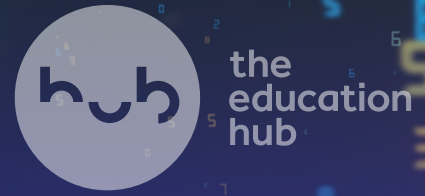


An introduction to fetal alcohol spectrum disorder



School resources

In New Zealand and around the world, the concern about fetal alcohol spectrum disorder (FASD) as a lifelong neuro-disability has gained momentum in the last two decades¹. The exact size of the population living with the effects of FASD in New Zealand is unknown because, despite calls for a prevalence study, no study has yet been undertaken. Estimates of general population rates of FASD in the United States range from 2% to as high as 5%, and an international meta-analysis put rates of prevalence in New Zealand at similar levels (about 21 per 1000)². Anecdotally it is suggested that in New Zealand up to 3000 babies are born each year prenatally exposed to alcohol³. It is therefore likely that most teachers in New Zealand and around the world will knowingly or unknowingly come across students in their classes who are living with FASD.

What is FASD?

FASD is the result of gestational exposure to alcohol on a developing fetus. It occurs because alcohol is a teratogen, a toxic substance that can cause a baby's abnormal development whilst in the womb⁴. In New Zealand, the Ministry of Health advises that there is no known safe amount of alcohol consumption during pregnancy⁵. The severity and type of fetal damage caused by gestational exposure to alcohol will depend on factors including patterns of drinking, the timing of alcohol consumption, genetic influences, maternal age and health, and postnatal factors⁶.

FASD is an umbrella term that covers a range of neurodevelopment and physical abnormalities and may occur with or without facial abnormalities. Whilst alcohol can impact any part of the developing fetus's development, it is *always* related to the development of the brain. There are ten domains of brain development that are known to be affected by prenatal alcohol exposure. These domains are:

- Brain structure/neurology
- Motor skills
- Cognition
- Language
- Academic achievement
- Memory
- Attention
- Executive function, including impulse control and hyperactivity
- Affect regulation
- Adaptive behaviour, social skills or social communication

A diagnosis of FASD requires evidence of severe impairment of brain function in at least three of these domains⁷. Proven exposure of the fetus to alcohol in utero is also a requirement of diagnosis⁸.

Brain damage caused by FASD constitutes what are known as 'primary behaviour characteristics'. These are the behaviours that most clearly reflect the underlying brain injury, such as impulsivity, inattention, or

memory challenges. People living with FASD also experience 'secondary challenges', which are defensive behaviours that develop over time due to constant failure and poor self-esteem. These include anxiety, frustration, depression, and aggression. These behaviours may contribute to disengagement from school, which can lead to further challenges for the individual in society⁹. The earlier that primary behaviours can be identified, the more preventable are the secondary behaviours.

Individuals with FASD are diverse and unique, with differing patterns of physical, cognitive, behavioural, and social emotional functioning. The effects of FASD on an individual will continue across their lifespan¹⁰. Whilst FASD is often described by the individual impairments caused by the effects of alcohol on the developing brain, it is important to identify personal strengths, as these will become the foundations on which to develop personalised curricula, to encourage and develop further strengths, and to build emotional resilience¹¹.

Common myths about FASD

There are a number of myths about FASD and people who live with it, and it is important to address these myths in order to effectively support students with FASD in schools and the community.

FAS and FASD are interchangeable terms: In fact, these terms are distinct. The term Fetal Alcohol Spectrum Disorder or FASD was first used in 2000 by American researchers Streissguth and O'Malley¹² as an umbrella term that included a range of outcomes caused by prenatal alcohol exposure¹³. Within this range of outcomes is the specific diagnosis of Fetal Alcohol Syndrome or FAS. Unlike FASD, FAS can be diagnosed without confirmation of prenatal alcohol exposure, as the diagnostic criteria includes specific facial and growth differences which are most observable during early childhood¹⁴. Estimates suggest that FAS occurs about 0.5 to 3 per 1000 of population, compared with 10 or more in 1000 for FASD¹⁵.

People with FASD have characteristic facial features: As described above, there is a specific FASD called Fetal Alcohol Syndrome (FAS) that includes specific facial and growth measurements as part of the diagnosis. The facial features of a fetus form early in a pregnancy, in the first trimester, and evidence of the effects of prenatal alcohol exposure on the development of the facial features confirms the presence of alcohol during this specific window in the pregnancy¹⁶. However, the lifelong effects of FASD are more importantly determined by the effects of alcohol on the central nervous system or brain development, and the effects on the brain can occur at any stage of pregnancy.

All those with FASD have a low IQ: IQ is not a measure of FASD. Rather the converse is true, in that those with FASD regularly score within normal limits on measures of IQ. However, their IQ often does not match their academic ability due to the effects of FASD on other areas of functioning including life skills, communication skills, and [executive function](#) skills. Although students with FASD appear similar to their peers, the effects on these 'hidden' areas of their development mean that they have difficulty reaching their full academic potential¹⁷.

FASD is a childhood disorder: FASD is a lifelong disability, and there is no cure for it. Over a lifetime, the effects of FASD will change as a person grows and develops. However, while the physical features of FASD may diminish over time, the impairments to the brain will remain. Without knowledge and support, emotional, behavioural, and social problems will often get worse¹⁸.

FASD in the classroom

FASD is an individualised diagnosis and no two people with FASD will present in the same way. Research has shown that supporting those with FASD begins with the recognition that the behaviour that is presenting is a form of communication and a representation of need, rather than an act of will¹⁹.

There are certain generalised behaviours that teachers may choose to interpret as markers of the brain differences caused by FASD, sometimes called 'diff-abilities', which include:

- **Dysmaturity:** the student's behaviour is less mature than their chronological age. They may prefer to socialise with younger children than their peers, they may experience challenges with peer relationships, or they may act in a way more typical of younger children.
- **Inattention:** the student may not be able to focus for expected periods of time.
- **Impulsivity:** the student may act out, change focus quickly, or tend to act on a whim.
- **A lack of cause-and-effect thinking:** the student may not seem to learn from previous experiences, or display repeated behaviours.
- **Memory problems:** the student may experience an inability to retain learning from one day to the next, or even from one moment to the next. They may have difficulty retaining instructions between mat and desk, or can do something today but cannot remember tomorrow. They may also seem unable to tell the truth (known as confabulation, when a person with FASD makes up an answer as it is too hard to remember what actually happened).
- **Difficulties with decision making:** the student is seemingly unable to choose what to do and often defaults to what others are doing or to what they have always done.
- **Slower processing speed:** the student seems to struggle to 'get it', and they need time to think before answering or take a long time to respond.
- **Difficulties with abstract concepts such as maths, time and money:** the student is unable to hold onto ideas in their head without some form of concrete, discrete representation²⁰.

General strategies for supporting learners with FASD

Listed below are some phrases that families and whānau in Aotearoa New Zealand have suggested are useful in understanding their children and young people living with FASD²¹. They are included as helpful phrases for teachers to remember during their daily classroom practice.

- **'Can't not won't':** Remember that FASD is caused by brain damage. There are areas of functioning that are extremely challenged as a result. A seeming reluctance or refusal to do something is likely to be an inability to do it, based on differences in brain structure. Working from a 'can't not won't' perspective changes perception and encourages solution-focused support.
- **'Brain not blame':** If you find yourself making unhelpful judgements, remember this phrase. This sits alongside 'can't not won't'. It helps us re-interpret behaviour as brain-based and therefore needing support, rather than 'blaming' the child for the behaviour, which leads to consequences and punishment.
- **'Ten second kids/people in a one second world':** People with FASD need more time than others to process and understand. By providing time, we enable the person to show us what they can do.
- **'Gravel roads not highways':** Atypical neural pathways associated with FASD are easily disrupted. The neural pathways of children and adults with FASD do not function as typical neural pathways ('highways'), which means they may be easily distracted along the way. This can make reaching the end (a destination or objective) confusing, challenging and time-consuming. It is similar to a neurotypical person negotiating a gravel road: it is necessary to drive more slowly, think more, and be on the lookout for the unexpected.

- **‘Adapt the environment not the person’:** Safe, supportive environments are key for people with FASD to thrive. With appropriate support, students with FASD can and will succeed.
- **‘Short, simple, specific, slow’:** Effective communication that takes into account their difficulties with memory, their slower processing speed, and their need for concrete terms and representations is essential for people with FASD.
- **‘If it’s working, don’t change it!’:** If a support structure is working for a student with FASD, keep the experience the same to promote success. As soon as you make a change, it becomes a new experience, and therefore presents new difficulties and challenges for the student.

For more information on supporting students with FASD in the classroom and at school, see *Strategies for supporting students with FASD*. Remember that each person with FASD has strengths²². Seeking these out and ensuring the student can grow within their areas of strength will support them to develop other skills. When working with students with FASD, the words of this whakatauki are very apt: ‘Ko te ahurei o te tamaiti aroha o tātou mahi. Let the uniqueness of the child guide our work’.

Recommended further reading

More information and a selection of resources may be found at:

The [Eight Magic Keys](#).

<https://inclusive.tki.org.nz/guides/fetal-alcohol-spectrum-disorder-and-learning/>

<https://www.fasd-can.org.nz/about-us/>

<https://www.fasdhub.org.au/>

Endnotes

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Kirsty Griffith currently works as a Resource Teacher of Learning and Behaviour (RTLb), having completed her post graduate diploma in specialist teaching, Learning and Behaviour in 2012. She is studying towards a Masters of Educational and Developmental Psychology to provide her with a qualification enabling her to further support young people with FASD and other neurodiverse learners. She has a professional interest in FASD, ignited when teaching a young man many years ago. She was fortunate to visit schools in Alberta, Canada to gain an understanding of their support systems for those with FASD.



Tracey Jongens

Tracey is a mum, a doting grandmother, and a passionate educator. After more than three decades working in primary education, Tracey recently became Head of Department for Learning Acceleration at Te Aratai College (Linwood College) in Christchurch, New Zealand. Tracey has previously worked as a teacher trainer at the New Zealand Graduate School of Education (NZGSE) and as a Resource Teacher of Learning and Behaviour (RTLb). Her interest in FASD is both personal and professional. She has been raising awareness of FASD, particularly in education, for the last 12 years. Tracey is a founding member of FASD-CAN (www.fasd-can.org.nz), a New Zealand-based incorporated society founded to support families and caregivers of those living with FASD.