Beyond the Behaviour: An introduction to Fetal Alcohol Spectrum Disorder

Dr Leigh Henderson and Teesh Dowie-Lewis

SSPA Kai and Kōrero session

10 November 2026

FASD-CAN
Fetal Alcohol Spectrum Disorder
Care Action Network

What is FASD?

- A diagnostic term for a neurodevelopmental disorder caused by exposure to alcohol before birth
- Severe impairment of at least three brain domains
- Can result in complex physical, behavioural, learning and intellectual problems
- A life-long disorder which can not be ‘treated’ or ‘cured’ but can be accommodated



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FASD in Aotearoa

- No prevalence study
- Te Whatu Ora estimates 3-5% of population
- FASD-CAN has reviewed levels of prenatal alcohol exposure and gives a range of 2-5%
- Less than 5% of these are diagnosed
- ~50% of children in Oranga Tamariki care

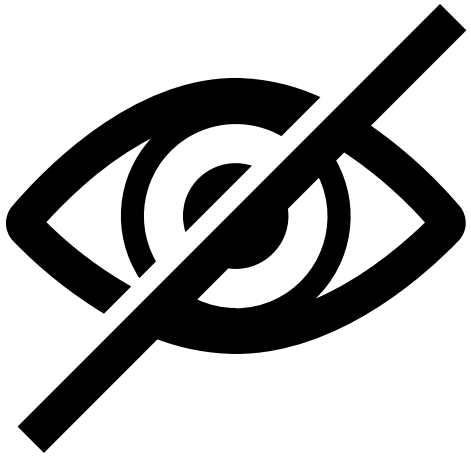


FASD is internationally recognised as the main contributor to non-genetic neurodisability in the world

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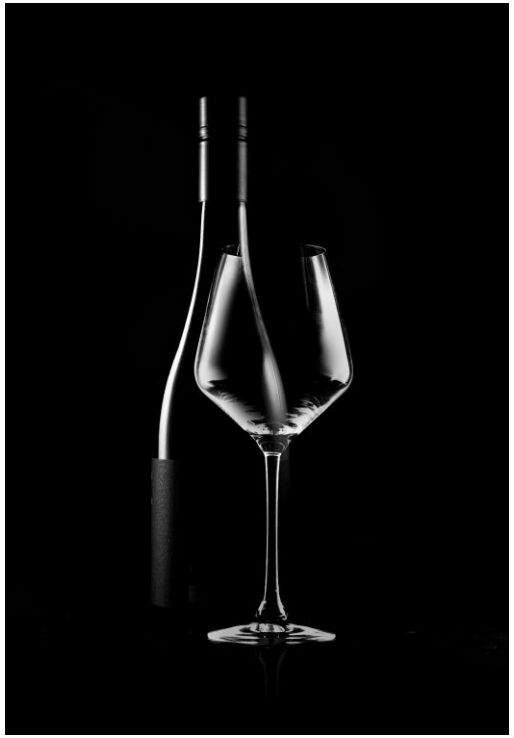
FASD – the hidden disability

- Less than 10% have the sentinel facial features
- Fewer than 20% have an intellectual disability
- Some have the ability to mask the full impact of their disability – articulate; appear knowledgeable; social



Pregnancy

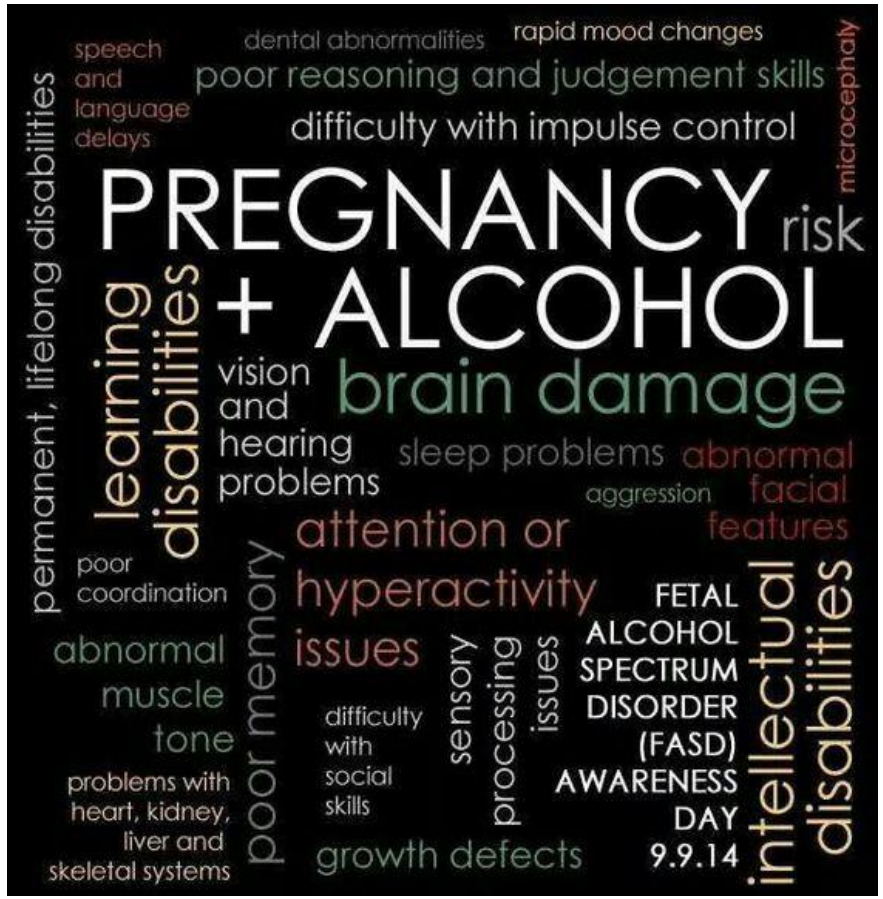
- 40-50% of pregnancies are unplanned in NZ
- 71% of women drank alcohol before pregnancy or becoming aware they were pregnant
- 23% of women drank alcohol during the first trimester
- 13% of women continued to drink after the first trimester
- 13,000 pregnancies exposed to alcohol per annum
- There is no safe limit of alcohol during pregnancy



Source: Microsoft stock image

Alcohol is a teratogen/toxin

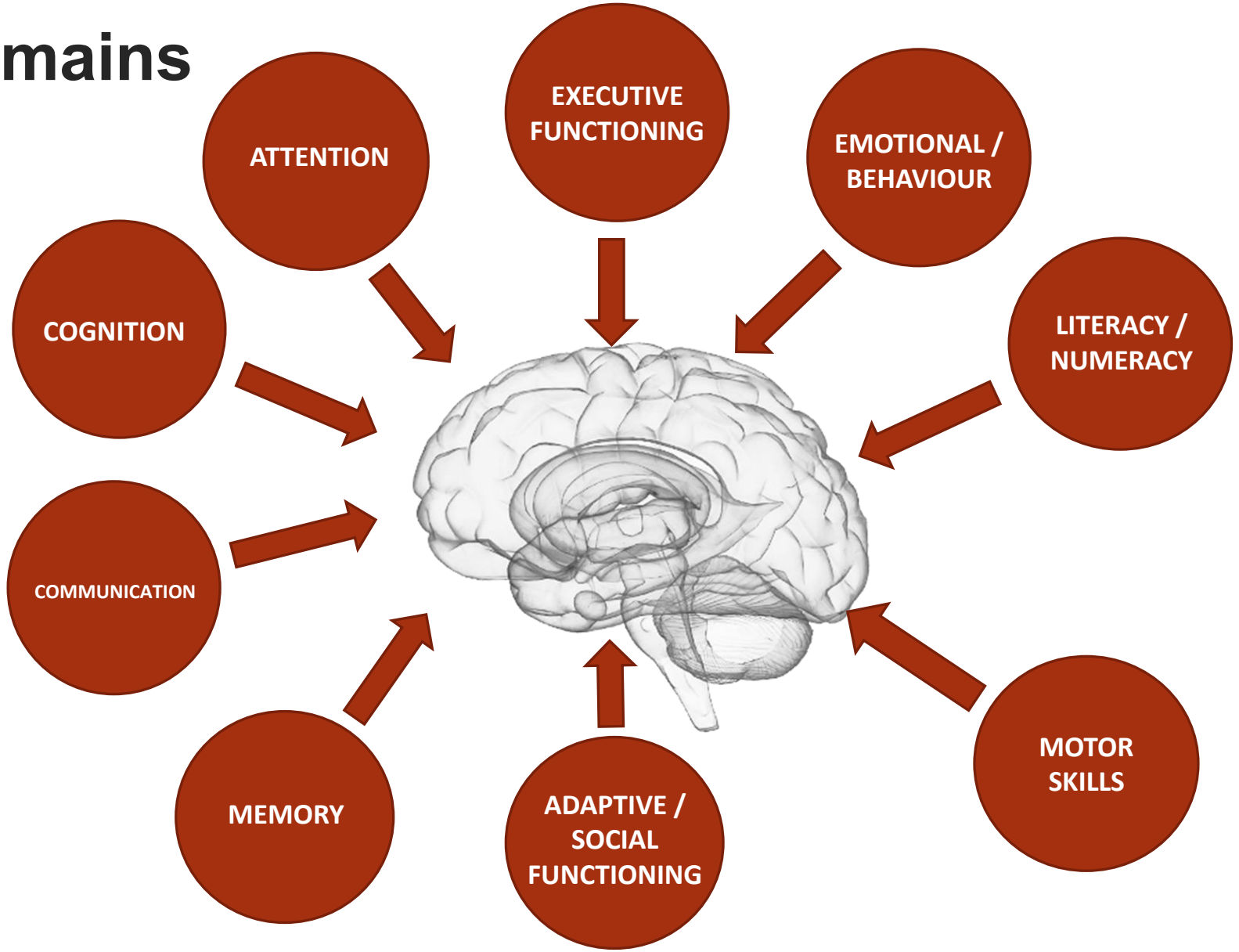
- Alcohol crosses the placenta and creates the same or higher blood alcohol level in the foetus as the mother
- Alcohol can impact the development of the foetus at any time during the pregnancy
- Alcohol affects brain, organ, and central and peripheral nervous system development in a foetus



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9 Brain Domains

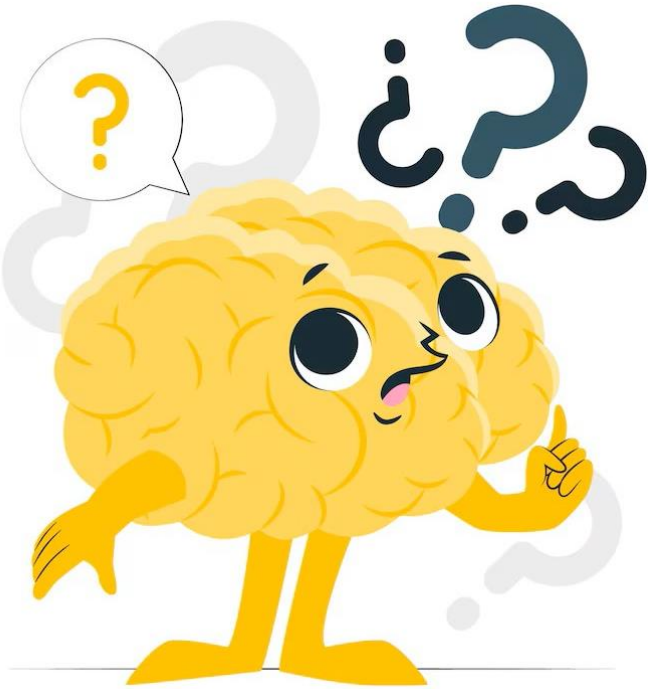


New Zealand
Diagnostic guidelines

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Executive Functioning Challenges

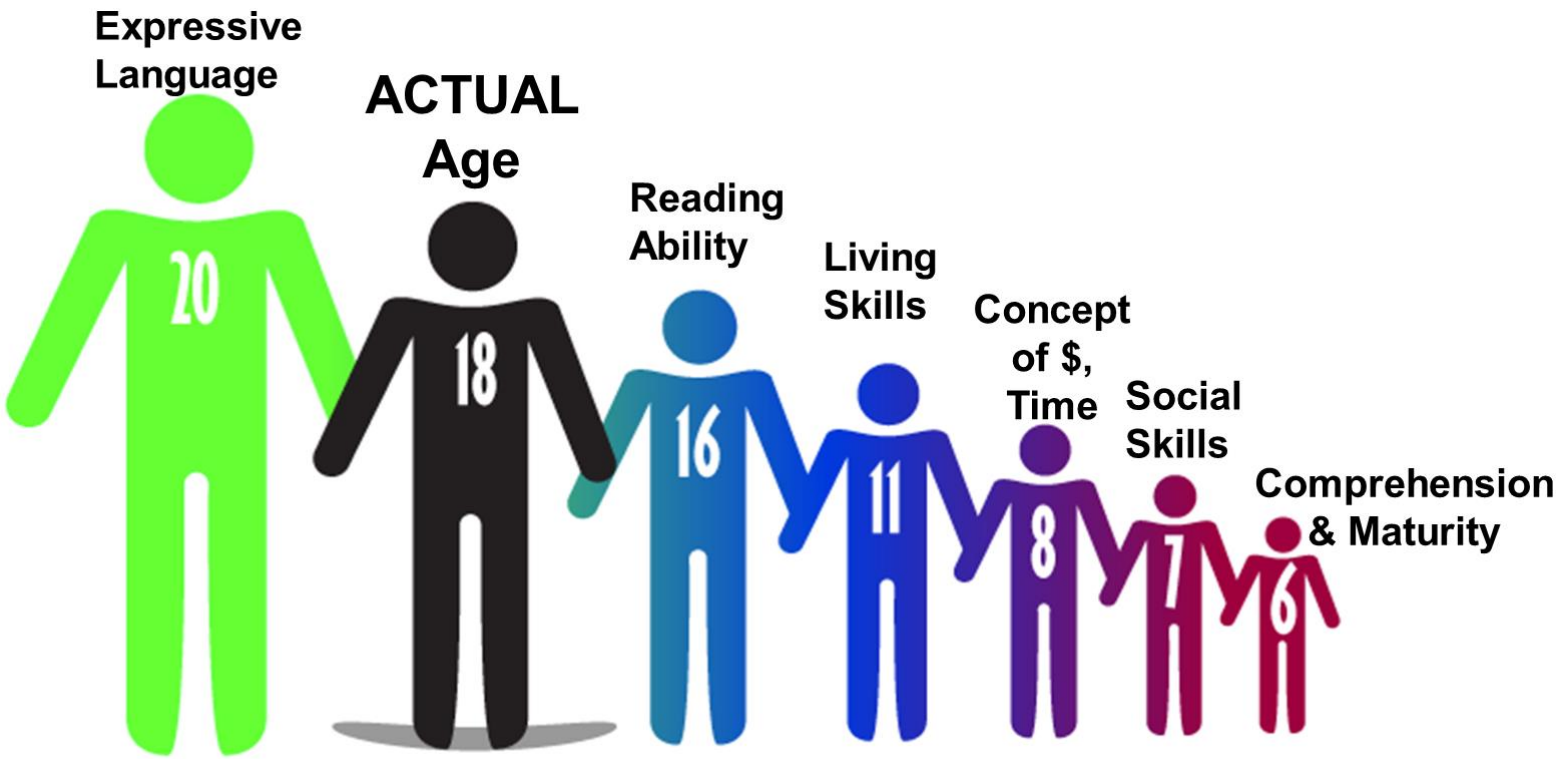
- Focus and attention/hyperactivity
- Perseveration/fixated-thinking
- Impulse control
- Planning and initiating
- Abstract concepts
- Organising and prioritising
- Problem solving
- Slow brain processing speed
- Working memory
- Understanding cause and effect



Adaptive Functioning Challenges

- communication skills
- self-care skills
- social skills
- school/home living tasks
- self-regulation and management
- personal health and safety

Age v maturity



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From the outside, we see, behaviours, risks and struggles:

- Impulsive behaviours
- Lying
- Stealing
- Risk-taking
- Inability or refusal to stick to a task / or start a task
- Refusal to do schoolwork
- Emotional regulation challenges
- Struggles in interactions with peers
- Difficulty sustaining relationships
- Illegal behaviours



Think 'Brain, not Blame'



- Language difficulties
- Concrete thinking
- Slower brain functioning
- Dysmaturity
- Poor inhibition control
- Difficulty with cause & effect (past/future)
- Inability to learn from experience
- Poor judgment
- Not understanding consequences
- Sensory issues
- Emotional dysregulation
- Stress (fight/flight) & fatigue
- Mental & physical health problems

FASD SECONDARY CHARACTERISTICS

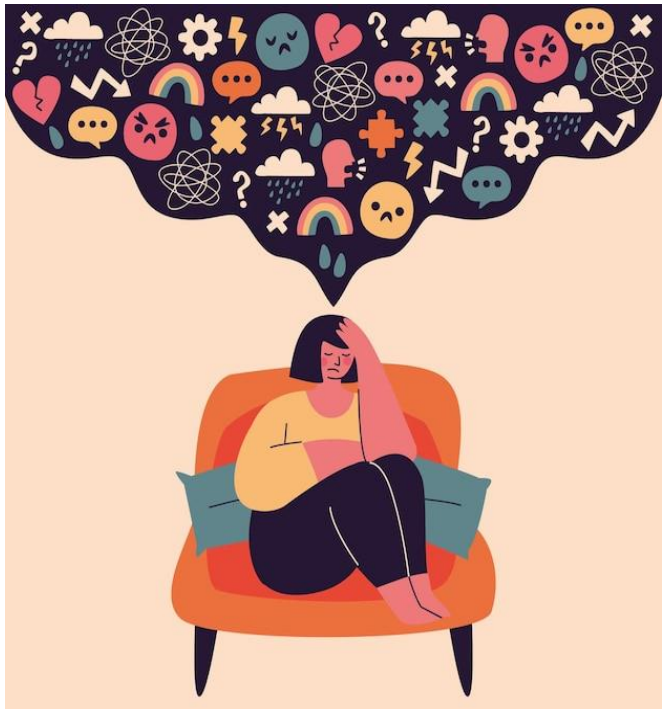
- mental health conditions
- disrupted school experience
- trouble with the law
- inappropriate sexual behaviour
- alcohol/drug problems
- inability to live independently
- homelessness – social isolation
- problems with employment
- problems with parenting
- exposure to violence/subject abuse

Image source: Microsoft stoc image

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FASD and Mental Health

- 90% of people have co-occurring mental health diagnoses, compared with 20% in the general population
- Depression (45%-50%) and anxiety (20%-40%) are the most common
- Higher rates of psychiatric disorders such as psychotic and personality disorders, conduct and oppositional defiance disorders
- People with FASD are more likely to have significantly higher Adverse Childhood Experience (ACE) scores than non-FASD people
- Suicide and suicide ideation are significantly higher than the general population and occur at earlier ages



What Works in FASD Land

- Communication FASD-style
- Reframing thoughts about people with FASD and their behaviour & learning ability
- Adjusting expectations - think developmental age
- Using FASD and trauma informed strategies
- Identifying and planning for triggers: environment, sensory, etc
- Investing in specific FASD training programmes
- Give time and patience
- Investing in early diagnosis and interventions
- Sustained investment across the life-span: time/expertise/funding
- Connection & relationship
- Repetition
- FASD-informed supports & scaffolding
- Programme/therapy modifications & adaptations
- Good Role Models
- Don't take it personally

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Caregiver stress - What does it take to deal with...

- Stealing
- Running away
- Self-harm
- Emotional outbursts
- Violence
- School exclusions
- Police and justice
- Isolation and blame





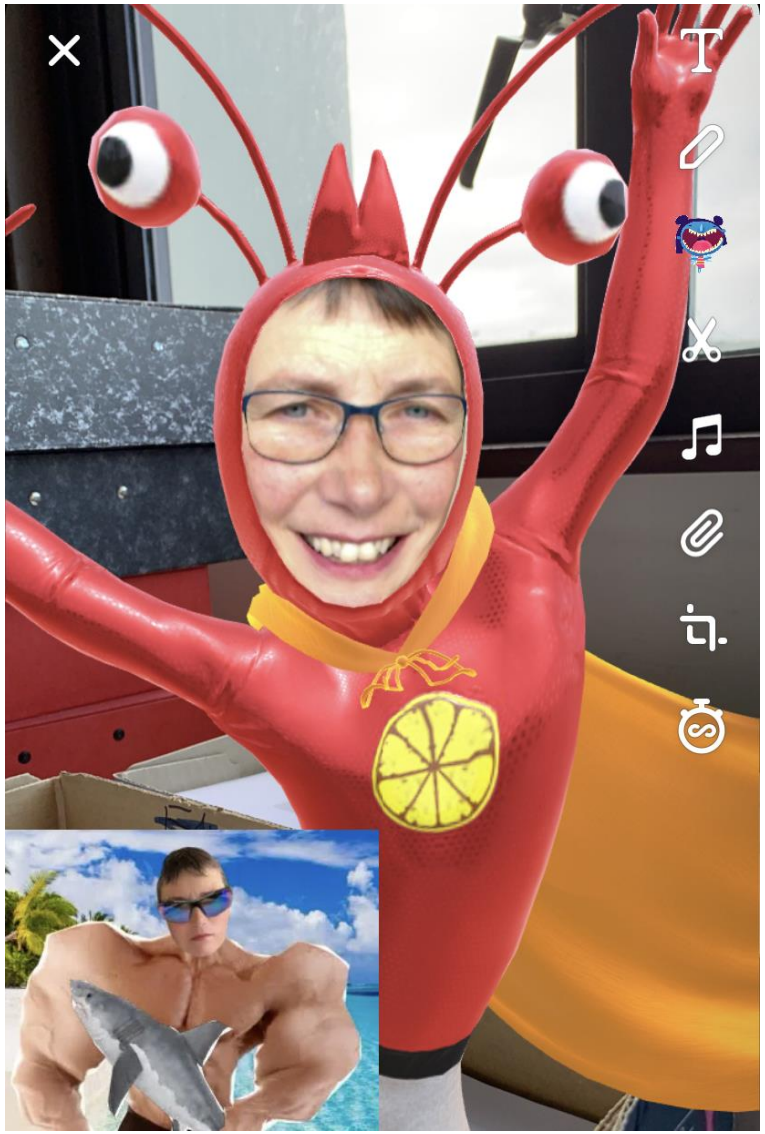
Living in the Fire: The impacts of Child and Adolescent to Parent Violence and Abuse (CAPVA) on Caregivers of Children with Fetal Alcohol Spectrum Disorder (FASD).

Professor Anita Gibbs

University of Otago
Te Whare Wānanga o Otāgo
New Zealand

“Treat us with dignity and respect, we know our child better than [everyone], be transparent, open and honest with us, work with us not against us, support us to support our child, look at our child through a neuro-behavioural lens, listen, educate yourselves, put accommodations and supports in place”.

Prof Anita Gibbs, research on Caregiver Lived Experience 2022



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What does FASD-CAN do and what can we provide?

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Member login | Join | Donate

E pā ana ki a mātou	Whai Māramatanga E Pā Ana Ki a FASD	Mō Te Hunga Pāngia e te FASD	Mō ngā Kaitiaki me ngā Whānau	Mō te Hunga Ngaio	Ko Ngā Rauemi	Ko ngā Taipitopito me ngā Takahanga
About us	Understanding FASD	For Individuals with FASD	Caregiver & Whānau support	For Professionals	Resources	News & Events

We're FASD-CAN Aotearoa New Zealand

We are united in our passion to improve the lives of those living with Fetal Alcohol Spectrum Disorder.

Learn more



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Ko ngā whakamāramatanga mō te hunga ngaio I Information for Professionals

- FASD: the basics for ALL professionals
- Educators
- Employers
- Police & Justice
- Support Workers
- Social Workers
- Mental Health
- Substance use and addictions in FASD
- Training for professionals

FASD: the basics for ALL professionals

In Aotearoa New Zealand, we are sadly behind other parts of the world in terms of specific resources for professionals who may routinely deal with individuals with FASD, but there is a wealth of resource internationally, particularly in Canada, America, Australia and the UK. Australian and Canadian studies are often comparable with New Zealand because of our similar social/alcohol cultures and indigenous populations.

In these tabs you'll find some specific information on FASD for 'frontline professionals' – a group defined as including 'anyone who encounters people with FASD in the course of their everyday work, and who is not a specialist in working with FASD and other neurodevelopmental impairments. For example, police, early childhood professionals, teachers, social workers, youth workers, counsellors, those working in kaupapa Māori services, other social services, courts, and health professionals for whom FASD and other neurodevelopmental impairment is not an area of specialisation.'

We have collated some of this specific information for you, but urge all professionals to continue with their own research, as information on FASD is being updated globally all the time.

Below there are a few essential resources for ALL frontline professionals to begin with when interacting with individuals with FASD.



FASD-CAN Wallet Cards



FASD-CAN pānui



IHC Library

Read more ›



FASD-CAN Webinar Recordings



The FASD-CAN Handbook

FACTS

FASD-CAN
Aotearoa New Zealand

Fact Sheets on FASD

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People with FASD

Empower the voice of those with FASD and provide connection and support

Pizza clubs in various cities

Tītoki weekend camps (including development, increasing FASD knowledge and FUN)

Advocacy









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FASD-CAN Navigators

















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Webinar Series





- [Fetal Alcohol Spectrum Disorder: The Basics]
- [The Dad role in FASD]
- [Professor Raja Mukherjee: FASD, co-occurring neurodiversities and misdiagnosis]
- [Caregivers Coping with Violence and Abuse]
- [Trying Differently Rather than Harder]
- [Cristina Fon - 'Why can't you just be good!']
- [What Works in Schools for Tamariki and Rangatahi Māori with FASD]
- [Focus on Health: The Clinician's Perspective]
- [Te Whare o Oro: Neurodiversity through the matapihi of the Whare Tūpuna]
- [PATH: Planning Alternative Tomorrows with Hope – a tool for change]
- [Focus on Justice - FASD in Youth Court]



RECORDINGS: https://www.fasd-can.org.nz/fasd_can_webinar_recordings_2022

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Tuesday 10 November,
04:00pm
Online

Quarterly Webinars for Social Workers and Support Workers

Social workers and support workers in Aotearoa NZ are key to improving the lives of individu...

Read more ›

Quarterly Webinars

LANSAS Group – Learning and Networking for Social Workers and Support Workers

NEXT Online
Tītoki: A Programme of Connection for Rangatahi and Adults with FASD
Tuesday November 10, 4-5pm

REGISTER:
On website under EVENTS
www.fasd-can.org.nz/events

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And also:

- Regional and online support groups
- Caregiver courses – Life with FASD: Understand and connect with aroha
- Professional training tailored to sectors
- Social media – caregiver, professionals and justice group
- De-escalation workshops



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