

# Tamariki, Neuropsychology and Fetal Alcohol Spectrum Disorder

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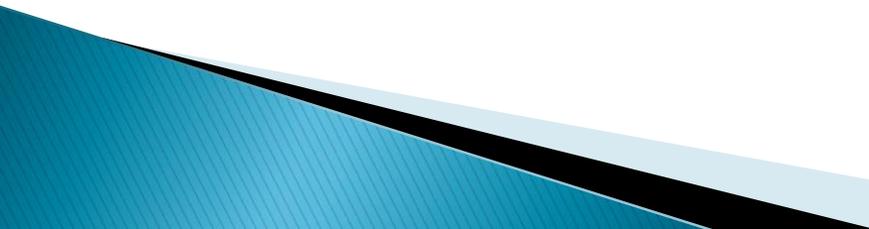
**He waka eke noa**

**A canoe which we are all in  
with no exception**

**We are all in this together.**



# Drinking Culture

- ▶ FASD is brain damage cause by consumption of alcohol in pregnancy
  - ▶ The only culture FASD is associated with is the DRINKING CULTURE (Christine Rogan AHW)
  - ▶ This is not a Maori problem it is an all of society problem
  - ▶ First Nations People in Canada take a leading role in prevention, research, service delivery and advocacy
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# Risks of maternal drinking

- ▶ Many indigenous people have elevated exposure to adverse life events that are associated with increased risk of substance abuse as a direct result of colonisation
  - ▶ Maori one of few cultures who had no alcohol or intoxicants prior to colonisation
  - ▶ Waipiro was used as a means of control by many colonising powers
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# FASD is not *New* to New Zealand!

1874

1874.  
NEW ZEALAND.

## PETITION OF HAIMONA TE AOTERANGI, AND 167 OTHERS.

*Presented to the House of Representatives on 18th August, 1874.*

Whanganui, 15th June, 1874.

A PETITION from all of us, whose names are signed at the foot hereof, to all the Members of the Parliament to grant this request of ours, for some law to be passed by the Assembly and the Government affecting this evil thing, grog, which is destroying us, so that a stop may be put to drinking among the Maoris, for that is at the root of the evils under which we suffer.

These are the evils: It impoverishes us; our children are not born healthy because the parents drink to excess, and the child suffers; it muddles men's brains, and they in ignorance sign important documents, and get into trouble thereby; grog also turns the intelligent men of the Maori race into fools.

Again, grog is the cause of various diseases which afflict us. We are also liable to accidents, such as tumbling off horses and falling into the water; these things occur through drunkenness. It also leads on men to take improper liberties with other people's wives. It also is the cause of men fighting with one another. In fact, there are innumerable evils brought upon the Maori race by grog. We therefore ask for a very stringent law to be passed to keep away this very evil thing from the Maoris altogether. Let only medical men have authority to allow the people to take liquor medicinally if they think it will lead to the recovery of the patient or patients whom they may be treating. That would be right. Sufficient. We trust that all the Members of the House will grant our prayer.

We hand this to Mr. Fox. Friend, we give this petition to you with a request that you will urge that the prayer of it may be granted, and an Act passed to stop the Maoris drinking.

If you have any regard for us, the Maori people, send away this evil leviathan which you brought to this island to destroy us, our lands and our children. Sufficient, friend. Be strong; God lives to look at the good work, and at the people who are good and show kindness to the poor and foolish ones of the earth.

Sir, do this for us. Long may you be spared on account of your energy in raising your voice against this great snake, liquor, during the years that have passed.

Sufficient. From your friends who are living in sadness on account of this evil.

HAIMONA TE AOTERANGI,  
And 167 others (males and females).

HE PITIHANA inoi tenei na matou katoa e mau ake nei o matou ingoa i te mutunga ake o tenei Pitihana, ki nga tangata katoa o te Paremete kia whakamanaia mai tenei tono a matou, kia rapua mai tetahi ture e Te Runanga o te Paremete, e te Kawanatanga hoki mo tenei hanga kino mo te waipiro, e patu nei i a matou, kia mutu ai nga tangata Maori te kai waipiro, notemea ko te putake tenei o a matou mate e mate nei matou te iwi Maori.

Ko nga mate tenei, ko te whakarawakore i a matou, ko te kore kaore e whanau pai ana o matou uri i te nui o te kai waipiro o te taone o te wahine, ka waiho hei mate mo te tamaiti. Ko te whakapohehe tetahi i nga whakaaro o te tangata, a ka tuhi pohche ki nga pukapuka whai ritenga, ka waiho tena hei mate. Me te whakakuare o te waipiro i nga tangata whakaaro nui o tenei iwi o te Maori.

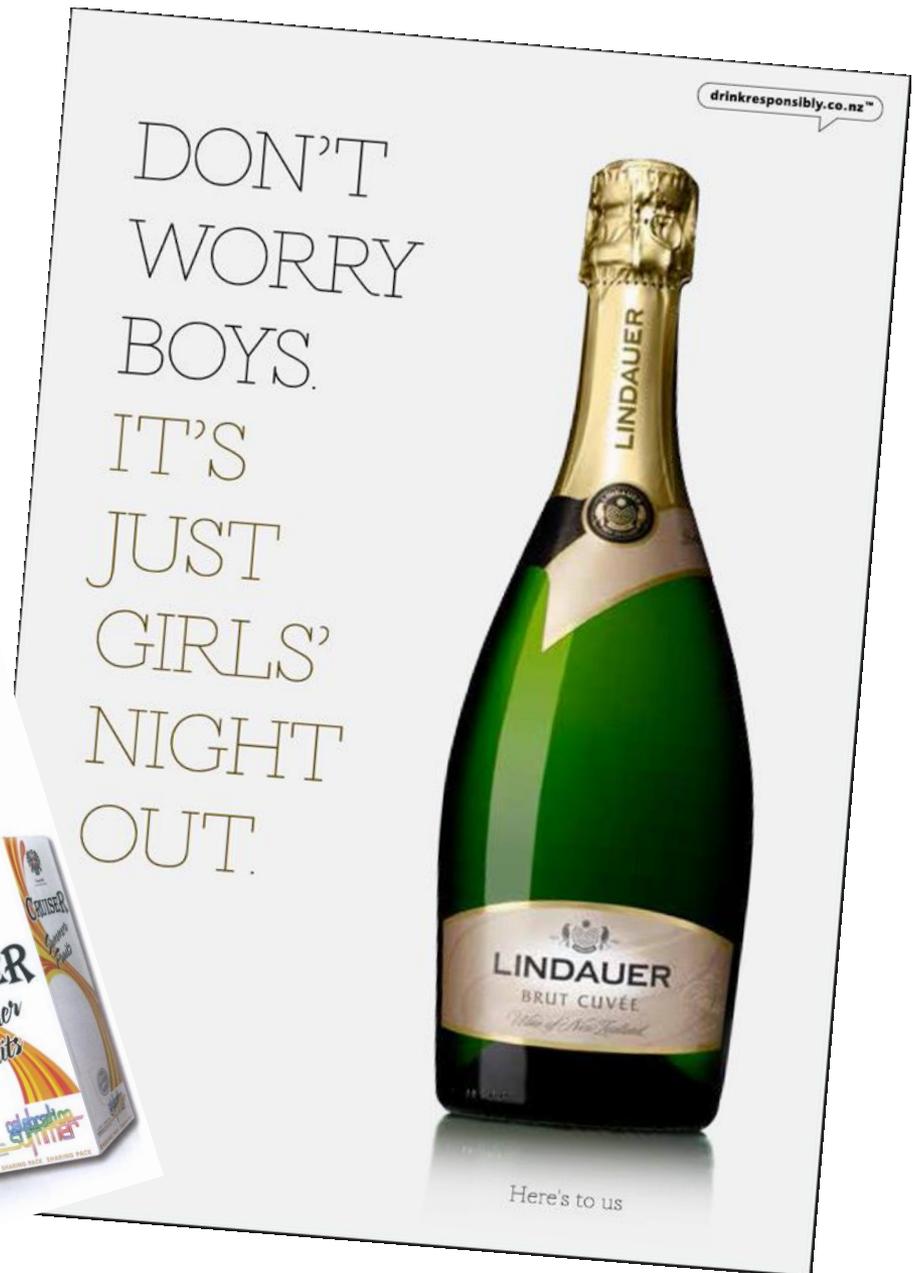
*“Our children are not born healthy because the parents drink to excess, and the child suffers”.*

# Poorly regulated alcohol industry, binge drinking and unplanned pregnancies



**Our 21<sup>st</sup> Century environment is challenging!**

**The burden of alcohol related harm is estimated at \$5 billion per annum (not counting FASD).**





## Drinking during pregnancy in NZ

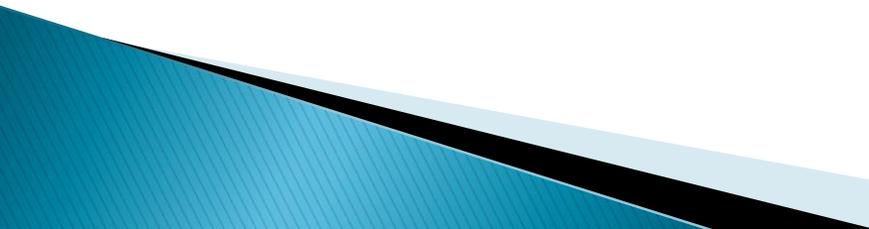
Despite Ministry of Health advice and some awareness that alcohol is harmful to the fetus, the rate of drinking during pregnancy in New Zealand remains high.

- Over 80% of non-pregnant New Zealand women report consuming alcohol (> 50% unplanned pregnancies)
- > 60 per cent reporting 'binge' drinking (4+ units per occasion) prior to pregnancy recognition
- 24–34% continued to drink some alcohol during their pregnancy (80% of teens?)
- NZ pregnant women drink > 4 times that of USA cohort.

Sources: Ho & Jacquemard (2009), Ministry of Health, (2009) Alcohol Healthwatch (2007), Parackal, (2001), Mallard (2013) Wouldes (2012).

# Maori Women Drinking

(Mallard, 2012)

- ▶ NZ women 25–39 pattern of increased drinking
  - ▶ 51% Maori women reported heavy episodic drinking prior to pregnancy
  - ▶ 75% Maori pregnancies reported unplanned
  - ▶ Maori women at 5x risk to HED in early gestation
  - ▶ Maori communities currently bear a disproportionate burden of alcohol related harm in New Zealand
- 

# Trading Off when making decision to drink (Keriata Stuart)

- ▶ To fit in where you are
  - ▶ Releasing the pressure
  - ▶ Carry on as normal
  - ▶ Amount and type
  - ▶ Freedom and defiance
  - ▶ Conflicting advice from health workers and aunties and sisters
  - ▶ Dynamic process depending on what is going on in life
- 

# Acknowledgement in Canada

“The history of Mr Charlie’s family is important because it identifies a direct link between the colonisation of the Yukon and the governments residential school policies to the removal of children from their families into abusive environments for extended periods of time, the absence of parenting skills as a result of the residential schools functioning as an inadequate parent, and their subsequent reliance on alcohol when returned to the communities. Mr Charlie’s FASD is the direct result of these policies of the Federal Government.”

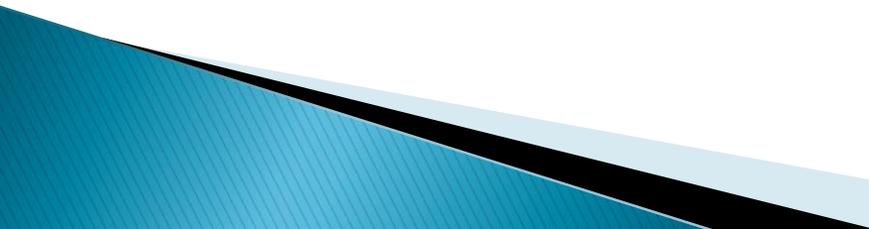


# Lililwan (all the little ones) Project

## June Oscar and Elizabeth Elliot

- ▶ At risk indigenous group in NW Western Australia
- ▶ community led
- ▶ 2006 55 alcohol related deaths, 13 suicides
- ▶ In 2007 concern about their children led to alcohol restrictions
- ▶ In 2009 invited FASD prevalence study
- ▶ 43 communities, 5 languages, pop 4500
- ▶ Trauma from loss of traditional lands and stolen generation
- ▶ About 25% of children have FASD, many severely affected
- ▶ Structuring circles of hope and community development

# Costs of FASD

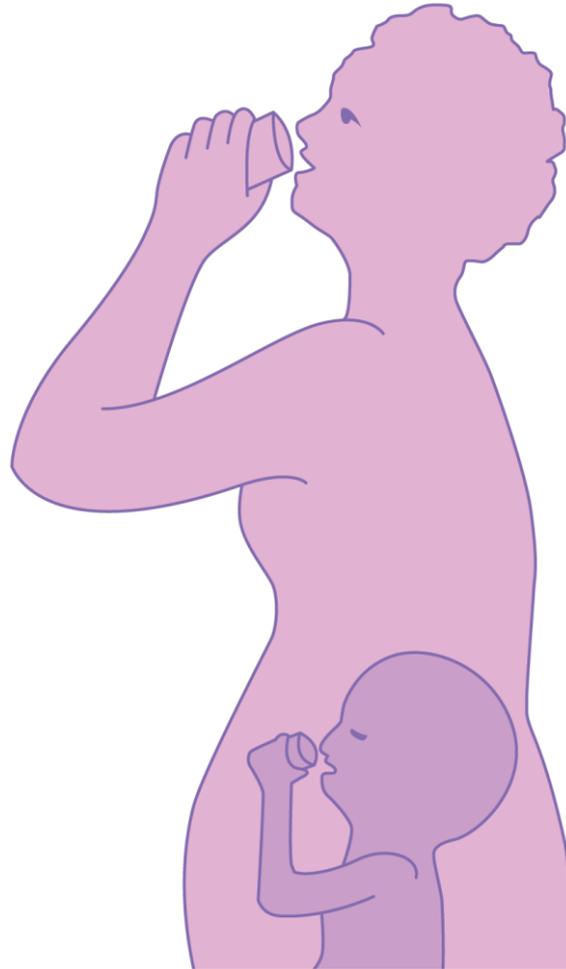
- ▶ USA was spending 4 Billion annually in 1988
  - ▶ Lifetime cost per person \$2 million in Canada
  - ▶ 50% of 6600 kids in care in Alberta have FASD
  - ▶ Each one costs \$3 million over lifetime
  - ▶ FASD is a critical issue in child welfare practice
  - ▶ Who is responsible?
  - ▶ Recognise FASD without perpetuating the stereotypes of indigenous peoples
  - ▶ No blame approach
- 

# Alcohol is a Teratogen

**Alcohol  
crosses the  
placenta**

**Whatever the  
mother drinks  
the baby  
drinks - and  
for a longer  
time**

**Alcohol is more  
common and more  
harmful than any  
other substance**



**The effect on  
development  
depends on  
dose, timing &  
interplay with  
genes and  
other factors**

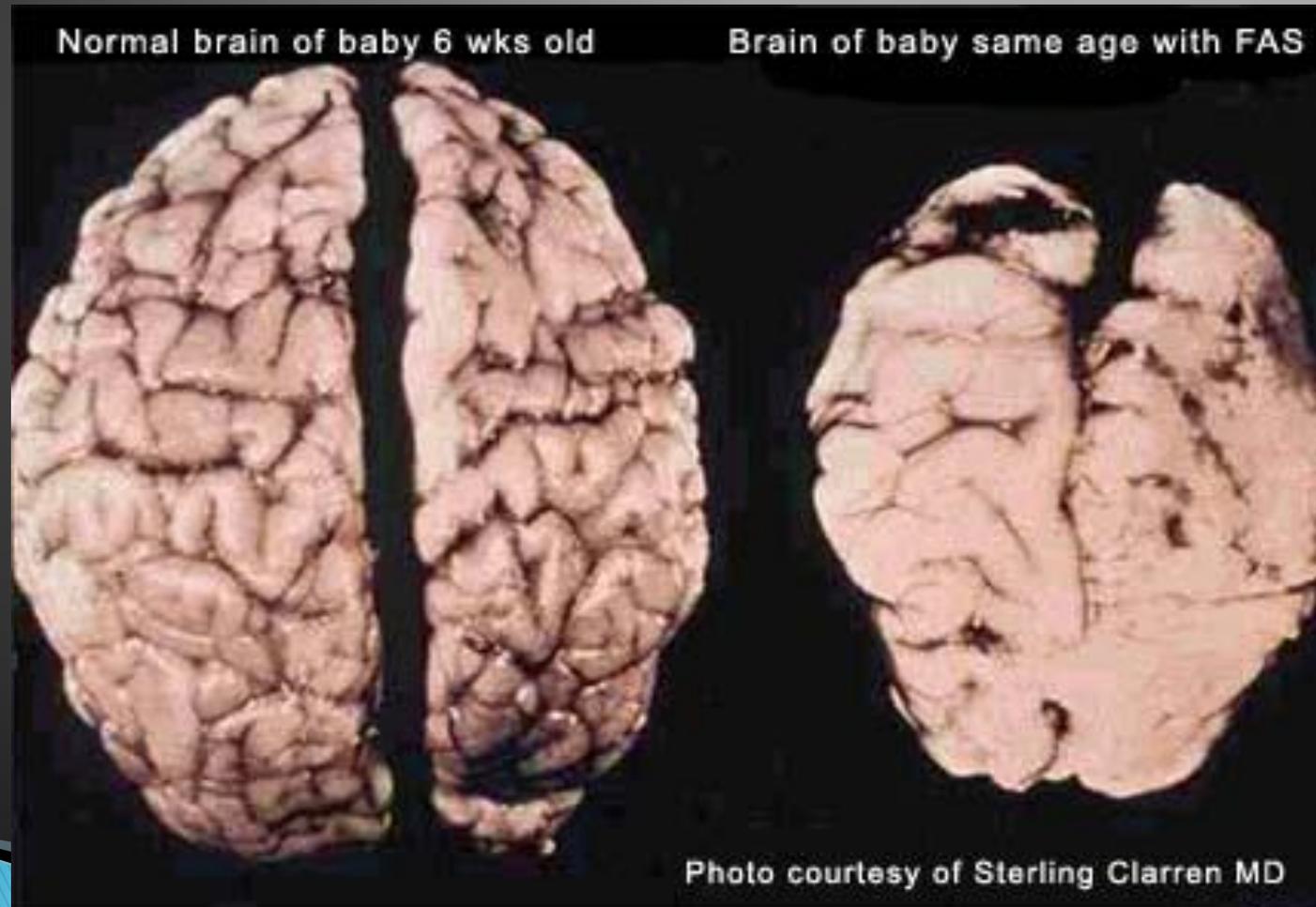
**There is no known  
safe amount or  
time for brain  
development**

***The Ministry of Health advice is to avoid alcohol  
when pregnant, planning to be pregnant and whilst***

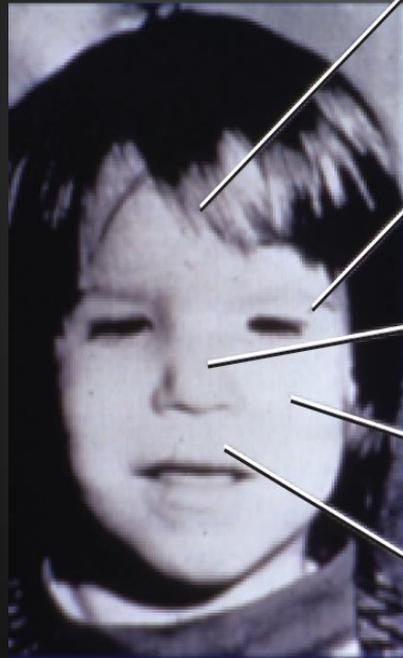
# Diagnostic Criteria – FAS



# FAS and the Brain



# Animal Models – mouse



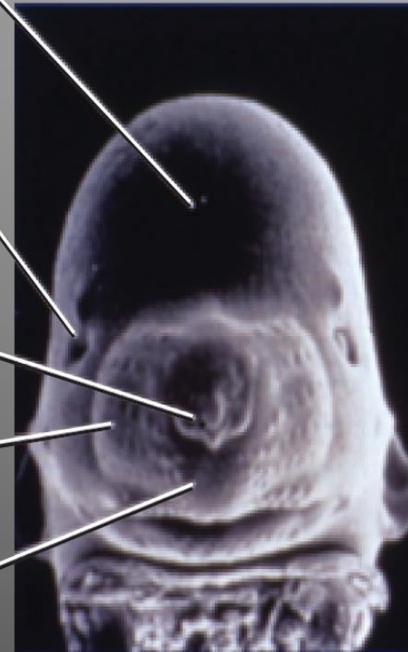
Narrow forehead

Short palpebral fissures

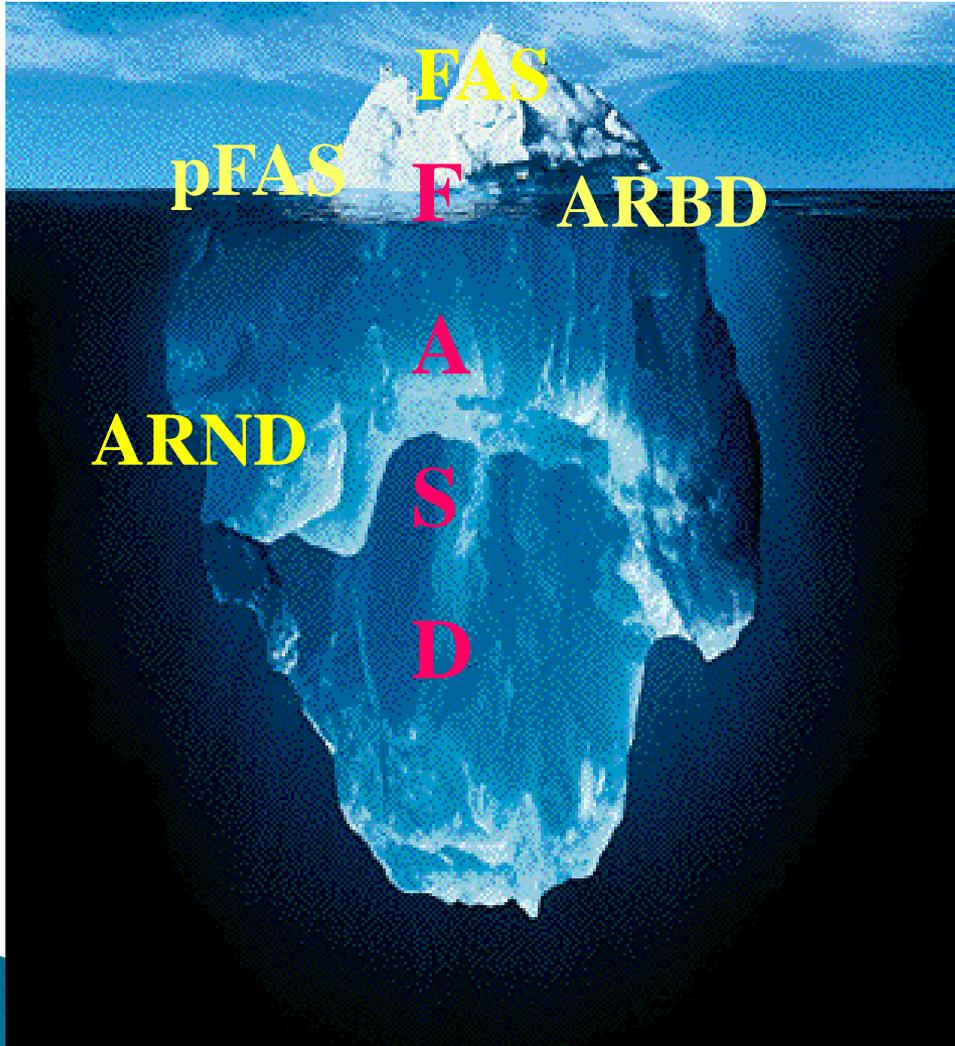
Small nose

Small midface

Long upper lip with deficient philtrum



# FAS – Only the Tip of the Iceberg



**Fetal alcohol syndrome**  
**partial FAS**

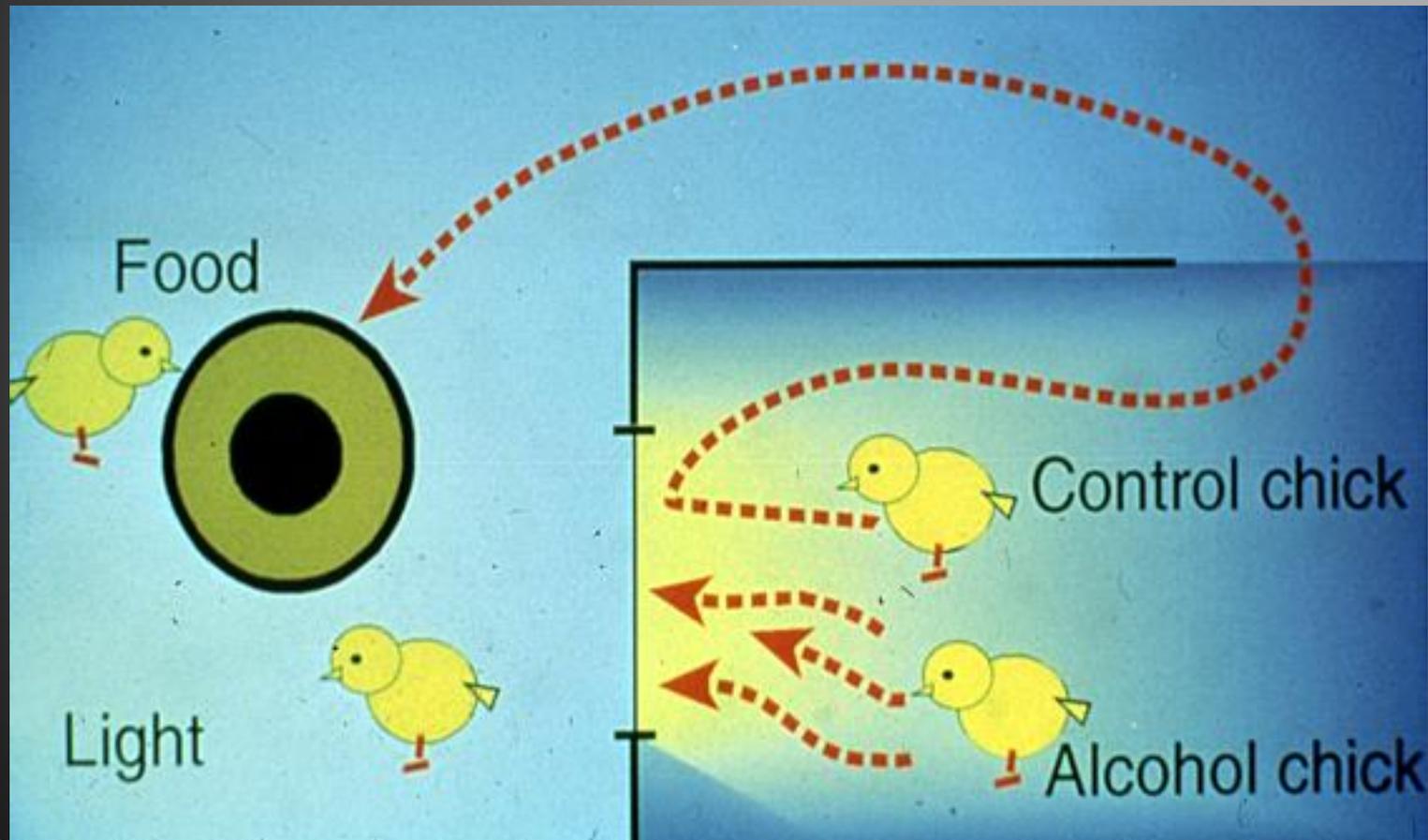
**ARND**

- Clinically appear normal, often behaviour reveals their deficit(s)
- Normal, but they cannot reach their potential

ALCOHOL EXPOSED CHICK



# Alcohol Chicks Fail Detour Learning Test



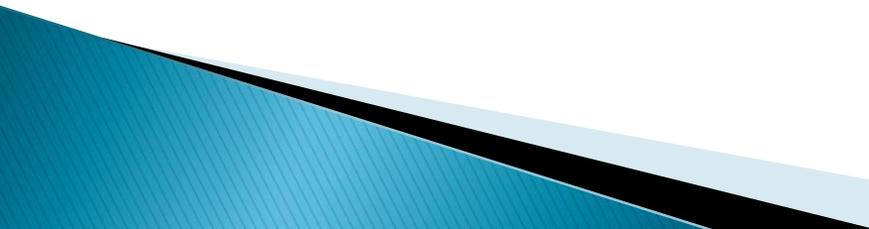
Children coming into state care are the group of most vulnerable and at risk children in society.

- ▶ Parents unable to provide adequate care. Many have suffered post natal adversity, poor nutrition, limited developmental experiences, inadequate attachments, homes with substance abuse, mental ill health and domestic violence.
- ▶ Children prenatally alcohol exposed have neurodevelopmental problems making them more difficult to parent
- ▶ Parents are blamed and children wrongly diagnosed with RAD, ODD, CD, ADHD and ASD
- ▶ Intergenerational FASD

# So... What's this all got to do with Neuropsychology

- ▶ Diagnosis around 6 years is a protective factor
  - ▶ For every child diagnosed the message ripples through a Whanau that alcohol is damaging the brains of our tamariki and prevents further pae pregnancies
  - ▶ Multidisciplinary diagnosis identifies the nature of the child's brain impairment so that they can get the best care, teaching and resources
  - ▶ It is a brain based disability expressed through behaviour and later criminalised if not recognised and accommodated in childhood
- 

# Why diagnose FASD?

- ▶ It is a medical disorder with neuro-behavioural symptoms
  - ▶ Enter into a dialogue with families, caregivers, professionals and others involved to describe and understand FASD
  - ▶ Qualify child for services: ID, social, ed
  - ▶ Define interventions to address disability and maximise potential
  - ▶ To stop wasting time and resources with misdiagnosis and mismanagement
- 

**Prenatal  
Alcohol**



**Primary  
Disability**

**Brain  
Damage**

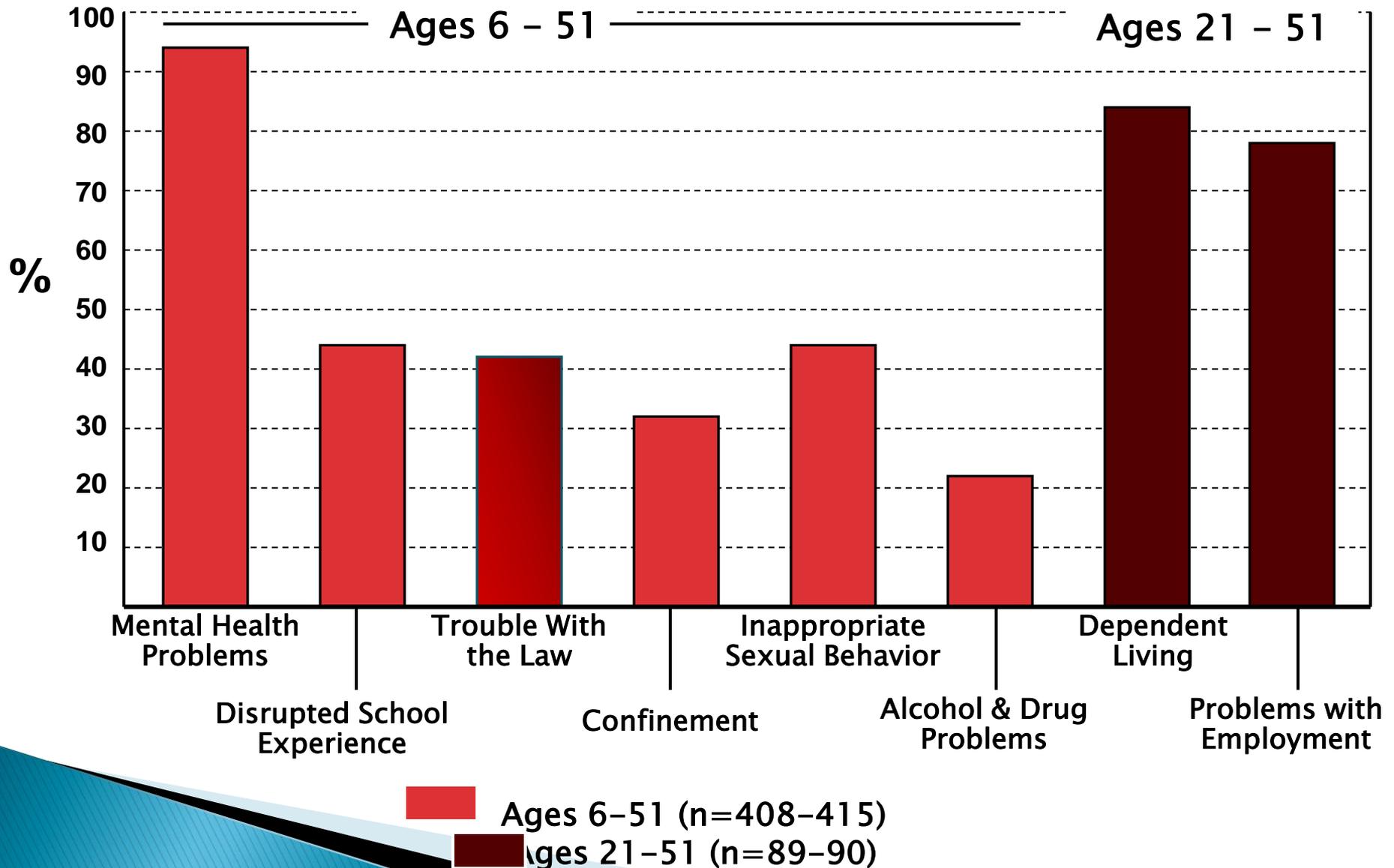
**Dysfunctional  
Behaviors**



**Secondary  
Disabilities**

**Trouble with the Law,  
School Disruption, Etc.**

# FASD Relevant in the Legal Context Because of: **Secondary Disabilities**



# Diagnosis

- ▶ Multidisciplinary (trained medical specialist & trained neuropsychologist at a minimum)
  - ▶ Not in DSM-4TR but in DSMV (appendix)  
Neurobehavioural Disorder associated with Prenatal Alcohol Exposure (NB-PAE)
  - ▶ University of Washington guidelines 2004
  - ▶ Canadian Harmonisation 2005
  - ▶ NZ investigations 2008
  - ▶ Canadian guidelines under revision
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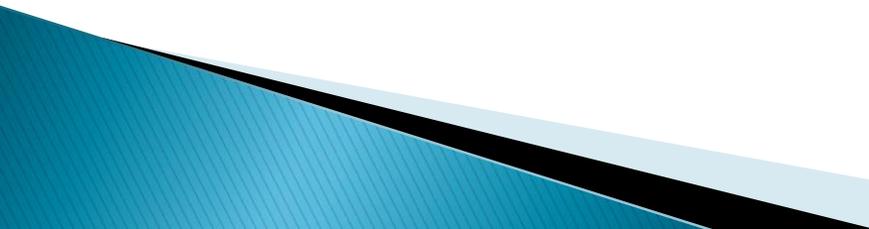
# Neuropsychological Assessment

- ▶ Identify how organic changes to the brain have resulted in a spectrum of difficulties and define them
  - ▶ Provide empirical data for diagnosis
  - ▶ Define strengths that can be harnessed for the future
  - ▶ Provide roadmap for future management
- 

# When diagnosed FASD

- ▶ Enter into a dialogue with families, caregivers, professionals and others involved to describe and understand FASD
  - ▶ Qualify child for services: ID, social, ed
  - ▶ Define interventions to address disability and maximise potential
  - ▶ To evaluate interventions and monitor change over time
- 

# Differential Diagnosis

- ▶ Diagnosis of FAS, PFAS, ARND requires deficits (2 sds below mean) over three brain domains to obtain ranking of 3 on 3<sup>rd</sup> digit, probable evidence of CNS Damage
  - ▶ Standardised psychometric tests used for each domain
  - ▶ Excludes normal variations, mild difficulties, behavioural without underlying CNS
- 

# Brain Domains Affected

(3 impaired domains required)

<b>Sensory/Motor/Regulatory</b> Hard and soft neurologic abnormalities (includes sensory-motor)	<b>Cognitive</b>	<b>Executive Function</b>
<b>Attention</b>	<b>Academic achievement</b>	<b>Adaptive Behaviour</b> <b>Social Skills</b> <b>Social Communication</b>
<b>Communication/Language</b>	<b>Memory</b>	<b>Small head circumference or other structural brain abnormalities</b>

# 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
- 

# Chronological vs Developmental Age

## Timelines

- ▶ Chronological Age ---  
--- 18
- ▶ Expressive Language ---  
--- 23
- ▶ Social Maturity --- 10
- ▶ Math Skills --- 8
- ▶ Reading Decoding ---  
14
- ▶ Reading Comprehension --- 9

Typical developmental variability seen in adolescents with an FASD.

## ▶ Paradigm Shifts and FASD

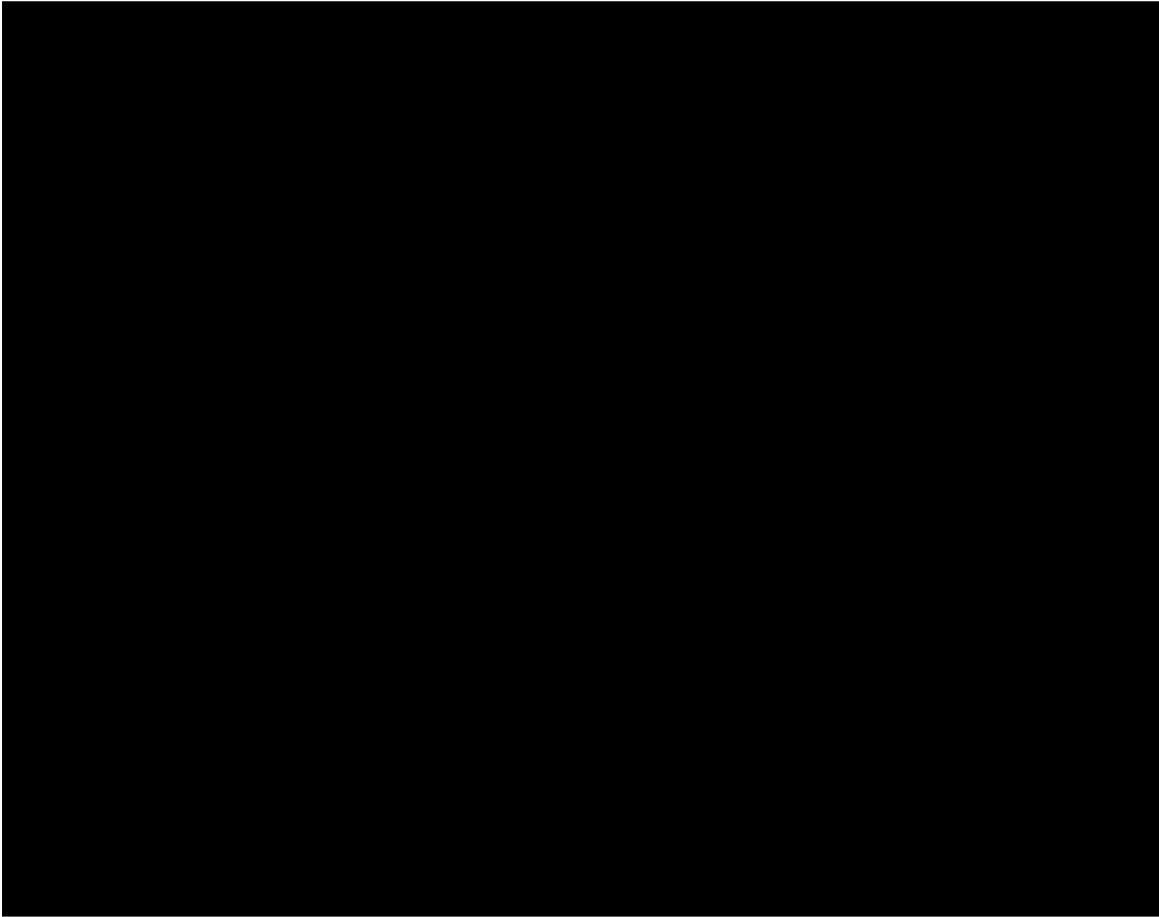
From                      Won't                      to                      Can't

- |                        |                               |
|------------------------|-------------------------------|
| ▶ Bad/annoying         | frustrated, challenged        |
| ▶ Lazy/ unmotivated    | trying hard, tired of failing |
| ▶ Lying                | Confabulating                 |
| ▶ Fussy                | sensitive                     |
| ▶ Acting young         | being young                   |
| ▶ Attention seeking    | needs support                 |
| ▶ Refuses to sit still | overstimulated                |
| ▶ Resisting            | doesn't understand            |
| ▶ Trying to annoy me   | can't remember                |
| ▶ Showing off          | needing contact               |
| ▶ Doesn't care         | can't show feelings           |

E Hara te pai I te tawhiti rawa  
Ki nga mea e haere tika ana

No horizon is too far for those  
properly prepared





# AlcoholHealthwatch

- ▶ Health promotion to reduce alcohol related harm funded by MOH
- ▶ Co-ordinates Fetal Alcohol Network NZ (FANNZ) and training
- ▶ [www.ahw.org.nz](http://www.ahw.org.nz)
- ▶ [www.fan.org.nz](http://www.fan.org.nz)
- ▶ Christine Rogan, AlcoholHealthwatch  
[christine@ahw.org.nz](mailto:christine@ahw.org.nz)

FASD-CAN (Care Action Network) for family support