

# **ANNOTATED BIBLIOGRAPHY: TOP FASD ARTICLES OF 2018**

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#### Introduction and Search Methods

The articles below, also summarized in our Top FASD Articles of 2018 list, were selected by a group of Canada FASD Research Network (CanFASD) staff, researchers, and Family Advisory Committee members to highlight some of the work that has been published over the last year in the field of FASD.

A literature search of Web of Science, PubMed, PsycInfo, Scholars Portal, Proquest Nursing and Allied Health, Google Scholar, CINAHL, Ovid, and Ovid Nursing Journals databases yielded over 460 articles published in 2018 on FASD. Many of these were excellent publications (especially in the areas of animal models of FASD, epigenetics, and brainbased research). However, the final list was narrowed down to focus on CanFASD's areas of emphasis in FASD prevention, intervention, diagnosis, social justice, child welfare, and family collaboration. Additional consideration for what constituted the "top" articles included:

- Generalizability to Canadians
- Influence on practice or policy
- » Novelty
- Scientific rigour
- Media attention

Final selections were categorized by area of focus, and limited to 10 articles or less per category. All articles are published in peer-reviewed journals. They are arranged in alphabetical order by first author's surname, and those marked with an asterisk (\*) are available in open access.

Top selected articles were sorted into 8 categories: diagnosis and presentation of FASD; intervention; prevention; caregivers/families; justice; prevalence; basic science and epigenetics; and research methodology/policy issues. For a summary of the prevention articles, please refer to the Prevention Network Action Team's Annotated Bibliography of Articles Published in 2018.<sup>2</sup>

https://canfasd.ca/wp-content/uploads/sites/35/2019/01/Top-Papers-of-2018-FINAL.pdf 1

https://canfasd.ca/wp-content/uploads/sites/35/2019/03/FASD-Prevention-Literature-2018.pdf 2

# Search Results: Top FASD Articles of 2018

# Diagnosis and Presentation of FASD

1. Ali, S., Kerns, K. A., Mulligan, B. P., Olson, H. C., & Astley, S. J. (2018). An investigation of intra-individual variability in children with fetal alcohol spectrum disorder (FASD). Child Neuropsychology, 24(5), 617-637. doi: 10.1080/09297049.2017.1302579

Individuals with FASD show significant within-person variability in behavioural performance and symptoms, which is known as Intra-Individual Variability (IIV). The authors of this study investigated IIV within children with FASD (age 12.7±2.4 years), as well as their attention, adaptive behaviour, and motor control. These variables were assessed while taking the degree of within-person variability into consideration. This assessment showed any within-person inconsistency of performance when the same task was tested multiple times. Higher levels of IIV indicate low levels of consistency in performance. This discrepancy is often described as children with FASD having "on" and "off" days, and having inconsistent daily behaviour, even though it has not been clinically investigated before. The authors used the University of Washington FASD 4-Digit Code to diagnose the children with FASD who were then categorized into three study groups: 1. Fetal Alcohol Syndrome (FAS)/partial FAS; 2. Static Encephalopathy with confirmed alcohol exposure (SE/AE) and; 3. Neurobehavioral Disorder with confirmed alcohol exposure (ND/AE). The results of the assessment of motor response, inhibitory control, attention, and adaptive behaviour of the three groups of children with FASD were compared with a control group of age-matched children who have no record of prenatal alcohol exposure. In contrast to the children within the control group, all the children with FASD showed higher levels of intra-individual variability. This observation is in agreement with the presence of performance inconsistency in children with FASD. Moreover, the children with FASD showed slower reaction times when tasks were changed from activation to inhibition. Additionally, the results suggest that the performance inconsistency and lower reaction times are not caused by poor attention.

2. \*Cook, J. L., Green, C. R., Lilley, C., Anderson, S., Baldwin, M. E., Chudley, A. E., ... Temple, V. (2018). Response to "A critique for the new Canadian FASD diagnostic Guidelines". Journal of the Canadian Academy of Child and Adolescent Psychiatry, 27(2), 83-87.

In 2016, a new guideline for the diagnosis of FASD across the lifespan was published the Canadian Medical Association Journal (Cook et al., 2016), updating the diagnostic criteria originally established in 2005 by Chudley et al. A critique of this new FASD diagnostic criteria and guideline was presented by McLennan & Braunberger in 2017, with four major questions regarding the process of FASD diagnosis, the newly introduced 'at-risk' for FASD designation, use of evidence-based approaches for making recommendations, and the mental health disorders associated with FASD. This publication is a Clinical Commentary which provides an extensive justification of the Appraisal of Guidelines, Research, and Evaluation (AGREE) process that was used to update the 2005 FASD diagnostic criteria and provides detailed responses to the four critiques presented by McLennan & Braunberger (2017). According to the AGREE framework, the 2016 FASD diagnostic criteria and guideline development was the result of appraisal of

the literature and advice from a group of national and international experts who reviewed the evidence available to produce the final draft of the manuscript. The authors of this article point out that the association between FASD and mental health disorders have been already established by the 5th edition of Diagnostic and Statistical Manual of Mental Disorders (DSM-5) which addresses one of their questions. The DMS-5 introduces 'Neurobehavioral Disorder Associated with PAE (ND-PAE)' to discuss the conditions that occur due to prenatal alcohol exposure. Moreover, the authors emphasize the main purpose of the new Canadian FASD diagnostic criteria and guideline is to outline a protocol for the diagnostic process rather than describing the abnormal physiological processes that cause FASD and mental health conditions. They highlight that a general scientific method of how a disease occurs should still be practiced along with the 2016 FASD diagnostic guideline, and make suitable recommendations for individuals with FASD or at the risk of having FASD.

3. Flannigan, K., Gill, K., Pei, J., Andrew, G., Rajani, H., McFarlane, A., . . . Rasmussen, C. (2018). Deferred diagnosis in children assessed for fetal alcohol spectrum disorder. Applied Neuropsychology: Child, 1-10. doi: 10.1080/21622965.2018.1427094

The FASD diagnostic process is a complicated task that involves not only the implementation of the basic diagnostic criteria, but also involves collecting patient information that confirms prenatal alcohol exposure, cognitive skills, and behaviours of the individual. In most cases, these are important factors that affect the diagnostic process, which can be quite challenging for professionals, individuals with FASD, and their families and caregivers. Despite these challenges, it is very important to collect valid information for the diagnosis of FASD in order to make intervention recommendations as early as possible. In this study, Flannigan and colleagues performed a reflective analysis of the deferred patient files from three FASD clinics in Canada. The first set of files belonged to 154 children (68 female, 86 male) aged 1.0-16.9 years who participated in an assessment of FASD for the first time. 51 of these children aged 2.7-17.2 years came back to the clinic for further assessments. The analysis of the data suggested that the children who had a deferred assessment did not have enough evidence to provide a solid diagnosis of FASD. However, 73% of these children were accurately diagnosed later as they presented with significant abnormalities in their brain functioning, FASD-associated conditions, and postnatal risk factors in comparison to the children (27%) who did not receive a diagnosis. Collectively, the authors of this study outline and provide a better understanding of the process of clinical diagnostic assessment for FASD.

4. \*Goldschmidt, L., Richardson, G. A., De Genna, N. M., Cornelius, M. D., & Day, N. L. (2018). Prenatal alcohol exposure and offspring alcohol use and misuse at 22 years of age: A prospective longitudinal study. Neurotoxicology and Teratology, 71, 1-5. doi: 10.1016/j.ntt.2018.11.001

Extensive alcohol use is one of the negative consequences observed in young adults who have a history of prenatal alcohol exposure. In this study, which is part of the Maternal Health Practices and Child Development Project, the authors investigate the relationship between alcohol use behaviours and history of maternal alcohol consumption during pregnancy, through assessments conducted during pregnancy, at birth, and at different time points during childhood to adulthood (up to 22 years of age). 608 assessments were used for analysis in this study. The authors observed that the children of mothers who reported heavy drinking (≥1 drink/day) during the first trimester of their pregnancy had high drinking problems at 22 years old. These young adults who had a history of prenatal alcohol exposure met two or more diagnostic criteria for Alcohol Use Disorders, even though none of them showed full symptoms of alcohol abuse or alcohol dependence. The authors of this study highlight a significant relationship between daily drinking patterns of the mother during pregnancy and the drinking behaviours of their children at early adulthood. Therefore, it is possible that the consumption of alcohol even at lower levels (1 drink per day) during pregnancy may pose a risk of alcohol abuse in their children.

5. \*Helgesson, G., Bertilsson, G., Domeij, H., Fahlström, G., Heintz, E., Hjern, A., ... Hultcrantz, M. (2018). Ethical aspects of diagnosis and interventions for children with fetal alcohol spectrum disorder (FASD) and their families. BMC Medical Ethics, 19. doi:10.1186/s12910-017-0242-5

Some scholars have argued that there are controversies regarding the proper diagnosis of individuals with FASD due to ethical issues associated with the diagnostic process. In this study, Helgesson and colleagues carried out a systematic analysis of the ethical aspects relating to three stages of FASD assessment and care that included: 1. diagnosis; 2. determination of interventions, and; 3. providing social and family support. The analysis involved consultations with FASD experts and medical ethics experts, as well as the reviewing of relevant literature. The researchers did not identify any specific interventions that are provided for individuals with a FASD diagnosis. However, they could be directed to programs and support services that are available for individuals with similar conditions such as intellectual disability, autism, and attention deficit hyperactivity disorder. When the direct and indirect consequences of formal FASD diagnosis were considered, the researchers were able to identify several advantages of a formal diagnosis. The families received explanations of the behaviours and symptoms observed in relation to FASD, and they were given information to be able to be prepared for potential problems that may occur in the future. With the diagnosis, the families received guidance related to the support services available, and where to seek help. Unfortunately, one of the biggest disadvantages of having a formal diagnosis of FASD the blame and stigmatization that comes from society, given the mother's admittance of alcohol use during pregnancy, and the resulting guilt felt by many biological parents. While having a formal diagnosis for FASD appeared to help the families in many ways, including opening doors for support and care, there are still no specified set of treatments, specific allocation of resources for individuals with FASD, or FASD-specific support systems. The development of FASD-specific treatments, interventions, and support systems in the future may change this situation.

6. Hendricks, G., Malcolm-Smith, S., Adnams, C., Stein, D. J., & Donald, K. A. M. (2018). Effects of prenatal alcohol exposure on language, speech and communication outcomes: A review longitudinal studies. Acta Neuropsychiatrica, 1-10. doi:10.1017/neu.2018.28

Individuals with FASD may develop communication deficits, including speech and language difficulties during development. Due to the impact of alcohol on the frontal lobe, children with fetal alcohol exposure may experience deficits in social interactions and communications at the age of preschool attendance (i.e., 6 years old). This study by Hendricks and colleagues systematically analyzed the literature related to communication and speech and language deficits in preschool children with confirmed prenatal alcohol

exposure during 1970-2018. In this systematic review, the researchers found six studies which met the eligibility criteria for review. Four of these studies focused on the impact of prenatal alcohol exposure on receptive and expressive communication, while the other two focused on speech acquisition. Thematic analysis of the data collected from these six articles identified two themes that represented the impact of prenatal alcohol exposure on receptive and expressive communication delay and associated risk factors. The longitudinal language development analysis indicated that children with prenatal alcohol exposure experienced language development delay until they were 3 years old. The authors identified environmental factors as being a significant confounding factor for language developmental deficits in children who have exposed alcohol prenatally. Therefore, enhancement of the environment is important for these children to improve their communication skills and language development.

7. Lange, S., Rehm, J., Anagnostou, E., & Popova, S. (2018). Prevalence of externalizing disorders and autism spectrum disorders among children with fetal alcohol spectrum disorder: Systematic review and meta-analysis. Biochemistry and Cell Biology, 96(2), 241-251. doi:10.1139/bcb-2017-0014

This study by Lange and colleagues investigates the externalizing behaviours displayed by children with FASD, among other neurodevelopmental disorders in the United States. The exposure of the fetus to alcohol during the prenatal period causes damage to the central nervous system that may contribute to the delinquent, aggressive, hostile, noncompliant and impulsive behaviours which are often identified as behaviour that falls under externalizing disorders such as Attention-Deficit Hyperactivity Disorder (ADHD), Oppositional Defiant Disorder (ODD) Conduct Disorder (CD), and Autism Spectrum Disorders (ASD). The authors carried out a systematic literature review related to the aforementioned diagnoses, followed by a meta-analysis of the results. The researchers found the most prevalent co-occurring neurodevelopmental disorders with FASD. The researchers identified 20 articles which met the inclusion criteria for the systematic review and meta-analysis. The most highly prevalent comorbid externalizing disorder with FASD was ADHD, which was present in 52.9% of children with FASD. ODD, CD, and ASD were observed in 12.9, 7.0, and 2.6% of children with FASD, respectively. The results suggest the possibility of misdiagnosis of children with FASD with other neurodevelopmental disorders due to the high comorbidity. This potential misdiagnosis can have negative consequences in terms of treatments and interventions for individuals with FASD. Therefore, it is important to characterize the distinct characteristics of these disorders to avoid misdiagnosis, as well as early and accurate diagnosis of children with FASD with co-occurring behavioural deficits. The clinicians who work with children with FASD should be aware of these comorbid conditions and tailor their treatments and interventions accordingly.

#### Intervention

8. Keightley, M., Agnihotri, S., Subramaniapillai, S., Gray, J., Keresztesi, J., Colantonio, A., ... Wiseman-Hakes, C. (2018). Investigating a theatre-based intervention for Indigenous youth with fetal alcohol spectrum disorder. Canadian Journal of Occupational Therapy, 85(2), 128-136. doi:10.1177/0008417417719722

Many children with FASD have behavioural and cognitive deficits that require specific interventions. Arts interventions have been shown to be useful in improving communication and social skills in children

with such impairments. Theatre-based interventions are arts interventions that employ arts and artistic media to improve psychological understanding of daily experiences and have proven benefits in individuals with developmental disabilities. Keightley and colleagues explored how theatre-based interventions as a form of occupational therapy could be used with young Indigenous adolescents with FASD (9-14 years old, n=3) to facilitate their social interactions and acceptability of theatre-based interventions by stakeholders in their lives. The intervention was an intensive art-based theatre skills training session. The results collected from the participants, caregivers, and program facilitators two weeks after the training program ended showed the creative process of the program had increased the self-confidence and self-esteem of the youth with FASD. The theatre-based creative environment provided them with a unique supporting atmosphere in which they were able to express themselves better, develop social skills, and increase emotional awareness of self and others. Collectively, the results of this study provide important insights and promise in using art-based creative interventions to enhance social skills and engagement of youth with FASD.

9. Kully-Martens, K., Pei, J., Kable, J., Coles, C. D., Andrew, G., & Rasmussen, C. (2018). Mathematics intervention for children with fetal alcohol spectrum disorder: A replication and extension of the math interactive learning experience (MILE) program. Research in Developmental Disabilities, 78, 55-65. doi:10.106/j. ridd.2018.04.018

Impairments in mathematics skills and academic functioning are common deficits observed in people with FASD, which may have life-long implications in many aspects of their lives. As the research on mathematics interventions is limited, the authors used an evidence-based approach to further Canadian research on mathematics interventions by employing and modifying the existing Math Interactive Learning Experience (MILE) program, originally conceptualized in the USA for children with FASD. The modified MILE intervention and a contrast mathematics intervention were introduced to Canadian children (10-year old) with either a formal diagnosis of FASD (n = 15) or prenatal alcohol exposure (n = 13). The analysis of their IQ, mathematics performance, and working memory, among other cognitive assessments prior to and after the interventions, resulted in the discovery that the MILE mathematics intervention significantly improved math achievement in children with FASD compared to the contrast intervention. Collectively, the results of this study provide evidence for the potential of replicating and extending the modified USA-based MILE intervention program to improve mathematics performance in Canadian children with FASD and prenatal alcohol exposure.

10. \*Mela, M., Okpalauwaekwe, U., Anderson, T., Eng, J., Nomani, S., Ahmed, A., & Barr, A. M. (2018). The utility of psychotropic drugs on patients with fetal alcohol spectrum disorder (FASD): A systematic review. Psychiatry and Clinical Psychopharmacology, 28(4), 436-445. doi:10.1080/24750573.2018.1458429

Currently, there is no 'cure' for FASD. The primary treatment methods typically involve interventions, environmental changes, and medications that mainly control mental and psychological aspects. As there are limited advances in the evidence-based development of pharmacological treatments for FASD, the use psychotropic drugs is still debatable. Mela and colleagues investigated the use of psychotropic drugs to treat FASD using a systematic review approach. They included articles published as early as 1823 to 2017 in the systematic review process and found 25 relevant articles that included clinical trials, systematic

reviews, qualitative studies, and quantitative studies. They identified a deficit in the amount of evidence available for the use of these medications to treat FASD. The studies that utilized psychotropic drugs were limited to the treatment of FASD-associated conditions such as seizure disorders, conduct disorders, ADHD, short-term aggressiveness, and depression. There was limited evidence in the effectiveness of psychotropic drugs in improving social skills and alleviating some of the behavioural problems. In general, the strength of the evidence available for the use of psychotropic drugs for FASD was weak and unsatisfactory, with limited guidance for patients. These results indicate the need for proper development of evidence-based treatment plans, along with an understanding of the pathophysiology of FASD coupled with patient guidance for treating different neurological conditions associated with FASD.

11. Pritchard Orr, A. B., Keiver, K., Bertram, C. P., & Clarren, S. (2018). FAST Club: The impact of a physical activity intervention on executive function in children with fetal alcohol spectrum disorder. Adapted Physical Activity Quarterly, 35(4), 403-423. doi:10.1123/apaq.2017-0137

Studies conducted using animal models have shown promising results for employing physical activity as an effective intervention for improving cognitive functioning deficits observed in individuals with FASD across the life span. Children with prenatal alcohol exposure display cognitive deficits that make nonroutine task management quite difficult for them, and these cognitive deficits are generally known as executive function deficits. In this study, Prichard and colleagues developed an effective physical activity intervention program called FAST Club for children with FASD. This program used different types of engaging motor activities for children, guided by adult play buddies, and focused on improving their inherent abilities and daily activities in a more familiar environment. 30 children, from ages 7-14 years, participated in the 8-week FAST Club intervention program with half of the children participating in the control group. The pre and post-program assessment indicated significant improvement in executive function in children with FASD which showed sustainable improvement of skills at three months after the intervention program. Therefore, the results of this study provide evidence for an effective and sustainable intervention strategy for using physical activity to enhance cognitive functioning in children with FASD.

### Caregivers/Families

12. Domeij, H., Fahlstrom, G., Bertilsson, G., Hultcrantz, M., Munthe-Kaas, H., Gordh, C. N., & Helgesson, G. (2018). Experiences of living with fetal alcohol spectrum disorders: A systematic review and synthesis of qualitative data. Developmental Medicine & Child Neurology, 60(8), 741-752. doi:10.1111/dmcn.13696

Understanding the lived experiences of people with FASD and their families through qualitative studies provides important insights regarding their lives, needs, and support. Domeij and colleagues conducted a systematic review of qualitative studies published from 1990 to 2016. They chose 18 qualitative research studies that explored the experiences of children and adults with FASD, experiences of parents and caregivers who were raising children with FASD, and experiences regarding respite care intervention programs. The experiences of children and adults with FASD included dealing with disabilities, difficulties and hurdles that they face in daily life and employment, and stigmatization. Parents and caregivers discussed their role as a parent of a child with FASD, challenges faced with their children's disabilities, and difficulties in their dealings with the society. These studies suggested lack of proper support from society and professionals within healthcare, social, and education systems. One study focused on discussing their experiences with a respite care intervention program which suggested the importance of having respite care for parents of children with FASD and the challenges in getting sustainable respite care programs. Overall, this qualitative synthesis highlights the different aspects of the lived experience of individuals with FASD and their families, identifying where they face challenges and require reliable support.

13. \*Pepper, J., Coons-Harding, K. D., Bibr, C., & Watson, S. L. (2018). Waving a magic wand: Supports for families raising school-aged children with autism spectrum disorder and fetal alcohol spectrum disorder in Ontario. Journal of Fetal Alcohol Spectrum Risk & Prevention, 1(1), E2-E16. doi: 10.22374/jfasrp.v1i1.2

Raising a child with FASD and associated disabilities demands a lot from their parents and families. For the same reason, these families are in need of support and care programs. Therefore, qualitative research studies that explore the needs of parents and families of children with FASD can provide significant insights for the development and allocation of resources for individuals and families requiring support. With this aim in mind, Pepper and colleagues conducted a qualitative study with 26 parents of children with FASD and autism spectrum disorders (ASD) living in the province of Ontario, Canada. The data collected were analyzed using thematic analysis of which four themes regarding their support needs were identified. The parents in this study discussed a deficit in the care services available for them and their children with FASD and ASD within the province of residence. They had formal and informal support needs, and in many cases reported difficulties with qualifying for services or a lack of services available that met the spectrum of disabilities experienced by their children. The authors of this study highlight the need for support programs that are specifically tailored to the children's individual needs.

14. \*Spruyt, K., Ipsiroglu, O., Stockler, S., & Reynolds, J. N. (2018). Challenging sleepwake behaviors reported in informal, conversational interviews of caregivers of children with fetal alcohol spectrum disorder. International Journal of Developmental Disabilities, 64(2), 65-74. doi:10.1080/20473869.2016.1229395

Among the different cognitive and behavioural challenges experienced by children with FASD, sleep disorders are very common. Given the clinical complexity of the sleep disorders and sleep-wake behaviours experienced by children with FASD, proper clinical assessment of sleep difficulties is challenging. In order to further explore this issue, Spruyt and colleagues have used a text-mining of transcripts from interviews with 59 caregivers of children with FASD, ages 4-12. The text mining analysis identified 4008 words associated with sleep difficulties in response to a question regarding the hardest situations faced by their children and their families. In terms of word importance, 69.2% and 64.7% importance were associated with 'sleep-related issues' and 'night-related issues, respectively. While the issues associated with sleep were identified by parents/caregivers as a family issue, the issues with sleeping and walking were described using the word 'clumsy'. 'Night' was a very frequent and predictive word associated with FASD. The analysis also identified the words 'Routines', 'Managing', and 'Planning' used by caregivers in association with sleep and night. This study contributes significantly to the understanding and characterization of sleep-wake problems that are common in children with FASD. The study results also highlight the importance of providing education and awareness training for caregivers regarding the management of sleep in children with FASD.

#### **Justice**

15. \*Baldry, E., Briggs, D. B., Goldson, B., & Russell, S. (2018). 'Cruel and unusual punishment': An inter-jurisdictional study of the criminalisation of young people with complex support needs. Journal of Youth Studies, 21(5), 636-652. doi:10.1080/13 676261.2017.1406072

The young populations engaged with the youth justice system often have troubled histories with mental health issues, poor socio-economic status, and disabilities that require complex support needs. The criminalization process that targets youth with mental health and cognitive disabilities, and other impairments such as traumatic brain injuries, further 'disable' them. Using a qualitative approach, Baldry and colleagues explored this understudied aspect of criminalization of youth with complex support needs. The authors investigate a youth penalty and justice research project named the Comparative Youth Penality Project that is active in four states of Australia, England, and Wales. Along with contributions to the development of critical disability criminology, this study, which involved a thematic analysis of interviews with 124 individuals who are engaged in the youth justice system, provides a description of the nature of the criminalization process of youth with disabilities and other disadvantages. The overarching themes that were identified by the authors of this study suggest the importance of early responding to the complex needs of children and youth with disabilities and complex care needs in a holistic manner as they enter into the youth justice system. The participants identified a very high prevalence of mental health disorders and cognitive disabilities among the youth entering the youth justice system and the lack of adequate community support (e.g., education, health, and welfare) available for them. Their criminalization process begins at the police station and the management of the youth with complex needs are left to the police, leading to a further problematic fate for them. There appears to be high criminalization incidences with youth with complex needs.

16. Flannigan, K., Pei, J., Burke, A., Frenzel, R., & Rasmussen, C. (2018). Neurocognitive functioning in young offenders with fetal alcohol spectrum disorder. International Journal of Law and Psychiatry. doi: 10.1016/j.ijlp.2018.04.007

One of the most common adverse outcomes associated with FASD is conflict with the justice system. It is often associated with other adverse outcomes of FASD, such as disruption or dropout of school, incarceration, substance abuse, engagement in inappropriate behaviours, and mental health issues. Flannigan and colleagues conducted a retrospective file review of young offenders (12-20 years old) with or without a formal diagnosis of FASD who were attending a treatment program in Alberta, Canada. The researchers collected neurocognitive scores from clinical assessments of 38 youth with FASD compared to 43 control participants. The authors identified many neurocognitive functioning differences between the youth with FASD and without FASD, including impairments in cognitive flexibility. In interventions for these individuals, the importance of stable and nurturing care and home environment are emphasized.

17. \*Flannigan, K., Pei, J., Stewart, M., & Johnson, A. (2018). Fetal alcohol spectrum disorder and the criminal justice system: A systematic literature review. International Journal of Law and Psychiatry, 57, 42-52. doi: 10.1016/j.ijlp.2017.12.008

Previous studies suggest that individuals with FASD are incarcerated more often than those without

FASD. In order to gain an understanding of the national prevalence of FASD within the criminal justice system, Flannigan and colleagues conducted a systematic review of articles published between 1985-2017. The quantitative synthesis included 25 articles that met the inclusion criteria. These studies provided perspectives on justice-involved individuals with FASD globally, including in Canada, the USA, Sweden, Brazil, and Australia. The authors focused on different topics associated with this population which included prevalence, screening for FASD, the cost associated with FASD in the criminal justice system, profiles, experiences, awareness and knowledge of FASD among criminal justice professionals, and how FASD impacts justice-involved individuals within the courtroom. The authors discuss how the prevention of criminal behaviours among individuals with FASD using strength-based approaches could be helpful to reduce their prevalence within the criminal justice system.

#### Prevalence

18. Greenmyer, J. R., Klug, M. G., Kambeitz, C., Popova, S., & Burd, L. (2018). A multicountry updated assessment of the economic impact of fetal alcohol spectrum disorder: Costs for children and adults. Journal of Addiction Medicine, 12(6), 466-473. doi:10.1097/adm.0000000000000438

The high degree of clinical complexity, comorbid conditions, and disabilities associated with FASD demand interventions and support programs that are very costly. Greenmyer and colleagues used a systematic review, followed by a quantitative analysis, to determine the economic impact of FASD in four countries: the USA, Canada, Sweden, and New Zealand. The literature review included all the studies published prior to 2017, and 32 articles were chosen for the quantitative analysis. The economic aspects taken into consideration included costs associated with healthcare, educational support (i.e., special education), involvement with the criminal justice system, morbidity and mortality, residential care, and productivity losses. Despite the variations in methodologies used to calculate the economic impact in these studies, the authors concluded an overall mean cost of \$22,810 and \$24,308 per year for children and adults, respectively. The authors also suggest that this calculation could be an underestimate of the full impact of the costs associated with FASD.

19. May, P. A., Chambers, C. D., Kalberg, W. O., Zellner, J., Feldman, H., Buckley, D., ... Hoyme, H. E. (2018). Prevalence of fetal alcohol spectrum disorders in 4 US communities. JAMA, 319(5), 474-482. doi:10.1001/jama.2017.21896

Previous studies on FASD prevalence suggest that the prevalence of FASD in the USA is 1 in 100. However, using a cross-sectional study design, that involved 13,146 children attending the first grade within four sites in the Midwest, Rocky Mountain, Southeast, and Pacific Southwest of the USA, May and colleagues provide an updated prevalence of FASD in the USA. The authors of this study identified 220 cases of FASD among this population between 2010-2016 The final weighted prevalence of 31.1-98.5 of children with FASD per 1000 children was calculated, also taking the conservative prevalence estimates (11.3-50.0/1000) into consideration. While this analysis may provide a more accurate prevalence of FASD among children in the USA, the researchers believe that this rate may not be applicable to all the communities in the USA. This discrepancy could be due to many factors that are not limited to ethnic differences, as well as variabilities in the reporting of alcohol consumption during pregnancy among women.

### **Basic Science and Epigenetics**

20. Bodnar, T. S., Raineki, C., Wertelecki, W., Yevtushok, L., Plotka, L., Zymak-Zakutnya, N., . . . Weinberg, J. (2018). Altered maternal immune networks are associated with adverse child neurodevelopment: Impact of alcohol consumption during pregnancy. Brain, Behavior, and Immunity, 73, 205-215. doi: 10.1016/j.bbi.2018.05.004

Using a network analysis of interacting cytokines (chemokines) in maternal blood samples from children with neurodevelopmental delay with and without prenatal alcohol exposure, Bodnar and colleagues investigated the relationship between the maternal immune system and neurodevelopmental delay caused by prenatal alcohol exposure. Cytokines are functional molecules secreted by the immune system, interactive functions of which play diverse roles in brain development. In this study, the researchers investigated 40 different types of cytokines found in maternal blood which were collected during the second and third trimester of their pregnancy. The researchers identified three unique maternal cytokine networks which were labelled as Alcohol-Exposure Network, Exposure/Neurodevelopmental Delay Network, and Vulnerability Network. The authors found a correlation between the cytokine networks, maternal alcohol consumption behaviours, and the child outcomes. It is possible that these unique profiles of cytokine networks could be used as early biomarkers for the detection of developmental delay with or without alcohol exposure, and determination of treatments or interventions. The results also provide insights into broadening the understanding of the role of the immune system in neurodevelopmental delay associated with prenatal alcohol exposure.

# Research Methodology/Policy Issues

21. \*Anderson, T., Mela, M., & Stewart, M. (2017). The implementation of the 2012 Mental Health Strategy for Canada through the lens of FASD. Canadian Journal of Community Mental Health, 36(4), 69-81. doi:10.7870/cjcmh-2017-031

'Changing Directions, Changing Lives' was a significant landmark of the Mental Health Strategy in Canada which was implemented as 'the National Strategy' in 2012 to enhance mental health and well-being using an inclusive approach. Anderson and colleagues provide a 6-year anniversary review of the National Strategy with special consideration of FASD. In 2013, FASD was included in the Diagnostic and Statistical Manual of Mental Disorders (DSM-5), categorizing it as a diagnosable mental health disorder caused by prenatal alcohol exposure. Approximately 94% of individuals with FASD experience mental health conditions, along with their high vulnerability to self-harm and involvement with the justice system. This strategy reminds clinicians and healthcare professionals to identify the comorbid mental health conditions associated with FASD which often go unseen and untreated. The Call to Action 19 presented by the Truth and Reconciliation Commission of Canada further strengthened the mental health and well-being of individuals with FASD. The continued activities of FASD-informed frameworks, with the focus on mental health promotion, prevention, and reformation of services, such as the justice system, under the Changing Directions, Changing Lives: The Mental Health Strategy for Canada provides hope for individuals with FASD to have access to effective treatment, care, and services.

22. \*Aspler, J., Zizzo, N., Di Pietro, N., & Racine, E. (2018). Stereotyping and stigmatising disability: A content analysis of Canadian print news media about fetal alcohol spectrum disorder. Canadian Journal of Disability Studies, 7(3). doi: 10.15353/cjds. v7i3.452

Both individuals with FASD and their biological parents (particularly biological mothers), face stigmatization, blame, and shame within society. Negative media stereotyping can change public perceptions and cause discrimination, leading to the marginalization of individuals with FASD and women who consume alcohol during pregnancy. In Canada and other countries, media stereotyping has been shown to negatively affect individuals with disabilities, including FASD. This study conducted by Aspler and colleagues aimed to investigate the media representation of FASD, alcohol consumption, and pregnancy in Canada. Using 286 articles collected from the ten most-distributed Canadian newspapers, published between 2002-2015, the authors performed a media content analysis. The results generated eight major themes with 'Crime associated with FASD' being the most frequently cited theme (37%). Additional themes included individuals with FASD being the perpetrator of the crime (29%) or victim of a crime (8%). The other themes focused on support for individuals with FASD, their family and environment, and awareness. 12% of the articles also discussed stigma and labelling associated with FASD. The identified themes related to alcohol use during pregnancy in the Canadian context were very similar to the themes observed in media studies conducted in UK and Australia, implying that the media may generally paint a negative picture of FASD and alcohol use during pregnancy. It appeared that Canadian media portrayed individuals with FASD as a 'villain' or 'disabled'; women who drink alcohol during pregnancy were also portrayed as being 'villainy'. Overall, this unbalanced negative portrayal of FASD and alcohol use during pregnancy should be balanced with well-intended awareness and social support to enhance the well-being of individuals with FASD and their families.

23. Badry, D., Coons-Harding, K. D., Cook, J., & Bocking, A. (2018). Finding answers, improving outcomes: A case study of the Canada Fetal Alcohol Spectrum Disorder Research Network. Advances in Dual Diagnosis. doi: 10.1108/ADD-05-2018-0006

The Canada Fetal Alcohol Spectrum Disorder (CanFASD) Research Network is an interdisciplinary, non-governmental organization working with the stakeholders including the Government, community partners, researchers, service providers, professionals, and policy makers, to carry out research regarding FASD and to promote knowledge translation into practice. Through national and international collaborations with research communities, CanFASD is a leader in key areas related to FASD including diagnosis, prevention, intervention, justice, and child welfare. This descriptive case study profiles the CanFASD Research Network, including its nature and the work of the network in national and international research endeavors. CanFASD highly values evidence-based approaches in research and decision-making, where the research findings are used in teaching, knowledge exchange, and translation into practice. Collectively, the activities of the CanFASD Research Network highlight the value of collaborative relationships to address the challenges faced by individuals with FASD, their families, and society.

24. Brownell, M., Enns, J. E., Hanlon-Dearman, A., Chateau, D., Phillips-Beck, W., Singal, D., ... Roos, N. (2018). Health, social, education, and justice outcomes of Manitoba First Nations children diagnosed with fetal alcohol spectrum disorder: A population-based cohort study of linked administrative data. The Canadian Journal of Psychiatry. doi: 10.1177/0706743718816064

Using a retrospective cohort study approach, Brownell and colleagues investigated resources available for First Nations children and youth with FASD (1-25 years old). Among the resources needed by individuals with FASD, healthcare, educational assistance, social services, and guidance related to dealings with the justice system are critical. In this study, the needs, services, and resources available to 743 First Nations individuals with FASD, 315 non-First Nations individuals with FASD, and 2229 First Nations individuals without FASD were compared. Even though the educational outcomes were similar between the three study groups, significant differences in child welfare and justice system needs were observed between the groups. First Nations individuals with FASD appeared to have a higher risk of being involved in the justice system, child welfare system, and with self-harm, in contrast to individuals without FASD and non-First Nations individuals with FASD. This data suggests that the needs for social services, justice system support, child welfare, and mental healthcare support are much higher in First Nation populations with FASD in contrast to the general population and thus require more resource allocations to meet their needs.

#### 25. Choate, P., & Badry, D. (2018). Stigma as a dominant discourse in fetal alcohol spectrum disorder. Advances in Dual Diagnosis. doi: 10.1108/ADD-05-2018-0005

Stigma is one of the major social barriers experienced by individuals with FASD and their families. Using a scoping review approach, Choate and Badry present an analysis of the impact of stigma on people with FASD and their families. An extensive literature survey was conducted to find relevant studies published in between 2008 and 2018 which resulted in 13 articles. Framed within a public health perspective, the authors identified a lack of publications that portrayed positive outcomes and strengths of individuals with FASD. Rather, the published articles focused on the mother's role in FASD and the long-lasting consequences faced by children and families. The overall negative picture regarding drinking during pregnancy, FASD, and stigmatization appeared to extend to their support system as well. Therefore, the authors of this study emphasize the need for multi-disciplinary conversations to direct public perspectives to a more positive and de-stigmatizing understanding of FASD.

