CanFASD
CANADA FASD RESEARCH NETWORK

July 2019

# Policy Action Paper: Toward a Standard Definition of Fetal Alcohol Spectrum Disorder in Canada

**Kelly Harding, PhD; Katherine Flannigan, PhD; Audrey McFarlane, MBA**
*Canada Fetal Alcohol Spectrum Disorder Research Network, Canada*

## Background:

Language is a reflection of how people in a society see one another, which can impact perceptions and consequently how people think [1, 2]. In particular, language is a powerful tool in influencing how society and culture constructs disabilities [2, 3]. Historically, individuals with disabilities have endured discrimination [2], and stereotypic language can send a negative message of alienation and apartness. As well, language can contribute to mindsets that limit the aspirations of persons with disabilities or mental health needs, causing them to doubt their self-worth. Therefore, changing the phrasing in the way we speak and write about Fetal Alcohol Spectrum Disorder (FASD), as well as focusing upon a person’s abilities, rather than their disabilities, can assist us in changing perspectives both inside and outside of the FASD community.

The United Nations Convention on the Rights of Persons with Disabilities was enacted to “promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity” [4]. Article 8 of the Convention is focused on *Awareness Raising*, which includes raising awareness throughout society regarding persons with disabilities, combatting stereotypes, prejudices, and harmful practices relating to persons with disabilities, and promoting awareness of the capabilities and contributions of persons with disabilities [4, 5]. One way to address these principles is through clear and concise language that can help to reduce ambiguities and facilitate clear communication devices for the exchange of information.

At CanFASD, we have been working to create a common definition of FASD for use in a Canadian context. We believe that if all governments, service agencies, and researchers use a common definition of FASD, it will:

- Reduce stigma [6-8], given that many existing definitions are quite harsh and use incorrect or outdated information
- Increase understanding of the disability [9]
- Increase consistency in our messaging and reduce confusion
- Facilitate a change in perspectives to a more strength-based, whole-body approach to FASD [10, 11], both inside and outside the FASD community

***The authors would like to thank Dr. Jacqueline Pei for reviewing this work.***

Standard definitions are needed to ensure consistency in administrative, clinical, and research operations. Researchers in other disciplines, such as oncology [12], have identified that it is good practice to clarify a term's meaning when it is poorly understood or has many different interpretations. Current variations in definitions of FASD may have negative implications, including the hindering of knowledge translation initiatives, the stigmatization of individuals with FASD, and misinformation about the characteristics of individuals with FASD. Consequently, there is a need to promote consistency in language regarding FASD across Canada.

**This policy action paper describes the approach taken to create a standard definition of FASD, as well as our proposed definition for use in FASD policy and practice.**

## Process of Development:

In order to assess the current breadth of definitions being used in policy, service delivery, and research, several existing definitions were compiled for review, including:

- **15 definitions from provincial and territorial organizations**, including the Ministry of Children and Family Development (British Columbia), HealthLinkBC, the Government of British Columbia, the Government of Alberta, the Saskatchewan FASD Network, Healthy Child Manitoba, the Government of Ontario, the Institut National de Sante Publique du Quebec, the New Brunswick FASD Centre of Excellence, the Nova Scotia FASD Intergovernmental Exchange Group, the Canadian Intergovernmental Conference Secretariat, the Fetal Alcohol Syndrome Society Yukon, the Yukon Government (Health and Social Services), and Health and Social Services in the Northwest Territories;
- **9 national definitions**, including health care organizations, the Government of Canada, and The Centre for Addiction and Mental Health;
- **7 definitions from international organizations**, such as the World Health Organization, the Centers for Disease Control and Prevention, the Australian Medical Association, the National Health Service, and the New Zealand Ministry of Health;
- **4 definitions from other organizations**, including the Kids Brain Health Network and NOFAS, and;
- A **sample of 10 academic definitions** from recent peer reviewed publications [13-22]

Each definition was reviewed and coded by CanFASD staff for components that were negative, positive, or neutral. For example, definitions that spoke to the range of effects of prenatal alcohol exposure, the invisible nature of FASD, the need to consider FASD across the lifespan, the strengths of individuals with FASD, and those that considered the social determinants of health, were generally rated as positive components for consideration in a standard definition. Neutral statements included those that referred to alcohol use during pregnancy (e.g., "any type, any amount, at any time") and factual statements, such as how many Canadians are suspected to have FASD.

Negative components of existing definitions included outdated information (e.g., reference to FASD being an umbrella term in Canada; reference to birth defects; or use of outdated diagnostic terminology in Canada), identifying that there is “no cure” for FASD, emphasizing FASD as a disability that occurs only in infants and children, and those that drew particular attention to the perceived fault and blame of mothers (e.g., “damaging the baby”). Other examples of negative components included fatalistic terminology, such as “afflicted”, “devastation”, “most disabling”, and “irreversible damage”, or outdated terminology in the developmental disabilities field (i.e., “mental retardation”).

After appraising the existing definitions, a draft document of recommendations was proposed for discussion, including suggested considerations for a Canadian definition. Based on these recommendations, an initial working definition of FASD was crafted for review by CanFASD staff, our team of Research Leads, our Family Advisory Committee, as well as the Canada Northwest FASD Partnership. Once agreement was reached on this working definition, it was then presented to the larger FASD community for feedback through the CanFASD Connect blog and on social media. Based on community input, the definition was further refined and finalized.

## Recommendations:

**CanFASD strongly recommends that policy makers and service providers adopt the following definition when writing FASD policy or addressing services to persons affected by FASD:**

*Fetal Alcohol Spectrum Disorder (FASD) is a diagnostic term used to describe impacts on the brain and body of individuals prenatally exposed to alcohol. FASD is a lifelong disability. Individuals with FASD will experience some degree of challenges in their daily living, and need support with motor skills, physical health, learning, memory, attention, communication, emotional regulation, and social skills to reach their full potential. Each individual with FASD is unique and has areas of both strengths and challenges.*

*Le Trouble du spectre de l’alcoolisation foetale (TSAF) est un terme diagnostique utilisé pour décrire les impacts au cerveau et le corps des individus exposés à l'alcool avant la naissance. Le TSAF est un handicap permanent à vie. Les individus atteints du TSAF connaîtront un certain degré de défis dans leur vie quotidienne et auront besoin d’être supportés dans les domaines suivants: habiletés motrices, santé physique, apprentissage, mémoire, attention, communication, régulation émotionnelle ainsi que les habiletés sociales pour atteindre leur plein potentiel. Chaque individu atteint du TSAF est unique et présente à la fois des forces et des défis.*

When talking about FASD, we also recommend that individuals **avoid**:

- Referring to FASD as something that is "caused by" or is "the result of" a mother consuming alcohol while pregnant, as this can inadvertently cause blame
- Fatalistic terminology and phrasing (e.g., "with no cure", "devastation", "100% preventable", "permanent", and "average life expectancy")
- Outdated terms, like "mental deficiency" and "mental retardation"
- In line with our Common Messaging Guide, avoid the terms primary and secondary disabilities

However, it is important to note that this definition is not static in nature. As new evidence emerges, we will continue to revisit this definition to ensure that we are staying current with existing research, principles of person- and identity-first language, and strength-based approaches to FASD.

## Conclusion:

In order to promote a common language about FASD, and to minimize misinterpretation of key issues, we have drafted this suggested definition of FASD. We believe that this lay language, common definition of FASD provides an opportunity to reach a wide audience. In line with our Common Messaging Guide [23], as well as other Language Guides for talking about FASD [24], this definition emphasizes the whole-body implications of FASD and highlights that each individual with FASD is unique, with their own individual strengths and challenges. Therefore, we recommend that this definition be used by governments and policy makers across Canada to promote standardization and consistent language when discussing FASD.

## References:

1. Clark, L. and S. Marsh. *Patriarchy in the UK: The language of disability*. 2002 [cited 2019 06-04]; Available from: https://disability-studies.leeds.ac.uk/wp-content/uploads/sites/40/library/Clark-Laurence-language.pdf.
2. Harpur, P., *From disability to ability: Changing the phrasing of the debate.* Disability & Society, 2012. **27**(3): p. 325-337.
3. Dunn, D.S. and E.E. Andrews, *Person-first and identity-first language: Developing psychologists' cultural competence using disability language.* American Psychologist, 2015. **70**(3): p. 255-264.
4. *Convention on the Rights of Persons with Disabilities*. 2006, United Nations General Assembly. Available from: https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/convention-on-the-rights-of-persons-with-disabilities-2.html
5. Canadian Association of Statutory Human Rights Agencies, *Canada and the UN Convention on the Rights of Persons with Disabilities*. 2011, Canadian Association of Statutory Human Rights Agencies: Toronto, ON.
6. Swaffer, K., *Dementia: Stigma, language, and dementia-friendly.* Dementia, 2014. **13**(6): p. 709-716.
7. Granello, D.H. and T.A. Gibbs, *The power of language and labels: "The mentally ill" versus "people with mental illnesses".* Journal of Counseling & Development, 2016. **94**(1): p. 31-40.
8. Jensen, M.E., et al., *Championing person-first language: A call to psychiatric mental health nurses.* Journal of the American Psychiatric Nurses Association, 2013. **19**(3): p. 146-151.
9. World Health Organization. *Understanding disability*. 2011 [cited 2019 06-30]; Available from: https://www.who.int/disabilities/world_report/2011/chapter1.pdf.
10. Flannigan, K., et al., *CanFASD Issue Paper: Strengths among individuals with FASD*. 2018, Canada FASD Research Network: Vancouver, BC.
11. Mela, M., K.D. Coons-Harding, and T. Anderson, *Recent advances in fetal alcohol spectrum disorder for mental health professionals.* Current Opinion in Psychiatry, 2019. **32**.
12. Hui, D., et al., *The lack of standard definitions in the supportive and palliative oncology literature.* Journal of Pain and Symptom Management, 2013. **43**(3).
13. Cook, J.L., et al., *Fetal alcohol spectrum disorder: A guideline for diagnosis across the lifespan.* Canadian Medical Association Journal, 2016. **188**(3): p. 191-197.
14. Tait, C.L., et al., *The lived experience of paroled offenders with fetal alcohol spectrum disorder and comorbid psychiatric disorder.* Transcultural Psychiatry, 2017. **54**(1): p. 107-124.
15. Reid, N., et al., *Profile of children diagnosed with a fetal alcohol spectrum disorder: A retrospective chart review.* Drug and Alcohol Review, 2017. **36**(5): p. 677-681.
16. Flannigan, K., et al., *Fetal Alcohol Spectrum Disorder and the criminal justice system: A systematic literature review.* International Journal of Law and Psychiatry, 2018. **57**: p. 42-52.
17. Pei, J., et al., *Intervention recommendations and subsequent access to services following clinical assessment for fetal alcohol spectrum disorders.* Research in Developmental Disabilities, 2017. **60**: p. 176-186.
18. Lange, S., et al., *Neurodevelopmental profile of Fetal Alcohol Spectrum Disorder: A systematic review.* BMC Psychology, 2017. **5**(1): p. 22.
19. Popova, S., et al., *Prevalence of alcohol consumption during pregnancy and Fetal Alcohol Spectrum Disorders among the general and Aboriginal populations in Canada and the United States.* European Journal of Medical Genetics, 2017. **60**(1): p. 32-48.
20. Rai, J.K., et al., *Parent rating of executive function in fetal alcohol spectrum disorder: A review of the literature and new data on Aboriginal Canadian children.* Child Neuropsychology, 2017. **23**(6): p. 713-732.
21. Lange, S., et al., *Global Prevalence of Fetal Alcohol Spectrum Disorder Among Children and Youth: A Systematic Review and Meta-analysisGlobal Prevalence of Fetal Alcohol Spectrum Disorder Among Children and YouthGlobal Prevalence of Fetal Alcohol Spectrum Disorder Among Children and Youth.* JAMA Pediatrics, 2017. **171**(10): p. 948-956.
22. Murawski, N.J., et al., *Advances in Diagnosis and Treatment of Fetal Alcohol Spectrum Disorders: From Animal Models to Human Studies.* Alcohol research : current reviews, 2015. **37**(1): p. 97-108.

23. Canada FASD Research Network, *Common messages: Guidelines for talking and writing about FASD*. 2018, Canada FASD Research Network: Vancouver, BC.
24. Manitoba FASD Coalition, *Language guide: Promoting dignity for those impacted by FASD*. 2016.