

MESSAGE FROM THE EDITORS

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Balancing the Story on Fetal Alcohol Spectrum Disorder

Fetal Alcohol Spectrum Disorder (FASD) was first formally recognized in the late 1960s and early 1970s (and in North America, specifically, in 1973¹). At that time, physicians identified unusual physical features and developmental delays in babies exposed to alcohol in utero. From this early identification, researchers and clinicians sought to better understand what they were seeing and to truly identify the potential impacts of prenatal alcohol exposure. The constellation of features that would later become more broadly labelled as FASD were defined, sparking research that gradually evolved through clarifying and confirming the teratogenic nature of alcohol and the results for development. This work opened the door to prevention initiatives and research efforts to legitimize the diagnosis of FAS(D) within support systems. The wealth of information produced helped to assert the importance of this topic and contributed to the establishment of diagnostic standards and consistent approaches to identification in Canada and beyond.²⁻⁷

Since that work, discourses regarding FASD have shifted. Research evidence, community input, and family and individual advocacy efforts have supported an evolution towards a more balanced conceptualization of FASD, including recognition of the complexities of FASD⁸ in parallel with the strengths and resiliencies of individuals, families, and communities.⁹⁻¹¹ Additionally, the FASD field

has expanded to consider the intersectional elements at play for individuals with FASD in various spaces, including within diagnostic, justice, child welfare, intervention, and prevention spaces. By expanding our thinking and approaches to FASD, including framing FASD from a more balanced and strengths-based perspective, researchers and clinicians are increasingly valuing the voices of those with lived experience and enacting tenets of intervention research¹² in which leveraging strengths to help mitigate challenges is underscored. Moreover, the centrality of the person and the humanizing of disability that has arched through all disability literature through advocacy and cultural shifts in attitudes has elevated the priority given to strengths and more holistic conceptualizations.¹³⁻¹⁵ This is not to suggest a rejection of past work and established understandings but rather to build upon and contextualize areas of deficit to reflect the potential of individuals with FASD and acknowledge their lives' inherent value and purpose.

A balanced narrative allows us to equitably consider multiple perspectives and experiences. The voices of individuals, families, and communities are valued just like those of researchers, clinicians, and service providers. The stories to be told, and the successes to be achieved, will be the product of the weaving together of these sources of knowledge rather than the elevation of one over the other. In

this way, we might move towards goal-oriented and humanizing practices beyond stigmatization and marginalization.

THIS SPECIAL ISSUE

This special issue was created to reflect the evolving approaches to conducting and conceptualizing research in the FASD field. We sought to capture research reflecting the diversity and complexity of the field, as well as the potential and hope. Our desire is not to minimize the challenges experienced by individuals with FASD and their families but rather to elevate strengths and collectively work together towards meaningful solutions. We have included articles that reveal significant challenges within the field, coupled with action-oriented calls by advocates with in-body and in-home lived experience and their allies. By leveraging the diverse wisdom of scholars and collaborators from the Canada FASD Research Network (CanFASD), we can together continue to leverage this unique partnership that brings together many scientific viewpoints to address the complexities of FASD with our focus on ensuring that research knowledge is translated into community and policy action.^{16,17} The contributions included in this special issue were specifically created by CanFASD staff, Research Leads, Family Advisory Committee (FAC) members, Adult FASD Expert Collaboration Team (AFECT) members, Trainees, board members, and community partners and collaborators.

Broadly, the key themes addressed in this special issue include FASD challenges,^{18,19} solutions,²⁰⁻²³ and evolving understandings and approaches.²⁴⁻²⁷ Our hope is that readers will take from this special issue that it is not about doing one type of work but rather all work with a sense of the desired and intentional impact. The articles in this special issue span a diverse range of topic areas in line with CanFASD's priority areas for FASD – prevention, intervention, diagnosis, justice, and child welfare – and how each can support a balanced story of FASD. They include a variety of methodological, theoretical, analytical,

and activist perspectives that make unique contributions to the literature on FASD.

This special collection took shape over much of 2021 and 2022 and ultimately includes ten academic articles. Various topics related to FASD are explored including the importance of language when discussing FASD²⁴; essential considerations for collaborative FASD research²²; recent patterns and trends in the field of FASD prevention²⁵; effective screening approaches for FASD²³; psychotropic medication usage among individuals with FASD with co-morbid psychiatric conditions²⁰; a policy analysis of Canadian Child Advocate reports of infants, children, and youth prenatally exposed to alcohol and other substances¹⁸; mathematics achievement among children and adolescents with FASD²¹; portrayals of alcohol and substance use on mainstream television¹⁹; meaningfully incorporating the voices of individuals with lived experience in FASD research²⁶; and advancing a strengths-based, person-centred lifespan approach to interventions for individuals with FASD.²⁷

We believe that by featuring the diverse voices within the FASD community, this collection of articles will advance knowledge in a strengths-based and human-centred way.

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