

Objectives

- Discuss overlapping features of FASD, Autism, Genetic Disorders, and Developmental Trauma.
- Review issues with FASD assessment in BC as highlighted by the BC Advocate for Children in her report “Excluded.”
- Review issues around structural and social determinants of health as well as bias in FASD.
- Encourage adopting a critical lens when making this diagnosis and highlighting the complexity and often multifactorial nature of FASD

CMAJ

GUIDELINES

CME

Fetal alcohol spectrum disorder: a guideline for diagnosis across the lifespan

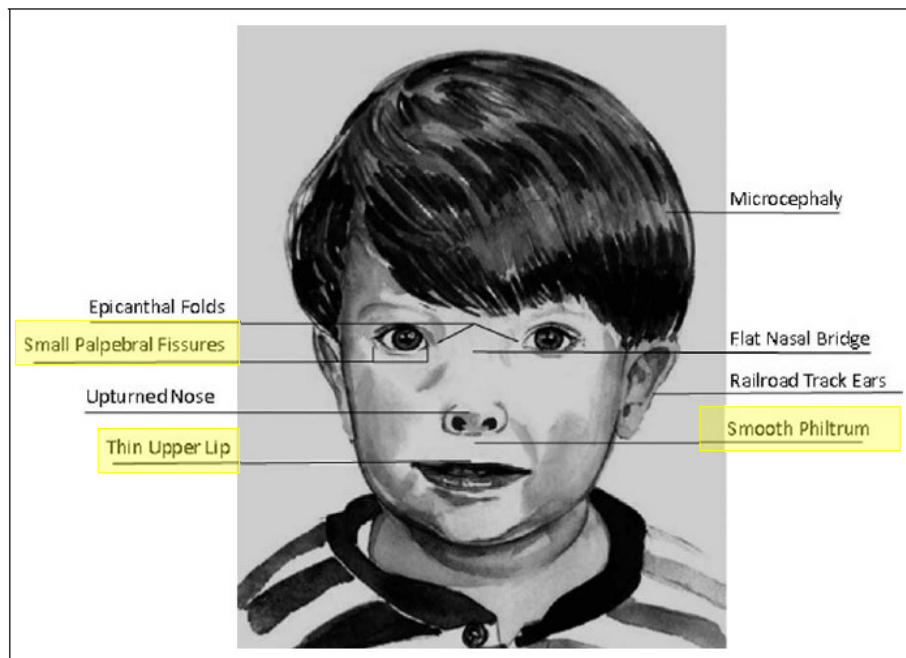
Jocelynn L. Cook PhD, Courtney R. Green PhD, Christine M. Lilley PhD, Sally M. Anderson PhD, Mary Ellen Baldwin, Albert E. Chudley MD, Julianne L. Conry PhD, Nicole LeBlanc MD, Christine A. Looock MD, Jan Lutke, Bernadene F. Mallon MSW, Audrey A. McFarlane MBA, Valerie K. Temple PhD, Ted Rosales MD; for the Canada Fetal Alcohol Spectrum Disorder Research Network

CMAJ Podcasts: author interview at <https://soundcloud.com/cmajpodcasts/141593-guide>

See also www.cmaj.ca/lookup/doi/10.1503/cmaj.151425

Fetal Alcohol Spectrum Disorder

- A disorder with VARIABLE patterns of cognitive, behavioural and morphological deficits associated with in utero alcohol exposure
- Can occur with or without distinct facial features called **sentinel facial features**
- Must have evidence of pervasive brain dysfunction



Pervasive Brain Dysfunction

- defined by severe impairment ($>2SD$) in **3 of more** of the following neurodevelopmental domains:
 1. motor skills
 2. neuroanatomy/neurophysiology
 3. cognition
 4. language
 5. academic achievement
 6. memory
 7. attention
 8. executive function, including impulse control and hyperactivity
 9. affect regulation
 10. adaptive behaviour, social skills or social communication.



Complex Developmental Behavioural Conditions Network
Handbook for the Diagnosis of
Fetal Alcohol Spectrum Disorder

October 6, 2021

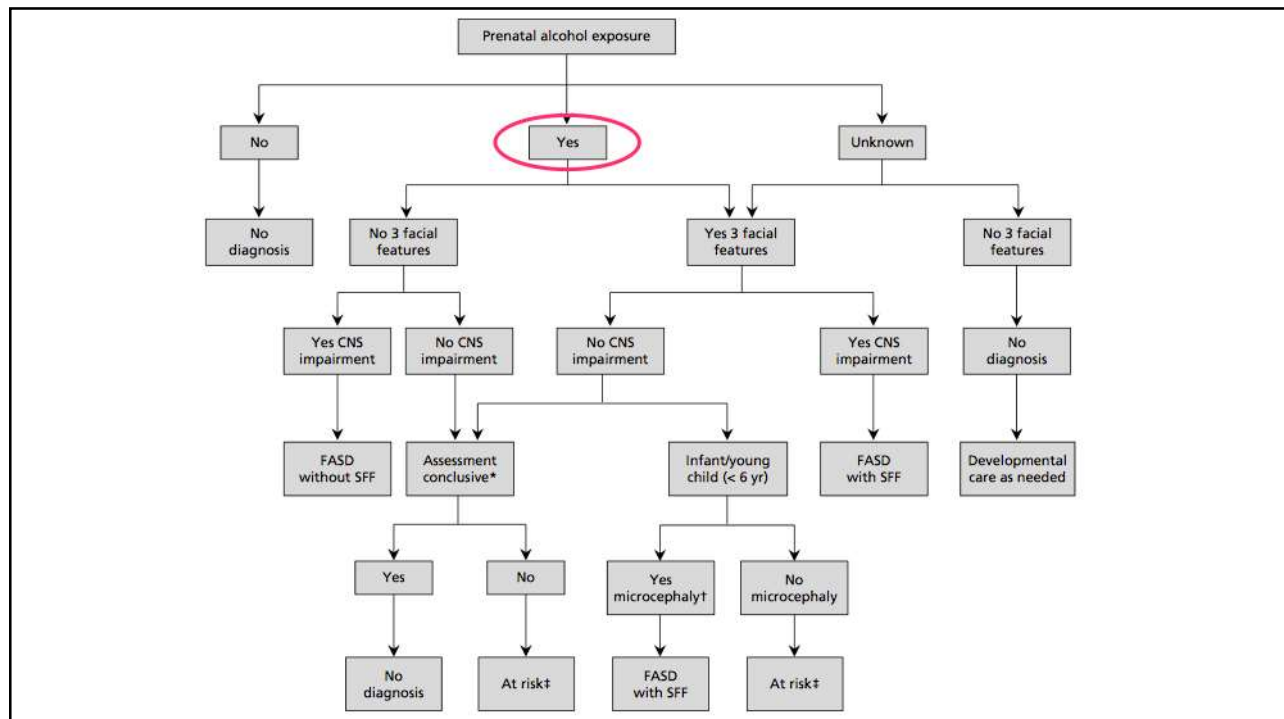
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Stacey Walsh, MSW

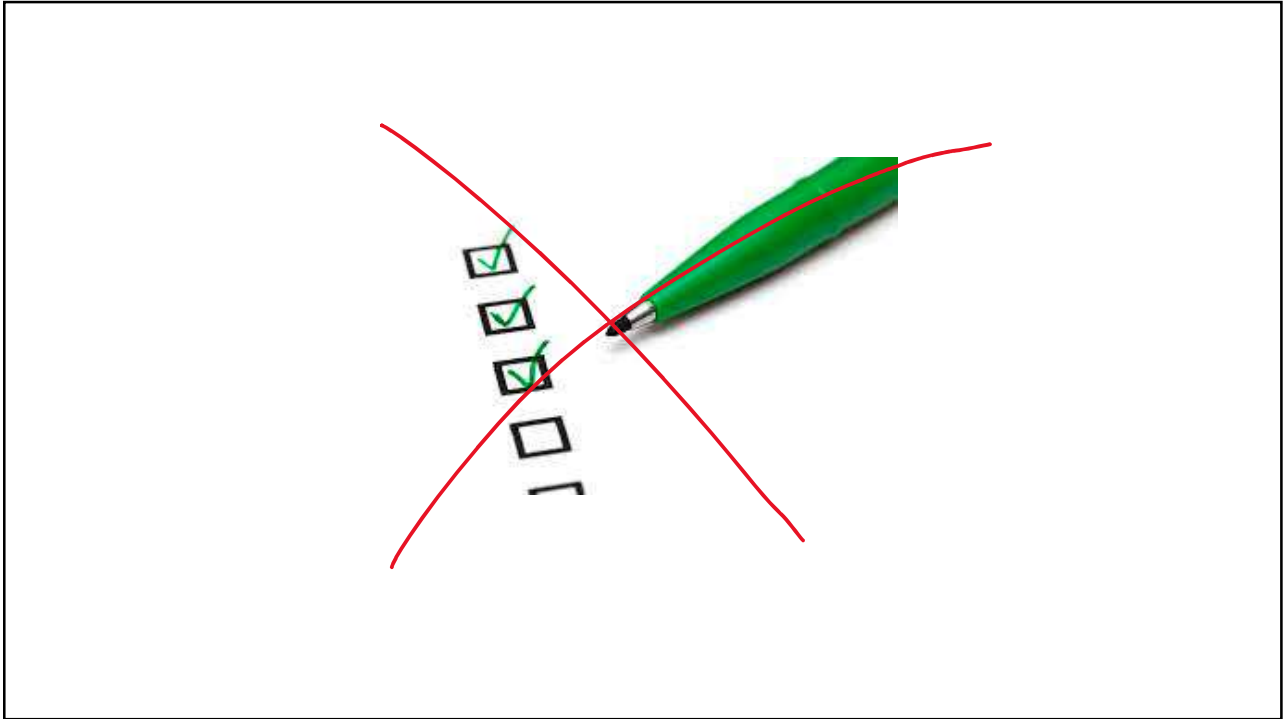
Sunny Hill Health Centre – BC Children's Hospital, Vancouver Canada
Sponsor: Priya Chetty, BScN., MHA, CDBC Provincial Program Manager

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Diagnostic Categories

- **FASD with sentinal facial features**
 - facial features + @ least 3 CNS domains + known or unknown exposure
 - EXCEPTION – infant w/ microcephaly + SFF
- **FASD without sentinal facial features***
 - Known exposure + @ least 3 CNS domains affected
- **At risk of Neurodevelopmental Disorder and FASD, associated with Prenatal Alcohol Exposure**
 - Known exposure but less than 3 CNS domains affected
 - May be too young for psychology testing





Genetic Disorders

Identify the Child with FASD



Williams
Syndrome

DeLange
Syndrome

Velocardiofacial
Syndrome

Manning & Hoyme (2007)

LOOK FOR GENETIC DISORDERS

- Dysmorphology exam
- Consider genetic workup (microarray + Fragile X) or referral to Genetics

Autism Spectrum Disorder

CASE – Child M - ASD or FASD?

- 5 yr old with multiple behavioural symptoms
 - Difficulty with transitions, multiple temper tantrums
 - Difficulty understanding social cues, turn taking and sharing
 - Sensory seeking behaviours → licks rocks, mouths crayons
 - Sensory aversion → dislikes having hair brushed or cut, refuses to wear tight fitting clothes including socks
 - History of speech delay (1st word @ 24 months)

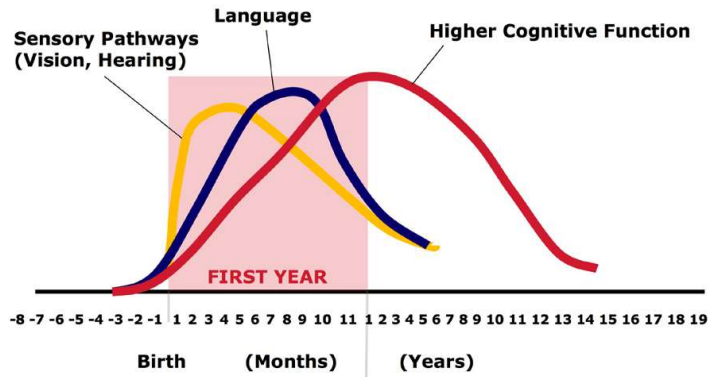
Possible areas overlap

1. motor skills
2. neuroanatomy/neurophysiology
3. cognition
4. language
5. academic achievement
6. memory
7. attention
8. executive function, including impulse control and hyperactivity
9. affect regulation
10. adaptive behaviour, social skills or social communication.

Childhood Trauma

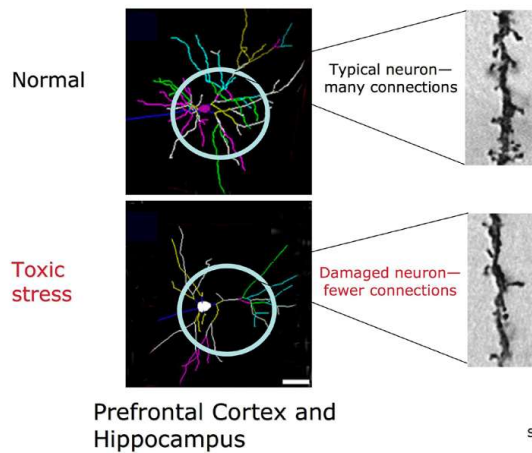
Human Brain Development

Neural Connections for Different Functions Develop Sequentially



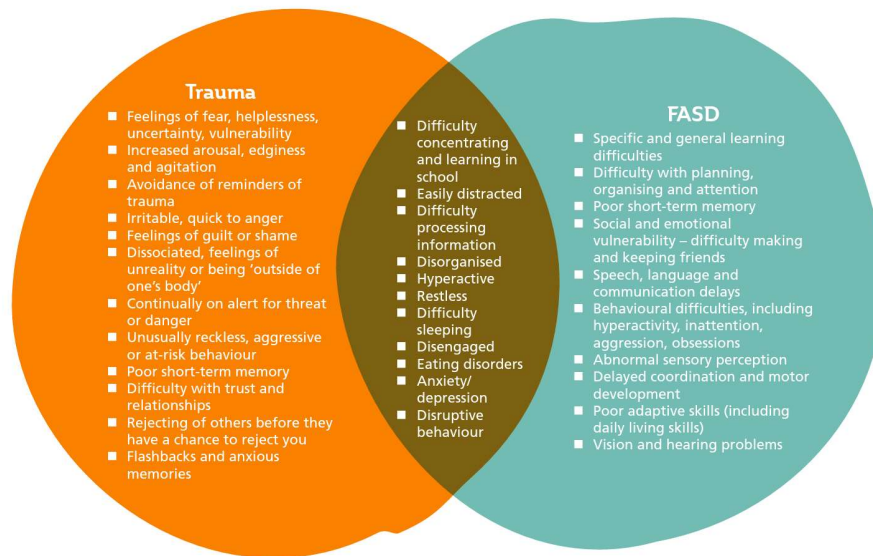
Source: C.A. Nelson (2000)

Persistent Stress Changes Brain Architecture



Sources: Radley et al. (2004)
Bock et al. (2005)

Figure 3: Symptoms of trauma and FASD and areas of overlap



FASD & Complex Trauma: A resource for educators,
2018, Marninwarntikura Women's Resource Centre, Australia,
<https://mwrc.com.au/pages/research-and-reports>

Trauma

- recent acute trauma, when the child is about to start treatment, or when the child is improving with treatment, clinicians should try to delay the FASD assessment or use the 'at risk' term.
- avoid overemphasizing the potential role of alcohol in situations where there is strong evidence of severe trauma and minimal alcohol exposure

Engle, J. A., Lanphear, N., Lilley, C., Lukas, M., Ruthven, L., Walsh, S. (2021). Complex Developmental Behavioural Conditions Network Handbook for the Diagnosis of Fetal Alcohol Spectrum Disorder. Vancouver: Sunny Hill Health Centre – BC Children's Hospital.

Trauma

- *both* exposure and trauma are clearly present + child in a relatively *stable* situation at the time of the assessment + realistically available *treatments* have been accessed
- > then can emphasize both alcohol exposure and adverse childhood experiences as likely contributing factors
- **neurodevelopmental disorder associated with prenatal alcohol exposure and adverse childhood experiences**, while also stating that the individual meets criteria for FASD.

Engle, J. A., Lanphear, N., Lilley, C., Lukas, M., Ruthven, L., Walsh, S. (2021). Complex Developmental Behavioural Conditions Network Handbook for the Diagnosis of Fetal Alcohol Spectrum Disorder. Vancouver: Sunny Hill Health Centre – BC Children’s Hospital.

Bias



Stigma

- Representative of Children and Youth repeatedly heard stories of stigma and racism from families
- “FASD is 100% preventable”
 - Discounts role of systemic issues such as trauma in alcohol use
 - Discounts alcohol use before aware of pregnancy
 - Blame on mother
- “FASD is an ‘Indigenous Problem’ ”
 - Stereotypes of alcoholics and substance users
 - Blame and shame at school
- Stigma --> less families seeing services or diagnoses

Biased Referrals

- Referred for FASD vs ASD assessments
 - At one centre – rare for Indigenous child to go through an ASD assessment
- Assumptions made based on family's race and SES status
 - Referrals suspecting FASD in Indigenous children and youth without history prenatal alcohol exposure
 - Referrals suspecting FASD stating mother's SES status or history substance use without history prenatal alcohol exposure

Structural racism

- “..racist connection between alcohol use and First Nations, Inuit & Metis populations creates **bias** that ripples into the **identification** of developmental concerns in children, the **referral and assessment** process, **societal responses** to an FASD diagnosis, and the fact that FASD **research** has primarily focused on Indigenous populations.”

Disparities in Canadian Indigenous Health Research on Neurodevelopmental Disorders

Nina C. Di Pietro, PhD,*† Judy Illes, PhD, FRSC, FCHAS*†

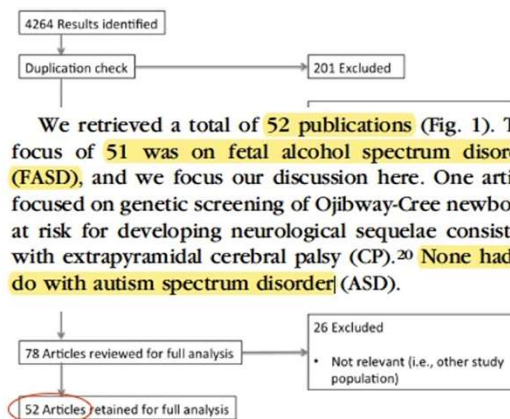


Figure 1. Flow diagram of review process and results.


Di Pietro, Nina C. PhD*,†; Illes, Judy PhD, FRSC, FCHAS*,† Disparities in Canadian Indigenous Health Research on Neurodevelopmental Disorders, Journal of Developmental & Behavioral Pediatrics: January 2014 - Volume 35 - Issue 1 - p 74-81

Falling Through the Cracks:
Canadian Indigenous Children with Disabilities


CANADIAN JOURNAL OF
Disability Studies
Published by the Canadian Disability Studies Association / Association Canadienne des Études sur l'Incapacité

**Absence and epidemic:
Autism and fetal alcohol spectrum disorder in Indigenous populations in Canada**


Caleigh Estelle Inman, Equity Studies Program
University of Toronto




International Human Rights Internships Program - Working Paper Series



McGill Centre for
Human Rights
and Legal Pluralism



Centre sur les droits de la
personne et le pluralisme
juridique de McGill



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MEDIA

Stigmatisation, Exaggeration, and Contradiction: An Analysis of Scientific and Clinical Content in Canadian Print Media Discourse About Fetal Alcohol Spectrum Disorder

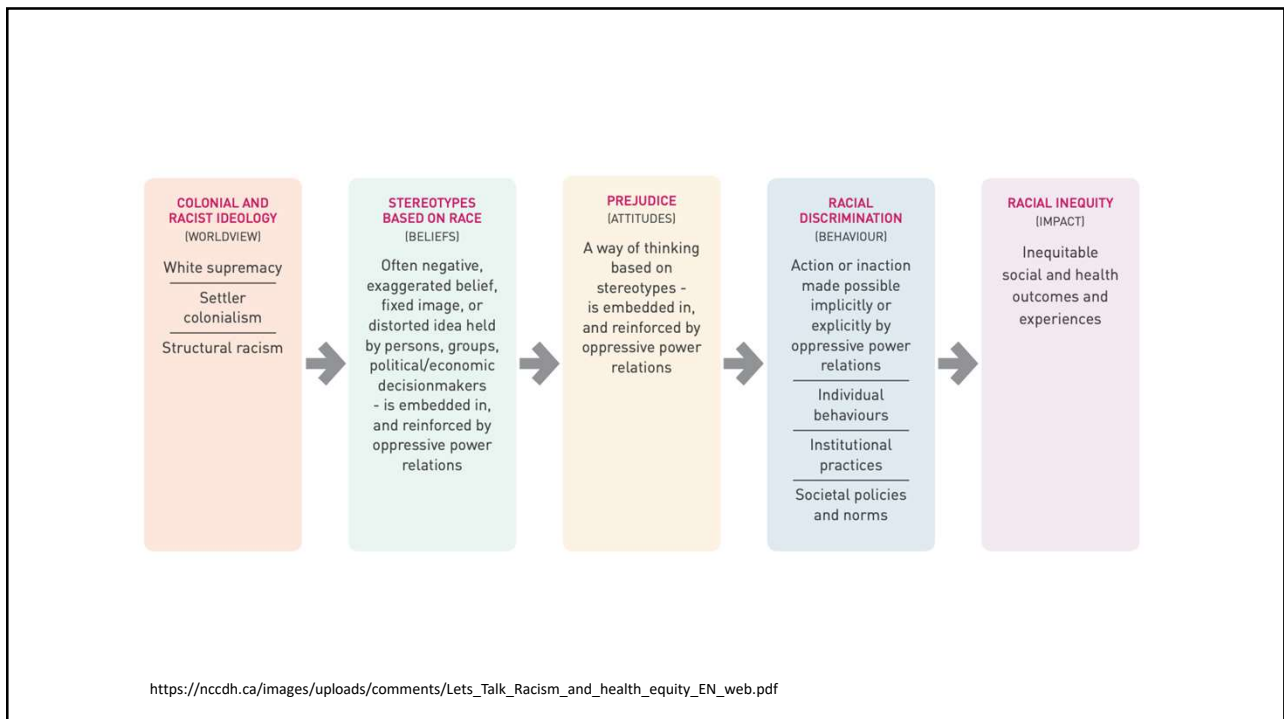
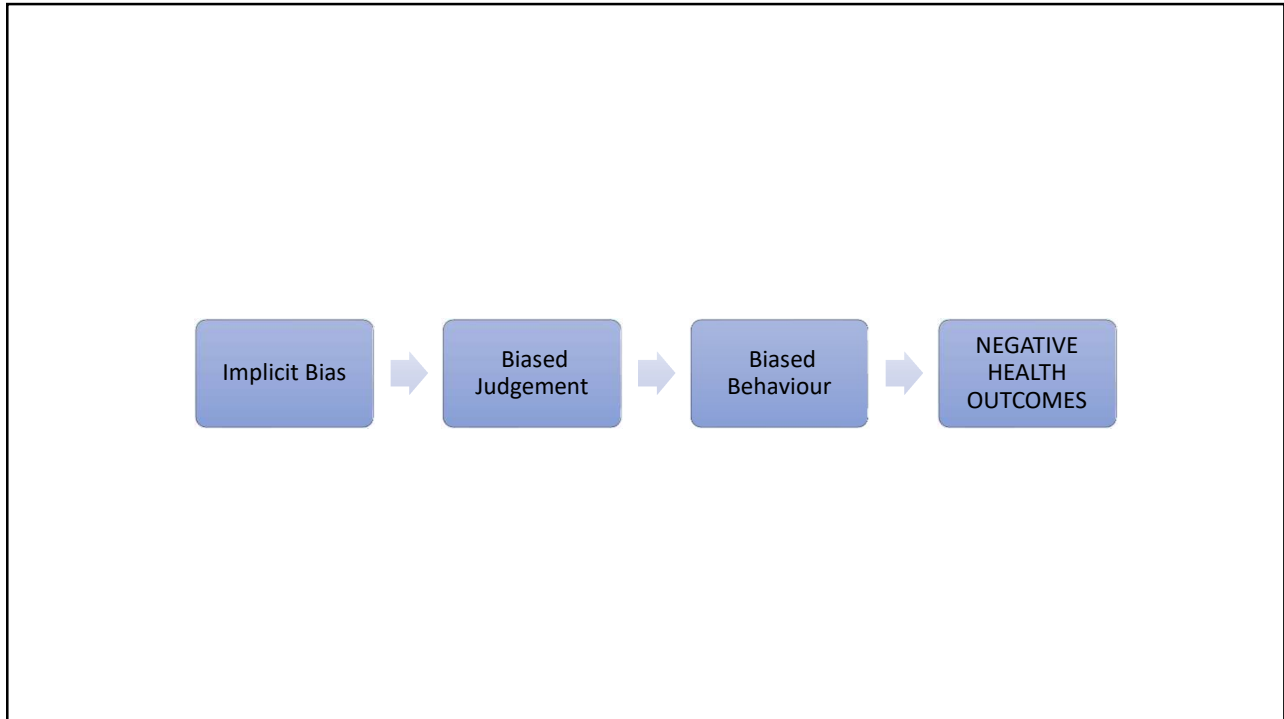
John Aspler, Natalie Zizzo, Emily Bell, Nina Di Pietro and Eric Racine

Structural determinants of health



What can we do as individuals?



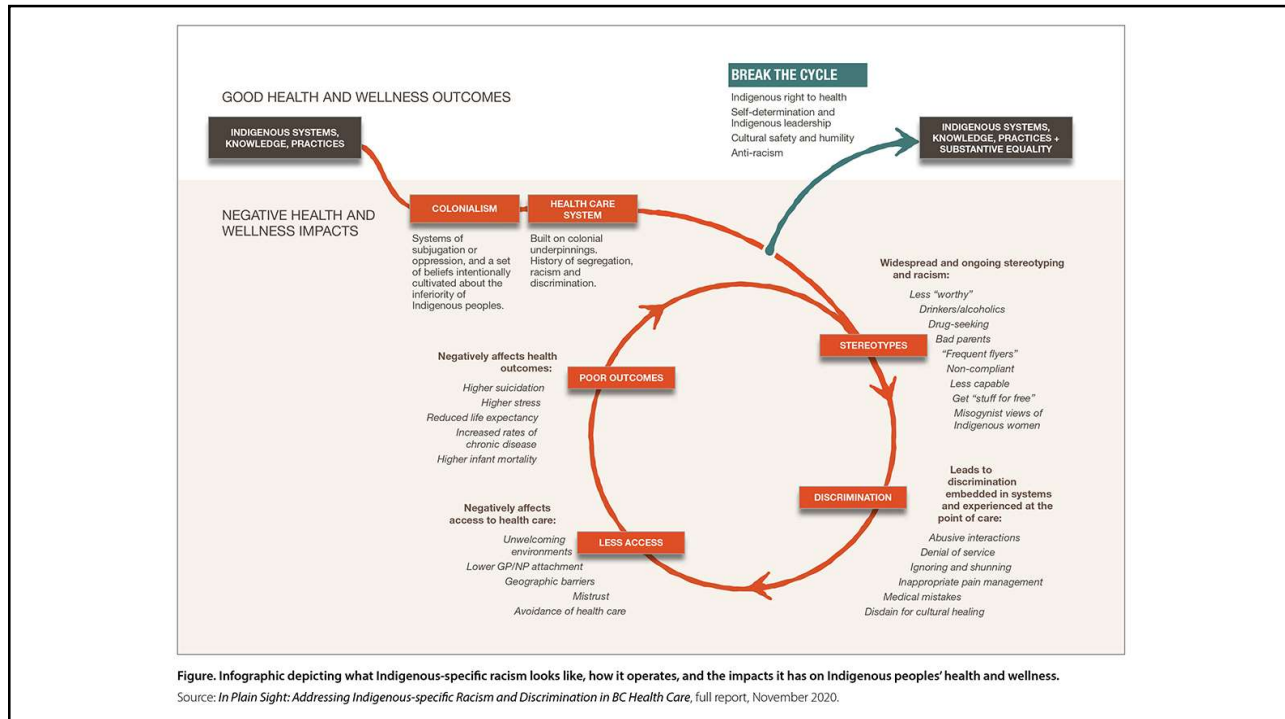


https://nccdh.ca/images/uploads/comments/Lets_Talk_Racism_and_health_equity_EN_web.pdf

Who are we asking about prenatal exposure? Who are we not asking?

What is not good enough for confirmation:

- alcohol exposure in another pregnancy
- alcohol use before or after this pregnancy
- confirmed exposure to other street drugs
- risk factors such as being homeless or being a sex trade worker
- alcohol exposure that is described as 'probable' or 'likely.'
- a general statement about alcohol exposure that can't be traced to the source, as is sometimes made by individuals who were not involved at the time of the pregnancy with the mother.



"FASD – Family Adversity Stress Disorder."

- Dr. Christine Look

In Summary

- Think about other possible diagnoses and diagnostic overlap
- Be aware of implicit and explicit bias that may be present
- Look for clear evidence of alcohol exposure – don't assume
- Look for signs of ASD in your CDBC assessment
- Be trauma informed – is it trauma? FASD? Or FASD + trauma?
- Ask for help / reach out to colleague for further discussion if needed.

Comments? Questions?

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