

Strength and Support: Addressing FASD as a Women's Health Issue

Amy Salmon, PhD

Clinical Assistant Professor, UBC School of
Population and Public Health

Managing Director, Canada Northwest FASD
Research Network

IHE Consensus Development Conference on

**Fetal Alcohol Spectrum Disorder
(FASD) – Across the Lifespan**

October 7 to 9, 2009, The Westin Edmonton, Edmonton, Alberta



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FASD is a women's health issue

- In Canada, care for women in pregnancy has been delivered from a social determinants of health framework: *“healthy women have healthier babies”*
- Alcohol seems to have a greater teratogenic potential in the presence of “permissive and provocative co-factors”, including low socioeconomic status. *(i.e. E. L. Abel and J.H. Hannigan (1995) Maternal risk factors in fetal alcohol syndrome: Provocative and permissive influences. Neurotoxicology and Teratology 17:4. 445-462)*



What Determines Health?

Social determinants of health include:

- Income and social status
- Social support networks
- Education
- Employment and working conditions
- Social environments
- Personal health practices
- Healthy child development
- Culture
- Gender

Public Health Agency of Canada (2001). What Determines Health?

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Social determinants of health are unevenly supported by governments

- **Child development** and **personal health practices** were self-reported by the majority of health regions to receive *greatest* attention, both internally and through intersectoral activities.
- **Culture, gender** and **employment/working conditions** received *least* attention in most regions.

Frankish, C.J. et al (2007) Addressing the non-medical determinants of health: A survey of Canada's health regions. CJPH January/February 2007, Vol.98, No.1

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What is known about women who give birth to children with FASD?

Women who give birth to children with FASD are more likely to have their own health and wellbeing compromised by:

- Addictions
- Mental ill health- including psychiatric disorders, high stress levels, depression, anxiety, trauma, grief, loss
- Violence
- Isolation
- Poverty
- Lack of supportive health and social care *before, during, and after pregnancy* [Astley, S. J., Bailey, D., Talbot, C., & Clarren, S. K. \(2000\). Fetal Alcohol Syndrome \(FAS\) Primary Prevention through FASD Diagnosis II: A comprehensive profile of 80 birth mothers of children with FAS. *Alcohol and Alcoholism*, 35\(5\), 509-519.](#)



Shame and Blame

- Lives of birth mothers of children with FASD are imbued with shame and blame
- Shame and blame approaches to FASD prevention are ***ineffective at reducing drinking among highest risk groups*** and result in ***missed opportunities for providing supportive care***

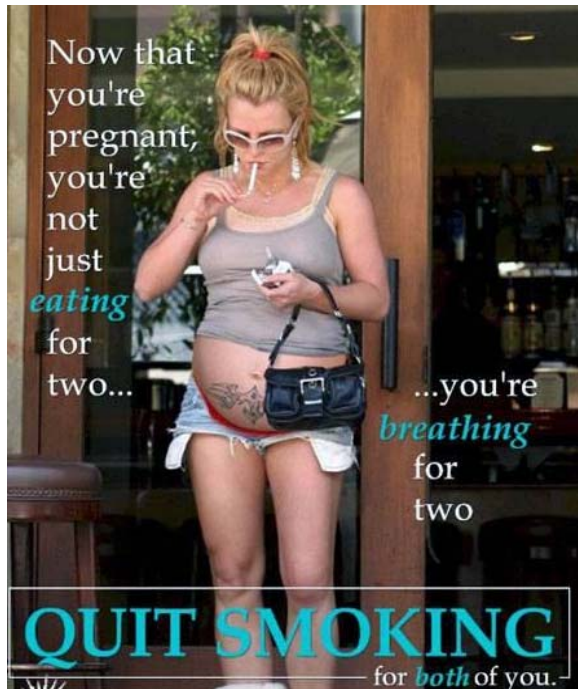


“ I was the one that was advocating to get her all these supports. I’m the one that put her on all the waiting lists, and signed her up, and filled out all the paperwork, and asked for and advocated for myself. And now, because she’s having problems, the principal is telling me it’s coming from home. Like, that’s where all the problems stem from. And I told him, “no, there’s stuff going on at school, too”. And I’ll take my blame, or my responsibility part of it, but there’s stuff going on at school. And he’s like, ‘no, I don’t think that’s the case.’ ”

(Super Woman)



Guilt, Shame, and “Fetal Abuse”



Access to addictions treatment for mothers

Barriers to accessing treatment cited by mothers:

- Shame (66%)
- Fear of losing children (62%)
- Fear of prejudicial treatment on the basis of their motherhood status (60%)

N. Poole and B. Isaac (2001). Apprehensions: Barriers to Treatment for Substance Using Mothers. Vancouver: BC Centre of Excellence for Women's Health

Social Support

Social Isolation and marginalization result in decreased access to timely and supportive care *(Salmon 2007)*

“It’s like I have to beg, and if it’s not begging for what I need, for the support for what my kids need, I’ll have to fall on my face before they recognise that I have some issues or problems, and that’s the frustrating thing... it makes life a lot harder.” *(Salmon and Ham 2008)*

“When you don’t get health care, you don’t get a sense of belonging, you don’t get the sense of your importance” *(VANDU Women CARE Team 2009)*



Mothers see social support as critical to having a healthy pregnancy

- Interventions to increase social support for pregnant women and new mothers with substance use problems reduce the likelihood of a future substance-exposed pregnancy (ie: P-CAP programs: Grant 1996; Shewey: Poole 2000, Burgelhaus and Stolk 2005; Breaking the Cycle: 2002)

“They still took me for who I was, they didn't care that I used, they didn't care that I was using when I was pregnant, they just wanted to make sure that I was fed and had somewhere to go...I honestly think that if it wasn't for this place, my children probably wouldn't have survived my whole pregnancy.” (Salmon and Ham 2008)



Lack of system coordination and cohesion also increase isolation and frustrate efforts to provide timely, comprehensive, and supportive care

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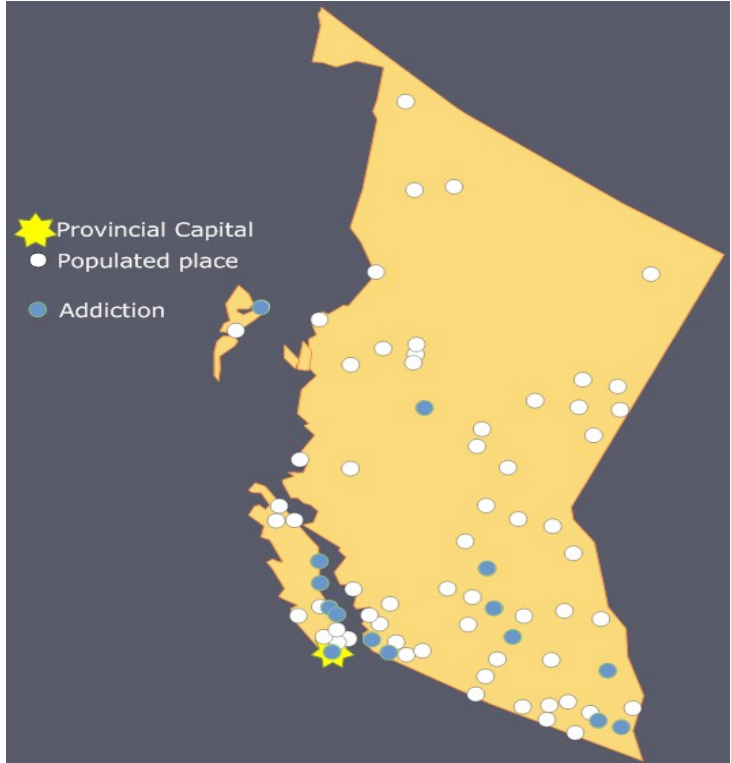
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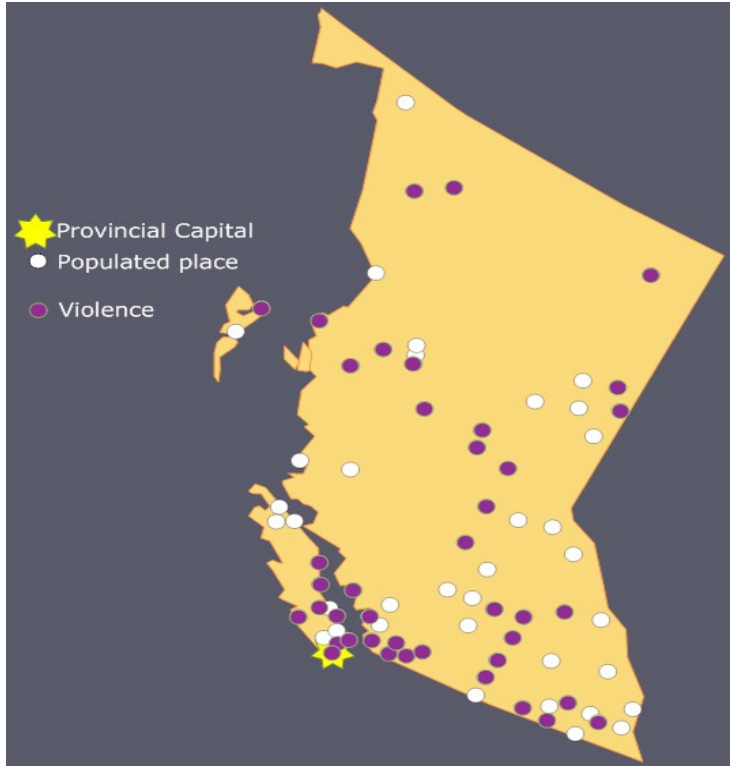
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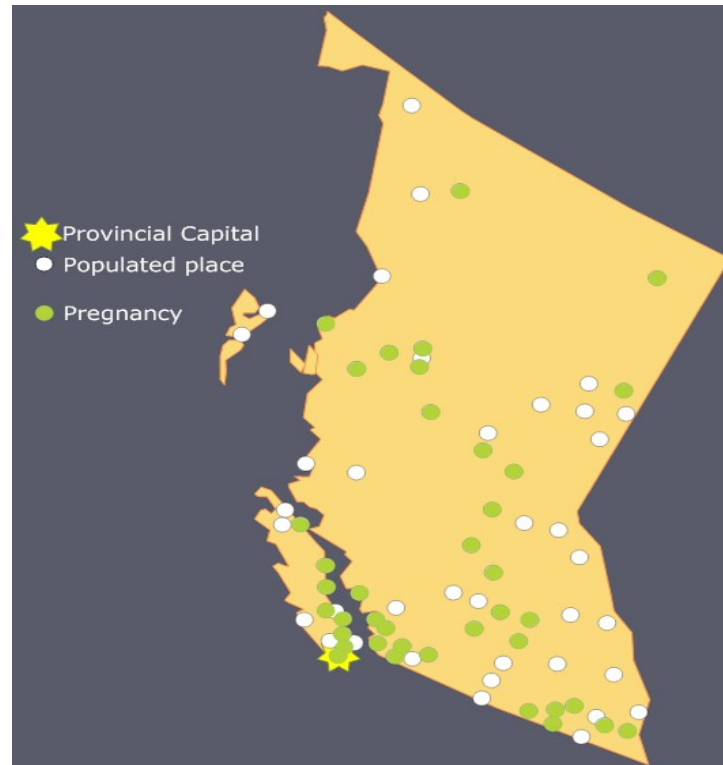
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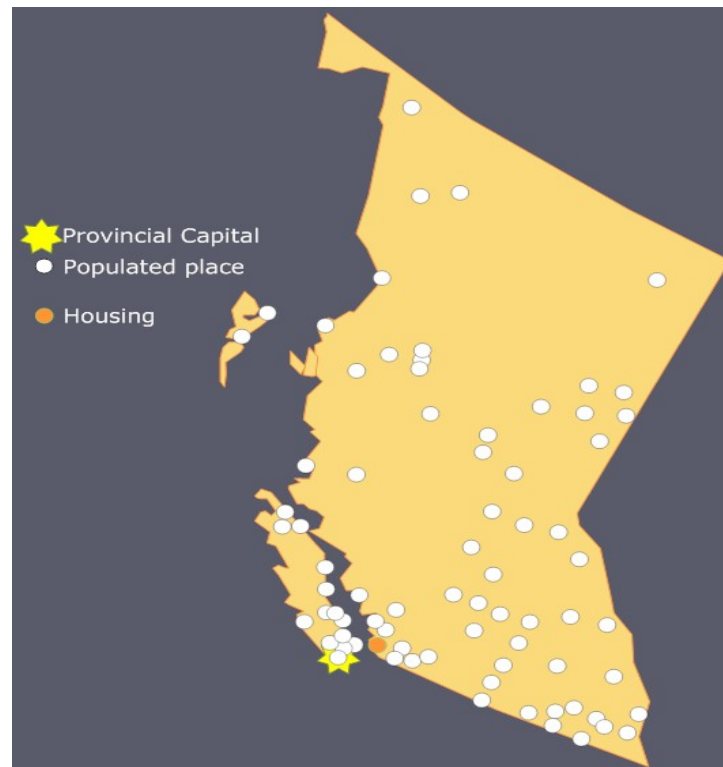
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Recommendations

Within services: The most important aspect of service provision is a welcoming, supportive, non-judgmental approach

- addressing fear, shame, blame, stigma, misinformation and discrimination
- “meeting women where they are at”
- helping women with related harms



Recommendations, cont.

- ***Between services:*** Intersectoral collaboration is critical. This requires: collaborative efforts at training, development of program mandates and policies, and support for staff. Collaboration is especially important between:
 - Primary care and maternity care
 - Addictions treatment
 - Mental health services
 - Child welfare authorities
 - Anti-violence services
 - Income and employment services



Conclusions: Increasing system capacity for FASD prevention

- Recognition of FASD as a women's health issue
- Responses to maternal substance use must be meaningful, effective, and compassionate
- This requires increased system capacity for interagency cooperation wrapped around the mother, child, and family

