

Common Messages

Guidelines for talking and writing about FASD

2021

Guidelines for Writing and 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 language, statistics, and framing of topics. 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 they are informed by emerging research.

Key Communication Themes:

The following are some overarching recommendations for all messaging about FASD:

- Respect, dignity, and inherent human worth should be promoted among individuals with FASD, women who use alcohol during pregnancy, and their families:
 - FASD awareness or prevention programs and initiatives should avoid guilt-ridden, blameful, or shameful messaging
 - When using imagery, refrain from using pictures of fetuses, pregnant bellies without heads, and naked pregnant people
 - Fatalistic or deficits-focused terminology should be replaced with person-first, strength-based, and hope-focused language (see the definition below)
 - These [language guides](#) provide additional context and information about dignity promotion for individuals with FASD
- Always rely on information that is accurate and based on rigorous, high-quality research (i.e., evidence-based)
- Refrain from stating that FASD is “100% preventable” as this statement greatly oversimplifies the issue and can stigmatize individuals and families

In order to promote a common language about FASD and to minimize misinterpretation of key issues, CanFASD has developed a [standard definition of FASD](#). Standard definitions are needed to ensure consistency in administrative, clinical, and research operations. We recommend that this definition be used by governments and policy makers across Canada to promote accurate and consistent language when referring to FASD.

The Canada FASD Research Network recommends using the following definition when writing FASD policy, developing supports, and providing services for individuals with 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.

Le Trouble du spectre de l'alcoolisation fœtale (TSAF) est un terme diagnostique utilisé pour décrire les impacts au cerveau et le corps des individus exposés à l'alcool avant la naissance.

Le TSAF est un handicap permanent à vie. Les individus atteints du TSAF connaîtront un certain degré de défis dans leur vie quotidienne et auront besoin d'être supportés dans les domaines suivants: habiletés motrices, santé physique, apprentissage, mémoire, attention, communication, régulation émotionnelle ainsi que les habiletés sociales pour atteindre leur plein potentiel.

Chaque individu atteint du TSAF est unique et présente à la fois des forces et des défis.

PREVALENCE & STATISTICS

Question/Issue	Research Tells Us	Say This	Why This Matters
<p>How many people have FASD?</p>	<p>In Canada</p> <ul style="list-style-type: none"> - In the Greater Toronto Area, researchers estimate the prevalence to be 2-3% among students aged 7-9 years¹ - In Alberta, estimates are 1-4% in the general population² <p>In the United States</p> <ul style="list-style-type: none"> - Researchers³⁻⁸ have conducted a series of studies with school-aged children in the US, suggesting a conservative estimate of up to 8% in some regions <p>FASD is often under-recognized and identified, so it is likely that prevalence estimates are conservative. For more information:</p> <ul style="list-style-type: none"> - The Prevalence of FASD⁹ - FASD Prevalence in Special Populations¹⁰ 	<p>Researchers currently suggest that at least 4% of individuals in Canada have FASD</p> <p>This translates to more than 1.5 million people</p>	<p>Research that helps us better understand how many people might have FASD in Canada, as well as in special 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.</p> <p>Limitations</p> <p>Limitations in prevalence research make it difficult to know the true rate of FASD in Canada. Discrepancies in reporting diagnoses, prenatal alcohol exposure may be under-reported due to stigma and fear of judgment, individual difficulties may not emerge until school years or later. Small samples, unique settings, use of different methodologies, voluntary participation, estimating the numbers using pre-existing data. Most prevalence studies have been done with children.</p>
<p>Rates of FASD in special populations</p>	<p>Children in care^{11,12}</p> <ul style="list-style-type: none"> - <i>Canada</i>: up to 11% - <i>International</i>: more than 20% <p>Justice populations¹³⁻¹⁶</p> <ul style="list-style-type: none"> - <i>Canada</i>: 10-23% in youth and up to 18% in adult settings - <i>International</i>: 36% in Australia 	<p>Rates of FASD are higher in special populations, including those involved in the child welfare and justice systems</p>	<p>Service providers in these professions should be knowledgeable about FASD, and screening tools may be especially useful in settings where there are high rates of FASD.</p> <p>Limitations</p> <p>Research in this area is limited and it is suspected that there are higher rates of undiagnosed FASD in special populations</p>

<p>How much alcohol is “too much” during pregnancy?</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 development¹⁷ - Researchers and clinical experts in maternal and fetal health recommend that no alcohol is best 	<p>Let’s reframe the question to better reflect the message we want to convey:</p> <p>“What do we know about alcohol and pregnancy?”</p> <p>Experts agree that there is no safe level of drinking during pregnancy</p> <p>It is safest not to drink during pregnancy</p>	<p>There are conflicting messages in the media about how much alcohol can be safely consumed during pregnancy, and these messages perpetuate controversy and confusion. Women of child-bearing age who are consuming alcohol should use birth control to prevent an unplanned, alcohol exposed pregnancy.</p> <p>Limitations</p> <ul style="list-style-type: none"> - Terms like ‘low’ and ‘moderate’ are unclear and subjective - There are many reasons why people may drink alcohol during pregnancy - Many people drink before they know they are pregnant
<p>FASD, mental health, and substance use</p>	<ul style="list-style-type: none"> - An estimated 90% of people with FASD experience an additional mental health diagnosis¹⁸⁻²⁰ - Some of the most common comorbidities in FASD are ADHD, Intellectual Disability, Learning Disorder, Oppositional Defiant Disorder, Conduct Disorder, depressive and anxiety disorders, substance use, and risk of suicide²¹ - Substance use has been reported in ~22-80% of adolescents/adults with FASD²² - There is a significant gap in the research on mental health and substance use interventions for people with FASD²³ 	<p>When unsupported, people with FASD may be more likely to experience high rates of mental health and substance use difficulties</p>	<p>Given the high rates of mental health and substance use issues reported among people with FASD, targeted interventions should be designed in this area.</p> <p>Limitations</p> <p>More research is needed to better understand and address challenges with mental health/substance use for individuals with FASD across the lifespan.</p>
<p>Social and economic costs</p>	<p>FASD has been associated with high social and economic costs:</p> <ul style="list-style-type: none"> - In Alberta:²⁴ <ul style="list-style-type: none"> o Long-term economic cost of \$130-400 million/year (predicted number of children born each year) 	<p>FASD is costly to support because of the increased need for services for individuals and families across sectors</p>	<p>There is conflicting evidence about true total cost of FASD, and caution should be taken against framing the disability as a burden.</p> <p>Limitations</p>

	<ul style="list-style-type: none"> ○ Short-term economic cost of \$48-143 million/year (those currently living with FASD) - In Canada:²⁵⁻²⁷ <ul style="list-style-type: none"> ○ Cost of supporting those aged 0 to 53 with FASD is \$5.3 billion/year ○ \$1.8 billion for health care, corrections, other direct/indirect costs ○ Total cost \$9.7 billion/year 		<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 when individuals with FASD and their families receive the services and supports they need - Very little research has been done outside of Canada - Cost estimates do not include social and cultural costs
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TERMINOLOGY & LANGUAGE

Question/Issue	Research Tells Us	Take-Away Message	Why This Matters
“Secondary disabilities”	Adolescents and adults with FASD can experience high rates of difficulties in daily living and adverse outcomes, including: ²⁸⁻³⁰ <ul style="list-style-type: none"> - Disrupted school experiences - Sexually inappropriate behaviours - Mental health issues - Substance use challenges - Challenges with independence - Unemployment - Housing problems - Trouble with the law - Confinement 	Replace “secondary disabilities” with: “adverse outcomes” “difficulties in daily living” “impacts” or “risks”	<div style="background-color: #800000; color: white; padding: 5px;"> Use of the term “secondary” may insinuate that these difficulties are not as prominent or important as the primary brain- and body-based deficits associated with FASD. </div> <div style="background-color: #003366; color: white; padding: 5px; text-align: center;"> Limitations </div> <ul style="list-style-type: none"> - Many of the challenges described in the research are not biologically-driven or “disabilities” per se, and are not specific to FASD alone - Researchers more recently suggest that mental health concerns and substance use challenges may be a primary symptom of the disability
“Invisible disability”	FASD has commonly been referred to as an “invisible” disability, because the majority of people with FASD have no <i>physical</i> signs of impairment.	Replace “invisible” with “hidden”	The use of the term “invisible” can invalidate and stigmatize people with FASD and their families. The term “hidden” more accurately and respectfully reflects the characteristics and experiences of this population.

<p>“Disease,” “disorder,” “disability,” “syndrome,” and “condition” used interchangeably</p>	<p>Canadian diagnosticians have moved away from using the term “syndrome” and now use the term “disorder” to refer to FASD.³¹</p>	<p>Replace “disease” and “syndrome” with “disorder” or “disability”</p>	<p>Adoption of the terms “disorder” or “disability” better reflects FASD as a spectrum and will ensure consistent language and clinical understanding.</p>
<p>Speaking respectfully about FASD within Indigenous¹ populations</p> <p>FASD is often still viewed as only an “Indigenous issue”</p>	<ul style="list-style-type: none"> - FASD affects people of all cultural and ethnic backgrounds - Canadian discourse in the 1980s and 1990s perpetuated the stereotype that FASD was an “<i>Indigenous issue</i>”³² - Indigenous women and communities have been continuously subjected to stigma, stereotyping, and surveillance³³ - The Canadian Truth and Reconciliation Recommendations identified FASD in calls to action #33 and #34 - CanFASD along with other groups are working to develop strategies and commitments to address these recommendations: <ul style="list-style-type: none"> o Developing an Indigenous Approach to FASD Prevention³⁴ o TRC Call to Action 34: A Framework for Action³⁵ o CanFASD Commitment to Indigenous Partnership, Reconciliatory Research, and Action³⁶ 	<p>All populations where alcohol is used are at risk for FASD</p> <p>Replace outdated terminology with the term of ‘Indigenous’</p>	<p>FASD is a highly complex disability, intertwined with the social determinants of health and other factors which can affect people from all economic, ethnic, religious, racial, or societal backgrounds.</p> <p style="text-align: center;">Limitations</p> <p>There is a lack of consistent and high-quality research comparing rates of FASD among diverse populations and groups.</p>
<p>Strength-based language and positive outcomes</p>	<ul style="list-style-type: none"> - Although people with FASD may experience many challenges, they also possess diverse strengths, abilities, and resilience³⁷ <ul style="list-style-type: none"> o Strengths Among Individuals with FASD - FASD-informed practice includes FASD awareness, safe relationships, and working from a person-centered and strength-based approach³⁸ - Individuals with FASD should always be referred to using person-first language 	<p>People with FASD are resilient and have many strengths</p> <p>A balanced approach in working with people with FASD that incorporates supports or adaptations is important</p>	<p>Focusing solely on the challenges associated with FASD continues to send the message that these are the main attributes of individuals with FASD. Highlighting strengths in FASD is more conducive to reducing stigma and supporting positive outcomes.</p> <p style="text-align: center;">Limitations</p> <p>Most of the literature on FASD is deficits-based, and there is a critical need for more research focused on strengths.</p>

¹In Canada, the term ‘Indigenous peoples’ refers to descendants of the peoples of North America who were present before colonization and encompasses three distinct groups: First Nations, Métis, and Inuit.

<p>FASD as a “permanent” disability</p>	<ul style="list-style-type: none"> - There is no “cure” for FASD, but early intervention and stable home environments are significant protective factors²⁸ - We have moved away from the medical model (which posits that disabilities should be “corrected”) to recognize that individuals with FASD may develop differently but they still develop - Use of the word “treatment” can imply that the effects of FASD are reversible 	<p>There is good evidence that early and appropriate support can improve outcomes for people with FASD</p>	<p>FASD is a life-long whole-body disorder, but early identification and intervention can foster more positive outcomes for people with FASD.</p> <p>Although there is no “cure” for FASD, focusing on the permanence of FASD can undercut the fact that intervention is important and beneficial.</p>
<p>Referring to challenges</p>	<ul style="list-style-type: none"> - Individuals with FASD are often referred to as having “significant brain damage” - Terms like “victim,” “suffering,” “damaged child,” and “injured” can further marginalize people with FASD and perpetuate stigma and blame towards parents and family members³⁹ - Stigmatizing terms should be replaced by neutral language 	<p>Replace terms like “brain damage” with “brain-based differences” “challenges,” “concerns,” or “difficulties”</p>	<p>A balance must be found between acknowledging that significant challenges exist for individuals with FASD and their families, and framing these challenges as permanent and unchangeable. This balance is needed to convey an accurate understanding of FASD while also reducing marginalization and building hope for positive outcomes.</p>
<p>Parents, caregivers, and families</p>	<ul style="list-style-type: none"> - Parents, caregivers, and families of individuals with FASD experience multiple layers of stigma and marginalization³⁹⁻⁴¹ - Biological parents of children with FASD face particularly high rates of stigma, and may be further marginalized by the use of harmful language - FASD should not be described as having been “caused by” or “the result of” a mother’s alcohol consumption; rather, describe the challenges simply as being associated with prenatal alcohol exposure 	<p>Replace harmful terms such as “alcoholic mother” with person-first terms such as “woman who use substances”</p>	<p>Stigmatizing language still exists in the FASD literature and serves to further marginalize vulnerable individuals and their families. Person-first, strength-based language should replace outdated and harmful messages about parents, caregivers, and families of those with FASD.</p>
<p>Gender-inclusive language</p>	<p>Not all individuals who give birth to a child with FASD will identify as female. Assumptions and biases about gender identity should be addressed, and gender-inclusive language is needed to acknowledge and respectfully refer to individuals who do not conform to gender normative identities. So as not to erase those who identify as women from this narrative, terms like “women and pregnant people” should be considered.</p>	<p>Adopt gender-neutral terms like “parent” or “birthing parent” for individuals who have given birth to a child with FASD and do not identify as female</p>	<p>Gender-inclusive language is needed to reduce gender bias and promote equality across the gender spectrum for parents of individuals with FASD as well as individuals who have FASD themselves.</p> <p>Limitations</p> <p>There is a significant gap in the research on gender identity issues experienced by individuals with FASD.</p>

LEGAL ISSUES

Question/Issue	Research Tells Us	Take-Away Message	Why This Matters
<p><i>Involvement in the justice system</i></p>	<ul style="list-style-type: none"> - There are high rates of FASD in youth and adult justice settings,^{15,16} and many people with FASD report experiencing legal trouble²⁰ - However, not all individuals with FASD end up in trouble with the law - Media portrayals of FASD in the justice system may perpetuate harmful generalizations about criminality in individuals with FASD⁴² - Individuals with FASD also find themselves involved in civil and family law - Individuals with FASD are also victims of crime <ul style="list-style-type: none"> o FASD and the Criminal Justice System: A Review⁴³ o Victimization in People with FASD⁴⁴ 	<p><i>The challenges and life events experienced by individuals with FASD may lead to increased risk for a range of adverse outcomes, including involvement in the criminal justice system</i></p>	<p>Gaps in services can leave individuals with FASD and their families unsupported, which can lead to negative outcomes such as justice involvement. However, not all individuals with FASD are justice-involved and we must consider the potentially damaging consequences of associating FASD with justice-involvement.</p> <p style="text-align: center;">Limitations</p> <p>FASD is not the only disability present in justice populations – intellectual disability and psychiatric diagnoses as also over-represented. More research and data are needed in corrections and legal systems to better understand individuals with FASD who are justice-involved</p>
<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 individuals with FASD commit more <i>violent</i> crimes than justice-involved individuals without FASD - Several studies suggest that justice-involved individuals with FASD are no more likely to commit violent crimes than justice-involved individuals without FASD, but may be more likely to show a “mixed” pattern of offending, with both violent and non-violent crimes^{45,46} 	<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> <p style="text-align: center;">Limitations</p> <p>The media often reports stories in which people with FASD are involved in <i>violent</i> crimes, giving FASD a violent connotation. We need more information about justice-involvement in FASD to tell the whole story</p>
<p><i>Alternative justice practices</i></p>	<p>There are numerous 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.</p>	<p><i>Alternative justice practices may be promising for working with some justice-involved individuals with FASD, but more research is needed to know</i></p>	<p>The traditional 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 justice practices.</p>

EMERGING RESEARCH

Question/Issue	Research Tells Us	Take-Away Message	Why This Matters
<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 result in FASD, but it has been associated with:⁴⁷</p> <ul style="list-style-type: none"> - Higher levels of maternal alcohol consumption during pregnancy - Lower levels of success in infertility treatments - Lower infant birth weight and gestational age - Higher rates of ventricular malformations and abnormal situs in infants³⁸ <p>For more information:</p> <ul style="list-style-type: none"> - The Role of Partners in Fetal Alcohol Spectrum Disorder Prevention⁴⁸ - Genetic and Epigenetic Perspectives on the Role of Fathers in Fetal Alcohol Spectrum Disorder⁴⁹ 	<p><i>Fathers’ drinking does not <u>result in</u> FASD but it has an important influence on mothers’ consumption and the healthy development of babies</i></p>	<p>Fathers have an important responsibility in supporting partners to stay healthy during pregnancy, and in the long-term health of their children</p> <p style="text-align: center;">Limitations</p> <p>This is a very new area of research, and more studies are needed to understand the role of father’s alcohol consumption in healthy child development.</p>
<p><i>How should the role of the DSM-5’s Neurobehavioral Disorder Associate with Prenatal Alcohol be described in relation to the Canadian Diagnostic Guidelines?</i></p>	<ul style="list-style-type: none"> - The DSM-5 defines ND-PAE as a condition characterized by PAE and impairment in neurocognitive, self-regulation, and adaptive functioning⁵⁰ - It is <i>not</i> a formal diagnosis, but proposed as a “condition for further study” - Researchers recommend a comprehensive assessment conducted by a multi-disciplinary team, regardless of diagnostic approach^{31,51} <p>For more information:</p> <ul style="list-style-type: none"> - Multidisciplinary Team Training for Diagnosis of FASD: An Online Curriculum 	<p><i>We encourage FASD practitioners and clinicians to receive training on the Canadian FASD diagnostic guidelines</i></p>	<p>In Canada, the 2015 Guidelines are primarily used to assess and diagnose individuals with PAE. 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.</p> <p style="text-align: center;">Limitations</p> <p>More research is needed to compare and contrast the different diagnostic systems used across the world.</p>
<p><i>FASD and Autism Spectrum Disorder are often compared</i></p>	<ul style="list-style-type: none"> - FASD and ASD are both neurodevelopmental and spectrum disorders, but their etiologies differ – there is a known cause of FASD, while the cause of ASD is unclear 	<p><i>FASD and ASD are both neurodevelopmental spectrum disorders with some overlapping</i></p>	<p>FASD and ASD share some similarities but they are managed and experienced differently</p> <p style="text-align: center;">Limitations</p>

	<ul style="list-style-type: none"> - Despite some overlapping symptoms (e.g., social and communication difficulties), FASD and ASD have distinct presentations in clinical and daily settings⁵² - Families of individuals with FASD/ASD have different experiences⁵³ 	<i>symptoms, but distinct presentations</i>	Some emerging epigenetic research explores the link between FASD and ASD, but little is known about the association between the two disorders.
<i>Life expectancy and hospitalization</i>	<ul style="list-style-type: none"> - Some researchers have recently reported that individuals with PAE and FASD may experience a reduced life expectancy,⁵⁴ accelerated aging processes,⁵⁵ and increased risk for hospitalization and mortality⁵⁶ - This research is preliminary and should therefore be interpreted with caution 	<i>Individuals with FASD may be at risk for poorer medical outcomes, but these are not guaranteed Access to adequate supports and services can alter long-term trajectories</i>	<p>Fatalistic messaging can increase stigma and hopelessness experienced by individuals with FASD Messages related to life expectancy should be appropriately contextualized and complemented with messages of positive outcomes.</p> <p>Limitations</p> <p>Research in this area is in its infancy, limited geographically, and lacks generalizability.</p>

OTHER ISSUES

Question/Issue	Research Tells Us	Take-Away Message	Why This Matters
<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 age⁵⁷ - Functioning may also be uneven across domains, with high abilities in some areas but not others⁵⁸ - With increasing age, societal expectations of autonomy and independence may be particularly problematic for those with FASD⁵³ 	<i>Although age descriptors can be helpful in describing an individual's situation, moving away from this will better support a strength-based FASD narrative</i>	<p>Individuals with FASD have strengths as well as challenges that should both be taken into consideration to best understand and meet needs.</p> <p>Limitations</p> <p>Focusing solely on developmental age may lead us to neglect the fact that, with support, individuals with FASD continue to develop and achieve success.</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 adulthood⁵⁹ - Researchers have shown that poor social competence and peer rejection can lead to delinquent behaviour in general,⁶⁰ but this has not been explored in FASD - Social psychological vulnerability may be an issue with people with FASD due to their inability understand manipulative ploys and suggestions used by others^{61,62} 	<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).</p> <p>Limitations</p> <p>More research is needed to explore how social pressure can impact individuals with FASD and their care systems.</p>

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