team
- Collaborative, Multisectorial, Holistic, Cultural Focus
- Women Centered, Listen To The Women's Stories, What About Their Children

Health Care Providers

Women report they…

- **Preferred receiving information about reproductive health by verbal discussion**
  - **With health care provider 92% but only 37% obtained**
  - **Compared to pamphlets (74% wanted and 49% obtained)**

(Tough)

Health Care Providers

Women report their…

- **Preferred sources:**
  - **Physicians 97%**
  - **Nurses 83%**
  - **Midwives 65%**
  - **Mothers 62%**
  - **Friends 59%**

(Tough)

Health Care Providers

Physicians reported that…

- **94% knew about FASD**
- **<50% consistently discussed alcohol use with women of child bearing age**
- **Only 54% felt prepared to care for pregnant women who had substance abuse problems**

(Tough 2002 Survey of Physicians and Midwives in Canada)

Health Care Providers

Physicians reported that barriers were:

- **Training**
- **Time**
- **Financial**
- **Lack of screening tools**
- **Lack of knowledge of resources**
- **Women not disclosing due to stigma**
- **Stereotyping**

(Tough 2002 Survey of Physicians and Midwives in Canada)

Biopsychosocial Team

Need for Multidisciplinary Team Approach

- Opportunity for FASD Networks in Alberta
- Holistic, multisectorial, collaborative, multiple points of contact in reproductive years
- Physicians, mental health, addictions, social workers, employment counselors, housing, etc
- Cultural sensitivity (Masotti: data on Urban Aboriginal women; involving the grandmothers)
- Woman centered plus child focused

What are the Strategies for Prevention?

- **Four Levels of Prevention**
- **Key References on FASD Prevention**

Level 1: Primary, Universal, Raising Awareness

- **Level 2: Secondary Targeted "Conversations"**
- **Level 3: Specialized Prenatal Supports**
- **Level 4: Postpartum Supports**

Four Levels of Prevention

- Primary
  (Universal, raising public awareness)
- Secondary
  (Targeted, for all women of child bearing age and their support networks)
- Tertiary
  (Specialized for women most at risk for an alcohol exposed pregnancy)
- Postpartum supports to maintain positive changes for mother and child

4 Levels:(Poole)

Key References on FASD Prevention

- www.phac-aspc.gc.ca/fasd-etcaf/index-eng.php
- Informed by a working group of experts in the field
- Public Health Agency of Canada
- Four part model of prevention
- Excellent web based resources

FASD Prevention: Canadian Perspectives (2008) Nancy Poole

Key References on FASD Prevention

- Double Exposure: A Better Practices Review on Alcohol Interventions During Pregnancy, prepared by Tessa Parkes, Nancy Poole, Amy Salmon, Lorraine Greaves & Christine Urquhart
- www.hcip-bc.org
- Act Now BC Healthy Choices in Pregnancy
- Systematic review of literature and better practice approach to inform policy and point to areas of future research

Level 1: Primary, Universal, Raising Awareness

- Message, Approach and Themes
- Barriers
- Research

Level 1: Message, Approach And Themes

Message of risk of drinking in pregnancy or in planning pregnancy, including what is FASD

- Social marketing: posters, labels, campaigns
- Engagement of broad range of people for social change
- Community development to reduce stigma and blame
- Resources for more information and help
- Develop system of support across sectors

Level 1: Message, Approach And Themes

- Should benefit ALL and be a starting point for discussion
- Where: health centers, community programs, social service agencies, restaurants and bars, media, school curriculum under healthy life choices and reproductive health

Level 1: Barriers

- Awareness does not mean change in behaviors and actions
- No clear pathway for supports in every community
- May increase not wanting to disclose due to stigma
- May not reach most at risk due to isolation, mental health issues, unable to make change alone in addressing the complex "why women drink" factors

Level 1: Barriers

- Over-focus on women as the problem and not emphasizing the benefits to her health and a healthy pregnancy outcome
- Responsibility of the woman's support network and partner not always emphasized
- Cost and benefit not measurable

Level 1: Research

- Canada Northwest FASD Research Network (www.canfasd.ca)
- NAT on Prevention: lead agency Saskatchewan Prevention Institute, Robin Thurmeir
- Electronic library catalogue of all primary messaging resources

Level 1: Research

- Limited evaluation of effectiveness, who listens and what actions
- Research planned on social marketing to change behavior
- Tools to evaluate outcomes need to be used

Level 2: Secondary Targeted "Conversations"

- Message, Approach and Themes
  - Method - 3 Tiers
  - Barriers/Research

Level 2: Message, Approach and Themes

Conversations brief counseling with ALL women and girls of child bearing age AND their support networks

- Themes:
  - Pregnancy planning and contraception
  - Asking about alcohol use with screening tools or conversation
  - Asking about stressors
  - Asking about support systems

Level 2: Message, Approach and Themes

Incorporate into ALL encounters

- Who and where, multiple touch point with consistent messaging
  - Regular health care: physicians and team members in health care networks
  - School based: L Baydala Alexis Project
  - Community workers: Saskatchewan Speakers Bureau and Youth for Action Project
  - Pharmacy: Pharmacists engaging with women, Alberta project

Level 2: Method - 3 Tiers

Teir 1 - Screening

- Use of tools: TACE, TWEAK, AUDIT, MAST asked directly or computer based
- Conversations: nonjudgmental, supportive, respectful, build trust and relationships, remove stigma of disclosure, cultural and contextual

Level 2: Method - 3 Tiers

Tier 2 - Brief Counseling

- Screen for readiness to change
- FRAMES: (Miller) Feedback on current alcohol use, emphasis on client Responsibility, clear Advice to make change, Menu of options, Empathy, and Support
- 5 A's: (Whitlock) Assess, Advise, Agree, Assist, Arrange
- www.MDcme.ca leaning module for physicians

Level 2: Method - 3 Tiers

Tier 3 - Motivational Interviewing

- **Based on goal setting with the woman and self efficacy with focus on her well being as well as a healthy birth outcome**
- **Based on stages of change theory; (Prochaska) precontemplation, contemplation, determination and preparation, action, maintenance, relapse**
- **Need time and skill set**

Level 2: Method - 3 Tiers

Tier 3 - Motivational Interviewing

- **Need network of resources to connect to: mental health, addictions, enhanced resources for women, housing and shelters, dealing with domestic violence, child assessment and care (previous child with41 FASD?)**
- **The HELP guide for professionals through Enhanced Services for Women www.aadac.com**
- **DVD from ACT Now BC through www.hcip-bc.org**

Level 2: Barriers/Research

- **Need for training for professionals and to measure uptake into practice – Alberta experience in tool development**
- **No one screening tool used consistently: research supports the TACE, self report screen followed by interview better that direct asking**
- **No one size fits all approachs, need to consider needs of population, community and cultural differences**

Level 2: Barriers/Research

- **Women more likely to abstain if partners and supports reduced drinking: modeling, encouragement, engaging in healthy choices together**
- **Women more likely to abstain if white, married and had post secondary education**
- **Brief interventions reduces use of alcohol in pregnancy but control group also reduced (Chang 2005) impact of being in a research project**

Level 2: Barriers/Research

- **Brief interventions increase use of contraception (O'Connor and Whaley 2007)**
- **Long term impact of Brief Interventions on sustained alcohol reduction or abstinence not known and factors of stress may change with subsequent pregnancies**
- **Studies did not set the intervention in the context of the woman's life**

Level 3: Specialized Prenatal Supports

- Message, Approach and Themes
- Specialized Prenatal Supports
- Examples of Specialized Prenatal Supports
- Research

Level 3: Message, Approach and Themes

Specialized and holistic supports for pregnant women or at risk of becoming pregnant and are using alcohol

- Woman centered
- Accessible, respectful, culturally relevant, comprehensive care across systems
- Case manager, mentor, trusting relationship, single point of contact
- Not mandated – woman wants help
- Integrated with services for their children (McMaster study)

Level 3: Specialized Prenatal Supports

Elements of program

- Crisis intervention
- Psychosocial and substance abuse assessment
- Individualized treatment plan development with the client
- Home visitation
- Parenting capacity and education
- Infant and child development assessment
- Transportation to appointments
- Help with financial
- Housing and legal issues

Level 3: Specialized Prenatal Supports

Elements of program

- Dealing with domestic violence
- Connecting to addiction treatment that is woman focused in the context of their family and retaining custody of their children
- Access to health needs including preconception and prenatal care
- Help in dealing with healing from past issues that may be multi-generational

Level 3: Examples of Specialized Prenatal Supports

P-CAP Parent Child Assistance Program, Theresa Grant, Seattle Washington

- **Mentorship model established 1991 based on relationship building**
- **Home visitation with 3 years intensive supports**
- **Entry criteria of high risk substance abusing mothers who are pregnant or 6 months postpartum**
- **Staff of paraprofessionals who have overcome similar experiences**

Level 3: Examples of Specialized Prenatal Supports

P-CAP Parent Child Assistance Program, Theresa Grant, Seattle Washington (continued)

- **Research has shown cost effectiveness compared to cost to support I individual with FASD in their life; 65% had reduced risk at exit from program**
- **Improved maternal physical and mental health**
- **Improved parenting, more permanent child custody**
- **Less pregnancies in succession and more access to contraception**

Level 3: Examples of Specialized Prenatal Supports

P-CAP Parent Child Assistance Program, Theresa Grant, Seattle Washington (continued)

- **Multiple mental health comorbidities**
- **Many of the women are FASD themselves but never diagnosed**
- **Women with FASD need more supports: external brain across their life not just 3 years, shift from won't to can't by others, help to access diagnosis (Step by Step CSS Edmonton)**

Level 3: Examples of Specialized Prenatal Supports

Examples based on P-CAP model

- **First Steps, CSS Edmonton, Alberta**
  - **Use professional with social work background**
  - **Recent evaluation by Rasmussen, Badry, Henneveld**
- **StopFAS Manitoba**
- **Sheway, Vancouver, B.C. specialized delivery**
- **Breaking the Cycle, Ontario (Motz 2006) www.breakingthecycle.ca mother and child**

Level 3: Research

- **Failed to find evidence that home visitation reduces risk of continuing drug or alcohol use**
- **Definite benefits included increased attendance in addictions programs**
- **Improved contraception use**
- **Reduction in non-voluntary foster care**

Cochrane review of the home visitation model (2005)

Level 3: Research

- **Many of the evaluation reports were of poor methodology and did not detail the drug and alcohol treatment component or provide long term follow up of clients: small sample sizes: different populations**
- **Qualitative research and interviews with women and the mentors support the benefit of the programs**

Cochrane review of the home visitation model (2005)

Level 3: Research

- Points to the need for more rigorous research with consistent methods: Canada Northwest FASD NAT on Interventions with high risk women

Cochrane review of the home visitation model (2005)

Level 4: Postpartum Supports

- Message, Approach and Themes
- Examples of Postpartum Supports
- Target Audience
- Barriers
- Research

Level 4: Message, Approach and Themes

To initiate or maintain positive changes for mother AND child after delivery (Woman focused)

- Prevent postpartum relapse
- Continue with supports around addictions
- Health maintenance including nutrition, exposure to violence, healthy support networks
- Dealing with stress of child rearing and prevention of child abuse
- Recognizing and help with postpartum depression

Level 4: Message, Approach and Themes

To initiate or maintain positive changes for mother AND child after delivery (Child focused)

- Access to basic health needs and appropriate stimulation and protection from violence
- Developmental screening and access to Early Interventions
- If alcohol exposed, monitor for FASD and refer to team for assessment at appropriate time

Level 4: Examples of Postpartum Supports

- Fir Square, Crab Tree, Sheway in Vancouver
- Breaking the Cycle, Toronto and New Choices, Hamilton, Ontario
- Incorporated into First Steps in Alberta
- StopFAS and Interagency FASD Manitoba
- Intertribal Health Authority Vancouver Island using postpartum discussion approach based on OAR (Own, Act, Reflect)

Level 4: Research

- Involved meta analysis of integrated treatment programs for substance using women and their children
- Effectiveness and moderating factors of treatment outcome
  - Review of 119 studies
  - Presented at International FASD Conference, March 2009
  - To be published

CIHR study from McMaster 2007-2008, Niccols et al

Level 4: Research

- Traditionally there is a disconnect between women's health, addictions services and children's services
- Integrated programs offering services in centralized setting for both woman and child compared to standard care: reduced maternal substance use and longer length of stay in support program with moderate effect size for both

CIHR study from McMaster 2007-2008, Niccols et al

Level 4: Research

- Improved maternal empathy at 3 months and child's social competency at 6 months
- Need for better design study, larger samples. More longitudinal data, also qualitative information

CIHR study from McMaster 2007-2008, Niccols et al

Next Steps

Do The Strategies Work?
Where To From Here?

Do The Strategies Work?

- Project evaluation
- Measuring outcomes and replication in other sites
- Sustainability of outcomes over time
- Cost effectiveness compared to cost of FASD across the lifespan
- Informing policy and public attitudes

Where To From Here?

Examples of Better Practices are available but need:

- Replication in different settings and subpopulations
- Development of standard measures of outcomes and evaluation methods
- To connect clinical practice to research and back to clinical practice (Knowledge Transfer)

Where To From Here?

Examples of Better Practices are available but need:

- To not lose the cost of FASD across the lifespan in both dollars and personal burden in analysis of cost benefits of prevention programs
- To focus on “WHY” women drink and not just the drinking
- To consider woman, child and family

Where To From Here?

Examples of Better Practices are available but need:

- **To engage women in what is working and not**
- **To engage with Aboriginal women and leaders in understanding their needs (Honouring Ourselves and Healing Our Pasts (Salmon & McDiarmid) and in research**
- **Participation in research: Canada Northwest FASD Research Network**

Reference

- **Contact Information**
- **Source Material**

Contact Information

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Source Material

- Double Exposure, A Better Practices Review on Alcohol Interventions during Pregnancy 2008, Parkes T, Poole N, Salmon A, Greaves L & Urquhart C: BC Center of Excellence for Women's Health part of Act Now BC Healthy Choices www.hcip-bc.org
- FASD Prevention: Canadian Perspectives 2008: Poole N www.phac-aspc.gc.ca/fasd-etcaf/index-eng.php

Source Material

- Tough, S et al:
  - Preconception practices: Results from a national survey of Family Physicians and Obstetricians, Journal of Obstetrics and Gynecology Canada JOGC 2006: 28 (9) 780-788
  - Attitudes and approaches of Canadian providers to preconception counseling and the prevention of Fetal Alcohol Spectrum Disorders Journal of FAS International 2005: 3e 3

Source Material

- **Tough, S et al: (continued)**
  - **Are women changing their drinking behaviors while trying to conceive? An opportunity for preconception counseling. Clinical Medicine and Research 2006: 4(2) 97-105**
  - **Reproduction in Alberta: A Look at Preconception, Prenatal and Postnatal Periods. 2008. Prepared for the Alberta Center for Child, Family and Community Research**

Source Material

- Grant T et al: Preventing Alcohol and Drug Exposed Births in Washington State: Finding from three Parent–Child Assistance Program Sites: Amer. Journal of Drug and Alcohol Abuse 2005, 31 (3) 471-490
- Motz et al: Breaking the Cycle: Measures of Progress 1995-2005 Journal of FAS International, Special Supplements 2006, 4 (e22)
- Alberta Health Services AADAC: Services for Women: www.aadac.gov.ab.ca

For Information on Upcoming Sessions in the Series: www.fasd-cmc.alberta.ca

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