



FASD: Preferred UK Language Guide

Created as part of the Seashell and The National Organisation for FASD partnership. Funded by the Department for Health and Social Care with input from experts and those with lived experience.

Funded by

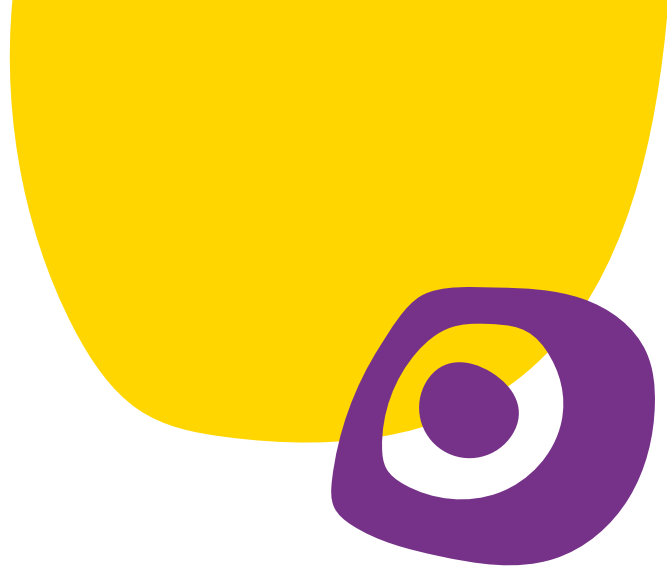


Department
of Health &
Social Care

Seashell |



NATIONAL
ORGANISATION
— F O R —
FASD



A little bit about the FASD: Preferred UK Language Guide

This guide was produced by Seashell and The National Organisation for FASD as part of “Resources and Training to Support Children and Young People with FASD,” funded by the Department of Health.

The project includes: development of this FASD: Preferred UK Language Guide, a Best Practice in FASD Training Guide, development of a 1-day “Introduction to FASD” training; a “Me and My FASD Toolkit” – including a website (www.FASD.me); and a 3-day training. The toolkit and 3-day training are focused on helping those with FASD understand and own the diagnosis.

Special thanks to our project advisors

Experts: Dr Carolyn Blackburn, Joanna Buckard, Sandra Butcher, Dr Cassie Jackson, Sharon Jackson, Michelle Jones, Susan McGrail, Janet Griffin, Dr Raja Mukherjee, Brian Roberts, Dr Inyang Takon. Adults and Young Adults with FASD: Tolka Butcher, Bailie Jordan-Collins, Nyrene Cox, Rossi Griffin, Lee Harvey-Heath, Andy Jackson, Rachel Jackson, Claire McFadden, Georgia Roberts.

With thanks also to: Joe Booker, Martin Butcher, Maria Catterick, Caroline Gosling, Emily Kellett, Maria McGrath, Vimia Ramrakhiani, Samantha Royle.

Thanks also to the 136 people who sent us comments via our survey, the comments and feedback confirmed that this language guide represents consensus of a wide range of individuals with FASD, their families and professionals.

Special thanks to Joanna Buckard for helping to draft this guide and for collating all the feedback and input into this format.



A little bit about Seashell

Our charity is dedicated to providing a creative, happy and secure environment for children and young people with complex and severe learning disabilities which include little or no language abilities.

With the expertise of our specialist teachers, care staff, on-site therapy team, assistive technologists, swimming teachers and sports coaches, our students learn how to express themselves, engage with the world around them, become more independent and live safe, creative and fulfilling lives.

A little bit about The National Organisation for FASD

The National Organisation for FASD (formerly NOFAS-UK) is dedicated to supporting people affected by Fetal Alcohol Spectrum Disorder (FASD), their families and communities. It promotes education for professionals and public awareness about the risks of alcohol consumption during pregnancy.

National FASD, founded in 2003, is a source for information on FASD to the general public, press and to medical and educational professionals. Our programmes are focused on promoting wellbeing for those with FASD and their families, providing materials for GPs, midwives, social workers, educators and creating cutting edge resources and experiences for people with FASD.

Aim

This is a guide. The goal is to avoid stigmatising or blaming language. Usage is highly personal - above all we respect how individuals with FASD choose to identify themselves.

We understand some of the preferred terms are not currently widely used. The goal is to make them better known.

Common description of FASD

FASD results when prenatal alcohol exposure affects the developing brain and body. FASD is a spectrum. Each person with FASD is affected differently. While more than 400 conditions can co-occur, FASD is at its core a lifelong neurodevelopmental condition. All people with FASD have many strengths. Early diagnosis and appropriate support are essential, especially for executive functioning.

Please say	Don't say	Why?
FASD	FAS, ARND, ARBD, pFAS, NDPAE or foetal alcohol	<p>FASD is becoming used as the diagnostic term in England. The new NICE Quality Standard is based on Scottish SIGN guidance. This uses the diagnostic terms:</p> <ol style="list-style-type: none">1. Fetal Alcohol Spectrum Disorder with sentinel facial features (formerly FAS)2. Fetal Alcohol Spectrum Disorder without sentinel facial features (formerly pFAS, ARND, ARBD, or NDPAE). <p>The acronym can be used to avoid giving away the causality of the condition if people prefer to keep that private. Use FASD rather than shortening to 'foetal alcohol' for this reason.</p> <p>Note: Fetal is the international medical usage and is used by NICE and SIGN.</p>

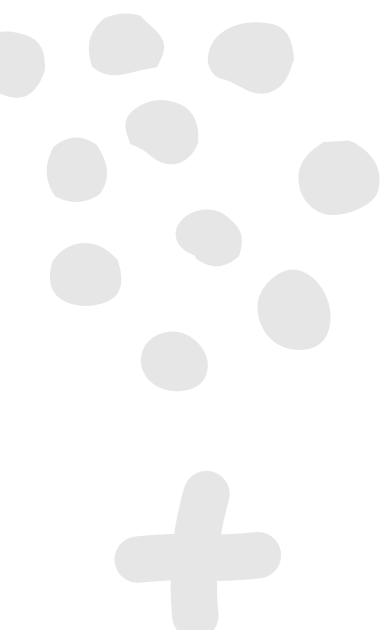
Please say	Don't say	Why?
Neurotypical brain	Normal brain	All brains are different, there is no typical.
FASD is the result of an alcohol-exposed pregnancy	FASD is caused by birth mother drinking alcohol	Focus on alcohol as the catalyst, not the consumer of it.
Person with FASD Young people with FASD Adults with FASD	FASD kids or FASling	Person first language emphasises that an individual is more than just their FASD diagnosis.
Support person Supporting adult Cognitive coach	External brain	Just because someone with FASD often needs others to support them in various ways, it doesn't mean they don't have a brain.

Please say	Don't say	Why?
They can't comply	They won't comply	Behaviour of people with FASD should not be viewed as an intentional choice not to comply. This does not mean that they cannot learn various coping strategies. But in the moment they may be unable to comply due to the way their brain is processing information.
People with FASD are affected differently	FASD kids are... These kids...	People with FASD are, like everybody, unique with their own set of skills and challenges. It is important to use language that refers to people with FASD so that FASD is understood to be lifelong and not as a condition that only affects children.
Lacks impulse control	Steals, lies	Difficulties with impulse control should be the focus rather than the implication of a wilful action – this can lead to serious issues, including with the justice system, if the cause is not clearly understood.
Associated difficulties Associated conditions Associated disabilities	Secondary disabilities	Positive language and strengths-based approaches should always be promoted.



A person is not defined by their diagnosis.

Please say	Don't say	Why?
Families need support to learn FASD-informed strategies	The child is ok at school and is dysregulated at home, therefore behaviours must be the parents' fault.	Parents, carers, guardians or families should not be blamed for children being dysregulated in one setting and not another. The reasons for this are complex. Families are the child's first and best advocates and need to be carefully listened to and supported in their role.
They have FASD	They are FASD FASD sufferer Suffers with FASD Victim	A person is not defined by their diagnosis. Whilst important to acknowledge the challenges posed by FASD, it is not accurate to imply it's a 'life sentence'. With appropriate support and understanding people with FASD can live positive lives.

Please say	Don't say	Why?
<p>Confabulates</p> <p>Compensates for memory loss</p>	<p>Lies</p>	<p>Lying implies a wilful action.</p> <p>Confabulation refers to the production of false memories without the intent to deceive. False memories may include exaggerations of actual events, inserting memories of one event into another time or place, recalling an older memory but believing it took place more recently, filling in gaps in memory or the creation of a new memory of an event that never occurred.</p>
<p>FASD is a spectrum</p> 	<p>FASD is a learning disability</p>	<p>Some with FASD have a learning disability (defined as an IQ <70) but most do not.</p> <p>The suggestion that people with FASD without a learning disability are less affected is an over simplification.</p> <p>All with FASD will require support for executive functioning challenges from people they have learnt to trust.</p>

Please say	Don't say	Why?
Family affected by FASD	FASD family	Person-first language.
Dysregulation They are dysregulated Unable to process information or control impulse	Violent, abusive	<p>Dysregulation is the inefficient functioning of the brain networks that controls behaviour and/or emotions. This can lead to decreased impulse control and emotional arousal from challenges processing both internal and external inputs. This may interfere with daily functioning at work and in private lives. This is commonly referred to as 'affect' or 'emotional' dysregulation but the definition can be wider.</p>
Neurodevelopmental disorder Cognitive disorder Executive functioning disorder Lifelong disorder Spectrum of coexisting disorders	FASD is a behavioural disorder	<p>FASD is a brain-based disability. There shouldn't be the implication that FASD is about wilfully poor behaviour where there has been conscious choice.</p> <p>Nor that behaviour seen is as a result of poor parenting, or classroom management technique.</p>

Please say	Don't say	Why?
<p>A person with FASD is susceptible to mental health difficulties</p> <p>They live with a mental health condition</p> <p>They are being treated for a mental health condition</p> <p>They experience mental health difficulties</p> <p>They are vulnerable to...</p>	<p>They have poor mental health because of birth mum's drinking in pregnancy.</p> <p>They are schizo</p> <p>They are bipolar</p>	<p>It is important to focus on alcohol as the catalyst, not the consumer of it. Person first language. A person is not defined by their diagnosis. Language around mental health conditions can further stigmatise.</p> <p>For more information please see: mentalhealth.org.uk/blog/whylanguage-we-use-describe-mental-healthmatters.</p>
<p>They are a person with FASD with autistic traits</p> <p>They have FASD with associated ADHD</p> <p>ASD is secondary to FASD</p> <p>They have FASD and attachment/trauma difficulties or disorder</p>	<p>They are autistic and has FASD</p> <p>They have ADHD because of mum's drinking.</p> <p>Attachment and developmental trauma are of primary importance.</p>	<p>When discussing co-existing conditions, FASD is the primary diagnosis so should be used first as any management of the condition must be FASD-informed for it to be effective.</p> <p>New research indicates that any interventions, therapies and strategies for those with both FASD and trauma/attachment must be FASD informed to be effective. See: tinyurl.com/AlanPriceFASDTrauma.</p>



“

**It is important to focus
on alcohol as the catalyst,
not the consumer of it.**

The following terms should be used with caution

When working with a person with FASD please use their preferred terms.

Term	Discussion points A	Discussion points B
Disability Difficulty	<p>Some people believe that the term disability should be empowered rather than avoided.</p> <p>People with FASD have a neuro-disability and many individuals with the condition may need additional support into adulthood.</p> <p>Some people believe if the word disability is removed, it reduces the support options - i.e. social care, financial, education, housing, etc. - as it gives weight to the issues.</p>	<p>Some people consider the medical model approach to FASD outdated, as it focuses on treatment of patients and considers the disability within the person. Instead they promote a social model of disability which focuses on the environment as the inhibitor of learning.</p>
FASD is preventable	<p>FASD is caused by prenatal exposure to alcohol, however to say it is entirely or 100% preventable is an over-simplification as there will be unplanned pregnancies, etc.</p>	<p>Through societal education and support many cases of FASD can be prevented.</p> <p>It is important to consider the identity of a person with FASD and their acceptance of how their condition occurred.</p>

Term	Discussion points A	Discussion points B
Meltdown	Some people prefer to use the terms episode, fizzy head, need to reset.	Some people use dysregulated. It can depend on the developmental age of the individual and the situation.
Disorder Condition Impairment	Some people use the term disorder when it is used within the title, i.e. SPD.	Some people prefer to use the term condition and refer to specific impairments.
Learning disability	Some people with FASD do have a learning disability – meaning they have an IQ less than 70.	Learning disability should be used with caution because most people with FASD do not have a learning disability. However, IQ is not a good predictor of executive functioning or adaptive behaviour. Having an IQ above 70 should not be a barrier to the services required. Those with IQs under 70 have many talents that should be recognised.
Brain damage	Brain injury Developmental Disorder	FASD results from the teratogenic effect alcohol has on the central nervous system as it's developing. This may have a permanent effect on the functionality of the individual. Some people with FASD will have been exposed prenatally to alcohol and then experienced trauma and neglect, further impacting the effect on the brain.

Example sentences

“

My child was diagnosed with FASD. Previously his diagnosis would have been FAS (Foetal Alcohol Syndrome). The new diagnostic term is FASD with sentinel facial features.

“

People on the FASD spectrum have many strengths.

“

FASD is caused by alcohol-exposed pregnancies.



“

**Our family has
been affected
by FASD.**



“

**Life can be
a challenge
for someone
with FASD.**



“

**Pat has
FASD.**



“

**I have FASD. My original
diagnosis was ARND but
under the new diagnostic
terms, the diagnosis is
FASD without sentinel
facial features.**

Glossary



Term	Formal Term	Explanation
ARBD	Alcohol-Related Birth Defects	<p>ARBD includes medical conditions linked to prenatal alcohol exposure such as: heart, kidney, and bone problems and other malformations; difficulty seeing and hearing; and reduced immune function.</p> <p>Now known as FASD without sentinel facial features.</p>
ARND	Alcohol-Related Neurodevelopmental Disorder	<p>ARND is a complex range of disabilities in neurodevelopment and behaviour, adaptive skills and self-regulation where there is confirmed PAE:</p> <p>Now known as FASD without sentinel facial features.</p>
PFAS	Partial Foetal Alcohol Syndrome	<p>At least 2 of the sentinel facial features present and neurobehavioural impairments.</p> <p>Now known as FASD without sentinel facial features.</p>



Term	Formal Term	Explanation
PAE	Prenatal Alcohol Exposure	Exposure to alcohol during pregnancy.
ND-PAE	Neurobehavioral Disorder Prenatal Alcohol Exposure	Diagnostic and Statistical Manual of Mental Disorders (DSM–5) includes the psychiatric diagnosis, ND-PAE. People who meet criteria for an FASD diagnosis may also meet criteria for ND-PAE.
SPD SID	Sensory Processing Disorder Sensory Integration Disorder	SPD is a neurological disorder in which the sensory information that the individual perceives results in inappropriate responses.
ASD	Autism Spectrum Disorder Autism	Autism is a developmental disorder that is characterised by difficulty in social interaction and communication and by restricted or repetitive patterns of thought and behaviour.

Term	Formal Term	Explanation
ADHD	Attention Deficit Hyperactivity Disorder	ADHD is a behavioural disorder that includes symptoms such as inattentiveness, hyperactivity and impulsiveness.
Teratogen	Teratogen	A teratogen is an agent which causes malformation of an embryo or foetus.
CCG	Clinical Commissioning Group	CCGs commission most of the hospital and community NHS services in the local areas for which they are responsible.
EHCP	Education Health and Care Plan	An EHCP (England) is for children and young people aged from 0 up to 25 who need more support than is available through special educational needs support already offered within the allocated mainstream budgets. EHC plans identify educational, health and social needs and set out the additional support to meet those needs.



Term	Formal Term	Explanation
NICE	National Institute for Health and Clinical Excellence	NICE provides national guidance and advice to improve health and social care.
SIGN	Scottish Intercollegiate Guidelines Network	SIGN develops evidence based clinical practice guidelines for the National Health Service (NHS) in Scotland.

People can be signposted to the FASD UK Alliance, an informal coalition of groups providing support and resources across the UK: www.FASD-UK.net

The National Organisation for FASD

Email: info@nationalfasd.org.uk

Website: www.nationalfasd.org.uk

Seashell

Email: info@seashelltrust.org.uk

Website: www.seashelltrust.org.uk

Funded by



Department
of Health &
Social Care

Seashell

