



STATEMENT

Why FASD is an essential diagnostic term: Response to the Lancet Article

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The Canada FASD Research Network, CanFASD, feels compelled to make an official statement on the recent opinion published in the [Lancet by Eliason et al.](#), calling for urgent “international attention to address the harms of using Fetal Alcohol Spectrum Disorder (FASD) as a diagnostic term.” As the first and only comprehensive FASD research network in Canada, we are seen as a national voice for FASD. We bring together scientific evidence and amplify the voices of individuals and families with living experience. Collectively, we are surprised and troubled by the views and opinions expressed in this paper which are not evidence-based and have caused concern among clinicians, individuals with FASD, families, and researchers. To be clear, we value and encourage tough conversations. Indeed, these tough conversations help to move the field forward, particularly when they include diverse perspectives, invite continued discourse, and are evidence informed. As a team of researchers, clinicians, and individuals with living experience, we outline our concerns on the conclusions identified by Eliason et al and our rationale in support of FASD as a diagnostic term.

- 1. Clear and Actionable Diagnosis:** FASD assessment and diagnosis offers a specific, identifiable framework for identifying and supporting individuals affected by prenatal alcohol exposure (PAE). The authors argue that an FASD diagnosis oversimplifies complex neurodevelopmental conditions. However, research evidence shows that FASD diagnosis provides a unified indicator for identifying those whose brain and body-based challenges stem primarily from PAE. An FASD diagnosis indicates the need for informed interventions, early screening, and access to specialized services. It is the heterogeneity of this diagnosis that makes it necessary to ensure that simplified assessment practices do not miss complex contributions to functional differences – a diagnosis signals complexity and that specialized services and further understanding are needed. The clarity of maintaining FASD as a diagnosis enables families and clinicians to navigate treatment pathways with greater precision, leading to more effective care. The diagnostic process is not perfect anywhere, but it is evolving with new evidence. More diagnostic capacity will increase understanding of this disorder among health professionals and service providers. The assessment process also specifically describes the strengths and challenges of the individual based on their neurophysiological profile; linking this informed profile to diagnosis provides specificity in intervention

recommendations. The harms of not getting the right diagnosis can be significant as noted by many parents.

Additionally, having a formal diagnosis can give people a sense of meaning and community, something to describe their strengths and challenges and help them to make sense of themselves and their engagement with the world. Stripping people of their diagnostic label may, for some, impact their identity and their self-understanding in terms of why they feel 'different' or struggle with certain things compared to others.

The article made me feel many things including grief, anger and sadness. Grief, that systems to support my children are going to evaporate should this be adopted and that my experiences as a parent of three with PAE are invalid. Anger that this article will get traction and remove funding and support for FASD-informed research and FASD-informed systems resulting in a backward shift in momentum. Anger that the impact on my children's body might be overshadowed by their brain impairment. And sadness, that as a society we are moving back to worrying about stigma. There is a need to support and have prevention conversations, and to support those with FASD. So many labels are stigmatizing, but removing the label does nothing to remove the stigma. When we know better, we do better... not by changing labels but by addressing those labels in appropriate ways and building better systems of support. – A caregiver's perspective

- Evidence of Alcohol as a Teratogen:** Although Eliason et al. argue that multiple factors beyond alcohol contribute to neurodevelopmental differences, alcohol's teratogenic effects are well-documented and uniquely damaging to fetal development. Indeed, the effects of PAE are not homogeneous (FASD is a "spectrum" disorder) and must be considered in the context of many other intersectional factors that impact neurobehavioural, physical, and mental health outcomes from pre-conception, through pregnancy and birth, into childhood, adolescence, and adulthood. Fifty years of evidence demonstrates unequivocally that alcohol is a powerful neurobehavioral teratogen, and undisputable evidence shows that individuals affected by PAE express aspects of brain function and behaviour differently than individuals with other neurodevelopmental disorders (NDDs). Disconnecting the effects of PAE from our clinical understanding of neurodevelopment will cloud the unique aspects and expression of the teratogenic effects of alcohol. Without this nuanced information and understanding of etiology, individuals with FASD will get lost in systems; while some interventions for other NDDs may be helpful for FASD, others may not. Without a clear diagnosis from a clinic team that understands the nuances of PAE, individuals are less likely to receive the best care and support.
- Reducing Stigma through Education, Not Terminology:** The authors claim that an FASD diagnosis perpetuates stigma and discrimination, particularly for equity seeking communities. Although it is true – and problematic – that FASD is a highly stigmatized disability, this issue lies not in the diagnosis itself, but in harmful stereotypes perpetuated at the societal level, including inaccurate media portrayals of people with FASD and attitudes toward alcohol consumption and maternal responsibility. Rather

than eliminating FASD as a diagnostic term, efforts should focus on better education and reduced judgment among service providers and the public. The availability of an FASD diagnosis can provide validation and access to care for individuals and families, shifting the narrative toward support and prevention rather than blame. Similarly, having open conversations to normalize and *name* FASD through diagnostic labelling may even help to promote agency, increase optimism, and reduce stigma for some families.

Before my child had a diagnosis, we knew something was different. At diagnosis, I agree there is stigma, shame, grief and loss and more. But, by growing knowledge, developing FASD-informed parenting skills, learning from others on this same journey, and by building my FASD-informed community and FASD-informed knowledge, I have grown and am a better parent because I know. I have moved past grief for what could have been to look forward to what can be. The label provides important access to programming, support, and systems my children need and helps engage in FASD-informed conversations. I fear removing the label will invalidate my experiences, will further limit FASD-informed care, and will prevent FASD-informed conversations that are essential for my child to become the best version of himself. More diagnostics, more support, more research, and more prevention strategies and systems need to be provided, NOT less. – A parent’s perspective

4. **Improving Health Equity:** Eliason et al. point out that Indigenous and equity seeking groups are disproportionately affected by FASD diagnoses. Mitigating racism, sexism, and classism in our health care systems seems to underlie the issue here rather than the diagnostic term of FASD. FASD is caused by PAE, not by race. Confusing these things continues to perpetuate harmful myths. Some people are at higher risk of alcohol consumption during pregnancy – *not* because of their race, but because of their living circumstances, their mental health status, their support systems, and their social determinants of health. Indigenous and underserved populations require more comprehensive resources and culturally safe care, not the removal of a diagnosis that can help provide access to these services. A health care system that is better informed about PAE and FASD may also reduce the referral bias that this paper alludes to.

Given the lack of culturally safe health care that Indigenous peoples have experienced for generations, it is incumbent upon clinicians and researchers to do better. We can only do better by authentically listening to the needs and priorities of Indigenous peoples, partnering with Indigenous communities toward culturally grounded paths for healing, and uplifting Indigenous voices through our research and service approaches. At CanFASD, we are taking steps to honour commitments to Indigenous and equity-seeking groups, and this means doing our part to address the Truth and Reconciliation Commission of Canada’s Calls to Action, two of which specifically call for recognition of FASD and access to FASD diagnosis as high priority. We encourage everyone connected to the FASD community to consider their role in addressing these inequities.

5. **Diagnosis as a Gateway to Services:** One of the strongest arguments for retaining FASD as a diagnosis is that it facilitates access to essential services, including educational and

health care supports. Eliason et al. advocate for a non-categorical approach to intervention, but removing a specific diagnosis could complicate eligibility for such services. The practical benefits of FASD-specific support structures, which include tailored educational plans and health care interventions, should not be dismissed. As the authors of the article suggest, inclusive and trauma-informed care models that recognize the complexity of neurodevelopmental challenges may alleviate the stigma associated with an FASD diagnosis, and this is exactly what diagnostic clinics around the world have been modelling. Clinics have also developed culturally safe traditional approaches to diagnosis including those centered around Indigenous Medicine Wheels. Those working with individuals and families with FASD are arguably among the *most* sensitive to these issues and have a deep understanding of addiction, trauma, and other social determinants of health. Furthermore, FASD-specific supports offer critical funding that can be key to improving long-term outcomes for affected individuals.

Removing the stigma from FASD is a slow process and there will always be those who will never admit that their child has a disability, no matter what it is. Still, there are considerable benefits to having a formal diagnosis. The issue here is that we don't have access to a diagnostic team with the capacity to diagnose all those who require one. Most are being diagnosed with autism and this will prove to be problematic in the grand scale of things. I strongly agree that more money needs to be invested in the realm of diagnosis. – A caregiver's perspective

- 6. The Need for Further Research, Not Diagnostic Elimination:** Eliason et al. call for the reconsideration of FASD as a medical diagnosis because of the complexity of neurodevelopmental diversity. However, rather than eliminating the diagnosis altogether, the solution is to refine and expand the research surrounding FASD, including comorbidities, the role of genetic and environmental factors, and the perspectives of those with living experience. Advances in research and understanding of the diverse range of neurodevelopmental disorders can complement, rather than replace, the existing FASD diagnosis.

Can you imagine walking into a doctor's office where someone says my child has an NDD, but in the back of their mind, they think, "I know the cause"? Tossing out the label of FASD, although it carries its baggage, does nothing to prevent these thoughts. It may even perpetuate further stigma, racism and more as those in positions of power hold judgment over my children's disorders. And it may also prevent my children from getting much-needed FASD-informed systems of care. When we know better, we do better, we don't just relabel it because it is uncomfortable. We know how to have better prevention conversations where blame is on societal factors, we know the importance of FASD-informed care, we know the importance of getting the correct diagnoses. Knowing these things, we can move forward. Knowledge is power and renaming something does nothing to remove the stigma, but it might remove the knowledge that comes with a correct diagnosis. – A parent's perspective

7. **The Critical Importance of Prevention Work:** Eliason et al. do not fulsomely discuss the implications of eliminating the FASD diagnostic label for prevention of PAE, which cannot be left out of this important conversation. Removing the term FASD eliminates space for conversations about prevention and creates another form of erasure of women and pregnant people's health issues. Removing the term camouflages stigma, and limits opportunities to work with women, providers, and systems to change how they view and act on the complexity of alcohol use in pregnancy. Additionally, removing the term FASD is not likely to protect women from experiencing internalized guilt and shame about alcohol use in pregnancy; most parents will carry these feelings, no matter what label they or their child received or did not receive. When we can talk about prenatal alcohol use openly and without judgment as a society and with individual women, we can prevent crippling burdens of isolation and guilt. Their internalized awareness of the impact of alcohol on their own health and the health of their child can only be made visible and alleviated when we talk about it and empower women to connect with other women and service providers to learn what has worked for others in reducing harm and developing self-compassion.

In conclusion, eliminating FASD as a diagnostic term risks undermining the very people the authors seek to protect. Instead of abolishing this diagnosis, we need to openly acknowledge neurodevelopmental complexity through enhancing understanding, improving access to care, and refining diagnostic practices to reflect the multifaceted nature of PAE and FASD.

We look forward to your comments and suggestions as we continue to work collaboratively with individuals with FASD, parents and caregivers, service providers, professionals, policy makers, and researchers toward addressing the complexities of FASD.