

FASD: How fetal alcohol spectrum disorder impacts the life course trajectory of children, teens and adults

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- PREGNANCY RELATED ISSUES IN THE MANAGEMENT OF ADDICTIONS*

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INTRODUCTION

Introduction

- Fetal alcohol spectrum disorder (FASD) is a complex neuro-behavioural disorder that is the result of alcohol consumption during pregnancy. Many children and most adults with FASD do not have access to an FASD diagnosis because of the cost of the assessment and the lack of assessment resources.
- Many clients with FASD present with behavioural issues but have no visible signs of the disorder, so the condition remains undiagnosed.
- Prison populations and pregnant women with FASD are two very high risk groups that are often missed.

Goals of Workshop

This session will review how FASD presents at different stages in the life cycle (newborn, infants, young children, teens, adults) and how earlier diagnosis and intervention strategies by family physicians and family health teams can improve clinical, developmental and life course outcomes.

- Highlights of the updated draft of the Canadian FASD Diagnostic Guidelines will be presented.
- CanFASD resources and prevention initiatives will be reviewed
- Links to clinical advocacy by physicians will be presented.

Learning Objectives

1. Describe how FASD impacts development from infancy through to adulthood.
2. Implement clinical strategies to improve communication with, and management issues in, clients with FASD.
3. Understand use of clinical tools for diagnosis of FASD in young children, teens, pregnant women and adults in a timely fashion.

FASD and Scope of Practice for Family Physicians

- Screen for alcohol use during pregnancy and possible FASD
- Contribute to the diagnosis. Physicians are funded to go this far by our healthcare system.
- Make the appropriate referral for further diagnostic work-up where necessary to determine severity and specific deficits.
- Plug the patient into the appropriate provincial social support network - i.e. disability funding, supportive co-employment, financial management and support for special talents that many of these patients have (e.g. music and art).
- Advocate for the patient and the family that struggle to navigate the "system".

UNDERSTANDING FASD

Case History – Infancy and Childhood

- Born 1970, Couchiching Reserve, Fort Frances, Ontario (Ojibway)
- CAS Scoop – maternal alcoholism and neglect
- Adopted age 3 months
- Happy baby. Happy childhood. No physical features of FASD
- FASD not described until the early 70's
- Frequent otitis media

Ken the Happy Baby



Behaviours Associated with FASD

Infancy

- Often tremble and are irritable
- Weak sucking reflex
- Erratic sleep patterns
- Sensitive to sight, sound and touch

Behaviours Associated with FASD

School-Aged Children

- Require constant reminders for basic activities at home and school
- “Flow-through” Learning: information is learned, retained for a while and then lost
- Very concrete thinker, will fall farther behind peers as the world becomes increasingly abstract and concept-based

Differential Diagnosis of FASD in Children

It's easy to misdiagnose a person as having a more well-known disorder when the person exhibits symptoms common to both disorders

- Conduct Disorder (CD)
- Attention Deficit Hyperactivity (ADHD)
- Oppositional Defiance Disorder (ODD)
- Autism

While each of these is a legitimate separate diagnosis in itself, they may also be diagnostic of a symptom of FASD and thus give only a partial explanation for the constellation of problems experienced by people with FASD⁸

FASD: Diagnosis in Children

- Do a complete history and physical exam
- Ask about ETOH use during pregnancy
- FASD Features
 1. pre or postnatal growth restriction (Disproportionate low wt. to growth, low birth wt., etc.)
 2. CNS involvement (microcephaly, behavior problems, etc.)
 3. Characteristic facial features (small eye openings, thin upper lip, flat midface, epicanthal folds, etc)
 - There may be subtle evidence of FASD without typical facial features

Cognitive Implications in Children with FASD

- Most children with FASD have no physical features so their “invisible” disability may go undetected
- Some people have average levels of IQ and *appear* to understand, so people expect them to perform beyond actual capabilities
- Psychometric IQ may be too high to qualify a child for special education, however functional IQ may be very low

Role of IQ in Children with FASD

- 1996 study of 473 people with FASD⁹
- IQ ranged from 29 to 142
- 86% had IQ in the “normal” range
- Academic skills were below IQ
- Living skills, communication skills and adaptive behavior levels were below academic skills

LINKING INTERVENTION TO OUR UNDERSTANDING OF FASD

Parenting a child with FASD

- Diagnosis done by interdisciplinary team
- “permanent brain injury”
- **Parenting tips:** STRUCTURE
SUPERVISION
SIMPLICITY
STEPS
CONTEXT

Protective Factors: High quality positive home environment without exposure to violence, receiving services for developmental disabilities, long term living arrangements and diagnosis before age 6 have all been identified to reduce adverse outcomes including mental health problems.

S.C.R.E.A.M.S

Seven Secrets to Success

AAAIIEEEEEEE!

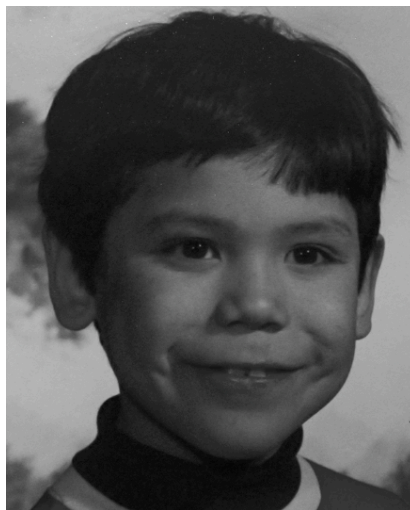
How to minimize screaming (yours, not theirs):



1. Structure with daily routine, with simple concrete rules
2. Cues (again and again and again), can be verbal, audio, visual, whatever works
3. Role models, show them the proper way to act
4. Environment with low sensory stimulation (small classrooms, not too much clutter)
5. Attitude of others, understanding that behaviour is neurological, not willful misconduct
6. Medications, vitamin supplements and healthy diet are quite helpful
7. Supervision - 24/7 (lack of impulse control and poor judgment at all ages)

1998 -2002 Tera Kellerman www.fasstar.com

Ken's School Days



Case History: FASD Issues Growing Up

- Poor executive functioning
- **Lack of organization – needed help with schoolwork and constant reminding**
- Lack of initiative except for things like music, break dancing etc.
- Forgetfulness
- **Impulsivity**
- Angry outbursts
- Needed help with schoolwork
- Needed help with Scouts
- **Inability to handle money**
- Inability to manage time
- Difficulty understanding verbal instructions
- Difficulty formulating complete sentences. Often used truncated sentences and had problems understanding why people didn't know what he was trying to communicate.
- **Despite trying hard to accomplish tasks properly, often they would get "screwed up"**

Case History: Teen Years

- **Began drinking alcohol at age 16 years (1986)**
- YMCA Camp Pinecrest – worked in out-trip department
- **Drank heavily and used marijuana in university**
- Rusticated from Trent due to drinking and poor performance
- Academics: Trent University Diploma in Native Studies (2 year program) – required help
- **Athletics: talented** – skiing (downhill and cross country), break dancing, canoeing, baseball, floor hockey
- **Music: talented** – multiple instruments: piano, guitar, drums, school band
- Health: fatty liver on U/S age 18 years
- **Social: well-liked, friendly, respected. Kind and charitable person**
- Scouts: good outdoor skills, Chief Scout Award

*Poor school performance = increased stress = alcoholism
= avoiding getting a driver's license*

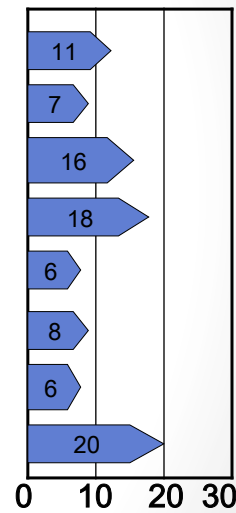
The Party Begins



FASD Timelines⁸

A study of 18-year-old youth with an FASD revealed that they were functioning at the following developmental levels:

- Organization (self-care hygiene, etc.) like an 11-year-old
- Social skill development like a 7-year-old
- Word recognition like a 16-year-old
- Physical maturity of an 18-year-old
- Emotional maturity of a 6-year-old
- Understand time and money like an 8-year-old
- Think and process like a 6-year-old
- Sound verbally like a 20-year-old



SCREENING: CRAFFT (teens)

- **C:** Have you ever ridden in a **CAR** driven by someone (including yourself) who was “high” or using alcohol or drugs?
- **R:** Do you ever use alcohol to **RELAX?** Feel better about yourself?
- **A:** Do you ever use alcohol while **ALONE?**
- **F:** Do you ever **FORGET** things you did while using alcohol?
- **F:** Do your **FAMILY/FRIENDS** ever tell you to cut down?
- **T:** Have you ever gotten into **TROUBLE** while using alcohol?



CRAFFT: SCORING

- Two or more yes responses indicate a potential problem with alcohol
- Further assessment is advised



Behaviours Associated with FASD

Adolescents and Adults

- Increased truancy
- Increased problems linking cause and effect
- Problems managing time and money
- Difficulty showing remorse or taking responsibility for their actions
- Say they understand instructions but can't carry them out

FASD Functioning

Normal Functioning		FASD Functioning
Abstract thinking	➔	Concrete thinking
Able to analyze	➔	Can't analyze
Good problem solving	➔	Poor problem solving
Good judgement	➔	Lack common sense
Learns by example	➔	Learns by repetition
Learns from experience	➔	Always in trouble

FASD and Adulthood

- **Physical Health Issues** – congenital heart disease, renal defects, congenital vision and hearing deficits
 - if childhood health unknown may wish to consider: echo, renal US, vision/hearing Ax
- **Dysmorphic features of FAS/FAE diminish over time** (microcephaly, long philtrum, thin vermillion border, even short stature and underweight)
- **Mental handicaps persist including intellectual disability** (avg IQ 68, academic fn 2nd-4th grade), limited occupational options and ability for independent living including navigating health, social and educational/vocational systems
- **Maladaptive Behavioural Problems are significantly increased** including poor judgement, distractibility, impulsivity and difficulty perceiving social cues
- **Family Environments remarkably unstable**

Importance of considering both Cognitive and Adaptive Functioning

Definitions:

- “cognitive functioning” means a person’s intellectual capacity, including the capacity to reason, organize, plan, make judgments and identify consequences.
- “adaptive functioning” means a person’s capacity to gain personal independence, based on the person’s ability to learn and apply conceptual, social and practical skills in his or her everyday life ***Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act, Ontario, 2008, c.14, s.3 (2).***
- Genetic and Environmental factors influence intellectual and adaptive functioning

Intellectual vs. Adaptive Functioning (con't)

- Discrepancies are important to identify:
 - Low IQ scores but strong adaptive skills
 - Ex. 21 year old man with IQ of 70 with strong interpersonal skills and family support network attends an adapted college program, lives in a supported independent living, can manage many IADLs
 - Borderline IQ scores but impairments in adaptive functioning
 - Ex. 21 year old man with IQ of 80 with co-morbid FASD and chaotic home environment. Moved frequently as a child, attending many different schools, IEPs not put in place, poor literacy skills and difficulties with attention, impulsivity and difficulties perceiving social cues make it very difficult for him to work and manage independent living

Developmental Disabilities Program Committee Resources

- Sullivan et al. Primary care of adults with developmental disabilities: Canadian consensus guidelines.
Canadian Family Physician May 2011 vol. 57 no. 5 541-553
- Guidelines Overview:
 - General Issues
 - Physical Health
 - Mental Health
- Clinical Tools and CME opportunities/Clinical Support
- FASD Health Watch Table – in final stages of publication

[LINK to DDPC Website](#)

Importance of Identification of Developmental Disability in the Criminal Justice System

Highly Vulnerable in community – limited understanding of legal terminology, court proceedings, their rights and cooperating with attorney, confessing during interrogation

- anxious to fit in – ‘cloak of competence’, ‘cheating to lose’, ‘halo effect’
- rates of ID are high in inmates: studies show 4-10% with mild ID (up to 5 fold of the rates in the general population), and an additional 10% with borderline ID
- many of these individuals are not diagnosed
- difficulties following rules or recommendations (including health related), highly vulnerable to victimization by other inmates, receive little in the way of services on release

Hayes Ability Screening Index (HASI)

- validated instrument to screen for ID in prison system (Sens 82%, Spec 72%)
- can be administered by non psychologists, 5-10 min to administer, culture and gender fair, available in Canadian French

DIAGNOSIS AND ASSESSMENT

FASD Assessments

A comprehensive assessment includes input from a trained multi-disciplinary team including:

- Physician
- Psychologist
- Speech-Language Pathologist
- Occupational Therapist

Other team members may be required, depending on the context (i.e., cultural interpreter, addiction counsellor)

Diagnostic Criteria for FASD (draft)

- Sentinel Facial Features
 - Short palpebral fissures, at or below the 3rd percentile (2 standard deviations below the mean)
 - Smooth or flattened philtrum, 4 or 5 on the 5-point Likert scale of the University of Washington Lip-Philtrum Guide
 - Thin upper lip (rank 4 or 5 on the Lip-Philtrum Guide)
- CNS
 - 3 domains of impairment
- Prenatal Alcohol Exposure
 - Confirmation required in cases without all sentinel facial features present
- Growth impairment and other alcohol-related birth defects should be documented if present.
- Hereditary and prenatal factors that may influence developmental outcome should be recorded.
- Postnatal factors that may influence developmental outcome should be recorded

Brain Domains (Draft)

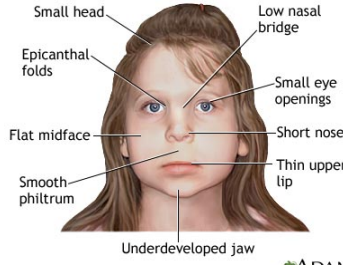
- Motor Skills
- Neuroanatomy /Neurophysiology
- Cognition
- Language
- Academic Achievement
- Memory
- Attention
- Executive Function, including Impulse Control
- Affect Regulation
- Adaptive Behaviour, Social Skills, or Social Communication

Diagnostic Categories (Draft)

	FASD with sentinel facial features	FASD without sentinel facial features	PAE: Risk of Neurodevelopmental Disorder
PAE	Not required	Known alcohol exposure	Known alcohol exposure
Face	3 Facial Features	None requires	None required
CNS	3 domains of impairment	3 domains of impairment	At least 1 domain of impairment

**Growth, PAE, birth defects, microcephaly, other pre and postnatal factors all need to be recorded if present


Fetal Alcohol Syndrome



ADAM

Williams Syndrome

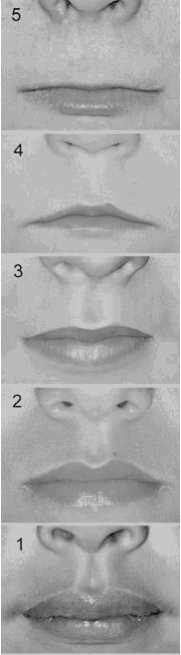
- ❖ microcephaly
- ❖ long smooth philtrum
- ❖ short palpebral fissures
- ❖ prenatal growth deficiency




De Lange Syndrome

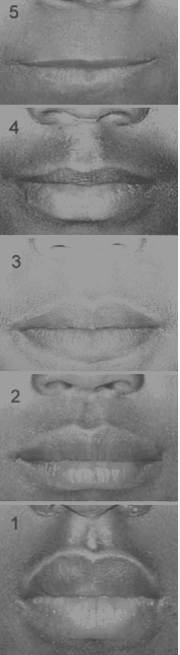
- ❖ long philtrum
- ❖ thin upper lip
- ❖ prenatal growth deficiency

Lip-Philtrum Guide



Lip-Philtrum Guide 1





Lip-Philtrum Guide 2

(Astley, 2004)

Short Palpebral Fissure Length

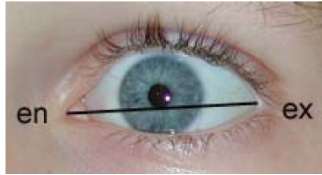
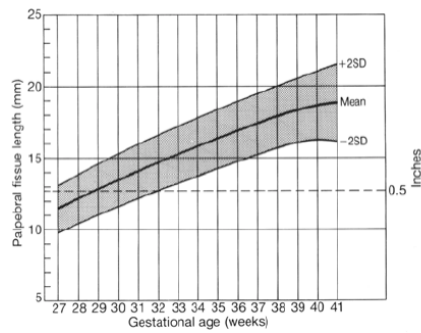


Figure 2A. Palpebral Fissure Length (PFL). Distance from endocanthion to exocanthion.



Figure 2B. PFL measured with a small ruler while patient looks up to fully expose exocanthion.

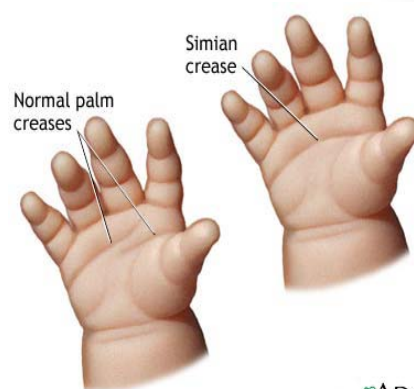


“Railroad track” Ears



(Hoyme et al., 2005)

Abnormal Palmar Crease



ADAM.

ADULTS WITH FASD

Back to our Case History : Adulthood

- **Poor memory, poor executive functioning and lack of initiative** = poor work performance.
- **Poor time management** = late for work.
- **Poor money management** = avoiding jobs where money was involved (e.g. cashier jobs in grocery store), CIBC wrote off \$16,000 worth of credit card debt due to his diagnosis and their failure to heed warnings that he was unable to handle money because of his disability.
- **Poor organizational skills** = inability to work on his own (e.g. Granny's Candy business – required to fill vending machines across Southern Ontario and collect cash).

Case History: Consequences of Alcohol in Adulthood

- Poor job performance = increased stress = alcoholism = unemployment = divorce and alienation of family and friends = loss of home and hospitalization.
- Secondary alcoholism.
- Unable to get and hold jobs except as a musician in bars.
- Bicycle courier in Toronto – lost job due to performance failure.
- Married university sweetheart.
- One daughter.
- Divorced over drinking and the resulting relationship issues.

Case History: Major Health Issues as an Adult

- Chronic alcoholism
- Cirrhosis of the liver – fibroscan 75 on scale of 1-75
- Confusion
- Fatigue/ lethargy
- Portal hypertension
- Esophageal varices
 - UGI hemorrhage – bled 50% of blood volume
- Paroxysmal atrial fibrillation
- Grand mal seizures
- Delirium tremens
- Metabolic syndrome
 - Hypertension
 - Hypercholesterolemia
 - IDDM
- Hyperuricemia
 - Gout
- IgA nephropathy
 - 30% renal function remaining
 - Rx prednisone – precipitated IDDM
- Depression
 - Boredom

Case History: Medical Course

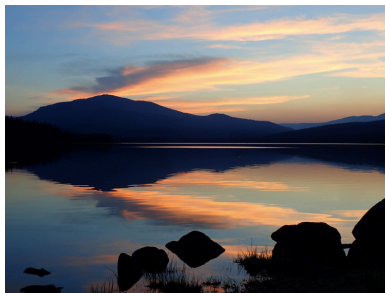
Current Status

- 2007 – Admitted to Sagashtaweo (treatment centre in Moosonee, ON) – sober for 2 ½ years and worked at the Northern Store, Moose Factory, Ontario.
- 2011 –Admitted to Wings As Eagles (recovery centre in Cranbrook, BC) – developed a strong religious focus that has helped him since that time. Sober since 2011 (3 years) – attends church weekly and has a supportive social network
- FASD (ARND) diagnosis confirmed 2012

Disability pension (\$940 per month) = less fear of living on the street

- Money handled by direct deposits, parental POA and food cards
- Lives in rental accommodation owned by parents

20 years later the party's over



Case History: Social Networks

Current Status

- Lives with girlfriend = companionship and support
- Understands his diagnosis = less stress = less anger, fewer outbursts, easier to relate to, happier person
- Major problems with cognitive FASD symptoms, but has insight and coping much better
- Gives talks on his life at church and at Three Voices of Healing (aboriginal drug and alcohol treatment centre). Plays music at various local venues.
- Still copes with addictions (computer games), but has given up alcohol, marijuana and cigarettes.

Managing Boredom and Depression

- FASD patients on long-term disability may still be able to work and benefit from a part time job. (In BC, they are eligible for \$800 a month of employment income without jeopardizing their pensions.)
- However, they require the security of a disability pension in case of unemployment so the pension serves to protect them from homelessness.
- Obtaining a part-time job is challenging for FASD patients (and other patients with major cognitive impairments) because of problems with initiative, organization and often a previous history of job loss and employer criticism.
- A program to assist them obtaining part-time non-competitive employment would be very helpful.

Case History: Health Impact of Alcohol Use

Managing Diabetes

- Following a diet for diabetes and renal disease is a challenge for the FASD patient as is managing insulin.

Managing Chronic Alcoholism

- Combatting the urge to drink is a daily struggle for many FASD/ alcoholic patients.

Managing ESRD and Hepatic Failure

- Hepato-renal failure will ultimately raise the issues of dialysis and potential transplantation.
- Patient is being followed by nephrology and hepatology at Foothills Hospital, Calgary.

Intervention Issues for Pregnant Women with FASD

- Self monitoring (drinking diary) – hard to remember; hard to resist temptation
- Pacing tips – hard to remember tips; hard to resist temptation
- Assess level of motivation – hard to maintain enthusiasm; easily distracted
- Non-compliance – may be inability to follow through (executive functioning)

Adapting Interventions

If the mother is suspected of having FASD, then interventions to reduce alcohol use and prevent future children with FASD need to accommodate her specific learning needs

i.e. Standard interventions may need to be adapted

- Processing differences:
 - **1)** Poor receptive language skills
 - **2)** Difficulty with social cognition
 - **3)** Difficulty with generalizing learning
 - **4)** Not always connecting cause and effect

Pregnancy and Impact of Addictions and Ongoing Alcohol Use

- Pregnant women who have already given birth to babies with FASD may have FASD themselves, and they also may need treatment for addiction
- **Key Issues are 1) "potential for neglect " for child and 2) appropriate intervention and support of mothers** (as well as supporting the mother's health it may prevent another case of prenatal alcohol exposure.
- Prenatal alcohol use in itself, should not translate to CAS reporting. Ongoing use to point of intoxication, and other indications of addiction and inability to parent, while responsible for care is an indication of the need for CAS intervention.
- Child Protection may need to be involved with some women earlier in treatment and may need family physician advocacy to decide on better child care arrangements. Prenatal voluntary referral may be optimal for action plan.

SCREENING: T-ACE

Adapted from CAGE questionnaire:

- **T**: how many drinks does it take to make you feel high? (**tolerance**)
- **A**: have you ever been **annoyed** at criticism of your drinking/ drug use?
- **C**: have you ever felt the need to **cut down** on your drinking/ drug use?
- **E**: have you ever had an **eye-opener**? (withdrawal)



T-ACE: SCORING

- Score 1 for each positive response for A, C, E (annoyed, cut-down, eye-opener)
- Tolerance question: score 2 if it takes 3 or more drinks to feel high or experience intoxicating effects
- Score of 2 or more indicates problem drinking

Note: More sensitive than CAGE for detecting at-risk drinking in pregnant women



PREVENTION OF FASD WITH ALL WOMEN

Why might women drink alcohol during pregnancy? Common explanations

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.
7. 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
8. **Physicians report that they don't feel fully prepared to discuss substance use with women**
9. Unless proactive, problem alcohol use in women is often not recognized or treated



See resources for health care providers at:
<http://bccewh.bc.ca/publications/resources/key-project-reports-2/>

Why might Women Drink Alcohol During Pregnancy and/or Breastfeeding? Research Evidence

Many diverse groups of women are more likely to consume alcohol during pregnancy, including women who:

- are older (over 30)
 - have high income or who are unemployed or living in poverty
 - are in an abusive relationship
 - use other substances
 - are depressed
 - are coping with trauma
 - have a partner who drinks heavily
 - are coping with the intergenerational effects of colonization
- (Skagerström et al, 2011; Niccols et al, 2009; Best Start, 2003; Bakhireva et al, 2011)

Study of Birth Mothers of 160 children with FAS Of the 80 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.

Research: light drinking in pregnancy

Evidence is inconsistent at low-moderate levels of consumption

Some studies suggest NO EFFECT of light- moderate drinking during pregnancy

- **Recent examples:**
- Kelly *et al* (2008, 2012, 2013) - No increased risk of clinically relevant behavioural difficulties, cognitive deficits at age 3, 5, and 7 (N=10,534 - 12,495); differences in scores between boys and girls
- Humphriss *et al* (2013) - No effect of moderate (3-7 glasses/week) maternal alcohol consumption on balance at age 10;

Some studies suggest ADVERSE EFFECTS of light-moderate drinking during pregnancy

- **Recent examples:**
- Andersen *et al* (2012) - Low to moderate consumption of alcohol increased risk of spontaneous abortion substantially in first trimester (N= 92 719)
- Feldman *et al* (2012) - Increased risks for physical features of FAS and growth deficiencies (reduced birth length and weight); dose-related effects, no evidence of safe threshold at lower amounts of alcohol use

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)
- 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

"No safe time. No known safe amount. No safe kind."

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.
- There is potential for misunderstanding of drink sizes and actual alcohol content of various types of drinks
- There is compelling evidence from research on animals that even low doses of alcohol at any time during pregnancy can affect fetus

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

- Brief interventions (both formal and informal) using Motivational Interviewing approach and non-judgmental stance
- Discussion of drink size and "alcohol literacy" overall using tools such as low risk drinking guidelines
- Screening - Routine screening, screening for polydrug use (e.g., alcohol and tobacco), screening with tools: CAGE, AUDIT, T-ACE, TWEAK, web- and computer-based screening, telephone screening and screening using dialogic approaches (open ended questions such as "how does alcohol fit in your life?")
- Medical school training and continuing education in screening and brief intervention approaches



For more information see SOGC guidelines

Role of Health Professionals

Supporting and empowering women around alcohol and pregnancy and related concerns :

- **Engage Focus**
 - listen to her story; explore where alcohol fits in
 - collaboratively identify the focus; share information as needed
- **Evoke**
 - draw out her own motivations for change and level of readiness
- **Plan**
 - together identify next steps and any additional supports needed, keeping the discussion open and revisiting
- **Engage**
 - Normalize the conversation
 - **Listen** more - supports engagement, greater empathy = better outcomes
 - **Affirm** and explore what she is already doing to take care of her health
 - Use **open-questions** to explore overall health, including the role of alcohol:
 - “Tell me about a typical day. Where does alcohol fit in?” Y “Before you knew you were pregnant, where did alcohol fit in your life?”
 - “What changes, if any, have you made since knowing you are pregnant?”

Sharing Information: E-P-E

- **Elicit**
 - Find out what information the woman already has: “What have you heard about ...?”
 - Ask permission: “Would you like to know more about the effect of ... on?”
- **Provide information**
 - Use general statements such as, “It is common for women to...” or “The message we share will all women is...”
- **Elicit**
 - Inquire about how she understands the information: “What does this mean for you?” or “How does this fit with your experience...?”
- **Evoke**
 - What people say about change influences whether or not it occurs
 - Evoking involves eliciting the woman’s own motivations for change
 - Personal change requires active participation – Use open-questions to gain an understanding of her hopes, values, abilities, reasons, needs:
 - Why might you want to make this change? What do you value most? What are you already doing to have a healthy pregnancy?
 - How have you managed to make other changes in your life?

PLAN:

Summarize what you have heard as her motivations for change

- Follow the summary with a key question, such as:
- So, where do we go from here? What might be the next step?
- Create a tailored plan – the actual plan will depend on the situation and needs of the woman, and might include:
- Follow-up visit. Consider the information shared; discuss with partner
- Referral to other supports

What Matters?

- Focus on both *mother and baby*
- Recognize the role that alcohol and other substances may play in a woman's life and the interconnections between substance use, mental health and trauma/violence
- Find balance between risk and self-efficacy
- Pacing, timing and relationship are essential
- Use harm reduction strategies – encourage any and all small changes that reduce risk and recognize the context of a woman's life
- Develop rapport, express concern and compassion
- Offer choice and ask permission

Preconception Prevention Strategies

- Asking about alcohol use at every well woman visit, Pap Smear, annual general check
- Birth control renewal visit will allow preconception planning to occur.
- Explore alcohol use and especially binge drinking in teens and young adults.
- Discuss alcohol use with male patients as well to allow them to support family members.

Keep FASD on your differential!

Ask every woman about alcohol use, in the preconception period hopefully!

PREVENTION IS KEY!

Early diagnosis and intervention improves outcome!

Refer if you are concerned!

Breastfeeding: Do I need to abstain from alcohol?

- The infant is exposed to very small amounts of the alcohol ingested by the mother, but detoxifies it at half the rate of adults (especially in the first few weeks of life).
- Can consult Motherisk recommendations and table.
- Avoid heavy drinking → it can decrease milk production and interfere with mother's ability to care of infant.

(Koren G, Drinking alcohol while Breastfeeding. Motherisk Update, Can Fam Phys., 2002).

Alcohol and Breastfeeding

- Alcohol: with moderate, occasional alcohol use: delay nursing for 1 - 2 hours per drink to minimize infant exposure; heavy alcohol consumption should be avoided while breastfeeding
- For specific info re alcohol, weight of mother and time delay before feeding, consult Best Start Resources (www.beststart.org)

References for FASD

1. Fetal Alcohol Spectrum Disorder (FASD). Public Health Agency of Canada 2005, Cat. No.: H124-4/4004, ISGN: 0-662-68619-5, Publication No.: 4200
2. Robinson, GC, Conry, JL, Conry, RF. Clinical profile and prevalence of fetal alcohol syndrome in an isolated community in British Columbia. *CMAJ* 1087; 137(3); 203-7.
3. Williams, RJ, Odaibo FS, McGee JM. Incidence of fetal alcohol syndrome in northeastern Manitoba. *Can J Public Health* 1999; 90(3): 192-4.
4. Square, D. Fetal alcohol syndrome epidemic on Manitoba reserve. *CMAJ* 1997; 157(1): 59-60.
5. Habbick, BF, Nanson, JL, Snyder, RE, Casey, RE, Schulman, AL. Foetal Alcohol Syndrome in Saskatchewan: Unchanged incidence in a 20-year period. *Can J Pub Health* 1996; 87(3): 204-207.
6. Asant, KO, Nelms-Maztke, J. Report on the survey of children with chronic handicaps and Fetal Alcohol Syndrome in the Yukon and Northwest British Columbia. Council for Yukon Indians 1985; Whitehorse, YT.
7. Mueller, Daniel P., Wilder Research Center, Amherst H. Wilder Foundation. Alcohol, Tobacco and Pregnancy: The Beliefs and Practices of Minnesota Women. Minneapolis, MN: Minnesota Department of Public Health, March, 1994, pg. 25-29.
8. Malbin, Diane. Timelines and FAS/FAE, Adapted from research findings of Streissguth, Clarren et al., 1994
9. A Layman's Guide to Fetal Alcohol Syndrome and Possible Fetal Alcohol Effects, FAS/E Support Network of B.C. 1997 pg. 43-44

References

- Hayes S. et al Early Intervention or early incarceration? Using a screening test for intellectual disability in the criminal justice system. *Journal of Applied Research in Intellectual Disabilities*, 2002(15):120-128
- Hayes Ability Screening Index (HASI) 2002-2013 University of Sydney, Department of Behavioural Sciences in Medicine
- Herrington, V. Assessing the prevalence of intellectual disability among young male prisoners. *J Intellect Disabil Res* 2009 May;53(5):397-410
- O'Leary et al. Prenatal Alcohol Exposure and Risk of Birth Defects *Pediatrics* 2010;126:e843
- Scheyett et al. Are we there yet? Screening processes for intellectual and developmental disabilities in jail settings. *Intellect Dev Disabil.* 2009 Feb;47(1) 13-23
- Sondenaa et al. The prevalence and nature of intellectual disability in Norwegian prisons. *J Intellect Disabil Res.* 2008 Dec;52(12):1129-37
- Sphor et al. Fetal Alcohol Spectrum Disorders in Young Adulthood *J Pediatr* 2007;150:175-9
- Streissguth et al. Fetal Alcohol Syndrome in Adolescents and Adults *JAMA* 1991;265:1961-1967