



# COMMON MESSAGES

Guidelines for Talking and Writing About  
FETAL ALCOHOL SPECTRUM DISORDER

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2026

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# INTRODUCTION

## PURPOSE

This document is made to assist those talking and writing about FASD – and related issues – to use the same language, statistics, and framing of topics. The intended outcome, over time, will be an improved understanding by the listener/reader with consistent and respectful FASD messaging. A French version of this guide is also available.



## A NOTE ABOUT OUR PROCESS

This guideline is a “living document” that is collaboratively developed and updated each year by Canada FASD Research Network (CanFASD) researchers, staff, and partners. Annually, we review emerging research in the field to identify new studies that pertain to language use and/or narratives around FASD. When additions are made to the document, we consult with subject matter experts to ensure that our recommendations reflect the most current literature and best practice. We also maintain an ongoing list of topics that arise in conversations between CanFASD staff, researchers, Adult FASD Expert Collaboration Team, Family Advisory Committee, our member community, and partners to capture evolving messaging in the broader FASD community, particularly related to those with living experience.

# KEY COMMUNICATION THEMES

## Here are some overarching recommendations for all messages about FASD:

- Respect, dignity, and inherent human worth should be promoted among individuals with FASD, people who use alcohol during pregnancy, and their families.
- FASD awareness or prevention programs and initiatives should avoid messaging that places blame, shame, or guilt on people who use alcohol during pregnancy and/or on individuals with FASD.
- When using [imagery](#), refrain from using pictures of fetuses, pregnant bellies only (separated from the person's body), and naked pregnant people.
- Fatalistic or deficit-focused terminology should be replaced with person-first, strength-based, and hope-focused language (see the definition on next page).
- When referring to FASD refrain from using terms such as “leading cause”. FASD is a disability and not the cause of one. Prenatal Alcohol Exposure is the cause.
- Instead of saying FASD is “the most common” or “the leading” neurodevelopmental disability, say FASD is “one of the leading” or “one of the most common” neurodevelopmental disabilities.
- 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.



**It is important to remember that a “one-size-fits-all” approach to language and messaging may not apply when talking and writing about FASD. The suggestions in this guide are intended to be inclusive and respectful for all individuals with FASD and their families. However, recognizing the diversity and uniqueness of each person with FASD, we always recommend consulting at an individual level to ensure that language choices are reflective and respectful of each person’s experience.**



# STANDARD DEFINITION

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. CanFASD recommends using the following definition when discussing FASD policy, developing supports, and providing services for individuals with FASD across Canada to promote accurate and consistent language when referring to 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.**

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## TABLE OF CONTENTS

|                                |    |
|--------------------------------|----|
| PREVALENCE & STATISTICS .....  | 2  |
| RESPECTFUL TERMINOLOGY .....   | 6  |
| WHEN DISCUSSING OUTCOMES ..... | 12 |
| LEGAL SYSTEM .....             | 15 |
| EMERGING RESEARCH .....        | 17 |
| <b>REFERENCES</b> .....        | 21 |

# PREVALENCE & STATISTICS

| Question/Issue                                     | Research & Advocacy Work Tell Us                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                              | Take Away Message                                                                                                                                                                               | Why This Matters                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                    |
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| <p><i>How many people have FASD?</i></p>           | <p><b>In Canada</b></p> <ul style="list-style-type: none"> <li>- In the Greater Toronto Area, researchers estimated the prevalence of FASD to be 2-3% among students aged 7-9 years<sup>1</sup></li> <li>- In Alberta, estimates are 1-4% in the general population<sup>2</sup></li> <li>- Teacher-reported prevalence of children <i>diagnosed</i> with FASD in kindergarten ranged from .01 to .22%<sup>3,4</sup></li> </ul> <p><b>In the United States</b></p> <ul style="list-style-type: none"> <li>- Researchers<sup>5-11</sup> have conducted a series of studies with school-aged children in the US, suggesting a conservative estimate of up to 8% in some regions</li> </ul> <p>FASD is often under-recognized and identified, so it is likely that prevalence estimates are conservative.</p> <p>For more information: <a href="#">The Prevalence of FASD</a></p> | <p><i>Researchers currently estimate that at least 4% of individuals in Canada have FASD</i></p> <p><i>This estimate translates to more than 1.6 million Canadians or at least 1 in 25.</i></p> | <p>Research that helps us better understand how many people in Canada may have FASD, as well as in certain 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><b>Limitations</b></p> <p>Limitations in prevalence research make it difficult to know the true rate of FASD in Canada. For example, there may be discrepancies in reporting diagnoses, prenatal alcohol exposure may be under-reported due to stigma and fear of judgment, and individual difficulties may not emerge until school years or later. Additional limitations include small study samples, unique settings, use of different methodologies, voluntary participation, and estimating the numbers using pre-existing data. Most prevalence studies have been done with children. Estimates vary widely depending on the study approach, population, and location.</p> |
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| <p><i>Rates of FASD in certain populations</i></p> | <p><b>Children in Care</b><sup>12,13</sup></p> <ul style="list-style-type: none"> <li>- <i>Canada</i>: up to 11%</li> <li>- <i>International</i>: more than 20%</li> </ul> <p><b>Criminal Legal System</b><sup>14-18</sup></p> <ul style="list-style-type: none"> <li>- <i>Canada</i>: 10-23% in youth and 18-46% in adult settings</li> <li>- <i>International</i>: 36% in Australia</li> </ul> <p>For more information: <a href="#">FASD Prevalence in Special Populations</a></p>                                                                                                                                                                                                                                                                                                                                                                                          | <p><i>Researchers suggest that FASD is more common in certain populations, including those involved in the child welfare and criminal legal systems</i></p>                                     | <p>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>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                          |
|                                                    |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                               |                                                                                                                                                                                                 | <p><b>Limitations</b></p> <p>Research in this area is limited and it is believed that there are higher rates of undiagnosed FASD in other populations.</p>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                          |
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| Question/Issue                                                 | Research & Advocacy Work Tell Us                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                               | Take Away Message                                                                                                                                                                                                                                                                                                                  | Why This Matters                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                         |
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| <p><i>How much alcohol is “too much” during pregnancy?</i></p> | <ul style="list-style-type: none"> <li>- Despite extensive research, there has been no established safe level of alcohol to consume during pregnancy</li> <li>- Alcohol is a neurotoxic and teratogenic substance, which means that it influences fetal development when consumed at any time during pregnancy</li> <li>- Even “low” levels of prenatal alcohol exposure have been shown to have negative effects on long-term development<sup>19,20</sup></li> <li>- Researchers and clinical experts in maternal and fetal health recommend that <b>no alcohol is best</b></li> </ul> <p>For more information:</p> <ul style="list-style-type: none"> <li>- <a href="#">Why do some women drink alcohol during pregnancy?</a></li> <li>- <a href="#">The Prevalence of Alcohol Use During Pregnancy in Canada</a></li> </ul>                                                                                                 | <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 alcohol use during pregnancy</i></p> <p><i>It is safest not to drink during pregnancy or when trying to conceive</i></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. It is safest for people of child-bearing age who are consuming alcohol to use birth control to prevent an unplanned, alcohol exposed pregnancy.</p>                                                                                                                                                                                                              |
|                                                                |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                |                                                                                                                                                                                                                                                                                                                                    | <p><b>Limitations</b></p>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                |
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| <p><i>FASD, mental health, and substance use</i></p>           | <ul style="list-style-type: none"> <li>- An estimated 90% of people with FASD experience co-occurring mental health needs<sup>21-23</sup></li> <li>- Some of the most common mental health and neurodevelopmental diagnoses among people with FASD are ADHD, intellectual disability, learning disorder, oppositional defiant disorder, conduct disorder, depressive and anxiety disorders, substance use, and risk of suicide<sup>24</sup></li> <li>- Substance use has been reported in ~22-80% of adolescents/adults with FASD<sup>25,26</sup></li> <li>- An estimated 26% of people with FASD experience past or present suicidal thoughts and behaviours; substance use, trauma, and depression/anxiety are associated with a higher risk of suicidality<sup>27</sup></li> <li>- There is a significant gap in the research on mental health and substance use interventions for people with FASD<sup>28</sup></li> </ul> | <p><i>When unsupported, people with FASD may be more likely to experience mental health and substance use difficulties</i></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>                                                                                                                                                                                                                                                                                                                                                                           |
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|                                                                |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                |                                                                                                                                                                                                                                                                                                                                    | <p>More research is needed to better understand and address challenges with mental health/substance use for individuals with FASD across the lifespan. In addition, research designed to understand people with FASD who <i>do not</i> experience mental health/substance use challenges or are managing these needs can provide information about what supports, or protective factors may be important.</p>                                                                                                                            |

| Question/Issue                               | Research & Advocacy Work Tell Us                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                     | Take Away Message                                                                                                                                                                                                                                                                                                              | Why This Matters                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                            |
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| <p><i>Social and economic investment</i></p> | <p>FASD has been associated with high social and economic investment:</p> <ul style="list-style-type: none"> <li>- In <b>Alberta</b>:<sup>29</sup> <ul style="list-style-type: none"> <li>○ Long-term economic investment of \$130-400 million/year (predicted number of children born each year)</li> <li>○ Short-term economic investment of \$48-143 million/year (individuals with FASD)</li> </ul> </li> <li>- In <b>Canada</b>:<sup>30-32</sup> <ul style="list-style-type: none"> <li>○ Investment for supporting those aged 0 to 53 with FASD is \$5.3 billion/year</li> <li>○ \$1.8 billion for health care, corrections, other direct/indirect costs</li> <li>○ Total investment \$9.7 billion/year</li> </ul> </li> </ul> | <p><i>Significant and increased social and economic investment is needed to support adequate resources and services to address prevention, intervention, and diagnosis, and foster healthy outcomes for people with FASD and their families</i></p> <p><i>Replace terms such as “cost” and “burden” with: “investment”</i></p> | <p>There is conflicting evidence about true total financial investments associated with FASD, and caution should be taken against framing the disability as a burden, which can stigmatize people affected by the disability.</p>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                           |
|                                              |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                      |                                                                                                                                                                                                                                                                                                                                | <p><b>Limitations</b></p>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                   |
|                                              |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                      |                                                                                                                                                                                                                                                                                                                                | <ul style="list-style-type: none"> <li>- Emphasis on the financial investment associated with FASD can perpetuate the stigma experienced by individuals with FASD and their families.</li> <li>- Many studies reflect different financial impacts in society depending on what systems they measure (e.g., medical, education, social services, corrections, prevention/research, productivity loss)</li> <li>- Other social impacts are not measurable (e.g., productivity losses for parents, stress/guilt of mothers)</li> <li>- We do not know how social and economic investments may be impacted when individuals with FASD and their families receive the services and supports they need</li> <li>- Very little research has been done outside of Canada</li> </ul> |

# RESPECTFUL TERMINOLOGY

| Question/Issue                                                                                      | Research Tells Us                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                      | Say This                                                                                                                                                                                                                                                                                           | Why This Matters                                                                                                                                                                                                                                                                                                                          |
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| <i><b>“Invisible or hidden disability”</b></i>                                                      | FASD has commonly been referred to as an “invisible or hidden” disability because most people (around 90%) with FASD have no <i>physical</i> signs of impairment. However, using these terms can make individuals with FASD feel their disability is something they need to hide. Using the term FASD specifically or using the term disability on its own is less stigmatizing.                                                                                                                                                                                       | <i><b>Use the term disability as a stand alone or disability/FASD with no physical signs</b></i>                                                                                                                                                                                                   | The use of the terms “invisible or hidden” can invalidate and stigmatize people with FASD and their families. However, many individuals with living experience choose to refer to FASD as an “invisible” disability. Respect should be given to how people with living experience choose to describe their own lives and disability.      |
| <i><b>“Disease,” “disorder,” “disability,” “syndrome,” and “condition” used interchangeably</b></i> | Canadian diagnosticians have moved away from using the term “syndrome” and now use the term “disorder” to refer to FASD. <sup>33</sup>                                                                                                                                                                                                                                                                                                                                                                                                                                 | <i><b>Replace “disease” and “syndrome” with “disorder” or “disability”</b></i>                                                                                                                                                                                                                     | Adoption of the terms “disorder” or “disability” better reflects FASD as a spectrum and will ensure consistent language and clinical understanding.                                                                                                                                                                                       |
| <i><b>“Secondary disabilities”</b></i>                                                              | <p>Adolescents and adults with FASD can experience high rates of difficulties in daily living and adverse outcomes, including:<sup>26,34,35</sup></p> <ul style="list-style-type: none"> <li>- School disruption</li> <li>- Independent living needs</li> <li>- Mental health issues</li> <li>- Substance use challenges</li> <li>- Challenges with independence</li> <li>- Employment difficulties</li> <li>- Housing instability</li> <li>- Interaction with the legal system</li> <li>- Institutionalization in psychiatric or correctional institutions</li> </ul> | <p><i><b>Replace “secondary disabilities” with:</b></i></p> <p><i><b>“adverse outcomes”</b></i></p> <p><i><b>“difficulties in daily living”</b></i></p> <p><i><b>“impacts”</b></i></p> <p><i><b>“associated difficulties”</b></i></p> <p><i><b>or</b></i></p> <p><i><b>“areas of need”</b></i></p> | Use of the term “secondary” may insinuate that these difficulties are not as prominent or important as the brain- and body-based differences associated with FASD. Comments about adverse outcomes in FASD should also be considered alongside success and possibility, so as not to bias or limit expectations around life trajectories. |
|                                                                                                     |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                        |                                                                                                                                                                                                                                                                                                    | <p><b>Limitations</b></p> <p>Many of the challenges described in the literature are not biologically-driven or “disabilities” per se, and are not specific to FASD alone.</p>                                                                                                                                                             |

| Question/Issue                                                                                                                                       | Research Tells Us                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                            | Say This                                                                                                                                                                                                                                                           | Why This Matters                                                                                                                                                                                                       |
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| <p><i>Speaking respectfully about FASD within Indigenous* populations</i></p> <p><i>FASD is often still viewed as only an “Indigenous issue”</i></p> | <ul style="list-style-type: none"> <li>- FASD affects people of all cultural, ethnic, and socioeconomic backgrounds</li> <li>- Canadian discourse in the 1980s and 1990s perpetuated the stereotype that FASD was an “<i>Indigenous issue</i>”<sup>36</sup></li> <li>- Indigenous women and communities have been continuously subjected to stigma, stereotyping, and surveillance<sup>37,38</sup></li> <li>- The Canadian Truth and Reconciliation Recommendations identified FASD in calls to action #33 and #34</li> <li>- CanFASD along with other groups are working to develop strategies and commitments to address these recommendations: <ul style="list-style-type: none"> <li>o <a href="#">Developing an Indigenous Approach to FASD Prevention</a></li> <li>o TRC <a href="#">Call to Action 34: A Framework for Action</a></li> <li>o CanFASD <a href="#">Commitment to Indigenous Partnership, Reconciliatory Research, and Action</a></li> </ul> </li> </ul> | <p><i>All populations where alcohol is used are at risk for FASD.</i></p> <p><i>Emphasis should be moved away from specific groups of people and placed on the broader contexts and conditions in which risk for alcohol use during pregnancy is elevated.</i></p> | <p><b>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.</b></p> |
|                                                                                                                                                      |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                              |                                                                                                                                                                                                                                                                    | <p><b>Limitations</b></p> <p>There is a lack of consistent and high-quality research comparing rates of FASD among diverse populations and groups.</p>                                                                 |
| <p><i>Living and Lived Experience(s) of FASD</i></p>                                                                                                 | <ul style="list-style-type: none"> <li>- When describing lived experiences of FASD the terms “in-home” and “in-body” can be used to distinguish the experiences of people who live with an individual who has FASD such as a partner, a caregiver, other family member, etc. (i.e., “in-home” lived experience) and those who have FASD (i.e., “in-body” lived experience)</li> <li>- Engaging meaningfully with people with in-body and in-home lived experience in all FASD research, policy, and practice allows for the knowledge and voices of those most impacted to be highlighted.<sup>48</sup></li> <li>- Involving the perspectives of people with in-home living experiences of providing support, advocacy, and mentoring to people with FASD, as well as the experiential wisdom of people with in-body lived experience, will help to keep research real, impactful, meaningful, and practical<sup>39</sup></li> </ul>                                         | <p><i>Consider using the terms “in-body” and “in-home” to specify people with living experience.</i></p>                                                                                                                                                           | <p><b>Using these terms may help to distinguish the unique experiences of people with FASD and those with experiences of caregiving or supporting someone with FASD.</b></p>                                           |
| <p><i>“Suspected FASD”</i></p>                                                                                                                       | <p>For some people, the word “suspected” may connote associations with criminal legal involvement.</p>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                       | <p><i>Replace the term “suspected FASD” with “possible FASD” or someone who “may have FASD”</i></p>                                                                                                                                                                | <p><b>Using the term “suspected FASD” may add to the misperception that FASD is linked to criminal offending and may further stigmatize individuals with FASD.</b></p>                                                 |

\* In 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.

| Question/Issue                                    | Research Tells Us                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                           | Say This                                                                                                                                                                                                                                                                       | Why This Matters                                                                                                                                                                                                                                                                                                                         |
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| <i>Use of the term “damaged”</i>                  | <ul style="list-style-type: none"> <li>- Individuals with FASD are often referred to as having “significant brain damage”</li> <li>- Terms like “victim,” “suffering,” “damaged child,” and “injured” can further marginalize people with FASD and perpetuate stigma and blame towards parents and family members<sup>40</sup></li> <li>- Using terms like “external brain” can further stigmatize and imply that people with FASD do not have a brain</li> </ul>                                                                                                                                                                                                                                                                                                                           | <p><i>Replace terms like “<b>brain damage</b>” with “<b>brain-based differences</b>” “<b>challenges</b>,” “<b>concerns</b>,” “<b>needs</b>” or “<b>difficulties</b>”</i></p>                                                                                                   | A balance must be found between acknowledging significant challenges that exist for individuals with FASD and their families and framing these challenges as permanent and unmalleable. This balance is needed to convey an accurate understanding of FASD while also reducing marginalization and building hope for healthier outcomes. |
| <i>“Won’t” vs “Can’t” vs “How?”</i>               | <ul style="list-style-type: none"> <li>- There has been a gradual shift from understanding FASD-related learning and behavioural difficulties as willful (i.e., a person ‘<i>won’t</i>’) to understanding these difficulties as resulting from the brain-based impacts of FASD (i.e., a person ‘<i>can’t</i>’).</li> <li>- However, asserting that people with FASD “can’t” contributes to negative stereotypes and expectations, and may perpetuate feelings of hopelessness, self-fulfilling prophecies, and inadequate support.<sup>41</sup></li> <li>- Researchers and advocates encourage a continued evolution of this narrative, replacing “can’t” with “how?” That is, <i>how</i> might service providers and others support success with people with FASD?<sup>42</sup></li> </ul> | <p><i>Replace terms like “<b>won’t</b>” and “<b>can’t</b>” with “<b>how?</b>”</i></p>                                                                                                                                                                                          | Building on the evolving narrative of “won’t” to “can’t” to “how?” we can reframe our understanding and approaches to intervention and support to better identify ways of facilitating growth and wellbeing for people with FASD.                                                                                                        |
| <i>Blame on parents, caregivers, and families</i> | <ul style="list-style-type: none"> <li>- Parents, caregivers, and families of individuals with FASD experience multiple layers of stigma and marginalization<sup>40,41,43,44</sup></li> <li>- Biological parents of children with FASD face particularly high rates of stigma, and may be further marginalized by the use of harmful language</li> <li>- 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</li> </ul> <p>For more information:</p> <ul style="list-style-type: none"> <li>- <a href="#">FASD Media Guide</a></li> <li>- <a href="#">Mothers' Experiences of Stigma</a></li> </ul>                                        | <p><i>Replace stigmatizing terms such as “<b>alcoholic mother</b>” with person-first terms such as “<b>birth mother, or parent who use(d) substances during pregnancy</b>”</i></p> <p><i>When referring to prenatal alcohol exposure avoid language that places blame.</i></p> | Stigmatizing language still exists in the FASD literature and serves to further marginalize equity seeking individuals and their families. Person-first, strength-based language should replace outdated and harmful messages about parents, caregivers, and families of those with FASD.                                                |

| Question/Issue                          | Research Tells Us                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                       | Say This                                                                                                                                                                                                                                                                                | Why This Matters                                                                                                                                                                                                                                                                                                                                                                                 |
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| <p><i>Gender-inclusive language</i></p> | <ul style="list-style-type: none"> <li>- Not all individuals who give birth to a child with FASD will identify as women. In interactions with those who are pregnant, <b>it is important to ask about how they identify their gender and respectfully refer to them using their pronouns.</b></li> <li>- To be inclusive, clear, and respectful of how all people wish to be referred to, gender additive terms such as “pregnant women and gender diverse individuals” may be considered. When writing generally about those who are pregnant, gender-neutral language such as “pregnant people” and “birthing parent” may also be considered.</li> <li>- At the same time, it is important for some women to be referred to as women or mothers. And for some people, the gender-neutral terms such as “pregnant person” lacks clarity and may be understood to refer to the birth partner not only the pregnant woman.</li> <li>- In many Indigenous cultures “mother” and “mothering” often have particular importance as roles and may be important to use.</li> <li>- To be inclusive and avoid “othering,” consult people with lived experience as to what language is appropriate for them.</li> </ul> <p>For more information: <a href="#">Sexual Orientation, Gender Identity, Gender Expression, and Fetal Alcohol Spectrum Disorder</a></p> | <p><i>To be inclusive of individuals who have conceived or given birth to a child with FASD and do not identify as women, when writing about FASD and PAE consider the use of terms such as “birthing parent(s)” or “women and gender diverse individuals who have given birth”</i></p> | <p><b>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.</b></p>                                                                                                                                                                                    |
|                                         |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                         |                                                                                                                                                                                                                                                                                         | <p><b>Limitations</b></p> <p>There is a significant gap in the research on gender identity among individuals with FASD, and among people who have given birth to a child with FASD. It is important that individuals see themselves reflected in the language we use, including in research, and to ask people directly how they want to be referred to and be respectful of their identity.</p> |
| <p><i>Prevention language</i></p>       | <ul style="list-style-type: none"> <li>- Using terminology such as “FASD prevention” or “prevention of FASD” may be received in some spaces as being stigmatizing and may cause individuals with the disability to feel as though they, as people, should be prevented.</li> <li>- We acknowledge the importance of the concept of prevention in the context of FASD and emphasize that this work is not about preventing people with FASD from existing, but rather about supporting women and gender diverse people to avoid or reduce their alcohol use during pregnancy.</li> <li>- FASD prevention encompasses many <a href="#">fundamental components</a> including respect, women+ centred, harm reduction oriented, trauma and violence informed, culturally safe, and using an FASD-informed and disability-informed lens that remains respectful of people with living experience.</li> </ul>                                                                                                                                                                                                                                                                                                                                                                                                                                                 | <p><i>Focus on the prevention of alcohol use during pregnancy rather than the prevention of the disability.</i></p>                                                                                                                                                                     |                                                                                                                                                                                                                                                                                                                                                                                                  |

| Question/Issue                       | Research Tells Us                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                      | Say This                                                   | Why This Matters                                                                                                                         |
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| <i>Use of the term “stakeholder”</i> | <p>The term ‘stakeholder’ is often used to describe groups of people who are responsible for or affected by health-related decisions. These groups may include patients, members of the public, care providers, and/or policy makers. However, the term ‘stakeholder’ has colonial connotations, referring to a stake driven into the ground to claim land. Because of this connotation, it is suggested that the term be replaced with ‘interest-holder’. Using this new term shifts the focus away from ownership to having legitimate interests and impacts.</p> <p>For more information: <a href="#">“Interest-holders”: A new term to replace “stakeholders” in the context of health research and policy</a></p> | <p><i>Replace “stakeholder” with “interest-holder”</i></p> | <p>Using terminology that accurately describes the groups related to research and decision making conveys an equitable relationship.</p> |

# WHEN DISCUSSING OUTCOMES

| Question/Issue                                      | Research and Advocacy Efforts Tells Us                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                       | Take-Away Message                                                                                                                                                                                                                                                                                                   | Why This Matters                                                                                                                                                                                                                                                                                                            |
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| <i>Strength-based language and healthy outcomes</i> | <ul style="list-style-type: none"> <li>Although people with FASD may experience many challenges, they also possess diverse strengths, abilities, and potential<sup>45,46</sup> <ul style="list-style-type: none"> <li><a href="#">Strengths Among Individuals with FASD</a></li> </ul> </li> <li>Considering the <i>whole</i> person, including strengths, difficulties, as well as interests and preferences is important for building a balanced and human-centered understanding and supports</li> <li>FASD-informed practice includes FASD awareness, safe relationships, and working from a person-centered and strength-based approach<sup>46,47</sup></li> </ul>                                                                                                                                      | <p><i>People with FASD are all unique and have many strengths.</i></p> <p><i>A balanced approach in working with people with FASD that incorporates supports or adaptations is important.</i></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 healthy outcomes.</p>                                                               |
|                                                     |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                              |                                                                                                                                                                                                                                                                                                                     | <p><b>Limitations</b></p>                                                                                                                                                                                                                                                                                                   |
|                                                     |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                              |                                                                                                                                                                                                                                                                                                                     | <p>Most of the literature on FASD is deficits-based, and there is a critical need for more research focused on strengths.</p>                                                                                                                                                                                               |
| <i>FASD as a permanent disability</i>               | <ul style="list-style-type: none"> <li>There is no “cure” for FASD, but early intervention and stable home environments are significant protective factors against later life adversity<sup>34</sup></li> <li>We have moved away from the medical model (the belief that disabilities should be “corrected”) to recognize that individuals with FASD may develop differently but they still develop</li> </ul> <p>Use of the word “treatment”, “cure”, or “healing” without context and caution can imply that the effects of FASD are reversible, and that supports should be removed once an individual with FASD is coping well or thriving</p>                                                                                                                                                           | <p><i>There is good evidence that early and appropriate support can improve outcomes for people with FASD.</i></p> <p><i>Varying levels of supports may be needed across the lifespan, and services should not be removed when a person with FASD is doing well.</i></p>                                            | <p>FASD is a life-long, whole-body disorder, but early identification and intervention can foster healthy 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 can be important and beneficial.</p>                       |
| <i>Life expectancy and hospitalization</i>          | <ul style="list-style-type: none"> <li>Researchers in a small number of studies have reported that individuals with PAE and FASD may experience a reduced life expectancy,<sup>48</sup> accelerated aging processes,<sup>49</sup> and increased risk for hospitalization<sup>50,51</sup> and mortality<sup>52</sup></li> <li>This research is preliminary and should therefore be interpreted with extreme caution</li> <li>There may be some factors that can lead to an earlier death when people with FASD are unsupported (i.e., trauma, comorbid mental health and substance use challenges, psychological experiences, etc.). This issue is very ecological in nature and context is important to fully understand the relationship between FASD, life experiences, and access to supports.</li> </ul> | <p><i>Individuals with FASD may be at risk for poorer medical outcomes, but these are not foregone conclusions.</i></p> <p><i>Access to adequate supports and services can alter long-term trajectories and support healthy outcomes.</i></p> <p><i>There is no known life expectancy for people with FASD.</i></p> | <p>Fatalistic messaging can increase stigma and hopelessness for individuals with FASD. Messages related to life expectancy should be appropriately contextualized and accompanied by messages of healthy outcomes. It is recommended to stop using a life expectancy number when reporting about FASD and early death.</p> |
|                                                     |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                              |                                                                                                                                                                                                                                                                                                                     | <p><b>Limitations</b></p>                                                                                                                                                                                                                                                                                                   |
|                                                     |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                              |                                                                                                                                                                                                                                                                                                                     | <p>Research in this area is in its infancy, limited geographically, and lacks generalizability.</p>                                                                                                                                                                                                                         |

| Question/Issue         | Research and Advocacy Efforts Tells Us                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                             | Take-Away Message                                                                                                                                                                                                                                                       | Why This Matters                                                                                                                                                                                                                                                                                                                |
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| <i>Interdependence</i> | <ul style="list-style-type: none"><li>- Whereas <i>independence</i> is the idea that we should be able to do everything on our own, <b><i>interdependence</i></b> is the notion that we all rely on one another, and there is a spectrum within which we access support to navigate different elements of functioning.</li><li>- We are all interdependent to some extent and it is important to normalize this truth, and find the appropriate level of interdependence on an individual basis, which may differ between people and tasks.<sup>42</sup></li><li>- Priorities for and levels of interdependence can differ depending on an individual’s values, perspectives, abilities, and needs as well as a person’s family or cultural values.</li><li>- It is important that when people with FASD begin to thrive within networks of interdependence, supports not be taken away.</li></ul> | <i>Consider replacing the idea of “independence” with the concept of “interdependence,” whereby all individuals, regardless of ability, rely on people and systems to varying degrees, and that interdependence can mean different things to each person with FASD.</i> | Interdependence is a reasonable and achievable goal for all people with FASD. Recognizing this goal while understanding that interdependence will look different for all people is important. Needs around interdependence should be considered throughout the lifespan, and maintained even when an individual is living well. |
|                        |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                    |                                                                                                                                                                                                                                                                         | Limitations                                                                                                                                                                                                                                                                                                                     |
|                        |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                    |                                                                                                                                                                                                                                                                         | Additional research is needed to explore needs and priorities around interdependence and how best to support people with FASD throughout their lifespan.                                                                                                                                                                        |



LEGAL SYSTEM

| Question/Issue                         | Research Tells Us                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                | Take-Away Message                                                                                                                                                                                        | Why This Matters                                                                                                                                                                                                                                                                                                                                                 |
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| <i>Involvement in the legal system</i> | <ul style="list-style-type: none"> <li>- There are high rates of FASD in youth and adult criminal legal settings,<sup>16,17</sup> and many people with FASD report experiencing trouble with the law as victims, witnesses, and those who offend<sup>26,34</sup></li> <li>- Individuals with FASD also find themselves involved in civil and family law</li> <li>- It is important to remember that <b>not all individuals with FASD end up in trouble with the law</b><sup>53,54</sup></li> </ul> <p>For more information:</p> <ul style="list-style-type: none"> <li>- <a href="#">FASD and the Criminal Legal System</a></li> <li>- <a href="#">Victimization in People with FASD</a></li> </ul>                                                                                                                                                                              | <p><i>The challenges and life events experienced by individuals with FASD may lead to increased risk for a range of adverse outcomes when unsupported, including involvement in the legal system</i></p> | Gaps in services can leave individuals with FASD and their families unsupported, which <i>can</i> lead to negative outcomes such as legal system involvement. However, not all individuals with FASD are legally-involved and we must consider the potentially damaging consequences of associating FASD with legal-involvement.                                 |
|                                        |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                  |                                                                                                                                                                                                          | Limitations                                                                                                                                                                                                                                                                                                                                                      |
|                                        |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                  |                                                                                                                                                                                                          | FASD is not the only disability over-represented in criminal legal contexts– there are also high rates of intellectual disability and psychiatric diagnoses in both youth and adult settings.. More research and data are needed to better understand the prevalence, support needs, and outcomes of individuals with FASD who are involved in the legal system. |
| <i>Portrayal of FASD in the media</i>  | <ul style="list-style-type: none"> <li>- Media portrayals of FASD in the justice system may perpetuate harmful generalizations about criminality in individuals with FASD<sup>41</sup></li> <li>- Several studies suggest that individuals with FASD involved in the criminal legal system are <i>no more likely</i> to commit violent crimes than individuals without FASD, but may be more likely to show a “mixed” pattern of offending, with both violent and non-violent crimes<sup>55,56</sup></li> </ul> <p>For more information:</p> <ul style="list-style-type: none"> <li>- <a href="#">Representation Matters: race, Gender, Class, and Intersectional Representations of Autistic and Disabled Characters on Television</a></li> <li>- <a href="#">Media portrayals of alcohol use in pregnancy and fetal alcohol spectrum disorder: A scoping review</a></li> </ul> | <p><i>There is no consistent pattern of criminal behaviour that has been identified for individuals with FASD involved in the criminal legal system.</i></p>                                             | Media portrayals of violent crime and FASD tend to be sensationalized and can serve to misrepresent individuals with FASD involved in the criminal legal system.                                                                                                                                                                                                 |
|                                        |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                  |                                                                                                                                                                                                          | Limitations                                                                                                                                                                                                                                                                                                                                                      |
|                                        |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                  |                                                                                                                                                                                                          | 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 legal involvement in FASD to tell the whole story.                                                                                                                                            |
| <i>Alternative justice practices</i>   | <p>There are numerous initiatives across the country to better address FASD in the legal system (e.g., restorative justice, diversion programs, FASD courts, conditional or alternative sentencing, mental health courts) but very little research has been done to examine long term outcomes of such programs. For more information:</p> <ul style="list-style-type: none"> <li>- <a href="#">Restorative Justice Practices with Adult Offenders with FASD</a></li> </ul>                                                                                                                                                                                                                                                                                                                                                                                                      | <p><i>Alternative practices <u>may</u> be promising for working with some individuals with FASD involved in the legal system, but more research is needed.</i></p>                                       | The traditional legal system is not adequately set up to support individuals with FASD involved in the legal system. More research is needed to assess the long-term impact of alternative justice practices for people with FASD.                                                                                                                               |



EMERGING RESEARCH

| Question/Issue                                                                                                            | Research Tells Us                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                      | Take-Away Message                                                                                                                                                   | Why This Matters                                                                                                                                                                                                                                                                                                                |
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| <b><i>The role of men and fathers in FASD</i></b>                                                                         | <p>There is very little research on the connection between FASD and alcohol consumption by male partners (or gender diverse partners who can contribute to conceptions) during the preconception or prenatal period). However, male/gender-diverse partner alcohol consumption has been associated with:<sup>57,58</sup></p> <ul style="list-style-type: none"> <li>- Higher levels of maternal alcohol consumption during pregnancy</li> <li>- Lower levels of success in infertility treatments</li> <li>- Lower infant birth weight and gestational age</li> <li>- Higher rates of ventricle malformations and abnormal situs in infants</li> </ul> <p>For more information:</p> <ul style="list-style-type: none"> <li>- <a href="#">The Role of Partners in Fetal Alcohol Spectrum Disorder Prevention</a></li> <li>- <a href="#">Genetic and Epigenetic Perspectives on the Role of Fathers in Fetal Alcohol Spectrum Disorder</a></li> <li>- <a href="#">Maternal and Paternal Risk Factors for FASD</a><sup>59</sup></li> <li>- <a href="#">Does Paternal Alcohol Consumption Affect the Severity of Traits of Fetal Alcohol Spectrum Disorders</a></li> </ul> | <p><b><i>Fathers’ drinking does not result in FASD, but it has an important influence on mothers’ consumption and healthy infant and child development.</i></b></p> | <p><b>Fathers and all partners have an important responsibility in supporting their pregnant partners to stay healthy during pregnancy, and in the long-term health of their children</b></p>                                                                                                                                   |
|                                                                                                                           |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                        |                                                                                                                                                                     | <p><b>Limitations</b></p>                                                                                                                                                                                                                                                                                                       |
|                                                                                                                           |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                        |                                                                                                                                                                     | <p>This is a very new area of research, and more studies are needed to understand the role of fathers’ alcohol consumption in healthy child development.</p>                                                                                                                                                                    |
| <b><i>How should the role of the DSM-5-TR’s ND-PAE be described in relation to the Canadian Diagnostic Guideline?</i></b> | <ul style="list-style-type: none"> <li>- The Diagnostic and Statistical Manual of Mental Disorders defines ND-PAE as a condition characterized by PAE and impairment in neurocognitive, self-regulation, and adaptive functioning<sup>60</sup></li> <li>- It is <i>not</i> a formal diagnosis, but proposed as a “condition for further study”</li> <li>- Researchers recommend a comprehensive assessment conducted by a multidisciplinary team, regardless of diagnostic approach<sup>33,61</sup></li> </ul> <p>For more information:</p> <ul style="list-style-type: none"> <li>- <a href="#">Multidisciplinary Team Training for Diagnosis of FASD: An Online Curriculum</a></li> </ul>                                                                                                                                                                                                                                                                                                                                                                                                                                                                            | <p><b><i>We encourage practitioners and clinicians working with individuals with PAE to receive training on the 2015 Canadian FASD diagnostic guideline</i></b></p> | <p><b>In Canada, the 2015 FASD Diagnostic Guideline is primarily used to assess and diagnose individuals with PAE. The Canadian Guideline supports a multidisciplinary approach to diagnosis which is important for a full understanding of the neurocognitive impairments and the required interventions and supports.</b></p> |
|                                                                                                                           |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                        |                                                                                                                                                                     | <p><b>Limitations</b></p>                                                                                                                                                                                                                                                                                                       |
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| <b><i>Breastfeeding and FASD</i></b>                                                                                      | <ul style="list-style-type: none"> <li>- Based on preliminary research the effects of alcohol consumption when breastfeeding is unknown which means the safest amount to drink while breastfeeding is no alcohol.</li> </ul> <p>For more information:</p> <ul style="list-style-type: none"> <li>- <a href="#">Alcohol and Breastfeeding</a></li> </ul>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                | <p><b><i>It is safest not to drink while breastfeeding.</i></b></p>                                                                                                 | <p>Research in this area is in its infancy, limited geographically, and lacks generalizability.</p>                                                                                                                                                                                                                             |

| Question/Issue                                 | Research Tells Us                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                             | Take-Away Message                                                                                                                                                                                                                                                                                      | Why This Matters                                                                                                                                                                                                                                                                                     |
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| <i>FASD and autism</i>                         | <ul style="list-style-type: none"> <li>- FASD and autism are both neurodevelopmental and spectrum disorders, but their etiologies differ – there are known causes of FASD, while the cause of autism is unclear</li> <li>- Despite some overlapping symptoms (e.g., social and communication difficulties), FASD and autism have distinct presentations in clinical and daily settings<sup>62</sup></li> <li>- Families of individuals with FASD and autism have different experiences<sup>63</sup></li> <li>- FASD is at least two times more common than autism</li> </ul> <p>For more information: <a href="#">Autism Spectrum Disorder and Fetal Alcohol Spectrum Disorder: A Literature Review</a></p>                                                                                                                   | <p><i>FASD and autism are both neurodevelopmental spectrum disorders with some overlapping symptoms, but distinct causes, presentations, and best practices</i></p>                                                                                                                                    | <b>FASD and autism share some similarities, but they are experienced differently by individuals and families.</b>                                                                                                                                                                                    |
|                                                |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                               |                                                                                                                                                                                                                                                                                                        | <b>Limitations</b>                                                                                                                                                                                                                                                                                   |
|                                                |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                               |                                                                                                                                                                                                                                                                                                        | Some emerging epigenetic research explores the link between FASD and autism, but little is known about the association between the two disorders.                                                                                                                                                    |
| <i>Developmental age vs. chronological age</i> | <ul style="list-style-type: none"> <li>- People with FASD may have needs associated with younger levels than their chronological age<sup>52</sup></li> <li>- Functioning may also be uneven across domains, with limited abilities in some areas but typical or advanced abilities in others</li> <li>- With increasing age, societal expectations of autonomy and independence may be particularly challenging for those with FASD<sup>42</sup></li> </ul>                                                                                                                                                                                                                                                                                                                                                                   | <p><i>Although age descriptors can be helpful in describing an individuals' situation and needs, moving away from this framing will better support a strength-based narrative of FASD.</i></p>                                                                                                         | <b>Individuals with FASD have strengths, challenges, and interests that should all be taken into consideration to best understand and meet their individual needs.</b>                                                                                                                               |
|                                                |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                               |                                                                                                                                                                                                                                                                                                        | <b>Limitations</b>                                                                                                                                                                                                                                                                                   |
|                                                |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                               |                                                                                                                                                                                                                                                                                                        | Focusing solely on developmental age may lead us to neglect the fact that, with support, individuals with FASD continue to develop and achieve success.                                                                                                                                              |
| <i>Neurodiversity</i>                          | <ul style="list-style-type: none"> <li>- At its core, neurodiversity is a concept that represents the wide variety of differences among humanity.</li> <li>- Neurodiversity is a concept encompassing both individual level (i.e., identity) as well as systemic level (i.e., political movement) considerations. It is a relatively new phenomenon and as such a clear definition and understanding of neurodiversity is not currently shared.</li> <li>- The concept of neurodiversity does not disregard the uniqueness of individuals with FASD. The terms neurodiversity and FASD are not interchangeable, but each term is valuable.</li> <li>- It is important to respect how individual people wish to be identified and referred to.</li> </ul> <p>For more information: <a href="#">Neurodiversity and FASD</a></p> | <p><i>The concept of neurodiversity does not disregard the uniqueness of individuals with FASD. People may identify as having FASD, and/or as being neurodivergent, and/or both. People may find different labels preferable in different spaces, especially given the stigma attached to FASD</i></p> | <b>Neurodiversity as a concept for both individual identity and a social movement has received increased attention. Understanding where FASD fits into this framing is an important continued consideration. It is always important to respect how people wish to be identified and referred to.</b> |
|                                                |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                               |                                                                                                                                                                                                                                                                                                        | <b>Limitations</b>                                                                                                                                                                                                                                                                                   |
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