

Webinar Report

Examining Opportunities and Challenges in Addressing Stigma through policy

December 5, 2022



This event was to stimulate discussion for policymakers and enhance understanding of the opportunities and challenges of reducing stigma for individuals with FASD, their families and support systems. Dr. Peter Choate walks us through the latest literature and case examples of how policy decisions can impact discrimination and support for those with FASD. This webinar provided opportunity for discussion and questions as Dr. Choate moved through the presentation. Unfortunately, Dr. Badry was unable to attend the webinar but was involved in the development of the presentation.




This report is intended to assist you with sharing the information with others in your government. Canada FASD Research Network (CanFASD) is honoured to support the efforts to improve the knowledge and possible solutions to reducing the stigma in this field.

Facilitator

Mr. Darren Joslin worked for the Government of Alberta for 31 years in the Social Services and Health sectors. His work focused on a number of different areas including Fetal Alcohol Spectrum Disorder (FASD), Mentoring and Youth Homelessness. He was the Co-Chair of the Alberta FASD Cross-Ministry Committee during the development and initial implementation of Alberta's FASD 10-Year Strategic Plan. As a member of the Canada Northwest FASD Partnership he was involved in the establishment of the Canada FASD Research Network.


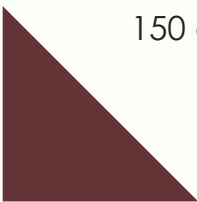
Presenters

Dr. Dorothy Badry, PhD, MSW, RSW is a professor in the Faculty of Social Work, University of Calgary with 16 years experience in the child welfare system in Alberta.



Her research focuses on FASD and child welfare issues, disability, women's health and FASD prevention, housing and homelessness, advancing knowledge through education on FASD, issues of loss and grief, and FASD and suicide prevention in Alberta. She has received research grants from provincial and national funders, including PolicyWise, Public Health Agency of Canada, First Nations & Inuit Health Branch of Canada and the Social Sciences and Humanities Research Council. She is co-editor of the Youth in Care Chronicles published in November 2020 that included several young adults living with FASD and received the Canadian Association of Social Workers Distinguished Service Award in 2021. Also in 2020 Dorothy co-authored the recently published book Decolonizing Justice for Aboriginal youth with Foetal Alcohol Spectrum Disorders (FASD) along with co-authors Harry Blagg, Tamara Tulich, Robyn Williams, Raewyn., Mutch, R., Suzie May & Michelle Stewart. She cares deeply about child welfare issues and those involved on the edges of society and systems.

Dr. Peter Choate, PhD, RCSW, is a Program Coordinator and Professor of Social Work at Mount Royal University in Calgary, AB. His research focuses upon colonization and the child welfare system. In particular, his work looks at the role of assessment and the application of psycho-social theory to sustain colonization and racism. He also looks at the intersection of disability, particularly Fetal Alcohol Spectrum Disorder, and the systemic discrimination that exists within people-serving stems such as health, criminal justice and social services. His teaching focusses upon child and adolescent mental health, addictions and social work across the lifespan. He has been qualified as an expert witness in social work, including assessment of parents, addictions, mental health and domestic violence on more than 150 occasions.



Pre-Reading Material

The Unique Complexities of Fetal Alcohol Spectrum Disorder
Mothers' Experience of Stigma: Multi-Level Ideas for Action
Individuals with Fetal Alcohol Spectrum Disorder and Experiences of Stigma

Summary

FASD is a disability that is often underrecognized and misunderstood. The best way to support individuals with FASD is to refer for assessment and diagnosis in order to promote recognition of the disability and to provide interventions and support. FASD is a stigmatized disability due to the cause. A holistic approach includes both prevention and intervention. FASD prevention involves working with the family and providing supports to prevent further alcohol exposed births. When FASD goes unrecognized the risk to the individual is that they will not receive the required supportive interventions needed to navigate all aspects of daily living. As children, many individuals with FASD are involved in the child welfare system. As youth, many become involved in the youth justice system. As adults, many individuals with FASD live in poverty, experience homelessness and become involved in the adult justice system. At all stages of life, individuals with FASD remain extremely vulnerable to victimization and stigma, and adolescence is a particular time of risk. Policy that responds to FASD needs to be flexible and adaptable to meet the needs of children, family and community. How are policy and practice impacted by stigma in relation to FASD?

Presentation

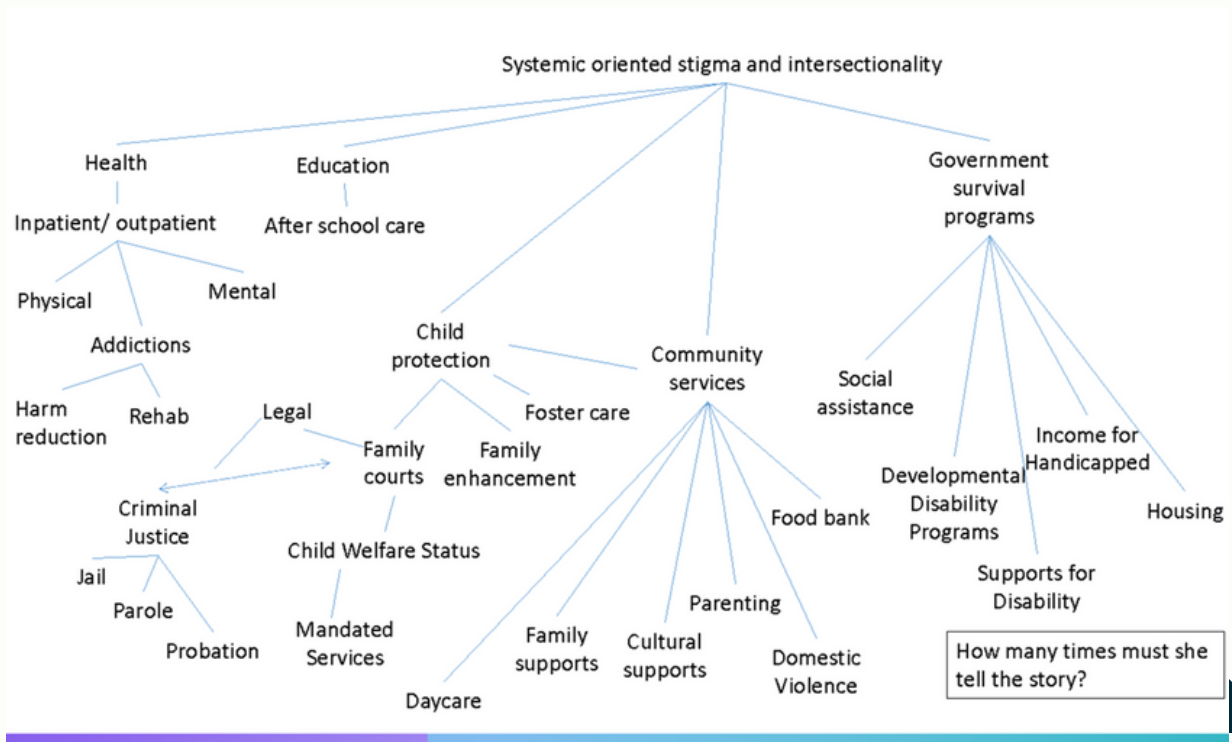
Media headlines commonly use statements to evoke a reaction from readers, and therefore are highly stigmatizing when violent acts are coupled with the mention of FASD. In one such example in the Calgary Herald ([Man who slashed stranger's throat on CTrain avoids federal prison; judge considers FASD diagnosis](#)), the judge passes a sentence that avoids extended jail time, having viewed incarceration as detrimental to the individual's welfare and that has been impacted by colonialism. But what has the public taken away from a headline that has linked violence and FASD? A first impression that perpetuates the discrimination and stigma faced by those with FASD. What is needed instead are supports to assist someone to be healthier in society. Systems have a responsibility to facilitate their intersections with people with FASD.

[Critical Race Theory](#) describes the notion that a person's race and disability impacts access to services and how they will be treated by those systems. FASD does not have any connection to race, although there have been historical views of race and social positioning as linked to the presence of FASD. Even so, given that people with FASD are perceived as having differences, they will encounter systemic barriers in accessing services.

[Two key principles](#) underline this presentation of public policy and FASD: 1) there is a substantial gap in policy and practice for children and families living with FASD; 2) the CanFASD Research Network is committed to highlighting key policy and practice issues in FASD nationally and globally. Public policy is not consistent across the country for services for people with FASD

since provinces and territories hold the responsibility for health, education, child protection and social services delivery and therefore services are managed differently by each jurisdiction. It is of interest to know which provinces and territories are serving this population best. Individuals with FASD do not always have a strong voice in the political process, nor is there a mechanism to voice their concerns in order to influence policy. FASD requires unique policy approaches that do not currently exist.

The diagram below is part of a **mapping project** that highlights the various systems one family encountered in efforts to obtain supports. A common intake process is missing and is needed to reduce the number of times families must repeat their story. Lack of system integration and coordination between departments and ministries adds to the stigma and disconnect of what the family needs and what they receive. It also increases the vulnerability of the individual with FASD for harm due to lack of coordination between systems.



Mother dialogue in systems.

Women who have children with FASD come from a number of backgrounds, and those with cumulative impacts of marginalization and trauma and who lack supportive systems are disadvantaged when it comes to supports and services. Women have quite distinct needs based on historical trauma. If our systems fail to recognize historical trauma, people will experience more trauma and ongoing stigmatization as a result. For mothers with a high ACE (Adverse Childhood Experiences) score, their child in-utero is subject to the adverse events along with the mother, therefore both mother and child will experience marginalization to the same degree.

The “bad mother” dialogue emerges and perpetuates stigma when thinking and beliefs propagate that only bad mothers have a child with FASD because of the woman’s action of using alcohol. This has been seen in health and child protection services but also in others. Instead, one must consider what is the place of drinking in the mother’s life without making the judgment that alcohol use is solely a voluntary choice. The dyadic narrative is not helpful – such as “baby or the bottle”; “stop and think: Don’t drink”. When a mother or child with FASD intersects with our systems, consider what dialogue the system has about them. Is the conversation about the mother or child stigmatizing or inclusive?

A language of inclusion and support enables effective connection. Cumulative stigma language related to FASD, addiction and substance use, trauma and mental health creates unnecessary barriers, cumulative meaning it is being experienced across multiple systems. Why would a person with FASD come to a system if they are facing language and

perceptions that blame or stigmatize? Why would women and families engage with a system if they are anticipating judgment as they have with other systems?

Root cause dialogue examines the “why” and frames situations in ways that reflect one’s reality as opposed to only the outcome. For example, examine why a woman is using alcohol as opposed to focusing on the alcohol use itself.

Dysfunction dialogue focusses on problems and lack of strengths instead of resilience dialogue. Terminology and language such as “lifelong dependency, prognosis of failure, susceptibility to exploitation, involvement with child intervention, etc.” fails to highlight an individual’s abilities, strengths and resiliency.

What kind of conversations do we need to have within our systems to minimize the barriers, open the conversation, share the experiences on the frontline? How do we make policy that contemplates the challenges of someone with FASD? Offer the supports in a consumer-friendly way.





Conversation about access points – how does policy hinder or support access to systems for people with FASD?

- The bad mother dialogue/conversation has been witnessed at policy, political and media tables.
- From a prevention standpoint, women need to feel safe to access services. Feeling judged or stigmatized may prevent them from seeking services which can have implications for prenatal care.

- In some cases, without amenity, women would not seek health services in an example provided by a participant.
- The qualifying criteria to receive services for persons with disabilities can make accessing services impossible.
- The need to understand one's own biases and the vulnerability of FASD is not only for the service professional but also for front staff members who are often the first people clients encounter in the system. This interaction can impact individuals in accessing services.
- For example, an Individual with FASD who exhibits a behaviour that appears ungrateful or unresponsive, might provoke a negative reaction from front staff members leading to that individual being turned away from, or refusing, the services they need.
- And with the demand for services in general putting pressure on the medical system, those most in need of support are at risk of being turned away.
- People face many challenges with understanding and navigating the system in general. For someone with FASD, and furthermore one who is undiagnosed, the difficulties are even greater, even more limiting access to supports.
- Without the ability to share across systems, how do we build trust and get individuals the services they need?
- Often services are diagnosis based instead of needs based. This is a conundrum: assessment is more important, not just the diagnosis.

FASD as a whole body disorder



A group of individuals with FASD conducted a survey study and are publishing this work looking at other physiologic issues associated with FASD having higher occurrence and earlier occurrence than in the general population. This includes a wide range of physiological conditions including irritable bowel



syndrome, sleep apnea, rheumatoid arthritis, adult chronic ear infections, Crohn's Disease, Celiac disease, ulcerative colitis and early dementia. When taken into consideration, the concept of vulnerability emerged, that the FASD population is experiencing vulnerability to a greater degree. The idea that criminality isn't biologically rooted, rather having poor judgment and a higher predisposition to being vulnerable are the source of such behaviour. Consider the intersection of persons with FASD and the justice system as a vulnerable situation in which they are unable to assess risk.

Child welfare (CW) intersects with multiple systems through domestic violence, education, criminal justice, etc. and touches on every system for someone affected by FASD.

Independent child advocate reports across the country were reviewed, and the review had some limitations since the legislation in each province varies, complicating comparison across all provinces. Child and Youth advocates exist in Canada and are the major point of review about the intersection of FASD with other systems, because it is the only one that contemplates all the intersections in systematic reviews. A major issue is the transition from youth to adult services. As a youth, one qualifies for many supports but when one becomes an adult there are fewer, and diagnosis becomes more important in being able to access those supports. How do we create policy to create good outcomes for this transition? We do not have good transition policies across the country; some jurisdictions allow people with FASD to stay in the system beyond 18, the age of maturity. But what is the age of maturity for this population? Consider maturation age vs chronological age in one's ability to make decisions. Youth in general are staying in the care of family systems much longer, so for the CW population - a vulnerable



population, expecting them to navigate this transition on their own at a defined age and without ongoing supports adds to their vulnerability.

Discussion – transition for youth with FASD from youth to adult supports – challenges, a new option, alternatives

- Transition is a strengths-based process. However, some policy statements in FASD state people with FASD are supported across the lifespan and might imply that everyone will need a full wrap around support, without recognizing an individual's strengths. We all require support in some fashion across our lifespans, so how do we make it individualized and available across all support systems?
- Be wary of exceptionalism when speaking about strengths-based approaches. Supports will be needed at all levels of ability and exceptionalism takes away from recognizing the individual needs each person with FASD may have. For example, as important as it is to have post-secondary support, it is equally as important to keep available the continuation of supports from childhood across into adulthood for some.
- Policy [makers] like universal applications and diagnoses, and prefer solutions that apply to everybody. But the FASD population requires decisions that take into account the unique needs of individuals.

Excluded: Increasing Understanding support and inclusion for children with FASD and their families

British Columbia Child & Youth Advocate



The report made a series of recommendations:

- In cases of suspected (possible) or confirmed FASD, provide access to services available for other children who have neurodevelopmental conditions in order to activate supports and services.
- Examine what training is available and support the development of evidence-based, culturally attuned and regularly updated training materials.
- Develop and plan for training on FASD across sectors (child welfare, education, foster care, justice and allied services).
- Consider the needs of First Nations, Metis, Inuit and Urban Indigenous children and youth for FASD assessments to reduce bias in the process, based on the 2020 In Plain Sight report.

Child death reviews in Canada: Child Welfare is the key system involved but not the only one. Multisystemic common understanding is critical.

Researchers reviewed reports from most provinces and territory of Canada. Not all reports are made public and they are often framed differently. Importance of child death reviews for children in the child welfare system: (child death review in Canada 2016)

- Supports systemic data collection
- Offers a process to examine systemic gaps and issues (a public lens)
- Offers a process for community/professional engagement in reviews
- Provides recommendations for future practice
- Highlights areas for improvement and change
- Ensures that no individual death goes unnoticed or is “swept under the rug”
- Helps to ensure that children are receiving services they are entitled to

Key findings of the analysis of the Canadian child advocate reviews of infants, children and youth with prenatal substance exposure and FASD in child welfare care.

Scoping Review

Key learnings:

- Children and youth with FASD are heavily involved in the child welfare system
- Often overrepresented yet unrecognized in the child welfare system
- FASD is not well understood as a disability

- Child welfare workers are not trained in FASD or disability
- Alcohol use disorders are strongly connected to trauma history in parents, psychiatric problems and other adversities
- Parental substances misuse puts children and youth at risk on multiple levels
- FASD is a distinct disability that contributes to unique risks and vulnerabilities for children and youth.

An intersectionality-based policy analysis of Canadian child advocate reviews of infants, children and youth with FASD in child welfare care.

Key Considerations to reduce stigma and discrimination within systems:

- Understanding Child welfare intersects with all human service systems
- Child welfare workers typically lack sufficient training in FASD to offer effective and long term interventions
- Recognizing FASD is critical in child welfare care
- Infants, children and youth with FASD have unrecognized and underestimated risks and vulnerabilities
- Safety planning is critical to reduce risk and manage challenges
- When prenatal exposure to alcohol is known to child welfare, early assessment and intervention is required
- FASD assessment and diagnosis is critical to safety and wellbeing
- The risk trajectory for children with FASD is far too high
- The need exists to promote FASD informed case management
- Children with disabilities have rights.
- Regular training with current evidence on FASD for all service sectors is necessary, including admin and front-line staff.