Extending Learning about Girls Women, Alcohol and Pregnancy A Virtual Learning Series

Webinar 1

Working with women who may themselves have FASD

Sponsored by the BC Ministry of Health , Population Public Health
in collaboration with the British Columbia Centre of Excellence for Women's Health

British Columbia
Centre of Excellence
for Women's Health

Outline

- Women with FASD - Anne Guarasci
- Research on strategies for working with women – Dr. Deborah Rutman
  - Pause for questions or comments
- Successful strategies from the SOAR program – Hanna Scrivens and Rita Marshall
- Summary - Anne Guarasci
  - Pause for questions or comments

- Moderators – Nancy Poole, Cristine Urquhart and Fran Jasiura

- Anne Guarasci
- College of New Caledonia

Program Participant Profile

- Poverty
- Unemployment
- Lack of transportation
- Low education
- Crowded/unstable living
- Childhood trauma
- Domestic violence
- Depression/low self esteem
- Dependency issues
- Justice system involvement

Secondary Disabilities Study

- Unemployment
- Early School Drop Out (Low Education)
- Dependent Living
- Mental Health Issues
- Alcohol Drug Problems
- Trouble with the Law
- Inappropriate Sexual Behaviour
- Confinement

Striessguth, A., Barr, H., Kogan, J., & Bookstein, F. (1996)

Real life stories that illustrate how FASD can present:

- Literal minded – health/medical (2)
- Gaps in short term memory
- Safety

Characteristics of FASD

Physical brain injury

Cognitive pace

Sequencing

Over stimulation

Over/under sensitive

Developmental age

Fatigue

Perseveration

Easily Misled

Impulse control

Generalizing information

Abstract concepts

Staying still

Paying attention

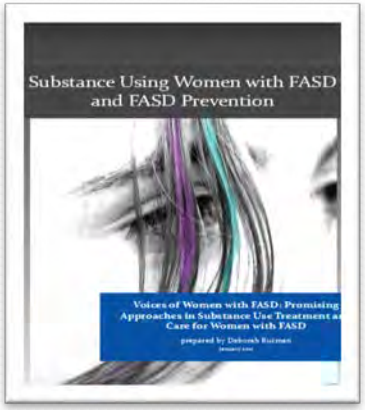
Predicting outcomes

Reality

Memory

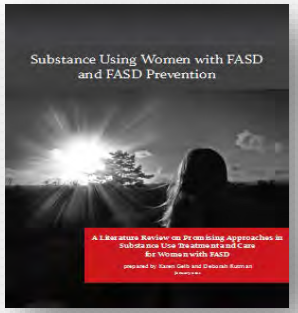
- Deborah Rutman
- Note Bene Consultants
- University of Victoria

Substance Using Women with FASD & FASD Prevention Project



Project's Purpose

- To expand knowledge regarding promising substance use treatment approaches for women living with FASD.



Why do this project?

Research tells us women with FASD are at high risk of having a baby with FASD

Practice wisdom tells us that women with FASD with substance use problems:

- don't do well in traditional programs
- are "very challenging" & have "poorer outcomes"

Research Methodology

Project had 3 inter-related components:

1. Comprehensive review of literature and practice knowledge
2. Interviews with service providers in British Columbia
    - 40 interviews (from 12 BC communities)
3. Interviews with substance-using women with (suspected) FASD
    - 13 women (from 4 communities)

Women's Lives
Situating Substance Use & FASD

- 12 of the 13 women were mothers.
- All mothers had involvement with child welfare.

- The majority reported being survivors of violence, abuse or trauma, and all reported mental ill-health issues.
- 10 of the 13 women shared information about their mother drinking in pregnancy; four self-identified as having FASD; ***none reported having been diagnosed***.

Women's Lives
Situating Substance Use & FASD

Core constellation of issues:

- Parenting/child welfare/child care
- Lack of/need for safe & affordable housing
- Mental health: depression, trauma, shame, guilt
- Poverty / income needs

Overarching theme in women's self-description:

- Women don't compartmentalize their substance use from other areas of life
- Most likely, they won't disclose having FASD.

Findings from interviews with women

What Works:

- Focus on women's readiness for change
- Relational approach - *wherein women feel respected and safe, and not judged, blamed or shamed*
- Wholistic, women-centred, integrated programs
- One-to-one care from a skilled professional *combined with* women-centred, group-based support
- Linkages with FASD-related programs
- Flexibility in extending program's duration

What does an FASD-informed approach look like?

- **Program, Environmental & Practice Accommodations**
  - ✓ Reminder calls and transportation assistance
  - ✓ Consistency in program timing
  - ✓ Flexibility for late arrivals or missed appointments
  - ✓ Reducing noise level or visual clutter
  - ✓ Adapting motivational interviewing

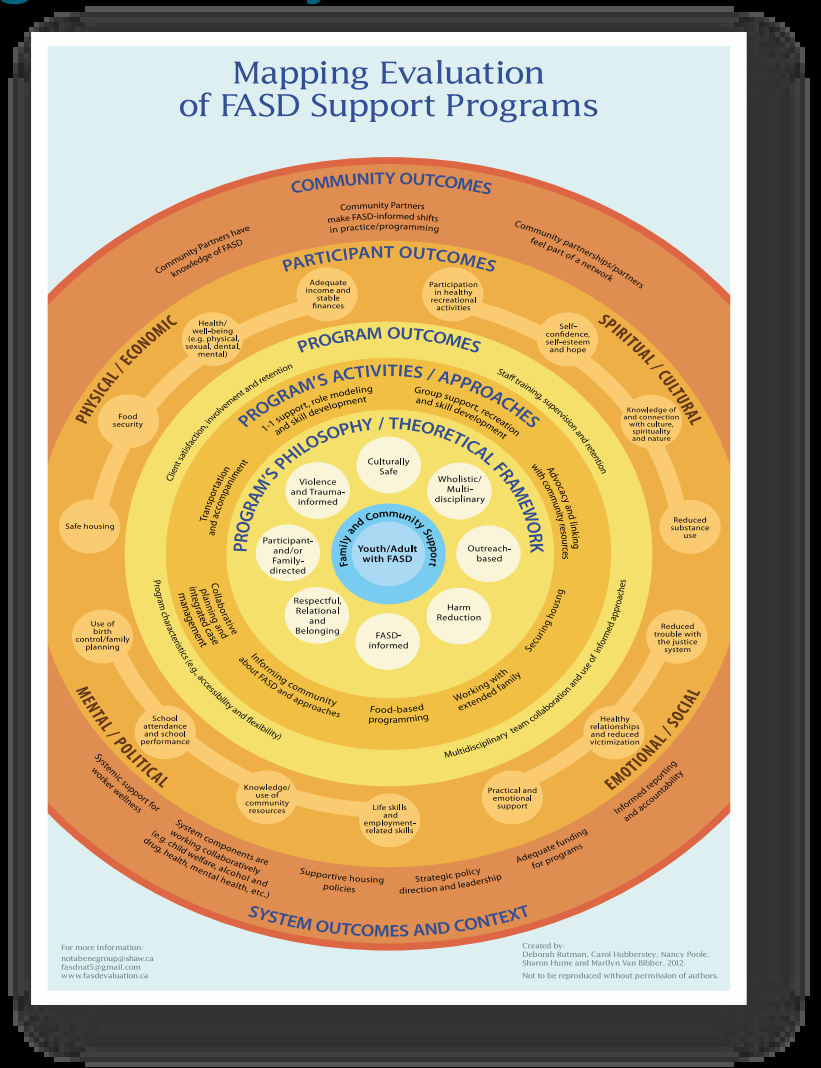
- **Wholistic, Collaborative Programming & Advocacy**
  - ✓ Individualized support & Intensive case management
  - ✓ Supportive housing
  - ✓ Collaborating with child welfare on child protection issues

- **Ongoing FASD Training & Service Provider Support**
  - ✓ Skilled supervision; Smaller case loads; Additional staffing

Towards an Evaluation Framework for Community-based FASD Prevention Programs Project

We created Visual Maps that includ

- Theoretical/philosophical foundations of programs
- Program activities and outcomes
- Participant outcomes
- Community outcomes & context
- Systemic outcomes
- **Created project website:** www.fasd-evaluation.ca



FASD-informed Approach as a core component of Program Philosophy

Some reflective practice questions:

- Why do we do things in a particular way?
- Is our approach responsive to the needs of our program participants with FASD?
- **How would we know?**

Questions or comments?

- Hanna Scrivens
- Rita Marshall
- Intertribal Health, SOAR Program

SOAR Mentoring Program

- FASD Mentoring Programs follow the PCAP Model. There are 7 programs in BC that work with First Nations women who are pregnant or parenting and are at risk of using alcohol or drugs during pregnancy

What works for us

- Building a positive and trusting relationship
  - Confidentiality is very important
  - Remember that executive functioning is impaired and it is not her fault…don't take personally when things don't go as you expect or hope
  - Remember she has likely experienced lots of trauma and negative experiences – an unexpected response may be due to being triggered
  - Try to be curious and ask what is happening?

- Advocating and building a support network
  - Professional and family support
- Brainstorm who her support people are
- Involve family supports and partners in the plan – encourage support network involvement
  - Crucial for success

- Reminders – use texting and calendars to remind of appointments with us and other service providers
- Make it safe to say “I don’t understand” – ask her what she understands or to share what she has heard you say
- Go to appointments with physicians or social workers to be an advocate and ensure she truly understands expectations
- Observe her actions to confirm understanding – generalizing information is difficult – ice tea story
- Use picture books to demonstrate multiple steps – ie. how to mix formula and sterilize bottles properly

- Work with her on setting goals
  - Review steps – write it out – may need to do this many times
  - In some cases, it takes a lot longer
  - What skills / knowledge does she have and what would help (ie learning to use the bus, process of finding housing, family planning)
- Put information into chunks
- Help fill in the gaps – don't assume she understands everything
- Verbal skills can be misleading – may seem to understand and be capable of more than they really are, which can lead to confusion in communication.

- Educating both the woman you work with and family/ professionals about FASD – many professionals have limited understanding
- Many of those who are affected say they have never learned what FASD is – Dad's story
  - "How do you know me?"
  - *"No one-no one, not my doctor or school has ever told me about FASD. Wish I knew back then."*

- Review the characteristics of FASD with women and their partners –
- Simplify the characteristics and use the first person
  - I often say yes to things even when I don't understand
  - I have a hard time filling out forms
  - I have a hard time managing money
  - I often get fooled by other into lending them money or buying things for them
  - I get myself into unsafe situations (especially with sexuality and exploitation)

- Ask what she has learned from an experience or group? (may reveal gaps in understanding)
- Help her link her experience – what do you usually do? What can you do next time?
- Develop a crisis plan – who can she call?

- Women often feel relieved when they learn about the characteristics of FASD – less self-blame
- “I have a problem – I am not the problem” (from Diane Malbin)

- Be creative and collaborative with other services to get womens' needs met
- Support participation in cultural activities
- Organizational support and understanding of FASD and the additional time needed to provide excellent care is key
  - Clinical supervision/ support for staff

Questions or comments?

Summary

Strategies

- Relationship
- Concrete
- Consistency/Routine/Structure
- Repetition
- Simplicity
- Specific
- Supervision
- Recognition/action around basic needs
- Assistance/support (forms, navigating systems)
- Advocacy
- Creativity/Flexibility
- Cultural safety

Adapted from "Eight Magic Keys: Developing Successful Interventions for Students with FAS" D. Evensen and J. Lutke 1997

Supportive Agency Policies

No limits to service based on:

- Missed appointments
- Discomfort with formal institutions
- Lack of transportation
- Location of residence
- Inability to understand expectations
- Inability to follow through
- Literacy issues

Other considerations

Ethical considerations in absence of diagnosis

Determining the level/type of support

Ongoing training/support for frontline workers

Policies to support working with women who have FASD

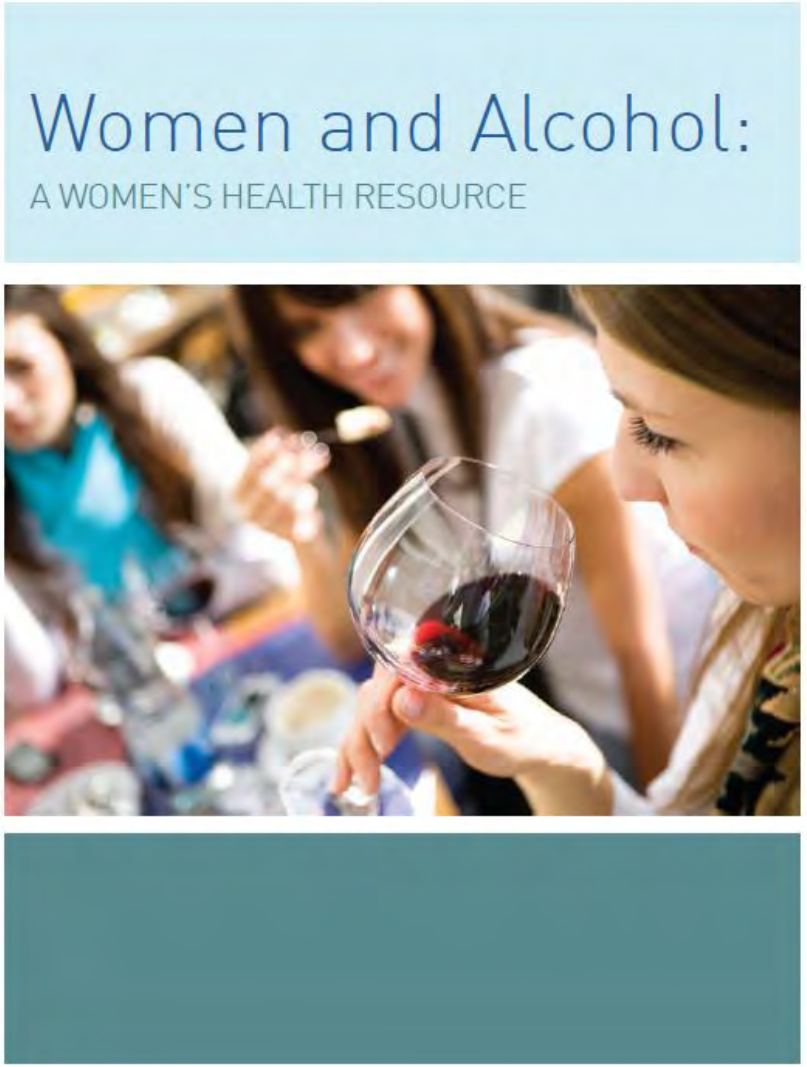
Websites for further reading

FASD informed practice for community based programs, College of New Caledonia www.cnc.bc.ca/programs-courses/FASD_Advanced_Diploma_Online/Resources

FASD informed as a principle when planning programs and evaluation – www.fasd-evaluation.ca/

Substance using women with FASD research documents http://www.uvic.ca/hsd/socialwork/research/home/projects/index.php

KnowFASD - Offers info on signs of FASD for girls and women at various ages www.knowfasd.ca

Maternal and child health for First Nations women www.fnhc.ca/index.php/health_actions/maternal_and_child/

Next in the series –
A discussion of the use of this updated and enhanced resource on women and alcohol
Date TBD