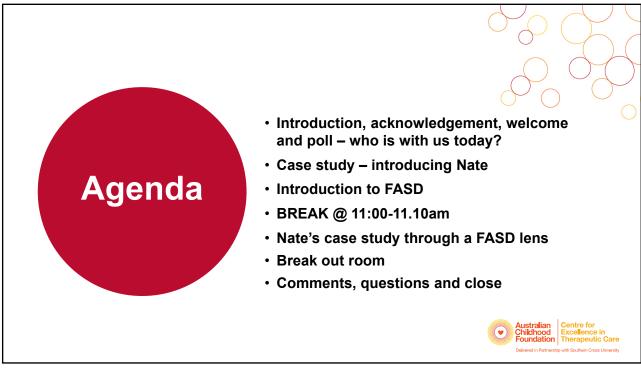


The Centre for Excellence in Therapeutic Care acknowledges Aboriginal and Torres Strait Islander peoples as the traditional custodians and owners of this land. We pay our respects to their elders past and present and to the children who are their leaders of tomorrow. We acknowledge their history and living culture and the many thousands of years in which they have raised their children to be safe and strong.

Centre for Excellence in Therapeutic Care acknowledges and to the children who are their leaders of tomorrow. We acknowledge their history and living culture and the many thousands of years in which they have raised their children to be safe and strong.

This workshop will help you: • identify the key features of FASD • recognise the possible effects of prenatal alcohol exposure over the lifespan • Identify the range of behavioural and emotional presentations of FASD and the overlap with trauma • identify features of appropriate support, intervention and planning • reflect on opportunities to apply learnings with residential space





Nate's background



- · Parental substance use, mental health issues and family violence
- Child protection pre-birth report, family homeless, violence, older siblings in permanent care
- Nate born withdrawing from opiates
- Placed with MGM, mother in the home, IVO against father
- Nate seemed well cared for, appeared attached to MGM
- · FV incident, father incarcerated when Nate 6 mo
- · mother using substances, placed Nate at risk
- Order breached at 18 months, Long term care with MGM
- Placement ended age 3 due to MGM's health



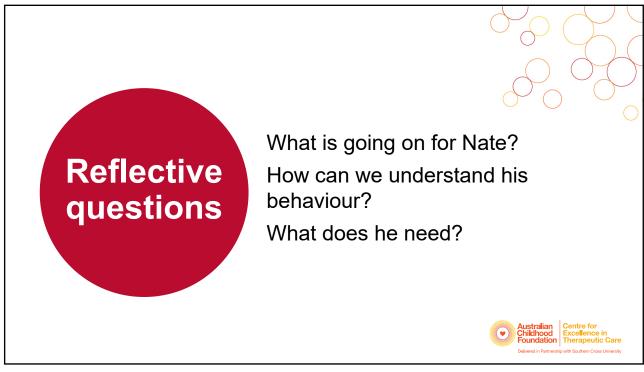
Nate's early childhood



- · Difficulties adapting to kinder routine
- · Social skills delay, difficulty expressing himself
- · Hitting, biting, aggression
- Delayed toilet training
- · Hard to understand speech
- · Emotionally dysregulated, impulsive
- At home, hurt the dog, needed constant supervision
- · Didn't appear to listen or follow instructions
- Psych assessment at 5 language delay, ADHD, repeated 4 yr old kinder
- Multiple placements between 3 4 1/2.



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Nate's primary school years - at school



- Difficulty sitting still, focusing, some improvement with Ritalin
- · Emotional and physical outbursts, aggression
- School exclusion
- · Difficulty with social skills, conflict with other children
- · Struggling academically, made some gains with reading, challenged by maths



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Nate's primary school years - at home



- · Behaves like a much younger child
- Lying, stealing items, not showing remorse
- · Gets fixated,
- · Doesn't often show empathy or appreciation
- Doesn't sustain attention for long, except gaming gets obsessed
- · Conflicts with other children, can be verbally abusive or hit others
- Carers avoiding many situations loud, noisy, over stimulating
- Can be loving and affectionate with carers, worries if someone gets hurt, helpful around the house



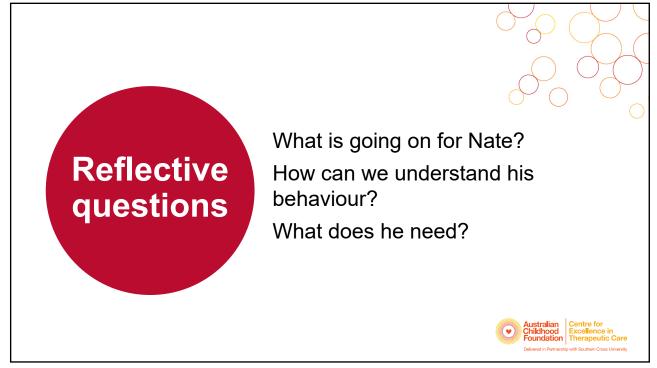
Supports/interventions



- Psychology, child psychiatry, play therapy, equine therapy
- · Social skills groups, speech pathology, tutoring
- Child mental health services diagnosed Attachment disorder, anxiety, ODD
- Supervised contact with siblings, respite, camps
- Carers trained in trauma-informed care, Tuning into Kids, parenting supports, life story work
- Tried activities can't sustain them. Asked to leave camp (hurt animal)
- · Sexting at school, accessing porn. Restricted to half days at school
- Incident at home aggression, threats, property damage placement breakdown



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Nate at 14, in residential care



- In his 4th unit in 2 years, conflicts with other residents
- Attending specialised learning unit but rarely goes
- · Challenges around boundaries and routines, sleeping, showering
- Fixated on x-box, gets aggressive
- Significant damage to the unit
- · Difficulty sharing attention of staff with other residents
- Behaviour upsetting to other residents
- · Unrealistic hopes for future as a rapper



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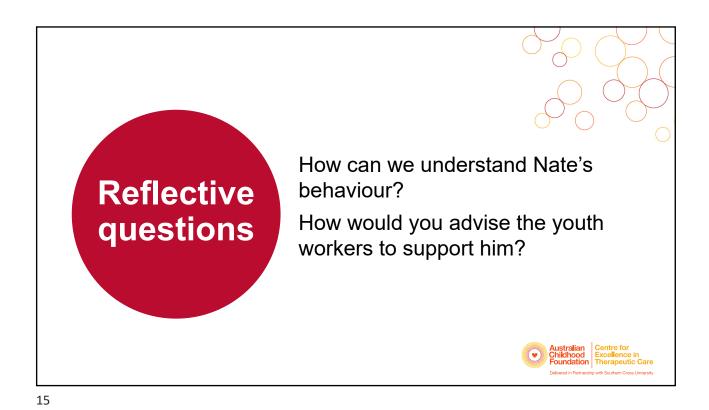
Nate at 14, in residential care



Currently:

- Drawn towards 16 year old resident Andy
- · Started going out, staying out late, come back alone, substance affected
- · Has been assaulted
- Preoccupied with revenge, talking about stabbing someone
- · Asked 13 year old girl to be his girlfriend





The child protection worker contacts you and says Nate's younger brother (Tyson, 6) has been diagnosed with FASD.

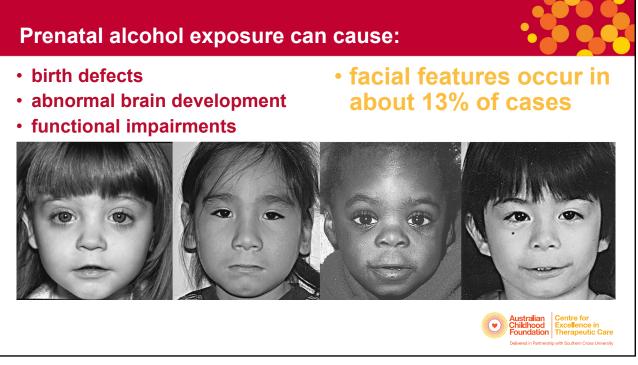
Australian Centre for Excellence in Therapeutic Co.

Childhood Childhoo









Greatest impact of prenatal alcohol exposure is to the brain



cognition memory

attention

language

planning

social skills

communication

making choices



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Features of FASD include:



Developmental delays

- speech, language, social skills
- cognitive impairment may be present, but often isn't

Learning difficulties

- difficulty with reading, maths, abstract concepts
- difficulty learning and remembering routines
- · problems with planning and sequencing



Features of FASD include:



Behavioural characteristics

- difficulty controlling impulses
- may not show empathy
- may not take responsibility for their actions
- difficulty controlling frustration and anger
- · difficulty identifying consequences of their actions



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Challenges for carers and professionals



- FASD often looks like the effects of trauma, or what we think of as trauma
- making sense of FASD as a disability
- may say they understand when they don't
- good verbal skills mask underlying impairments
- "talk better than they think"
- show insight at times, but can't follow through
- · doesn't seem to make progress



What carers say



"He presented as being a lot more competent than he actually was because of his verbal skills. Despite his speech not being clear, his written verbal skills were really quite excellent and he was quite creative, you know, he used to write stories, he had good computer literacy from an early age and music."



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What carers say



Without a plan or advance warning my son loses it. It's impacted on every part of his development – and he struggles.

They get put in the too hard basket at school.

I don't get him to sleep till 2 or 3 in the morning, then he wakes up at 6am.



What carers say



There is no cause and effect – they don't understand the consequences.

They can switch from abuse and anger to loving in an instant and they don't remember what happened.

I am on standby every hour of the day to respond.



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What carers say



When I finally found out (when she was 17) what was wrong, as much as it was a really difficult thing to deal with in the beginning, I could finally breathe. I knew what the problem was. I knew I had to re-adjust my expectations.



Every child is unique, but there are patterns



- · different dose, timing
- · different amount of exposure
- different genetics
- mother's health, age, diet all have an effect
- post-birth environment has an impact
- trauma exacerbates the effects of FASD

Each child has unique strengths and abilities



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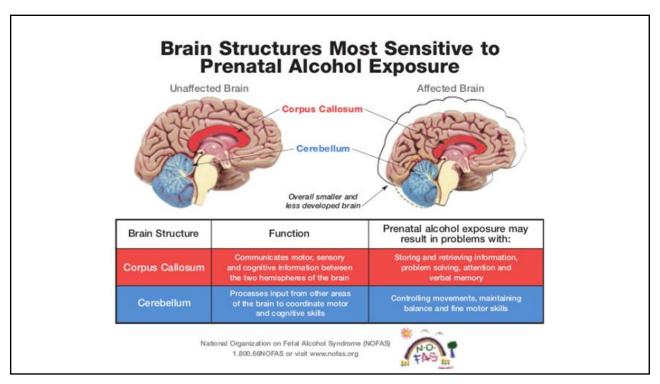
How does alcohol affect the developing brain?

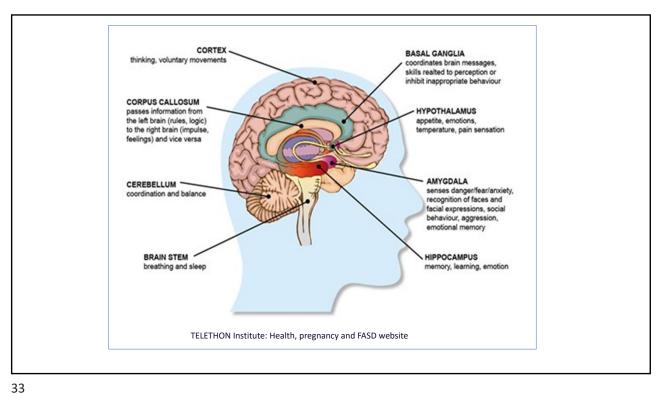


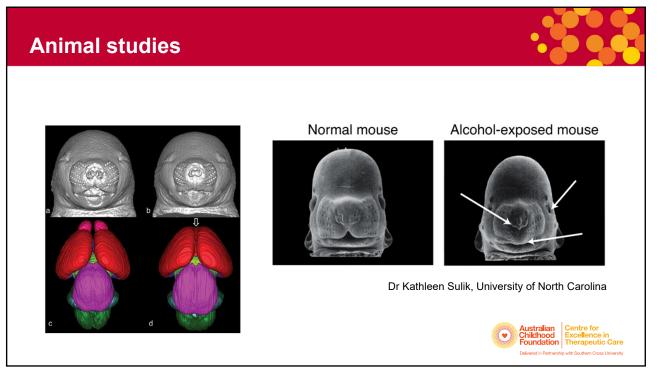
- Alcohol is a teratogen
- More harmful than other illicit substances
- Affects the fetus in many different ways development of cells, blood flow to placenta, development of neural pathways
- Can change the structure of the brain
- Brain functions show the impact

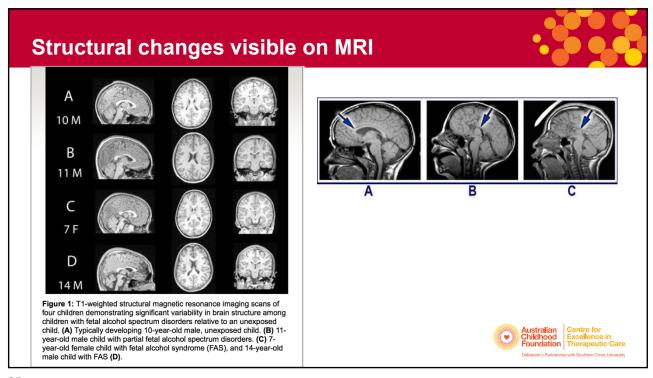


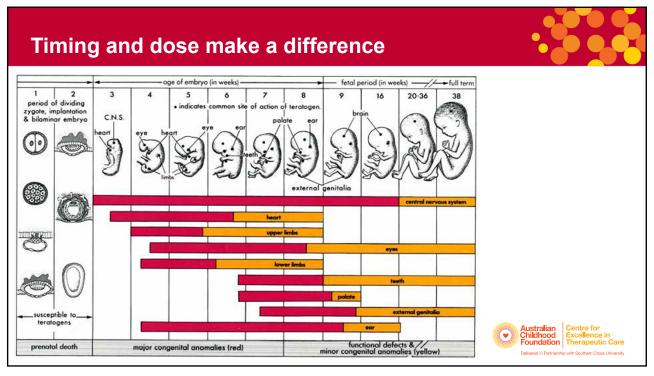
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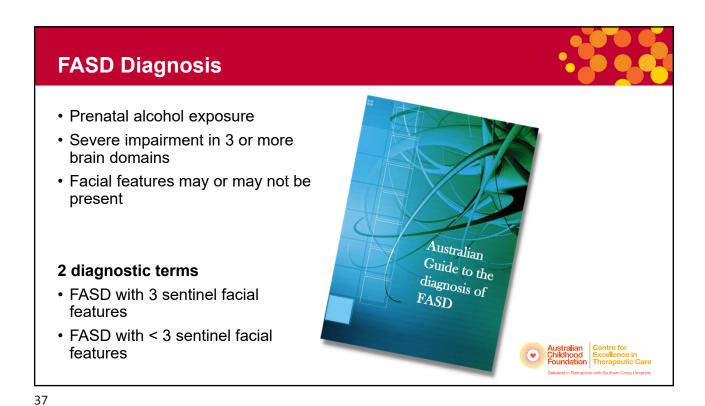


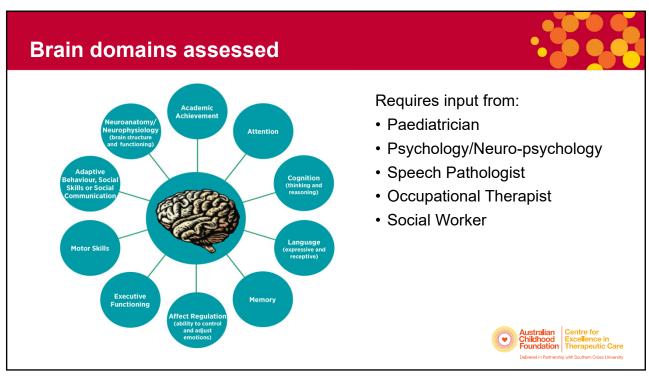














A neuro-behavioural approach

The environment influences the way some FASD symptoms affect a child or young person.

Primary symptoms reflect the brain injury, eg:

- Poor memory
- · Difficulty paying attention
- Hyperactivity
- Slow learning pace



A neuro-behavioural approach

The environment influences the way some FASD symptoms affect a child or young person.

Primary symptoms reflect the brain injury, eg:

- Poor memory
- Difficulty paying attention
- Hyperactivity
- Slow learning pace

Secondary effects emerge when there is a poor fit between the person and their environment, eg:

- Frustration
- Anger
- Overwhelmed
- Depression
- Self harm



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Without appropriate supports:

The likelihood of negative long term outcomes increases, including risks of

- Being in trouble with the law
- · Mental health problems
- Drug and alcohol problems
- Homelessness
- Dropping out of school
- Living in violent relationships
- · Having children taken into care



Infants



- Prematurity
- · low birth weight
- · withdrawal from substances
- · slow to reach milestones
- slow growth
- irritable
- · over-sensitive to stimulation



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Preschoolers



- slow to speak
- fine and gross motor difficulties
- clumsy, poor balance
- · delayed toilet training
- · feeding issues
- sleep problems
- · emotional outbursts

- · familiar with strangers
- social skills delay
- don't understand danger
- take longer to learn routines
- oversensitive to sensory input
- anxiety



In Primary School



- not keeping up academically
- repeat mistakes, don't learn from mistakes
- difficulty following instructions
- · doesn't seem to listen
- over-active, over stimulated
- misreads social cues
- difficulty making and keeping friends
- · easily distracted
- doesn't complete tasks
- can be rigid



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In Primary School



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- · easily distracted
- doesn't complete tasks
- can be rigid

- · can't generalise rules and expectations
- · loses belongings
- · doesn't tell the truth
- say they understand when they don't
- · takes risks
- · gets obsessed
- may want to be in control
- can't see things a different way
- · seems oppositional
- escalates quickly
- anxiety continues



As expectations of the child increase...



- · self-regulation
- managing social situations
- learning
- independence
- · responsibility for self care

...it becomes harder for the child to meet them

- child becomes more frustrated, dysregulated
- consequences for aggression become more serious



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Young people



- · academic difficulties continue
- disorganised
- · needs prompting for self care
- · can't remember routines
- seem immature, shows off annoys others
- lying confabulation
- stealing difficulty with ownership
- · wants independence but struggles when unsupervised
- · seems oppositional
- difficulty shifting thinking



Risks increase with age



- · low self esteem
- school refusal
- running away
- · excluded from school
- self harming/depression
- drug and alcohol use
- · placement breakdown
- victim of assault
- injuries to self accident or intentional
- risk of exploitation



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In adulthood



- make agreements but don't follow through
- miss appointments
- don't engage with services
- lacks insight
- doesn't seem to make progress
- can't keep a job

- makes poor choices and doesn't learn
- lacks parenting skills/children in out of home care
- anxiety, depression, other mental health issues
- · victim of violence
- drug and alcohol issues
- homeless



FASD is often missed because



- The child's symptoms can look like trauma
- No-one has asked about prenatal alcohol exposure, or information is missing
- Professionals aren't aware of FASD psychology, childcare, school – so it's not raised
- Lack of clarity about who/how to diagnose
- Cost/funding/availability/access
- People are not sure if the diagnosis will make a difference



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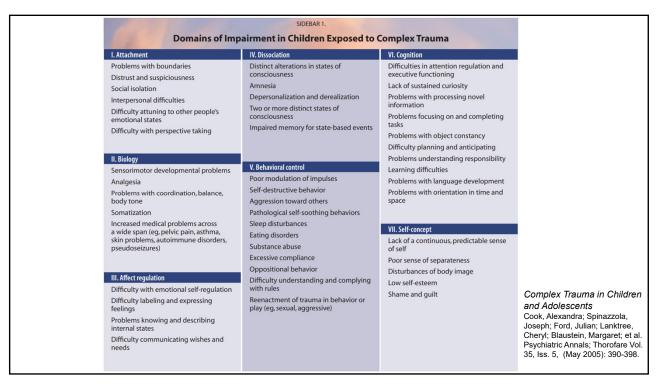
Trauma has been associated with

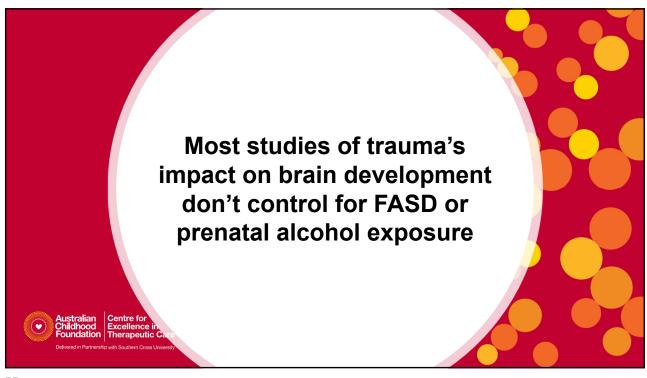


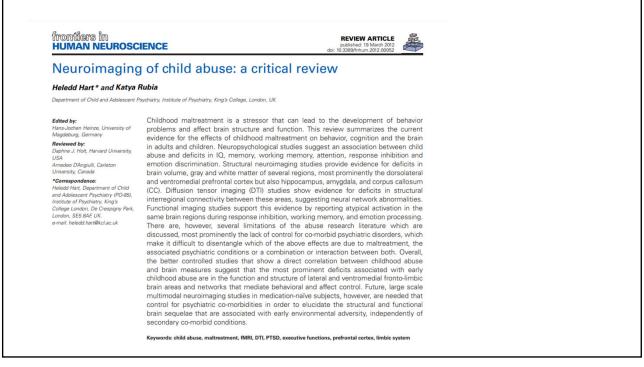
- · Cognitive and language delay
- · Problems with memory
- · Pattern of dysregulation
- · Hyperarousal, hypervigilance, reactivity, even when there is no threat
- · Dissociation, inattention, zoning out
- · Difficulties processing emotional information
- · Lack of cognitive flexibility
- · Behavioural regulation problems
- · Sensory integration issues
- · Forgetfulness, not paying attention, disorganised thinking
- · Sleep problems
- · Sense of bodily dislocation



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Comparison of children with PAE and PAE+ trauma



The combined effects of prenatal alcohol exposure and childhood trauma: findings from a four-year research project at the University of Salford.

By pcook Oct.14, 2019

By Alan Price, PhD

Foetal alcohol spectrum disorder (FASD) is the range of conditions that can be caused by prenatal alcohol exposure (PAE). People with FASD can have a wide range of physical and mental difficulties, especially with planning, attention, impulsivity, coordination, social communication, emotional arousal, and memory. These difficulties can impact daily living, school, work, social relationships, and long-term health and wellbeing. In the UK, it is estimated that at least 3%, and possibly up to 17% of the population would quality for a diagnosis on the foetal alcohol spectrum, although the majority will never be diagnosed. FASD has been known about for several decades but does not yet receive appropriate attention in schools and universities, meaning that many doctors, teachers, social workers and other professionals are not trained to spot the signs of FASD. This can leave children and adults with FASD struggling with the academic and social demands of everyday life without the support they need. Unsupported, people with FASD are more likely to be excluded from school, lose their job, struggle with addictions, and be convicted of a crime. FASD is thought to be especially common in looked after and adopted children and care leavers. Many of these individuals also have histories of traumatic experiences such as abuse or neglect in early childhood, which are also known to lead to developmental difficulties similar to those seen in FASD.

"... children with both PAE and a history of trauma appear to function similarly to children with just PAE and tend to have more severe difficulties than children with just trauma. Therefore, the difficulties seen in children with both of these exposures seem to be primarily caused by PAE rather than childhood trauma."

https://hub.salford.ac.uk/salfordpublichealth/2019/10/14/the-combined-effects-of-prenatal-alcohol-exposure-and-childhood-trauma-findings-from-a-four-year-research-project-at-the-university-of-salford-by-alan-price-phd/



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Children with FASD over-represented in OOHC



Prevalence of FASD among children in child care system – orphanage, foster care, child welfare system internationally

• 23%

Lange, S., Shield, K., Rehm, J., & Popova, S. (2013). Prevalence of fetal alcohol spectrum disorders in child care settings: a meta-analysis. Pediatrics, 132(4), e980-995.

- Prevalence of FASD among children in care meta-analysis
 - USA 39%
 - Chile 34%
 - Russian orphanages 68%

Popova, S., Lange, S., Shield, K., Burd, L., & Rehm, J. (2019). Prevalence of fetal alcohol spectrum disorder among special subpopulations: a systematic review and meta-analysis. *Addiction (Abingdon, England)*, 114(7), 1150–1172.



FASD - missed diagnosis in care



Random sample of 547 children in care who had undergone a medical behavioural or neurodevelopmental assessment, usually for 'behavioural problems':

- 156 children were assessed with FASD
- 125 had never been diagnosed

86.5% had either:

- · Never been diagnosed
- · Had been misdiagnosed

Chasnoff, I. J., Wells, A. M., & King, L. (2015). Misdiagnosis and Missed Diagnoses in Foster and Adopted Children With Prenatal Alcohol Exposure. *Pediatrics*, 135(2), 264–270. https://doi.org/10.1542/peds.2014-2171



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Prenatal alcohol exposure in children in care



Audit of children seen at UK community paediatric clinic between 2010-2013 where there was history of prenatal alcohol exposure

- 72 children diagnosed with FASD during this period
- 34% of children in out of home care had prenatal alcohol exposure
- 75% of children placed for adoption had prenatal alcohol exposure

Gregory, G., Reddy, V., Young, C., 2015. Identifying children who are at risk of FASD in Peterborough: working in a community clinic without access to gold standard diagnosis. Adoption & Fostering 39, 225–234.. doi:10.1177/0308575915594985







Key principles



- 1. Understand the brain and behaviour
- 2. Adapt and accommodate
- 3. Keep it simple, support and scaffold
- 4. Focus on strengths and reframe success
- 5. Manage risks



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1. Understand the brain and behaviour



- Assessment and diagnosis
- Read the detail! Understand the impact of the child's impairments
- · Reframe behaviours as brain-based
- Notice when frustration/anger is overload/overwhelm
- If it's can't not won't what can you do differently?
- Acceptance FASD is a permanent disability but a diagnosis can open doors



1. Understand the brain and behaviour



When we see FASD, we can recognise that a young person:

- · has been masking an impairment
- · hasn't been understanding
- · struggles to remember information
- · gets angry when feels vulnerable
- · needs reminders
- · has difficulty with planning
- · will need transport to get to appointments
- · needs targeted skills training
- · manages with support but can't manage when support ends
- · might need ongoing support in areas of daily life to succeed and maintain gains



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2. Adapt and accommodate



- Physical environment
- · Rules and expectations
- Simplify tasks
- Use visual supports
- Reduce expectations
- · Identify what is helping or not helping in the environment
- Explicit teaching of skills



Adapt our usual strategies



- understand limitations of cognitive-based and behavioural approaches
- identify when we are using methods that rely on cognitive skills when we expect the young person to change their thinking
- focus on prevention of behavioural issues
- adapt positive behaviour support approaches
- · consequences need to be natural, immediate and concrete
- reduce expectation that young person can apply their skills in other settings
- reduce expectation that young person can manage themselves
- applying these principles to OT, therapies
- avoid approaches that don't have evidence for FASD



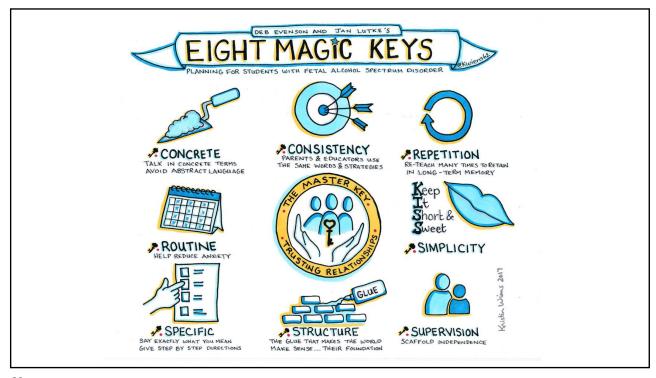
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3. Keep it simple, support and scaffold



- · Keep language concrete and simple
- Short sentences
- Check for true understanding
- · Lots of repetition
- Structure and consistency
- Recognise disconnect between expressive and receptive language skills
- Provide support to use strategies don't expect independence
- Supervision to reduce risk
- Anticipate challenges and plan ahead
- Consistency between home and school
- · Supports may need to be long term





4. Focus on strengths and success



- · Lots of time doing things they are good at
- · Create opportunities to use their strengths and talents to build self esteem
- Reframe what 'success' looks like
- Identify opportunities for future learning, work and create pathways
- Use NDIS funding to tailor supports
- Educate the young person about FASD



Strengths



A small study exploring the school and life experiences of adults with FASD found that individuals derived strength from

- · asking for help
- having FASD-informed teachers
- being involved in school activities that fit their interests and abilities and create opportunities for friendship
- · participating with youth groups
- engaging in elder support
- reaching out to help others
- · gaining self-insight through FASD diagnosis

Flannigan, K., Harding, K., & Reid, D. (2018). Strengths among individuals with FASD. CanFASD, September, 1–4



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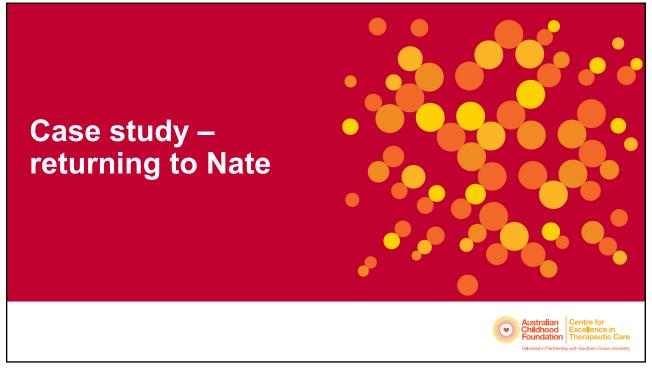
5. Manage risks

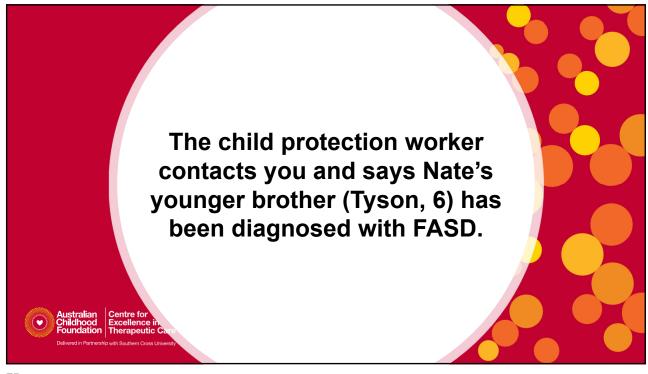


- Recognise when increased risks are due to impulsivity and executive function impairments
- Don't expect the young person to use strategies that rely on learning, memory, controlling impulses, making better choices
- Reduce expectation that the child or young person will be able to take an active role in keeping themselves safe
- Increase supervision
- Focus on relationships
- Change environments









Could FASD have been missed?



- No-one has previously suggested that Nate's mother consumed alcohol in pregnancy
- · Case notes say that both parents had substance use
- Mother did have a well documented history of drug and alcohol use could it have occurred during the pregnancy?



Could FASD have been missed?



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- · Case notes say that both parents had substance use
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The case team makes a plan....



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Information gathering



- Child protection file review some information relevant but it's unclear
- Paediatrician requests birth records alcohol indicated
- MGM confirms she saw alcohol being consumed in pregnancy



Information gathering



- Child protection file review some information relevant but it's unclear
- Paediatrician requests birth records alcohol indicated
- MGM confirms she saw alcohol being consumed in pregnancy

Prenatal alcohol exposure is confirmed...



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Further assessments?



- Needs speech, OT and neuro-psych but Nate may not agree
- Paediatrician gets birth records head circumference was under 3%ile
- OT assessment at the house fine motor skills severely impaired
- ADHD already diagnosed combined type, so goes to Executive Function
- Staff and teachers complete questionnaires Executive Function and Adaptive Function severely below
- School psychologist reviews reports reading ok, maths very low (**Academics**)
- Nate agrees to a short session with Neuro-psych who identifies impaired working memory (Exec Function) as well as strengths in Memory
- Language impairment previously assessed



Diagnosis



Paediatrician reviews results and diagnosis Nate with FASD with <3 facial features.

Severe impairment in 6 domains:

- Neurology (small head circumference at birth)
- Academics
- Executive function
- · Fine motor skills
- Receptive and expressive language
- Adaptive function/social communication.



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