

Introduction to Volume 19, Issue 3: The Special Collaborative Issue on Fetal Alcohol Spectrum Disorder

We are very pleased to introduce a Special Issue on Fetal Alcohol Spectrum Disorder (FASD) produced collaboratively by the *First People's Child and Family Review* and the *Journal on Developmental Disabilities (JODD)*. This Special Issue presents original research reports, literature reviews, environmental scans, media reviews, artwork and messages from people with FASD and those supporting them. Together they offer a broad perspective on the topic including information and commentary from academics, clinicians, community service providers, advocates, individuals, and family members living in diverse communities across Canada.

FASD is a widespread international issue which is of concern to all people. Individuals from Aboriginal communities, however, have been leaders in bringing this issue to the fore advocating for services and producing research, programs, and practices that are instructive to their own communities and to the broader public. Those working in the field of developmental disabilities have also had, whether they are aware of it or not, extensive experience with FASD. This is because according to the Public Health Agency of Canada approximately 1 in 100 individuals born in this country have FASD (Government of Canada, 2012). As such it one of the most common forms of developmental disability currently recognized.

When a child is born with FASD the constellation of presenting symptoms can vary a great deal across individuals. Despite this broad range of possible effects all those receiving a diagnosis will have significant neurodevelopmental challenges (Chudley et al., 2005). These include differences in executive functioning, social skills, academics, memory, and learning to name just a few. Such challenges can lead to significant behavioural and functional difficulties. Differential responses to the challenge of FASD have emerged within the disability supports sector, child welfare, justice, and mental health/substance abuse treatment sector. Still, resources are unavailable in many communities and governmental or other responsibility has not yet been fully developed.

A diagnosis of FASD presumes that the biological mother of an individual consumed alcohol during her pregnancy. Women who drink during pregnancy, however, are not a homogenous group and a number of risk factors contribute to drinking behaviour during pregnancy as well as a woman's risk for having a child with FASD. These and other issues surrounding outcomes in FASD are important to examine and are reviewed here in a paper by Kelly Coons.

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Keywords

fetal alcohol spectrum disorders,
maternal alcohol consumption,
prenatal alcohol exposure,
First People,
First Nations,
community intervention,
education,
DSM-5,
media review,
adult,
children,
parenting,
participatory action research,
community programs,
community program effectiveness,
autism

Having identified the wide-spread nature of FASD it is concerning that services and supports for individuals and their families are often limited. Danielle Naumann, James Reynolds, Mary Ann McColl, and Holly Smith report on an environmental scan undertaken across Eastern Ontario of community and government services for FASD. The authors provide a comprehensive inventory of programs available but also note problems with access to services, fragmented programming, gaps, and shortages. Jessica Wheeler, Kara Kenney and Valerie Temple present a review of the literature on interventions for FASD that have been empirically validated. They discovered very few options are currently available but offer some interesting suggestions for a way forward in this area of research. An initiative to develop school-based supports for children with FASD is presented by Gal Koren, Alexander Sadowski, and Tali Scolnik. These authors describe a new resource book and educational sessions for teachers and other school-based professionals around Ontario and provide the results of their educator feedback from over 800 school staff.

An important subject raised in this Special Issue is the inclusion of an FASD-related diagnosis as a “Condition for Further Study” in the latest version of the *Diagnostic and Statistical Manual of Psychiatric Disorders* (DSM-5). An article by James Sanders discusses the history of FASD in the DSM, how DSM-5 will define and categorize the effects of prenatal alcohol exposure, and implications for diagnosis and identification of FASD within the fields of psychiatry and psychology.

This issue also gives voice to individuals with FASD, their caregivers, and their family members. Beginning with the issue’s cover art, we see the importance of family and being connected to the people we care about expressed by artist Roy Wilson. Mr. Wilson’s body art depicts his love for his daughter and his wish that an “angel” will watch over her and keep her safe in this world. Mothers and fathers such as Elizabeth Russell and Stephen Clifford offer heart-felt poetry and stories adding a personal and emotional layer to the research facts and figures about FASD. An article by Debbie Michaud and Valerie Temple paints a vivid picture of the thoughts, joys, and fears of both birth mothers and adoptive mothers

when speaking about their children with FASD reminding us that there are real people and communities at stake in this disorder. Shelly Watson, Stephanie Hayes, Elisa Radford-Paz and Kelly Coons place FASD in direct contrast to another developmental disability--autism. The authors look at parents’ hope for the future of their children and found that parents of children with FASD had more trepidations and less hope than parents of children with autism, highlighting the challenges and difficulties of supporting individuals with this disability.

Finally, looking at the broader social landscape outside of health services it is interesting to note how FASD has made an impression on the popular culture. In *Defendor*, a recently released Hollywood movie, well-known actor Woody Harrelson portrays a man described as having FASD. Reviews of this movie are provided by Bruce Edwards and Ann Fudge Schormans and her colleagues – people with and without intellectual and developmental disabilities. Placing FASD in the public eye through books, movies and other forms of media will undoubtedly help raise public awareness and understanding of the disorder.

Abstracts from the *First People’s Child and Family Review’s* Special Issue on FASD are also included in this edition of *JODD* with the express hope that this cross-pollination of ideas and information will encourage greater collaboration and sharing of knowledge across all communities. The topics addressed in these abstracts highlight the depth and diversity of discussion around FASD in First Nations communities across Canada.

Beginning with the topic of prevalence, Christine Werk and colleagues report on rates of FASD among Aboriginal children under six years of age living off reserve. They found numbers to be higher in Alberta and Manitoba compared to other provinces and noted that across all provinces only about half of those diagnosed received treatment.

In the domain of prevention, we hear from Erin Atkinson and her colleagues who used visual data collection methods to study FASD prevention with Parent Child Assistance Program workers across Alberta. As well, Dorothy Badry, Aileen Wight Felske, and Annie Goose

offer several papers on the “Brightening our Home Fires Project” aimed at women’s health and FASD prevention efforts in the Northwest Territories. Deborah Rutman interviewed women with a diagnosis of FASD to identify promising and innovative approaches to substance use treatment from the perspective of the women themselves. Steven Koptie offers thoughts on ceremonial approaches for coping with FASD and the importance of open discussion to deal with the devastation of alcohol and FASD in communities.

In the domain of support and intervention, Tasnim Nathoo and colleagues review several programs across western Canada aimed at supporting women who use alcohol and other substances during pregnancy. They outline several “Best Practices” for such programs including engagement/outreach, harm reduction, support to mother and child, and cultural safety. Linda Burnside and Don Fuchs describe the experiences of individuals with FASD transitioning from child welfare agencies to adult services in Manitoba, highlighting the supports and services needed by this vulnerable group. Looking at FASD through the lens of a social worker, Andrew Wilson notes the need for human services workers to understand and focus on the social aspects of FASD including possible economic, legal, and cultural influences. Peter Choate takes on the difficult issue of parents who may have FASD themselves and how parenting capacity assessments must be accomplished within a cultural context and focus on functional skills as well as the provi-

sion of supports to facilitate parenting. Billie Joe Rogers and Kaitlin MacLachlan studied youth offenders with FASD and found an association between enculturation and resilience. They discuss the importance of incorporating cultural components into services designed to increase resilience in youth.

FASD is a broad and complex issue with implications for individuals, families, communities and Canadian society as a whole. The contributions in both the *First People’s Child and Family Review* and the *JODD* make plain not only the work that is being done, but also the need for continued attention, responsibility, and action. It is the goal of this collaborative Special Issue on FASD to promote education, understanding, and awareness for front-line service providers, healthcare professionals, and all levels of government in order to improve the quality of life for individuals living with this disability.

References

- Chudley, A., Conry, J., Cook, J. L., Loock, C., Rosales, T. & LeBlanc, N. (2005). Fetal alcohol spectrum disorder: Canadian guidelines for diagnosis. *Canadian Medical Association Journal*, 172(5 Suppl.), S1-S21.
- Government of Canada (2012). *Fetal alcohol spectrum disorder*. Retrieved from <http://www.phac-aspc.gc.ca/hp-ps/dca-dea/prog-ini/fasd-etcaf/index-eng.php>