FASD AND CHILD WELFARE ISSUES ACROSS THE LIFESPAN: RESEARCH, POLICY AND PRACTICE

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• We would like to begin by acknowledging that the land on which we gather is the unceded territory of the Coast Salish Peoples, including the territories of the x̱w̓μəθkw̓ey̓əm (Musqueam), Skwxwú7mesh (Squamish), and Səl̓ílwətaʔ/Selilwitulh (Tsleil-Waututh) Nations.
THE CORE QUESTION

• What would the life course look like, change, if systems assumed a life long need for supports in a continuous fashion?
PRESENT ASSUMPTION

• People live in life stages so services, supports and belief about people are also staged
THE NOTION OF PREDICTABLE STAGES OF LIFE

- 0 - 5 YEARS: BIRTH TO PRE-SCHOOL
- 6-11 YEARS: PRE-ADOLESCENT PERIOD
- 12-20 YEARS: ADOLESCENT TO TRANSITION YEARS
- 21-30 YEARS: ESTABLISHING ADULT SELF
- 30 - 50 YEARS: ADULT, PRODUCTIVITY, MARRIAGE, FAMILY
- 50 - 65 YEARS: MOVING TOWARDS SENIOR CITIZEN
- 65 + SENIOR CITIZEN

INDIVIDUAL INTERSECTS WITH SERVICES, SUPPORTS AND SYSTEMS BASED UPON SOME LEVEL OF EXPECTATIONS OF NATURAL TRANSITIONS.
THE DISABILITY DOES NOT GO AWAY, GET BETTER OR DIMINISH SO WHY MIGHT SUPPORTS?
CHILD

CHILD WELFARE

INDIGENOUS

REFUGEE / IMMIGRANT

OTHER RACIALIZED POPULATIONS

OTHER

PARENT WITH FASD

PARENT WITHOUT FASD

CHILD SEeks POINT OF ORIGIN
CHILD NARRATIVE – POINTS OF ORIGIN

- WE HAVE A RESPONSIBILITY TO HOLD AND CARRY THE CHILD’S STORY SO THEY HAVE A POINT OF REFERENCE AND CONNECTION FOR THEIR LIFE
When children ask “Who am I” we need to be able to answer
BRANDY CRAZYBULL - SAAAMI’INIHKIAAKII (HEAD DRESS SINGING WOMAN)

• I WAS BORN IN 1995 BUT I DIDN’T LEARN MY NAME UNTIL 2019
The child’s pathway has been broken by competing pressures

**Mitigating**
- Relationship
- Consistency across environments
- Trained staff and supports
- Cultural and kin connections
- Life course perspective

**Diminishing**
- Diagnostic as a limiting label
- Assumptions about personal capacity and diagnosis
- Instability
- Poorly planned transition in the life course
STAGES OF SYSTEMS ARE AGE DEPENDENT AS OPPOSED TO LIFE COURSE SUPPORTIVE

CHILDHOOD TO LATE TEENS TO POSSIBLY YOUNG ADULT STAGE - CHILD WELFARE SYSTEMS MAY SUPPORT TO MID 20’S

THE EARLY ADULT YEARS ONWARDS - SUPPORT SYSTEMS ARE DIFFERENT - CRITERIA DIFFERENT, SUPPORTS LESS COMPREHENSIVE

LATE ADULTHOOD - SUPPORTS CHANGE AGAIN AS PERSON MOVES INTO SENIOR SYSTEM - CRITERIA AGAIN DIFFERENT, COMPREHENSIVENESS OF SUPPORTS AGAIN DIFFERENT - ACCESS MORE CHALLENGING - NATURAL SUPPORTS MAY BE LOST DUE TO THEIR OWN AGING
CRITERIA – WHAT TIME OF LIFE

• CRITERIA FOR SUPPORTS SHIFT DUE TO AGE – E.G., UP TO 18 THE DIAGNOSIS MAY BE THE BASIS OF SUPPORT. AFTER 18, REQUIREMENTS SUCH AS I.Q. MAY DETERMINE ELIGIBILITY – SUCH CRITERIA ARE NOT STRUCTURALLY RELATED TO FASD
17 YEARS AND 364 DAYS IS A CHANGE MARKER BUT AT 18 YEARS 0 DAYS THE DISABILITY HAS NOT CHANGED

CRITERIA MAY CHANGE ELIGIBILITY MAY CHANGE

WHY IS ALWAYS A BLURRY ANSWER AS IT IS NOT BASED IN LIVED REALITY
FAMILIES SPEAK CONSTANTLY OF THEIR LIMITATIONS, DIFFICULTIES WITH SUPPORTS AS WELL AS THE IMPACT OF THEIR OWN AGING AND LIFE PURSUITS
Families complain of working at odds with formal systems as criteria changes, supports are narrowly defined and maturity of the client is expected.
WHEN FACED WITH COST ISSUES, FASD BECOMES A LOWER PRIORITY POLITICAL ISSUE
SYSTEM MENTAL HEALTH BARRIERS

- Families face the cumulative stress of mental health challenges without sustained support.
- Adolescence occurs which is not only a life stage change but also the period of greatest mental health onset period.
- The great period of identity search is adolescence.
POLICY BARRIERS

- **GOVERNMENT CHANGES** = **POLICY PRIORITY CHANGES** = **FUNDING SHIFTS**
- **THE STRONGER THE STRUCTURE**
  **THE LESS LIKELY IT IS TO BE DISRUPTED**
- **SYSTEM ADVOCATES**
- **POLICY CHAMPIONS – FASD CROSS MINISTRY COMMITTEE**
- **V**
- **ONTARIO’S LOSS OF CHILD ADVOCATE**
Health care dollars are being challenged while we need to recognize the need for lifelong supports for those moderately to severely disabled.

Mildly disabled are not without support needs.

There is a large question of public policy supports over lifetime competing with budgetary priorities and pressure on public spending.
OUR 7 HURDLES

DO YOU HAVE OTHERS?
THE INABILITY OF FAMILY TO SUSTAIN – THEY TOO ARE TRAVELLING THE LIFE SPAN OF FASD

• THE CHALLENGES NEVER STOP
• THE GRIEF STAYS
• THE PHYSICAL AND EMOTIONAL TOLL
• THE PRICE IS STEEP
System intersectionality is often poor creating complex pathways to supports that may be harder as client ages.
POVERTY IS EMBEDDED IN THE SUPPORT SYSTEMS
RESOURCES AND ECONOMIC INTERSECTIONS ARE BASED IN PUBLIC POLICY AND THE PERCEIVED WORTH OF THE POPULATION
Virtually all families must navigate multiple systems over time.

- Behavioural issues over time may lead to involuntary system involvement which may hamper access to voluntary services.

- E.g. Criminal Incarceration
systems expect family or caregiver support follow through with little consideration of fatigue and grief
MISINFORMATION AND RIGIDITY OF UNDERSTANDING FASD IS A CONSTANT BARRIER
THE BEST WORK FOR THE CHILD???

• CONTRARY TO FUNDING – WE NEED TO FIT THE ENVIRONMENT TO THE FUNDING NOT THE REVERSE
There is a complicated social contract with society and people with disabilities.
WHAT IS THAT SOCIAL CONTRACT?

• PEOPLE WHO ARE LIMITED IN THEIR CAPACITY TO CARE FOR THEMSELVES WILL BE CARED FOR

• WHAT DO WE AS A SOCIETY REALLY MEAN BY THAT?
What happens when it is not honoured?

- Poverty more embedded
- Isolation and exclusion
- Loss of the ability to know who you are and where you fit
- Loss of meaning
- What would you add?