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

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#### Learning Objectives

O 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?



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#### **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

O "Occasional drink is fine only after first trimester"

O "But no harm shown for occasional consumption"

O "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
- O 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

O Discrepancy between FASD knowledge and application of that knowledge

### Health Care Professionals' Knowledge and Awareness of FASD

O Women believe that their healthcare provider holds <u>expert</u> knowledge

 Few studies examining medical students' knowledge, awareness, and selfefficacy

Based on American medical curricula

Heavy reliance on survey methods

O Limited research examining nurse practitioners and midwives

#### **Primary Research Question**

O 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

- O Phase 1: Questionnaires
  - O 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)

O Phase 2: In-depth, semi-structured interviews + Vignettes

#### Phase I Participants

Three programs

Recruited via e-mail and via social media

O Draw to win a Microsoft Surface Pro 3

#### O Characteristics of health care students (n = 45)

Medical Students	22
Lower Year (3)	12
Upper Year (4)	10
Age (SD)	27.95 (5.03)
% Female	63.6%
Ever Pregnant (n)	2
Currently Pregnant (n)	0
Midwifery Students	12
Lower Year (3)	5
Upper Year (4)	7
Age (SD)	25.75 (3.08)
% Female	91.7%
Ever Pregnant (n)	5
Currently Pregnant (n)	1
Nurse Practitioner Students	11
Lower Year (1)	6
Upper Year (2)	5
Age (SD)	30.00 (8.88)
% Female	90.9%
Ever Pregnant (n)	4
Currently Pregnant (n)	1

#### Phase II Participants

O 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

#### $\circ$ Characteristics of health care students (n = 21)

Medical Students	7	
Lower Year (3)	2	
Upper Year (4)	5	
Age (SD)	28.71 (6.05)	
% Female	57.1%	
% Ever Pregnant	0%	
% Currently Pregnant	0%	
Midwifery Students	8	
Lower Year (3)	2	
Upper Year (4)	6	
Age (SD)	26.63 (2.83)	
% Female	87.5%	
% Ever Pregnant	50%	
% Currently Pregnant	0%	
Nurse Practitioner Students	6	
Lower Year (1)	3	
Upper Year (2)	3	
Age (SD)	33.33 (11.15)	
% Female	83.3%	
% Ever Pregnant	50%	
% Currently Pregnant	0%	



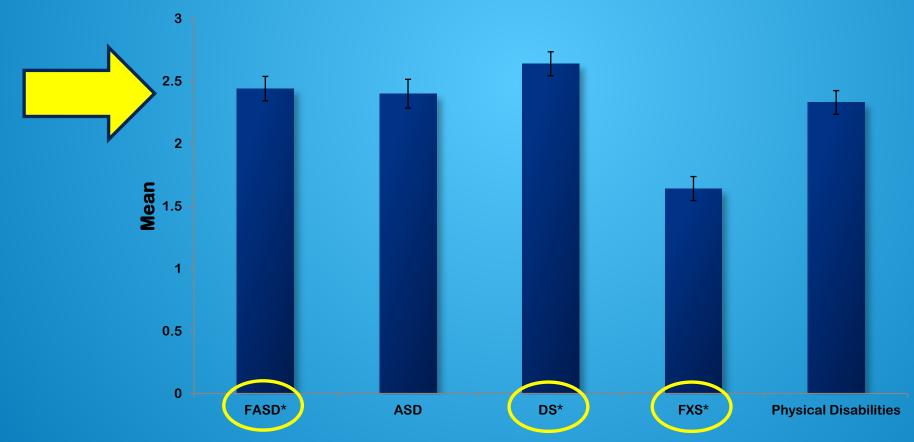
#### Knowledge of Developmental Disabilities: Assessment and Diagnosis

We would like to ask you some questions on your knowledge about developmental disabilities.						
10. How would you rate your current level of knowledge regarding the <u>assessment/diagnosis</u> of individuals with the following:	Very limited	Limited	Moderate	Extensive		
Autism spectrum disorders						
Down syndrome						
Fragile X syndrome						
Fetal alcohol spectrum disorder						
Physical disabilities (e.g., cerebral palsy)						
Hearing and/or visual difficulty						
Other disability (please specify):						

1 = very limited
 2 = limited
 3 = moderate
 4 = extensive

#### Knowledge of Developmental Disabilities: Students

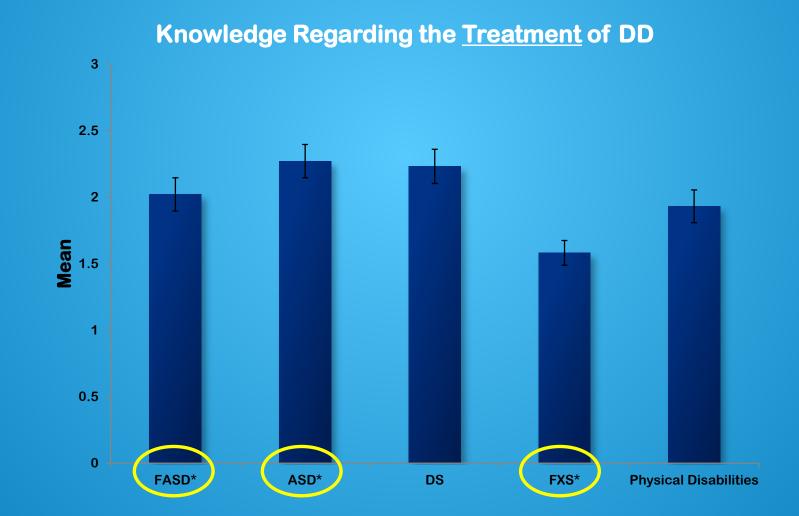
Knowledge Regarding the <u>Assessment and Diagnosis</u> of DD



#### Knowledge of Developmental Disabilities: Treatment

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

#### Knowledge of Developmental Disabilities: Students

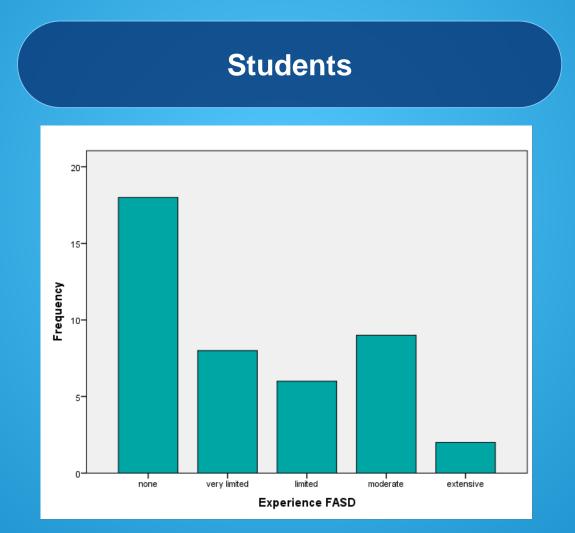


#### **Competency Providing Collaborative Care**

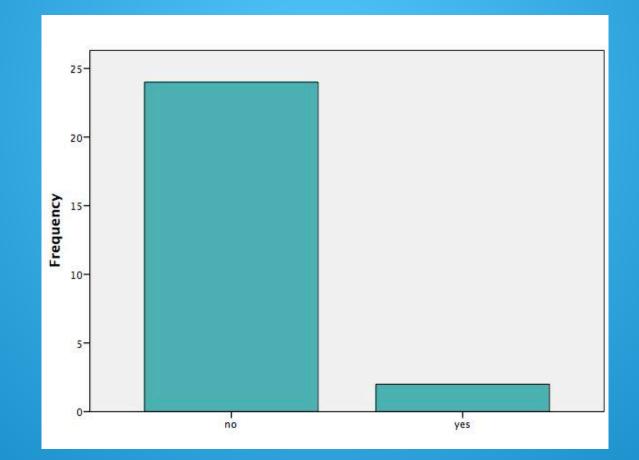
How competent do you feel in meeting the needs of individuals with developmental disabilities?

**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**

O Diagnosis:

O Deferring responsibility to make a diagnosis and treat FASD
O 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

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%



Please read the distributed vignette and discuss with your table

#### Vignettes: Consider the following

O What are your first impressions of this vignette?

O Do you think what \_\_\_\_\_ is doing during her pregnancy poses any risks to her unborn child? Why or why not?

O Do you think the advice the family doctor gave poses any risks to her unborn child? Why or why not?

#### Vignette #1: Shannon

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### Vignette #2: Kimberly

Kimberly has 23-treng sldcinh support network valious of hern pattfoultine, friends and the function of the investigation of the invest

#### Vignette #3: Jessica

Jessica is eußtentlyttotelermoniths voregmanhd/l/shenedessic antadefiast appoint seinatolsteinheiraf Baib/hebotorf shresex housesid Songlis concean and lankiet f abbut the program sy Becau Senthis is indesside/s Witsite pressinan by shreis invarried and bancertaite about evhat to get a doct of yreassed do bert that elverything was rithelin her relax and to get a better sleep. Although Jessica never drinks alcohol, she accepted the doct or's advice.

### Vignette Questions

- O 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?
- O you think what \_\_\_\_\_ is doing during her pregnancy poses any risks to her unborn child? Why or why not?
- O 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

O Amount of alcohol exposure

Obligation, but no conclusive evidence

Responsibility to talk to patients

- Knowledge of potential risks
- O 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

O 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. 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

O "technical" or "theoretical" risk

Lack of "clear", "conclusive", or "concrete" evidence

It 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

"Wolkespateeti'ce' iprofiessiplatedihents/teasibility of avise' with altinizer dihograd/definition well-off the 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 Wolfned Winkingte. "Offer and for their education of the pregnancy and if that one drink is gonna tip somebody back into the wolf education of the pregnancy of selective types." So the recommendations that are made to women who don't have the higher level of education of university or college or "if you can they often are in the pregnane; recommendations in terms of alcohol use.

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

"trift's ackadthing them is a cansbe prevented a Busyoweahd?stop's women that drink for yogetting pregnantly Eventshough with have resolvere some in and they're hapings their servade one to want to tell...Children's Aid and they instead back to the domerany ways, I'm sorry to say. I'm being negative, from experience."

- 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

O "Concerned" or "worried" about Kimberly's situation

"pretty normal almost" and "common" in rural and Northern Ontario
 "
 "

- Stressors for families as a result of limited support (e.g., locating educated professionals)
- O 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
  - O Continued debate about a threshold effect, below which there is no harm to the developing fetus

 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

Need for partner involvement
 FASD thought of as a female issue

### O Personal choice

Students' perceptions that it is an informed choice
Unique moral and ethical dilemma
Messaging to women about alcohol consumption during pregnancy

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**

Specialized port

### Introduction

At the 2007 International Conference on FASD, a panel presented an FASD prevention framework. comprised of four interconnected levels of prevention.

The 12 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.
- The resource reminds us to take strength from joining efforts and that no one service provider can accomplish all this work alone.

### Fetal Alcohol Spectrum Disorder (FASD) Prevention: **Canadian Perspectives**

"No known safe amount or

safe time to drink alcohol

during pregnancy."

This level is directed broadly to all sectors of society with the goals of:

M raising awareness of the risks of drinking in pregnancy; and alternatives to alcohol use;

M signalling where help is available;

m promoting involvement by community members in bringing awareness to FASD prevention.

### KEY RESOURCES:

Level 1

- Examples of initiatives:
- Media campaigns
- · Booklets with basic information

- This level involves supporting new mothers to: M maintain healthy changes they have been able to make during pregnancy;
- access post-partum 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.
- KEY RESOURCES:
- **Examples of initiatives**
- Home visiting programs
- · On-going discussions of alcohol and health,

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- · Info sheets
- Community-based speakers bureaus
- Community-wide development strategies

### Level 4

- Community-based mentoring programs
- Community Action Program for Children
- with service providers and lactation consultants

Level 2

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

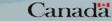
### KEY RESOURCES

- Multi-sectoral training for service providers
- Information and support lines for women Canada Prenatal Nutrition Program (CPNP)

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

### **KEY RESOURCES:** Examples of initiatives:

- · Holistic, "one-stop" community services
- · Mother-centred addiction treatment
- · Low threshold drop-in and outreach services
- · Networked services, supporting "wrap-around" care



### **Project leads:**

Nancy Poole, BC Centre of Excellence for Women's Health, Vancouver Holly McKay, Public Health Agency of Canada, Ottawa

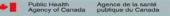
### **Project Collaborators:**

Anne-Marie Bédard, Public Health Agency of Canada (PHAC), Ottawa Arlene Hache, Centre for Northern Families, Yellowknife Cristine Urguhart, ActNow BC Healthy Choices in Pregnancy, Vancouver Donna De Filippis, PHAC, Ont/Nunavut Donna Malone, PHAC, Atlantic Doris Toy-Pries, PHAC, AB/NWT Elaine Prince, Inter Tribal Health Authority, Nanaimo Enid Harrison, Canadian Centre on Substance Abuse, Ottawa Ian Andrews, Health Canada, Ottawa Judy Kay, Healthy Generations Family Support Program, Sioux Lookout Karen Gelb, BCCEWH, Victoria Kirsten Madsen, Women's Directorate, Whitehorse Lisa Kehler, PHAC, MB/SK Lucy Hume, Jean Tweed Centre, Toronto Margaret Leslie, Mothercraft/Breaking the Cycle, Toronto Marilyn Van Bibber, Inter Tribal Health Authority, Nanaimo Mary Johnston, PHAC, Ottawa Pam Woodsworth, Kids First, Saskatoon Reetha Parthiban PHAC Ottawa Robin Thurmeler, Saskatchewan Prevention Institute, Saskatoon Stacy Taylor, Beauséjour Regional Health Authority, Moncton Susan Santiago, Motherisk, Toronto Wendy Burgoyne, Best Start, Wawa Wendy Reynolds, AWARE, Kingston



Fetal Alcohol Spectrum Disorder (FASD) Prevention: Canadian Perspectives is available on the Public Health Agency of Canada Fetal Alcohol Spectrum Disorder website: www.publichealth.gc.ca/fasd

For a hard copy email: DCA\_public\_inquiries@phac-aspc.gc.ca



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- **Examples of initiatives**
- On-line learning programs for health care professionals

"...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
- ✓ Funders
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- Supervisor: Dr. Shelley Watson; Supervisory Committee: Dr. Nicole Yantzi, Dr. Nancy Lightfoot, and Dr. Sylvie Larocque
- O All of the students who participated in this study!

## Questions or Comments?

### THINK BEFORE YOU DRINK.

Contact: Kelly D. Coons School of Rural and Northern Health Laurentian University kd\_coons@laurentian.ca "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."

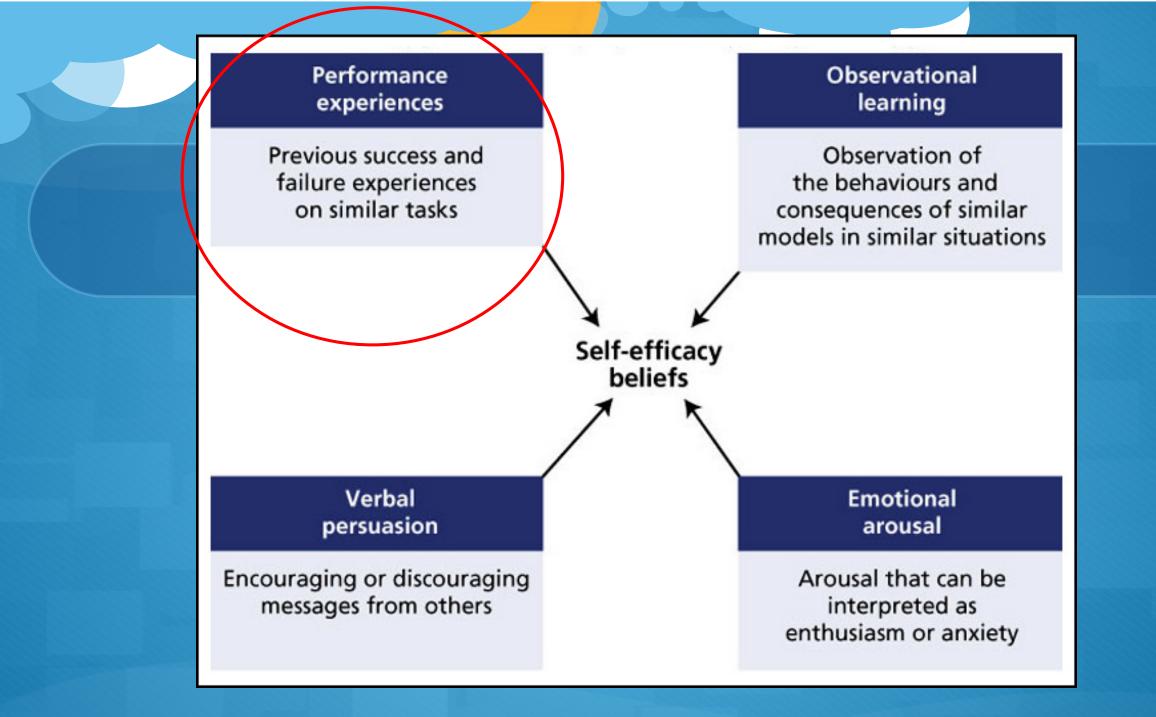
> - Jennifer, Adoptive mother to one son with FASD

### Self-Efficacy



Ø Belief that one can master a situation and produce positive outcomes
 Ø Judgments we make about how effective we are in given situations
 Ø Important in determining our choices of activities and in influencing the amount of interest and effort we expend

- Mastery experiences
  - Success raises efficacy expectations



## 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