

# FASD AND CHILD WELFARE PRACTICE - A FOCUS ON LIFE COURSE THEORY

8th International Research Conference on Adolescents and Adults with

Fetal Alcohol Spectrum Disorder

Review, Respond and Relate: Integrating Research, Policy and Practice around the World

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## LEARNING OBJECTIVES

- I. Develop an understanding of FASD and best practice in child welfare practice from a lifespan perspective
- 2. Examine a life course theory approach for children and youth with FASD
- 3. Recognition of the distinct needs of children with FASD and prenatal substance exposure in care
- Develop an understanding of the current issues in relation to child welfare practice in this area based on two concurrent projects completed in 2017

# HISTORY

- Project I Lenora Marcellus & Team
- 2016-2017
- Caring for Infants with Prenatal Substance Exposure in Foster Care – A Scoping Review of the Literature
- Project Funder: BC Ministry of Children and Development

- Project 2 Dorothy Badry & Team 2017
- Care of Children & Youth with Prenatal Exposure in Child Welfare: A Scoping Review of Best Practices
- Project Funder: CanFASD Research Network

#### Project 3

Advancing Knowledge on Best Practice and Care of Infants, Children and Youth with Prenatal Substance Exposure/Fetal Alcohol Spectrum Disorder in Child Welfare Funded by PolicyWise 2018 (Expanded Team in BC and Alberta)

#### RECOGNIZING DISTINCT NEEDS OF CHILDREN WITH FASD AND PRENATAL SUBSTANCE EXPOSURE

- Every child is unique and presentations of Prenatal Substance Exposure (PSE) and FASD will vary
- If one were to describe the disabilities associated with the primary diagnosis these would also vary
- Infants and children with FASD in particular have a life course trajectory of early life adversity
- This provides an opportunity for supporting resilience, enhancing developmental pathways and supporting family preservation (Guralnick, 2011)
- These children are also key populations in children in foster care (Popova, Lange, Burd, & Rehm, 2014)

#### WHAT GOT US THINKING..

Donahue, E. (2008). What was sick is now bad: The shift from pathologized victim to deviant identity for those diagnosed with Fetal Alcohol Spectrum Disorder. Ottawa, ON: Carleton University Department of Law.

Victims of poor parenting Irresponsible mothers Bad start in life Blame for deficiencies placed elsewhere "Worth saving"



Deviant Destined for failure and criminality Blame moves on to the individual with FASD themselves "Hopeless"

#### RESILIENCY IN A LIFE COURSE PERSPECTIVE- LIVING WITH FASD

# EXCERPT FROM A LETTER TO ELIZABETH (1993) AT AGE 7

Dear Liz,

When you were born in Toronto in 1986, [we] were living in Calgary, entirely unaware that you existed. I think often of all the circumstances that conspired to bring you into our orbit thirteen months later, all the decisions and chance events and impulses that ... bear the mark of some benign cosmic mischief. You got off to a rough start, Liz. You were 13 weeks premature and weighted only 2.5 pounds at birth. Your eyes would have been closed...you were definitely unfinished, especially our lungs.You lived in brightly-lit hospital rooms, your sleep interrupted. The noise of the machine at your bedside that did your breathing for you. No wonder you don't like loud noises and have what they call "attention deficit"... You were very fragile when you came to us...Now here you are at age seven, our busy Lizzie, oxygen tubes long gone...a dandy skater...finishing up grade one, part of the family and already in your young life a vital part of the community and a rich and welcome presence in our lives...We want you to be proud of the toughness and thirst for life that has seen you through so much...You have already learned to compare yourself to others...We hope that you will also come to realize in all ways that really matter, you are irreplaceable, and beyond compare.

# EXCERPT FROM A LETTER TO ELIZABETH (2000) AT AGE 14

Dear Elizabeth,

...One sign of your growth into adolescence is your preference for "Elizabeth" rather than "Lizzie". Today you are astonishingly healthy, not at all easily related to the sickly baby who came to us in the spring of 1987. The best gift we can pass along to you...as you confront your challenges, dream your dreams is a certain perspective on the endeavor to be human. Our view of that endeavor is grounded in realism — in a readiness to face and accept FASD and ever other kind of human limitation; to embrace what is real. It is rooted in humor and pathos, those constant poles in the human drama that underlie our understanding that there is a time to laugh, a time to weep. It is a view of the world that encourages awe and wonderment at the movement of the spheres. It is a belief, finally, that we live and move and have our being within a purposeful mystery; that our lives are stories...worth living and worth the telling, every one of them.

Written by Dad, Ontario, Canada

(2018 update forthcoming at conference)

#### LIFE COURSE THEORY 101

- "The notion that changing lives alter developmental trajectories" is what ties together studies on the life course. (Glen H. Elder Jr. 1998)
- This approach has generally been used to understand how transitions and trajectories impact one's life (see Clausen, 1986; Grenier, 2012; Hareven, 1994; Hutchison, 2015).
- Elder suggested that human development occurs over the life span and is connected to the "pattern and dynamic" of life
- Elder's work emerged from studies initially focused on child development and the Great Depression and how families adapted using "human agency"
- Gaps in theories exist to explain the differential outcomes for individuals with FASD
- Life history has a significant impact on outcomes

# THE LIFE COURSE PERSPECTIVE

- Elder's (1974; 1994) life course perspective is based on four major concepts.
  - First, *human lives and historical times*, whereby lives are seen as intertwined and defined by significant events that produce long-lasting effects.
  - Second, the *timing of lives*, indicates how events occurring at specific points during a timeframe could have different consequences for different people.
  - Third, *linked lives,* denotes the interrelatedness and interdependence of human relationships across the lifespan.
  - Finally, the life course perspective takes into account the key concept of *human agency* and the ways in which people make choices, adopt strategies, and articulate experiences of resilience when encountering structural constraints (also see Settersten, 2003; Settersten & Dannefer, 2010; Hutchinson, 2015).



#### LIFE COURSE THEORY 101

- Elder (1974; 1994, 1998) outlined how the life course can be understood through:
  - Structured pathways (i.e. social institutions and organizations), and
  - Individual trajectories (i.e. roles, statuses, development) that shift over time to

to impact individual identities and behaviours.

- The timing of events in life is important
- The issue of "age expectations" was tied to "role sequences" (p. 7) or expected life events that are expected to unfold in one's life. Elder provides the example of an event such as an early pregnancy that can impact the trajectory of one's life – linked to a "cumulation of disadvantages"

- Elder (1998) suggested that life course theory as it developed provides a framework to recognize the connection between "social pathways" to a persons history and this affects "developmental trajectories"
- Key principles: "historical time and place, the timing of lives, linked or interdependent lives and human agency" (Elder, p. 4)
- Hutchison (2008) indicates it is important to consider "the twists and turns in the paths of individual lives" (p. 3)
- Elder refers to this as "interlocking trajectories that connect changing environments with behavioral changes" (p. 7) – which in turn affect transitions in life
- "Transition experiences represent a strategic approach to the possibilities of studying lives in motion. Transitions make up life trajectories, and they provide clues to developmental change... lasting effect of early transitions" (Elder, p. 7)
- Human Development needs to be considered over the life course which has major implications for fragmented systemic responses to FASD/PSE

- Life course theory and research alert us to this real world, a world in which lives are lived and where people work out paths of development as best they can. It tells us how lives are socially organized in biological and historical time, and how resulting social pattern affects the way we think, feel and act...Human development is embedded in the life course and historical time...its proper study challenges us to take all life stages into account through the generations, from infancy of the grandparents of old age" (Elder, 1998, p. 10)
- Hutchison's work has identified the concepts of
  - Cohorts (born around same time which contributes to similarity in experiences)
  - Transitions (change such as role, status, change of circumstances
  - Trajectories (long term view of a person's life)
  - Life events events with a lasting impact [can close or open opportunities,] (Rutter, 1996 in Hutchison, 2008, p. 18)
  - Turning Points impact the life trajectory



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- Hutchison's work furthers the concepts of:
  - "Diversity in life course trajectories" (p. 20)
  - "Development risk and protection: Experiences with one life transition have an impact on subsequent transitions and events, and may either protect the life course trajectory or put it at risk" (p. 20)
  - Age is a critical factor in life because so many expectations are associated with age
  - The issues of age that Hutchison proposes based on her work and other studies include expanded dimensions: biological age, psychological age, social age and spiritual age
  - We know standardized age categories do not work for people with FASD and flexibility is important

Reference: Hutchison, E. D. (2008). A life course perspective. Dimensions of human behavior: The changing life course (3rd edition). Thousand Oaks, CA: Sage.

#### DEVELOPMENTAL RISK AND PROTECTION – RESILIENCE IN LIFE COURSE THEORY

#### CUMULATIVE ADVANTAGE

- Social institutions are generally aimed at those with early success in life
- Early support, stability, structure
- Timing of life events (Elder, 1998 & Hutchison, 2008)
- Engagement in Protective Factors low distress over developmental phases
- "Human behavior is driven by a desire for growth and competence" (Hutchison, p. 35)

#### CUMULATIVE DISADVANTAGE

- Life events Conflict
- Early trauma
- Transitions
- "Early transitions can have enduring consequences by affecting subsequent transitions, even after many years and decades have passed" (Elder, 1998, p. 7)
- Example approaches with Mom and new baby where PSE/FASD are a concern

Reference: Hutchison, E. D. (2008). A life course perspective. Dimensions of human behavior: The changing life course (3rd edition). Thousand Oaks, CA: Sage.

## RESEARCH FINDINGS FROM PROJECTS I & 2

- Best practice is housed in various disciplines that intersect with
- early childhood development
- child welfare,
- health,
- education,
- social work,





#### CARING FOR INFANTS WITH PRENATAL SUBSTANCE EXPOSURE IN FOSTER CARE (PROJECT 1)

### A scoping review of the literature

Dr. Lenora Marcellus & Lindsay Shaw

Completed in 2017



# **OVERVIEW**



- Background
  - Team and project
  - Issue
- Research questions
- Methodology
- Key findings
- Implications for practice, policy, research
- Limitations
- Next steps

# TEAM



#### • UVIC:

- Lenora Marcellus, School of Nursing
- Karen MacKinnon, School of Nursing
- Carol Gordon, librarian
- Lindsay Shaw, research assistant
- Project advisory group:
  - Sheila Best, MCFD
  - Anne Clayton, MCFD
  - Rachel Douthwaite,VCHA
  - Anne Fuller, MCFD
  - Annette Harding, MCFD
  - Tracey Hulten, MCFD
  - Dan Malone, VI FPSSS

Project funding gratefully received from the British Columbia Government through the Ministry of Children and Family Development through a BC Government Sponsored Research Agreement (2016-2017)



# BACKGROUND



- Infants represent a significant proportion of children in foster care (in BC: 302 out of 7,004, February 2017)
- They may have experienced prenatal substance exposure, neglect, maltreatment
- Their parents often have experienced substance use issues, mental health issues, trauma and violence, multiple challenges with determinants of health (i.e., poverty, unsafe housing), intergenerational issues
- Infants are vulnerable to the effects of disruption of primary attachments
- Infants have a great capacity for overcoming early adversity



# **RESEARCH QUESTIONS**



What are the characteristics of interventions and programs ("best practices") that support the health and development of infants with prenatal substance exposure in foster care?

- 1. What care strategies support optimal physical, cognitive, and socioemotional development for infants who have a history of prenatal substance exposure?
- 2. What infant foster care program components improve the satisfaction and retention of foster care providers?
- 3. How can foster care providers support birth parents with substance use challenges to stay connected to their infants and gain confidence in their parenting role.



- "Rapid" scoping review, using Joanna Briggs Institute methodology
- Rapid reviews shorter timeframes, limited resources, practice urgency
- Scoping reviews are used for three reasons:
  - I. To provide a broad overview of this area
  - 2. To report on the types of evidence that address and inform practice in this area
  - 3. To be more inclusive of diverse forms of evidence

# **INCLUSION CRITERIA**



- Participants:
  - Infants less than 12 months of age in foster care
  - Prenatal substance exposure
- Context:
  - Countries with similar resource and social service contexts
- Study types:
  - All research methodologies
  - Literature reviews, policy documents, QI and evaluation sources, grey literature (including theses and dissertations)

# **SEARCH STRATEGY:**



- 2006-2016
- Preliminary search to check search terms
- Primary databases: MEDLINE, Psychlnfo, CINAHL
- Key words: infant, foster care, prenatal substance exposure (and variations on these)
- Key websites: CCECW, Zero to Three, Child Welfare Information Gateway, CWL, CCWLC, Ontario Practice and Research Together

# **SOURCE SELECTION**





# **OVERVIEW OF SOURCES**

- 63 sources
- Location:
  - 41 from US
  - 12 from Canada
  - The rest from Australia (3), UK (2), Netherlands (2), Finland (1)
- Type of source:
  - Peer reviewed primary research (35)
  - Peer-reviewed non-research and grey literature: narratives (10), practice guidelines/information sheets (4), policy documents (5), training program resources (3), literature review (2), commentaries (1), thesis (1)
- Research design: range
- Sample: focus on infants under 12 months





### YEAR OF PUBLICATION





#### THEME I: INFANT MENTAL HEALTH PROMOTION FOR INFANTS IN CARE



- General review brain science update and translation
- Importance of relationship between foster care provider and infant
- Specific targeted infant mental health interventions
  - Attachment and Bio-behavioral Catch-up (ABC Delaware) Dozier
  - Foster Carer-Foster Child Intervention (FFI Netherlands) van Andel
  - New Orleans Zeanah
  - Promoting First Relationships (PFR Seattle) Kelly & Spieker
- Assessment of infant mental health
- Policy considerations

# THEME 2: CHILD WELFARE PROGRAM COMPONENTS

INcare

- Visitation
- Placement
- Models of care:
  - Collaborative Mental Health Program (Calgary) Wotherspoon
  - CASA Court Appointed Child Advocate Program (US)
  - Crisis nurseries (US Susan Cole
  - Safe Babies Program (Victoria) Marcellus
  - Safe Babies Court Teams (US Zero to Three
  - Vulnerable Infants Program (Rhode island) Twomey
- Resource utilization

#### THEME 3: IDENTIFICATION OF INFANTS AND FAMILIES AT RISK OF REQUIRING FOSTER CARE



- Maternal characteristics
- Infant characteristics
- Screening tools:
  - BabyFirst (Manitoba) Brownell et al.
- Partnership consultation models

# THEME 4: OUTCOMES FOR INFANTS IN CARE AND THEIR FAMILIES



- Developmental
- Placement stability

# **IMPLICATIONS FOR PRACTICE**



- Providing services from developmental perspective for infants – consider the importance of stability in relationships on early brain development
- Data!
- Participatory approaches to program development with foster care providers, birth families, kinship providers, adoptive families, Indigenous communities
- Continued education related to infant mental health (includes attachment, stress and trauma), substance use
- Collaborative, cross-sectoral approaches



#### **IMPLICATIONS FOR RESEARCH**



- Significant gaps:
  - Interventions and programs
  - Experiences
  - Epidemiology
- Within Canadian context culture, geography, social service systems, legislation

### KEY INFANT/CHILD WELFARE RESEARCHERS



- Richard Barth, University of Maryland
- Susan Cole, University of Illinois
- Mary Dozier, University of Delaware
- Brenda Jones Harden, University of Maryland
- Barry Lester, Brown University
- Jean Twomey, Brown University
- Charles/Paula Zeanah, Tulane University



# LIMITATIONS



- Rapid review
- English only, similar service context
- Limited to ten year time period and three key databases
- Sources excluded for toddlers
- No quality appraisal of evidence



# **KEY REFERENCES**



- Center on the Developing Child at Harvard University (2016). Applying the science of child development in child welfare systems. Retrieved from <u>www.developingchild.harvard.edu</u>.
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CARE OF CHILDREN AND YOUTH WITH PRENATAL SUBSTANCE EXPOSURE IN CHILD WELFARE (PROJECT 2)

A Scoping Literature Review of Best Practices Dorothy Badry, PhD, MSW, RSW, Devin Allen, Liz Schweizer, Tiffany Talen – MSW Student Research Team

Faculty of Social Work, University of Calgary

2017

#### OVERVIEW

Research team & funding Objective Research questions Methodology Findings Implications for practice, research, and policy Limitations Next steps



#### TEAM

Lead: Dr. Dorothy Badry, Faculty of Social Work, University of Calgary

Research Assistants: Devin Allen, Liz Schweizer, Tiffany Talen



Project co-aligned with project headed up by Dr. Lenora Marcellus out of the School of Nursing at the University of Victoria: Scoping literature review on caring for infants with prenatal substance exposure in foster care (April 2017)



Project funding gratefully received from the Canada FASD Network, Research Agreement with the University of Calgary (2016-2017) the CanFASD research network, a unique Canadian NGO whose aim is to stimulate meaningful research for FASD intervention, prevention, and diagnosis

#### OBJECTIVE

• To identify and describe within the existing literature child welfare best practices for children and youth with prenatal substance exposure, with a specific focus on FASD, who have come into care.

#### **RESEARCH QUESTIONS**

- I. What are best practices to support children ages 3-19 with prenatal substance exposure who are in the care of child welfare?
- 2. What is taking place across Canada, the United States and elsewhere in child welfare practice, policy, intervention, and training for this population?
- 3. What are gaps for future studies and system mapping for this population?

#### METHODOLOGY

#### Scoping literature review methodology

- exploratory
- undertaken within shorter periods of time
- used when an area hasn't been reviewed comprehensively before
- gather broadly as much information as possible and map the available literature
- identify gaps and inform practice, policy, and research



#### INCLUSION CRITERIA FOR ARTICLES

Considered sources relevant to child welfare professionals to children and youth ages 3 to 19 who had been prenatally exposed to substances, with a primary focus on fetal alcohol spectrum disorders.

#### • Concept & Study Types:

- ✓ Best practices to support children ages 3-19 with prenatal substance exposure involved in child welfare.
- Looked at quantitative, qualitative, mixed methods, systematic literature review, and program evaluation studies for inclusion.
- In addition grey literature such as rapid or scoping literature reviews, training manuals, conference materials, policy documents, quality improvement, and program evaluation reports.

#### SEARCH STRATEGY - TIME FRAME: 2006-2017

- Peer-Reviewed Academic Databases: SocINDEX, Social Work Abstracts, Social Services Abstracts, PsycINFO, Medline, Dissertation & Theses, CINAHL Plus, and Cochrane
- Keywords: Child, Children, Youth\*, Adolescent, Teen\*, Foster\*, Kinship, Out of home care, Child welfare, Prenatal substance abuse, Prenatal substance exposure, Substance related disorder, Substance-exposed, Drug us\*, Drug abuse, Prenatal exposure, Neonatal Abstinence Syndrome NAS, Fetal Alcohol Spectrum Disorder, FAS\*, Drug exposed, Alcohol exposed, Cocaine related disorder, Alcohol related disorder, Amphetamine related disorder, Impaired parent

#### GREY LITERATURE AND FASD – PRENATAL SUBSTANCE EXPOSURE

- Grey Literature: Included a scan of federal, provincial and territorial government websites in Canada for:
- policy documents, reports, and educational materials relevant to the study
- The Canadian Child Welfare Research Portal
- CanFASD Research Network
- FASD & Child Welfare Community of Practice websites

# SOURCE SELECTION PROCESS



#### SOURCE INFORMATION

#### Total of 74 sources included:

**61** from academic databases: 43 primary research (*methodological breakdown on next slide*); 12 peer-reviewed non-research, 5 systematic literature reviews, 1 thesis

□ 13 from grey literature: all Canadian; 4 environmental scans of policy and practice guidelines, 3 program/strategy evaluations, 3 training and educational materials, 2 policy documents, and 1 news article

# PRIMARY RESEARCH DESIGNS

**7 sources were qualitative**, including: grounded theory studies (3), case study (1), Photovoice study (1), participatory action research study (1), and thematic analysis (1)

**29 sources were quantitative**, including: randomized control trials (10), cohort studies (11), descriptive studies (3), online surveys (3), and longitudinal studies (2)

7 studies were mixed methods

# LOCATIONS OF PUBLICATIONS



# Literature review findings organized into 4 key thematic areas - Key themes



# THEMATIC AREA I: DIAGNOSIS

>Importance of early screening and diagnosis

- >Early intervention
- Communication of diagnosis
- Challenges
- >Implication for child welfare

# THEMATIC AREA 2: CHILDREN & YOUTH

#### >PRACTICE RECOMMENDATIONS:

- Strengths-based approach
- ✤ Ecological approach
- ♦ Mental health
- Educational supports
- ♦ Youth-specific practice
- ♦ Transition planning

#### EVIDENCE-BASED RECOMMENDATIONS

- Self-regulation and emotional control: ALERT Program, Neurocognitive Habilation Therapy (adaption of Alert)
- Social skills: Children's Friendship Training
  Project Brain Buddies
- Specific skills: Computer Game Fire Safety Skills, Math Interactive Learning Experience (MILE), Language and Literacy Training (LLT), Rehearsal Training to Improve Working Memory
- Youth-specific: Youth Outreach Program

## **THEMATIC AREA 3:CAREGIVERS**

#### 

- ♦ Biological and kinship
- $\diamond$  Adoptive parents
- $\diamond$  Parents with FASD
- ♦ Caregiver placements
- Caregiver resilience and support needs

#### EVIDENCE-BASED RECOMMENDATIONS:

- Child Welfare Community of Practice
- Parent/Caregiver Education
- Coaching Families (CF) Program
- Parent-Child Interaction Therapy
- Families Moving Forward (FMF) Program
- Step-by-Step Program

### THEMATIC AREA 4: SYSTEM WIDE RESPONSES

>Specialized education and resources



# IMPLICATIONS FOR PRACTICE

- Early screening and diagnosis
- Increased specialized education and training
- Permanent, early, long-term stable placements
- Communities of practice
- Interdisciplinary, collaborative, systems-based, multi-level approaches needed

# IMPLICATIONS FOR PRACTICE

- Increase youth-level interventions, especially as approaching age of majority
- Better adaptations to educational environments
- Life span, developmental, ecological, strengths-based approaches
- Interventions on improving self-regulation and emotional control, social skills, and specific skill development showing promise
- Mentorship programs showing positive results

# **IMPLICATIONS FOR RESEARCH & POLICY**

- Advocate for comprehensive statistical tracking of FASD population prevalence
- Lack of research and interventions for preschool-aged children
- Very limited research and lack of interventions at the youth levels interventions analyzed in this review go up to age 11, then research drops off
- Need for increased research and policies for transition planning as youth age out of care
- Further research needed on home community and visitation supports + adoptive family supports
- Advocate for early screening, diagnosis policies in juvenile courts systems
- More research needed into how poverty, trauma, and insecure housing affects development
- System mapping required to identify gaps and areas of potential networking
- Social work education should take a leadership role in advocating for mandatory, comprehensive education for students and increased research in this area

#### LIMITATIONS

- Review limited to a ten-year span
- Mainly focused on North American sources written in English.
- Rapid scoping review, formal quality appraisal of the sources was not conducted.
- Because the primary focus was on FASD in this project, information related to other prenatal substance exposed children may not have been included to the same extent.

#### WHERE ARE WE GOING WITH CURRENT PROJECT

- Meta-synthesis of the two scoping reviews
- Interviews with key informants
- Review of children's representatives reports for FASDrelated recommendations

#### GOAL

To develop life course best practice recommendations for infants, children and youth in care with FASD/PSE

#### LIFE COURSE THEORY AND ITS CONNECTION TO PRENATAL SUBSTANCE EXPOSURE/FASD

- Offers an approach for viewing FASD from a lens that reflects life as a generative process and considers life trajectories early on
- Recognizes that the prenatal environment and adult life are connected (Heller and Parker Harris, 2011)
- Life trajectories for individuals with disabilities are often fragmented by disconnections in systems and this needs to change
- It is critical that decisions made in the care and protection of individuals with PSE/FASD can have a lifelong impact
- "Early transitions can have enduring consequences by affecting subsequent transitions even after many years and decades have passed..." (Elder, 1998, p. 7)



#### THANK YOU

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