

FASD Media Guide

Guidelines for talking & writing about FASD

2018

Guidelines for Writing & Talking about FASD

The purpose of this document is to assist those writing and talking about FASD and the issues related to the disability to use the same statistics, framing of topics, and language. The intended outcome, over time, will be an improved understanding by the reader/listener with consistent and respectful FASD messaging.

This is a living document and areas will be updated as it is informed by emerging research.

In order to promote a common language about FASD and to minimize misinterpretation of key issues, we have drafted a suggested definition of FASD. Standard definitions are needed to ensure consistency in administrative, clinical, and research operations. Therefore, we recommend that this definition be used by governments and policy makers across Canada to promote standardized and consistent language when discussing FASD.

Other Key Communication Notes:

- Dignity promotion among individuals with FASD and their families:
 - This theme should be emphasized in any awareness or prevention programs and an attempt not to make guilt-ridden programs (Manitoba FASD Coalition, 2016)
 - When using images, refrain from using photos of fetuses, pregnant bellies without heads and naked women (Canada FASD Research Network, 2018)
 - Refrain from stigma-inducing language and use 'dignity-promoting' words and phrases. Use language guides resources as a reference (Manitoba FASD Coalition, 2016)
- Becoming FASD-Informed:
 - Practice FASD-informed approaches comprised of awareness, strength-based and person-centred (Rutman, 2016)
 - Use accurate and empirically proven facts.
 - Refrain from using the statement that FASD is "100% preventable" as this statement greatly oversimplifies the issue.
 - In Canada, the terminology 'Indigenous' mirrors constitutional language (Retzlaff, 2005) and includes: First Nations, Inuit, and Métis peoples; When referring to specific groups or cultures, ensure to use the appropriate distinction

CanFASD recommends using the following definition when writing FASD policy or addressing services to persons affected by FASD:

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.

PREVALENCE AND STATISTICS

ISSUE	RESEARCH TELLS US	SAY THIS	WHY THIS MATTERS
<p><i>How many people have FASD?</i></p> <p><i>What are the numbers?</i></p>	<ul style="list-style-type: none"> - 2018 Canada, Greater Toronto Area, estimate → 2% - 3% among elementary school students, aged 7 to 9 years (Popova et al., 2018) - 2013 Canada, Alberta estimate: → 1.4-4.4% of the general population (Thanh et al., 2014) - 2014 USA estimate: → 2.4-4.8% (May et al., 2014) - May and colleagues have conducted a series of studies with school-aged children in the US, suggesting a conservative estimate of 2-5% (May et al., 2014; May et al., 2018; May et al., 2015) - Older estimates: 9.1/1000 (Sampson, 1997) - FASD is an '<i>invisible disability</i>' so it is likely that these numbers under-estimate true prevalence (Flannigan et al., 2018a, 2018b) <ul style="list-style-type: none"> o The Prevalence of FASD o FASD Prevalence in Special Populations 	<p><i>Current studies suggest that up to 4% of individuals in Canada have FASD</i></p> <p style="text-align: center;">↓</p> <p><i>1,451,600 people with FASD in Canada today.</i></p>	<p>Research that helps us better understand how many people might have FASD in Canada, as well as in different vulnerable populations, is important to identify the scope of the needs and types of services and supports required to assist individuals and families with FASD across the country (Flannigan et al., 2018a, 2018b)</p> <div style="background-color: #004a7c; color: white; padding: 5px; text-align: center; font-weight: bold;">LIMITATIONS</div> <ul style="list-style-type: none"> - Significant limitations to prevalence research (e.g., discrepancies in reporting diagnoses, prenatal alcohol exposure may be under-reported, difficulties associated with FASD may not emerge until school years or later) - Many prevalence studies involve small samples, unique settings, use different methodologies, involve voluntary participation, or focus on estimating the numbers using pre-existing data sources. These limitations make it difficult to know the true rate of FASD in Canada - Almost all Canadian research has been done with children

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<p><i>How much alcohol is 'too much' during pregnancy?</i></p>	<ul style="list-style-type: none"> - Despite extensive research, there has been no established safe level of alcohol to consume during pregnancy - Even 'low' levels of prenatal alcohol exposure have been shown to have negative effects on long-term development (Day et al., 2013) - Research and clinical experts in maternal and fetal health recommend that no alcohol is best 	<p><i>Let's reframe the question to better reflect the message we want to convey:</i></p> <p><i>What do we know about alcohol and pregnancy?</i></p> <p><i>Experts agree that there is no safe level of drinking during pregnancy.</i></p> <p><i>It is safest not to drink during pregnancy.</i></p>	<p>There are conflicting messages in the media about how much alcohol can be safely consumed by pregnant women, and these messages perpetuate controversy and confusion</p> <p>LIMITATIONS</p> <ul style="list-style-type: none"> - Terms like 'low' and 'moderate' are unclear and subjective - Many women drink before they know they are pregnant - Women of child-bearing age who are consuming alcohol need to ensure they are using birth control to prevent an unwanted, alcohol exposed pregnancy
<p><i>Rates of FASD in special populations</i></p>	<p>Children in care:</p> <ul style="list-style-type: none"> o Canada: up to 11% (Fuchs & Burnside, 2014) o International: >20% (Lange et al. 2013) <p>Justice populations:</p> <ul style="list-style-type: none"> o Canada: 10-23% in youth (Popova et al., 2011) and up to 18% in adult settings (McLachlan, 2017) o International: 36% in Australia (Bower et al., 2018) 	<p><i>Rates of FASD are higher in vulnerable populations, including those involved in the child welfare and justice systems</i></p>	<p>Research is limited and it is suspected that there are higher rates of undiagnosed FASD in vulnerable populations</p> <p>LIMITATIONS</p> <ul style="list-style-type: none"> - Service providers in these professions should be knowledgeable about FASD - Screening tools may be especially useful in settings where there are high rates of FASD
<p><i>FASD, Mental Health & Substance Use</i></p>	<ul style="list-style-type: none"> - 90% of people with FASD also experience mental health diagnosis (O'Connor et al., 2009; Pei et al., 2011) - Most common MH comorbidities: depression, mood/anxiety, ADHD, CD, addictions, and risk of suicide - Substance use has also been reported in ~22-80% of adolescents/adults with FASD (Popova et al., 2013) 	<p><i>When unsupported, people with FASD are faced with especially high rates of mental health and substance use difficulties</i></p>	<p>LIMITATIONS</p> <ul style="list-style-type: none"> - More research is needed to better understand FASD and mental health/addictions across the lifespan - Given the high rates of mental health and addictions issues in FASD, targeted interventions should be designed in this area

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<p><i>Costs to Society</i></p>	<p>FASD has been associated with high social and economic costs.</p> <p>Alberta (Thanh et al., 2009):</p> <ul style="list-style-type: none"> - Long-term economic cost (predicted number of children born each year): <ul style="list-style-type: none"> o \$130-400 million/year - Short-term economic cost (those currently living with FASD): <ul style="list-style-type: none"> o \$48-143 million/year o \$105-306,000/day <p>Canada:</p> <p>Cost of supporting those aged 0-53 with FASD:</p> <ul style="list-style-type: none"> o \$5.3 billion/year <ul style="list-style-type: none"> o direct/indirect costs and productivity losses (Stade et al., 2009) <p>2013 costs:</p> <ul style="list-style-type: none"> o \$1.8 billion/year for health care, corrections, other direct/indirect costs (Popova et al., 2015) <p>Total costs in Canada:</p> <ul style="list-style-type: none"> o \$9.7 billion/year (Thanh et al., 2015) 	<p><i>FASD is costly, due to increased need for services for individuals and families across sectors</i></p>	<p>There is conflicting evidence about true total cost and caution should be taken against framing the condition as a burden</p> <p style="text-align: center;">LIMITATIONS</p> <ul style="list-style-type: none"> - Many studies reflect different costs to society depending on what systems they measure (e.g., medical, education, social services, corrections, prevention/research, productivity loss) - Other 'costs' are not measurable (e.g., productivity losses for parents, stress/guilt of mothers, etc.) - We do not know how costs are impacted with individuals with FASD and their families receive the services and supports they need - Very little research outside of Canada - Economic costs to society are mostly what has been reported on and does not include social or cultural costs

TERMINOLOGY AND LANGUAGE

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<i>Secondary Disabilities</i>	<p>Adolescents and adults with FASD report high rates of adverse outcomes, resulting from the combination of brain impairment and insufficient or inappropriate support.</p> <p>These include:</p> <ul style="list-style-type: none"> ○ Disrupted school experiences ○ Inappropriate behaviours ○ Mental health issues ○ Substance abuse ○ Unemployment ○ Trouble with the law ○ Confinement (correctional and psychiatric) (Streissguth et al., 2004) <p>- Recent studies in Sweden indicate high rates of unemployment, need for special education and disability pension, hospitalization for substance use and psychiatric disorders, and psychotropic drug prescription among adults with FAS (Rangmar et al., 2015)</p>	<p><i>Replace</i> <i>'secondary disabilities'</i> <i>with:</i> <i>'adverse outcomes'</i> <i>'challenges'</i> <i>'impacts'</i> <i>or</i> <i>'risks'</i></p>	<p><i>'Secondary'</i> may insinuate that these difficulties are not as prominent or important as the primary brain deficits associated with FASD</p> <div style="background-color: #003366; color: white; text-align: center; padding: 5px;">LIMITATIONS</div> <ul style="list-style-type: none"> - Many of the items described in the research are not biologically driven or disabilities (e.g., criminal activity, unemployment) and they are also not specific to FASD alone - More recent research suggests that mental health concerns and addictions may be a primary part of the disability
<i>'Disease', 'disorder', 'disability', 'syndrome', and 'condition' used interchangeably</i>	<p>Canadian diagnosticians have moved away from using the term <i>'syndrome'</i> and now use the term <i>'disorder'</i> to refer to FASD</p>	<p><i>Replace</i> <i>'disease' and 'syndrome' with:</i> <i>'disorder'</i> <i>or</i> <i>'disability'</i></p>	<p>Adoption of the terms <i>'disorder'</i> or <i>'disability'</i> better reflects FASD as a spectrum, and will ensure consistent language and clinical understanding</p>

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<p><i>'Umbrella Term'</i></p>	<p>Recent updates to the Canadian diagnostic guidelines have moved away from FASD as an umbrella term, and designated it as a diagnostic term in and of itself</p>	<p><i>FASD is a diagnostic term</i></p> <p><i>Represents a range of abilities and impairment</i></p>	<p>The new 2015 Canadian Guidelines is now using FASD as a diagnostic term. The term FASD is understood to encompass any alcohol-related diagnoses from the past. Other acronyms will no longer be used for diagnostic purposes in Canada</p> <div style="background-color: #004a7c; color: white; text-align: center; padding: 5px;">LIMITATIONS</div> <p>International literature may use a variety of different diagnosis such as FAS; ARND (Alcohol Related Neurodevelopmental disability); Neurodevelopmental Disorder, alcohol exposed; pFAS (partial Fetal Alcohol Syndrome)</p>
<p><i>Speaking respectfully about FASD within Indigenous populations</i></p> <p><i>FASD is often still viewed as only an 'aboriginal issue'</i></p>	<ul style="list-style-type: none"> - FASD does not <i>only</i> affect Indigenous populations. - Canadian discourse in the 1980s and 1990s perpetuated the stereotype that FASD was an "<i>Aboriginal problem</i>" (McKenzie et al., 2016) <ul style="list-style-type: none"> o Consequently, Indigenous women and communities have been continuously subjected to stigma, stereotyping, and surveillance - FASD is a highly complex disorder, associated with trauma, victimization, and other life adversities – these issues can affect women from all cultural groups 	<p><i>All populations where alcohol is used are at risk for FASD</i></p> <p><i>Use new terminology of Indigenous</i></p>	<ul style="list-style-type: none"> - Alcohol is an equal opportunity toxin that affects developing fetuses regardless of economics, ethnicity, religion, race, or societal status - Framing FASD as an indigenous issue perpetuates stigma and disparity in an already marginalized group - The Canadian Truth and Reconciliation Recommendations identified FASD in Calls to Action #33 & #34 (The Truth and Reconciliation Commission of Canada, 2015) <ul style="list-style-type: none"> o CanFASD, along with other groups, is working to develop strategies to address these recommendations (Stewart et al., 2018) o Truth & Reconciliation Call to Action #34: A Framework for Action <div style="background-color: #004a7c; color: white; text-align: center; padding: 5px;">LIMITATIONS</div> <p>There is a lack of consistent and high-quality research comparing rates of FASD among different ethnic groups</p>

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<p><i>Strengths-based language and positive outcomes</i></p>	<ul style="list-style-type: none"> - Although people with FASD experience complex challenges, they also possess resilience, strengths, and abilities, and offer unique and valuable contributions to society (Flannigan, Harding, et al., 2018) - FASD-informed practice includes ‘Being strengths-based’ which may be achieved by assistance, empowering people with FASD to recognize their own strengths and abilities and praising and honoring their strengths and coping mechanisms (Rutman, 2016) <ul style="list-style-type: none"> o Strengths Among Individuals with FASD 	<p><i>People with FASD are resilient and have many strengths to offer</i></p> <p><i>A balanced approach that focuses on how supports or adaptations have made good things possible is important</i></p>	<ul style="list-style-type: none"> - Highlighting strengths in FASD is more conducive to reducing stigma and supporting positive outcomes - A continual focus on the challenges associated with FASD continues to put forth the message that these are the main attributes of individuals with FASD <div style="background-color: #004a7c; color: white; text-align: center; padding: 5px;">LIMITATIONS</div> <ul style="list-style-type: none"> - Language such as ‘victim’ and ‘suffering’ can further marginalize people living with FASD. These terms should never be used and, instead, individuals with FASD should always be referred to using person-first language - The terms ‘suffering’, ‘victim’, and ‘injured’ perpetuate the stigma surrounding birth mothers and places blame on mothers. Birth mothers do not seek to harm their children
<p><i>FASD as a permanent disability</i></p>	<ul style="list-style-type: none"> - There is no “cure” for FASD, but early identification and intervention are shown to foster more positive outcomes for people with FASD (Streissguth, 2004) <ul style="list-style-type: none"> o FASD is a life-long condition o FASD can impact the entire body including the brain and is considered a whole body disorder - We have moved away from the medical model to recognize that individuals with FASD may develop differently but they still develop 	<p><i>Although FASD is a spectrum, research shows us that early and appropriate supports can make a positive impact and improve outcomes for those with the disability</i></p>	<p>Focusing on the permanence of FASD can often undercut the fact that intervention is important and beneficial</p> <div style="background-color: #004a7c; color: white; text-align: center; padding: 5px;">LIMITATIONS</div> <p>The use of the word ‘<i>treatment</i>’ can imply that the effects of FASD are reversible</p>

LEGAL ISSUES

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<p><i>Handling questions related to individuals with FASD who are involved in the justice system</i></p>	<ul style="list-style-type: none"> - There are high rates of FASD in youth and adult justice settings (McLachlan, 2017; Popova et al., 2011) - However not all individuals with FASD end up in trouble with the law - Individuals with FASD also find themselves involved in civil, and family law - Individuals with FASD are also victims of crime (Glowatski et al., 2018; Pei et al., 2018) <ul style="list-style-type: none"> o FASD and the Criminal Justice System: A Review o Victimization in People with FASD 	<p><i>The complex challenges and life experiences that individuals with FASD experience may lead to increased risk for a range of adverse outcomes, including involvement in the criminal justice system</i></p>	<p>We must consider the potentially damaging consequences of associating FASD with justice involvement</p> <div style="background-color: #003366; color: white; text-align: center; padding: 5px;">LIMITATIONS</div> <ul style="list-style-type: none"> - FASD is not the only disability relevant among offenders; there are high rates of other conditions (e.g., learning disabilities, intellectual disability, psychiatric diagnoses) in justice populations - There is very little funding for FASD assessments and judges may not be able to mandate assessment (especially for adults) - More research and data are required in the corrections and legal systems to better understand this population and their specific needs
<p><i>Violent crimes and portrayal of FASD in the media</i></p>	<ul style="list-style-type: none"> - There is no research to suggest that justice-involved offenders with FASD commit more violent crimes than offenders without FASD - Several studies suggest that offenders with FASD are no more likely to commit violent crimes than offenders without FASD but may be more likely to show a 'mixed' pattern of offending, with both violent and non-violent crimes (MacPherson et al., 2011; McLachlan, 2012) 	<p><i>There is no consistent pattern of criminal behaviour that has been identified for justice-involved individuals with FASD</i></p>	<p>Media portrayals of violent crime and FASD tend to be sensationalized and can serve to misrepresent justice-involved individuals with FASD</p> <div style="background-color: #003366; color: white; text-align: center; padding: 5px;">LIMITATIONS</div> <ul style="list-style-type: none"> - The media often reports stories in which people with FASD are involved in <i>violent</i> crimes specifically, giving FASD a violent connotation - Many gaps in services can lead to individuals with FASD and their families being unsupported which can lead to negative outcomes - We need more information about justice-involvement in FASD to tell the whole story

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<i>Alternative Justice Practices</i>	There are several initiatives across the country to better address FASD in the justice system (e.g., restorative justice, diversion programs, conditional or alternative sentencing, mental health courts) but very little research has been done to examine long term outcomes of such programs	<i>Alternative justice practices may be promising for working with some justice-involved individuals with FASD, but more research is needed</i>	<div style="text-align: center; background-color: #003366; color: white; padding: 5px;">LIMITATIONS</div> <p>The justice system is not adequately 'set up' to manage justice-involved individuals with FASD, but more research is needed to assess the long-term impact of alternative</p>

EMERGING RESEARCH

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<p><i>If a man drinks, will the sperm cause FASD?</i></p>	<p>Alcohol consumption by male partners during the preconception or prenatal period does not directly <i>cause</i> FASD, but it has been associated with:</p> <ul style="list-style-type: none"> - Higher levels of maternal alcohol consumption during pregnancy - Lower levels of success (i.e., live births) in IVF and GIFT - Lower infant birth weight and gestational age - Higher rates of ventricular malformations and abnormal situs in infants (McBride & Johnson, 2016) 	<p><i>Fathers' drinking behaviours have an important influence on both maternal prenatal alcohol consumption and the healthy development of their babies</i></p> <p><i>Fathers' drinking does not cause FASD</i></p>	<p>Fathers play a very important role in supporting partners to stay healthy during pregnancy as well as the long-term health of their children</p>
<p><i>How should the role of the NeuroDevelopmental Disorder, Alcohol Exposed in the DSM-5 be described vs the Canadian Diagnostic guideline</i></p>	<ul style="list-style-type: none"> - The DSM-5 defines ND-PAE as a condition characterized by confirmed PAE along with impairment in neurocognition, self-regulation, and adaptive functioning - Researchers recommend a comprehensive assessment conducted by a multi-disciplinary team be used with both the DSM-5 or Canadian guideline approach (Doyle & Mattson, 2015) 	<p><i>We encourage practitioners and clinicians to receive training on the Canadian FASD diagnostic guidelines.</i></p>	<p>LIMITATIONS</p>
<p><i>FASD and Autism Spectrum Disorder get compared because they are both 'spectrum' disorders</i></p>	<ul style="list-style-type: none"> - Although FASD and ASD are both neurodevelopmental disorders, their etiologies are different; there is a known cause of FASD, while the cause of ASD remains unclear - Despite some symptom overlap (e.g., social and communication difficulties), FASD and ASD are heterogeneous with distinct presentations in both clinical and day-to-day settings - Families living with the two disabilities have different experiences (Watson et al., 2013) 	<p><i>FASD and ASD are both neurodevelopmental disorders and while although there can be overlapping symptoms, they are managed differently and families experience them differently.</i></p>	<p>LIMITATIONS</p>

OTHER ISSUES

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<i>Developmental age versus chronological age</i>	<ul style="list-style-type: none"> - People with FASD often function at a level younger than their chronological age (Bennett, 2009) - Functioning may also be uneven with high levels in some areas but low in others (Minnesota Organization on Fetal Alcohol Syndrome, 2016) - With increasing age, societal expectations of autonomy and independence may be particularly problematic for those with FASD (Watson et al., 2013) 	<i>Although age descriptors can be helpful in describing an individuals' situation, moving away from this will better support a strengths-based FASD narrative</i>	<p>Focusing solely on developmental age may lead us to neglect the fact that individuals with FASD continue to develop and achieve success with adequate supports</p> <div style="background-color: #003366; color: white; text-align: center; padding: 5px;">LIMITATIONS</div> <p>Individuals with FASD have strengths as well as challenges that should both be taken into consideration to best understand and meet needs</p>
<i>Peer pressure and FASD</i>	<ul style="list-style-type: none"> - People with FASD tend to have difficulty with social functioning and peer interactions that persist into adulthood (Kully-Martens et al., 2012) - Research has shown that poor social competence and peer rejection can lead to delinquent and criminal behaviour, but this relationship has not been explored in the FASD population specifically - The communication deficits of children with FASD combined with peer pressure may cause inability to control their impulses (Wartnik et al., 2016) - Social psychological vulnerability is an issue with people with FASD due to their inability understand manipulative ploys and suggestions used by others (Brown et al., 2011; Greenspan et al., 2016) 	<i>People with FASD may have characteristics and experiences that increase their vulnerability to environmental influences or external pressures</i>	<p>Social vulnerability and peer pressure can lead to a range of negative outcomes (e.g., criminal offending or victimization), and more research is needed to explore these issues (Greenspan et al., 2016; Wartnik et al., 2016)</p>

References

- Bennett, B. (2009). *Life stages and transitions*. Paper presented at the Fetal alcohol spectrum disorder (FASD): Across the lifespan: Proceedings from an IHE consensus development conference.
- Bower, C., Watkins, R. E., Mutch, R. C., Marriott, R., Freeman, J., Kippin, N. R., Safe, B., Pestell, C., Cheung, C. S. C., Shield, H., Tarratt, L., Springall, A., Taylor, J., Walker, N., Argiro, E., Leitao, S., Hamilton, S., Condon, C., Passmore, H. M., & Giglia, R. (2018). Fetal alcohol spectrum disorder and youth justice: A prevalence study among young people sentenced to detention in Western Australia. *BMJ Open*, *8*(2), e019605. doi:10.1136/bmjopen-2017-019605
- Brown, N. N., Gudjonsson, G., & Connor, P. (2011). Suggestibility and fetal alcohol spectrum disorders: I'll tell you anything you want to hear. *The Journal of Psychiatry Law*, *39*(1), 39-71. Retrieved from <http://journals.sagepub.com/doi/abs/10.1177/009318531103900103>
- Canada FASD Research Network. (2018). Reflections on FASD awareness day- one community's experience. *Girls, Women, Alcohol, and Pregnancy Perspectives on FASD Prevention*. Retrieved from <https://fasdprevention.wordpress.com/category/fasd-awareness-day/>
- Day, N. L., Helsel, A., Sonon, K., & Goldschmidt, L. (2013). The association between prenatal alcohol exposure and behavior at 22 years of age. *Alcoholism: Clinical & Experimental Research*, *37*(7), 1171-1178. doi:10.1111/acer.12073
- Flannigan, K., Harding, K., Reid, D., & The Family Advisory Committee. (2018). *Strengths among individuals with FASD*. Canada FASD Research Network. Canada. Retrieved from <https://canfasd.ca/wp-content/uploads/sites/35/2018/10/Strengths-Among-Individuals-with-FASD.pdf>
- Flannigan, K., Unsworth, K., & Harding, K. (2018a). *The prevalence of Fetal Alcohol Spectrum Disorder*. Canada FASD Research Network. Canada. Retrieved from <https://canfasd.ca/wp-content/uploads/sites/35/2018/08/Prevalence-1-Issue-Paper-FINAL.pdf>
- Flannigan, K., Unsworth, K., & Harding, K. (2018b). *FASD prevalence in special populations*. Canada FASD Research Network. Canada. Retrieved from <https://canfasd.ca/wp-content/uploads/sites/35/2018/08/Prevalence-2-Issue-Paper-FINAL.pdf>
- Fuchs, D., & Burnside, L. (2014). *A tri-province initiative to expand understanding of costs, services & prevention of a public health issue: Fetal alcohol spectrum disorder & children/youth in care [2010-2014]: Study on the prevalence of FASD in Canadian child welfare settings: Final report*. University of Manitoba. Manitoba, Canada. Retrieved from <http://fasdchildwelfare.ca/sites/default/files/research/Ap26%20O3b%20%20PHAC%20FASD%20Prevalence%20Study%20Report%20FINAL%202014.pdf>
- Glowatski, K., & Stewart, M. (2018). *Victimization in people with FASD*. Canada FASD Research Network. Canada. Retrieved from <https://canfasd.ca/wp-content/uploads/sites/35/2018/07/FASD-and-Victimization-FINAL.pdf>
- Greenspan, S., & Driscoll, J. H. (2016). Why people with FASD fall for manipulative ploys: Ethical limits of interrogators' use of lies. *Fetal alcohol spectrum disorders in adults: Ethical and legal perspectives*, (pp. 23-38): Springer.
- Kully-Martens, K., Denys, K., Treit, S., Tamana, S., & Rasmussen, C. (2012). A review of social skills deficits in individuals with fetal alcohol spectrum disorders and prenatal alcohol exposure: Profiles, mechanisms, and interventions. *Alcoholism: Clinical & Experimental Research*, *36*(4), 568-576. doi:10.1111/j.1530-0277.2011.01661.x

- Lange, S., Shield, K., Rehm, J., & Popova, S. (2013). Prevalence of Fetal Alcohol Spectrum Disorders in child care settings: A meta-analysis. *Pediatrics*, *132*(4), e980-e995. doi:10.1542/peds.2013-0066
- MacPherson, P. H., Chudley, A. E., & Grant, B. A. (2011). *Fetal Alcohol Spectrum Disorder (FASD) in a correctional population: Prevalence, screening and characteristics*, Correctional Service of Canada. Ottawa, Canada. Retrieved from <http://www.csc-scc.gc.ca/research/005008-0247-eng.shtml>
- Manitoba FASD Coalition. (2016). *Language guide: Promoting dignity for those impacted by FASD*. Manitoba FASD Coalition, Manitoba, Canada. Retrieved from <http://www.fasdcoalition.ca/wp-content/uploads/2016/10/LAEO-Language-Guide.pdf>
- May, P. A., Baete, A., Russo, J., Elliott, A. J., Blankenship, J., Kalberg, W. O., Buckley, D., Brooks, M., Hasken, J., Abdul-Rahman, O., Adam, M. P., Robinson, L. K., Manning, M., & Hoyme, H. E. (2014). Prevalence and characteristics of Fetal Alcohol Spectrum Disorders. *Pediatrics*, *134*(5), 855-866. doi:10.1542/peds.2013-3319
- May, P. A., Chambers, C. D., Kalberg, W. O., Zellner, J., Feldman, H., Buckley, D., Kopald, D., Hasken, J. M., Xu, R., Honerkamp-Smith, G., Taras, H., Manning, M. A., Robinson, L. K., Adam, M. P., Abdul-Rahman, O., Vaux, K., Jewett, T., Elliott, A. J., Kable, J. A., Akshoomoff, N., Falk, D., Arroyo, J. A., Hereld, D., Riley, E. P., Charness, M. E., Coles, C. D., Warren, K. R., Jones, K. L., & Hoyme, H. E. (2018). Prevalence of fetal alcohol spectrum disorders in 4 US communities. *The Journal of the American Medical Association*, *319*(5), 474-482. doi:10.1001/jama.2017.21896
- May, P. A., Keaster, C., Bozeman, R., Goodover, J., Blankenship, J., Kalberg, W. O., Buckley, D., Brooks, M., Hasken, J., Gossage, J. P., Robinson, L. K., Manning, M., & Hoyme, H. E. (2015). Prevalence and characteristics of Fetal Alcohol Syndrome and partial Fetal Alcohol Syndrome in a Rocky Mountain Region City. *Drug & Alcohol Dependence*, *155*, 118-127. doi:10.1016/j.drugalcdep.2015.08.006
- McKenzie, H. A., Dell, C. A., & Fornssler, B. J. C. A. R. (2016). Understanding addictions among indigenous people through social determinants of health frameworks and strength-based approaches: A review of the research literature from 2013 to 2016. *Current Addiction Reports*, *3*(4), 378-386. doi:10.1007/s40429-016-0116-9
- McLachlan, K. (2017). *Fetal alcohol spectrum disorder in Yukon corrections. Final report to Yukon justice: Estimating the prevalence of FASD, mental health, and substance use problems in the justice system* Yukon Department of Justice. Yukon, Canada. Retrieved from [http://www.justice.gov.yk.ca/pdf/Corrected McLachlan Final Report to Yukon August 2017.pdf](http://www.justice.gov.yk.ca/pdf/Corrected_McLachlan_Final_Report_to_Yukon_August_2017.pdf)
- McLachlan, K. E. (2012). *An examination of the abilities, risks, and needs of adolescents and young adults with Fetal Alcohol Spectrum Disorder (fasd) in the criminal justice system*. (Doctoral Thesis, Simon Fraser University, British Columbia, Canada). Retrieved from <http://summit.sfu.ca/item/12102>
- Minnesota Organization on Fetal Alcohol Syndrome. (2016). *Raising children with Fetal Alcohol Spectrum Disorders (FASD)* Minnesota Organization on Fetal Alcohol Syndrome. Minnesota. Retrieved from <https://www.mofas.org/wp-content/uploads/2015/09/Tips-for-New-Families2016.pdf>
- O'Connor, M. J., & Paley, B. (2009). Psychiatric conditions associated with prenatal alcohol exposure. *Developmental Disabilities Research Reviews*, *15*(3), 225-234. doi:10.1002/ddrr.74
- Pei, J., Denys, K., Hughes, J., & Rasmussen, C. (2011). Mental health issues in Fetal Alcohol Spectrum Disorder. *Journal of Mental Health*, *20*(5), 438-448. doi:10.3109/09638237.2011.577113
- Pei, J., Flannigan, K., Keller, S., Stewart, M., & Johnson, A. (2018). *FASD and the criminal justice system: A review*. Canada FASD Research Network. Alberta & Saskatchewan, Canada. Retrieved from <https://canfasd.ca/wp-content/uploads/sites/35/2018/08/FASD-Justice-Review-Issue-Paper-FINAL.pdf>

- Popova, S., Lange, S., Bekmuradov, D., Mihic, A., & Rehm, J. (2011). Fetal Alcohol Spectrum Disorder prevalence estimates in correctional systems: A systematic literature review. *Canadian Journal of Public Health, 102*(5), 336-340. Retrieved from <https://www.ncbi.nlm.nih.gov/pubmed/22032097>
- Popova, S., Lange, S., Burd, L., & Rehm, J. (2015). Cost attributable to Fetal Alcohol Spectrum Disorder in the Canadian correctional system. *International Journal of Law & Psychiatry, 41*, 76-81. doi:10.1016/j.ijlp.2015.03.010
- Popova, S., Lange, S., Burd, L., Urbanoski, K., & Rehm, J. (2013). Cost of specialized addiction treatment of clients with Fetal Alcohol Spectrum Disorder in Canada. *BMC Public Health, 13*, 570. doi:10.1186/1471-2458-13-570
- Popova, S., Lange, S., Chudley, A. E., Reynolds, J. N., Rehm, J., May, P. A., & Riley, E. P. (2018). *World health organization international study on the prevalence of Fetal Alcohol Spectrum Disorder (FASD): Canadian component*. The Institute for Mental Health Policy Research & Centre for Addiction and Mental Health. Ontario, Canada. Retrieved from <https://canfasd.ca/wp-content/uploads/sites/35/2018/05/2018-Popova-WHO-FASD-Prevalance-Report.pdf>
- Rangmar, J., Hjern, A., Vinnerljung, B., Stromland, K., Aronson, M., & Fahlke, C. (2015). Psychosocial outcomes of Fetal Alcohol Syndrome in adulthood. *Pediatrics, 135*(1), e52-e58. doi:10.1542/peds.2014-1915
- Retzlaff, S. (2005). What's in a name? The politics of labelling and native identity constructions. *The Canadian Journal of Native Studies, 25*(2), 609-626. Retrieved from http://www3.brandonu.ca/cjns/25.2/cjnsv25no2_pg609-626.pdf
- Rutman, D. (2016). Becoming FASD informed: Strengthening practice and programs working with women with FASD. *Substance Abuse: Research & Treatment, 10*(Suppl 1), 13-20. doi:10.4137/SART.S34543
- Sampson, P. D., Streissguth, A. P., Bookstein, F. L., Little, R. E., Clarren, S. K., Dehaene, P., Hanson, J. W., & Graham, J. M., Jr. (1997). Incidence of Fetal Alcohol Syndrome and prevalence of alcohol-related neurodevelopmental disorder. *Teratology, 56*(5), 317-326. doi:10.1002/(SICI)1096-9926(199711)56:5<317::AID-TERA5>3.0.CO;2-U
- Stade, B., Ali, A., Bennett, D., Campbell, D., Johnston, M., Lens, C., Tran, S., & Koren, G. (2009). The burden of prenatal exposure to alcohol: Revised measurement of cost. *Canadian Journal of Clinical Pharmacology, 16*(1), e91-102. Retrieved from <https://www.ncbi.nlm.nih.gov/pubmed/19168935>
- Stewart, M., & Glowatski, K. (2018). *Truth and reconciliation call to action #34: A framework for action*. Canada FASD Research Network. Regina, SK. Retrieved from <https://canfasd.ca/wp-content/uploads/sites/35/2018/10/TRC34-A-Framework-for-Action.pdf>
- Streissguth, A. P., Bookstein, F. L., Barr, H. M., Sampson, P. D., O'Malley, K., & Young, J. K. (2004). Risk factors for adverse life outcomes in Fetal Alcohol Syndrome and fetal alcohol effects. *Journal of Developmental & Behavioral Pediatrics, 25*(4), 228-238. Retrieved from <https://www.ncbi.nlm.nih.gov/pubmed/15308923>
- Thanh, N. X., & Jonsson, E. (2015). Costs of Fetal Alcohol Spectrum Disorder in the Canadian criminal justice system. *Journal of Population Therapeutics & Clinical Pharmacology, 22*(1), e125-e131. Retrieved from <https://www.ncbi.nlm.nih.gov/pubmed/26072470>
- Thanh, N. X., & Jonsson, E. (2009). Costs of Fetal Alcohol Spectrum Disorder in Alberta, Canada. *Canadian Journal of Clinical Pharmacology, 16*(1), e80-e90. Retrieved from <https://www.ncbi.nlm.nih.gov/pubmed/19151424>

Thanh, N. X., Jonsson, E., Salmon, A., & Sebastianski, M. (2014). Incidence and prevalence of Fetal Alcohol Spectrum disorder by sex and age group in Alberta, Canada. *Journal of Population Therapeutics & Clinical Pharmacology*, 21(3), e395-e404. Retrieved from <https://www.ncbi.nlm.nih.gov/pubmed/25381628>

The Truth and Reconciliation Commission of Canada. (2015). *Honouring the truth, reconciling for the future: Summary of the final report of the Truth and Reconciliation Commission of Canada*. The Truth and Reconciliation Commission of Canada. Canada. Retrieved from http://www.trc.ca/websites/trcinstitution/File/2015/Findings/Exec_Summary_2015_05_31_web_o.pdf

Wartnik, A. P., & Brown, J. (2016). Fetal Alcohol Spectrum Disorders (FASD) and the criminal justice system: Causes, consequences, and suggested communication approaches. *Forensic Scholars Today*, 1(4), 1-5. Retrieved from <https://online.csp.edu/blog/forensic-scholars-today/fasd-and-criminal-justice-system>

Watson, S., Hayes, S., Radford-Paz, E., & Coons, K. (2013). "I'm hoping, I'm hoping..." Thoughts about the future from families of children with autism or Fetal Alcohol Spectrum Disorder in Ontario. *Journal on Developmental Disabilities*, 19(3), 76-93. Retrieved from <http://psycnet.apa.org/record/2014-06811-007>



Thank you to all the CanFASD researchers and staff who provided valuable input into this document.

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