CanFASD
CANADA FASD RESEARCH NETWORK

Meeting Summary Report

FETAL ALCOHOL SPECTRUM DISORDER RESEARCH PRIORITY SETTING SESSION

Held on August 30, 2016 in Regina, Saskatchewan

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Prepared by Katy Flannigan, PhD

MEETING GOAL

To engage Canada Fetal Alcohol Spectrum Disorder Research Network (CanFASD) researchers, funders, stakeholders, and partners in a collaborative day to identify areas that require FASD research that will inform public policy.

An additional goal was to share key findings from a patient engagement workshop with caregivers and individuals with FASD that took place in the two days prior to the meeting. The goal of this workshop was to explore emerging priorities for individuals and families living with FASD.

MEETING OVERVIEW

The meeting began with a report to attendees about preliminary findings from the engagement workshop. CanFASD researchers then presented in the following areas:

- FASD prevention in the preconception period
- Interventions for children and youth with FASD
- Important issues for youth/adults with FASD (justice, mental health, addictions)

Presentations were followed by "breakout" sessions, where attendees gathered in smaller groups to discuss each of the areas of focus, and then shared with the larger group the key issues raised. At the end of the meeting, findings from FASD prevalence research were presented to the group, before a general discussion and reflections were offered.

The full agenda and list of speakers are included in Appendix 1.

PARTICIPANTS

A full list of workshop participants is attached as Appendix 2. Forty-four people attended the meeting, from 6 provinces and 3 territories, with expertise in research, health care, policy, and supporting children and adults living with FASD. Organizations represented included:

- Public Health Agency of Canada
- First Nations and Inuit Health Branch
- Centre for Addiction and Mental Health
- Government of Saskatchewan
- Assembly of First Nations
- Indigenous and Northern Affairs Canada
- CanFASD researchers, staff, and Family Advisory Committee
- Canada Northwest FASD Partnership
- Canadian Centre on Substance Abuse

SUMMARY OF PRESENTATIONS

Full slides are included in Appendix 3.

PATIENT ENGAGEMENT WORKSHOP FINDINGS

The first presentation was given by Dorothy Reid, Co-Chair of the CanFASD Family Advisory Committee (FAC), and Dr. Michelle Stewart, CanFASD Research Lead for Justice Interventions. They provided background information about the Patient Engagement Workshop and a brief overview of the findings that emerged from the preceding days' discussions. Themes included:

1. **FASD as a Whole Body Disorder –** A discussion that builds on the need to understand FASD as more than a brain-based injury. Conversations included the following subthemes:
    - Multiple Medical Conditions
    - Mental Health
    - Non-Medical Interventions
    - Lack of Awareness about FASD
    - Quality and Continunity of Care and Information
2. **Aging and Transitions** – Consideration about what it means to age with a disability and the impact of aging caregivers. Discussions included:
    - Aging Caregivers
    - Autonomy
    - Challenging Systems
    - Barriers to Continuity of Supports
    - Lifespan Development
    - Social Determinants of Health
3. **Strategies and Supports** – Services for those living with FASD can be very challenging to access and maintain. Discussion included the following subthemes:
    - Caregiver Needs
    - Supporting Function
    - Strengths and Hopes
    - Brain and Body
    - The Role of Relationships
4. **Advocating for Support** – Key to not only accessing appropriate supports and services but also enhancing and expanding those supports. As an emerging discussion, the subthemes included:
    - Training and Education
    - Stigma
    - Justice Interventions
    - Prevention
    - Defining Success for FASD

The analogy of a tree was used to assist in the collection and sharing of information gathered throughout the workshop, with each main theme becoming the trunk of a tree, and subthemes becoming the branches. Workshop participants brainstormed specific research questions that became the leaves on the trees. It is important to note that participants expressed overwhelmingly positive feedback about the workshop, and 97% of participants confirmed that the four themes were consistent with their own lived experiences.

Workshop participants also engaged in an activity, "panning for gold," where they shared their experiences with strategies for success. In small group sessions, they also discussed the essential components of effective collaboration, including structure, respect, FASD knowledge and training, effective communication, inclusiveness, strong relationships, adequate resources, and a strengths-based focus. Discussions around next steps for advancing FASD research in Canada revealed that individuals and caregivers would prefer to receive information in ways that are brief and relevant, through multiple modalities, and in a centralized platform.

FASD PREVENTION IN THE PRECONCEPTION PERIOD

Dr. Nancy Poole, CanFASD Research Lead in Prevention provided an update on preconception health research in Canada, the US, and internationally over the past 10 years (2005 to 2015). Following a brief description of preconception care (PCC), Dr. Poole highlighted the need for preconception interventions to prevent adverse pregnancy outcomes and support maternal, paternal and infant wellbeing. Points covered:

- Men's contribution to FASD and the need for synchronized preconception interventions
- Preconception health initiatives in Canada
  Public Health Agency of Canada's National Guidelines for Family-Centered Maternity and Newborn Care, Best Start and Society of Obstetricians and Gynecologists of Canada's Health Beginnings report, Ontario Public Health Association's Shift position paper, and the Alberta Perinatal Health Program preconception health framework
- PCC initiatives and campaigns in the US
  National Preconception Guidelines and Strategic Plan, the Preconception Health and Healthcare Initiative, Centres of Disease Control Preconception Health Goals, and the Delaware Division of Public Health preconception health campaign
- Key findings from different forms of preconception interventions
  Multiple risk factor, single/dual risk factor, group health education, community-based social marketing campaigns, technology-assisted interventions, and preconception counselling for sub-populations with pre-existing health issues
- Models for preconception care delivery and barriers to preconception care
- Gender-synchronized and gender-transformative approaches for improving reproductive health

Dr. Poole closed with a discussion of the work currently underway through the CanFASD Prevention Network Action Team.

INTERVENTIONS FOR CHILDREN AND YOUTH

This topic area was presented by Dr. Jacquie Pei, CanFASD Research Lead in Intervention. She provided a brief update of the work being done in the Intervention Network Action Team, including research publications, presentations, new funding secured, and active projects. Dr. Pei spoke in more detail about three projects currently underway in the iNAT:

- **Improving capacities**: Presentation of a literature review on interventions to meet the needs of individuals with FASD across the lifespan, and the development of a best practice manual and evaluation toolkit for FASD service delivery
- **Innovating approaches**: Discussion of a virtual reality program for adolescents with FASD designed to improve social skills

- **Ensuring cultural relevance**: Examples of ways in which existing intervention programs might be adapted, and the research process might be modified to ensure that measurement and data collection are more relevant and meaningful to participants (e.g., visual data analysis)

Dr. Pei's discussion concluded with emphasis on the need to provide interventions based on individual function, reflection on the shifting research landscape towards a cross-disability versus diagnosis-specific approach, and highlighting the importance of focusing on strategies and strengths versus gaps and deficits when working with people with FASD.

YOUTH AND ADULTS WITH FASD

This area was co-presented by Dr. Mansfield Mela, CanFASD Research Co-Lead in Diagnostics, and Dr. Michelle Stewart, Research Lead in Justice Interventions.

Dr. Mela opened the discussion with comments on how most of the work that clinicians and researchers engage in with youth and adults with FASD involves identification, intervention, and influencing various systems to be sensitive to FASD. He spoke of the various reasons why identification and diagnosis are important, and how appropriate interventions have the potential to prevent negative outcomes (e.g., criminal involvement). He described several suggestions for tailoring approaches to working with youth and adults with FASD, and in particular highlighted mentorship and peer-to-peer support as essential for supporting these individuals in their communities. Dr. Mela then provided a brief overview of several of the research initiatives in which he is currently involved:

- **Algorithm for FASD psychotropics**: Literature review on medications used for treating people with FASD, followed by a symposium to 1) train physicians on the new guidelines for FASD diagnosis, and 2) generate an expert panel to review the relevant literature and develop a consensus on an algorithm for treating patients with FASD using psychotrophic medications
- **"Red Flagging" study**: Data gathered from 21 clinics and ~1800 cases in Alberta and BC with the goal of developing a profile that can be used by clinicians to recognize FASD and take steps to connect individuals with appropriate services
- **Clinical pathways study**: A systematic review of relevant clinical pathways to identify the best way for individuals with FASD, mental health, and addictions issues to navigate the system to better meet their needs

Dr. Mela also discussed the impact of funding decisions on youth and adults living with FASD, noting that budget cuts significantly affect caregivers and families supporting these individuals.

Dr. Stewart's presentation began with a brief overview of her professional background and how her research focus has evolved over the years. She began her career studying FASD in the justice system and has since branched out to explore strengths-based programs and conduct cross-Canadian research studies. From her "FASD road trip," she described emerging themes of tragedy, trauma, the foster-to-justice pipeline, and racialization of FASD, and noted that most people she has interviewed have inquired about how FASD research is moving forward.

She then described several of her ongoing research initiatives:

- FASD in resourced and under-resourced locations
- Navigating systems and diagnosis
- Therapeutic courts
- FASD and improv
- Emerging work in aging and sexuality in FASD

Dr. Stewart closed by emphasizing the importance of taking up the calls to action in FASD through research design and dissemination, and moving forward on the Truth and Reconciliation Commission (TRC) of Canada recommendations specific to FASD.

PREVALENCE

Dr. Svetlana Popova, Senior Scientist at Centre for Addiction and Mental Health provided an overview of recent research on the prevalence of alcohol use during pregnancy, and worldwide rates of FAS/FASD. This research involved a literature review, meta-analysis, and data prediction based on rates of drinking and FAS/FASD across the world. Highlights included:

- By country, the highest rates of drinking during pregnancy in the general population were found in Ireland, Denmark, and the United Kingdom, and the lowest rates were found in Venezuela, Sweden, and Nigeria
- By World Health Organization region, the prevalence of alcohol use during pregnancy was highest in Europe and lowest in the Eastern Mediterranean region
- In Canada specifically, there is some research to suggest higher rates of alcohol use during pregnancy in "northern regions"
- Worldwide rates of FAS/FASD may rise in the near future due to increased rates of drinking during pregnancy and binge drinking among young women, as well as high rates of unplanned pregnancies
- Rates of FAS/FASD showed the highest prevalence in the WHO region of Europe and lowest in the Eastern Mediterranean, and higher rates in "northern regions" of the Canadian population
- The prevalence of FASD among children in care is markedly higher than in the general population, both in Canada and internationally
- Rates of FASD are also disproportionately high in the Canadian justice system

Dr. Popova concluded with a discussion of the importance of early identification and intervention, and a call for more rigorous epidemiological research on FASD prevalence. She also cautioned against the misuse of prevalence statistics to further stigmatize mothers, and rather emphasized the utility of this research for informing policy on FASD.

GENERAL AND BREAKOUT GROUP DISCUSSIONS

Notable group conversations arose after the researcher presentations, specifically regarding FASD advocacy at the provincial and federal government levels, questions around support for people who are assessed but not diagnosed with FASD, and considerations for conducting FASD research with Aboriginal communities (e.g., mental wellness frameworks for continuum of care).

Meeting attendees then broke out into smaller groups to explore the following questions:

1. What are the top 5 research areas where CanFASD should focus its efforts over the next 5 years, based on capacity, fundability, and expertise?
2. How can we best incorporate the recommendations from the Caregiver and Family Workshop into the priority setting agenda and implementation of research?
3. What strategies do you suggest for the translation and dissemination of new knowledge gained through CanFASD activities?
4. Are there other partners that CanFASD should engage with to move this area forward?

Attendees formed groups in three assigned topic areas.

FASD PREVENTION IN THE PRECONCEPTION PERIOD

Participants in this group spoke of the need for prevention efforts to be targeted not only at women who are at-risk of having a child with FASD, but initiated as early as possible, for instance teaching children in school about the risks of drinking during pregnancy. Conversations arose around the need to partner with multiple systems and professionals (e.g., education, federal and provincial agencies, indigenous organizations, reproductive health care professionals) about general health, including mental health and wellbeing, and in particular maternal and child health. Specific areas for potential exploration included mental health and addiction, homelessness and housing, FASD as an intergenerational issue, long acting contraception, group education, access to alcohol, the need for evidence around cost-benefit of programs to inform funders, and how to engage men in the prevention conversation. Participants also expressed interest in learning more about how people with FASD understand FASD and how this understanding impacts choices over the lifespan. Participants suggested that there is wisdom in other fields (e.g., LGBTQ and bullying) that could be built upon to inform FASD prevention efforts.

Knowledge Translation. Participants noted that research communications need to be circular, messages must be tailored appropriately to the audience, individuals and caregivers must be involved in the entire research process, and clear statements should be made on the relevance of research at both the practical and policy level.

INTERVENTIONS FOR CHILDREN AND YOUTH

Some of the research interests identified in this group included how to improve quality of life for people living with FASD, creating opportunities for partnerships in evidence-based approaches, increasing access to services (especially in remote communities), conducting longitudinal studies to evaluate the impact of services, and ensuring that services are adaptable, flexible, and long-term. Participants also emphasized the importance of advocacy and mentorship for individuals with FASD, having a designated person to navigate supports systems, implementing training for all professionals who encounter FASD, and developing wrap-around clinical pathways or support systems that follow an individual with FASD across the lifespan. Additional questions arose related to the brain vulnerabilities associated with self-regulation in FASD, the role of technology and alternative approaches to service delivery, innovative ways to deliver supports for complex needs, addressing comorbid conditions of FASD, and being responsive and supporting the changing needs of families of individuals with FASD.

Knowledge Translation. Suggested strategies included regular scheduled updates and dissemination of new research (e.g., quarterly newsletters, annual webinar updates from research leads), efforts to strengthen communication between researchers and remote communities, and use of social media to share information. Participants in this group also stressed that messages must highlight how research is relevant to practice and policy.

YOUTH AND ADULTS WITH FASD

One of the main conversations in this group centered on the need for increased awareness and recognition of FASD among health care providers, including developing tools for screening, adapting the medical education curriculum to reflect consistent and up-to-date information about FASD, and encouraging the use of clear and consistent messaging for low risk drinking guidelines. Participants spoke of the importance of re-engaging youth and adults with FASD who have "fallen through the cracks" of service systems, empowering families to advocate for positive change in these systems, and promoting stronger partnerships across systems to better support those living with FASD. Discussions also focused on the justice system, with participants calling for changes in this system to better identify and divert at-risk individuals, and better support individuals with FASD who are already involved.

Participants explored the social determinants of health for individuals with FASD, emphasizing the importance of identifying predictors of success and factors that promote quality of life, and evaluating interventions and services that have made a positive difference. The TRC calls to action were also discussed, and participants stressed the need for all individuals, agencies, and organizations to implement these calls to action. Finally, participants noted that a family-centered approach is critical in working with FASD, particularly in terms of finding better ways to support foster families, working from a goals- and strengths-based approach, addressing the multiple traumas experienced by individuals and families, reducing stigma, supporting families to remain intact, and re-conceptualizing the common understanding of a "family unit."

Knowledge Translation. Strategies proposed by participants in this group included building "toolkits" of information to be used in the community, tailoring research messages to better engage physicians and other health care providers, and translating information into a format that can be used by families to share with their service providers.

NEXT STEPS & AREAS FOR EXPLORATION

The day concluded with a general discussion around Next Steps. Audrey McFarlane thanked everyone for participating in the day and confirmed that the Network would be exploring a number of areas that were raised during the proceedings. The CanFASD website is currently under renovation and the new template will allow a more comprehensive approach to the use of Social Media and electronic communication for Knowledge Translation. Potential research areas for further explorations include:

FASD PREVENTION IN THE PRECONCEPTION PERIOD

- Expanding prevention efforts (beyond women at-risk) to include brief conversations on low risk drinking, including not drinking in pregnancy with all women and men
- Partnering with multiple professions and systems, and learning from other fields
- Encouraging those working on mental health, addictions, homelessness to be involved in FASD prevention with women at highest risk
- Specific strategies: access to long acting and effective contraception, group and peer education, restrictions on access to alcohol, engaging men
- Evidence around cost-benefit of prevention programs

INTERVENTIONS FOR CHILDREN AND YOUTH

- Improving quality of life
- Creating opportunities for partnerships
- Ensuring services are accessible, flexible, and long-term
- Longitudinal research to evaluate long term impact of services
- Advocacy, mentorship, and wrap around support systems for individuals with FASD
- Professional training programs
- Specific intervention approaches (self-regulation, technology)
- Innovative ways to deliver supports for complex needs and comorbid conditions
- Supporting the changing needs of families of individuals with FASD

YOUTH AND ADULTS WITH FASD

- Screening tools for health care professionals
- Clear and consistent messaging for low risk drinking guidelines
- Engaging youth and adults with FASD who have "fallen through the cracks"

- Empowering families to advocate for positive change
- Changing the justice system (better identify/divert those at-risk, support those involved)
- Social determinants of health (predictors of success, promoting quality of life)
- Implementing the TRC calls to action
- Family-centered approaches (supporting foster families, goals- and strengths-based approaches, addressing trauma, reducing stigma, helping families to remain intact, re-conceptualizing the "family unit")

KNOWLEDGE TRANSLATION

- Messages that are circular, tailored to the audience
- Involving individuals and caregivers in all aspects of the research process
- Highlighting the relevance of research to practice and policy
- Regularly scheduled updates and dissemination of new research
- Stronger communication between researchers and remote communities
- Use of social media
- "Toolkits" of information for community service providers
- Targeting research messages to engage health care providers
- Use of KT formats that can be used by families to share with service providers

APPENDICES

1. WORKSKHOP AGENDA AND SPEAKERS

FASD Research Priority Day: Wednesday, August 31, 2016

University of Regina (Education 191)

Purpose:

To engage Canada Fetal Alcohol Spectrum Disorder Research Network (CanFASD) researchers, funders, stakeholders and partners in a collaborative day to identify areas that require FASD research that will inform public policy.

Areas of focus:

- FASD prevention in the preconception period
- Youth and adults with FASD (Justice, Mental Health, and Addictions)
- Interventions for children and youth

Meeting Agenda

0800–0830	**Coffee and Muffins**
0830–0845	**Welcome and Introductions** (*Alan Bocking, CanFASD Scientific Advisor*)
0845–0915	**Report on Patient Engagement Workshop Outcomes** (*Dorothy Reid, Co-Chair CanFASD Family Advisory Committee; Michelle Stewart, CanFASD Justice Research Lead*)
0915–0945	**FASD Prevention in the Preconception Period** (*Nancy Poole, CanFASD Prevention Research Lead*)
0945–1015	**Interventions for Children and Youth** (*Jacqueline Pei, CanFASD Intervention Research Lead*)
1015–1045	**Break**
1045–1130	**Youth and Adults with FASD** (*Michelle Stewart, CanFASD Justice Research Lead; Mansfield Mela, CanFASD Diagnostic Research Co-Lead*)
1130–1200	**General Discussion** (*All*)
1200–1300	**Breakout Groups** X3
1300–1400	**Lunch** (provided)
1400–1440	**Report Back**
1440–1500	**Prevalence Research** (*Svetlana Popova, Senior Scientist Centre for Addiction and Mental Health*)
1500–1540	**Reflections from PHAC and FNIHB**
1540–1600	**Break**
1600–1645	**General Discussion and Next Steps** (*Alan Bocking, CanFASD Scientific Advisor*)
1645–1700	**Summary and Thanks** (*Tim Moorhouse, CanFASD Board Chair*)

2. LIST OF MEETING PARTICIPANTS

Name	Affiliation
Carla Beck	New Democratic MLA Regina Lakeview Constituency
Heather Caughey	Policy Analyst Health Promotion and Chronic Disease Prevention Branch Public Health Agency of Canada
Lisha Di Gioacchino	Knowledge Broker Canadian Centre on Substance Abuse
Marlene Drey	Coordinator, FASD Prevention Program Saskatchewan Prevention Institute
Dina Juras	Regional Director Public Health Agency of Canada
Wendy Laxdal	Program Consultant First Nations and Inuit Health Branch, Health Canada
Kelly Lerat	Program Consultant First Nations and Inuit Health Branch, Health Canada
Melanie Musgrove-Morningstar	Strategic Policy Advisor Assembly of First Nations
Aradhana Patel	Policy Advisor Healthy Children and Youth Unit First Nations and Inuit Health Branch, Health Canada
Svetlana Popova	Senior Scientist Institute for Mental Health Policy Research Centre for Addiction and Mental Health
Saqib Shahab	Chief Medical Health Officer Ministry of Health, Population Health Branch Government of Saskatchewan
Anne-Marie Ugnat	Senior Manager Healthy Children and Youth Unit First Nations and Inuit Health Branch, Health Canada
Canada Northwest FASD Partnership Steering Committee	
Anne Fuller	Provincial FASD Consultant BC Ministry of Children and Family Development
Holly Gammon	Manager, FASD Initiatives Healthy Child Manitoba Office
Caitlin Knutson	Policy Analyst Yukon Health and Social Services
Patricia Living	Director, Social Marketing and Communication Health and Social Services, H-1, Yukon Government

Tara MacAskill	Territorial Lead Healthy Children Families and Communities Department of Health, Government of Nunavut
Sandra Mann	Health Planner, Rehabilitation Services Department of Health and Social Services Government of the Northwest Territories
Janice Penner	Manager, FASD Initiatives Provincial Disability Supports Initiative Disability Services Division, Alberta Human Services
Stefanie Wihlidal	Cognitive Disabilities Programs Consultant Government of Saskatchewan
CanFASD Family Advisory Committee	
Wanda Beland	Member
Françoise Corbin-Boucher	Member
Simon LaPlante	Member
Ray Marnoch	Co-Chair
Dorothy Reid	Co-Chair
Tammy Roberts	Member
Sonja Schmidt	Member
Marva Smith	Former FAC Member, and Current CanFASD Alumni
Marsha Wilson	Member
CanFASD Staff, Researchers, and Members	
Tara Anderson	Research Assistant, Diagnostics
Dorothy Badry	Child Welfare Research Lead
Alan Bocking	Scientific Advisor
Jocelynn Cook	Data Research Lead
Katy Flannigan	Research Coordinator
Ana Hanlon-Dearman	Diagnostics Research Co-Lead
Alex Johnson	Research Assistant, Intervention
Aamena Kapasi	Research Assistant, Intervention
Audrey McFarlane	Interim Executive Director
Mansfield Mela	Diagnostics Research Co-Lead
Tim Moorhouse	Board Chair
Jacqueline Pei	Intervention Research Co-Lead
Nancy Poole	Prevention Research Lead
Michelle Stewart	Intervention Research Co-Lead
Kathy Unsworth	Director, Business and Partnership Director

FASD Prevention in the Preconception Period (Dr. Nancy Poole)

Update on Preconception Health Research

"Finding the intersection between public health, clinical care and real life"

Nancy Poole, PhD
CanFASD Research Network
Research Planning Meeting – Regina August 31, 2016

Research/KT Overview

Funding:
CIHR Planning Grant

Organization:
BC Centre of Excellence for Women's Health

Researchers:
Nancy Poole
Lorraine Greaves
Natalie Hemsing
Rose Schmidt

- To consolidate knowledge and information related to preconception and interconception care in Canada, the USA, and internationally.
- To draft a research agenda on preconception and interconception health in Canada, and provide recommendations regarding the utility of, and necessary components of a national guideline on preconception care
- To disseminate findings at the community, provincial and federal level, invite comment, and contribute to the expansion of preconception policy and programming.

Methods

- Search Terms: Preconception health OR interconception health OR family planning OR reproductive health AND program OR intervention OR care OR approach OR guidelines OR assessment OR screening tool OR tool
- Dates: January 2005 to September 2015
- Databases: Medline full text; CINAHL complete; Studies of Women and Gender Abstracts; Social Services Abstracts; Social Sciences Citation Index; Health and Psychosocial Instruments; Cochrane Library; Native Health Database; Google Scholar; reference chasing
- Websites: Search of key websites for grey literature
- After removing duplicates, and title, abstract and full text screening = 258 papers

What is preconception care?

PCC is a set of health promotion, educational and counselling interventions that aim to identify and modify risks to men's and women's health or pregnancy outcome through prevention and management:

- Giving protection – e.g. folic acid supplements
- Avoiding teratogens – e.g. alcohol
- Managing conditions – e.g. obesity

The goal of preconception care is to reduce the risk of adverse health effects for the woman, fetus, or neonate by optimizing the woman's health and knowledge before planning and conceiving a pregnancy. Because reproductive capacity spans almost four decades for most women, optimizing women's health before and between pregnancies is an ongoing process that requires access to and the full participation of all segments of the health care system(ACOG, 2005)

Need for Preconception Interventions

- Substance use, nutritional deficiencies, chronic diseases are associated with poor outcomes for women, pregnancy (if/ when occurs) and fetal health
- Many of the maternal and paternal risk factors for poor birth outcomes, are modifiable in the preconception period
- Is cost effective for specific interventions, such as folic acid supplementation and diabetes care
- Preconception interventions can contribute to preventing preterm births, improving birth weight, preventing congenital anomalies, reducing infant and maternal mortality
- Particularly salient for socially disadvantaged women and their partners

Men's contribution to FASD

Two studies published in 2016

1. McBride and Johnson from Australia looked at 150 research studies (11 good quality). The associated effects of paternal drinking fell into three themes: impact on maternal drinking, sperm health, and fetal/infant health. [2].
2. Day and Savani et al. focused on birth defects and links to paternal alcohol consumption, age and environmental factors. Deficiencies in brain size, heart formation, and cognitive and motor abilities were linked to paternal alcohol use even when there was no maternal alcohol consumption.

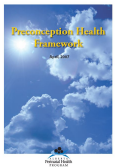
More research is needed in order to understand the full impact of alcohol and epigenetics, and the interplay between maternal and paternal factors.

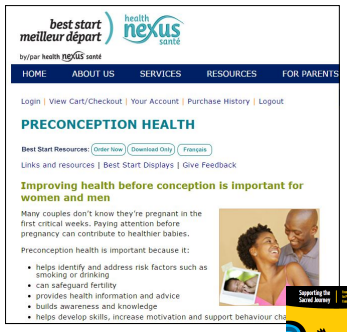
1.Abel, E., *Paternal contribution to fetal alcohol syndrome.* Addiction Biology, 2004. **9**(2): p. 127-133.
2.McBride, N. and S. Johnson, *Fathers' role in alcohol-exposed pregnancies: Systematic review of human studies.* American Journal of Preventive Medicine, 2016
3.Day, J., et al., *Influence of paternal preconception exposures on their offspring: Through epigenetics to phenotype.* American Journal of Stem Cells, 2016. **5**(1): p. 11-18.

Context- Canada

- Preconception health chapter in *Family-Centred Maternity and Newborn Care: National Guidelines* (PHAC 2000)
  - advocates community based & diversity sensitive approach to PCC, and that PCC be provided as part of general preventive care/ during primary care visits
  - No evidence of implementation
  - The *National Guidelines* are currently being updated, writing and revisions in process with expected release in 2016

Examples of other efforts:
- Best Start & SOGC report, *Healthy Beginnings* (updated 2009)
- Ontario Public Health Association (OPHA) – *Shift* position paper advocates for coordinated and comprehensive action on preconception health (2014)
- Alberta Perinatal Health Program preconception health framework (2007)

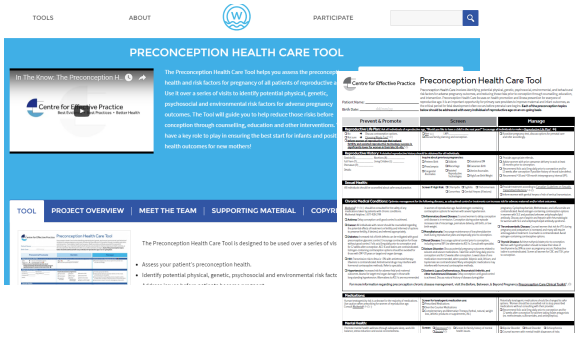




- 3 Preconception Health reports on physician practices, public health initiatives, and awareness and behaviours (2009)

Best Start Resources

- *My Life My Plan* booklet for teens (2014)
- *Is there a baby in your future? Plan for it – Health Before Pregnancy* workbook and poster (2011)
- *Men's Information- How to build a healthy baby* brochure
- *Supporting the Sacred Journey: From Preconception to Parenting for First Nations Families in Ontario* booklet



The Centre for Effective Practice – Ontario
http://thewellhealth.ca/preconception

Alberta Health Services
https://readyornotalberta.ca/

Context- USA

- National preconception guidelines & strategic plan (2006, updated 2012)
- Public–private partnership, the Preconception Health and Health Care (PCHHC) Initiative supports implementation of the recommendations
  - 5 working groups —clinical, public health, consumer, policy and finance, and surveillance and research
  - many achievements: 2 strategic plans, policy briefs to support reforms in health care coverage, 3 national summit meetings, published reports and articles including 3 journal supplements, federally funded preconception and interconception programs, development of 45 preconception health indicators, national branding & social marketing campaign

CDC checklist
http://www.cdc.gov/preconception/planning.html

CDC Preconception Health Goals (2006; 2012)

Table 1. Preconception Health and Healthcare Initiative Goals from 2006 and 2012

MMWR Goals 2006[6]	*Updated MMWR Goals 2012**
Goal 1: Improve the knowledge and attitudes and behaviors of men and women related to preconception health.	**Goal 1**: To improve the knowledge, attitudes, and behaviors of men and women related to preconception health.
Goal 2: Assure that all women of childbearing age in the United States receive preconception care service (i.e., evidence-based risk screening, health promotion, and interventions) that will enable them to enter pregnancy in optimal health.	**Goal 2**: To create health equity and eliminate disparities in adverse maternal, fetal, and infant outcomes.
Goal 3: Reduce risks indicated by a previous adverse pregnancy outcome through interventions during the interconception period, which can prevent or minimize health problems for a mother and her future children.	**Goal 3**: To assure that all U.S. women of childbearing age receive preconception care services—screening, health promotion, and interventions—that will enable them to achieve high levels of wellness, minimize risks, and enter any pregnancy they may have in optimal health.
Goal 4: Reduce the disparities in adverse pregnancy outcomes.	**Goal 4**: To reduce risks among women who have had a prior adverse maternal, fetal, or infant outcome through interventions in the postpartum/interconception period.

Floyd et al., 2013 p.798

Welcome.

Before, Between and Beyond Pregnancy is designed to be a "one stop" resource for clinicians and others who want to learn more about preconception health, its history, the evidence supporting it and strategies for incorporating relevant content into daily clinical practice. It includes CME opportunities, quick access to key articles, clinical guidance, and news of special interest to providers. Before, Between and Beyond was created as a key component of the National Preconception Health and Healthcare Initiative (PCHHC), a public-private partnership of over 70 organizations which engages the CDC, HRSA, and other government agencies, nonprofit organizations, professional organizations and hundreds of individuals. PCHHC is made up of five workgroups: Consumer, Clinical, Policy & Finance, Surveillance and Research, and Public Health.

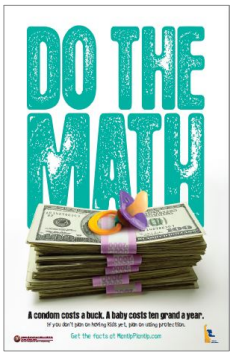
PCHHC Vision: All women and men of reproductive age will achieve optimal health and wellness, fostering a healthy life course for them and any children they may have.

Preconception Health+Health Care Initiative
A National Public-Private Partnership

http://beforeandbeyond.org/

The Delaware Division of Public Health have created a website (also Facebook and Twitter locations) that support preconception health planning by offering videos, interactive quizzes and planning tools about making important life/health choices.

They have tailored pages on life and reproductive health planning for adult men and women, and young men and women.



example of info card

Delaware Division of Public Health

http://dethrives.com/

They encourage men to plan to be fathers, to use condoms, to plan for the financial costs of having children, overall to "Man Up, Plan Up"

Key Findings – re preconception interventions

Types of preconception interventions found

- Clinical interventions – multiple or single/dual risk factors
- Group health education interventions
- Online/technology-assisted interventions
- Community-based social marketing interventions
- Policy interventions – e.g. workplace

Multiple risk factor interventions

- Address multiple risks via assessment & advice/ MI, range in intensity
- In a systematic review - multiple risk interventions effective in improving at least one risk factor (Temel et al 2014)
  - e.g. brief primary care clinic counseling intervention (diet, exercise, folic acid, substance use, sexual health, partner violence, contraception), low income African American and Hispanic women; improvements in knowledge of risks (Dunlop, Logue et al. 2013).
  - e.g. RCT of risk assessment & preconception health advice in a family practice setting; improved folic acid use, reduced alcohol use in first trimester, adverse pregnancy outcomes 16% vs 20% standard care (Elsinga, de Jong-Potjer et al. 2008).

Single/dual risk factor interventions

- Primarily SBI/MI to prevent alcohol exposed pregnancy (AEP) risk; address alcohol use + contraception
  - e.g. PROJECT CHOICES (4 manual-guided individual MI sessions address alcohol + contraception, high risk women) decrease in AEP risk (Floyd et al., 2007).
  - e.g. assessment + one session MI associated with decreased risky drinking and increased contraception (Ingersoll et al 2013; Farrell-Carnahan et al 2013)

Group health education

- delivered in high school/ college settings
- primarily pilot/descriptive studies
- tend to report improved knowledge, but not/ or don't measure behaviour changes
  - e.g. pilot peer-led education intervention for nursing students → improvements in PCH knowledge (p=0.01) (Wade, Herrman et al. 2012).
  - e.g. 4 week interactive group college-based intervention → increased knowledge & interest in PCH, but no significant difference in health behaviours (DeJoy 2014).

Community-based social marketing campaigns

Amor y Salud, radio novela for young Latinas (18– 29) in USA, risks/ concepts based on CDC recommendations. No evaluation of KAB change but received positive feedback and high viewership (Dixon Gray et al 2013).

Healthy from Birth for Life - youth driven social marketing campaign (choose and lead community events) for youth at risk of poor birth outcomes due to obesity and diabetes → increased PCH knowledge, and self esteem (Gordon et al, 2010)

Technology assisted

- Virtual agent "Gabby"- assesses & addresses PCH risks over 1 yr
- addressed majority of health risks in feasibility test (Gardiner et al 2013)
- reduction in # (8.3 vs. 5.5 risks, p < 0.05) and % (27.8% vs 20.5%, p < 0.01) of risks among African American women (Jack, Bickmore et al. 2015)

e.g. web based self-guided change intervention for women at risk for AEP; decreased AEP (Tenkku et al 2011)

e.g. Italian web based risk assessment + tailored information; decrease in alcohol (-46.5% 95% CI -53.28; -38.75), increase folic acid (-23.4% 95% CI -31.0; 15.36) at 6 mos; improved knowledge of PCC (Agricola et al 2014)

Preconception counselling - sub-populations with pre-existing health issues

- Several SRs show improvements in knowledge, pregnancy and birth outcomes among women with pre-existing & gestational diabetes (Wahabi, Alzeidan et al. 2010; Lassi, Imam et al. 2014; Mielke, Kaiser et al. 2013)

  e.g. individual preconception counselling program (READY-Girls) for teen girls with diabetes; significant improvements in perceived benefit, knowledge and reproductive health (p=0.01) (Fischl, Herman et al. 2010).

- Couples with fertility issues- may be particularly motivated
  e.g. improvements in nutrition, alcohol use, physical activity among subfertile Dutch couples who received assessment + couples counselling (Hammiche, Laven et al. 2011).
  e.g. reduced alcohol and caffeine use among subfertile Australian couples who received an assessment + MI intervention (Homan et al. 2012).

For general population Implications for preconception

e.g. Ohio workplace smoke free act associated with small but significant reduction in odds of preconception smoking among low income women (Klein, Liu et al. 2014)

Discussion/ Recommendations

Models for Delivery of Care

Four public health models for preconception care (Shannon, Alberg et al. 2014):

1. Primary care model- family doctors provide initial screening and health education, referrals as needed to specialists for more complex needs
2. Hospital based preconception care- delivered in the hospital, regardless of the initial reason for admission, either inpatient or outpatient level
3. Clinic model- resource intensive but benefit of offering more specialized and efficient care
4. Community outreach- labour and resource intensive, specialized staff and community follow up

-The authors suggest that the ideal model would be flexible, patient-centred and include combination of all models depending upon presenting needs

Barriers

In 1990, Jack and Culpepper identified seven barriers to preconception care:
1.Women most in need of preconception care are the least likely to receive counseling
2.Fragmented health care service delivery system
3.Lack of treatment services for high-risk behaviors
4.Inadequate physician reimbursement providing counseling services
5.Lack of efficacy of counseling provided to unmotivated patients and their partner
6.Limited number of conditions with evidence-based preconception interventions
7.Lack of emphasis on risk assessment/health promotion in training programs

+ changes in addressing some of these barriers, particularly in the US (expanded health insurance coverage, clinical practice guidelines, etc), but many of these barriers continue to exist

- One article by Bello and colleagues (2013) is aptly titled *Pregnancy Intentions, Reproductive Life Plans and Preconception Care: Finding the intersection of Public Health, Clinical Care and Real Life*
- This difficult balance can be seen in recent criticism of CDC re guidelines on drinking alcohol by women of reproductive age (See Time Magazine "The CDC's Alcohol Warning Shames and Discriminates Against Women")

Gender synchronized & transformative

- Gender-synchronized approaches reach both men and boys and women and girls (of all sexual orientations and gender identities).
- Such approaches can occur simultaneously or sequentially, under the same "programmatic umbrella" or in coordination with other organizations.
- Gender-synchronized approaches seek to equalize the balance of power between men and women in order to ensure gender equality and transform social norms that lead to gender-related vulnerabilities.

Greene, M. E., & Levack, A. (2010). *Synchronizing Gender Strategies: A Cooperative Model for Improving Reproductive Health and Transforming Gender Relations. Retrieved from www.prb.org and* www.igwg.org

Gender transformative approaches

Gender-transformative approaches actively strive to examine, question, and change rigid gender norms and imbalance of power as a means of reaching health as well as gender equity objectives.

Source: Elisabeth Rottach, Sidney Ruth Schuler, and Karen Hardee for the IGWG, Gender Perspectives Improve Reproductive Health Outcomes: New Evidence. Washington, DC: PRB for the IGWG, 2009
See also Greaves, L., Pederson, A., & Poole, N. (Eds.). (2014). Making it Better: Gender -Transformative Health Promotion. Toronto, ON: Canadian Scholars Press.

Discussion

- For preconception care to be well integrated in health care, need an overall shift to include focus on preventive interventions and to prioritize women's and men's overall health across the lifespan (rather than pregnancy/ fetal outcomes)
- Incorporate PCC into care already being provided, not siloed
- Need a national approach
- Need for further development and evaluation of programs for men, lesbians, single women
- Important that preconception care be gender transformative - does not mimic gender-exploitative prenatal HP messages
- Addressing SDOH requires a shift from individual programs and interventions to community level strategies and initiatives
- Need to consider who will provide PCC and training/engaging providers
- Need to consider the potential of online tools and interventions

pNAT Plans

Application submitted	• Apply to CIHR for meeting with Indigenous researchers re enhancing action on T&R recommendations re FASD prevention overall, and on preconception interventions specifically
By Sept 16th	• Apply to PHAC NSPF to map and catalyse preconception interventions with alcohol focus
In progress - Meeting with RNAO Sept 1	• Work with CCSA on SBIR
Sept 12-14	• Discuss with Australians and others at European conference (also application with McBride re men)
Invitation accepted	• Present half day workshop at Best Start Conference in February
Abstract submitted	• Oral presentation at Int'l conference in March?
	• Work with Partnership governments?

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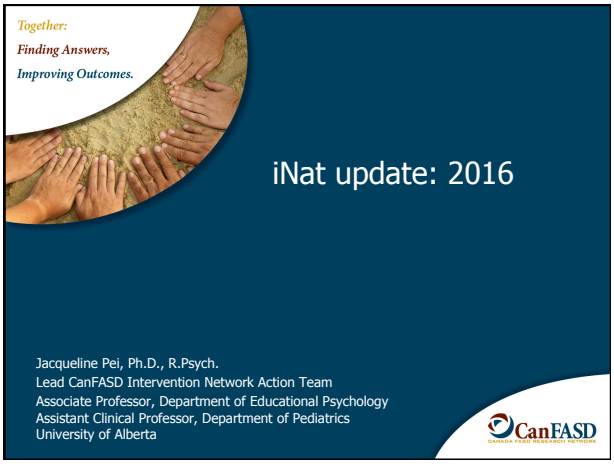
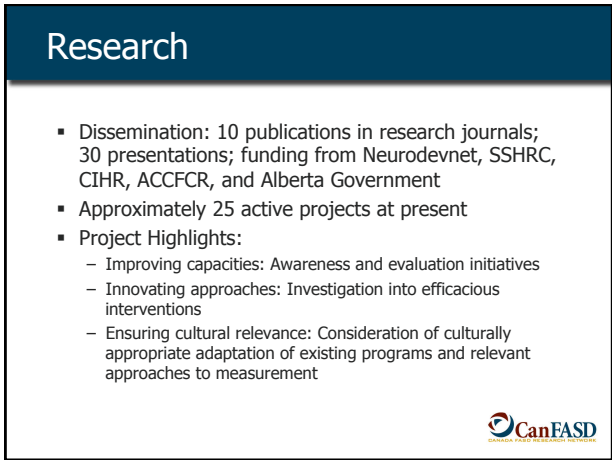
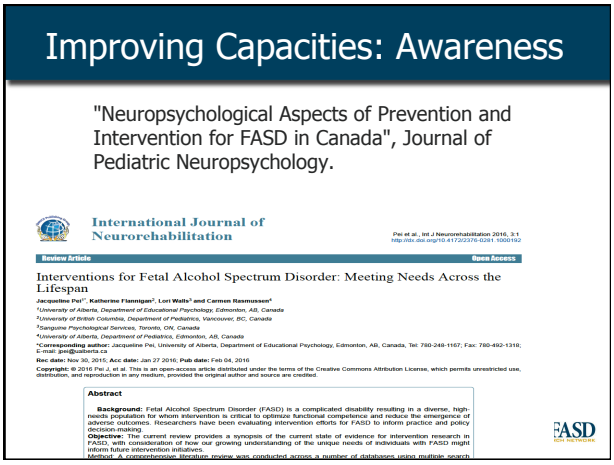
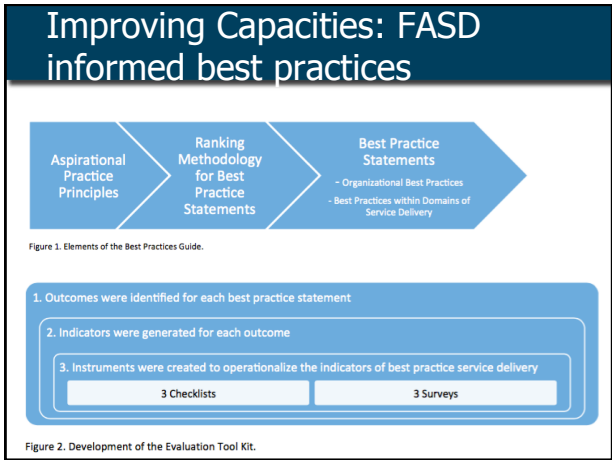
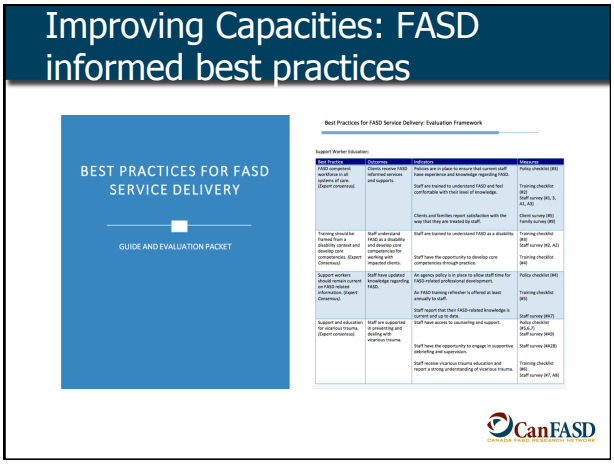
Interventions for Children and Youth (Dr. Jacqueline Pei)



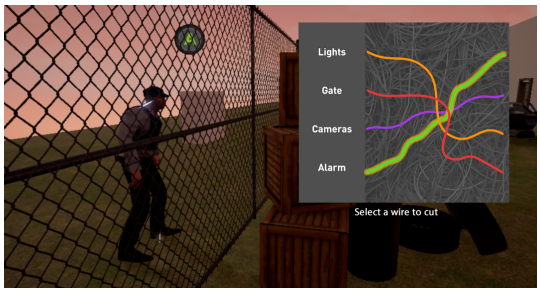








Innovating: Efficacious Interventions



Innovating: Efficacious Interventions

Innovating: Efficacious Interventions

Cultural Relevance: Adapting

- Two overarching questions:
  - What are you doing?
  - How do you know it is working?

Cultural Relevance: Adapting

Cultural Relevance: Adapting

Cultural Relevance: Adapting

IJADR International Journal of Alcohol and Drug Research
The Official Journal of the Kettil Bruun Society for Social and Epidemiological Research on Alcohol
doi: 10.7895/ijadr.v3i1.129 IJADR, 2014, 3(1), 71 - 80 ISSN: 1923-7066

Combining visual methods with focus groups: An innovative approach for capturing the multifaceted and complex work experiences of Fetal Alcohol Spectrum Disorder prevention specialists

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[2]Measurement, Evaluation, & Cognition, Department of Educational Psychology, University of Alberta
[3]NWC Alberta FASD Services Network
[4]Heart Sights Consulting

Abstract

Aims: This paper discusses the untapped potential of an innovative methodological approach for capturing the experiences of

Beyond the current work

- Intervention response based on function
- Cross disability work
- Moving from gap/deficit analysis to strategy/strength identification

Youth and Adults with FASD (Dr. Mansfield Mela and Dr. Michelle Stewart)

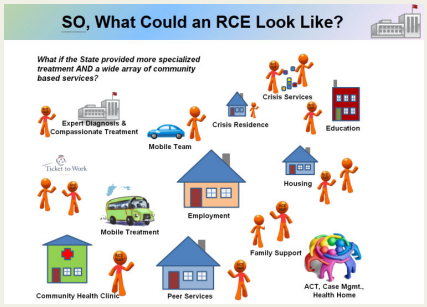
Youth & Adults with FASD

Dr. Mansfield Mela
Research Co-Lead
Diagnostic Team

Dr. Michelle Stewart
Research Lead
Justice Interventions

Dr. Mansfield Mela
University of Saskatchewan

Objectives



Why Identify and diagnose

- Expectations
- A source of great strength and weakness data
- Assessment informed appropriate interventions
- Avoiding harm
- Research into profile and intervention
- Prevention of additional disabilities
- Support and access to financial assistance

Risk of not diagnosing

- Frustration and countertransference
- Cost of secondary disabilities
- Risk of impulsive acts due to risk unawareness
- Economic costs – current and projected

Youth/Adult Approaches

- Appropriate expectations
- Strength based
- Mentoring
- Participatory research (transferability)
- Symptomatic – sleep, daytime behavioral modification
- Relational, Support, Structure, Supervision
- Trauma informed interventions

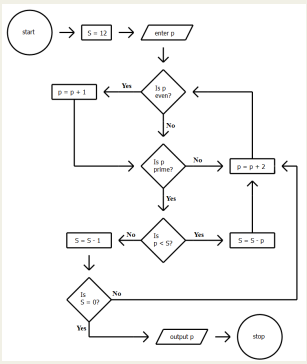
Peer to peer support

Algorithm for FASD and Psychotropics

- Findings of research activates and evidence based summaries packaged for Experts
- Symposium scheduled for October 24th at U of S
- Training physicians on updated diagnostic guidelines
- Expert panel to reach consensus on algorithm
- Goal of a Cochrane review
- Present results (2017 Vancouver FASD conference)

Delphi consensus

Algorithm



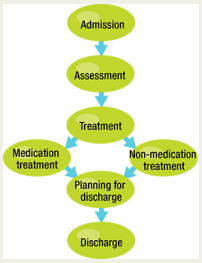
RED FLAGGING STUDY

- All network data from AB and BC (total of ~1800 cases)
- Plus 21 Clinics (total of ~3900 cases)
- Additional qualitative "red-flagging" data from ~40 clinicians

Funding priorities

Preventing bad outcomes

Clinical pathways study

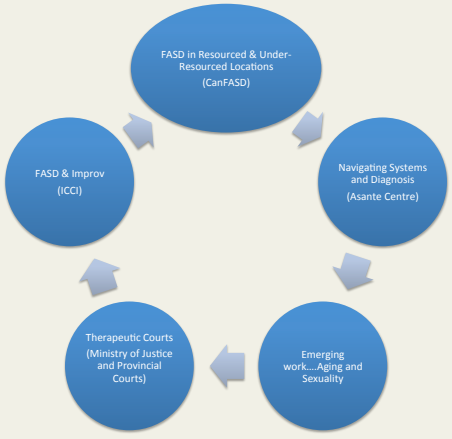


Dr. Michelle Stewart
University of Regina

Quick Background

- Research started in justice field
  - How do justice professionals understand FASD and how does that impact frontline practices
- Research mobilized into frontline resources and training(s)

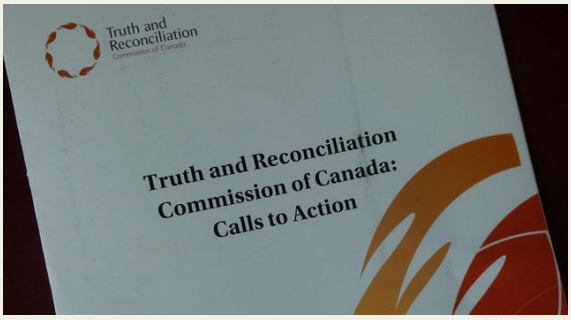
Then…
- Broader engagement in justice
- Strength-based projects emerged
- Cross-Canada project took shape



FASD in Resourced & Under-Resourced Locations

- Fall 2015: E-Scan released
- Cross-Canada Trip 22,500km and counting …
  - Emerging themes:
    - » FASD & justice must be a **deeply** contextualized
    - » Levels of tragedy and trauma are under-valued
    - » FASD across lifetime to think carefully about foster-to-justice pipeline; FASD as racialized and how that impacts policy and support + what it means when FASD is experienced by Aboriginal people(s) and First Nations communities.

Taking up the Calls to Action through Research Design and Dissemination



33. We call upon the federal, provincial, and territorial governments to recognize as a high priority the need to address and prevent Fetal Alcohol Spectrum Disorder (FASD), and to develop, in collaboration with Aboriginal people, FASD preventive programs that can be delivered in a culturally appropriate manner.

34. We call upon the governments of Canada, the provinces, and territories to undertake reforms to the criminal justice system to better address the needs of offenders with Fetal Alcohol Spectrum Disorder (FASD), including:

    i. Providing increased community resources and powers for courts to ensure that FASD is properly diagnosed, and that appropriate community supports are in place for those with FASD.

    ii. Enacting statutory exemptions from mandatory minimum sentences of imprisonment for offenders affected by FASD.

    iii. Providing community, correctional, and parole resources to maximize the ability of people with FASD to live in the community.

    iv. Adopting appropriate evaluation mechanisms to measure the effectiveness of such programs and ensure community safety.

Next Steps…

- Revised E-Scan – November 2016
- Preliminary Findings Canada Trip – December 2016
- FASD & Justice Symposium – Feb 2017
- FASD & Justice: Pre-Conference Day - March 2017
- Project Integrations:
  - – Website relaunch
  - – Expansion of Improv Project
  - – TRC and FASD Working Group

Thanks!

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Research supported by: Social Sciences and Humanities Research Council, Canada FASD Research Network, University of Regina.

Prevalence of Alcohol Consumption during Pregnancy and Fetal Alcohol Spectrum Disorder

Presented by
Svetlana (Lana) Popova, MD, PhD, MPH

Centre for Addiction and Mental Health, University of Toronto, PAHO/WHO Collaborating Centre Toronto, Canada

2016 FASD Research Priority Setting Day
University of Regina, Regina, Saskatchewan
August 31, 2016

OVERVIEW

- Prevalence of alcohol consumption during pregnancy in general population and Northern communities of Canada, as well as around the world
- Prevalence of FAS/FASD in different populations (general population, Northern communities, children in care and corrections) in Canada, as well as around the world
- WHO Global FASD Prevalence study (in progress)

Prevalence of Alcohol Use During Pregnancy and FASD

Manuscript submitted to The Lancet (Popova S, Lange S, Rehm J, et al.)

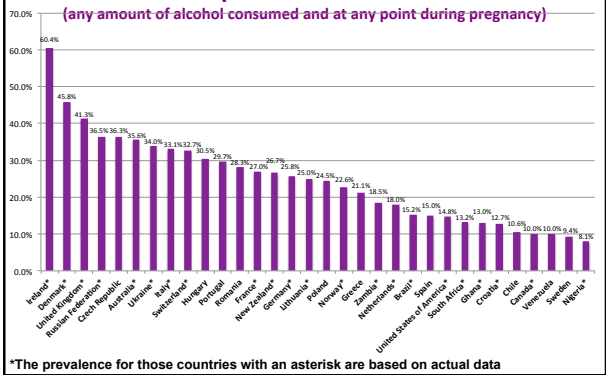
Objective: To investigate the prevalence of alcohol use during pregnancy and FAS/FASD by country, Word Health Organization region, and globally

Methodology

- **Literature search:** not limited geographically or by language of publication and included studies published between January 1984 and June 2015
- **Meta-analyses:** For those countries with 2 or more studies, assuming a random-effects model
- **Data prediction:** For those countries with no empirical studies (or less than 2), using fractional response regression modelling (for AC) and Monte Carlo simulation (for FAS/FASD)

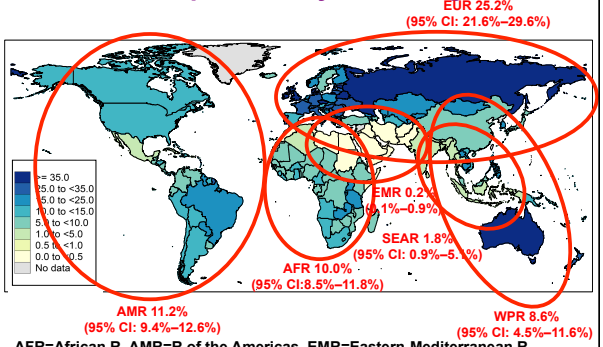
Pooled Prevalence of Alcohol Use During Pregnancy in General Population for Select Countries

(any amount of alcohol consumed and at any point during pregnancy)



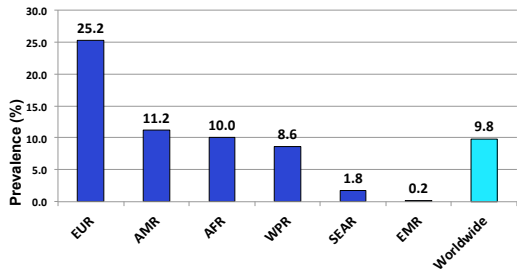
*The prevalence for those countries with an asterisk are based on actual data

Prevalence of Alcohol Use During Pregnancy in General Population by WHO Region, 2012



AFR=African R, AMR=R of the Americas, EMR=Eastern-Mediterranean R, EUR=European R, SEAR=South-East Asia R, WPR=Western Pacific R

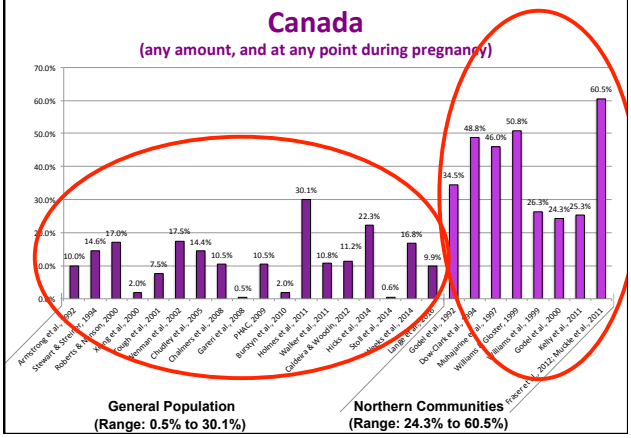
Prevalence of Alcohol Use During Pregnancy in General Population by WHO Region and Globally, 2012



AFR=African R, AMR=R of the Americas, EMR=Eastern-Mediterranean R, EUR=European R, SEAR=South-East Asia R, WPR=Western Pacific R

Prevalence of Alcohol Use During Pregnancy in Canada

(any amount, and at any point during pregnancy)

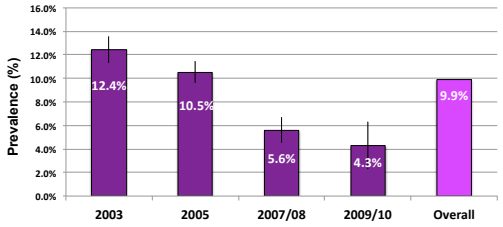


General Population (Range: 0.5% to 30.1%)

Northern Communities (Range: 24.3% to 60.5%)

Prevalence of Alcohol Use During Pregnancy in Canada (cont')

(any amount, and at any point during pregnancy)



Source: Statistics Canada, Canadian Community Health Survey (CCHS) 2003, 2005, 2007/08, 2009/10

Note: "Alcohol use during pregnancy" was an optional module for the provinces/territories after 2005. Therefore, these data are based on the provinces/territories that opted for this module in subsequent years.

Lange et al. (2016) *BJOG, 123*(6), 900-909.

Prevalence of Alcohol Use During Pregnancy (cont') Discussion

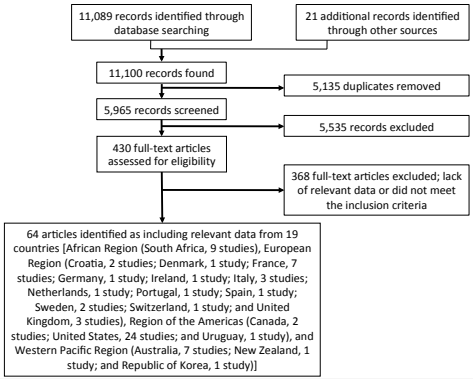
- Alcohol consumption during pregnancy is a significant public health concern worldwide and an established cause of FASD
- FASD is theoretically, largely preventable
- However, FASD may increase in the near future due to two reasons:

  1) the rates of alcohol use, binge drinking and drinking during pregnancy appear to be increasing among young women in a number of countries including Canada; and

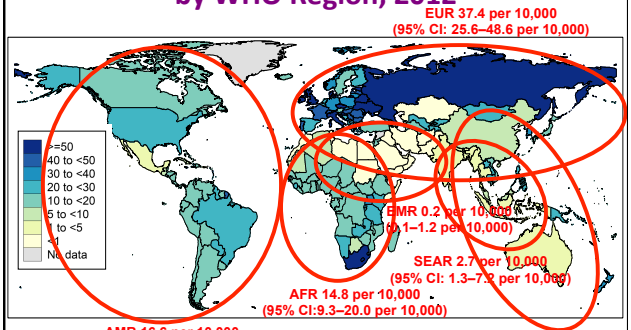
  2) a vast majority of pregnancies are unplanned

Prevalence of FASD

Flow chart for systematic literature search on prevalence of FAS/FASD

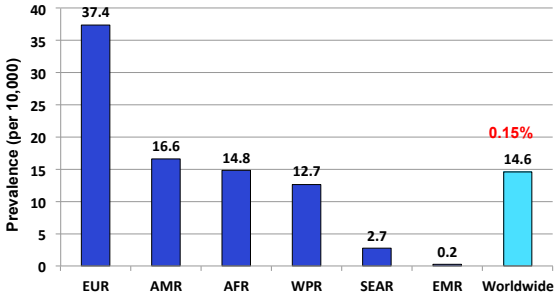


Prevalence of FAS in General Population by WHO Region, 2012



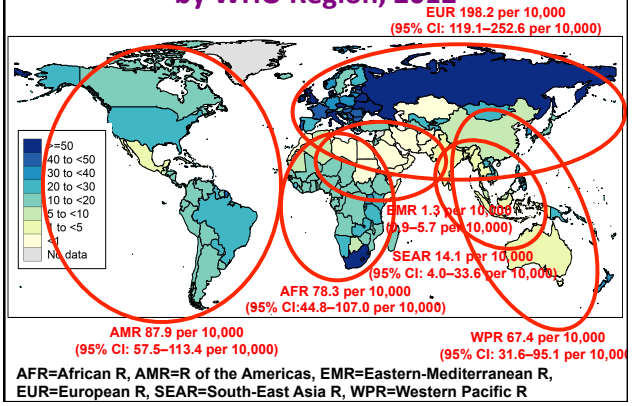
AFR=African R, AMR=R of the Americas, EMR=Eastern-Mediterranean R, EUR=European R, SEAR=South-East Asia R, WPR=Western Pacific R

Prevalence of FAS in General Population by WHO Region and Globally, 2012



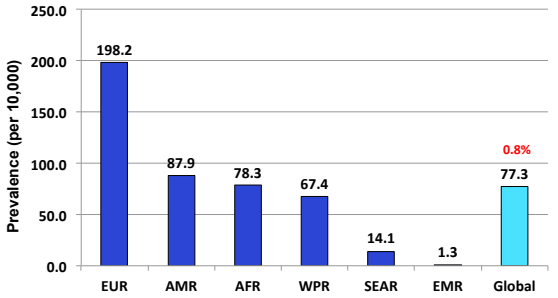
AFR=African R, AMR=R of the Americas, EMR=Eastern-Mediterranean R, EUR=European R, SEAR=South-East Asia R, WPR=Western Pacific R

Prevalence of FASD in General Population by WHO Region, 2012



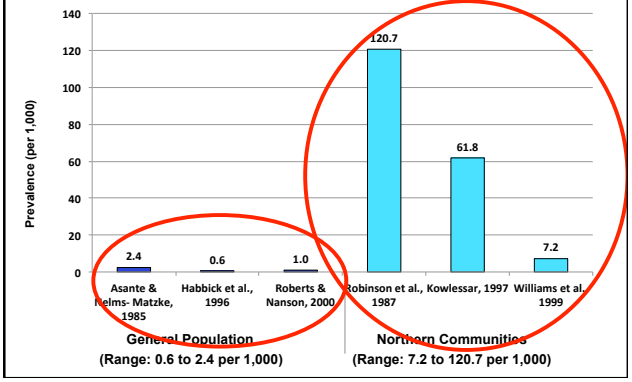
AFR=African R, AMR=R of the Americas, EMR=Eastern-Mediterranean R, EUR=European R, SEAR=South-East Asia R, WPR=Western Pacific R

Prevalence of FASD in General Population by WHO Region and Globally, 2012

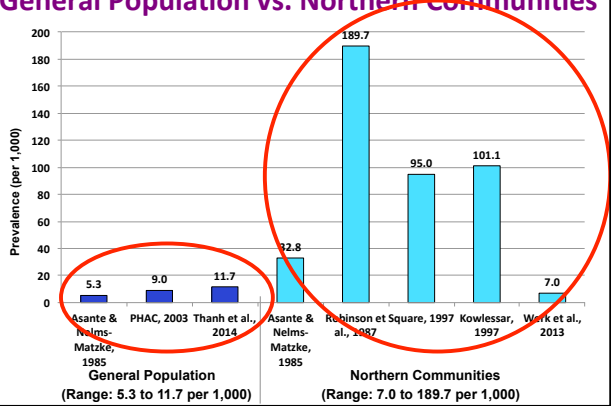


AFR=African R, AMR=R of the Americas, EMR=Eastern-Mediterranean R, EUR=European R, SEAR=South-East Asia R, WPR=Western Pacific R

Prevalence of FAS in Canada General Population vs. Northern Communities



Prevalence of FASD in Canada General Population vs. Northern Communities



Studies on the Prevalence of FAS/D among the General Population in Canada

Table 1. Study characteristics and prevalence of FAS and FASD among the general population in Canada

Reference	Country (State/Province/Territory)	Study year(s)	Sample size	Number of cases of FAS	Prevalence of FAS (per 1,000)	Number of cases of FASD	Prevalence of FASD (per 1,000)	Diagnostic guidelines/Case definition	Sex (% male)	Age range (years)	Method
Asante & Nelms-Matzke, 1985	Canada (Northwest British Columbia & Yukon)	1983-84	33,485	82	2.45	176	5.26	Guidelines established by the Fetal Alcohol Study Group of the RSA (Rosett, 1980)	63.0	0-16	ACA
Habbick et al., 1996	Canada (Saskatchewan)	1992-94	331,475	194	0.59	n/a	n/a	Guidelines established by the Fetal Alcohol Study Group of the RSA (Rosett, 1980) and the criteria by Sokol & Clarren (1989)		0.5-28.3	Mixed methods (ACA & PS)

ACA: Active case ascertainment; FAS: Fetal Alcohol Syndrome; FASD: Fetal Alcohol Spectrum Disorder; PS: Passive surveillance; RSA: Research Society on Alcoholism

Studies on the Prevalence of FAS/D among Northern Communities in Canada

Table 2. Study characteristics and prevalence of FAS and FASD among Northern communities in Canada

Reference	Country (State/Province/ Territory)	Study year(s)	Sample size	Number of cases of FAS	Prevalence of FAS (per 1,000)	Number of cases of FASD	Prevalence of FASD (per 1,000)	Diagnostic guidelines/Case definition	Sex (% male)	Age range (years)	Method
Asante & Nelms-Matzke, 1985	Canada (Northwest British Columbia & Yukon)	1983-84	5,065	n/a	n/a	166	32.77	Guidelines established by the Fetal Alcohol Study Group of the RSA (Rosett, 1980)	63.0	0-16	ACA
Kowlessar, 1997	Canada (Manitoba)	1981-90	178	11	61.80	19	101.12	IOM criteria (Stratton et al., 1996)	n/a	5-15	ACA
Robinson et al., 1987	Canada (British Columbia)	1984-85	116	14	120.69	22	189.66	Guidelines established by the Fetal Alcohol Study Group of the RSA (Rosett, 1980)	49.6	3-18	ACA
Werk et al., 2013	Canada	2006	11,868	n/a	n/a	83	7.00	n/a	n/a	0-5	PS (survey)
Williams et al., 1999	Canada (Manitoba)	1994-96	696	5	7.18	n/a	n/a	IOM criteria (Stratton et al., 1996)	n/a	n/a	Mixed methods (ACA & PS)

ACA: Active case ascertainment; FAS: Fetal Alcohol Syndrome; FASD: Fetal Alcohol Spectrum Disorder; IOM: Institute of Medicine; PS: Passive surveillance; RSA: Research Society on Alcoholism

The Prevalence of Children with FASD in Various Child Care Systems

The Prevalence of Children with FASD in Various Child Care Systems (cont')

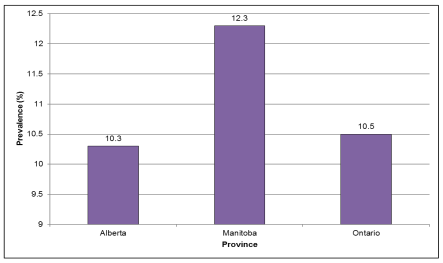
Literature Review

- **In total, 33 studies were identified and included in the analysis (*Lange et al., 2013, Pediatrics; 132: e980-e995*)**
- **Data on the prevalence of FAS/D in child care systems are available from only 11 countries/regions, including: Brazil, Chile, Canada, Eastern Europe (Romania, Ukraine, Moldova), Israel, Russia, Spain, Sweden, and USA**
- **The prevalence was reported for six major settings: boarding schools, child welfare agencies, foster care, homes for children with mental deficiencies, orphanages, and mixed-care settings**

The Prevalence of Children with FASD in Various Child Care Systems (cont')

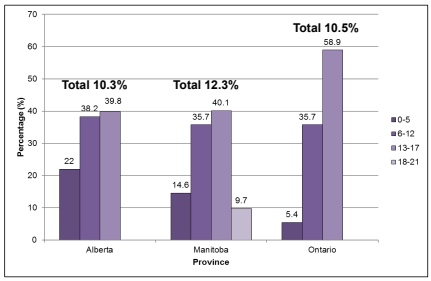
- **Fuch et al. (2005): 11.3% of children and youths in care have FASD in Manitoba**
- **Burge (2007): 3.3% children who are permanent wards in Ontario have FASD**
- **=> Prevalence of FASD in child welfare system is 3 to 11 times higher as compared to FASD prevalence in general population of Canada (1%)**

The Prevalence of Children with FASD in Various Child Care Systems (cont') Canada



Source: Tri-Provincial FASD Project, a collaborative initiative between ON, MA, AB (Fuchs & Burnside, 2014)
Note: Includes both diagnosed and suspected cases of FASD

The Prevalence of Children with FASD in Various Child Care Systems (cont') Canada (by age groups)



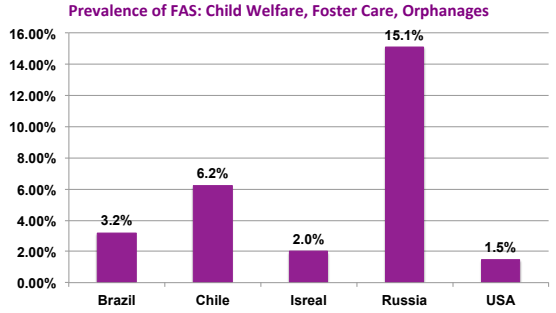
Source: Fuchs & Burnside, 2014
Note. In Alberta and Ontario, children in care include children 0-17 years of age; In Manitoba, children in care include children 0-21 years of age

The Prevalence of Children with FASD in Various Child Care Systems (cont')

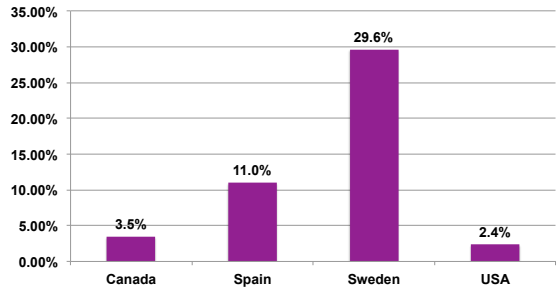
- Wide Ranges -

- **The prevalence of FAS ranges from 5 per 1,000 (child welfare system, USA; Ringeisen et al., 2008) to 680 per 1,000 (orphanage for children with special needs, Russia; Palchik & Legonkova, 2011)**
- **The prevalence of FASD ranges from 37 per 1,000 (foster care, USA; Astley et al., 2002) to 521 per 1,000 (adoptees from Eastern Europe, adopted in Sweden; Landgren et al., 2010)**

The Prevalence of Children with FASD in Various Child Care Systems (cont')



The Prevalence of Children with FASD in Various Child Care Systems (cont')



The Prevalence of Children with FASD in Various Child Care Systems (cont')

- The pooled prevalence of FAS in child care settings is approximately 70 times higher than the prevalence of FAS in the general population of Canada
- Screening for FASD in this high-risk population is necessary, in order to facilitate early diagnosis!

Studies on the prevalence of FAS/D among children in care in Canada

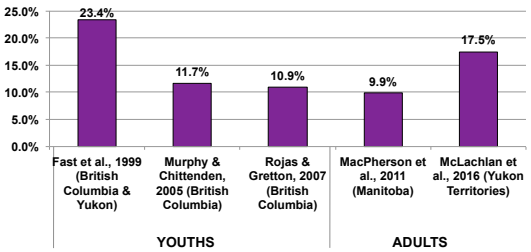
Table 3. Study characteristics and prevalence of FAS and FASD among children in care in Canada

Reference	Country (Province, Territory or State, if available)	Study year(s)	Sample size	Number of FAS cases	Prevalence of FAS (per 1,000)	Number of FASD cases	Prevalence of FASD (per 1,000)	Diagnostic guidelines/ Case definition	Type of Institution/ Country of origin for adoptees[a]	Sex (% male)	Age range (years)	Method
Burge, 2007	Canada (Ontario)	2003	429	n/a	n/a	14	33	Not specified	Permanent wards	57.0	0-18 (Avg. age 7.3)	PS
Fuchs et al., 2005	Canada (Manitoba)	2004-05	5,664	n/a	n/a	640	113	Not specified	Child welfare agencies	n/a	0-20	PS
Fuchs & Burnside, 2014	Canada (Alberta, Manitoba, & Ontario)	2013	15,623	n/a	n/a	1,776[b]	114	Canadian diagnostic guidelines (Chudley et al., 2005)	Child welfare agencies	51.3	0-16/18/ 22[c]	ACA
Robert et al., 2009	Canada (Quebec)	2004-06	29	1	34.5	2	69	4-Digit Diagnostic Code (Astley et al., 2004	Adoptees from Europe (BLR 35%, GEO 3%, POL 7%, ROU 10%, RUS 42%, YUG 3%)	59.0	4.2-8.9	ACA

[a] Country of birth. The first column indicates the country into which the children have been adopted (the country where the study was based)
[b] Includes both diagnosed and suspected cases of FASD
[c] Upper age cut-off differs depending on the province
ACA: Active Case Ascertainment; FAS: Fetal Alcohol Syndrome; FASD: Fetal Alcohol Spectrum Disorders; PS: Passive Surveillance

Prevalence of FASD in Canadian Correctional System

(Range – youths: 10.9% to 23.4%, adults: 9.9% to 17.5%)



Youths with FASD are *nineteen times* more likely to be incarcerated than youths without FASD in any given year (Popova et al., 2011)

Popova et al. (2011) *Canadian Journal of Public Health*, *102*(5), 336-340.

Studies on the Prevalence of FAS/D among the Canadian Correctional Population

Table 4. Study characteristics and prevalence of FAS and FASD among the correctional population in Canada

Reference	Country	Study year(s)	Total population of offenders/Sample size	Number of FAS cases	Prevalence of FAS (per 1,000)	Number of FASD cases	Prevalence of FASD (per 1,000)	Diagnostic guidelines/Case definition	Method
Burd et al., 2003	Canada (National)	2001-02	148,797; inclusive of all major correctional facilities	Actual: 13 Estimated: 49 & 417	Actual: 0.087 Estimated (based on existing prevalence estimates): 0.33 & 2.8	Estimated: 1,354 (FAS & ARND)	Estimated: 9.1	Not specified	PS
Fast et al., 1999	Canada (British Columbia)	1995-96	287 youths (12-18 years of age); Inpatient Assessment Unit of Youth Forensic Psychiatric Services	3	10.45	64 (FAE: 52 pFAS & 12 ARND)	233.5	Definition by Sokol & Clarren (1989)	CB
MacPherson et al., 2011	Canada (Manitoba)	2005-06	91 adult male offenders (19-30 years of age); male-only medium-security penitentiary for adults	n/a	n/a	9 (1 pFAS & 8 ARND)	98.9	Canadian diagnostic guidelines (Chudley et al., 2005)	CB & PS
McLachlan et al., unpublished	Canada (Yukon)	2014-15	80 adults (18-40 years of age); Custodial and community settings; supervised on an active legal order	n/a	n/a	14 (2 pFAS & 12 ARND)	175.0	Canadian diagnostic guidelines (Chudley et al., 2005)	ACA
Murphy et al., 2005	Canada (British Columbia)	2004	137 youths (14-19 years of age); Juvenile detention centres	n/a	n/a	16 (FAS/FAE)	116.8	Not specified	PS
Rojas & Gretton, 2007	Canada (British Columbia)	1985-2004	230 youths (12-18 years of age)	n/a	n/a	25 (FAS/FAE)	108.7	Case definition provided	PS

ACA: Active Case Ascertainment; ARND: Alcohol-Related Neurodevelopmental Disorder; CB: Clinic-based; FAE: Fetal Alcohol

Why is it Important to Detect Children/Adults with FAS/FASD?

The cost of inaction is high!

- Identification and diagnosis pave the way for interventions and supports, which may help prevent secondary disabilities (e.g., mental health problems, disruptive school experiences, trouble with the law, dependent living and inappropriate sexual behaviour
- The earlier the child is identified and diagnosed, the better!
- Having a diagnosis of FAS is a protective factor – Early diagnosis and providing an appropriate environment decreases these risks for secondary disabilities up to four fold (e.g., Burd et al., 2003)

More Rigorous Epidemiological Prevalence Studies are Needed!

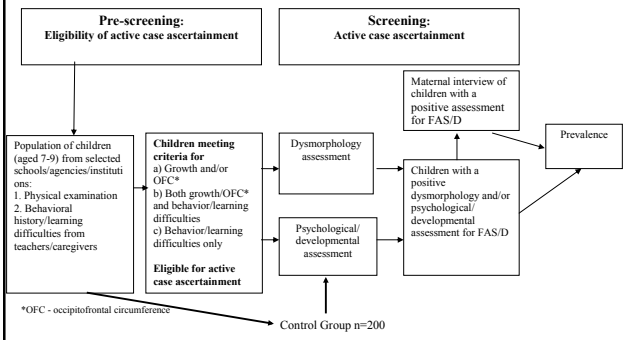
- To understand the severity and impact of FASD
- To plan policies and programs that will benefit people with FASD and to prevent children from being born with these conditions
- Data on the incidence/prevalence of FASD are completely absent for the majority of countries
- Existing data is outdated and have many methodological limitations
- FASD is expensive!
- Urgently need to monitor and lower the rate of these conditions effectively throughout the world

World Health Organization Global Prevalence Study on FASD

WHO Research Initiative on Alcohol, Health and Development with support of National Institute on Alcohol Abuse and Alcoholism (NIAAA)

- Objective: To estimate the prevalence of FASD among children (7-9 years of age) using an active case ascertainment approach
- Participants: ~10 selected countries in Europe, Africa and Asia as well as Canada
- CAMH, a Collaborating Centre of the WHO, will provide research support to all involved countries

Global Prevalence Study on FASD Method: Active Case Ascertainment



Centre for Addiction and Mental Health
Centre de toxicomanie et de santé mentale

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Last Word

These cost figures, as a powerful argument, should not be misused for the further stigmatization of mothers with alcohol dependence, but rather, they should be used as a strong scientific evidence base demonstrating the cost and utilization requirements for policy makers formulating policies on FASD