

Common FASD Messaging

The purpose of this document is to assist those writing and talking about people with FASD or the issues related to the disability to use the same statistics, framing of topics, and language. The outcome over time will be an improved understanding by the reader/listener with consistently using these suggestions. This is a living document and areas will be updates as it is informed by the research.

Issue	Research Tells Us	Take-Away Message	Why This Matters
Prevalence and Statistics			
Prevalence <i>"How many people have FASD"</i> <i>"What are the numbers?"</i>	<ul style="list-style-type: none"> - 2013 Alberta estimates → 1.4-4.4% of the general population (Thanh, 2014) - 2014 US → 2.4-4.8% (May, 2014) - Older estimates: 9.1/1000 (Sampson, 1997) - FASD is an "invisible disability" so it is possible that these numbers under-estimate true prevalence 	<p><i>Current studies suggest that up to 4% of individuals in Canada have FASD</i></p> <p><i>This is 1,406,069 people with FASD in Canada today.</i></p>	<ul style="list-style-type: none"> - Significant limitations to prevalence research (e.g., discrepancies in reporting dx's, outdated research – most done before 2000s) - Estimates vary by methodology, geography, and sample (e.g., high risk vs. general populations) and only exist in 10 countries - Almost all Canadian research done with children
How much alcohol is "too much" during pregnancy?	<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 	<p><i>Let's reframe the question: 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>	<ul style="list-style-type: none"> - 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 - Terms like "low" and "moderate" are unclear and subjective

	<p>development (Day et al., 2013)</p> <ul style="list-style-type: none"> - Experts in research and prenatal health recommend that no alcohol is best 	<p><i>It is safest not to drink during pregnancy.</i></p> <p>How many women drink during pregnancy?</p>	<ul style="list-style-type: none"> - 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
Rates of FASD in various settings	<ul style="list-style-type: none"> - Child welfare system: >20% (Lange et al. 2013) - Justice populations: 10-23% according to older research (Popova); ~17% in adult settings according to newer research (McLachlan) 	<p><i>When unsupported for their disability, rates of FASD are higher in vulnerable populations, including those involved in the child welfare and justice systems</i></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 - Research is limited and it is suspected that there are higher rates of undiagnosed FASD in vulnerable populations
FASD, mental health, and substance use	<ul style="list-style-type: none"> - 90% of people with FASD also experience mental health diagnosis (O'Connor, 2009; Pei, 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, 2013) 	<p><i>When unsupported, people with FASD are faced with especially high rates of mental health difficulties</i></p>	
Costs to society	<p>These are the economic costs when an individual is not well supported. We do not know the costs associated when individuals with FASD receive the</p>	<p><i>FASD is costly</i></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,

	<p>system and family supports needed.</p> <p>Alberta:</p> <ul style="list-style-type: none"> - Long-term economic cost (predicted number of children born each year): \$130-400 million/year - Short-term economic cost (those currently living with FASD): \$48-143 million/year - Daily cost: \$105-306 thousand (Thanh, 2009) <p>Canada:</p> <ul style="list-style-type: none"> - Cost of supporting those aged 0 to 53: \$5.3 billion/year (Stade, 2009) – measured direct/indirect costs and productivity losses - 2013 costs: \$1.8 billion for health care, corrections, other direct/indirect costs (Popova, 2015) - Total costs in Canada: \$9.7 billion/year (Thanh, 2015) 		<p>corrections, prevention/research, productivity loss)</p> <ul style="list-style-type: none"> - Other “costs” are not measurable (e.g., productivity losses for parents, stress/guilt of mothers, etc.) - Caution against framing the condition as a burden - Conflicting evidence about true total cost - Very little research outside of Canada - <i>Economic costs to society is mostly what has been reported on and does not include social and cultural costs.</i>
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Terminology and Language			
“Secondary Disabilities”	<p>Adolescents and adults with FASD report high rates of adverse outcomes, resulting from the combination of brain impairment and insufficient or inappropriate support. These include:</p> <ul style="list-style-type: none"> - Disrupted school experiences 	<p><i>Replace the term “secondary disabilities” with “adverse outcomes”, “challenges”, “impacts”, or “risks”</i></p>	<ul style="list-style-type: none"> - Many of the items described in Streissguth’s work are not disabilities (e.g., criminal activity, unemployment) - Many of these items are also not biologically driven and should not be termed a disability (e.g.,

	<ul style="list-style-type: none"> - Inappropriate behaviours - Mental health issues - Substance abuse - Unemployment - Trouble with the law - Confinement (correctional and psychiatric) <p>(Streissguth, 2004; Rangmar, 2015)</p>		<p>homelessness); they are also not specific to FASD alone</p> <ul style="list-style-type: none"> - “Secondary” may insinuate that these difficulties are not as prominent or important as the primary brain deficits - More recent research suggests that mental health concerns and addictions may be a primary part of the disability
Umbrella term	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	<i>FASD is a diagnostic term. Represents a range of abilities and impairment.</i>	<p>New 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> <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>
Speaking respectfully about FASD within Indigenous populations. FASD is often still viewed as only an aboriginal issue	<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 “Aboriginal problem” (McKenzie, Dell, & Fornssler, 2016) and, consequently, Indigenous women and 	<p>Use new terminology of Indigenous.</p> <p>All populations where alcohol is used are at risk for this disorder.</p> <p>The Truth and Reconciliation Recommendations in Canada</p>	<ul style="list-style-type: none"> - There is a lack of consistent and high-quality research comparing rates of FASD among different ethnic groups - Framing FASD as an indigenous issue perpetuates stigma and disparity in an already marginalized group

	<p>communities have been continuously subjected to stigma, stereotyping, and surveillance</p> <ul style="list-style-type: none"> - FASD is a highly complex disorder, associated with trauma, victimization, and other life adversities – these issues can affect women from all cultural groups - Alcohol is an equal opportunity toxin that affects developing fetuses regardless of economics, ethnicity, religion, race, or societal status. 	<p>identified FASD in Recommendation #33 and #34. CanFASD along with other groups are working to develop strategies to address these.</p>	
<p>“Disease,” “disorder,” “disability,” “syndrome,” “condition” are used interchangeably</p>	<p>Canadian diagnosticians have moved away from using the term “syndrome” and now use the term “disorder” to refer to FASD</p>	<p><i>Replace the terms “disease” and “syndrome” with “disorder”</i></p>	
<p>Strengths-based language and positive outcomes</p>	<p>Although people with FASD experience challenges, they also possess resilience, strengths, and potential, and offer valuable contributions to society</p>	<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"> - Language such as “victim” and “suffering” can further marginalize people living with FASD. These terms should never be used and, instead, persons/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.

			<ul style="list-style-type: none"> - Highlighting strengths 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.
FASD as a permanent disability	<p>There is no “cure” for FASD, but early identification and intervention are shown to foster more positive outcomes for people with FASD (Streissguth, 2004)</p> <ul style="list-style-type: none"> - FASD is a life long condition - FASD can impact the entire body including the brain and is considered a whole body disorder. 	<i>Although FASD is a spectrum, research shows us that early and appropriate supports can make a positive impact on the lives of those with the disability and improve outcomes.</i>	<ul style="list-style-type: none"> - Focusing on the permanence of FASD can often undercut the fact that intervention is important and beneficial - The use of the word “treatment” can imply that the effects of FASD are reversible - <i>We have moved away from the medical model to recognize that individuals with FASD may develop differently but they still develop.</i>
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Legal Issues			
Handling questions related to incarcerated or charged individuals with FASD	<ul style="list-style-type: none"> - Not all individuals with FASD end up in legal trouble - There is very little funding for FASD assessments and judges may not be able to mandate assessment (especially for adults) - Individuals with FASD also find themselves involved in civil, and family law. - Individuals with FASD are also victims of crime. 	<i>People with FASD are over-represented and vulnerable in both youth and adult justice settings because of the lack of resources to support them in the community.</i>	<p>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</p> <p>More research and data is required in the corrections and legal systems to better understand this population and their specific needs.</p>

Violent crimes and portrayal of FASD in the media	<ul style="list-style-type: none"> - There is no research to suggest that offenders with FASD commit more <i>violent</i> crimes than offenders without FASD – in fact, 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 (McLachlan, MacPherson) 	<i>There is no consistent pattern of criminal behaviour that has been identified for offenders with FASD</i>	<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 - These stories tend to be sensationalized and can serve to misrepresent offenders with FASD - Many gaps in services can lead to individuals with FASD and their families being unsupported which can lead to negative outcomes. - Need more information to tell the whole story
Alternative justice practices	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 offenders with FASD, but more research is needed.</i>	<ul style="list-style-type: none"> - The justice system is not adequately “set up” to manage offenders with FASD - Research is needed to assess the long-term impact of alternative practices - More research is required.
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Emerging Research			
If a man drinks, will the sperm cause FASD	Alcohol consumption by male partners during the preconception or prenatal period does not directly <i>cause</i> FASD, but it has been associated with:	<i>Fathers’ drinking behaviours have an important influence on both maternal prenatal alcohol consumption and the healthy development of their babies</i>	<ul style="list-style-type: none"> - Fathers play a very important role in supporting partners to stay healthy during the pregnancy

	<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 <p>(McBride & Johnson, 2016)</p>	Fathers' drinking does not cause FASD	
How should the role of the NeuroDevelopmental Disorder, Alcohol Exposed in the DSM-5 be described vs the Canadian Diagnostic guidelines	<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 <p>(Doyle & Mattson, 2015)</p>	In Canada, the 2015 Canadian FASD diagnostic guidelines are primarily used to diagnose individuals prenatally exposed to alcohol. The Canadian Guidelines support a multi-disciplinary approach to diagnosis which is important for a full understanding of the neurocognitive impairments and the required interventions and supports.	<ul style="list-style-type: none"> -More research is needed in comparing and contrasting the different diagnostic systems in the world. - We encourage practitioners and clinicians to receive training on the Canadian FASD diagnostic guidelines.
FASD and Autism Spectrum Disorder get compared because they are both "spectrum" disorders	<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 both neurodevelopmental disorders and while there can be overlapping symptoms, they are managed differently.	Some emerging epigenetic research explores the link between FASD and ASD, but little is known about the association between the two disorders

	<p>FASD and ASD are heterogeneous with distinct presentations in both clinical and day-to-day settings</p> <ul style="list-style-type: none"> - There are also differences in the experiences of families living with the two disabilities (Watson, Hayes, Coons, & Radford-Paz, 2013; Watson, Hayes, Radford-Paz, & Coons, 2013) 		
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Other Issues			
Developmental age versus chronological age	<ul style="list-style-type: none"> - People with FASD often function at a level younger than their chronological age - Functioning may also be uneven with high levels in some areas but low in others - With increasing age, societal expectations of autonomy and independence may be particularly problematic for those with FASD 	Individuals with FASD have strengths as well as challenges.	<ul style="list-style-type: none"> - Moving away from age descriptors, although this can be helpful in describing an individuals' situation.
Peer pressure and FASD	<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 	People with FASD may have characteristics that increase their vulnerability to environmental influences or external pressures.	<ul style="list-style-type: none"> - In media portrayals of crimes committed by people with FASD, peer pressure is often named as a contributor to the crime - More research is needed to explore this relationship

	behaviour, but this relationship has not been explored in the FASD population specifically		
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Other recommendations:

Images

- Refrain from using pregnant bellies without heads in photo's
- Refrain from using the statement that FASD is "100% preventable" as this statement greatly oversimplifies the issue

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

If you have comments or suggestions, please send them to Audrey.McFarlane@canfasd.ca

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