

FETAL ALCOHOL SPECTRUM DISORDER: THE IMPORTANCE OF ADOPTING A STANDARD DEFINITION IN CANADA

Kelly D. Harding^{1,2}, Andrew J. Wrath¹, Katherine Flannigan¹, Kathy Unsworth¹, Audrey McFarlane¹, Jacqueline Pei^{1,3}

¹Canada FASD Research Network, Vancouver, BC, Canada

²Laurentian University, Sudbury, ON, Canada

³University of Alberta, Edmonton, AB, Canada

Corresponding Author: Kelly D. Harding: kelly.harding@canfasd.ca

Submitted: 12 April 2021. Accepted: 31 December 2021. Published: 21 September 2022.

ABSTRACT

Background and Objective

The manner in which language is used reflects how people in a society view one another. Historically, individuals with disabilities have experienced discrimination through the use of stereotypic or demeaning language. Individuals with Fetal Alcohol Spectrum Disorder (FASD) may be particularly susceptible to these negative impacts, particularly given the stigma associated with the disability. We discuss how individuals with disabilities may be affected by our use of language.

Materials and Methods

Current definitions of FASD from Canadian provincial/territorial, national, and international governments and organizations were collated. Recent academic definitions found in the peer-reviewed literature were also reviewed. All definitions were independently coded by the two authors to identify definitions which were based upon current and emerging evidence and which included factual information about FASD. A standard definition of FASD was developed through an iterative process, including expert consultation and feedback from the larger FASD community.

Results

We propose an evidence-based, lay-language standard definition of FASD to be used in a Canadian context, intended to reflect the range of strengths and challenges of individuals with FASD as well as the whole-body implications of the disability.

Conclusion

Our standard definition of FASD provides an opportunity to ensure consistency in language, increase awareness of FASD, promote dignity, and reduce stigma upon people with FASD and their families. We encourage governments, policy makers, service providers, and researchers to adopt the authors standard definition of FASD, with the goal of increasing awareness of FASD, reducing stigma, and improving communication and consistent messaging about the disability.

Keywords: fetal alcohol spectrum disorder; disability; language; standard definition

INTRODUCTION

The manner in which language is used reflects how people in a society view one another; this affects perceptions, and, consequently, people's thinking.^{1,2} Language is a powerful tool that is used to influence the manner in which society and culture construct disabilities.^{2,3} Historically, individuals with disabilities have endured discrimination, and the use of stereotypic language can send a negative message of alienation and isolation.² Stereotypic or negatively valenced language could develop or propagate a negative self-view among individuals with disabilities.⁴⁻⁶ The consequences of viewing oneself in this pessimistic light may limit the aspirations of individuals with disabilities or those with mental health challenges. These self-perceived limitations could potentially cause individuals to doubt their possibilities of growth, their ability to develop practical skills (e.g., vocational), or their ability to contribute to the society.⁷ Conversely, an emphasis on the strengths of individuals with disabilities allows them, their families, and their communities to focus less on challenges and instead increase awareness and understanding of their abilities and potentiality.^{7,8}

In clinical contexts, there is an opportunity to direct the use of language which may influence attitudes and beliefs. Standard clinical definitions are required to create consistency in administrative operations, service provision, and research initiatives.^{9,10} Ensuring that standard definitions are client-centered and contextualized with care to promote healthy outcomes can facilitate more positive experiences from that point forward. For example, consistent language is beneficial within diagnostic practice, given that a formal diagnosis entails naming a cluster of characteristics in order to make certain shared understandings and clear communication. Researchers and clinicians in various disciplines, such as oncology,¹⁰ nursing,¹¹ and cardiology,¹² have identified that standard definitions can improve communication between physicians, researchers, and patients. Additionally, these

standard definitions improve the messaging that is communicated *about* a particular phenomenon (e.g., disability), indicating the importance of both context and content of this messaging.¹³

LANGUAGE USE REGARDING DISORDERS AND DISABILITIES

When something is assigned a particular name, such as in the case of labelling a disorder or disability, there are associated attributions, both positive and negative, that come with that label. In fact, having a diagnosis provides relief to the individual diagnosed, as well as their family members and caregivers, by removing the possible perception that the individual is responsible for having the condition.¹³ However, naming a disorder or disability can also have negative consequences, such as putting the individual into the category of "suffering" or contributing to the perception that they are "abnormal" in some manner.¹³

In Canada, there is no agreement around the general term "disability," nor is there a consistent manner to refer to individuals with disabilities.¹⁴ For example, definition of a learning disability (LD) can vary internationally, nationally, provincially, regionally, and/or locally.^{15,16} Some researchers have argued that discrepancies between various definitions of LD, and the lack of consensus on diagnostic criteria, can lead to a failure to adequately support these individuals.¹⁶ Moreover, inconsistency in disability language and its definitions can make it challenging for researchers to compare the prevalence of disabilities across regions, populations, or studies,¹⁷ or to make comparisons between individuals having the same disability. The caveat of not having a standard definition hinders our ability to synthesize findings across studies. On the other hand, the development of standard definitions may allow for more consistent practices and communication between service providers, researchers, governments, the public, and other relevant stakeholders.

The benefits of standard definitions extend beyond our ability to share consistent language as

well. These definitions also have the potential to guide intervention responses, facilitating access to treatment and positively impacting outcomes by explicitly identifying potential areas of support and growth.^{18,19} The use of standard definitions allows for an emphasis not only on a common understanding but also on the associated descriptions of a particular disability, including the abilities and potential of individuals with diagnoses.¹³ In this manner, common language can promote an understanding of not only “what is” but also of “what is possible,” which aligns with the call for strength-based approaches to disability that emphasize hope, motivation, and destigmatizing frameworks of practice.²⁰

FETAL ALCOHOL SPECTRUM DISORDER (FASD) IN THE CANADIAN CONTEXT

Fetal alcohol spectrum disorder was first recognized in North America in 1973.²¹ However, it was not until 1996²² that a formal definition of the disability and associated diagnoses were established. The Institute of Medicine in the United States released guidelines for the diagnosis and treatment of individuals with FASD, which included definitions of various diagnoses under the FASD “umbrella,” including partial fetal alcohol syndrome, fetal alcohol effects, and alcohol-related neurodevelopmental disorder (ARND).²² These varied definitions emphasized the complexity, yet specificity, of disorders related to prenatal alcohol exposure (PAE). To address this complexity and prevent potential inconsistencies in FASD diagnosis, researchers later developed a 4-Digit Diagnostic Code system, representing the assessment areas of growth deficiency, facial dysmorphism, central nervous system (CNS) damage, and gestational alcohol exposure.²³ Development of this 4-Digit Code system allowed for physicians and other service providers to identify and support individuals with PAE.²⁴

Canadian FASD diagnostic guidelines were first developed in 2005 with the intention of supporting clinicians to increase their understanding of FASD and thus their ability to participate in the

diagnostic process.²⁵ In the decade that followed the release of the first Canadian guidelines, there were significant advances in FASD research and clinical expertise that revealed that the Canadian guidelines required revision.²⁶ A collaborative effort between researchers and clinicians with expertise in the study, diagnosis, and treatment of FASD resulted in the 2015 Canadian guidelines for FASD diagnosis across the lifespan.²⁶ This updated guidelines took into account the strengths of individuals with FASD, acknowledged FASD as a whole-body disorder, and introduced a new “at risk” category to assist in monitoring individuals who experienced substantial challenges but did not meet diagnostic criteria at the time of assessment.²⁶

Although Canadian researchers and service providers have reached a consensus on how FASD should be identified and diagnosed, there is still a requirement to build awareness and knowledge of FASD within the Canadian public.^{27,28} This increased awareness must include consistency in the use of diagnostic language as well as language used when discussing FASD in general. Owing to the significant stigma associated with FASD,^{27,29} its diagnosis is especially relevant with respect to the implications surrounding the use of language. Being intentional and sensitive in the manner we speak and write about FASD, such as focusing upon a person’s strengths and abilities, rather than solely on their challenges and disabilities, can assist us in changing perspectives both inside and outside the FASD community.

The current variations in definitions and classifications of FASD have negative consequences, such as hindering knowledge translation initiatives, stigmatizing individuals with FASD and their families, and perpetuating misinformation about the characteristics of individuals with FASD.^{30,31} Consequently, there is a requirement to promote consistency in language concerning FASD across Canada. In order to address this requirement, we developed a standard definition of FASD for use in a Canadian context. We believe that adopting a standard definition of FASD will reduce stigma; enhance understanding

of the disability; increase consistency in our messaging; and facilitate a change in perspectives to a more strength-based, whole-body approach to FASD.

METHODS

Our procedure for developing the definition aligned with the mandates and intent of evidence-based messaging. Specifically, we followed a three-step process to develop our definition guided by scientific research as well as gray literature (i.e., definitions from government and other disability, mental health, and substance use organizations), targeting a specific audience (i.e., the general population) and incorporating accessible language.^{32,33} For an overview of the locations, agencies, and sources reviewed as part of our three-step process for developing our definition, please see the supplementary material that accompanies this commentary.

Step 1: Synthesizing the evidence to develop a working definition

In order to understand the breadth of language being used in relation to FASD, a multi-pronged approach was used to compile current definitions at the provincial/territorial, national, and international levels. Two researchers (KH and KF) compiled a list of all available definitions used by Canadian provincial and territorial governments and/or government departments (n = 15) via a manual search of their websites and published government documents. This list was further expanded from a search of gray literature, drawing on resources from other disability, mental health, and substance use organizations (e.g., The Centre for Addiction and Mental Health; n = 9). Using the same procedure, relevant international definitions were retrieved from other disability, health, and social services organizations (e.g., the World Health Organization, the Centre for Disease Control and Prevention; n = 7). Finally, we compiled definitions from other FASD organizations and/or the Canada Fetal Alcohol Spectrum Disorder Research Network (CanFASD) partners and collaborators (n = 4), such as the Kid's Brain

Health Network. In order to ensure that we captured language currently being used in the scientific literature, we also selected a small random sample of recent (2015–2019) academic definitions from peer-reviewed publications (n = 10).

Using an inductive coding approach, two researchers (KH and KF) independently reviewed all definitions to identify components that (i) were consistent with current and emerging evidence related to FASD; (ii) reflected research that was outdated or stigmatizing; and (iii) represented factual information about FASD. For example, components were coded as consistent with current evidence if they referred to FASD as a lifelong, heterogenous, or “hidden” condition; acknowledged the full constellation of effects associated with PAE; or referred to the strengths of individuals with FASD. Components were coded as outdated or stigmatizing if they referred to diagnostic labels that are no longer in use (e.g., Fetal Alcohol Syndrome), used pejorative language to refer to individuals with disabilities or women who consume alcohol during pregnancy, or included fatalistic language (e.g., “devastation,” “irreversible damage,” and “no cure”). Components were coded as factual if they referred to statistics, such as the prevalence or economic impacts of FASD in Canada. The researchers then synthesized their findings and generated a preliminary list of recommendations for elements that must be included (i.e., consistent and factual components) and excluded (i.e., outdated and stigmatizing components) in the definition, and developed the first draft of FASD definition.

Step 2: Consultations with experts

Once a preliminary definition was created, we sought feedback via in-person consultations with and inputs from stakeholders and experts within the FASD community across multiple sectors. Their feedback was sought to provide information regarding the context of the working definition, including accuracy, comprehensiveness, and tone. Consulting stakeholders included Canadian academic and medical experts, including the CanFASD Research Leads and staff. In order to ensure that the defini-

tion was accessible, written in the language appropriate for the general public, and representative of the experiences of individuals with FASD, we also sought feedback from families and caregivers of the CanFASD Family Advisory Committee (FAC). Further, feedback at a policy level was afforded through consultations with the Canada Northwest FASD Partnership.

Canada Northwest FASD Partnership

This collaborative process allowed us to generate our working definition among a diverse team of researchers, including scientists, physicians, psychologists, social workers, and individuals with lived experience to ensure that our definition was both evidence-based and practically relevant. Given the diversity of the CanFASD Research Network, we were also able to obtain feedback from individuals who worked across a wide range of professional backgrounds and areas of expertise, including prevention, intervention, assessment and diagnosis, justice, and child welfare. Feedback was obtained in-person at an annual meeting in August 2018. Following this in-person meeting, further feedback was obtained from the experts noted here via iterative emails. All on-going feedback was collected and integrated by the first author (KH) who continued to share revised definitions with collaborators in an effort to reach a consensus on the final definition.

Step 3: Feedback from the community

After incorporating feedback from experts, families, caregivers, and policy makers, we sought an additional level of review from the larger Canadian FASD community to ensure that the definition was strength-based and accessible to the lay audience. This feedback was achieved by advertising the opportunity to participate in developing the Canadian standard definition through our organizational website and social media platforms. Feedback was solicited from individuals connected to the CanFASD Research Network via social

media (e.g., CanFASD Connect Blog, Twitter, Facebook, LinkedIn, etc.) in early November 2018. Individuals were asked to consider the draft working definition of FASD and were invited to share any feedback about the definition via email with the first author (KH). The response from the community was generally positive, with many individuals sharing both their appreciation of the definition in general, their appreciation of the opportunity to provide feedback, and their specific and tangible suggestions for phrasing changes and/or additions/deletions to the draft definition. More than 20 individuals, including caregivers, policy makers, educators, health care professionals, FASD advocates, and FASD specialists, program coordinators, and/or frontline service providers from across Canada sent in feedback for consideration. In total, 270 people viewed the CanFASD Connect Blog post – 241 in November 2018 and an additional 29 in December 2019. Furthermore, the Twitter post sharing the invitation to submit feedback on the working definition had 1042 impressions and 26 engagements. All feedback and suggestions were assembled by one researcher (KH) and incorporated, when appropriate, into revised drafts of definition after further discussion and revisions amongst the CanFASD team. Community feedback included suggestions for challenges that must be incorporated into the definition (e.g., communication), changes in wording to reduce redundancy as well as modifications to highlight the spectrum nature of FASD. Community feedback also provided confirmation from caregivers, service providers, and others in the field that the tone and word choice of the proposed definition was accurate and appreciated. All feedback was compiled and discussed, and final decisions were made about any additional changes to the definition. Once a final consensus was reached for our proposed definition, the intended definition was also translated into French to ensure accessibility in both of Canada's

*Please note that the term Fetal Alcohol Syndrome (FAS) is no longer used within the Canadian context, specifically, in line with the updated Canadian FASD Diagnostic Guideline.²⁶ The term FAS is still used in other countries, such as the United States, and within other diagnostic systems internationally.

official languages. Following this final iteration of feedback, a consensus for a standard definition was reached by CanFASD staff, research leads, and the FAC.

RESULTS

A standard definition of FASD

Based on the current disability literature, existing clinical and research evidence related to FASD, and comprehensive feedback from stakeholders across Canada, the following definition of FASD was proposed. We strongly recommend that the Canadian government, policy makers, service providers, and researchers adopt the following definition when writing FASD policy, developing FASD services, or engaging in practice with individuals with FASD:

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

Le Trouble du spectre de l'alcoolisation foetale (TSAF) est un terme diagnostique utilisé pour décrire les impacts au cerveau et au corps des fœtus individuellement 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 soutenus sur les plans 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.

This proposed definition is dynamic in nature. As new evidence emerges, we continue to revisit the

definition to ensure that it reflects current research and includes principles of strength-based and person-first language.

DISCUSSION

Recommendations for discussing FASD

Based on our synthesis of the current research and clinical evidence, we made the following recommendations for discussing and writing about FASD^{34,35}:

- When considering etiology, simply note that the individual's disability and associated challenges are due to PAE. Avoid referring to FASD as being "caused by" or "the result of" a mother consuming alcohol while pregnant, as this language can inadvertently make blame.
- Although FASD is a lifelong disability, individuals with FASD can experience growth and healthy outcomes through the earliest possible intervention and ongoing support. Use language that reflects this hope and potential and move away from the use of fatalistic terminology and phrasing such as "with no cure," "devastation," "permanent," and "average life expectancy."
- When discussing prevention, focus on providing information on why FASD occurs (e.g., unknown pregnancy) and how risks for an alcohol-exposed pregnancy could be mitigated. Avoid using terms such as FASD is "100% preventable," as this may reinforce stigmas, blame, and guilt already associated with FASD.
- Refer to FASD as a "disorder" or "disability" instead of using outdated terms such as "mental deficiency," "mental retardation," or "disease."
- Use the terms "needs," "challenges," and "adverse outcomes," in place of "secondary disabilities," as the term "secondary" may insinuate that these requirements are not as prominent or important as the brain- and body-based impairments associated with FASD.

CONCLUSION

The manner in which we use language significantly reflects self-views and perpetuates experiences of discrimination and alienation for people with disabilities and their families. These reflections are especially relevant for individuals having highly stigmatized disabilities, such as FASD. Conversely, strength-based and person-centered language has the potential to help individuals with disabilities feel validated and understood. Standard definitions can improve our ability to accurately identify people with disabilities, facilitate their access to required services, support disability-specific research capacity, and promote consistent messaging. Our standard definition of FASD ensures consistency in language, increases awareness of FASD, promotes dignity, and reduces stigma upon people with FASD and their families. Given the recognized limitations of nonstandard definitions in other medical fields, it is desired that this standard definition will mitigate these barriers for all activities related to FASD in Canada. Therefore, it is recommended that this definition be used by governments, policy makers, service providers, and researchers across the country when discussing and writing about FASD.

ACKNOWLEDGEMENTS

Some of the material used in this commentary was drawn from the authors' original drafting of a standard definition of FASD published in the July 2019 policy action paper: *Toward a standard definition of Fetal Alcohol Spectrum Disorder in Canada*. The material in this commentary was used with the authors' permission and the Canada FASD Research Network.

CONFLICT OF INTEREST

On behalf of all authors, the corresponding author states that there was no conflict of interest to declare.

REFERENCES

1. Clark L, March S. Patriarchy in the UK: The language of disability [Internet]. [cited 2002]. 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. *Disabil Soc.* 2012;27(3):325–37. <http://dx.doi.org/10.1080/09687599.2012.654985>
3. Dunn DS, Andrews EE. Person-first and identity-first language: Developing psychologists' cultural competence using disability language. *Am Psychol.* 2015;70(3):255–64. <http://dx.doi.org/10.1037/a0038636>
4. Pelleboer-Gunnink HA, van Weeghel J, Embregts PJCM. Public stigmatisation of people with intellectual disabilities: A mixed-method population survey into stereotypes and their relationship with familiarity and discrimination. *Disabil Rehabil.* 2019;1–9. <http://dx.doi.org/10.1080/09638288.2019.1630678>
5. Rohmer O, Louvet E. Implicit stereotyping against people with disability. *Gr Process Intergr Relations.* 2018;21(1):127–40. <http://dx.doi.org/10.1177/1368430216638536>
6. Watermeyer B, Gorgens T. Disability and internalized oppression. In: David E, editor. *Internalized oppression: The psychology of marginalized groups*. New York, NY: Springer; 2014. pp. 251–73.
7. Sevak P, Khan S. Psychiatric versus physical disabilities: A comparison of barriers and facilitators to employment. *Psychiatr Rehabil J.* 2017;40(2):163–71. <http://dx.doi.org/10.1037/prj0000236>
8. Hammel J, Magasi S, Heinemann A, et al. What does participation mean? An insider perspective from people with disabilities. *Disabil Rehabil.* 2008;30:1445–60. <http://dx.doi.org/10.1080/09638280701625534>
9. Hui D, De La Cruz M, Mori M, et al. Concepts and definitions for “supportive care,” “best supportive care,” “palliative care,” and “hospice care” in the published literature, dictionaries, and textbooks. *Support Care Cancer.* 2013;21(3):659–85. <http://dx.doi.org/10.1007/s00520-012-1564-y>
10. Hui D, Mori M, Parsons HA, et al. The lack of standard definitions in the supportive and palliative oncology literature. *J Pain Sympt Manag.* 2012;43(3):582–92. <http://dx.doi.org/10.1016/j.jpainsymman.2011.04.016>
11. Rutherford MA. Standardized nursing language: What does it mean for nursing practice? *Online J Issues Nurs.* 2008;13(1):1–7.

12. Hicks KA, Mahaffey KW, Mehran R, et al. Cardiovascular and stroke endpoint definitions for clinical trials. *Circulation*. 2018;137(9):961–72. <http://dx.doi.org/10.1161/CIRCULATIONAHA.117.033502>
13. Chiong W. Diagnosing and defining disease. *J Am Med Assoc*. 2001;285(1):89–90. <http://dx.doi.org/10.1001/jama.285.1.89-JMS0103-2-1>
14. McColl MA, Jaiswal A, Jones S, et al. A review of disability policy in Canada [Internet]. [cited 2017]. Kingston, ON: Canadian Disability Policy Alliance (CDPA). Available from: <http://www.disabilitypolicyalliance.ca/wp-content/uploads/2018/01/A-Review-of-Disability-Policy-in-Canada-3rd-edition-Final-1-1.pdf>
15. Kozey M, Siegel LS. Definitions of learning disabilities in Canadian provinces and territories. *Can Psychol*. 2008;49(2):162–71. <http://dx.doi.org/10.1037/0708-5591.49.2.162>
16. Harrison A, Holmes A. Easier said than done: Operationalizing the diagnosis of learning disability for use at the postsecondary level in Canada. *Can J Sch Psychol*. 2012;27(1):12–34. <http://dx.doi.org/10.1177/0829573512437021>
17. Dionne CE, Dunn KM, Croft PR, et al. A consensus approach toward the standardization of back pain definitions for use in prevalence studies. *Spine (Phila Pa 1976)*. 2008;33(1):95–103. <http://dx.doi.org/10.1097/BRS.0b013e31815e7f94>
18. Mills RJ, Young CA. A medical definition of fatigue in multiple sclerosis. *Quart J Med (QJM)*. 2008;101(1):49–60. <http://dx.doi.org/10.1093/qjmed/hcm122>
19. Chan LS, Razaque Ahmed A, Anhalt GJ, et al. The first international consensus on mucous membrane pemphigoid: Definition, diagnostic criteria, pathogenic factors, medical treatment and prognostic indicators. *Arch Dermatol*. 2002;138(3):370–9. <http://dx.doi.org/10.1001/archderm.138.3.370>
20. Flannigan K, Harding K, Reid D. Strengths among individuals with FASD [Internet]. [cited 2018]. Available from: <https://canfasd.ca/wp-content/uploads/publications/Strengths-Among-Individuals-with-FASD.pdf>
21. Jones KL, Smith DW, Ulleland CN, et al. Pattern of malformation in offspring of chronic alcoholic mothers. *Lancet*. 1973;301(7815):1267–71. [http://dx.doi.org/10.1016/S0140-6736\(73\)91291-9](http://dx.doi.org/10.1016/S0140-6736(73)91291-9)
22. Stratton K, Howe C, Battaglia FC. Fetal alcohol syndrome: Diagnosis, epidemiology, prevention, clinical trials. *Circulation*. 2018;137(9):961–72. <http://dx.doi.org/10.1161/CIRCULATIONAHA.117.033502>
13. Chiong W. Diagnosing and defining disease. *J Am Med Assoc*. 2001;285(1):89–90. <http://dx.doi.org/10.1001/jama.285.1.89-JMS0103-2-1>
14. McColl MA, Jaiswal A, Jones S, et al. A review of disability policy in Canada [Internet]. [cited 2017]. Kingston, ON: Canadian Disability Policy Alliance (CDPA). Available from: <http://www.disabilitypolicyalliance.ca/wp-content/uploads/2018/01/A-Review-of-Disability-Policy-in-Canada-3rd-edition-Final-1-1.pdf>
15. Kozey M, Siegel LS. Definitions of learning disabilities in Canadian provinces and territories. *Can Psychol*. 2008;49(2):162–71. <http://dx.doi.org/10.1037/0708-5591.49.2.162>
16. Harrison A, Holmes A. Easier said than done: Operationalizing the diagnosis of learning disability for use at the postsecondary level in Canada. *Can J Sch Psychol*. 2012;27(1):12–34. <http://dx.doi.org/10.1177/0829573512437021>
17. Dionne CE, Dunn KM, Croft PR, et al. A consensus approach toward the standardization of back pain definitions for use in prevalence studies. *Spine (Phila Pa 1976)*. 2008;33(1):95–103. <http://dx.doi.org/10.1097/BRS.0b013e31815e7f94>
18. Mills RJ, Young CA. A medical definition of fatigue in multiple sclerosis. *Quart J Med (QJM)*. 2008;101(1):49–60. <http://dx.doi.org/10.1093/qjmed/hcm122>
19. Chan LS, Razaque Ahmed A, Anhalt GJ, et al. The first international consensus on mucous membrane pemphigoid: Definition, diagnostic criteria, pathogenic factors, medical treatment and prognostic indicators. *Arch Dermatol*. 2002;138(3):370–9. <http://dx.doi.org/10.1001/archderm.138.3.370>
20. Flannigan K, Harding K, Reid D. Strengths among individuals with FASD [Internet]. [cited 2018]. Available from: <https://canfasd.ca/wp-content/uploads/publications/Strengths-Among-Individuals-with-FASD.pdf>
21. Jones KL, Smith DW, Ulleland CN, et al. Pattern of malformation in offspring of chronic alcoholic mothers. *Lancet*. 1973;301(7815):1267–71. [http://dx.doi.org/10.1016/S0140-6736\(73\)91291-9](http://dx.doi.org/10.1016/S0140-6736(73)91291-9)
22. Stratton K, Howe C, Battaglia FC. Fetal alcohol syndrome: Diagnosis, epidemiology, prevention, and treatment. Washington, DC: National Academy Press; 1996.
23. Astley SJ, Clarren SK. Diagnostic guide for fetal alcohol syndrome and related conditions: The 4-digit diagnostic code. Seattle, WA: University of Washington; 1997.
24. Hoyme HE, Coles CD. Alcohol-related neurobehavioral disabilities: Need for further definition and common terminology. *Pediatrics*. 2016;138(4):e20161999. <http://dx.doi.org/10.1542/peds.2016-1999>

25. Chudley AE, Conry J, Cook JL, et al. Fetal alcohol spectrum disorder: Canadian guidelines for diagnosis. *Can Med Ass J (CMAJ)*. 2005;172(5 Suppl.):S1–21. <http://dx.doi.org/10.1503/cmaj.1040302>
26. Cook JL, Green CR, Lilley CM, et al. Fetal alcohol spectrum disorder: A guideline for diagnosis across the lifespan. *Can Med Ass J (CMAJ)*. 2015;188(3): 191–7. <http://dx.doi.org/10.1503/cmaj.141593>
27. Choate P, Badry D. Stigma as a dominant discourse in fetal alcohol spectrum disorder. *Adv Dual Diagn*. 2019;12(1–2):36–52. <http://dx.doi.org/10.1108/ADD-05-2018-0005>
28. Choate P, Badry D, MacLaurin B, et al. Fetal alcohol spectrum disorder: What does public awareness tell us about prevention programming? *Int J Environ Res Public Health*. 2019;16(21):4229. <http://dx.doi.org/10.3390/ijerph16214229>
29. Morrison K, Harding K, Wolfson L. Individuals with fetal alcohol spectrum disorder and experiences of stigma [Internet]. [cited 2019]. Available from: <https://canfasd.ca/wp-content/uploads/publications/Individuals-with-FASD-and-Experiences-of-Stigma-FINAL.pdf>
30. Bell E, Andrew G, Chudley AE, et al. It’s a shame! Stigma against fetal alcohol spectrum disorder: Examining the ethical implications for public health practices and policies. *Public Health Ethics*. 2016;9(1):65–77. <http://dx.doi.org/10.1093/phe/phv012>
31. Jones KL, Streissguth AP. Fetal alcohol syndrome and fetal alcohol spectrum disorders: A brief history. *J Psych Law*. 2010;38:373–82. <http://dx.doi.org/10.1177/009318531003800402>
32. Agency for Healthcare Research and Quality. Communication and dissemination strategies to facilitate the use of health and health care evidence [Internet]. [cited 2012]. Available from: www.effectivehealthcare.ahrq.gov
33. Davidson B. Storytelling and evidence-based policy: Lessons from the grey literature. *Palgrave Commun*. 2017;3(1):1–10. <http://dx.doi.org/10.1057/palcomms.2017.93>
34. Canada FASD Research Network. Common messages guidelines for talking and writing about FASD [Internet]. [cited 2018]. Available from: <https://canfasd.ca/wp-content/uploads/2019/01/Common-Messages-FINAL-Dec-14-2018.pdf>
35. Canada FASD Research Network. Language matters: Talking about fetal alcohol spectrum disorder (FASD) [Internet]. [cited 2019]. Available from: <https://canfasd.ca/wp-content/uploads/2019/11/3-LanguageImages-Matter-5.pdf>

Supplementary Material

Table of sources sampled and reviewed for the development of our standard definition of FASD.

| Provincial and Territorial Definitions | | |
|---|---|---|
| Location | Agency | Reference |
| British Columbia | Ministry of Children and Family Development | Ministry of Children and Family Development. (n.d.). <i>Fetal Alcohol Spectrum Disorder: Building on Strengths. A provincial plan for British Columbia 2008 – 2018</i> . Available at https://www2.gov.bc.ca/assets/gov/health/managing-your-health/fetal-alcohol-spectrum-disorder/fetal_alcohol_spectrum_disorder_building_strengths.pdf |
| British Columbia | HealthLinkBC | HealthLinkBC. (2017). Fetal alcohol spectrum disorder. Retrieved from https://www.healthlinkbc.ca/healthlinkbc-files/fetal-alcohol-spectrum-disorder |
| British Columbia | Government of British Columbia | Government of British Columbia. (2018). Fetal Alcohol Spectrum Disorder (FASD). Retrieved from https://www2.gov.bc.ca/gov/content/health/managing-your-health/healthy-women-children/child-behaviour-development/special-needs/fetal-alcohol-spectrum-disorder-fasd |
| Alberta | Government of Alberta | Government of Alberta. (2018). Fetal alcohol spectrum disorder (FASD). Retrieved from http://www.humanservices.alberta.ca/disability-services/14853.html |
| Alberta | Government of Alberta | Government of Alberta. (2013). Get to know FASD. Retrieved from http://fasd.alberta.ca/get-to-know-fasd.aspx |
| Saskatchewan | FASD Network | FASD Network. (2018). What is FASD? Retrieved from http://www.skfasnetwork.ca/learn#whatis |
| Manitoba | Healthy Child Manitoba | Healthy Child Manitoba. (2018). FASD. Retrieved from https://www.gov.mb.ca/healthychild/fasd/ |
| Ontario | Government of Ontario | Government of Ontario. (2015). <i>Fetal alcohol spectrum disorder provincial roundtable report: A report from parliamentary assistant Granville Anderson to the Ministry of Children and Youth Services</i> . Available at http://www.children.gov.on.ca/htdocs/English/documents/specialneeds/fasd/FASD_Roundtable_Report.pdf |

| | | |
|-----------------------|---|---|
| Quebec | Institut National de Sante Publique du Quebec | Institut National de Sante Publique du Quebec. (2004). <i>Status report on fetal alcohol syndrome in Quebec. Quebec: Institut national de sante publique Quebec.</i> Available at https://www.inspq.qc.ca/pdf/publications/365-FetalAlcoholSyndrome.pdf |
| New Brunswick | NB FASD Centre of Excellence | NB FASD Centre of Excellence. (2018). What is fetal alcohol spectrum disorder (FASD)? Retrieved from https://www.vitalitenb.ca/en/points-service/mental-health/new-brunswick-fetal-alcohol-spectrum-disorder-fasd-centre-excellence/what-fetal-alcohol-spectrum-disorder-fasd |
| Nova Scotia | Nova Scotia FASD Intergovernmental Exchange Group | Nova Scotia FASD Intergovernmental Exchange Group. (n.d.). <i>Fetal Alcohol Spectrum Disorder (FASD): A Nova Scotia Perspective.</i> Available at https://novascotia.ca/dhw/healthy-development/documents/NS-FASD-DVD-Pamphlet.pdf |
| Nova Scotia | Canadian Intergovernmental Conference Secretariat | Canadian Intergovernmental Conference Secretariat. (2016). Final report to the federal/provincial/territorial ministers responsible for justice and public safety. Retrieved from http://www.scics.ca/en/product-produit/final-report-to-federalprovincialterritorial-ministers-responsible-for-justice-and-public-safety/ |
| Yukon | Fetal Alcohol Syndrome Society Yukon | Fetal Alcohol Syndrome Society Yukon. (2018). What is FASD? Retrieved from http://fassy.org/ |
| Yukon | Yukon Government – Health and Social Services | Yukon Government – Health and Social Services. (2015). <i>Yukon FASD Diagnosis and Case Management in Adult Corrections Population.</i> Available at http://www.hss.gov.yk.ca/pdf/fasddiagnosesmanagementreport2015.pdf |
| Northwest Territories | Health and Social Services | Health and Social Services. (2018). Fetal alcohol spectrum disorder. Retrieved from https://www.hss.gov.nt.ca/en/services/ensemble-troubles-causes-alcoolisation-f%C5%93tale |

| National Definitions, including Health Care Organizations | | |
|--|---|--|
| Location | Agency | Reference |
| Canada | Government of Canada | Government of Canada. (2017). About fetal alcohol spectrum disorder (FASD). Retrieved from https://www.canada.ca/en/public-health/services/diseases/fetal-alcohol-spectrum-disorder/about.html |
| Canada | First Nations and Inuit Health Committee, Canadian Paediatric Society, & First Nations, Inuit, and Metis Health Committee | First Nations and Inuit Health Committee, Canadian Paediatric Society, & First Nations, Inuit, and Metis Health Committee. (2002). Position statement: Fetal alcohol syndrome. <i>Paediatr Child Health</i> , 7(3), 161-174. Available at https://www.cps.ca/en/documents/position/fetal-alcohol-syndrome |
| Canada | The Centre for Addiction and Mental Health | CAMH. (2018). Fetal alcohol spectrum disorders (FASD). Retrieved from http://www.camh.ca/en/health-info/mental-illness-and-addiction-index/fetal-alcohol-spectrum-disorder |
| Canada | Paukuutit Inuit Women of Canada | Paukuutit Inuit Women of Canada. (2018). Fetal Alcohol Spectrum Disorder. Retrieved from https://www.paukuutit.ca/health/fetal-alcohol-spectrum-disorder/ |
| Canada | Canadian Observatory on Homelessness | Canadian Observatory on Homelessness. (2017). Fetal Alcohol Spectrum Disorder. Retrieved from http://homelesshub.ca/about-homelessness/substance-use-addiction/fetal-alcohol-spectrum-disorder |
| Canada | The College of Family Physicians of Canada | Trusler, M. Trusler, K., Mousmanis, P., Grier, E., & Graves, L. (2014). <i>FASD: How fetal alcohol spectrum disorder impacts the life course trajectory of children, teens and adults</i> . Retrieved from http://www.cfpc.ca/uploadedFiles/Directories/Committees_List/T55642_FASD_Trajectory_Handout_FMF_2014_QC.pdf |
| Canada [Ontario] | Registered Nurses Association of Ontario | The Registered Nurses' Association of Ontario (RNAO). (2014). <i>Submission to the Select Committee on Developmental Services</i> . Retrieved from |

| | | |
|------------------------------------|---|---|
| | | http://rnao.ca/sites/rnao-ca/files/RNAO_submission_to_Select_Committee_on_Developmental_Services.pdf |
| Canada [Ontario] | College of Dental Hygienists of Ontario Advisory | College of Dental Hygienists of Ontario Advisory. (2011). <i>College of Dental Hygienists of Ontario, CDHO Advisory Fetal Alcohol Spectrum Disorder 2011-09-01</i> . Retrieved from http://www.cdho.org/Advisories/CDHO_Advisory_Fetal_Alcohol_Spectrum_Disorder.pdf |
| Canada | Society of Obstetricians and Gynaecologists of Canada | Society of Obstetricians and Gynaecologists of Canada. (2010). Alcohol use and pregnancy consensus clinical guidelines. <i>Journal of Obstetrics and Gynaecology Canada</i> , 32(8). Available at https://sogc.org/wp-content/uploads/2013/01/gui245CPG1008E.pdf |
| International Organizations | | |
| Location | Agency | Reference |
| International | World Health Organization | World Health Organization. (2014). Protecting unborn babies from alcohol-related harm: Aboriginal women in Australia are taking the lead. Retrieved from http://www.who.int/features/2014/aboriginal-babies-alcohol-harm/en/ |
| International | World Health Organization: Canada | Popova, S., Lange, S., Chudley, A. E., Reynolds, J. N., & Rehm, J. (2018). <i>World Health Organization International Study on the Prevalence of Fetal Alcohol Spectrum Disorder (FASD): Canadian Component</i> . Toronto, ON: Centre for Addiction and Mental Health. Available at https://canfasd.ca/wp-content/uploads/sites/35/2018/05/2018-Popova-WHO-FASD-Prevalance-Report.pdf |
| USA | Centers for Disease Control and Prevention | Centers for Disease Control and Prevention. (2018). Basics about FASDs. Retrieved from https://www.cdc.gov/ncbddd/fasd/facts.html |
| USA | American Academy of Pediatrics | American Academy of Pediatrics. (2018). The facts. Retrieved from https://www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/fetal-alcohol-spectrum-disorders-toolkit/Pages/The-Facts.aspx |
| Australia | Australian Medical Association | Australian Medical Association. (2016). Fetal Alcohol Spectrum Disorder (FASD) – 2016. Retrieved from https://ama.com.au/position-statement/fetal-alcohol-spectrum-disorder-fasd-2016 |

| | | |
|-----------------------------|--|--|
| United Kingdom | NHS | NHS. (2017). Foetal alcohol syndrome. Retrieved from https://www.nhs.uk/conditions/foetal-alcohol-syndrome/ |
| New Zealand | Ministry of Health | Ministry of Health. (2015). <i>Taking action on fetal alcohol spectrum disorder (FASD): A discussion document</i> . Wellington: Ministry of Health. Available at https://www.health.govt.nz/system/files/documents/publications/taking-action-fetal-alcohol-spectrum-disorder-discussion-document-dec15.pdf |
| Other Definitions | | |
| Location | Agency | Reference |
| Canada | Kids Brain Health Network | Kids Brain Health Network. (2018). FASD FAQs. Retrieved from http://kidsbrainhealth.ca/index.php/quick-links/fetal-alcohol-spectrum-disorder/ |
| Ontario | FASD Waterloo Region | FASD Waterloo Region. (2018). What is FASD? Retrieved from https://www.fasdwaterlooregion.ca/learn-about-fasd/what-is-fasd |
| Ontario | Fetal Alcohol Spectrum Disorder Ontario Network of Expertise | Fetal Alcohol Spectrum Disorder Ontario Network of Expertise. (2018). What is FASD? Retrieved from http://www.fasdontario.ca/cms/about-us/what-is-fasd/ |
| USA | NOFAS | National Organization on Fetal Alcohol Syndrome. (2018). FASD. Retrieved from https://www.nofas.org/about-fasd/ |
| Academic Definitions | | |
| Location | Agency | Reference |
| Canada | - | Cook, J. L., Green, C. R., Lilley, C. M., Anderson, S. M., Baldwin, M. E., Chudley, A. E., ... Rosales, T. (2016). Fetal alcohol spectrum disorder: A guideline for diagnosis across the lifespan. <i>CMAJ</i> , <i>188</i> (3), 191-197. doi: https://doi.org/10.1503/cmaj.141593 |
| Canada | - | Tait, C. L., Mela, M., Boothman, G., & Stoops, M. A. (2017). The lived experience of paroled offenders with fetal alcohol spectrum disorder and comorbid psychiatric disorder. <i>Transcult Psychiatry</i> , <i>54</i> (1), 107-124. https://doi.org/10.1177/1363461516689216 |

| | | |
|---------------|---|---|
| Australia | - | Reid, N., Shelton, D., Warner, J., O'Callaghan, F., & Dawe, S. (2017). Profile of children diagnosed with a fetal alcohol spectrum disorder: A retrospective chart review. <i>Drug Alcohol Rev</i> , 36(5), 677-681. https://doi.org/10.1111/dar.12519 |
| Canada | - | Flannigan, K., Pei, J., Stewart, M., & Johnson, A. (2018). Fetal Alcohol Spectrum Disorder and the criminal justice system: A systematic literature review. <i>Int J Law Psychiatry</i> , 57, 45-52. https://doi.org/10.1016/j.ijlp.2017.12.008 |
| Canada | - | Pei, J., Baugh, L., Andrew, G., & Rasmussen, C. (2017). Intervention recommendations and subsequent access to services following clinical assessment for fetal alcohol spectrum disorders. <i>Res Dev Disabil</i> , 60, 176-186. doi: https://doi.org/10.1016/j.ridd.2016.11.007 |
| Canada | - | Lange, S., Rovet, J., Rehm, J., & Popova, S. (2017). Neurodevelopmental profile of Fetal Alcohol Spectrum Disorder: A systematic review. <i>BMC Psychol</i> , 5(1). https://doi.org/10.1186/s40359-017-0191-2 |
| International | - | Popova, S., Lange, S., Probst, C., Parunashvili, N., & Rehm, J. (2017). Prevalence of alcohol consumption during pregnancy and Fetal Alcohol Spectrum Disorders among the general and Aboriginal populations in Canada and the United States. <i>Eur J Med Genet</i> , 60(1), 32-48. https://doi.org/10.1016/j.ejmg.2016.09.010 |
| Canada | - | Rai, J. K., Abecassis, M., Casey, J. E., Flaro, L., Erdodi, L. A., & Roth, R. M. (2017). Parent rating of executive function in fetal alcohol spectrum disorder: A review of the literature and new data on Aboriginal Canadian children. <i>Child Neuropsychol</i> , 23(6), 713-732. https://doi.org/10.1080/09297049.2016.1191628 |
| International | - | Lange, S., Probst, C., Gmel, G., Rehm, J., Burd, L., & Popova, S. (2017). Global prevalence of fetal alcohol spectrum disorder among children and youth: A systematic review and meta-analysis. <i>JAMA Pediatr</i> , 171(10), 948-956. doi: 10.1001/jamapediatrics.2017.1919 |
| USA | - | Murawski, N., Moore, E. M., Thomas, J. D., & Riley, E. P. (2015). Advances in diagnosis and treatment of fetal alcohol spectrum disorders: From animal models to human studies. <i>Alcohol Res</i> , 37(1), 97-108. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4476607/ |