

Trying Differently

Strategies to use in the classroom to support learners with FASD.

Prepared by Tracey Jongens, Oct 1 2014

Fracey Jongens 2014

Fetal Alcohol Spectrum Disorder (FASD) Iceberg

FASD — Umbrella term in international literature since 2004

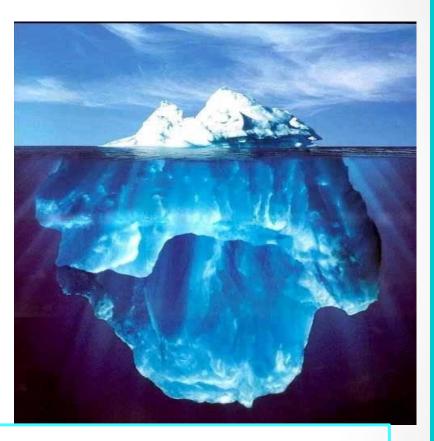
FAS — Fetal Alcohol Syndrome identified in 1973

FAE – Fetal Alcohol Effect (Historical Term)

pFAS – Partial Fetal Alcohol Syndrome

ARBD – Alcohol-Related Birth Defect

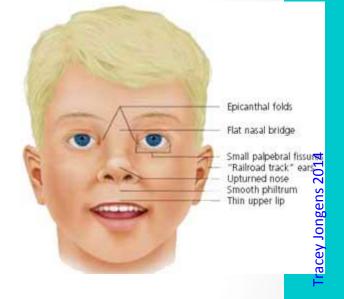
ARND - Alcohol-Related Neurodevelopmental Disorder



Outcome influenced by: Dose, Pattern and Timing of exposure, Maternal age and health, Genes, Environment Each person born with FASD is UNIQUE

Diagnosing FASD

- Canadian Guidelines for Diagnosis
- 4 Digit Code applied over 4 domains
 - Growth Deficiency,
 - FAS Facial Phenotype,
 - CNS Damage or Dysfunction,
 - Gestational Exposure to Alcohol

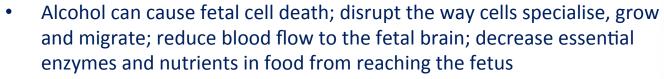


Multidisclipinary diagnostic team, may include
 Physician/Paediatrician trained in FASD diagnosis,
 Psychologist, Occupational Therapist, Speech Language Therapist,

Social Worker or Case Manager. Et al

How Alcohol Effects the Developing Baby

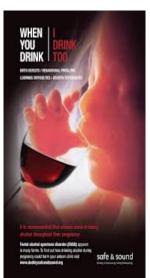
- Alcohol is a teratogen crosses the placenta freely. It is more common and more harmful than any other substance
- Within 10 15 minutes of ingestion by the mother, alcohol crosses into the fetus's blood supply
- The fetus is exposed to same blood alcohol level as the mother
- Alcohol is also absorbed into the amniotic fluid which acts as a reservoir increasing the exposure time



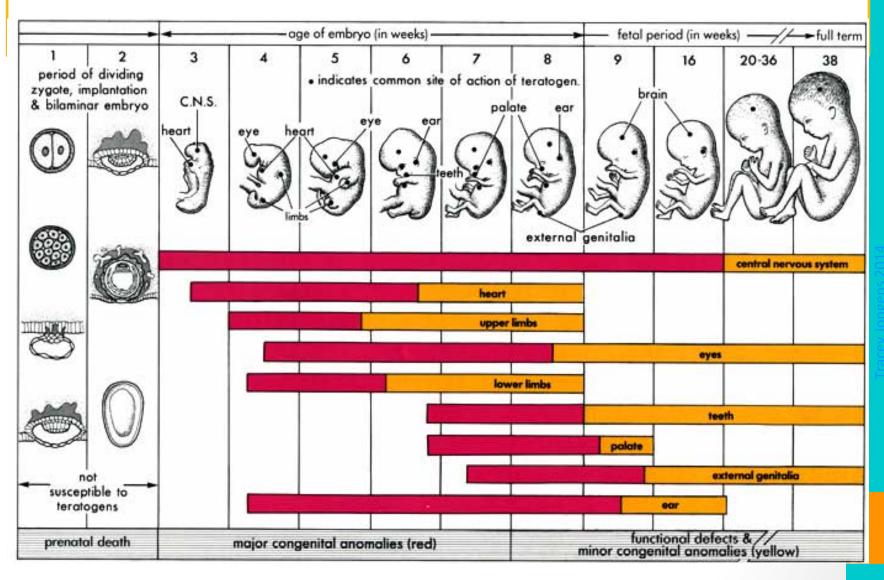
Therefore alcohol both permanently changes how a baby is formed and deprives it of the food needed for healthy development'

Blackburn, Carpenter, Egerton 2012

"indications that fathers who are heavy drinkers produce infants with lower birth weight and increased likelihood of heart defect" Carpenter et al 2014



MOH/WHO state No safe time! No safe amount!



How much damage heavy drinking can cause to an infant brain

The alcohol damage to the brain on the left caused death.

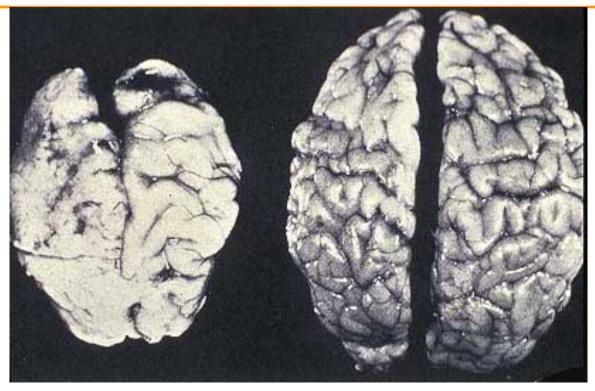


Photo by Sterling Clarren MD

6 wks old with FAS

6 wks old without FAS

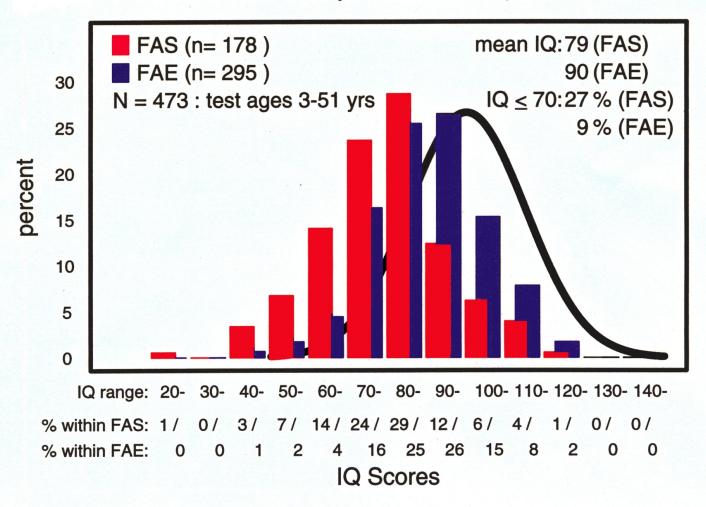
At least 10 brain domains that can be adversely affected by FASD

- Achievement
- Cognition
- Attention
- Language
- Adaptation
- Reasoning/Executive Functioning
- Memory
- Motor
- Sensory and Soft Neuro
- Social Communication

(Jeanette Lange, JFas Int, 2006)

Think ALARM!

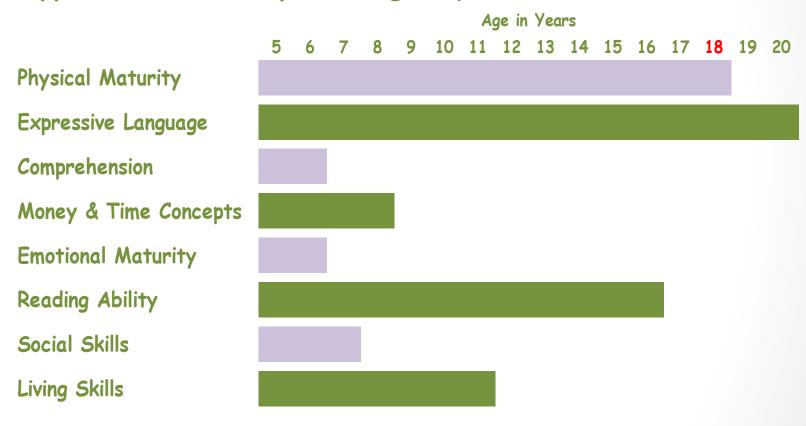
IQ distributions in the Primary Disabilities Sample: FAS and FAE



IQ does not give you the complete picture!

When appearances and actions don't match

Typical Skill Development Age Equivalent

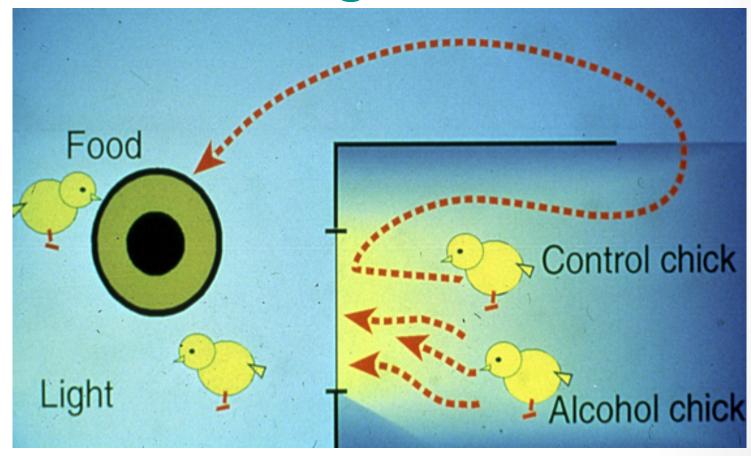


Source: Malbin, 1994

Alcohol Exposed Chick



Alcohol Exposed Chick Fails Detour Learning Test





Brain Damage

Secondary Disabilities

Trouble with the Law, School Disruption, Etc.



Drinking during pregnancy in NZ

Despite Ministry of Health advice and some awareness that alcohol is harmful to the fetus, the rate of drinking prior to and after pregnancy recognition remains high.

- Over 80% of NON-pregnant New Zealand women report consuming alcohol, with > 60 per cent reporting 'binge' drinking in some communities (4+ units per occasion) prior to pregnancy recognition
- 24-34% continued to drink during their pregnancy (midwives report 80% of teens)
- Binge drinking exposure by 12 percent of women aged 18+ in 2013
- Unplanned pregnancy rate of >50%.

Sources: Ho & Jacquemard (2009), Ministry of Health, (2009) Alcohol Healthwatch (2007), Parackal, (2001), Mallard (2013).

How big is the problem thought to be in NZ?

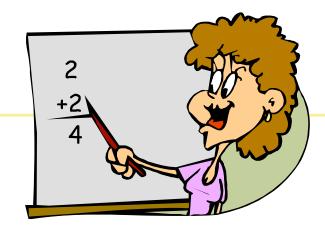
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- The estimated prevalence of FASD internationally is 1-4% of live births (Sampson et al, 1998)
- At that rate, New Zealand could expect 632 2528 babies born affected in 2011 based on live births recorded by Statistics Dept.
- Based on Canadian econometric figures, (Stade et al, 2009) the annual cost per person born affected could be NZ\$31,826 PA (accruing).
- A very small proportion of affected children in NZ have received a diagnosis (Leversha et al, 2000).
- Estimating FASD prevalence at 1-4% and extrapolating from US findings, 10 to 60% of NZ children in state care have an FASD disability. (McGinn, 2012)

In NZ today we have eight multidisciplinary assessment teams based at DHB's. All are based in the North Island.



Trying differently, Shifting paradigms.

Strategies to help.





We cannot change behaviour that is caused by organic brain damage. With support through structure, supervision, routine, and consistency, your child may experience success.

FASD Strategies not Solutions, Child and Youth Working Group, Alberta, Canada

"... it is important to set the learning difficulties of children and young people with FASDs in the context of their strengths. Children and young people with FASDs have stated ambitions (Blackburn, 2010) and have a range of practical strengths which are useful in their educational careers and throughout life.

.... These strengths will become the foundations on which to develop personalised curricula, to encourage and develop further strengths and to build emotional resilience."

Blackburn, Carpenter and Egerton, 2012, p 29



Things That Don't Work

- Expectation to manage self
- Star charts
- Time Out
- Losing privileges
- Bribes
- Rewards
- Natural Consequences
- Easing up on structure and supervision
- Punishment

For traditional parenting/teaching techniques to be effective, the child must understand the concept of "future earning" and have the impulse control to change her behaviour for the future.

A child affected by FASD does not have this ability. (FASD Strategies not Solutions)



Executive Skill Deficits Typically Seen in FASD

- Poor organization, planning, strategy use
- Concrete thinking
- Lack of inhibition
- Difficulty grasping cause & effect
- Inability to delay gratification
- Difficulty following multistep instructions
- Difficulty changing strategies mid-stream (perseveration)
- Poor judgment / illogical decisions
- Inability to learn from experience
- "Fight or flight" panic under pressure
- Lack insight, think they are right
- Confabulation



Social Skill Deficits Typically Seen in FASD

- Lack of stranger fear
- Often scapegoated
- Naïve and gullible, easily manipulated
- Immaturity
- Lack of self-awareness
- Lack of other-awareness (boundary problems, empathy deficit)
- Excessive demand for attention
- Poor understanding of social cues
- Clinically significant inappropriate interactions



Dr Valerie McGinn 2013

Emotional Dysregulation



- Stay calm and quiet
- Be realistic so child can be successful
- Give clear simple instructions
- Behavioural consequences don't work
- Support does work
- Change environment to suit the child
- Disability will remain but how child is managed determines outcome

Dr Valerie McGinn 2013

Paradigm Shifts and FASD

"Building Strengths, Creating Hope"— Alberta Learning. By Diane Malbin (2004)



From seeing the child as Won't

Bad, annoying

Lazy, unmotivated

Lying

Fussy

Acting young, babied

Trying to get attention

Inappropriate

Doesn't try

Mean

Doesn't care

Refuses to sit still

Resisting

Trying to annoy me

Showing off

From Personal Feelings of:

Hopelessness

Fear Chaos, confusion

Power struggles

Isolation

Professional shifts from:

Stopping behaviours

Behaviour Modification

Changing people

To understanding the child as Can't

Frustrated, challenged

Trying hard, tired of failing

Story telling to compensate for

memory, filling in the blanks

Oversensitive

Being younger

Needing contact, support

Displaying behaviours of a

younger child

Exhausted or can't get started

Defensive, hurt

Can't show feeling

Over stimulated

Doesn't get it

Can't remember

To Feelings of:

Hope

Understanding

Organization, comprehension

Working with

Networking, collaboration

To:

Preventing Problems

Modelling, using cues

Changing environments

Teaching Strategies

- Environmental Adaptations, routines, seating
- Visuals rather than verbals, simple instructions
- Direct Teaching, one thing at a time, generalise
- Scaffold curriculum
- Enable and reward success
- Chunking and repetition, rote learning
- Evaluate differently
- Be aware of vulnerability to bullying
- Don't present choices
- Set up opportunities for positive social interactions



Behaviour Management

- Remember behaviours are brain based and not wilful
- Manage environment to avoid behaviour problems
- Use simple language that student understands
- Focus on building positive relationships
- Realistic expectations eg. homework
- Lack of cause and effect reasoning
- Reduce opportunities for negative behaviours eg. stealing
- Divert before problems arise-predict and prevent
- Warn of and help with transitions
- Praise and reward efforts not achievement
- Identify stressors and avoid them



A Positive Example of Trying Differently

- Special Character Area School
- Head of Primary
- Year 11 Literacy Class established
- Double amount of class time
- Small class 7 students
- NCEA Level 1 Literacy Unit Standards
- All standards taught within an Inquiry based, real life context
- Each standard modelled, guided practice, feedback/feedforward before being submitted for assessment
- Out of school visits

Class is supported by BOT by .2 FTE funding to fund the teacher.



Naseem – An Example of Personalised Learning

- 15 yrs, diagnosed with FASD and moderate learning difficulties, attachment disorder and behavioural emotional and social difficulties, health issues.
- Focus: Completing an Activity.
- How did Naseem behave when engaged in a favourite activity? This lead to high expectations.
- Identified individual strengths, difficulties and motivation and transferred these to low engagement activities.

"Fetal Alcohol Spectrum Disorders Interdisciplinary Perspectives" eds Barry Carpenter, Carolyn Blackburn and Jo Egerton pub 2014

Strategies used by the teacher

- Visual photographic prompts
- Teacher physical modelling and rehearsal which incorporated kinaesthetic learning
- Repetition
- Praise
- Begin small and build

Teacher Conclusion:

"It was an amazing success. I will now start to photograph all practical's to have a set of photo packages for all children and young people to use."

> "Fetal Alcohol Spectrum Disorders Interdisciplinary Perspectives" eds Barry Carpenter, Carolyn Blackburn and Jo Egerton Pub 2014 pp 133 - 137

Provide a quiet working space
Use ear plugs,
Check on more regularly
Digital devices
Regular contact with home

What our families are saying

Visual cues and supports Allow Visual recording of information

Be flexible

- allow

rest days

or half

days..

specific seating
space, mat.
Squishy ball
Listen to parents
and work with
them
Homework –
ensure it is do able
and relevant

Regular movement opportunities, ensure opportunities to do "interest" subjects, regular PE times

A final note

F requently

A bused

S eldom

D iagnosed

"Once we know better we do better" (Lisa, a parent of an FASD child)