

FASD HUB
Australia

Language Guide

This guide is intended to provide suggested language for use in conversations, presentations and reports about FASD in Australia

Language Guide

Adapted from the FASD Language Guide developed as part of the Looking After Each Other: A Dignity Promotion Project. Information can be found on the Manitoba FASD Coalition website <http://www.fasdcoalition.ca/looking-after-each-other-project/fasd-language-guide/>

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This guide is available on the FASD Hub Australia website <https://www.fasdhub.org.au/>

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Language Guide

Fetal Alcohol Spectrum Disorder (FASD) is a condition that has lifelong impacts on individuals, their families, carers and the wider community.

FASD is only one part of a person's identity. People with FASD have the same hopes and fears as others. They have families who love them and friends they cherish. They have strengths and difficulties as we all do. Just like other people with or without a disability, they enjoy a variety of activities and can make a valuable contribution to their community.

The language we use has a powerful impact on the way people with FASD are perceived and are treated. This guide is intended to suggest language that can be used in conversations, presentations and reports about FASD in Australia. The use of such language is intended to enhance respectful engagement with those with FASD and their families to reduce the negativity and stigma often associated with FASD.

People with FASD

Please use	Instead of	Why
Person with FASD or living with FASD	Suffering with/from or damaged by	<p>This terminology suggests that people with FASD are unable to live happy, meaningful and productive lives. Most people with disabilities prefer others to recognise their strengths and successes as well as acknowledging their need for support and assistance with some areas of their lives.</p> <p>In Australia, best practice language is to use 'person with disability' or 'people with disability'. Many Australian disability networks recommend use of the term 'person without a disability' rather than 'able-bodied'. They also refer to 'person living with disability' and 'person with lived experience of disability'.</p> <p>Whilst the importance of person first language is paramount it is not necessary to avoid using the terminology 'living with disability'. All too often FASD is not seen as a disability but rather a behaviour disorder and this leads to inappropriate responses.</p> <p>'Living with FASD' has merit, that is, as a term that is inclusive of people with FASD and those who are carers or family members. For this reason, it was agreed that the term 'living with FASD' should be included in the Australian FASD Language Guide.</p>
Person with FASD or living with FASD	FASD kids	<p>'Person first' language is the most widely accepted terminology in Australia. Person centred language recognises that the individual is more than their disability. It reflects the difference between referring to 'a person with an addiction' rather than an 'addict'.</p>
Person with FASD or living with FASD	(Innocent) victim OR injured	<p>These words imply that there has been a perpetrator and is very negative towards mothers. Many people with FASD do not blame their mothers, and don't want others to. Birth mothers do not seek to harm their children. This language jeopardises both women's willingness to seek help and children's future relationships with their mother.</p>
Affected by/impacted by	Afflicted by	<p>The term 'afflicted' implies that a person with FASD is weak or should be pitied. It does not recognise that a person with FASD is more than their disability. People without FASD such as the person's family, can also be impacted by FASD. The alternative terms are descriptive and more neutral in tone.</p>
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People with FASD

Please use	Instead of	Why
Support person/people External brain		<p>The term 'external brain' has been used in the past to explain how people with FASD may require support by someone else at times to assist with deficits in certain areas of brain functioning eg. memory or problem solving. However, there is some concern about the use of this term and that it may imply that someone with FASD needs a whole new brain to be 'normal'.</p> <p>Many people with disabilities require assistive devices which may include a guide dog, hearing aids, a wheelchair etc. to function and have the opportunity to reach their potential. For people with FASD a support person who can help with a range of activities such as daily living, planning, interviews, making some decisions and help understanding what is required of them in different circumstances is essential. This does not mean that a person with FASD requires a support person at all times or that the person cannot have some freedom. Following input from parent & carers and health professionals it was agreed that the term 'external brain' should be retained in this language guide.</p>
Neurodevelopmental impairment Neurodevelopmental disorder Intellectual disability	Mentally disabled	<p>The Australian Guide to the diagnosis of FASD refers to neurodevelopment impairment and guidelines for other conditions also use 'neurodevelopmental disorder'.</p> <p>In Australia, the term 'Intellectual disability' refers to an identified disability occurring in the developmental phase of life (ie. before the age of 18) and is characterised by below average intellectual functioning and impairments in adaptive behaviour.</p> <p>Whilst all individuals with FASD have significant impairments in adaptive behaviour, not all will be diagnosed with below average intellectual functioning (IQ)</p>

Women who drank alcohol during pregnancy

Please use	Instead of	Why
FASD is caused by prenatal alcohol exposure	FASD is caused by maternal alcohol use or drinking in pregnancy	Changing the term 'prenatal alcohol exposure' places the emphasis on the substance of alcohol rather than on the behaviour of the birth mother as the centre of the harm.
Reported alcohol use/consumption	Admitted to alcohol use	The term 'admitted' has legal connotations and implies a confession of wrong doing. It also has a moral judgement undertone. The term 'reported' may be more appropriate. To make a diagnosis under the Australian Guide it is necessary to 'confirm' prenatal alcohol exposure which may come from maternal report or other sources e.g. medical records.
Person who drank alcohol and/or took other drugs OR If an alcohol use disorder has been diagnosed and relevant to the topic presented, it should be 'person with confirmed alcohol use disorder'	Alcoholics/addicts OR Women who choose to drink	Most women do not intentionally seek to harm their unborn children. Many women will be unaware of their pregnancy when drinking alcohol. Other factors such as pre-pregnancy alcohol consumption, a lack of knowledge about the effect of alcohol, stress, domestic violence, loneliness, pressure from partners. Mental health issues and difficulties abstaining from alcohol use to an alcohol use disorder can impact on alcohol use during pregnancy.
Do not use these terms	Don't care about their children OR Bad parents OR Poor choices OR Irresponsible OR Child abusers	

FASD in general

Please use	Instead of	Why
Preventable	100% preventable	While theoretically possible, stating that FASD is 100% preventable is an over simplification of a complex issue. We know that many pregnancies are unplanned. For many women who are planning a pregnancy or who find out they are pregnant, quitting is a simple choice. For other women, complex issues make total abstinence from alcohol more difficult. Use of the term '100% preventable' can be seen as further shaming these women.
Not drinking alcohol during pregnancy is the safest option	Just one drink can cause FASD	<p>The brain continues to develop throughout pregnancy and alcohol exposure at any time can damage different parts of the brain. There is no level of prenatal alcohol exposure that can be guaranteed to be completely 'safe' or 'no risk' to drink alcohol during pregnancy.</p> <p>However, there is no scientific evidence that one alcohol drink during an entire pregnancy will cause harm. The NHMRC published Australian Guidelines to reduce health risks from drinking alcohol includes the following: Guideline 4</p> <ul style="list-style-type: none"> • For women who are pregnant or planning a pregnancy, not drinking is the safest option. • For women who are breastfeeding, not drinking is the safest option.
A balanced approach on both the strengths and difficulties of a person with FASD	Focusing on the challenges of FASD	Sole focus on challenges or difficulties does not give the 'whole picture' of a person with FASD. Persistent attention to only these aspects of their life reinforces the view of the general public and potentially caregivers, that people with FASD cannot do anything well. Every person with FASD has strengths and positive attributes that should be acknowledged.
Neurodevelopmental impairment as the basis for diagnosis	Focusing on facial features	Focus on facial features leads many to assume that this is essential to a diagnosis of FASD and that is all there is to a diagnosis. Only a small percentage of people who have been prenatally exposed to alcohol will have sentinel facial features, however everyone with FASD will have a neurodevelopmental impairment. The range of impairment will vary from person to person.
FASD	FAS, pFAS, ARND, ARBD, FAE	<p>The Australian Guide to the diagnosis of FASD was published in 2016. The diagnosis of FASD in Australia is divided into two sub-categories:</p> <ul style="list-style-type: none"> • FASD with three sentinel facial features • FASD with less than three sentinel facial features <p>Diagnostic terms used outside of Australia and previously used diagnostic terms should not be used.</p>
Secondary issues, effects or risks	Secondary disabilities	This term has been used for decades to describe adverse life experience for people with FASD. New science is suggesting that mental health concerns and addictions may be a primary part of FASD. Other issues such as homelessness, poor educational outcomes and engagement with the justice system are not biologically driven and should not be termed a disability. They should be recognised as significant secondary risks and issues that have impacts on the life of a person with FASD.

Language and age

While people with FASD can have an intelligence score in the average range, it is important to consider their language and communication skills together with their overall neurocognitive profile. People with FASD may appear as competent communicators, and some will be – they will be able to understand what is said to them, and they will be able to express themselves with appropriate words and sentence structures.

For many people with FASD however, the act of communicating can be hard. They may appear chatty, but an underlying language disorder, and/or difficulties with skills in, for example, working memory, speed of processing, impulse control, and inferring meaning can make it difficult for an individual to be successful in their interactions with others. They may find it hard to accurately process what is being said, interpret the social context, and provide a response, all in real time. This means modifications may be helpful, such as keeping language simple, taking extra time, and teaching social skills explicitly.

While it is important to consider the developmental age of a person with FASD when we are communicating with them, it is also important to remember their chronological age. The way we communicate with people with FASD and their families needs to be respectful and in a way that is not misinterpreted as ‘talking down to the person’. FASD is a life-long condition and it is important to recognise their increasing age, changing interests and level of independence when communicating with individuals with FASD.

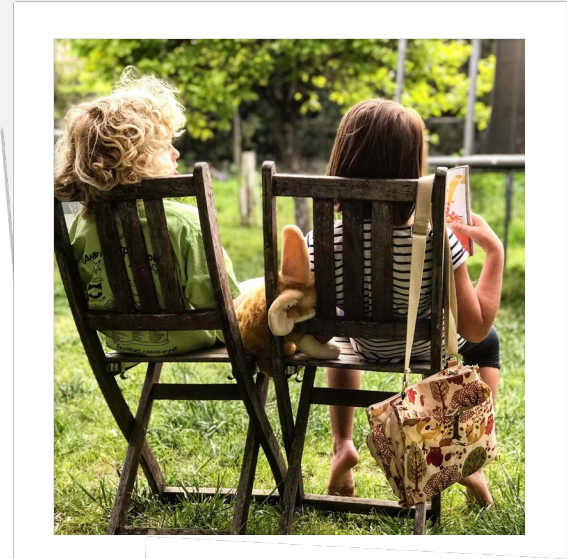
For more information about language and other neurocognitive impairments please refer to:

[FASD Hub Australia Brain impairment in FASD](#)

[NOFASD Parent Toolkit](#)

The [FASD Hub website](#) provides information on FASD for Australian health and other professionals (including justice, education, child protection and disability services), parents and carers, researchers and policy makers.

FASD Hub Australia is certified by the international body [Health on the Net](#) as providing transparent and reliable health information.



If you have any questions about the language used in this Guide please [email us](#).