

The Bio-Parent Experience: Findings from Research and Implications for Service Providers

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The FASD Learning Series is part of the Alberta government's commitment to programs and services for people affected by FASD and those who support them.

Session Goals

Participants will understand and appreciate:

- A conceptual framework for the lives of birth mothers which attends to:
 - Research timeline on FASD
 - Context: environment and ecology
 - Birth mother's experience from a feminist lens
 - Complexity of circumstances

Session Goals

Participants will be informed about:

- CanFASD Northwest Research Network Action Team on FASD Prevention from a Women's Health Determinants Perspective
- What works for birth mothers: implications for service responses

“ I heard your mother drank when she was pregnant with you”

Voice of a child diagnosed with FASD

Quote from the video: Finding Hope: Fetal Alcohol Spectrum Disorder, Force Four Entertainment Inc. 2009

FASD is a Moralized and Stigmatized Disability



Women throughout the Western world and non-Western world give birth to children affected by alcohol exposure on a daily basis. Some have children with FASD and some don't.

***Critical Question:
Why do women drink when pregnant?***

Differing perspectives exist whether women who drink while pregnant are alcoholic or social drinkers who overuse alcohol on occasion (i.e. binge drinking)

“Dependence develops, as choice, over time, becomes necessity.”

- R. Durrant & J. Thakker

Durrant, R. & Thakker, J. (2003). *Substance Use & Abuse: Cultural and Historical Perspectives*. Thousand Oaks: SAGE, p.ix.

“I have never met a mother who drank during pregnancy because she wanted to hurt her child or because she didn’t care.”

- Dr. Ann Streissguth

Streissguth, A. (1997). *Fetal alcohol syndrome: A guide for families and communities*. Baltimore, MD: Brookes, p. 264

Brief Historical Overview

- **Brief Historical Overview**
- **Brief Historical Timeline**
- **Brief Historical Timeline:
Women’s Studies**
- **Brief Historical Timeline:
A Ten Year Profile,
1999 - 2009**

Brief Historical Overview

1973

First article on
FAS published in
North America
(Jones, Smith,
Ulleland & Streissguth)

Brief Historical Overview

1980 - 2000

Dissemination of knowledge on FAS from scientific/research fields to practice including early research on birth mothers of children with FAS.

Primary Finding: Birth mothers not present in their children's lives. Children were often in the care of the state.

(Astley, Bailey, Talbot & Clarren, 2000)

Brief Historical Overview

2000 - 2009

- Rapid development of scientific knowledge about FASD
- Focus on cause and prevention
- Term FASD emerges in research literature*

Broad dissemination of knowledge through learning conferences - moving science to fields of practice such as medicine, psychology, social work including child welfare development of CanNorthwest FASD Research Network**

*Streissguth & O' Malley, 2001

**Dr. Sterling Clarren, CEO
<http://www.canfasd.ca/>

Brief Historical Timeline

- 1700s – Concern raised by London College of Physicians that children born to parents using alcohol had health problems*
- 1800s – Early research about alcoholism**
- Children of women “incarcerated during pregnancy and thus unable to drink had higher survival rates than their siblings born when the mother was free to drink during pregnancy”**

*Boyd, 2004

**Sullivan, n.d. as cited in Armstrong, 2003, p. 56

Brief Historical Timeline

- 1900s – “It is true that if a woman keeps in a besotted state during the entire period of gestation the tissues of the child in utero are necessarily injured; but the injury here in one acquired by the developing child: it is no sense an inherited one [injury]”*
- Development of Eugenics Movement – Elderton and Pearson, 1910, “saw alcoholism...as a way to demonstrate the link between unfit parents and unfit progeny, a basic plank of eugenic thinking”**

*Leonard Darwin, as cited in Armstrong, 2003, p. 55

**Armstrong, 2003, p. 43

Brief Historical Timeline: Women’s Studies

- 1980s – Emerging agenda for qualitative research from a feminist lens
- “Studying women is not new, studying them from the perspective of their own experiences so that women can understand themselves in the world can claim virtually no history at all” (p. 8).
- Developing awareness of substance use during pregnancy: *Cocaine and Pregnancy, Narcotics and Pregnancy, Tobacco and Pregnancy, Alcohol and Pregnancy* (Boyd, 2004)

Emerging Concern:

Limited focus on alcohol use negates examination of environmental factors in women’s lives.

Brief Historical Timeline: Women's Studies

- Cassidy, Lord and Mandell (1995) suggested it was time for research to consider the experiences of "differently raced, abled and classed women" (p.32); and suggested that poor women experience a sense of defeat and "fear, anger, isolation, frustration and despair characterize their daily lives" (p. 38).
- Women who give birth to children with FAS often live in poverty, have mental health problems such as depression, and many are single mothers (Astley, S.J., Bailey, D. Talbot, C. & Clarren, S., 2000).

Emerging Concern:
Children apprehended by child welfare authorities:

Where are their parents?

Brief Historical Timeline
A Ten Year Profile: 1999 - 2009

- The Alberta Response
- 1999 – 2002: Expert Panel on FAS
- 1999 – First Steps (PCAP Replication Program) in Edmonton
- Development of the FASD Cross Ministry Committee
- Alberta FASD Conferences: practice and research focus
- Developing network now known as CanNorthwest FASD Research Network

Brief Historical Timeline
A Ten Year Profile: 1999 - 2009

- 2003 – Development of FASD practices in Children’s Services
- PCAP replication programs to support women with original programs in Edmonton, Lethbridge and Calgary
- Emergence of PCAP replication programs across western provinces and specific programs in urban, rural and Aboriginal communities with linkages to the University of Washington, Dr. Therese Grant as primary trainer.

Brief Historical Timeline
A Ten Year Profile: 1999 - 2009

- Development of FASD Service Networks across Alberta in response to conceptualization of FASD from a disability paradigm
- Alberta participation in the CanNorthwest FASD Research Network Action Team (NAT) on women’s determinants of health. Leads: Nancy Poole and Amy Salmon (British Columbia)
- FASD NAT on Intervention launched in Alberta in 2009. Leads: Dr. Ben Gibbard and Dr. Ted Prince

Value of the FASD NAT on Women’s Health

- Value of the FASD NAT on Women’s Health
- Participation by Researchers in the FASD NAT on Women’s Health Offers...
 - Research Activities in Alberta

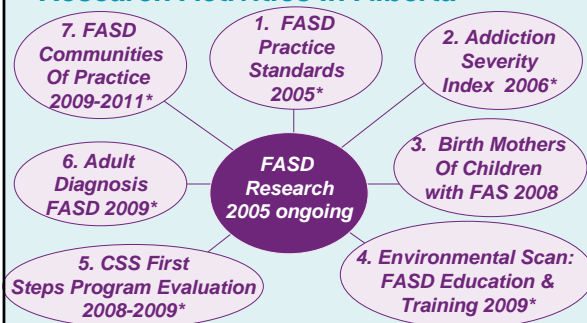
Value of the FASD NAT on Women's Health

- Collaborating nationally with colleagues – women researchers with similar interests across Canada
- Collaboration on “difficult issues” and best practice in support of women
- Consideration of “mothering policy” as an important construct in working with women
- Consideration of “best practice”

Participation by Researchers in the FASD NAT on Women's Health Offers...

- Access to current “state of the art” research from across Canada collaborating nationally with colleagues – women researchers with similar interests across Western Canada and Territories
- Diverse professions of participants allows for concerns to be discussed from the front line issues to policy development
- Collaboration on “difficult issues” and best practice in support of women

Research Activities In Alberta



*Note: Research applications done collaboratively with colleagues in Alberta engaged in research on FASD 1. Badry & Pelech 2. Badry, Benzies, Trute & Tough 4. Anderson, Baynton & Badry 5. Rasmussen, Denys, Badry, Henneveld & Andrew 6. Badry & Bradshaw 7. Badry, Pelech, Milne & Stoddard

Contextualizing Research to Inform Understanding of Biological Parents

- Systemic overview is critical to development of policy and practice
- Policy and practice developed based on findings of research
- Research in FASD has largely been housed in the biomedical field and is emerging in the social sciences

Dominant Discourse on Alcohol Use

- Blames women for lack of self-restraint
- Considers drinking an amoral behavior for a woman while pregnant
- Reality check based on research
- Most pregnancies are unplanned
- Many women do not realize they are pregnant from 1-6 months
- Women do not intend to harm the developing fetus

Complexity

Intervention and Prevention

- Terms utilized concurrently and independently
- In relation to the birth mother intervention leads to prevention
- Intervention consists of the utilization of intensive supports on a long term basis

Prevention Perspective

- Understanding individuals experiencing the phenomenon will assist in prevention efforts
- Both quantitative and qualitative research important
- Published research leads to greater acceptance of strategies aimed at prevention

Contextualizing the Stigma for Bio-Parents

Who do we think of when hearing about a child with FASD?

- Women who consume alcohol while pregnant

Why?

- Because FASD is identified as a preventable disability

Do we think about men and ask the question: Where the fathers are?

Who are the women/families that have children with an FASD?

Common Misunderstandings and Misinterpretation of Alcohol Use During Pregnancy

Reality check based on research

- Alcohol abuse/misuse is a response to a woman's history of trauma
- Women do not intend to harm the fetus and have challenges in connecting their alcohol use to potential developmental harm
- Pregnancy often provides an opportunity for profound change in women's lives that support better health, increased psychosocial supports and brings awareness of the need for change

Research on Birth Mothers

- Research on birth mothers remains a relatively new phenomenon
- Not many opportunities to raise the voice of birth mothers
- A recognition that we have a great deal to learn from birth mothers
- A need to fully include women in this topic
- The voice of women belongs in the discourse

Birth Mothers

- Characteristics of Birth Mothers
 - Birth Mothers Family of Origin History
 - History of Sexual Abuse of Birth Mothers
- Birth Mother: Age of first drinking experience and age of first pregnancy
- Birth Mothers Involvement with Child Welfare
 - Critical Themes Emerging from Interviews with Birth Mothers to Inform Practice
 - Comments from Birth Mothers
 - Standpoint
 - Recommendations

Based on doctoral dissertation research by Badry (2005-2007).
Data derived from qualitative interviews with 8 women

Characteristics of Birth Mothers

- Often single mothers – historical abuse
- Unplanned pregnancies
- Transient relationships
- Involvement with child welfare
- Heavy alcohol use combined with drug use
- Exposure to alcoholism in the family of origin

Characteristics of Birth Mothers

- Often invisible in systems that may be able to help them
- Need time to develop trust
- Find ways to protect themselves from the perceived threat of helping systems such as health care and social services
- Live with many fears that need to be addressed

Birth Mothers Family of Origin History

Birth Mother – Race & Age	Family of Origin Mother <small>*bio-mother deceased</small>	Family of Origin Father <small>*bio-father deceased</small>
38-Caucasian	Alcoholic*	Alcoholic <small>*(killed by mother)</small>
41-Caucasian	Alcoholic*	Alcoholic*
28-Caucasian	Alcoholic*	Father unknown
39-Caucasian	Alcoholic*	Alcoholic*
47-Caucasian	Alcoholic	Alcoholic*
31-Caucasian	Not Alcoholic	Not Alcoholic
31-Aboriginal	Alcoholic	Father unknown
56-Caucasian	Not Alcoholic*	Not Alcoholic*

Characteristics of Birth Mothers

Biological Mother Deceased	Biological Mother Alcoholic	Biological Father Alcoholic
5/8	5/8	Yes-5 u/k-2 Deceased 1
Prior CW history as a youth (5/8)	Current CW history (7/8)	History of family of origin violence (6/8)

History of Sexual Abuse of Birth Mothers

Birth Mother	History of Sexual Abuse as a Child (Yes/No)
1	Yes
2	Yes
3	Yes
4	Yes
5	Yes
6	No
7	Yes
8	No

Birth Mother: Age of first drinking experience and age of first pregnancy

Pregnancies/Live births	First Drink	First Pregnancy
8/5	12	15
3/2	10	17
1/1	15	16
3/1	As a teen	18
3/2	15	31*
5/3	18	18
3/3	11	15
2/2	16	16

*Reason for outlier: Advised by physician she was unable to conceive.

Birth Mothers Involvement with Child Welfare

Birth Mother Race & Age	Child Welfare Involvement	Child Welfare Status: # of children permanently in care
38-Caucasian	Yes	3 children
41-Caucasian	Yes	Supervision Order
28-Caucasian	Yes	Support Agreement
39-Caucasian	Yes	Closed- Child in care and returned to mother when 18

Birth Mothers Involvement with Child Welfare

Birth Mother Race & Age	Child Welfare Involvement	Child Welfare Status: # of children permanently in care
47-Caucasian	Yes	2 children
31-Caucasian	Yes	Investigations
31-Aboriginal	Yes	Past TGO
56-Caucasian	No	No history

Characteristics of Biological Father Based on In-Depth Interviews with Eight (8) Birth Mothers

Birth Mother	# of children	Father
1	8 – 5 live births	Multiple partners - All A + V
2	3- 2 live births	V + A + D
3	1 – 1 live birth	A + D
4	3 – 1 live birth	A + V
5	3 – 2 live births	A + D
6	5 – 3 live births	A
7	3 – 3 live births	A + V, V, V (3 fathers)
8	2 – 2 live births	A

Code: A – Alcoholic V – Violent D – Drug Use

Total Number of Pregnancies: 28 /19 live births

Emerging Question:
Where are the fathers?

Critical Themes Emerging from Interviews with Birth Mothers to Inform Practice

- The birth mother's experience in the family of origin
- The birth mother's experience with alcohol
- The birth mother's pregnancy experience
- The birth mother's relationship with the father of the child diagnosed with FASD

Critical Themes Emerging from Interviews with Birth Mothers to Inform Practice

- The birth mother's history of trauma including violence
- The birth mother's involvement with child welfare
- The meaning of the child diagnosed with FAS to the birth mother

Comments by Birth Mothers

- "I waited 18 years to parent" (child apprehended at 3 months and returned to mother as an adult)
- "Lots of joys and frustrations. He is my gift from God, my lifesaver...Could you imagine where I'd be if I didn't have him?"
- And I told them, "You don't want to grow up to be an alcoholic. Mommy's an alcoholic. I will always be an alcoholic, doesn't mean I'm a bad person."

Standpoint

To say that FAS is 100% preventable is akin to stating that violence, poverty and inequality are individual versus societal problems. An informed perspective looks beyond the use of alcohol to the environment from which this behavior emerges...

The social discourse that holds maternal factors as singly responsible for the birth outcome requires a paradigm shift, as this is a stigmatizing and unjust notion, reflective of a paternalistic medical model.

Standpoint

Surely it is time for a new discourse about women's culpability as solely responsible for the problem of FASD within society.

FAS is not simply a woman's issue, or is it an issue of individual pathology as it has been constructed, but rather FAS is a societal / environmental issue that would benefit from an increased educational focus regarding the whole topic of how persons need to care for their health.

Recommendations

- That more research attention be paid to the lived experiences of birth mothers of children with FAS in terms of issues associated with the family, relationships with men in their lives and community environments that may contribute to a deeper understanding of their support needs
- Further studies that encourages large and small-scale cross-generational and cross-cultural studies of the lived experiences of women who have children diagnosed with FAS

Recommendations

- That awareness of and training with dealing with addictions – especially alcohol – should be required in school curricula and certainly for practitioners in the health and child welfare systems
- That child welfare agencies and health/care systems need to become a place where women can turn to for help within their own communities and women can work in partnership with care systems long before there is cause for interventions

Recommendations

- A message to policy makers, implementers and evaluators as well as to support/care practitioners must be sent that they need to work collaboratively and further, a woman-centered approach to care must be implemented within child/health/welfare support systems

Boyd and Marcellus, 2006; Poole, 2003; Rutman et al. 2000

Recommendations

- I recommend that the mother and child dyad needs to be the focus of support and care efforts. To separate mother from child and child from mother and to place conditions on any re-unification adds stress to both the child and mother's lives. There needs to be facilities constructed where mother and child can be co-treated with the intent to foster a healthy mother-child relationship

Recommendations

- **Vigilance is required to reduce further systematic socio-cultural discrimination and marginalization of both children with FAS and their birth mothers by the media as well as governments, health and welfare and childcare systems. The terms FAS/FASD are culturally loaded and can lead to stigma within broader society and blame towards birth mothers while those working to support the individual offer understanding and compassion**

Addiction Severity Index Research Findings 2006

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Addiction Severity Index Research Findings 2006

Purpose of the Study

- **For this study, we collected data from 205 ASI intake questionnaires**
- **The purpose of this initial study was to assess the scientific quality of the data and identify future potential studies**

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Addiction Severity Index Research Findings 2006

- For the study we obtained ethical approval, agency approval and accessed ASI records with all identifying information removed
- All data from the initial ASI intake forms was entered by research assistants into a common template and assessed for its scientific quality
- The data was analyzed in order to develop a descriptive profile of the women

Addiction Severity Index Research Findings 2006

- Mean maternal age – 25 years
- Characteristics: smokers, less than high school education, single poor and often unemployed
- Often socially isolated
- History in family of origin of abuse, being in foster care and exposure to alcoholism as children
- 55% Aboriginal or Métis
- Long history (more than 2 years) of the woman being in foster care as a child (60%)

Addiction Severity Index Research Findings 2006

- The pregnancy
 - Less than half abstinent in second trimester
 - Heavy binge drinking for most in first trimester
 - Heavy use of crack cocaine
 - Majority had unplanned pregnancies (85%)
- Despite previous medical emergency care related to alcohol ingestion, over 65% felt that alcohol treatment was not very important

Addiction Severity Index Research Findings 2006

- Greater interest in treatment for drug addiction
- 60% smoked crack cocaine during pregnancy
- 45% had no prenatal care in first trimester
- 6% had no prenatal care at all
- Housing instability a major problem

Addiction Severity Index Research Findings 2006

- Involvement with Child Protection Services for over half of the women
- Almost 40% had worked in the sex trade
- Child welfare involvement and violence are prevalent characteristics in their lives
- The women were mostly single parents and have a history of substance abuse in the family of origin

Addiction Severity Index Research Findings 2006

- Further analysis of the data to inform practice issues (i.e. Child Guardianship)
- Adapt ASI to a Canadian context
- Gather additional information on the ASI regarding woman's age and number of children at time of intake interview

Rutman et al. (2000) stated, “We support that the fetus is as a living entity and believe that the state, the corporate/private sector, communities, families and parents have responsibility to promote healthy fetal development.

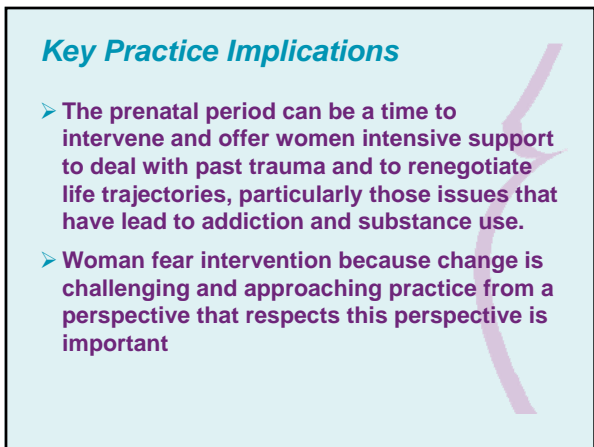
Moreover, our findings indicate that pregnant women, even those who use substances during pregnancy, are deeply concerned about their fetus’ health and proper development.”

- Critical Research Reading for Practitioners: Rutman, D., Callahan, M, Lundquist, A, Jackson, S, & Field, B. (2000).
- Substance use and pregnancy: Conceiving women in the policy making process.
- Ottawa: Status of Women Canada.

For some women with addictions problems, seeing “pictures” of their fetus through ultrasound technology strengthens their connection to the fetus and consequently supports their efforts to reduce or abstain from substance use.” (p. 152).







Key Practice Implications

- Child protection needs remain crucial and interventions framed in consideration of a mother/child dyad is important. An ongoing relationship between the mother and child is an important factor in motivating change while not diminishing the potential needs for child protection
- Practitioners who do not have training in addiction should be offered this opportunity by their agencies in order to inform their understanding of the complexity of alcohol addiction

Key Practice Implications

- Decrease systemic responses that assume women are intentionally harming their child by engaging with them from a compassionate perspective that recognizes women themselves were victims of abuse as children
- In consideration of intergenerational issues, vigilance is required in terms of the age that adolescents begin using alcohol and offer education related to healthy pregnancies

Key Practice Implications

- Practitioners must recognize that birth mothers are often isolated and have limited social supports within their own family and community connections are frequently fragile. Working to strengthen these connections is crucial in the change efforts to assist women in improving their health and circumstances

Key Practice Implications

- Supportive relationships such as those offered by mentors in the PCAP replications programs in Canada are essential for change. Women benefit from these programs which offer long term supportive relationships. (Qualitative research on the work of the mentors is forthcoming as part of the evaluation of CSS First Steps Program in Edmonton, 2008-2009)

Society is Vulnerable to Alcohol, Not Just Children with FASD or Birth Mothers

“We as a society...I think have a responsibility to ensure as much as we can that that pregnancy is healthy. It a bit of a cliché – it takes a village and a society to raise a child, but it also takes a village and a society to support women’s pregnancies.”

Dr. Jonathan Down, 2009

knowledge.ca/findinghope (video link)

Closing Thoughts

➤ Women who become birth mothers of children with FAS have already faced multiple forms of complex oppression throughout their lives, and they continue to deal with these oppressions and victimizations in terms of partner and family and community and institutional relationships

➤ Engage with research literature as it is informative and relevant to practice issues and a rich body of literature is evolving

Reference

➤ Contact Information

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