

The Canada Fetal Alcohol Spectrum Disorder Research Network: Understanding and Benefiting from Collaboration, Experience and Expertise

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Issue:

The Canada Fetal Alcohol Spectrum Disorder Network (CanFASD) is Canada's first comprehensive organization to support this country's leadership in addressing the extraordinary complexities of Fetal Alcohol Spectrum Disorder (FASD). CanFASD is a national, charitable organization with a mission to produce multidisciplinary, collaborative evidence that can be shared with all Canadians, leading to prevention strategies and improved outcomes for people affected by FASD.

CanFASD's primary focus is providing structure and support for research that sets the foundation for the development of effective, evidence-based programs and policies on FASD in Canada including federal, provincial and organization level strategic plans to address FASD, training resources and FASD-informed programs and services. By bringing together invested stakeholders- including member jurisdictions, researchers, parents and caregivers, clinicians, front line service providers, community advocates, program planners, government employees, political leaders, and people living with FASD, CanFASD is fostering the development of high impact initiatives around prevention, diagnosis and intervention for FASD as well as the knowledge exchange activities to support and promote them.

Background:

Fetal alcohol spectrum disorder is a major public health issue in Canada, affecting 4% of the population (1). This means **over 1.4 million Canadians are living with FASD today**. While other disabilities are also important, the prevalence of FASD is greater than autism, cerebral palsy and Down's syndrome combined.

Fetal Alcohol Spectrum Disorder (FASD) is a diagnostic term used to describe impacts on the brain and body of individuals prenatally exposed to alcohol. FASD is a lifelong disability. Individuals with FASD will experience some degree of challenges in their daily living, and need support with motor skills, physical health, learning, memory, attention, communication, emotional regulation, and social skills to reach their full potential. Each individual with FASD is unique and has areas of both strengths and challenges.

The sole cause of FASD is alcohol exposure during pregnancy, thus FASD can affect individuals of all ages, genders, cultural and socioeconomic backgrounds. However, because of a complex

combination of personal and environmental factors, some populations may be at a higher risk for FASD.

The indirect and direct costs of this disability to health care, education and social services sectors, as well as the criminal and justice system, is staggering — at about \$4 billion a year. The cost to the quality of life for those living with FASD is unquantifiable.

Individuals with FASD often experience a complex array of issues including attachment, trauma and instability as well as compromised social determinants of health and stigma that compound their disability and lead to poor outcomes for this population.

Given the prevalence, incidence, complexity, inherent challenges and the limited funding and support for FASD, it is imperative that leaders collaborate and share evidence and resources to adequately and efficiently address this public health issue.

Definitions of collaborative research networks differ, but they commonly identify relationships, resources and knowledge transfer as key features of networks that “...involve the creation, combination, exchange, transformation, absorption, and exploitation of resources...within a wide range of formal and informal relationships” ((5), p. 21). Collaborative research networks have the potential to translate knowledge across the research, policy and practice divides – domains where collaboration is often constrained by different priorities and languages (6,7).

Summary

CanFASD brings together an interdisciplinary network of researchers, scientists, policymakers, practitioners and families to support and produce high-quality research that is used to inform meaningful policy recommendations, tools and resources needed to ensure that governments are serving and supporting their citizens needs effectively.

Through collaboration and partnerships, CanFASD has become a centre of expertise — and made significant progress in the diagnosis, intervention and prevention of FASD, as well as in the development of policies that will enhance the lives of those with this disability and support families and caregivers.

Provinces and Territories of Canada that have invested in CanFASD have stronger policies and programs for individuals with FASD and are reaping the rewards of this investment with evidence-informed strategies that are improving outcomes.

Recommendations

CanFASD is a research network that provides the infrastructure and support for investigators to participate in multidisciplinary/sectoral research projects to better inform approaches aimed at developing effective prevention, intervention and support services for individuals with FASD and their families. Input and contributions come from basic researchers, behavioral scientists, clinical investigators, frontline service providers, policymakers and families who are willing to share their knowledge and experience to avoid replicating previous or ongoing work, and to move the field forward.

CanFASD is the only national organization that has the capacity, experience, network and data to do this work on behalf of families, individuals, service providers and researchers

1. That the remaining provinces and territories in Canada that are not members be encouraged to become members of CanFASD to promote and ensure a pan-Canadian perspective in research to inform policy and practice across the country.
2. That the Government of Canada recognize FASD as a major issue and allocate adequate funding to address it.
3. That CanFASD continues to offer the infrastructure to foster collaboration and coordinate research and knowledge translation activities related to FASD.
4. That all CanFASD members make FASD a priority, working with their provincial and territorial health, social, justice and education departments to support funding and policy decisions that will reduce the prevalence of FASD and improve the lives of those with FASD and their families.
5. That CanFASD continue to work towards Reconciliation, in particular TRC Calls to Action #33 and 34 through partnership and collaboration with Indigenous communities.
6. FASD is a common and complex disability with the unique aspects of prevention to address. Given this and the limited, but expanding research on evidence-based practices, it is recommended to build FASD knowledge into every sector of government service and in specialized supports where required and appropriate.

References

1. Flannigan, K, Unsworth, K and Harding K. (July 2018). Retrieved July 16, 2019, from <https://canfasd.ca/wp-content/uploads/sites/35/2018/08/Prevalence-1-Issue-Paper-FINAL.pdf>
2. Global status report on alcohol and health 2018. (2018, September 28). Retrieved May 16, 2019, from https://www.who.int/substance_abuse/publications/global_alcohol_report/gsr_2018/en/
3. SOGC Contraception Survey, 2017.
4. Denny, C. H., Acero, C. S., Naimi, T. S., & Kim, S. Y. (2019, April 26). Consumption of Alcohol Beverages and Binge Drinking Among Pregnant Women Aged 18–44 Years - United States, 2015–2017 | MMWR. Retrieved May 16, 2019, from https://www.cdc.gov/mmwr/volumes/68/wr/mm6816a1.htm?s_cid=mm6816a1_x
5. Sala A, Landoni P, Veganti R. R&D Networks: an evaluation framework. *Int J Technol Manag.* 2011;53(1):19–43.
6. Brownson RC, Royer C, Ewing R, McBride TD. Researchers and policymakers: travelers in parallel universes. *Am J Prev Med.* 2006;30(2):164–72.
7. Shonkoff JP. Science, policy and practice: three cultures in search of a shared mission. *Child Dev.* 2000;71(1):181–7.