

*Together:  
Finding Answers,  
Improving Outcomes.*

## *Still Fighting For a Future*

**Where We Were and Where We  
Are Now: Exploring 15 Years of  
Progress on FASD in Canada**

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Liyanage-Zachariah*

# Conflict of Interest

- The presenters have no conflicts of interest to disclose
- But, we are all affiliated with CanFASD

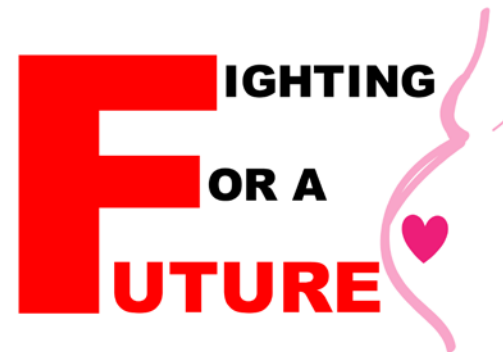
# Managing Potential Bias

- Presenters have no conflict of interests
- We are, however, very biased towards creating a better future for individuals with FASD
- We manage this bias by continuing to advocate for awareness, support, services and research on what works.

# The Beginning of Fighting for a Future: 2004 Project

- In British Columbia in 2004, a diverse group of caregivers of adolescents and adults diagnosed with FASD came together to identify actions for change to improve outcomes for individuals with FASD
- Focused on FASD and 'the system': Adolescents, adults and their families and the state of affairs
- Participants were invited on the basis of their experience parenting individuals with FASD and their professional experience thus providing a wide range of perspectives

A final report including the proceedings of the two-day forum with background information was prepared by Jan Lutke and Tina Antrobus and was entitled *"Fighting for a Future"*



# “Nothing changes until it does”

*“There is an urgent need for action to proactively support adolescents and adults with FASD rather than reactively apply ineffective costly measures.”*

*“Adults with FASD would greatly benefit from coordinated energized action by community, government, business and not-for-profit organizations.”*

(Fighting for a Future Report, 2004)

# 6 Broad Recommendations

1. 7S Model: **S**afe, **s**table, **s**ecure, **s**upported, **s**tructured, **s**upervised, **s**ubsidized housing
2. Financial resources specifically targeted at FASD service delivery
3. Targeted health care delivery and mental health treatment
4. Targeted educational, vocational, employment and other programming
5. Targeted legal and addiction services
6. Development and funding of consultative processes that have the authority to direct, monitor and evaluate changes specific to support the needs of families

# Strategic Needs Analysis

- Consensus from the original meeting identified that **six areas needed further research and support**:
  1. Housing and Homelessness
  2. Finances
  3. Health and Mental Health
  4. Education, Programming, and Employment
  5. Legal and Addictions
  6. Family Support

# Discussion Question

- Consider the six areas identified in 2004. Are we **still** *fighting for a future* for adolescents and adults with FASD? Why or why not?



# Methods

- Triangulation of findings from a literature review of (Canadian) research in the 6 identified areas, as well as a historical document review of pertinent CanFASD reports (e.g., annual reports)
- Synthesis of available information to identify the progress made, as well as the progress that is still needed, to support individuals with FASD and their families

# HOUSING AND HOMELESSNESS (UNHOUSING)

# UNHOUSING AND HOUSING STRATEGIES

2004 RECOMMENDATIONS

'Homelessness' currently referred to as '*Unhousing*' (Pei et al., 2018):

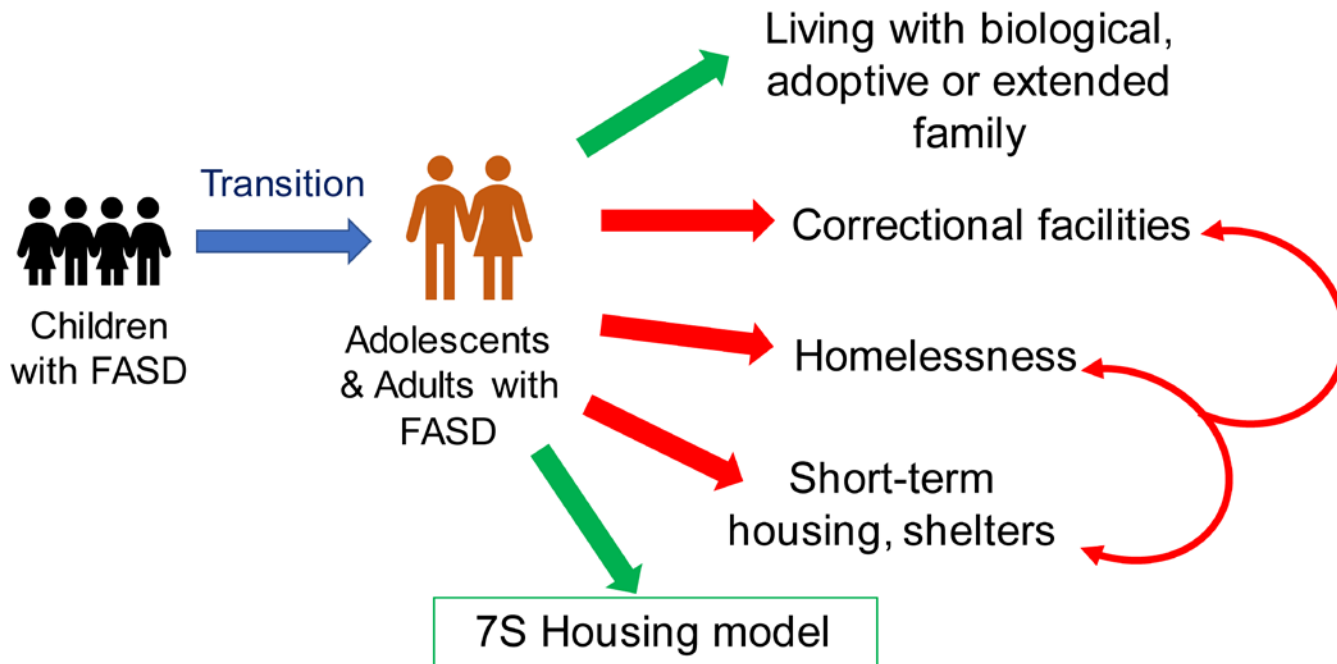
- A major adverse consequence associated with FASD
- Driven by many factors (e.g., unemployment, addictions)
- Often involve a cycle of unhousing

*“The absence of housing is the absence of everything”*

(Lutke, 2004)

# UNHOUSING AND HOUSING STRATEGIES

2004 RECOMMENDATIONS



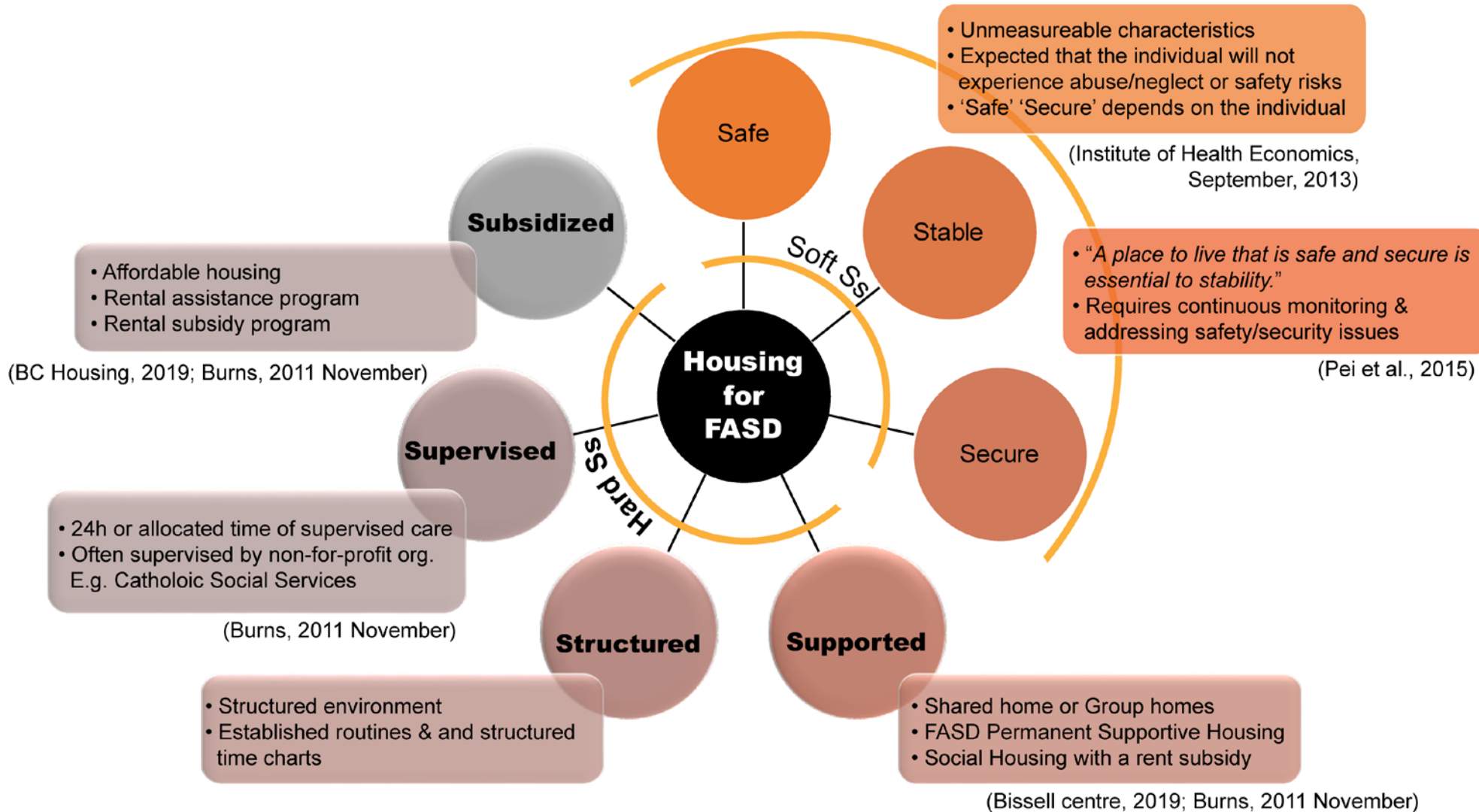
## 7S Model of Housing:

**S**afe, **S**table, **S**ecure, **S**upported,  
**S**tructured, **S**upervised, **S**ubsidized  
housing for unhoused individuals with  
FASD

(Burns, 2011 November; Lutke, 2004)

# UNHOUSING AND HOUSING STRATEGIES

KNOWLEDGE GAINED



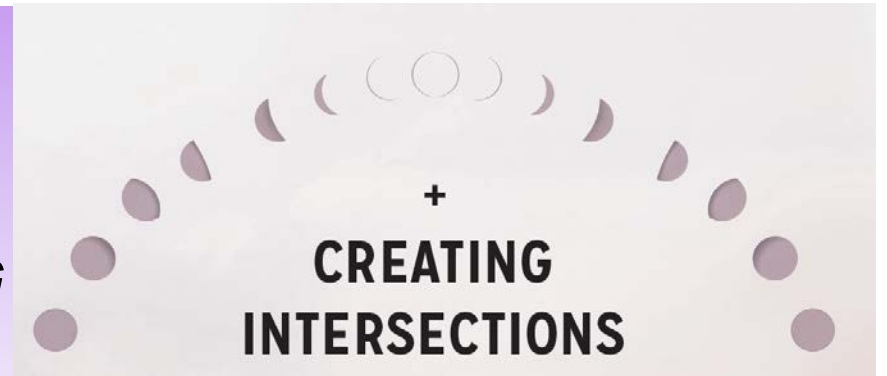
Require  
**'FASD informed model of Housing'**

# UNHOUSING AND HOUSING STRATEGIES

## ACTIONS

### A Systematic & Person-centered Harmonizing Framework For Housing for Individuals With FASD

A final report from a two-day gathering organized by CanFASD in collaboration with the University of Alberta with the participation of researchers and community experts, care providers and other experts in the areas of housing and FASD was prepared by Pei et al., 2018 and was entitled “*CREATING INTERSECTIONS*”

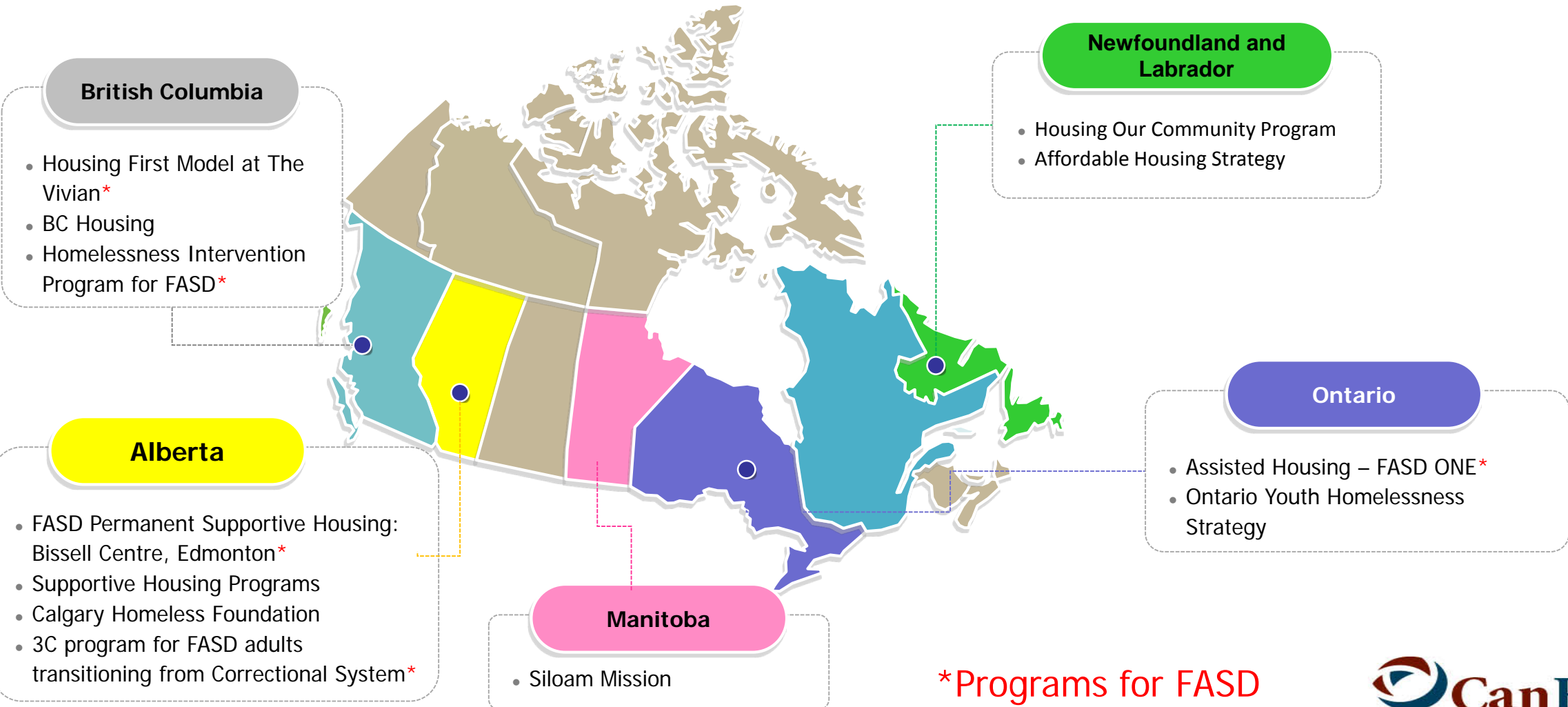


- Continuing objective: *"To amalgamate all of this valuable information to create an evolving harmonizing framework that reflects current understandings and that provides a guiding light forward for individuals with FASD"* (Pei et al., 2018)

# UNHOUSING AND HOUSING STRATEGIES

ACTIONS: A FEW EXAMPLES FROM ACROSS CANADA

(BC Housing, 2019; Burns, 2011; Burns, 2008; Badry, 2015; Brownstone, 2005; Brintnell, 2019; Pei, 2018)



\*Programs for FASD

# UNHOUSING AND HOUSING STRATEGIES

## GAPS AND NEEDS

- All housing models are not specific for FASD
- Current housing models may not match needs and assistance level of individuals with FASD
- ~80% of adults with FASD have difficulty sustaining independent living and requires assistance and services life-long
- Non-compliance with the housing arrangements
- Long waiting lists among all other applicants with disabilities
- Service providers' perspectives, fears and stereotypes, bias and discrimination
- Limited capacity in trained staff and resources to address FASD support needs
- Lack of funding for provincial housing initiatives

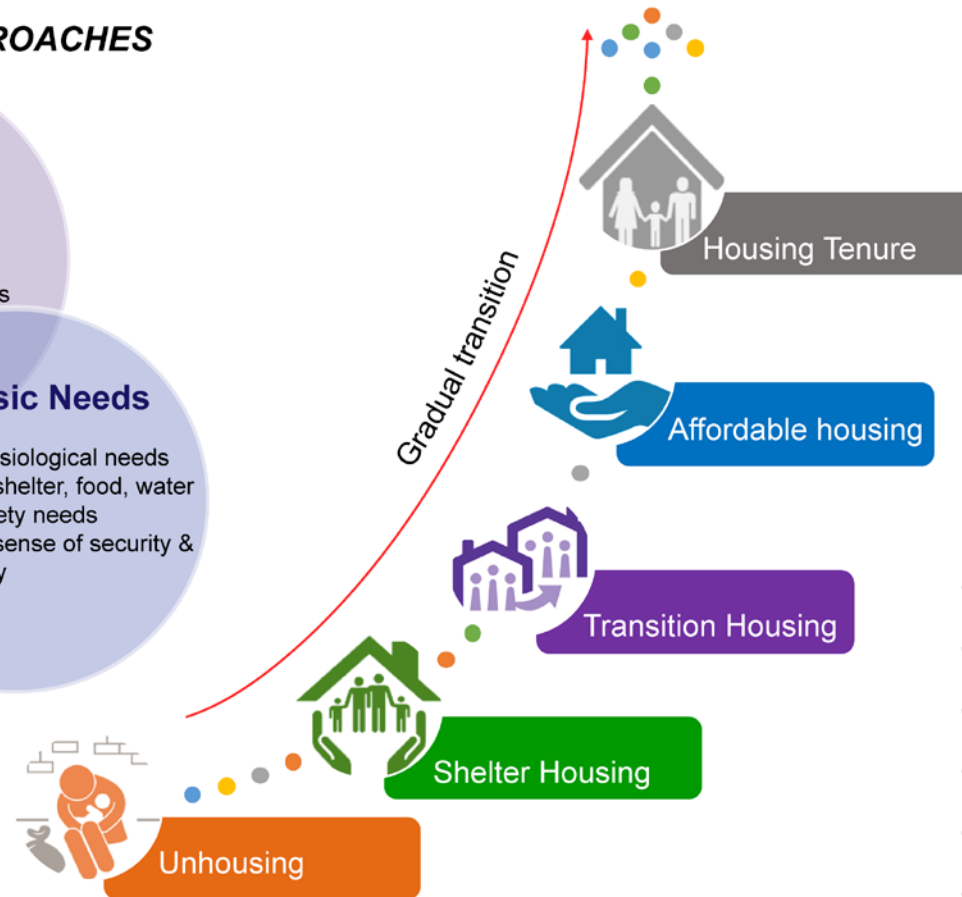


# UNHOUSING AND HOUSING STRATEGIES

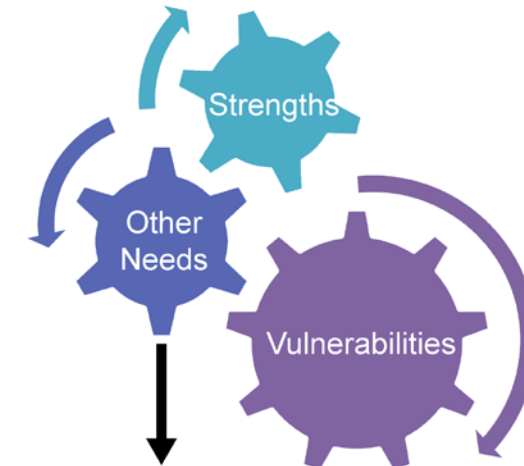
## NEEDS

### HARMONIZING FRAMEWORK FOR HOUSING FOR INDIVIDUALS WITH FASD

#### PERSON-FOCUSED APPROACHES



#### FASD-INFORMED PRACTICES



- Continuous support
- Education
- Employment training
- Financial assistance
- Help with addiction & recovery
- Special support offenders

*"Enough talking, let's make change!"*

(Pei et al., 2018)

# FINANCES

# FINANCES

## 2004 RECOMMENDATIONS



1. There is a critical need to develop a system of care for adolescents and adults with FASD that can adequately develop, fund, and implement a system of care.
2. The deployment of financial resources specifically targeted at FASD service delivery should be undertaken and considered a primary broad risk management tool for working with adolescents and adults with FASD.

(Fighting for a Future Report, 2004)

# Action for



1. Registered Disability Savings Plan
2. Disability Tax Credit

# HEALTH AND MENTAL HEALTH

# PHYSICAL AND MENTAL HEALTH

2004 RECOMMENDATIONS



- The development and funding of targeted health care delivery and mental health treatment should be considered as a primary broad risk management tool for working with adolescents and adults with FASD
- The provision of funded long-term mental health care to parents and other family members should be available, funded and encouraged as a risk reducing tool in the maintenance of essential supports to individuals with FASD

(Fighting for a Future Report, 2004)

# PHYSICAL AND MENTAL HEALTH

ACTION FOR CHANGE

## Action for



1. There is an urgent need to develop a comprehensive system of physical health care delivery designed to meet the needs of adolescents and adults with FASD.
2. There is a critical need to develop a comprehensive system of mental health care that is designed specifically to meet the needs of adolescents and adults with FASD.
3. There is an urgent need to provide mental health care services to parents and other family members.

(Fighting for a Future Report, 2004)

# PHYSICAL AND MENTAL HEALTH

## KNOWLEDGE GAINED

- The impact of prenatal alcohol exposure on addiction treatment (2013)
- New evidence is pointing towards FASD as a full-body diagnosis (2016)
- Life expectancy of people with fetal alcohol syndrome (2016)
- Comorbidity of fetal alcohol spectrum disorder: a systematic review and meta-analysis (2016)
- Healthy Survey (Myles Himmelreich, C.J. Lutke, Emily Travis) (2017)
- The Implementation of the 2012 Mental Health Strategy for Canada Through the Lens of FASD (2017)
- The prevalence of fetal alcohol spectrum disorder (2018)



# PHYSICAL AND MENTAL HEALTH

## ACTIONS

- Dr. Mela is actively engaging mental health professionals across the country improving their understanding of the special needs of individuals with FASD (2015-2016)
- Development of an Algorithm for FASD & Psychiatric Medications (2018)
- Free Online training being offered by CanFASD (2018)
- Specialized Primary Healthcare & Physician Consultation (2018)

# PHYSICAL AND MENTAL HEALTH

## GAPS AND NEEDS

- Lack of funding for targeted FASD physical and mental health services
- The recognition and accommodation of FASD in mental health systems in Canada
- Lack of trained health care/mental health care professionals in FASD
- Level of stigma associated with FASD is still incredibly high (for both individuals and mothers)
- Physical and mental health of caregivers

# EDUCATION, PROGRAMMING, AND EMPLOYMENT

# EDUCATION

## 2004 RECOMMENDATIONS



- The development and funding of targeted educational, vocational, employment and other programming that is specific to adolescents and adults with FASD should be considered as a primary broad risk management tool.
- It should also be considered as a risk reduction tool in its ability to help maintain both residential and family placements and to provide 'respite' to parents.

# Action for



1. Creation of an education system funding category for those with a diagnosis of FASD
2. Continuing to provide and fund education placements for adults with FASD past Grade 12
3. Triaging diagnosed students into specialized teaching teams in designated “expert” schools or streams

(Fighting for a Future Report, 2004)

1. Root causes of poor educational support and IPPs for students:
  - ineffective functional assessments and psychoeducational reports;
  - a lack of FASD education and training for teachers;
  - disjointed communication between all parties
2. Students with FASD tend to succeed more in elementary school, where the teachers, classroom settings, routines, and expectations remain relatively consistent all day

Brett, Harding, & The Family Advisory Committee (2018)

3. Students with FASD tend to find high school difficult because of the changing teachers, classrooms, routines, and expectations, and tend to struggle academically
  
4. Our knowledge about the role of trauma and early life experiences has expanded and so we know that school experiences for students with FASD will improve if educators are FASD and Trauma Informed in their practice
  - Need to ensure that Educational Assistants have access to the same training

Brett, Harding, & The Family Advisory Committee (2018)

# EDUCATION

## ACTIONS

1. Design and delivery of a provincial outreach program in British Columbia to serve teachers and educational assistants across the province (POPFASD)
2. Specialized school streams within an Elementary School-Bridges Program in Winnipeg, Manitoba
3. Specialized school stream in Secondary School in Surrey, British Columbia



# VOCATIONAL TRAINING, EMPLOYMENT, AND PROGRAMS

2004 RECOMMENDATIONS



1. Development and funding of FASD specific vocational skills college programs that can provide tutorial and academic supports and job placement services
2. Development and funding of “FASD employment service”
3. Development of a range of other volunteer, social, recreational and life skills programming to meet the daily needs of those adults with FASD who are unable to be employed

With the right job fit and supports in place,  
employment success is possible.

The needs of individuals with FASD evolve across the lifespan. In adulthood, issues with mental health, legal involvement, medical problems, sleep disturbance, and problems with activities of daily living can get in the way of employment.

(Makela, Kapasi, & Pei, 2018)

- Effectiveness of supported employment (Cochrane Review, 2013)
  - Increased levels of employment
  - Increased length of competitive employment
  - Found jobs faster than other approaches

- Example resources for supporting employment success:
  - Guide for Employment Professionals Supporting Employment in Adults with FASD
  - Employment and FASD: Strategies for Success
  - FASD ONE (Assisted Employment for People Affected by FASD)

# LEGAL AND ADDICTIONS

# LEGAL AND ADDICTIONS

2004 RECOMMENDATIONS



- Involvement with the legal and addictions systems occurs when other risk reduction strategies have been ineffective for a variety of reasons.
- However, because it is in the position of having to provide services to individuals with FASD regardless, it could also provide a pivotal intervention point.
- The development and funding of targeted legal and addiction services that are specific to adolescents and adults with FASD should be considered as a primary risk management tool.

(Fighting for a Future Report, 2004)



## Action for



1. There is a critical need to develop a true *system of justice* for adolescents and adults with FASD that crosses jurisdictions, systems, and authorities.
2. There is a critical need to develop, fund, and implement legal services for adolescents and adults with FASD

# LEGAL ISSUES

KNOWLEDGE GAINED



We have more information:



2011 Fetal Alcohol Spectrum Disorder (FASD) in a correctional population:  
Prevalence, screening and characteristics (MacPherson, Chudley, & Grant)

10% FASD diagnosis, 18% “possible” category  
43% CNS deficits – not alcohol related



2017 FASD in Yukon Corrections Study (McLachlan)

prospective case ascertainment design N=80  
PAE confirmed in 25% of cases, ruled out in 25% and unclear in 50%  
17.5% met criteria for FASD Diagnosis deferred for 13.8% (insufficient info)  
FASD ruled out for 68.7%

Systematic Review Articles:

Popova 2011 - global review on prevalence – 6 articles

Hughes, Clasby, Chitsabesan, & Williams 2016 – prevalence in youth 4 articles

Flannigan, Pei, Stewart, & Johnson 2017 – FASD and CJS – 25 articles

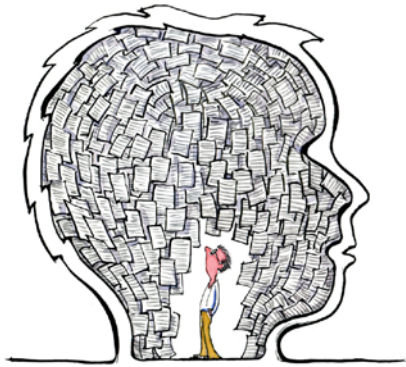




# LEGAL ISSUES

## ACTIONS

But



What good is knowledge  
without action?

[HkingArtist.com](http://HkingArtist.com)

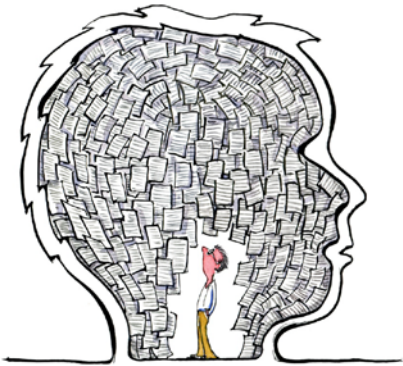
- Implementation of Mental Health Courts across Canada
- Canadian Bar Association statement - 2010
- Private members bills to amend the criminal code to address FASD (Bill C-583 in 2014 and Bill C-235 in 2016)
- Enhanced interventions for individuals with FASD in federal Corrections (adapted ICPM, FASD program RPC – Prairie, Pacific regions)



# LEGAL ISSUES

## ACTIONS

But



What good is knowledge  
without action?

HikingArtist.com

- Half-way house Pacific Region for released offenders with FASD – Maria Keary Cottage
- FASD court in Winnipeg
- Community Wellness Court in Yukon using supportive housing as an alternative to incarceration
- Asante FASD screening and referral tool for youth probation officers in justice involved youth
- Truth & Reconciliation Call to Action #34: A Framework for Action (2018) - CanFASD



# LEGAL ISSUES

## GAPS AND NEEDS



Are these components of a true *system of justice* for adolescents and adults with FASD that crosses jurisdictions, systems, and authorities?

What about those who become involved in the justice system as victims or witnesses? How are they cared for?

- Enhanced training for all those involved in the justice system on caring for individuals with FASD
- Accessible & affordable diagnostic services for adolescents and adults
- Community based, funded supports for individuals so the justice system does not become a primary care provider for individuals with FASD



## Action for

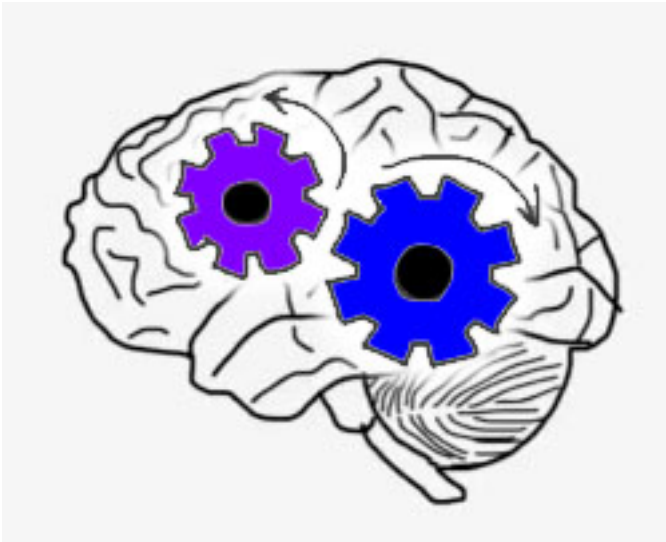


1. There is a critical need to develop, fund, and implement addictions services for adolescents and adults with FASD.

(Fighting for a Future Report, 2004)



Prevention efforts have grown:



- **Canada's Low-Risk Alcohol Drinking Guidelines**
- **Substance Using Women with FASD and FASD Prevention** - (Prepared by Deborah Rutman for the Research Initiatives for Social Change)
- **KNOWFASD: DRUG AND ALCOHOL USE**



Prevention efforts have grown:

- **National Framework for Action to Reduce the Harms Associated with Alcohol and Other Drugs and Substances in Canada** identified addressing FASD as one of the 13 priorities
- **Webinars:**
  - Treating Substance Abuse Among Prenatally Exposed Persons;
  - Talking with Women about Alcohol and Pregnancy;
  - Understanding Substance Use Problems and Addictions in Women as Key to FASD Prevention; Results from the Alberta Pilot of the Treatment Improvement Protocol (TIP) for FASD





## There is more information on FASD informed interventions strategies

- The Impact of Prenatal Alcohol Exposure on Addiction Treatment – Grant, Brown, Dubovsky, Sparrow, & Ries (2013)
  - Provides functional deficit treatment recommendations
- Rutman (2013) - The Voices of Women Living with FASD
  - Women want:
    - Affordable, safe and/or supported housing
    - Income
    - Mothering-related support
    - Mental health and trauma-related services
    - Employment readiness, job search, and life skills assistance



Here is the but again.....



informed interventions are still hard to find:

- Foundry – *Where Wellness Takes Shape* wellness centres for youth aged 12-24 – Mental Health and Addictions Programs
- PHS Community Services – community-managed alcohol program; on-site supervised injection facility; physical, emotional, and mental-health services





There remains a critical need to develop, fund, and implement addictions services for adolescents and adults with FASD, that will:

- Provide for research into what works in Addictions treatment for youth and adults with FASD,
- Provide priority access, non-punitive, supportive residential treatment, counseling and support services for pregnant women who have FASD and are dealing with substance use issues in all provinces and territories,
- Provide priority access, non-punitive, supportive residential treatment, counseling and support services to youth and adults with FASD and addictions

**Recognizing and addressing addiction needs for individuals with FASD is a matter of life or death**

# FAMILY SUPPORT

# FAMILY SUPPORT

2004 RECOMMENDATIONS



- Need to develop and fund family support services that can help to maintain or repair family systems
- Consulting with families to determine needs and most effective ways to meet them

# Family Coping and Support Research

- First-generation research on the impact of child disability on families (mothers) presented a bleak picture of stress, burden, depression, social isolation, and psychological dysfunction
- Solnit and Stark (1961)
  - parents go through a mourning reaction after giving birth to a child with any type of “defect”

# Families Raising Children with “Developmental Disabilities”

- Until more recently, researchers have tended to focus on the notion of “developmental disability” in general without examining issues related to specific differential diagnoses
- Family responses may differ based on the child’s unique disability and particular behavioural phenotype

Despite the wealth of literature on the experiences of parents caring for children with a variety of developmental disabilities, there has been limited examination of the experiences of families raising children with FASD

# But this is changing!

Action

for



- Increase in research exploring the lived experience of families raising children with FASD, particularly in Canada:
  - Experience of raising a child with FASD may be different from that of other developmental disabilities
  - Increased levels of reported parenting stress
  - ‘More rewarding and more difficult’
  - Enormous challenges emotionally, physically, socially, and financially
  - Challenges in dealing with professionals and the community, and accessing services

# Importance of Lived Experience: In their own words...

- Importance of listening to the stories and experiences of families
  - Play a key role in the direction of research priorities
- Importance of understanding both the **strengths** and **challenges** of families
- Promote an awareness of the positive benefits of raising a child with FASD
  - Helps promote positive parenting views and positive cognitive appraisal, especially for parents experiencing clinical levels of parenting stress

# FAMILY SUPPORT

## GAPS AND NEEDS

- Demonstrated need for formal support groups for parents of children with FASD (and siblings!), regardless of whether or not their child is formally diagnosed
  - E.g., recent funding in Ontario for the formulation of new FASD Support Groups
- Challenges for families arise based on their interaction with the larger environment and not necessarily driven by challenges internal to the family unit
  - E.g., further need for increased awareness and education about FASD



# FAMILY SUPPORT

## GAPS AND NEEDS

- Advocating for research that is relevant to families
  - CanFASD Family Advisory Committee
- Interventions including parent education/training programs, and child attention, meta-cognition, self-regulation, and adaptive functioning skills
  - Strongest Families FASD
  - Caregiver Education and Training for Behavioural Regulation
  - Coaching Families

*“It was a lifesaver, the FASD group”*

- Parent-to-parent FASD support groups appear to be the most important source of formal support for caregivers
  - Sense of community
  - Sense of belonging as a family unit
    - “We belong with them.”

# But, there are barriers to accessing support:

- Maladaptation
  - Need to meet families 'where they are at'
- Lack of child care
  - Need for safe, appropriate respite
- No existing group or unable to travel
  - Need for means of connecting those who are unable to attend local groups in-person

# Need for Individualized Support

Our life is like we can't sleep. You are in crisis ... You drive around the corner and your stomach, you feel nauseous 'cause you wonder 'what's happened? What will have happened? Will the kids be home?'

*- Peter, adoptive father of two adult sons with FASD*

# “Nothing changes until it does”

*“There is an urgent need for action to proactively support adolescents and adults with FASD rather than reactively apply ineffective costly measures.”*

*“Adults with FASD would greatly benefit from coordinated energized action by community, government, business and not-for-profit organizations.”*

(Fighting for a Future Report, 2004)

# Still Fighting for a Future – 15 Years Later

GOOD  
NEWS,  
BAD  
NEWS

- There has been significant progress in the last 15 years
  - Research evidence on prevalence and costs to assist us in advocating and communicating the urgency of dealing with the complexity of FASD
  - Promising pockets of programs or intervention strategies
  - More public awareness
- But... we still can't find services and supports for our loved ones

**We are still fighting but we need your help!**

# Group Discussion Activity

- How can we work together to insure there is more progress in the next 15 years?
- At your tables, please discuss concrete strategies to work together in any of these 6 areas to insure progress.
- Appoint a spokesperson from your group to report back during the larger group discussion.

# Reminder

- Identified **six areas**:
  1. Housing and Homelessness
  2. Finances
  3. Health and Mental Health
  4. Education, Programming, and Employment
  5. Legal and Addictions
  6. Family Support



# Implications

- We know more now, but question how much has really changed
- Inconsistency between provinces/territories and urban/rural/remote regions of Canada
- Continued vulnerability of youth and adults with FASD
- Demonstrated need for adult support
- Need for a **national strategy** to address the complexities of FASD

# Thank You!

- For further information:
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