Sterling Clarren Award Presentation:
Northern Ontario Health Care Students’ Knowledge and Self-Efficacy Regarding Fetal Alcohol Spectrum Disorder

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Learning Objectives

- Understand how health care delivery may be impacted by providers’ personal attitudes and beliefs
- Increase participants’ knowledge and self-efficacy regarding FASD and pregnancy counselling regarding alcohol use
Is it okay to drink alcohol during pregnancy?
Rachel Weisz causes controversy talking about drinking while pregnant

When asked at the premiere of *The Fountain* whether having a glass of wine during pregnancy is fine, she replied: "Personally I do. They say not in the first three months though, but I think that after that it’s fine. I mean in Europe they drink it".
Why I Drank While I Was Pregnant

More educated, thirtysomething women, myself included, are drinking in moderation during pregnancy. Why do we do it?
Parent Experiences

Both my girls have fetal alcohol [syndrome]. I listened to what the doctor said. I never drank [before I was pregnant], the doctor said ‘have a drink each night, it’ll help the baby sleep and you’ll get a better sleep.’ So I produced two fetal alcohol children. Those two have produced eleven fetal alcohol children.

- Adrianna

Biological grandmother to four grandchildren with FASD
"Doctors and Nurses...All Need to be Educated": More Training for Professionals

"[The GP] always argues with me... 'No, no, no. You know what? This does not apply. She does not have FASD.' Despite the diagnosis, every time I go in... 'She is way too smart for this...this report card indicates that she has an A in this [subject]. She cannot have FASD.'...But...literally that was the fourth [doctor] in town that I went to and he was the closest to understanding FASD."

- Patricia, adoptive mother of one daughter with FASD
Health Care Professionals in Ontario

Inconsistent Recommendations

- “If no history of alcohol abuse I say OK in moderation”
- “Occasional drink is fine only after first trimester”
- “But no harm shown for occasional consumption”
- “Occasional drink for special occasion only”

Coons, Clement, & Watson (in press)
Health Care Professionals’ Knowledge and Awareness of FASD

- Play a critical role in the prevention of FASD

- Canadian results suggest that:
  - Less than half of family physicians discuss the risks of alcohol use, drug use, or smoking during pregnancy
  - Physicians require clarification of the definition of moderate alcohol consumption
  - Confusion regarding what knowledge health care professionals do have compared to what knowledge they should have

- Discrepancy between FASD knowledge and application of that knowledge
Health Care Professionals’ Knowledge and Awareness of FASD

- Women believe that their healthcare provider holds expert knowledge
- Few studies examining medical students’ knowledge, awareness, and self-efficacy
  - Based on American medical curricula
  - Heavy reliance on survey methods
- Limited research examining nurse practitioners and midwives
Primary Research Question

What do Northern Ontario health care students (medical students, midwifery students, nurse practitioner students) know about FASD, and where do they obtain their information about FASD?

1. Knowledge of FASD and attitudes regarding drinking during pregnancy
2. Beliefs and attitudes
3. Self-efficacy and experiences
Methodology and Methods

- Two phase, sequential mixed methods approach
  - Phase 1: Questionnaires
    - Healthcare Student Questionnaire (Minnes et al., 2012)
    - Fetal Alcohol Spectrum Disorder Survey for Healthcare Students (Public Health Agency of Canada, 2005; Tough, Clarke, Hickes, & Clarren, 2005)
  - Phase 2: In-depth, semi-structured interviews + Vignettes
Phase I Participants

- Three programs
- Recruited via e-mail and via social media
- Draw to win a Microsoft Surface Pro 3
### Characteristics of health care students (n = 45)

<table>
<thead>
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<th>Medical Students</th>
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<tr>
<td>Lower Year (3)</td>
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<tr>
<td>Upper Year (4)</td>
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<tr>
<td>Age (SD)</td>
<td>27.95 (5.03)</td>
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<tr>
<td>% Female</td>
<td>63.6%</td>
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<tr>
<td>Upper Year (4)</td>
<td>7</td>
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<tr>
<td>Age (SD)</td>
<td>25.75 (3.08)</td>
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<tr>
<td>% Female</td>
<td>91.7%</td>
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<td>Currently Pregnant (n)</td>
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<tr>
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</tr>
<tr>
<td>Upper Year (2)</td>
<td>5</td>
</tr>
<tr>
<td>Age (SD)</td>
<td>30.00 (8.88)</td>
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<tr>
<td>% Female</td>
<td>90.9%</td>
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<tr>
<td>Ever Pregnant (n)</td>
<td>4</td>
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<tr>
<td>Currently Pregnant (n)</td>
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Phase II Participants

- Subset of the sample of participants who partook in Part I of the study
- All students who participated in Phase I were provided with the opportunity to participate in Phase II
- Students were given a $10 Tim Horton’s gift card to thank them for their participation
### Characteristics of health care students (n = 21)

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<td>Upper Year (4)</td>
<td>Age (SD)</td>
<td>% Female</td>
<td>% Ever Pregnant</td>
<td>% Currently Pregnant</td>
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<tr>
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<td>3</td>
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<td>28.71 (6.05)</td>
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<td>26.63 (2.83)</td>
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<td>% Ever Pregnant</td>
<td>% Currently Pregnant</td>
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<td>33.33 (11.15)</td>
<td>83.3%</td>
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## Knowledge of Developmental Disabilities: Assessment and Diagnosis

We would like to ask you some questions on your knowledge about developmental disabilities.

<table>
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<tr>
<th>10. How would you rate your current level of knowledge regarding the assessment/diagnosis of individuals with the following:</th>
<th>Very limited</th>
<th>Limited</th>
<th>Moderate</th>
<th>Extensive</th>
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<td>Down syndrome</td>
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<tr>
<td>Fragile X syndrome</td>
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<tr>
<td>Fetal alcohol spectrum disorder</td>
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<tr>
<td>Physical disabilities (e.g., cerebral palsy)</td>
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<tr>
<td>Hearing and/or visual difficulty</td>
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<tr>
<td>Other disability (please specify):</td>
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</table>

1 = very limited
2 = limited
3 = moderate
4 = extensive
Knowledge of Developmental Disabilities: Students

Knowledge Regarding the Assessment and Diagnosis of DD

Mean

0 0.5 1 1.5 2 2.5 3

FASD* ASD DS* FXS* Physical Disabilities
### Knowledge of Developmental Disabilities: Treatment

<table>
<thead>
<tr>
<th>11. How would you rate your current level of knowledge regarding the treatment of individuals with the following:</th>
<th>Very limited</th>
<th>Limited</th>
<th>Moderate</th>
<th>Extensive</th>
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<tbody>
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<tr>
<td>Other disability (please specify):</td>
<td></td>
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</table>

- Please note: The table includes various conditions and the participant is asked to rate their knowledge level from very limited to extensive.
Knowledge of Developmental Disabilities: Students

Knowledge Regarding the Treatment of DD

- FASD*
- ASD*
- DS
- FXS*
- Physical Disabilities

* Denotes a specific condition or disorder related to developmental disabilities.
Competency Providing Collaborative Care

*How competent do you feel in meeting the needs of individuals with developmental disabilities?*

*34.1% of participants indicated that they felt moderately competent or very competent.*
Do you have experience (work or volunteer) with individuals with FASD?
Did you participate in any training sessions or workshops on FASD as part of your undergraduate degree?
Perceived Self-Efficacy

Diagnosis:
- Deferring responsibility to make a diagnosis and treat FASD
- Belief that it is not within their scope of practice to diagnose or address FASD

Little training in school about FASD
- “I think the resources are there, but the education might not be”

Not comfortable discussing alcohol use in general or alcohol use during pregnancy
Addressing Fetal Alcohol Spectrum Disorder

Alcohol's effects on fetal development remains unclear. 35.9% of participants agreed or strongly agreed with this statement.

Prenatal alcohol exposure is a significant risk for permanent brain damage. 92.3% of participants agreed or strongly agreed with this statement.

Which of the following items would give you the most accurate information regarding the diagnosis of Fetal Alcohol Syndrome?

- Mother has history of alcohol abuse or dependency – 28.9%
- Small at birth
- Behaviour problems
- Cognitive problems
- Special facial characteristics – 5.3%
- Combination of growth, brain, and facial abnormalities – 65.8%

Which of the following best describes the advice you would give pregnant women regarding alcohol use during pregnancy?

- No alcohol is recommended – 84.2%
- Alcohol is only dangerous during the first trimester
- A glass of beer or wine in moderation is OK
- No specific recommendations would be given
- Other (please specify) – 15.8%
- Combination of growth, brain, and facial abnormalities – 65.8%
Vignettes

Please read the distributed vignette and discuss with your table.
Vignettes: Consider the following

- What are your first impressions of this vignette?
- Do you think what ___ is doing during her pregnancy poses any risks to her unborn child? Why or why not?
- Do you think the advice the family doctor gave poses any risks to her unborn child? Why or why not?
Vignette #1: Shannon

Shannon is a 32-year-old, married woman who is pregnant with her first child. Shannon has a bachelor's degree in Labour Studies and Communications from an Ontario university and works as a marketing consultant at a top marketing firm in Toronto, Ontario. Shannon has a very active social life, and has a weekly dinner date after work with five of her closest female friends.

Shannon is currently seven months pregnant. While Shannon did not drink at all during her first trimester, she drank occasionally and lightly throughout her second and third trimesters. Shannon has never binged drank or gotten drunk, and has never had any hard liquor during her pregnancy. She says that she often has a glass or two of wine or a couple beers per week. Shannon's friends frequently reassure her that having a few drinks during her pregnancy does not pose any risk to her baby.

While Shannon claims that she could get the time from the without drinking any alcohol, she believes there is no conclusive evidence that light drinking is safe during pregnancy. Only with a healthy baby, Shannon feels rested though keeping up as much of her non-pregnant life as possible is beneficial. While physically addicted to having a glass of wine or few drinks of beer at events like dinner or when celebrating important events and having a few drinks during her pregnancy does not pose any risk to her baby.
Vignette #2: Kimberly

Kimberly is a 23-year-old, unmarried woman who is pregnant for the first time. Kimberly lives in a small, rural community in northern Ontario that is two hours from the closest urban center. Kimberly owns her own car, but commuting is often problematic due to her erratic work hours and weather in the wintertime.

Kimberly is currently five months pregnant. Kimberly found out she was pregnant at eight weeks. Even though Kimberly rarely drinks, she stopped drinking completely upon finding out she was pregnant. However, Kimberly attended a friend's birthday party before she discovered she was pregnant and recalls drinking about ten drinks on that occasion, during her third week of pregnancy.

Kimberly has a strong social support network, particularly from her friends and her mother who still lives in the same community. However, Kimberly's partner and the father of her child continues to drink in front of her, even though Kimberly has requested that he not drink in certain social situations. In these instances, Kimberly has chosen to drink a non-alcoholic cocktail or a non-alcoholic glass of wine instead of an alcoholic beverage.
Vignette #3: Jessica

Jessica is currently three months pregnant. When Jessica went to see her family doctor for her first prenatal appointment, she expressed some concern and anxiety about her pregnancy. Because this is her first pregnancy, she is worried and uncertain about what to expect. Her doctor reassured her that everything was fine and that if she was really worried she should have a few drinks to help her relax and to get a better sleep. Although Jessica never drinks alcohol, she accepted the doctor’s advice.
Vignette Questions

- What are your first impressions of this vignette?
- As a health care professional, what advice would you give to _____ at this stage of her pregnancy? What advice would you have given to ____ at the beginning of her pregnancy?
- Do you think what ____ is doing during her pregnancy poses any risks to her unborn child? Why or why not?
- Do you think the advice the family doctor gave poses any risks to her unborn child? Why or why not?
- How comfortable do you feel addressing this situation?
“Officially, no alcohol is recommended, but...”

- Attitudes regarding amount of alcohol and timing of exposure
  - Alcohol exposure before pregnancy identification
  - Amount of alcohol exposure
- Obligation, but no conclusive evidence
  - Responsibility to talk to patients
  - Knowledge of potential risks
- Personal choice
- Respecting the mother
“Recommendations that are Selectively Made to Selective Types of People”

- Divergent recommendations for different women
  - Perceptions of level of education
  - Perceptions of culture and ethnicity
  - Perceptions of the ability to stop drinking

- Understanding the social determinants of health
  - Complex relationship between women and alcohol
  - Partner violence
“So many clients ask if they have ruined their babies”: Alcohol exposure before pregnancy identification

My first impression is that a lot of people drink before they realize that they are pregnant and often times what we say to people is there’s … this lovely all or nothing effect…I wouldn’t be concerned about that one incident of drinking and would talk to her about how we encourage…officially no alcohol…but not to hold on to worries about that one night.

- Eva

Fourth year midwifery student
At this point, from what she’s disclosed, I wouldn’t say I’m too worried”: Amount of alcohol exposure

“My understanding is that…there may be some consequences to her baby when it’s born. It could have issues related to FASD, whether they’re cognitive or behavioural, social, physical issues, they’re all possible. But just because she did drink, that doesn’t necessarily mean that that’s going to happen.”

- Layla
Third year medical student
“Obligation to inform that no alcohol is best”: Responsibility to talk to patients

- “technical” or “theoretical” risk
- Lack of “clear”, “conclusive”, or “concrete” evidence
- “right in the fact that there is no conclusive evidence”
- “no amount of alcohol is ever safe for a woman when she is drinking during her pregnancy”
“If we don’t know what the risks are, people aren’t making informed choices”: Knowledge of potential risks

“How many drinks she has and how big the beer is and how big the glass of wine is to see how much, in the measurement form, she is in-taking.”

- Grace

Fourth year midwifery student
“As long as she’s informed...she can make her own choice”: Respecting the mother

“If you preface with public health information you can pretty much say ‘as a health care provider, I’m required to say X-Y-Z’...Especially from the midwifery angle, talk about choice. So here is the guideline and of course...your pregnancy is your choice. Your lifestyle, your choice.”

- Sally

Fourth year midwifery student
Ability to conduct own research: Perceptions of level of education

- "Educated", "professional", "have a good job", are "organized", and from well-off communities tend to be "very well informed" and "fairly confident" about their pregnancies.

- Women who are "educated and stable" are the women who "tend to know more about the effects of alcohol on pregnancy and have more resources not to drink during pregnancy."

- "if you can trust that she never drinks alcohol"

- My experience in clinical placements has been a glass of wine with dinner once a week in the second or third trimester and beyond is probably okay. And those are recommendations that are selectively made to selective types of people, depending on their educational level, depending on whether or not we have concerns about alcohol and drug use otherwise in the pregnancy, and if that one drink is gonna tip somebody back into binge drinking.... Often women who have maybe just completed high school or not completed high school and then...it usually feels like one end of the spectrum or the other where they’ve gone to university or gone to college.... So the recommendations that are made to women who don’t have the higher level of education of university or college or beyond, they often aren’t the same recommendations in terms of alcohol use.

- Ruby
Third year midwifery student
Stereotypical beliefs: Perceptions of culture and ethnicity

“marginalized populations”, including mothers who have “an addiction or an illness”, “First Nations” and “Aboriginal populations [with] a high incidence of FASD”, and “more rural areas…that acknowledge they have a higher incidence of…alcohol consumption during pregnancy”

“everybody I’ve ever met who has FASD has been First Nations”

“tone” with which FASD and alcohol consumption during pregnancy are discussed compared to other disabilities like Down Syndrome or Autism
Harm reduction and binge drinking:
Perception of the ability to stop drinking

“try and work with her and see ‘okay, what can we do? Let’s do what’s best for you and your baby! Let’s work with the resources that we have. If the person really doesn’t want to stop, I have to do my very best to guide her.”

- Sierra,
First year nurse practitioner student

- Charlotte
Second year nurse practitioner student
Complex relationship between women and alcohol

“It’s interesting to mesh together that relationship between how people actually consume alcohol versus what the research actually says… There’s a normalizing of alcohol consumption… So I feel like… it doesn’t necessarily reflect the lived realities of people who are drinking during their pregnancies.”

- Eva,
  Fourth year midwifery student
Partner violence and recognition of other risk factors

- “Concerned” or “worried” about Kimberly’s situation
- “red flag”
- “pretty normal almost” and “common” in rural and Northern Ontario
Discussion

- Stressors for families as a result of limited support (e.g., locating educated professionals)
- Perception that some women are protected from having a child with FASD
  - Pressing need to educate about the risks of low to moderate alcohol consumption during pregnancy
  - Continued debate about a threshold effect, below which there is no harm to the developing fetus
Discussion

- Cognitive dissonance between students’ beliefs regarding safe levels of alcohol exposure, at different times and amounts during pregnancy, compared to an outright recommendation to drink.

- Women often do not feel safe about disclosing their use of alcohol out of fear or judgment by health care professionals.

- Belief that only certain types of women can have a child with FASD may perpetuate this fear and stigma.
Discussion

- Need for partner involvement
  - FASD thought of as a female issue
- Personal choice
  - Students’ perceptions that it is an informed choice
  - Unique moral and ethical dilemma
  - Messaging to women about alcohol consumption during pregnancy
Discussion

- Implications for health care curricula

- Implications for practice: self-reflection/self-positioning and **critical** reflection

- Improving the confidence of (future) health care professionals regarding FASD
  - Adequate knowledge + strong sense of self-efficacy
  - Primary, secondary, and tertiary prevention of FASD
Describing Four Levels of FASD Prevention:
Canada-wide Collaboration on the Creation of a Resource for Program Planners

Introduction
At the 2009 International Conference on FASD, a panel presented an FASD prevention framework, comprised of four interconnected levels of prevention.

The 26 panelists linked the four levels shown here, to their work in service provision and policy development.

Following the conference, the FASD Team at the Public Health Agency of Canada provided support to develop and produce a web and print resource of this framework.

Fetal Alcohol Spectrum Disorder (FASD) Prevention: Canadian Perspectives has been designed to inspire and support the work of prevention program planners.

Outcome
A large team of service providers, health system planners and researchers came together to prepare and edit the material. This FASD prevention resource illustrates how effectively collective efforts can work to:
- Capture what we know about multi-level prevention.
- Describe who is doing it successfully in Canada.

This resource honours all the work being done and demonstrates how it is interconnected:
- Embedded web links, for print resources and prevention-in-action projects, inspire learning from many jurisdictions across Canada.
- This resource reminds us to take strength from joining efforts and that no one service provider can accomplish all this work alone.

Level 1
This level is directed broadly to all sectors of society with the goal of:
- raising awareness of the risks of drinking in pregnancy, and alternatives to alcohol use;
- signaling where help is available;
- promoting involvement by community members in bringing awareness to FASD prevention.

Level 2
This level involves collaborative discussion with all women of childbearing years to:
- alcohol use and related risks;
- ways of coping without alcohol;
- available prenatal supports;
- supports for pregnancy planning.

Level 3
This level reaches girls and women who are using alcohol during pregnancy and involves:
- respectful and accessible health care and substance use treatment;
- holistic prenatal support, which may include assistance with nutrition, housing and income support.

Level 4
This level involves supporting new mothers to:
- maintain healthy changes they have been able to make during pregnancy;
- access postpartum support, and continuing addiction treatment if necessary;
- continue to improve their health as well as the health of their children;
- provide early intervention services for their children.

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Marjory Van Bilsen, Inter Tribal Health Authority, Nantes
Mary Johnston, PHAC, Ottawa
Debra Skidmore, B.C. Health Authority
Renuka Prakash, PHAC, HPO
Ruthie Thompkins, Lennox-Waters Institute, Fort Smith
Stacy Halsall, Inter Tribal Health Authority, Fort Smith
Rose Santiago, Mother2Mother, Toronto

Public Health
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Agence de santé publique du Canada

British Columbia Centre of Excellence for Women’s Health
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DCA: public_inquiries@phac-aspc.gc.ca
“...And even if they think they don’t need to be educated, they need to be re-educated. And that’s such a big deficit. Such a big deficit.”

-Stacey, adoptive mother to one son with FASD
Acknowledgements

- CanFASD

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  - Ontario Women’s Health Scholars Award
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- All of the students who participated in this study!
Questions or Comments?

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“They’re Better Out West…Ontario’s About the Slowest Province”: Lack of Perceived Support in Ontario

“I’m scared. I’m scared ‘cause there’s not a lot of things in Ontario for Mackenzie and not a lot of places. The neuropsychologist said that when Mackenzie turns 16, if something has not happened in Ontario yet, move out West. And when a neuropsychologist is telling you that, it’s sad. It’s scary.”

- Jennifer, Adoptive mother to one son with FASD
Self-Efficacy

- Belief that one can master a situation and produce positive outcomes
- Judgments we make about how effective we are in given situations
- Important in determining our choices of activities and in influencing the amount of interest and effort we expend
- Mastery experiences
  - Success raises efficacy expectations
  - Failure lowers them
Performance experiences:
Previous success and failure experiences on similar tasks

Observational learning:
Observation of the behaviours and consequences of similar models in similar situations

Self-efficacy beliefs

Verbal persuasion:
Encouraging or discouraging messages from others

Emotional arousal:
Arousal that can be interpreted as enthusiasm or anxiety
Limitations

- Changing terminology (e.g., fetal alcohol syndrome, fetal alcohol effects) and recently updated diagnostic guidelines
- Limited applicability outside of Ontario, given differences in provincial and territorial policies to address FASD
- Participant-selecting bias presented in qualitative research