





Stakeholder Perspectives on Risk factors and Opportunities for Suicide prevention among individuals with Fetal Alcohol Spectrum Disorder (FASD)

Lay Summary

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The Problem: Mental health concerns for individuals with FASD can contribute to a risk for suicide in this population. Few studies address this topic of FASD and suicide in the literature. Mela (2021) identified the concern that suicide risk is higher for those with prenatal alcohol exposure (PAE) due to experiencing higher rates of adverse childhood experiences (ACES), and highlights the need exists for FASD informed interventions. This research was underpinned by the Alberta Youth Suicide Intervention Strategy - *Building Strength, Inspiring Hope* Report (2019) - a plan for youth suicide prevention. Individuals living with FASD, a lifelong disabling condition experience higher risk of suicide than the general population.

Research Activities and Findings

- 1. **Scoping review of available literature** relative to youth suicide and FASD included both research and grey literature. **Findings:** 27 studies were included and tell us suicide risk is higher for individuals with FASD in comparison to the general population.
- Secondary data analysis of National FASD Database known as DataForm with the Canada FASD Research Network examined mental health diagnoses and rates of suicide/ or suicidal ideation across Canada.
 Findings: There were 796 participant files reviewed and 25.9% were reported to experience suicidality. Key risk factors include substance use, history of trauma and impaired affect regulation.
- 3. Caregiver Survey on 23 children and youth focused on life events, sleep habits and a suicide severity scale. Findings: Children and youth with FASD and co-occurring suicidality experienced a range of health conditions, including allergies(30%), asthma(22%), and heart conditions/disease(17%), as well as high rates of neurodevelopmental conditions including ADHD, learning disorders and depression. 78% of children/youth were taking medications and 44% of children had serious sleep problems. Caregivers report barriers to accessing supports including a lack of service or long waitlists. Over a one-month period 43.5% of children and youth experienced suicidal ideation.
- 4. **Qualitative Research Interviews** were conducted with stakeholder groups including professionals providing direct service, caregivers involved in the care of children/youth and young adults with FASD, FASD researchers and a small group of adults living with FASD.

Findings:

- Caregivers have serious concerns about the risk of suicide for youth with FASD and identify that even a
 minor crisis can precipitate talk of wanting to die. Youth with FASD do not always comprehend the finality
 of suicide. Youth who express suicidal thoughts are often experiencing emotional pain that they want to
 stop. Caregivers are often on high alert in caring for youth with FASD as the risk of suicide is real.
- Professionals are concerned about the risk of suicide in this population including high risk drug use that can contribute to death. Gaps exist in counselling, intervention supports and FASD training.
- Individuals with FASD are excluded from some mental health services due to a false belief that this population does not benefit from counseling or are too complex. Full access to these services is essential from a disability and human rights position.
- Adults with FASD inform us daily experiences of sensory overload and anxiety are real and, at times, they
 don't know how to make things better on their own. They don't want their disability dismissed because it
 may not be easily visible to others. Adults value counseling and supports from people who understand
 FASD and who focus on their strengths and hopes for the future.

Reference: Mela, M. (2021). Prenatal Alcohol Exposure: A Clinician's Guide. American Psychiatric Pub.

Research Team Members