Fetal Alcohol Spectrum Disorders

- Angela Geddes MSW candidate
- London Region FASD Assessment Clinic Coordinator
### Presenter Disclosure

**Presenter:** Angela Geddes

**Relationships with commercial interests:**

- **Grants/Research Support:** None
- **Speakers Bureau/Honoraria:** None
- **Consulting Fees:** None
- **Other:** None
Fetal Alcohol Spectrum Disorders

- Community based FASD programs and services
- Beyond pilots and piece work

- FASD effects multiple sectors, and requires a multidisciplinary approach to prevention, diagnosis and supports and services across the lifespan.
- Today, we’d like to explore opportunities to work more consistently and directly with community based primary health care agencies. The aim of the collaborative efforts would be to make the ‘invisible’ more ‘visible’, and to help make the journey for families experiencing the effects of prenatal exposure to alcohol a little bit easier.
Why should we be concerned about FASD?

- Prevalence rates are low estimated to have increased from 1 in 100 to 1 in 20. (this is still understood as an underestimate)
- Discrepancy between need for diagnosis and current capacity across Canada.
- 50% of women in childbearing years drink alcohol. 50% of pregnancies are unplanned.
- These individuals are not waiting patiently in their rooms waiting for us to understand them.
- We are seeing these kids as they are presenting with emotional and behavioural concerns in our schools and mental health agencies every day.
- The FASD – London Region Assessment clinic has received over 200 referrals and inquiries since 2012.
Behold, thou shalt conceive and bear a son: and now drink no wine or strong drinks

(Judges 13:7)

Parental drinking is a cause of weak, feeble and distempered children

(College of Physicians Great Britain 1726)
Fetal Alcohol Spectrum Disorder (FASD) is an umbrella term to describe the range of effects that can occur in an individual whose mother drank alcohol during pregnancy:

- Growth
- Facial features
- Central Nervous System impairment
- Prenatal alcohol exposure
FASD Diagnoses

Canadian Guidelines for diagnosis recommends a multi-disciplinary team approach.

• Medical provider
• Psychologist
• Occupational therapist
• Speech and language pathologist
Brain Domains

- Motor skills
- Neuroanatomy/neurophysiology
- Cognition
- Language
- Academic achievement
- Memory
- Attention
- Executive function
- Affect regulation
- Adaptive behaviour/social skills/social communication
FASD Diagnoses

Canadian guidelines

• Fetal Alcohol Syndrome (FAS)
• partial Fetal Alcohol Syndrome (pFAS)
• Alcohol Related Neurodevelopmental Disorder (ARND)
  (Chudley et al, CMAJ 2005)

DSM5

• Neurobehavioral Disorder Associated With Prenatal Alcohol Exposure
  (American Psychiatric Association, 2013)

*Neuro-behavioural criteria are the same*
Soon to be published New 2015 FASD Guidelines

* New nomenclature:

* 1. FASD: Neurodevelopmental Disorder associated with PAE with sentinel facial features
* 2. FASD: Neurodevelopmental Disorder associated with PAE without sentinel facial features
* 3. PAE: At risk for Neurodevelopmental Disorder
The role of the medical provider

- Medical Assessment to include growth and facial features
- On-line training through the University of Washington provides clinicians with a solid understanding of the complexities of the disorder along with the roles of each practitioner
- Approximately 20 hours of training for $110. Guides available at no cost.
- Facial measurement software requires a camera and the $60.00 software.
Facial Feature measurement

Fig. 1: Lip-philtrum guide.

Fig. 2: Palpebral fissure length.
Brain Domains

- Motor skills
- Neuroanatomy/neurophysiology
- Cognition
- Language
- Academic achievement
- Memory
- Attention
- Executive function
- Affect regulation
- Adaptive behaviour/social skills/social communication
What does FASD look like?

Consequences are life-long with difficulties that are often greater than quantifiable cognitive deficits
What does FASD look like?

Expressive, receptive and complex language difficulties
Sensory processing deficits
Fine and gross motor skill impairment
Behavioural, emotional and social difficulties
Memory problems
Confabulation
Dismaturity
Impulsivity and errors of judgement
Repeat the same mistakes
Poor money management
Vulnerable
Concrete thinkers

Case examples…………………………
Overlapping Behavioural Characteristics and Related MH diagnosis in children

<table>
<thead>
<tr>
<th>Overlapping Characteristics &amp; Mental Health Diagnoses</th>
<th>ADHD</th>
<th>ASD</th>
<th>CPTED</th>
<th>CPTED +</th>
<th>EBD</th>
<th>ID</th>
<th>ODD</th>
<th>SPD</th>
<th>TDAH</th>
<th>TDAH +</th>
<th>TDAH + Autism</th>
</tr>
</thead>
<tbody>
<tr>
<td>Easily distracted by extraneous stimuli</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Developmental Trauma in</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Feel different from other people</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Often does not follow through on instructions</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Often impulsive</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Often engages in activity without considering possible consequences</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Often has difficulty organizing tasks &amp; activities</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Difficulty with transitions</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No impulse control, acts impulsive</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sleep Disturbance</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Inappropriately responds with others</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lack of eye contact</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not credible</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lying about the obvious</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Learning lags: “I can’t learn, some can’t learn”</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Inconsistent, cluttered, or abnormal speech patterns</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Increased startle response</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Emotionally volatile, often exhibit wide mood swings</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Depression develops, often in teen years</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Problems with social interactions</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Defect in speech and language, delays</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Overreaction to stimuli</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Antisocial, inflexible</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Impulsive in response to stress</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Poor problem solving</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Difficulty writing cause &amp; effect</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Exceptional abilities in one area</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unusual or “normal” in one area</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Let me know what is right in the truth</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Difficulty initiating, following through</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Difficulties with relationships</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Manage time, poor self-comprehension of time</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Information processing difficulty</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Speech/language receptive vs. expressive</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Often loses temper</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Often angry with adults</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Often actively defines rules to be complex</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Often blames others for loss or fail mistakes</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Is often tactful, easily annoyed by others</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Is often angry and disrespectful</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
The cost of misdirected money *

A Case Example (0-9 Years)

<table>
<thead>
<tr>
<th>Service</th>
<th>Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Psychology assessment x2</td>
<td>$5000</td>
</tr>
<tr>
<td>Tyke Talk assessment and treatment</td>
<td>$1500</td>
</tr>
<tr>
<td>Speech and language assessment</td>
<td>$2000</td>
</tr>
<tr>
<td>Family Doctor visits and referrals x10</td>
<td>$1400</td>
</tr>
<tr>
<td>Pediatrician consults x7</td>
<td>$2800</td>
</tr>
<tr>
<td>Psychiatric consults x16</td>
<td>$3200</td>
</tr>
<tr>
<td>OT assessment and treatment x2</td>
<td>$6000</td>
</tr>
<tr>
<td>Residential treatment</td>
<td>$72000</td>
</tr>
<tr>
<td>Mental Health treatment groups</td>
<td>$1000</td>
</tr>
</tbody>
</table>

Estimated total: $94,900

Number of diagnoses = 6
*costs based on agency averages
Things to remember...

* Important to remember that this is brain damage
* Every child is unique
* Outcomes are often better for those who have the facial features
* Deficits present depend on many things such as time of alcohol use, how much, when, what kind, genetics, and other protective factors
* Scattered profile make it confusing for the individual and for teachers and caregivers
* The invisible disability
The importance of a diagnosis

- Prognosis is best with an early diagnosis
- Aids in prevention efforts
- FASD informed approach cuts against the grain of everything we come to learn about parenting and teaching, i.e. skills building on one another, independence etc. but the shifts are possible within current service delivery
- Appropriate interventions mitigate likelihood of secondary disabilities
- Screening helps so we can use the FASD lens even without a diagnosis in light of today’s capacity
Community based supports and services and a natural fit with AOHC member agencies

- Health promotion and education/prevention efforts
- Holistic approach – external brain
- Overlapping Mental Health characteristics
- Marginalized populations/reducing barriers to service
- Misunderstood
- Multidisciplinary team required for diagnosis
- Collaboration/partnerships
- Community development/capacity building
- Wellness initiatives across the lifespan
NorWest Community Health Centre

* FASD diagnosis and program
* Maureen Parkes Clinic Coordinator and FASD ONE Diagnostic Working group chair
* Discussion
* Cases presented
* Questions and answers
How do we begin?

* How can we influence policy
* How can we incorporate FASD within current service delivery and strategic plans?
* Why have we not already?
* Questions: contact

Angela Geddes
London Region FASD Clinic Coordinator
c/o London Family Court Clinic
519-679-7250 ext. 155
angela.geddes@lfcc.on.ca
FASD Links and Resources

www.fasd-londonregion.com
www.fasdchildwelfare.com
www.fasdjustice.com
www.fasdontario.ca
www.fasdelmo.wordpress.com
www.canfasd.ca