

Fetal Alcohol Spectrum Disorder - Finding the Fit

A presentation about FASD in Aotearoa New Zealand's Health System

*Presenter: Christine Rogan
christine@ahw.org.nz*

Alcohol Healthwatch & FANNZ

- **Alcohol Healthwatch is a Charitable Trust funded by the Ministry of Health since the early 1990s to reduce alcohol related harm through effective health promotion**
- **AHW coordinates the Fetal Alcohol Network New Zealand (FANNZ) providing information, advice and connections on alcohol and pregnancy prevention and intervention**
- **www.ahw.org.nz**
- **www.fan.org.nz**

Describing Fetal Alcohol Spectrum Disorders

FAS – Fetal Alcohol Syndrome identified in 1973

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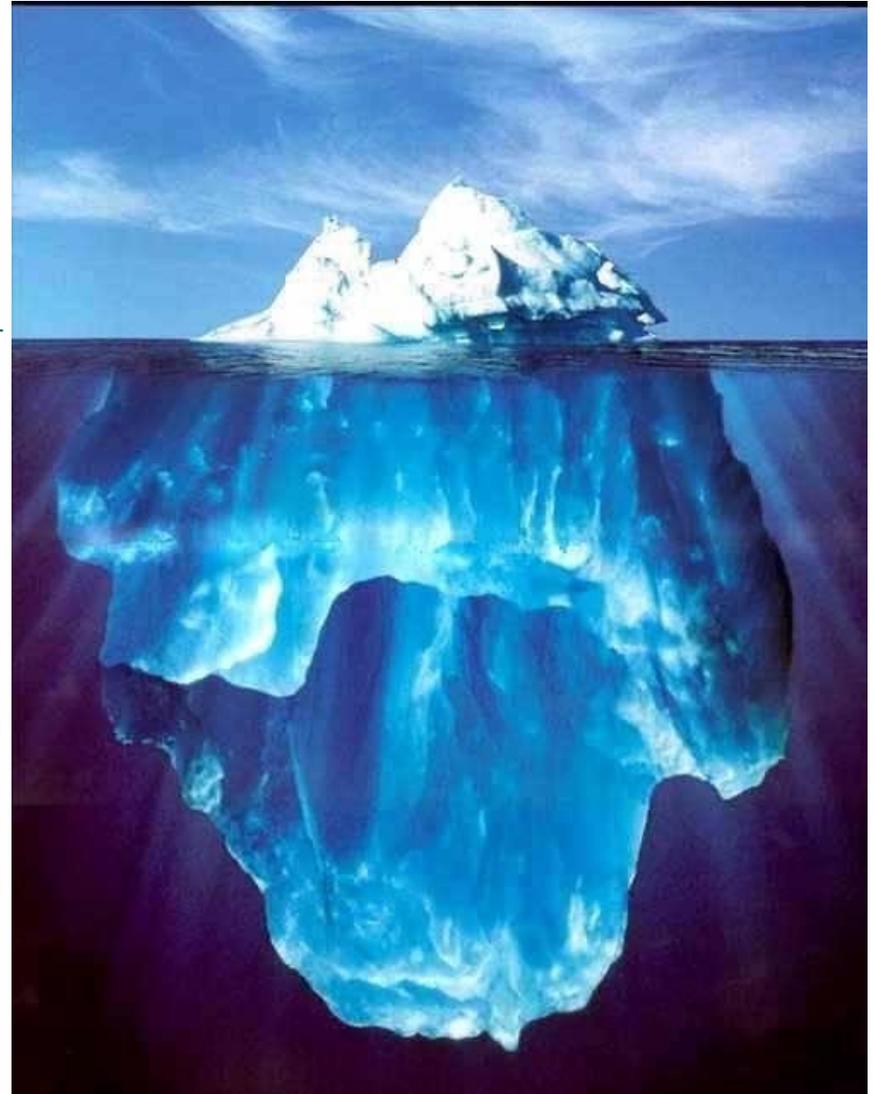
FAE – Fetal Alcohol Effect (Historical term)

pFAS – Partial Fetal Alcohol Syndrome

ARND - Alcohol-Related Neurodevelopmental Disorder

FASD – Umbrella term in international

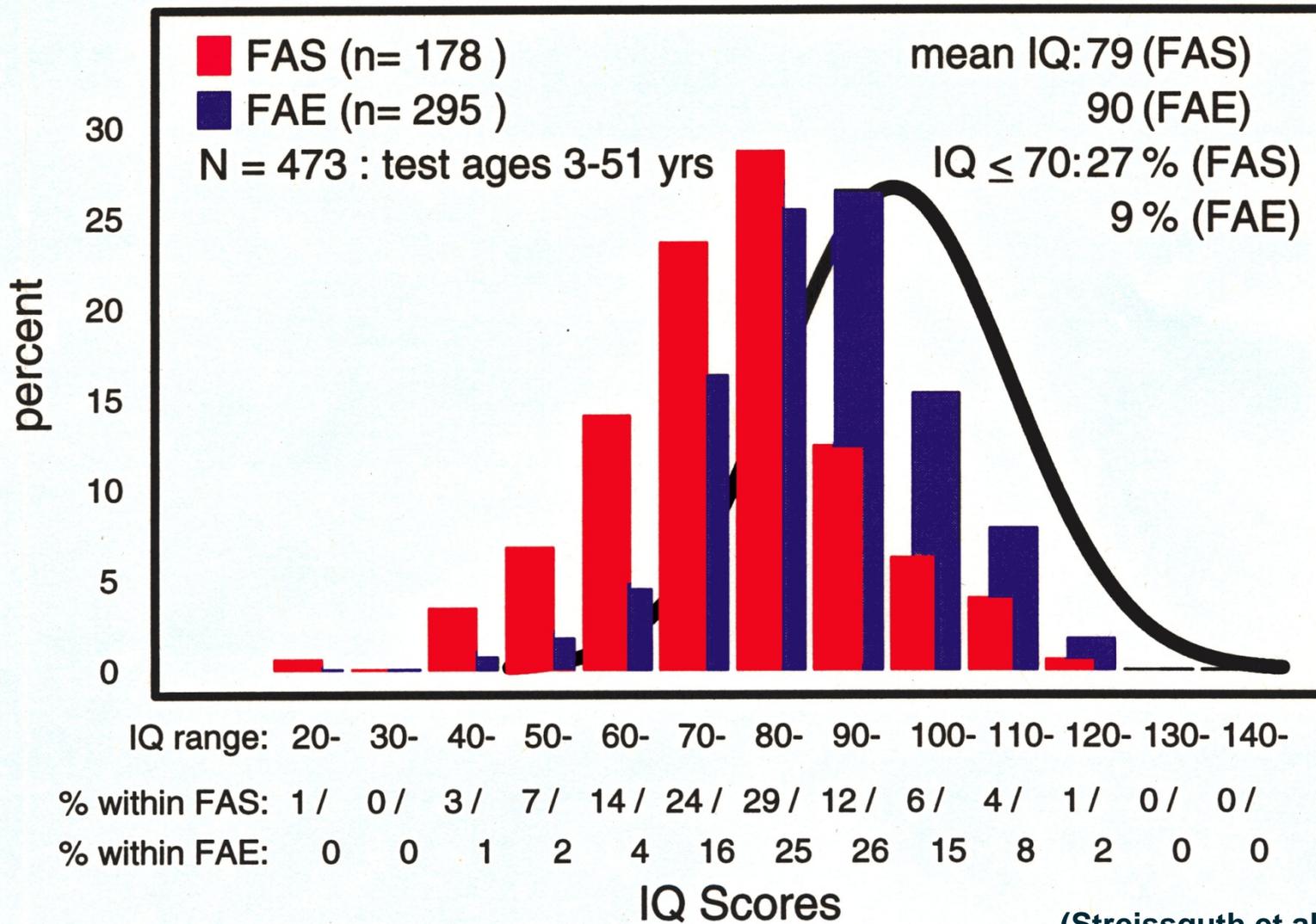
- **literature since 2004**



FASD is fundamentally about brain damage

- **No known safe amount and no safe time to consume alcohol.**
- **Eg. In the hour it takes for a healthy adult liver to detoxify one unit of alcohol, 15 million new fetal brain cells have emerged (second trimester).**
- **One glass of alcohol on its own will not cause fetal alcohol syndrome but it may alter the way brain cells grow and migrate to their intended destination, affecting their role in learning and functioning throughout life.**

IQ distributions in the Primary Disabilities Sample: FAS and FAE



(Streissguth et al, 1996)

But there are at least 10 brain domains that alcohol can adversely impact

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

(Jeanette Lange, JFas Int, 2006)

The long term prognosis

Population and longitudinal studies internationally of affected individuals have consistently found significant levels of secondary disability arising from their primary brain dysfunction and from a lack of appropriate care.

(Streissguth et al, 1996; Spohr, 2006; Burd, 2003, Fast & Conry 1999).

The Streissguth et al, longitudinal study of people affected showed:

- **90% had diagnosed mental health problems**
- **80% of adults were dependent for their daily needs**
- **80% had employment problems**
- **60% were expelled from or dropped out of school**
- **60% had been in trouble with the law**
- **50% had inappropriate sexual behaviour**
- **50% had been confined for mental health reasons, alcohol and drug treatment or as a consequence of law violations**
- **30% had alcohol and drug problems (prevented from being more significant due to family intervention)**

“ If we had known about FAS earlier, it is hard to say whether it would have stopped him [adolescent son] getting into such serious trouble but we would have been able to handle things very differently”.

(FASD and the criminal Legal System: Are we criminalising disability.”Uvic.ca, 2007)

How big is the problem thought to be?

- **The estimated prevalence of FASD internationally is 1% of live births (Sampson et al, 1998)**
- **At that rate, New Zealand could expect 600 babies born affected each year. [Note: BERL counted 2.17 NZ cases per annum in their report]**
- **Based on Canadian econometric figures, (Stade et al, 2009) the annual cost per person born affected could be NZ\$31,826 pa (\$18.6 million, accruing every year).**
- **A very small proportion of affected children in NZ have received a diagnosis (Leversha et al, 2000).**

Might we have a big problem here?

- 15 years of independent studies have show that between 20-40% of pregnant women in New Zealand report drinking during pregnancy.
- Around 10% are drinking to intoxication after pregnancy recognition (Watson & McDonald, 1999).
- A national survey of midwives reported that 80% of teenage pregnancies are alcohol exposed (Mathew et al, 2001).
- Fifty percent of women believe some alcohol during pregnancy is safe (Parackal 2006).
- In a survey of women who had just given birth, 60% reported binge drinking prior to pregnancy recognition (Jacquemard & Ho, 2006 Unpublished).

What about their advice?

- **AHW felt it was important to ask about the advice these women might be receiving from the health sector.**
- **Such information would also guide any workforce development.**
- **A survey of 240 primary healthcare professionals who routinely provide healthcare to women of reproductive age was commissioned (T Wouldes 2009, in press).**

What do health professionals know and do about alcohol and pregnancy?

- **The survey indicates a very mixed picture when it comes to knowledge, belief and practice.**
- **78% reported routinely ‘screening’ but this usually only involved asking one question “Do You Drink”.**
- **Only 7% were currently using a standardised questionnaire.**

- **40% were less likely to inquire when:**
 - it was the first visit;
 - if there were socio-economic or cultural factors that they perceived placed the woman at ‘low’ or ‘no’ risk;
 - or when there were no clear procedures in the clinical environment for managing women who reported using alcohol or drugs.
- **57% reported a need for training to assess the risk of alcohol (81% for other drug use).**
- **80% reported they would find a short standardised questionnaire useful .**

- **When it came to their knowledge of FASD, 33% of participants thought that health professionals were sufficiently aware of FASD.**
- **Only 23% were able to correctly identify all four major criteria for making a diagnosis of FAS.**
- **2/3 of clinicians in the survey believed that a diagnosis may lead to a child and family being stigmatised;**
- **while overwhelmingly agreeing that an early diagnosis may improve treatment plans for the affected child.**

Anecdotal experience with other health practitioners.

- A paediatrician willing to diagnose but “FAS or nothing”.
- Educational psychologists group advised by two psychiatrists to ignore FASD.
- A family therapist told by a paediatrician , ‘there is no such thing as FAS’.
- Psychiatrist told counsellor that FAS was, ‘just a learning disorder and not an area of interest to me’.
- An A&D counsellor over-ruled a medical diagnosis of an FASD of a patient in her care.
- A formal FAS diagnosis of an infant, blind since birth, never revealed to her foster parents until adolescence.

This is not just a Kiwi problem!

Was this [doctor's] reluctance a misunderstanding of the condition and its ramification or was it indeed sensitivity and compassion toward the person who had caused the condition? Either way it was harmful and did not help in any way."

(Elizabeth Russell, Australia, 2005).

Compare our experiences to Canada

- **Canada, like New Zealand has no established prevalence rate for FASD but this has not stood in the way of concerted efforts to recognise and respond to FASD as a significant public health issue.**
- **In the past decade, Canada has developed diagnostic guidelines, research, training & treatment programmes, conferences and strategic networks.**
- **Collaboration takes place at all levels:**
 - federal and provincial government ministries
 - doctors, researchers, teachers
 - corrections, police, justice
 - indigenous health services
 - the family/community support sector

A Kiwi example of 'finding the fit'

- Youth Justice sector - Intensive Monitoring Group (IMG) have set up to work together to better address the behaviour of high risk persistent young offenders with complex needs (including mental health and/or A&D).
- The IMG is a multidisciplinary team approach (CYFS, Police, GSE, RYFS, & health services) .
- The Auckland IMG has achieved a 38% reduction in reoffending rates (though it receives no extra funding).
- This is an example of the sort of collaboration needed to address the complex needs associated with FASD affected individuals.

When training takes place, good things happen

- By identifying FASD early as a risk factor, the child, their family and those they engage with have the opportunity to learn to approach their complex needs more effectively with knowledge and confidence.
- Alcohol Healthwatch has been coordinating an evaluated project to establish what would be an appropriate multidisciplinary diagnostic approach for FASD in the New Zealand context (in progress).
- The project (combined medical & neuropsychological assessment) includes Youth Court ordered psychiatric assessments.

“I’m much more confident professionally. I’ve got the training and the background to know what to do but it had been like a big gap in my experience – its quite complex and its not like I feel like I’m an expert but I feel more secure on my knowledge and what to do.”

(Project evaluation clinician’s commentary)

“The way people work in the youth court is to try and get underneath, find underlying causes and try to deal with them.

I can say we love these sorts of tools and interventions. It helps us make decisions, helps the family make decisions.”

(Project evaluation Judge’s commentary)

In conclusion

- **Up-skilling on FASD prevention and intervention is highly justifiable, desirable and beneficial**
- **There is a willingness of health professionals to engage**
- **Questions?**
 - **How can we ensure FASD assessments become part of the diagnostic mix?**
 - **How should we go about workforce development?**
 - **Who should take the lead?**
 - **Who should fund it?**