



CROSSROADS

Re-imagining better mental health care for kids and families

2021 CMHO Virtual Conference

November 22 to December 3

Sponsored by



Knowledge Institute on Child and Youth
Mental Health and Addictions

Institut du savoir sur la santé mentale et les
dépendances chez les enfants et les jeunes

Land Acknowledgement

We would like to acknowledge that we are joining from across Ontario from Aboriginal land that has been inhabited by Indigenous peoples from the beginning. As settlers, we're grateful for the opportunity to meet here, and we thank all the generations of people who have taken care of this land for thousands of years. We recognize that Indigenous practices of health and well-being have been in place in this territory for over 10,000 years and are maintained to this day. As healthcare leaders, we have much work to do ourselves to do our part and support the de-colonization of children's healthcare systems.





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FASD & Mental Health: A Fireside Chat with Providers and People with Lived Experience

Facilitated by Nancy Lockwood

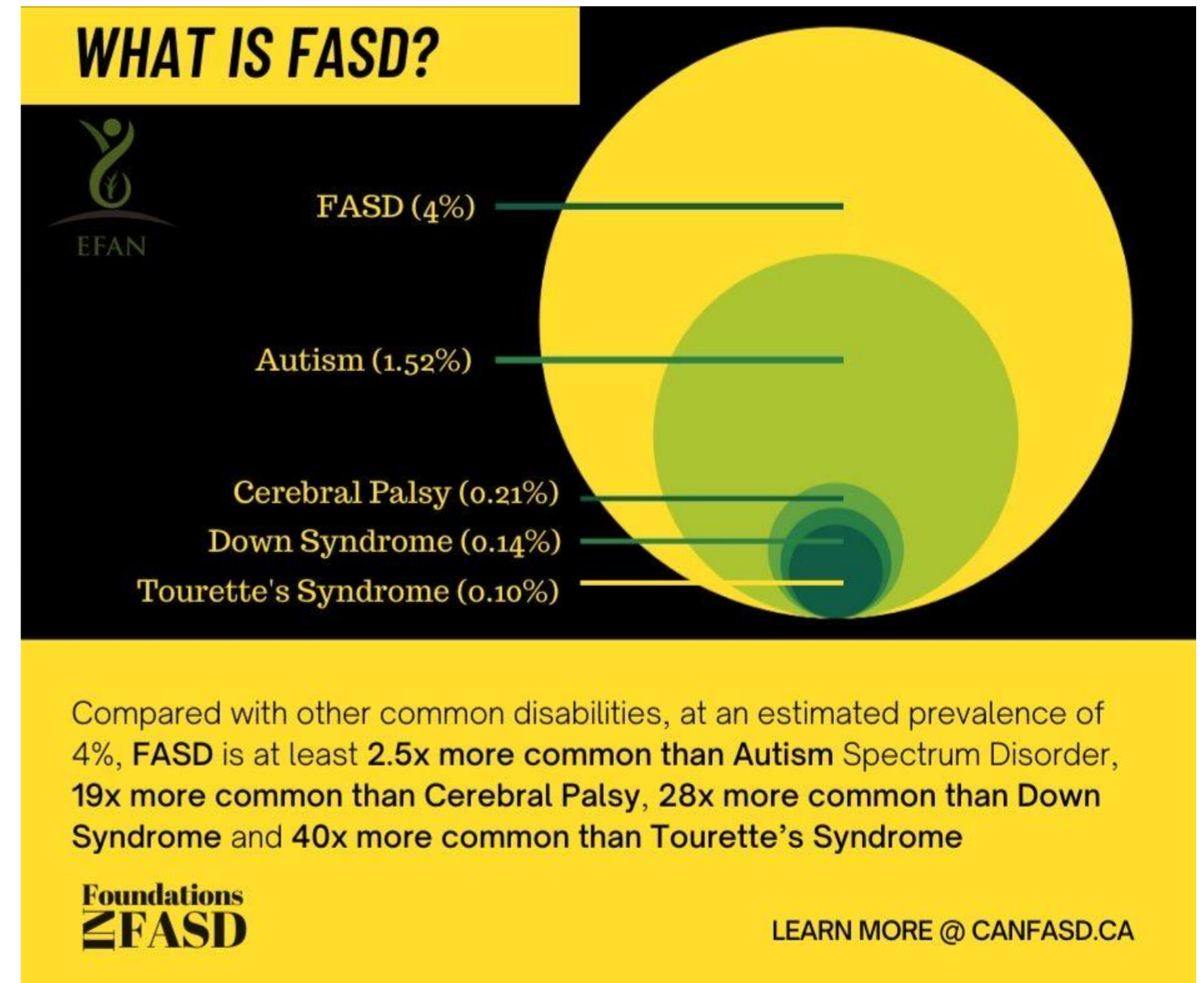
Angela Geddes (Panelist)

Janet Carioni (Panelist)

Reinier DeSmit (Panelist)

Prevalence rates in Canada: FASD is an issue for all demographic groups

<https://canfasd.ca/wp-content/uploads/publications/Prevalence-1-Issue-Paper-FINAL.pdf>



FASD prevalence in special populations

Researchers found rates 10-40 times higher in:

- In special education settings
- Correctional facilities
- Children in care
- Indigenous populations
- Specialized clinical settings (services for developmental disabilities and psychiatry)

(Popova, 2019)

FASD & the Child Welfare System in Canada

- Conservative estimates indicate 3-11% of children & youth in care have FASD
- Many undiagnosed / misdiagnosed
- Experience more abuse and neglect than other children
- Keys to improve outcomes: diagnosis; interventions; support to caregivers

<https://canfasd.ca/wp-content/uploads/publications/FASD-and-Child-Welfare-Final.pdf>



FASD & Mental Health

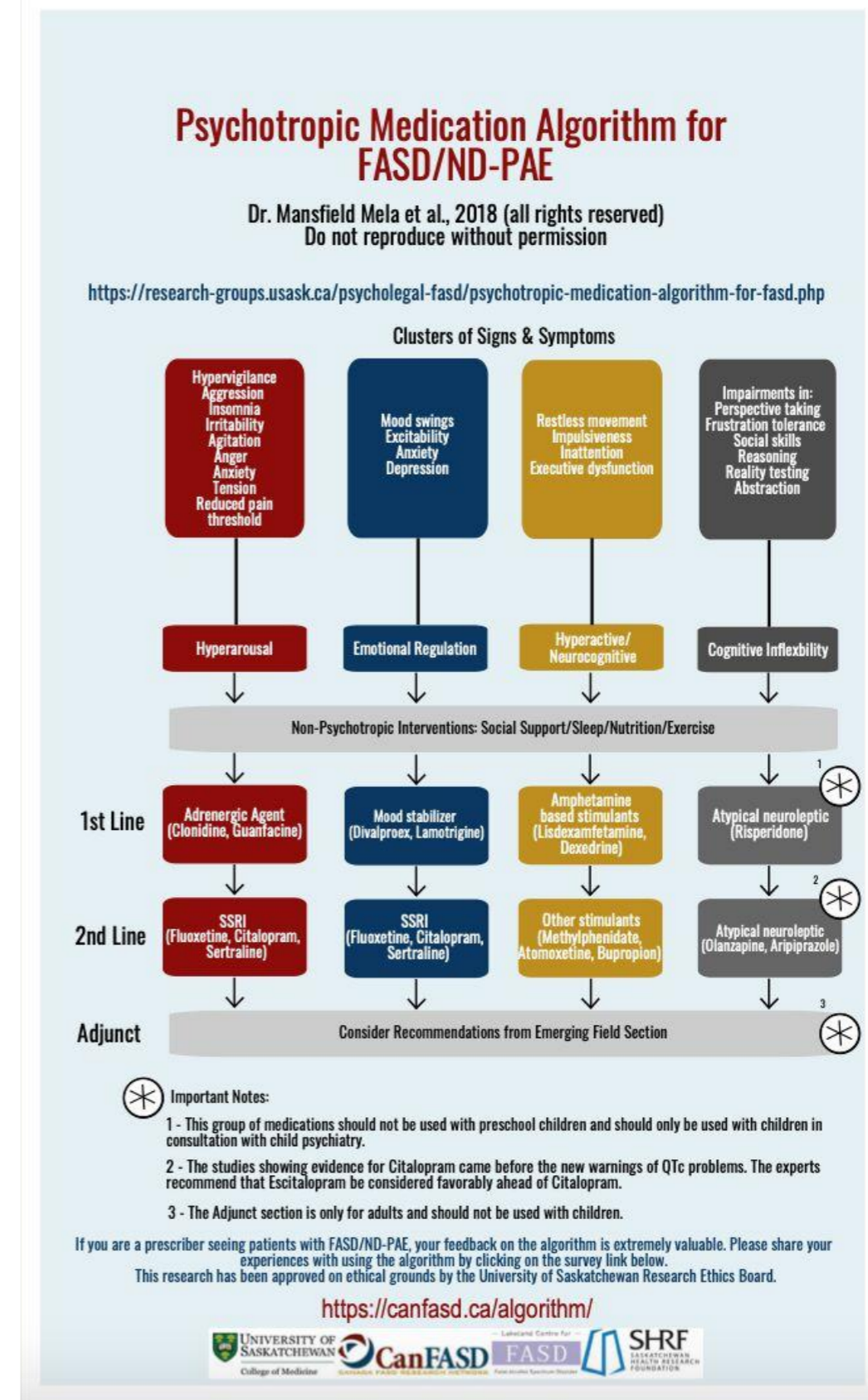


- Over 90% of people with FASD experience mental health issues (CanFASD, 2020)
- 20 times more likely to have substance use problems (Flannigan et al, 2020)
- Children / youth with FASD / PAE experience high rates of Adverse Childhood Experiences (ACEs) (Flannigan et al, 2020)
- Common ACEs: disruptions in caregiving situation; exposure to substance use and mental health issues in the home. (CanFASD, 2021)

FASD & Medications

Psychotropic Medication Algorithm for Fetal Alcohol Spectrum Disorder

<https://canfasd.ca/2020/09/28/canadian-experts-publish-the-first-medication-guidelines-for-people-with-fasd>





Local News



Fetal Alcohol Spectrum Disorder: New CHEO clinic aims to improve understanding of frequently- undiagnosed disability

Elizabeth Payne

Oct 05, 2021 • 1 day ago • 4 minute read • [Join the conversation](#)



L-R Grant Carioni, 12-year-old Seth Carioni, 13-year-old Hayden Carioni, and Janet Carioni, behind their east end home on Sunday October 3, 2021. PHOTO BY ASHLEY FRASER /Postmedia

Janet Carioni knew what to look for when her two young sons began showing symptoms of fetal alcohol spectrum disorder (FASD). The occupational therapist had worked with a FASD assessment team before moving to Ottawa.



THE LANGUAGE OF DIAGNOSIS: The Unintended Messages in the Language We Use

by NOFASD Australia | Jun 12, 2019 | CJ Lutke's Blog | 2 comments

“Diagnosis is, believe it or not, a GIFT to those of us lucky enough to actually have that diagnosis, and one that each of us will grow to understand and incorporate as only ONE part of ourselves provided we have the right support and acceptance.
It will not define us; it will guide us.”

Written by CJ Lutke on behalf of the Adult Leadership Committee of FASD Change Makers
Salzberg Memorial Ethics Lecture for the Provincial Health Services Association of British Columbia, May 30, 2019

<https://www.nofasd.org.au/blog/language-of-diagnosis/>



Guidelines for Diagnosing FASD in Canada

Cook et al. (2016) Fetal alcohol spectrum disorder: a guideline for diagnosis across the lifespan. CMAJ February 16, 2016

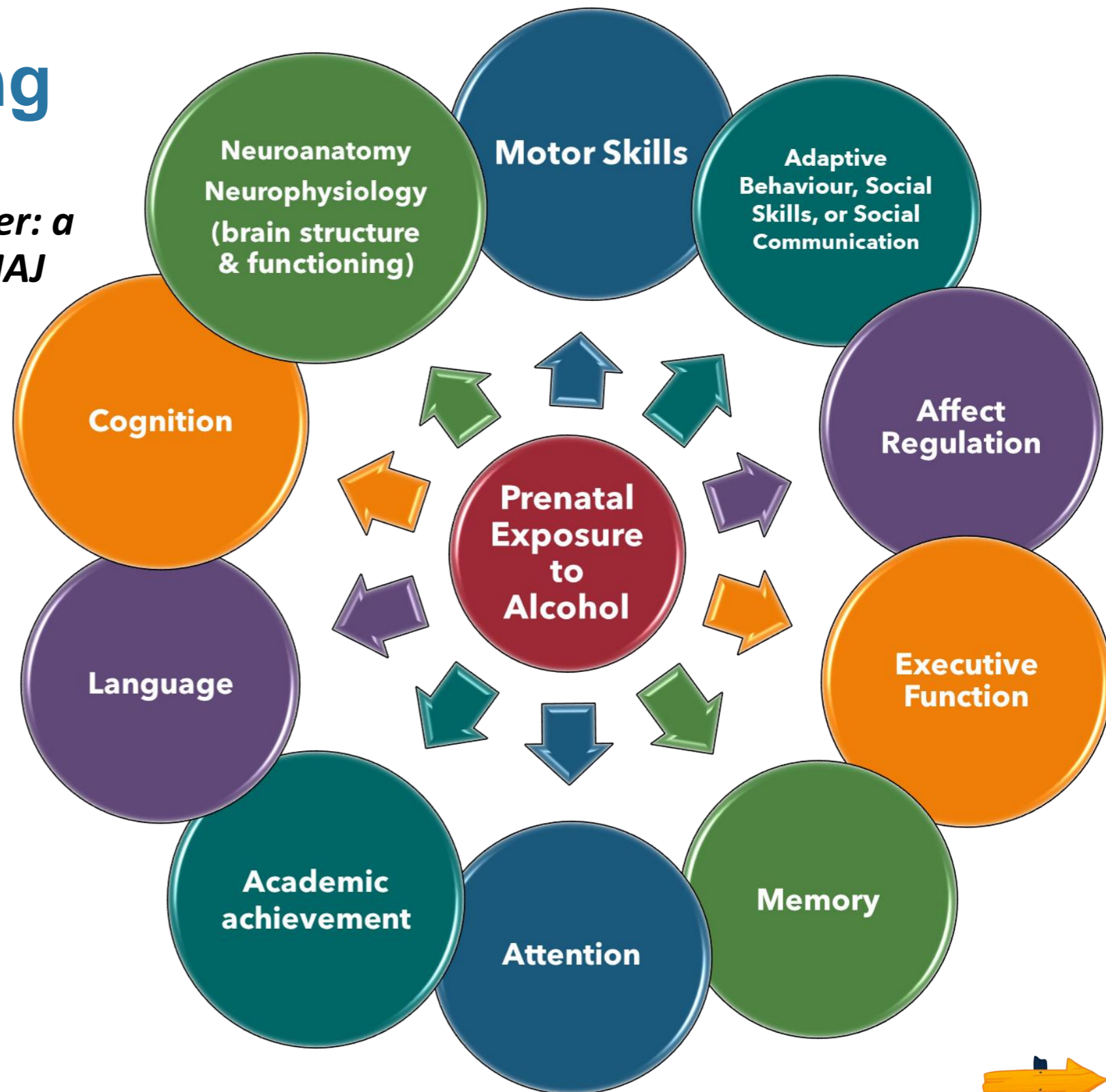
In order to receive a diagnosis of FASD there must be confirmation of pre-natal alcohol exposure (PAE)

AND

The brain must be severely impaired in 3 or more of the following domains

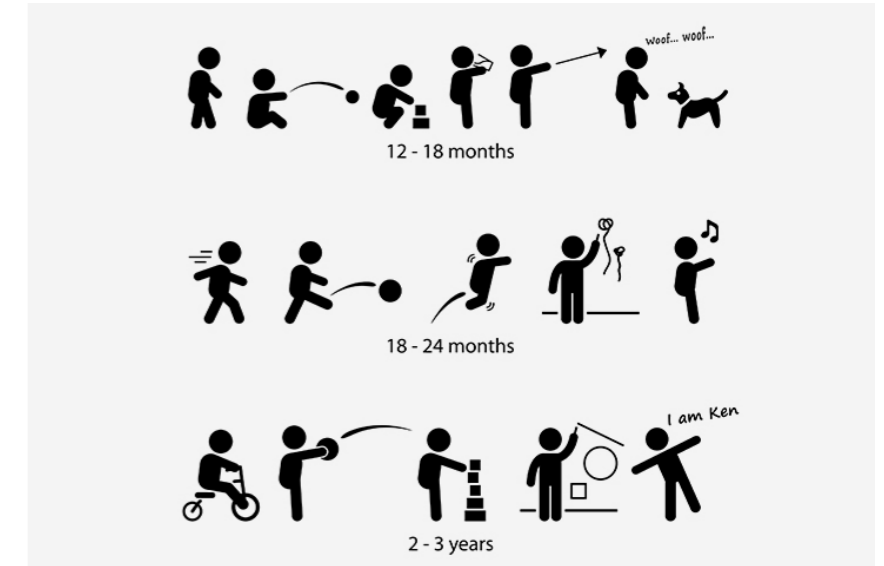
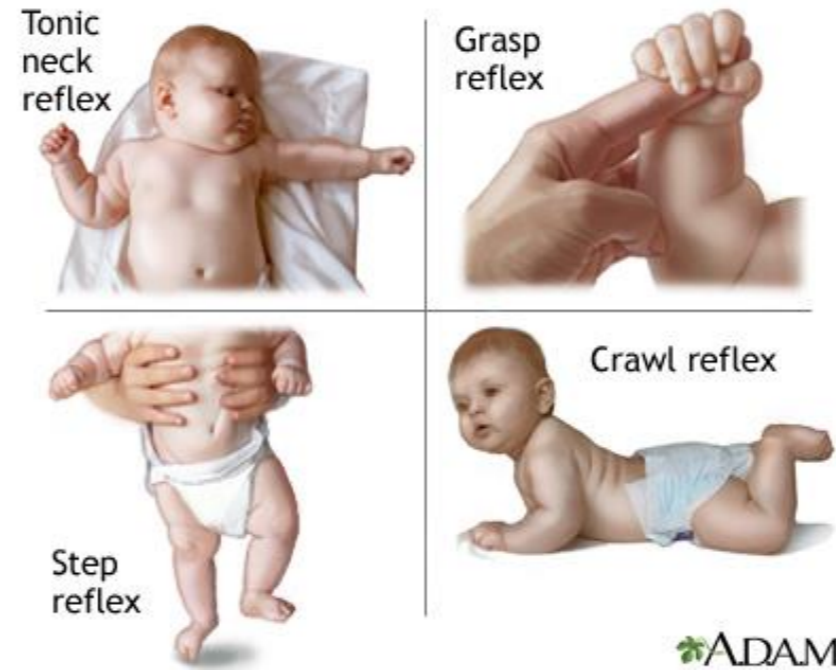
AND

An assessment by a **multidisciplinary team** is recommended



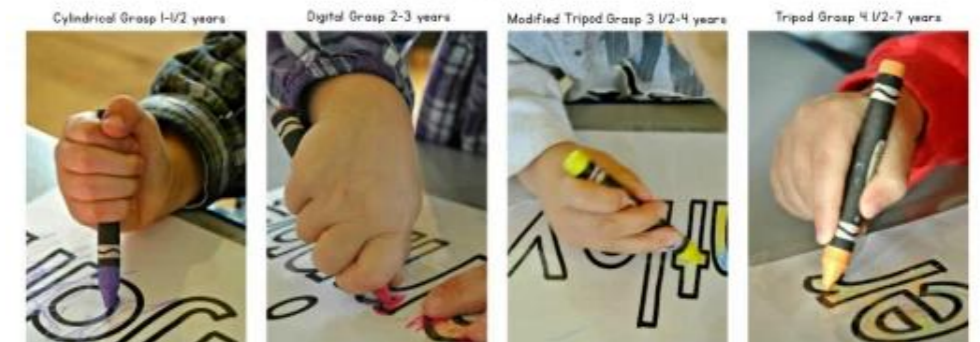
1. Motor Skills

- Gross & fine motor
- Graphomotor
- Visual-motor integration
- Tone
- Reflexes
- Balance
- Coordination
- Strength



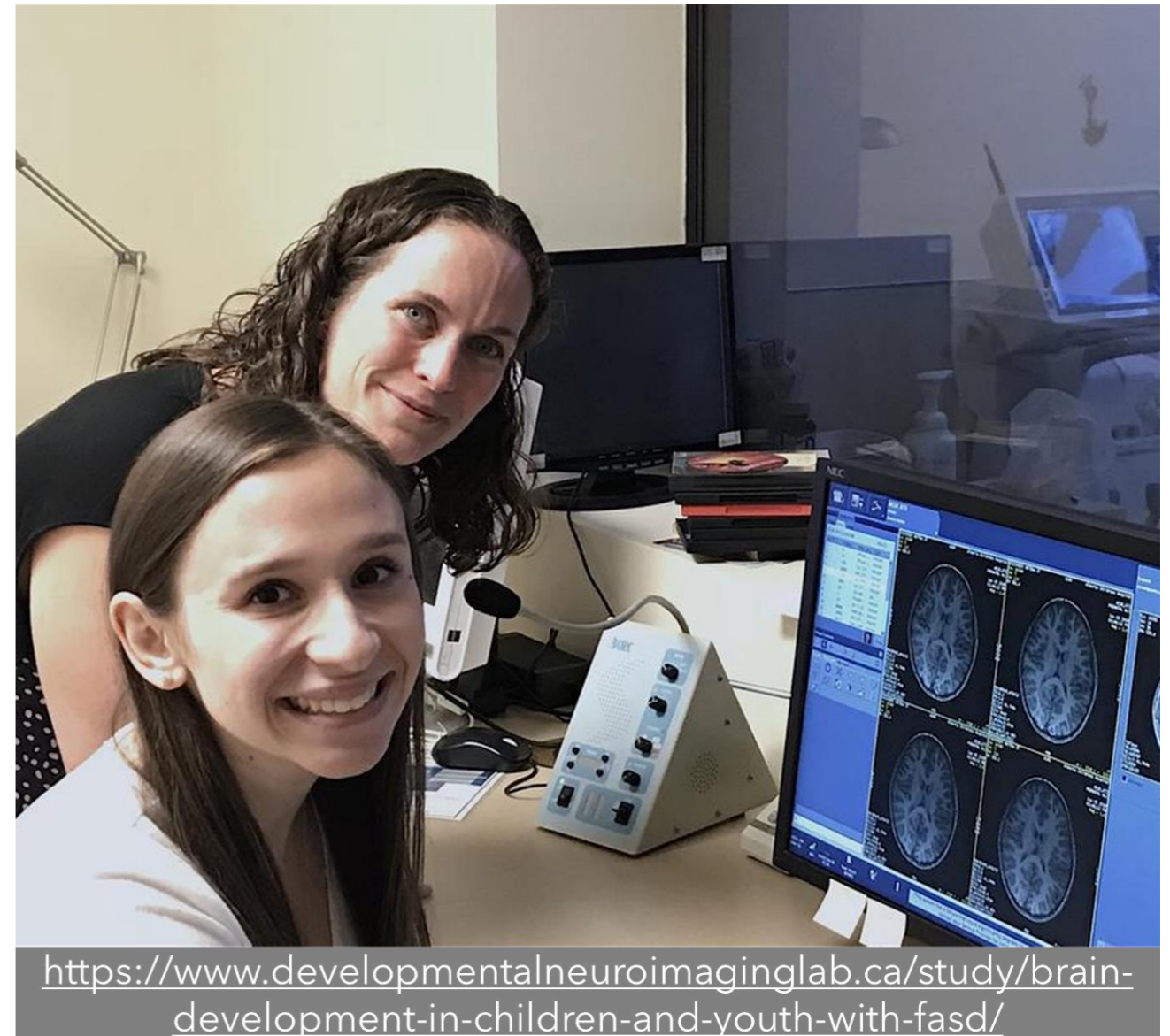
Pencil Grasp Development

Stay At Home Educator



2. Neuroanatomy/ Neurophysiology

- Structural abnormalities may exist
- Seizures may exist
- MRI is not a diagnostic tool for FASD, it is a research tool.
- Fascinating research occurring in Canada. Brain Development in Children & Youth with FASD at the Developmental Neuroimaging Lab, Dr. Catherine Lebel, University of Calgary



Sleep Issues

Hypothalamus is sensitive to prenatal alcohol exposure

- The hypothalamus is responsible for shutting down the brain's arousal signals and causing the transition to sleep

Individuals with FASD may experience difficulties with:

- Delayed sleep onset
- Abnormal melatonin secretion
- More phase shifts = Fragmented sleep cycles
- Pattern of phases different than normal sleep architecture
- Poor sleep quality
- Shorter sleep duration

1. Sarah Inkelis. *PAE & Sleep*. Presented at the 8th International Conference on FASD, March 9, 2019
2. Scott, L, Veenhof, W, Huber, K, Carioni, J, & Gravel, M. *Sleep Issues in Children and Adolescents with FASD*. Preliminary results presented at The 4th International Conference on Fetal Alcohol Spectrum Disorder (FASD), March 2011.



Recognizing Fatigue in Children with FASD

- May become more hyperactive
- Increased sensory symptoms
- May become more disorganized
- Previous behavioural strategies aren't working
- May become more aggressive

Dr. Ana Hanlon-Dearman. The Golden Tie – Understanding & Supporting Healthy Sleep in FASD
Presented at the 8th International Conference on FASD, March 9, 2019



3. Cognition

- Verbal
- Nonverbal
- Fluid reasoning (e.g. creative problem solving, outside the box thinking, reframe the situation, see a new perspective)

Understanding FASD and Cognitive Disabilities				
Processing	Memory	Confabulation	Perseveration	Communication
<i>What it means</i> Understanding information takes longer, needs extra time to process info	<i>What it means</i> Reduced ability to store and retrieve information in short and long term memory	<i>What it means</i> Filling in the blanks of memory with stories, not understanding truth vs fiction	<i>What it means</i> Difficulties making transitions or shifting topics, uncontrolled repetition	<i>What it means</i> A lack of comprehension, difficulty with expressive and receptive language
<i>What it looks like</i> slow to respond, difficulty completing tasks, struggles to follow directions	<i>What it looks like</i> inconsistent, unable to perform tasks they've been taught before, forgetful	<i>What it looks like</i> storytelling, unreliable when providing information, often interrupted as willful lying	<i>What it looks like</i> an inability to stop or change tasks, repetition, obsessive	<i>What it looks like</i> struggles to follow verbal instructions, unable to express self

<https://www.saskfasdnetwork.ca/resources>


Prenatal alcohol exposure leads to reduced cognitive abilities

Two primary types of brain damage occur with prenatal exposure to alcohol (PAE):

1. Brain cells do not develop. Gaps in early developmental stages. Further brain development does not occur.
 2. Neural networks are connected to the wrong neural networks.
- = Both lead to reduced cognitive abilities

Edward Riley, PhD, University of San Diego & Kathy Sulik, PhD, University of North Carolina, Bowles Institute for Alcohol Studies

<http://www.med.unc.edu/alcohol>



4. Language

- Expressive
- Receptive
- Articulation



5. Academic Achievement

- Reading
- Math
- Written expression



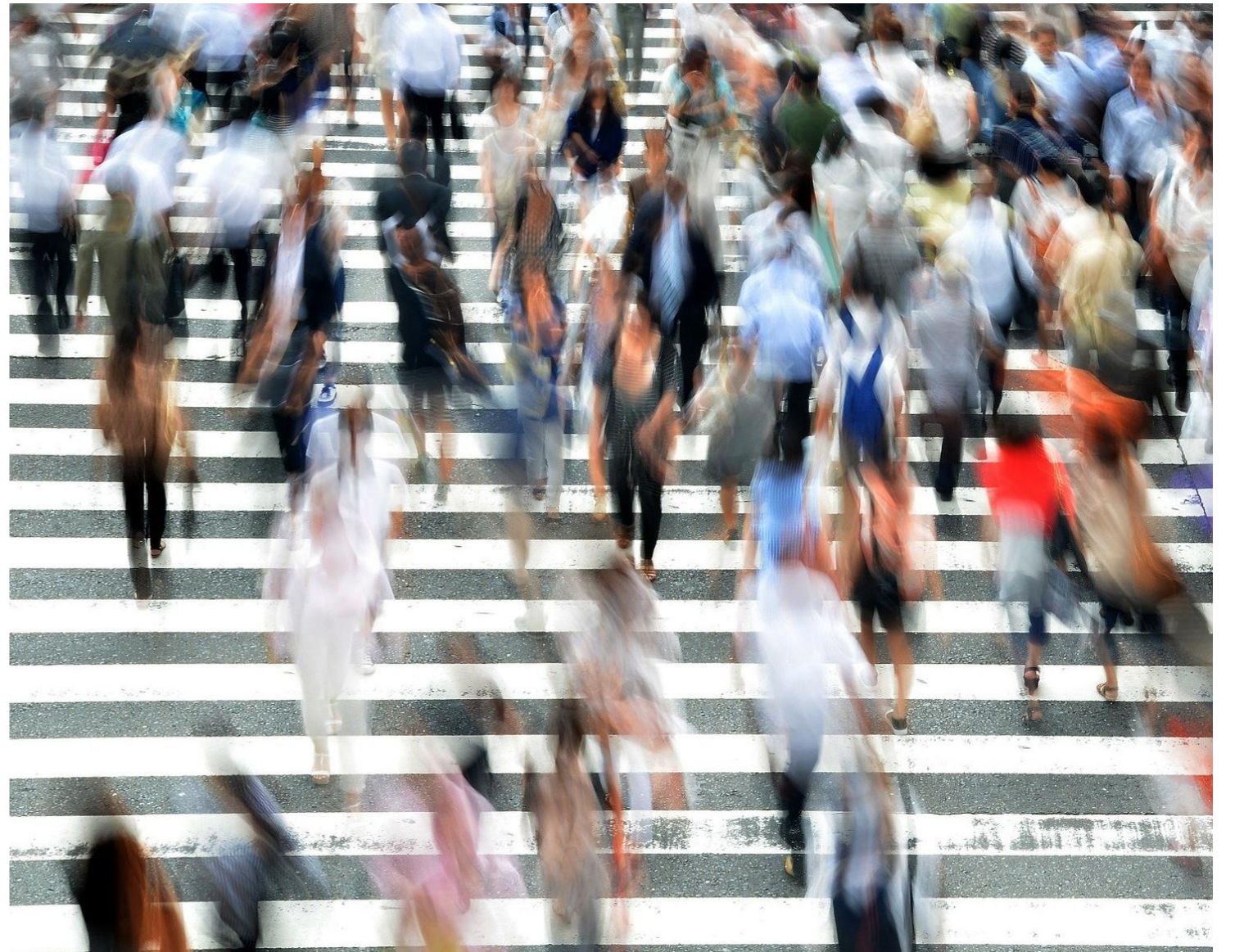
6. Memory

- Verbal memory
- Visual memory



7. Attention

- Sustained attention
- Selective attention
- Resistance to distractions



8. Executive Function, including Impulse Control

- Working memory
- Inhibition and impulse control
- Planning
- Problem solving
- Shifting
- Cognitive flexibility



9. Affect Regulation

Meets the DSM-5 criteria for a mood related disorder:

- Major Depressive Disorder (with recurrent episodes)
- Persistent Depressive Disorder
- Disruptive Mood Dysregulation Disorder (DMDD)
- Separation Anxiety Disorder
- Selective Mutism
- Social Anxiety Disorder
- Panic Disorder
- Agoraphobia
- Generalized Anxiety Disorder



FASD and Mental Health

- Mounting evidence is showing that oppositional, irritable or explosive behaviour in kids with neurodisabilities is rooted in the mental health of the child, and the child's family.
- Studies point to anxiety, depression and stress in FASD as the underpinnings of meltdowns, outbursts and defiance.

<https://kidsbrainhealth.ca/index.php/2018/02/07/supporting-mental-health-in-children-with-neurodisabilities/>



Emotional Regulation

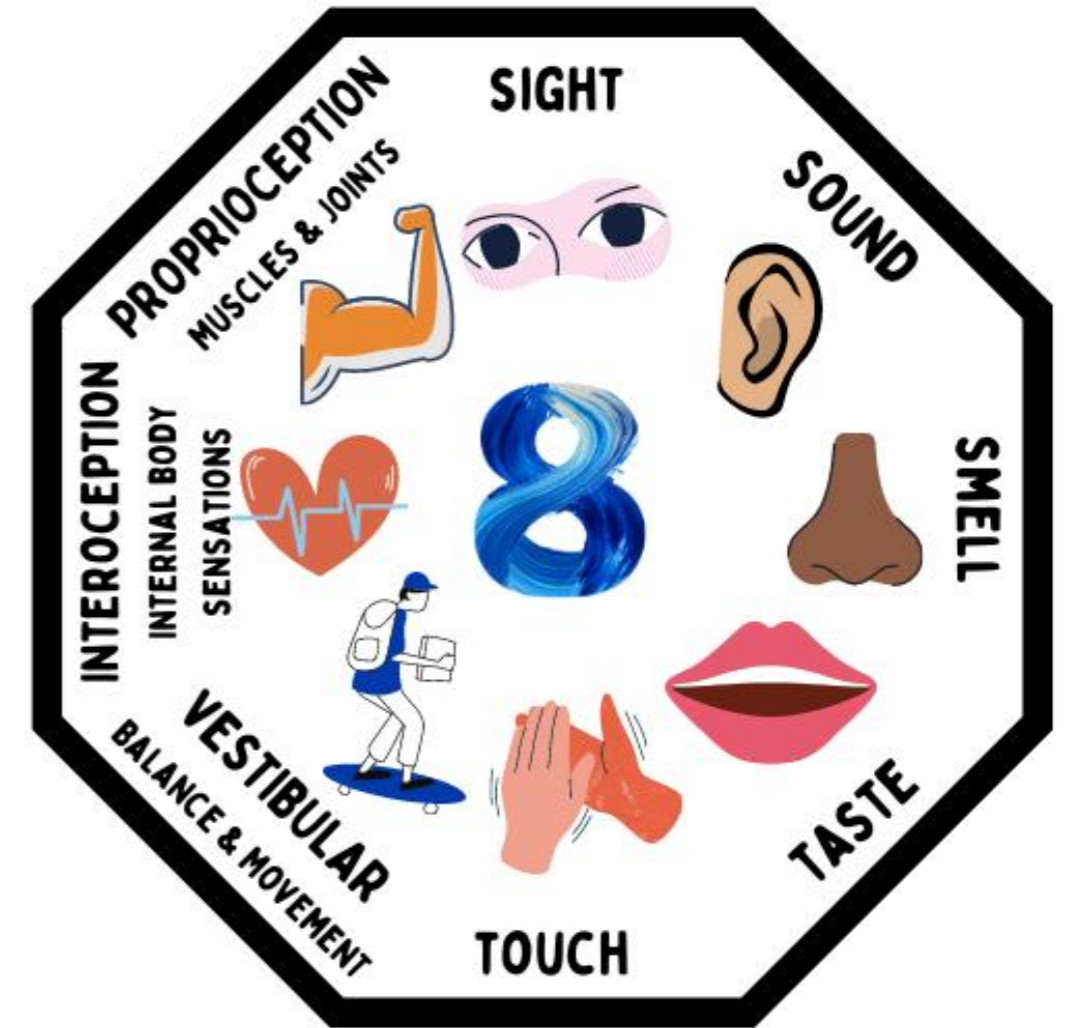
- Higher baseline cortisol level
- Greater reactivity
- Delayed recovery

Dr. Kim Hellemans, Department of Neuroscience,
Carleton University



Alcohol & the Sensory System

- **Sensory channels** often do not have filters¹
- **Altered sensory processing** as another teratogenic impact of PAE.² High levels of PAE associated with increased symptom prevalence.
- PAE and not postnatal neglect, is the primary contributor to additional mental health concerns, lower adaptive functioning, and **deficits in sensory perception.**³



1. Susan Astley, University of Washington
2. Schneider et al., 2001, 2017
3. Mukherjee, R. A. S., Cook, P. A., Norgate, S. H., & Price, A. D. (2019). Neurodevelopmental outcomes in individuals with fetal alcohol spectrum disorder (FASD) with and without exposure to neglect: Clinical cohort data from a national FASD diagnostic clinic. Alcohol, 76, 23-28.)



Behavioural Regulation

*“Difficulties with behavioral regulation frequently are **expressed through impulsivity**, and children and adolescents with FASD often are **perceived as breaking rules, cheating, fibbing, and stealing**. However, this most often is due to an **inability to regulate their behaviors and inhibit their impulses** rather than having a “conduct disorder.” Misdiagnoses such as attention deficit disorder (ADD) or attention deficit hyperactivity disorder (ADHD) also are frequently applied to the young people affected by prenatal alcohol exposure, although such difficulties are related to **problems in shifting attention and sustaining the mental effort required in order to complete tasks.**”*

Guided Growth: Fetal Alcohol Spectrum Disorders: Behavior Belongs in the Brain, Chapter 4, pg 13
Chasnoff & Powell (2018)



10. Adaptive behaviour, social skills, or social communication

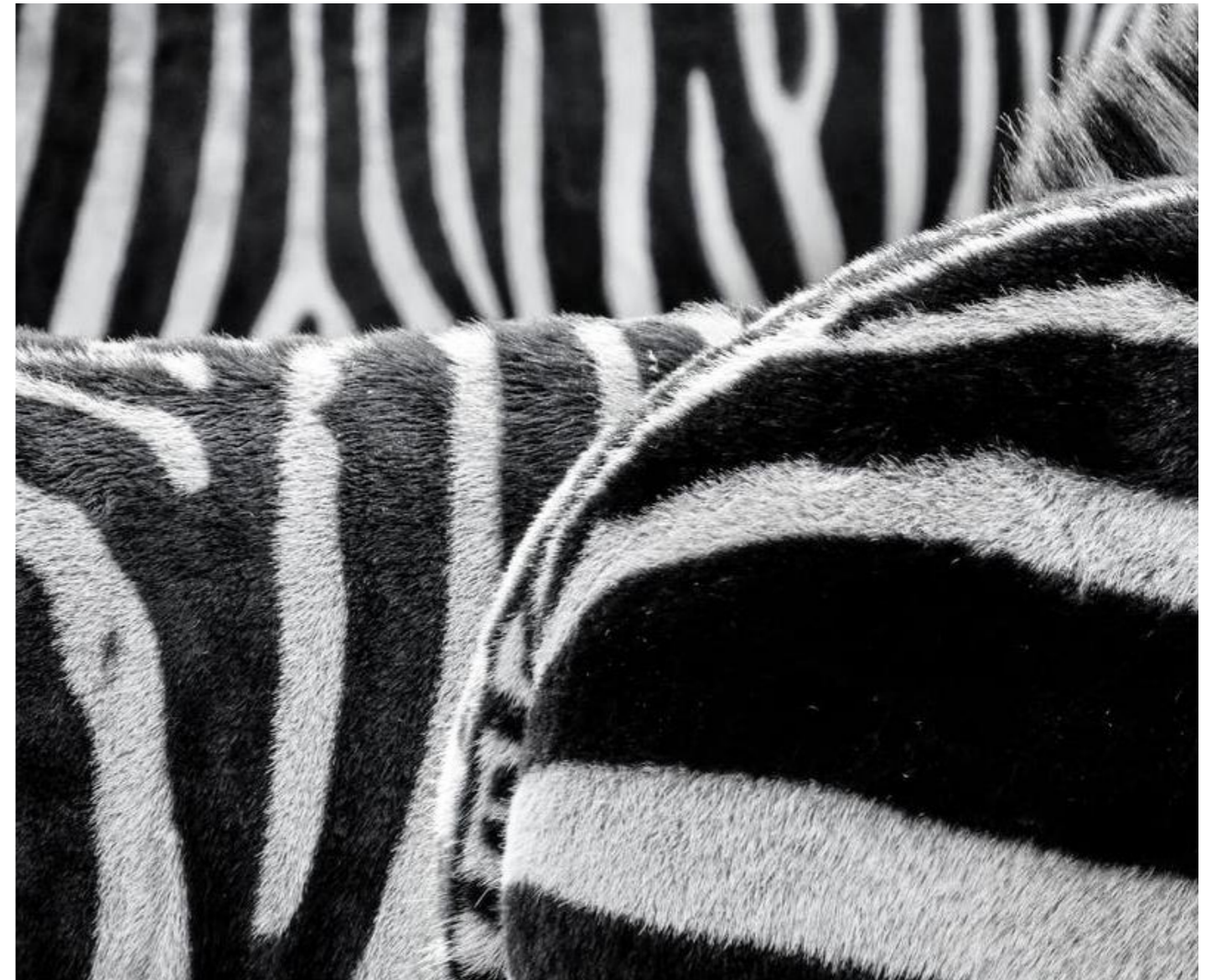
- Life skills
- Social vulnerability
- Social language
- Social communication skills
- Pragmatic language skills



Common Features of FASD

Difficulties with:

- Intellectual abilities
- Executive functioning (e.g., Planning, problem solving, abstract and flexible thinking, fluency, inhibition, working memory)
- Learning and memory
- Language and communication
- Visual spatial skills
- Fine and gross motor skills
- Attention and activity
- Academics, especially mathematics



Subtle Challenges

(Not always as easy to spot)

- Difficulties learning from consequences
- Verbal processing difficulties
- Slower processing speed
- Inconsistent memory
- Cognitive fatigue
- Dysfunctional sleep patterns
- Poor grasp of abstract ideas
- Navigating social interactions
- Impulsivity



A Fireside Chat with Providers & People with Lived Experience

Facilitated by Nancy Lockwood



Post Session Materials: Summary Notes

- FASD is an issue for all demographic groups.
- Early diagnosis and intervention are key to improving outcomes.
- Stigma is a barrier to diagnosis and intervention.
- We need to be proactive about supporting the mental health of individuals with FASD as opposed to providing crisis intervention.
- The true experts are people with FASD and their families.



Post Session Materials: Resources

Hear Reinier's story:

- My Adult FASD Diagnosis: Clarity for a Man and his Mom <https://youtu.be/1oNFd2jDiYA>
- My Adult FASD Diagnosis: Nothing Changed. And Everything Changed <https://youtu.be/hKaJyKaF1yM>

Read Angela's book:

- A Complicated and Beautiful Brain <https://www.angelageddes.ca/shop>

Stay current in FASD information:

- Canada FASD Research Network <https://canfasd.ca/>
- FASD Ontario <https://fasdinfotsaf.ca/>
- Kid Brain Health Network <https://kidsbrainhealth.ca/>
- FASD Ontario Network of Expertise <https://fasdontario.ca/>



Post Session Materials: Resources

Participate in FASD training:

- CanFASD online training <https://canfasd.ca/online-learners/>

FASD services in Ontario:

- FASD assessment clinics in Ontario https://fasdinfotsaf.ca/wp-content/uploads/2021/08/FASDDiagnosticClinics_ListForWebsite_2021-221.pdf
- FASD Workers in Ontario https://fasdinfotsaf.ca/wp-content/uploads/2021/08/FASDWorkersAgency_ListForWebsite_2021-22.pdf
- FASD Support Groups in Ontario https://fasdinfotsaf.ca/wp-content/uploads/2021/08/FASDSupportGroups_ListForWebsite_2021-222.pdf



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