FETAL ALCOHOL SPECTRUM DISORDER: GUIDELINES FOR DIAGNOSIS FOR ACROSS THE LIFESPAN

Learning objectives

- Provide a background of the development of the guidelines
- Describe the new nomenclature in the new guidelines
- Outline the 10 domains identified for assessment.

Background

- Canada FASD Research Network led a 2 year funded project by PHAC to:
  - **Improve diagnostic criteria and capacity for FASD based on emergent evidence and current practice**.

Steering Committee

- Dr. Sally Anderson, USA
- Ms. Mary Ellen Baldwin, AB
- **Dr. Albert Chudley, MB**
- **Dr. Julie Conry, BC**
- **Dr. Jocelynn Cook, ON**
- Dr. Courtney Green, ON
- **Dr. Nicole LeBlanc, NB**
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- Ms. Bernie Mallon, AB
- Ms. Audrey McFarlane, AB
- **Dr. Ted Rosale, NL**
- Dr. Valerie Temple, ON

Development timelines

- Comprehensive Literature Review (Fall 2012)
  - Gaps, Concerns and Limitations
- Clinic Survey (Spring 2013)
- Meetings
  - Quarterly conference calls
  - Annual Face-To-Face meetings (Feb. 2013; 2014)
- Workshop (Oct. 2013)
  - Invited International experts (Infants, Adults, Brain)
- Draft for external review (Spring 2014)
- Final draft (Fall 2014)
- Submission to CMAJ (Fall 2014)
  - Companion Review Paper
  - Anticipatory Guidance Paper

Screening and referral

- All pregnant and post-partum women should be screened for alcohol use with validated measurement tools by service providers who have received appropriate training in their use.
- Women at risk for heavy alcohol use should receive early brief intervention.
- Abstinence should be recommended to all women during pregnancy to ensure the safest outcome for the fetus.
- Referral of individuals for a diagnosis should be made when there is evidence of or suspected prenatal alcohol exposure at levels associated with physical or developmental effects.

Diagnostic team

- A multidisciplinary team is recommended for an accurate and comprehensive diagnosis and treatment recommendations.
  - The multidisciplinary diagnostic team can be regional or virtual; satellite clinics and telemedicine have been created to meet the needs of referrals from distant communities.
- The core team will vary according to the specific context and the age of the individual being diagnosed and should possess the necessary expertise to conduct all aspects of the functional assessment.
- Specific team member composition recommendations have been made based on the client age group.

Domains for assessment

- Evidence of impairment (≤ 2 SD below the mean) in 3 or more of the following domains:
  - Motor Skills
  - Neuroanatomy/neurophysiology
  - Cognition
  - Communication
  - Academic achievement
  - Memory
  - Attention
  - Executive Function
  * Affect Regulation
  - Adaptive behaviour, social skills, or social communication

Nomenclature

- Recommending the use of **FASD as a diagnostic term** when prenatal alcohol exposure is considered to be a significant contributor to the observed deficits that cannot be explained by other etiologies
- New nomenclature:
  - **FASD with Sentinel Facial Features** (dx)
  - **FASD without Sentinel Facial Features** (dx)
  - **At Risk for Neurodevelopmental Disorder and FASD, Associated with PAE** (designation not a dx)

Important but not diagnostic

- Growth
- Minor congenital anomalies
- Co-morbidities
- Sensory
- Sleep
- Pre and postnatal factors
- trauma

Also..

- Inclusion of infants and small children
- More information about diagnosing adults
- More clarity around alcohol confirmation
- Additional information about how evidence informed these guidelines and what future research might change as we progress, ie: epigenetics.

More…

- Submitted to CMAJ spring 2015
  - Concise Executive Summary (May/June 2015)
  - Online Link to full diagnostic guidelines (May/June 2015)
  - Companion review paper submission to be announced
- Published anticipatory guidelines for pediatricians
  - *Hanlon-Dearman A, Green CR, Andrew G, LeBlanc N, Cook JL. Anticipatory Guidance for Children and Adolescents with Fetal Alcohol Spectrum Disorder (FASD): Practice Points for Primary Health Care Providers. J Popul Ther Clin Pharmacol. 2015;22(1):e27-56.*

Canada

- www.canfasd.ca

- Executive Director, Amy Salmon

Alcohol and Pregnancy

Lisa Graves MD CCFP FCFP

Alcohol and Pregnancy

- All women should be asked about alcohol use in regular health exams
  - Single question
  - Motivational Interviewing
  - Supportive dialogue
- Where drinking is elicited in pregnancy
  - T-ACE, TWEAK, CRAFT

- **Alcohol use and pregnancy consensus clinical guidelines J Obstet Gynaecol Can. 2010 Aug;32(8 Suppl 3):S1-31**

Alcohol and Pregnancy

- The prudent choice is no alcohol in pregnancy
- If women cannot stop drinking, consider
  - Harm reduction approach
  - Referral for women centred treatment
  - Watch for medications that are currently being researched for pregnant women
- Remember women with FASD will present different challenges during pregnancy

Adult FASD

Dr. Bill Watson, MD, CCFP, FCPC
FASD Assessment Clinic, St Michael's Hospital

Dr. Liz Grier, MD, CCFP
Chair, Community of Practice – Developmental Disabilities

Clinical Description of FAS/ARND

(Striessgluth et al,Devel Behav Peds 25(4)2004)

- 415 pts, Seattle, Wash
- median age 14, median IQ 86
- 90% not raised by biological mothers
- 61% disrupted school experience
- 60% trouble with the law
- 50% confinement
- 49% inappropriate sexual behavior
- 35% drug/alcohol problems

Cognitive and Behavioral Symptoms of Adolescents and Adults with FASD

- Learning disabilities
- Mild mental handicap to normal IQ
- Short term memory deficits
- Expressive language better than receptive
- Attention problems; ADHD
- Poor judgment and executive functions—(they need an *external brain!)*

Mood Swings

- Impulsive and uninhibited
- Passive and with drawn one minute, switching to volatile temper tantrums the next.
- Unpredictable; may need 24 hour supervision

Defensive and Stubborn

- Unable (not unwilling) to accept responsibility.
- Self-centered; behave as if the world revolves around them.
- Always having to have their own way and willing to do anything to have it.
- Demand and expect immediate gratification.
- Skilled at shifting blame.
- Engaging and charismatic yet creative at re-framing reality (lying stealing, etc.).

Lack of Self-Discipline

- Moral chameleons; excessive vulnerability to peer influence.
- Hyperactive in non-goal directed activity.
- Unable to stay focused on task, ie to follow rules, finish household chores, school assignments or keep commitments.
- Shortsighted
- Impulsive sexually (aggressive or vulnerable)

Genuine Innocence and Detached Attitude

- Toward the predicaments they get themselves and their families into.
- Toward authority when caught breaking the rules of society.
- Toward their behavior and consequences.

FASD Secondary Disabilities

- Mental Health Problems (90% all ages
- Disrupted School Experience-suspended, expelled or dropped out (60%, 12 and older
- Trouble with the Law (60%, 12 and older
- Confinement Including Inpatient Treatment or Incarceration (50%, 12 and older)

FASD Secondary Disabilities

- Inappropriate Sexual Behavior (50%, 12 and older)
- Alcohol and Drug Use Problems (30%, 12 and older)
- Needing Dependent Living Situations (80%, 21 and older)
- Problems with Employment (80%, 21 and older)

Problems with FASD Teens/ Adults-1

- Residential placement
- Economic support and protection
- Job training and placement
- Depression and suicidal ideation
- Pregnancy or fathering of a child

Problems with FASD Teens/ Adults- 2

- Social and sexual exploitation, or inappropriate behavior
- Increased expectations of the patient by other people
- Increased dissatisfaction towards the patient by others
- Withdrawal and isolation
- Unpredictable behavior

The Importance of Early Diagnosis

- Being diagnosed with full blown FAS rather than ARND, together with a diagnosis before age 6, were found to be strong protective factors for secondary disabilities

- Early diagnosis with proper interventions may decrease the appearance and attenuate the course of the secondary disabilities

The Team Approach

- The screening process is to determine whether a pattern of learning and behavioral problems may be related to FASD/FAE.

- This process can be coordinated through the education system, mental health system, judicial system, or social services.

The Multi-disciplinary Team

- Coordinator for case management (front-line worker).
- Physician specifically trained in FASD diagnoses.
- Psychologist or Psychiatrist.
- Occupational therapist.
- Speech-language pathologist.
- Possibly, a neurologist or geneticist trained in diagnosing FASD.

Additional members may include

- Childcare workers
- Mental health workers
- Probation officers
- Teachers and vocational counselors

Developmental Disabilities Community of Practice Resources

- Guidelines:
  - *Sullivan et al. Primary care of adults with developmental disabilities: Canadian consensus guidelines.*
  - Source: Canadian Family Physician May 2011 vol. 57 no. 5 541-553
- Clinical Tools and CME opportunities/Clinical Support:
  - ***FASD Health Watch Table***
  - Source: www.surreyplace.on.ca/...HWT_FASD_2013_Nov_2013.pdf

LINK to DDPC Website

FASD Resources

- *The New Canadian FASD Guidelines:* will be published in the CMAJ Online: December 14, 2015 and CMAJ Journal: February, 2016.

- *FASD Resource Inventories:* by province/territory, in English and French, have been uploaded to the FASDChildwelfare website under Resources and Research Library. http://www.fasdchildwelfare.ca/resources/research

FASD Centre of Excellence

Lakeland Centre for Fetal Alcohol Spectrum Disorder

Cold Lake, Alberta

Audrey McFarlane BCR, MBA (CED), Executive Director
Lakeland Centre for FASD

LAKELAND CENTRE FOR FETAL ALCOHOL SPECTRUM DISORDER SERVICE DELIVERY MODEL

Learning Objectives

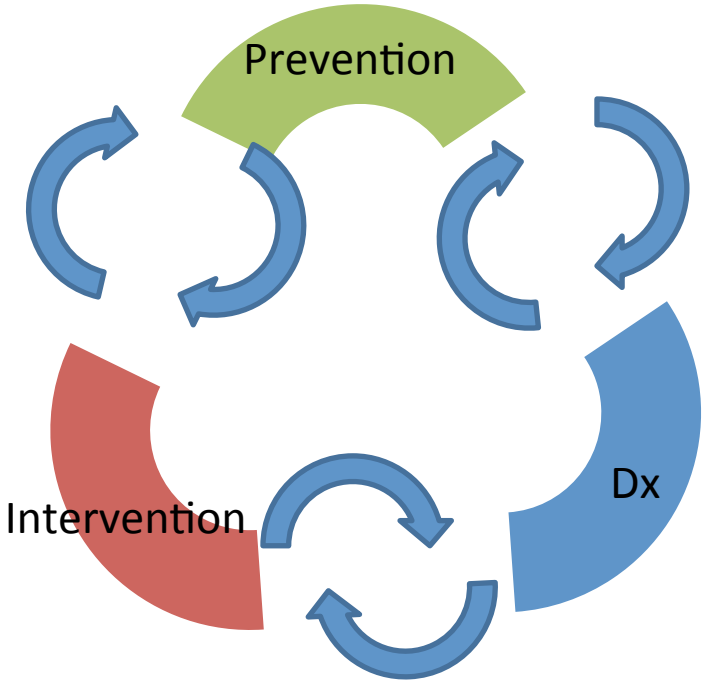
- Provide a model of service in FASD diagnosis/ intervention/and prevention
- Share benefits of this model specific to rural communities
- Inspire hope that this complex population can be served

Lakeland Centre for FASD Quick Facts

- Not for profit organization
- Started as an FASD committee in 1994
- Began operating dx services in 2000
- Official organization in 2003
- First Children's FASD dx/assess clinic in AB
- First Adult FASD clinic in Canada
- Trained most of the current FASD clinics in Canada
- Currently has more than 50 employees/contractors
- 3 satellite offices
- Service area has about 100,000 pop with a 3 hour driving distance
- Serve about 450 people per year
- Dx about 1000 people to date

Service Model

FASD



Diagnosis

- Following the Canadian guidelines
- Using a community based multi-disciplinary team
  - Team members are given in kind by various community organizations 1 or 2 days per month
  - Some professionals come from outside the region on a fee for service basis
  - Clinic coordinator funded by LCFASD
- 2 children's clinics per month (4 kids)
- 1 adult clinic per month (1 or 2 adults)
- 1 complex youth clinic (6 kids/yr)

- Team membership
  - Pediatrician
  - Psychologist
  - SLP
  - OT
  - Clinic Coordinator
  - Social worker
  - Public health nurse
  - Cultural liaison
  - Mental health therapist

  - Physician
  - Psychiatrist
  - Addictions therapist
  - Legal representative
  - Employment/disability worker

Intervention

- Our belief has been that it is unethical to give a diagnosis with no follow up supports
  - Every person going through clinic has an outreach worker assigned to them to assist with the clinic process and clinical recommendations (employees of LCFASD)
  - Parent/Caregiver Support Groups
  - Counselling supports for adults with FASD and caregivers
  - Art therapy and Drumming therapy groups
  - Employment Supports
  - Transition Planning Services
  - Summer Camp for kids with FASD

Prevention

- Significant work with the community members and it pays off in great donations.

- PCAP model program which provides intensive outreach supports to women at risk of having a child with FASD for up to 3 years.
- 2nd Floor Women's Recovery Centre – 9 bed residential treatment program specific to women who are pregnant or at risk of becoming pregnant and using substances.
  - Located in Cold Lake

Why does this model work?

- Understanding that diagnosis is prevention.
- Knowing that intervention and prevention leads to diagnosis.
- Prevention should be linked to diagnosis – this is where the mothers are.
- Working with all community agencies, governments, business and general public to raise awareness of FASD and services needed.
- Diagnosis is not rocket science it can be done with little training but with a team, coordination is the most difficult part to secure.
- Families are comfortable with the FASD language and services when they see the support that they get, support that is non-judgemental.
- Know it works because it has been duplicated across Alberta and Canada.
- Research informed.

Contact information

- www.lcfasd.com

- 1.877.594.5454
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Thank you and Questions??

- Questions??

- Food for thought: What are the evidence based effects of cannabis on the unborn fetus?