

Fetal alcohol syndrome: from surveillance to policy

RACP Congress, May 2008

Elizabeth Elliott

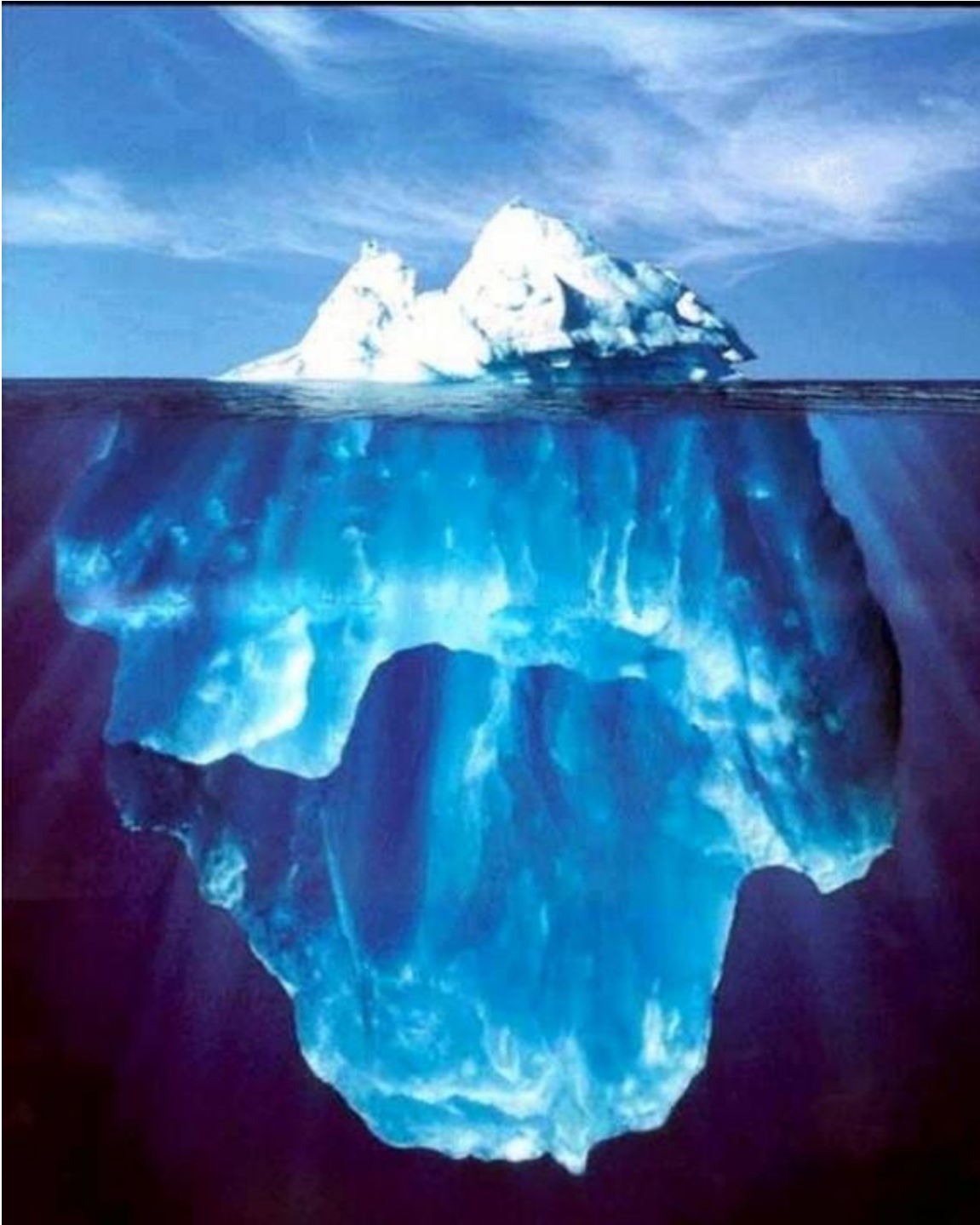
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Why do we need to know about FASD?

In Australia increasing rates:

- binge drinking teens
- women drinking high risk
- unplanned pregnancy
- alcohol use in pregnancy
 - 58.7% 1st trimester
 - 14.8% outside guidelines
- binging in Indigenous women
- FAS diagnoses





Alcohol and the fetus

Fetal alcohol syndrome

Alcohol-related birth defects

Alcohol-related neurodevelopmental disorders (x 10)

* Stillbirth, prematurity, miscarriage

FAS

- Preventable
- leading cause of mental retardation USA
- 60% young offenders have FAS
- Poor prognosis
- Costly:
 - \$US2.9 million lifetime costs
 - \$US 3.6 billion/year (Lupton, 2004)

Institute of Medicine Diagnostic Criteria FAS, 1996

- **FACE**
- **GROWTH** (pre- and/or postnatal)
- **CNS** (structure and/or dysfunction)
- **ALCOHOL** (exposure during pregnancy*)

**suspected* in absence of evidence of alcohol intake

Facial Features of FAS

Microcephaly

Flat nasal bridge

Inner epicanthic folds

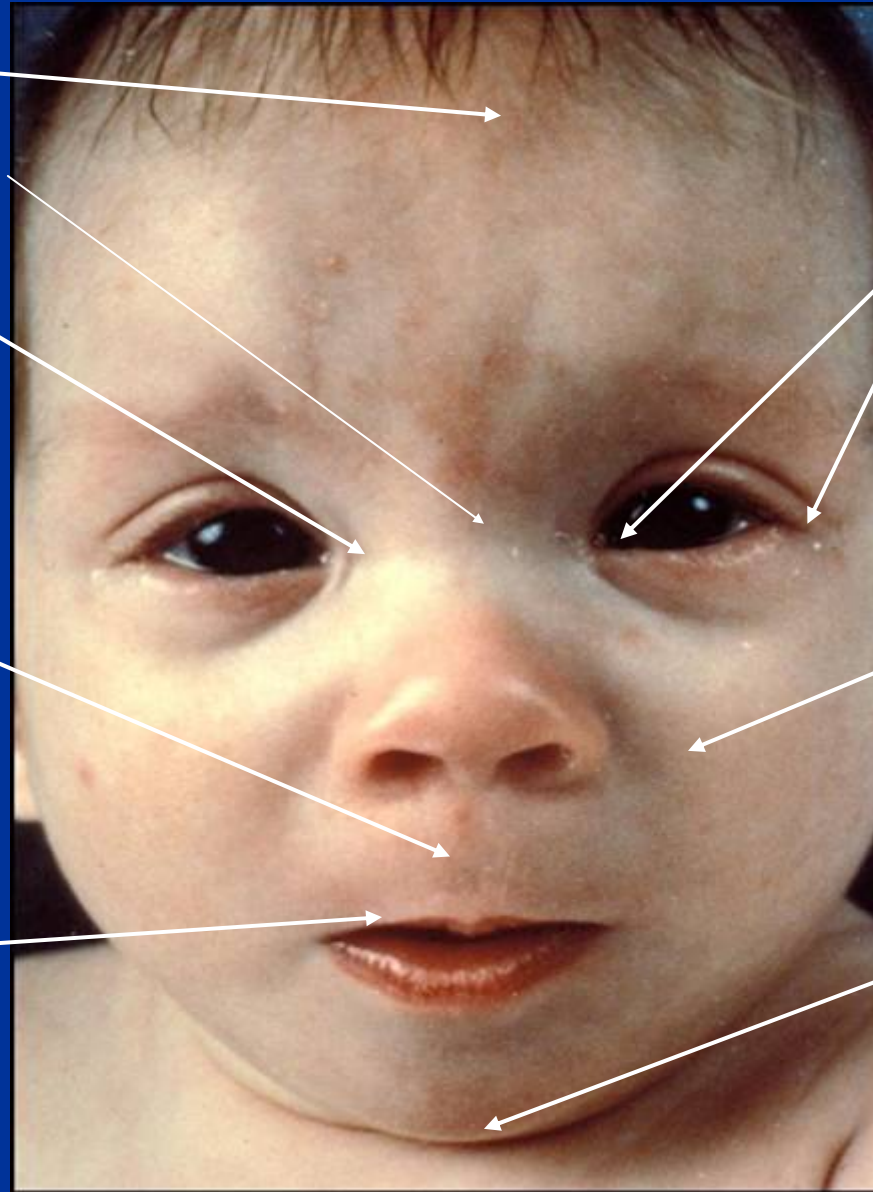
Long, smooth, indistinct philtrum *

Thin smooth vermilion border upper lip *

Short palpebral fissures ~ ocular volume optic vesicle*

Maxillary hypoplasia
Flat mid-face
Short nose *

Micrognathia



Facial features may be abnormal in the neonate; change with age

Four-Digit Code
FAS facial phenotype



Palpebral Fissure Length
endocanthion to exocanthion

FAS



Lip-Philtrum Guides 1 & 2



Astley, S. J. Pediatrics
2006;118:1532-1545

FAS: secondary disabilities

- Disrupted education (60%)
- Unemployment (80%)
- Mental health problems (90%)
- Trouble with the law and imprisonment (60%)
- Alcohol and drug abuse (30%)
- Vulnerable, inappropriate sexuality (50%)
- 10% >21y live, work independently,

2-4 fold reduction in adverse outcomes with early diagnosis

Streissguth, 1997 (n = 415)

Alcohol-related birth defects

Confirmed maternal alcohol exposure

- 2 or more facial abnormalities

and

- 1 or more congenital structural defects known to be linked to maternal alcohol use in man/animals e.g. Cardiac, Skeletal, Renal, Eyes, Ears

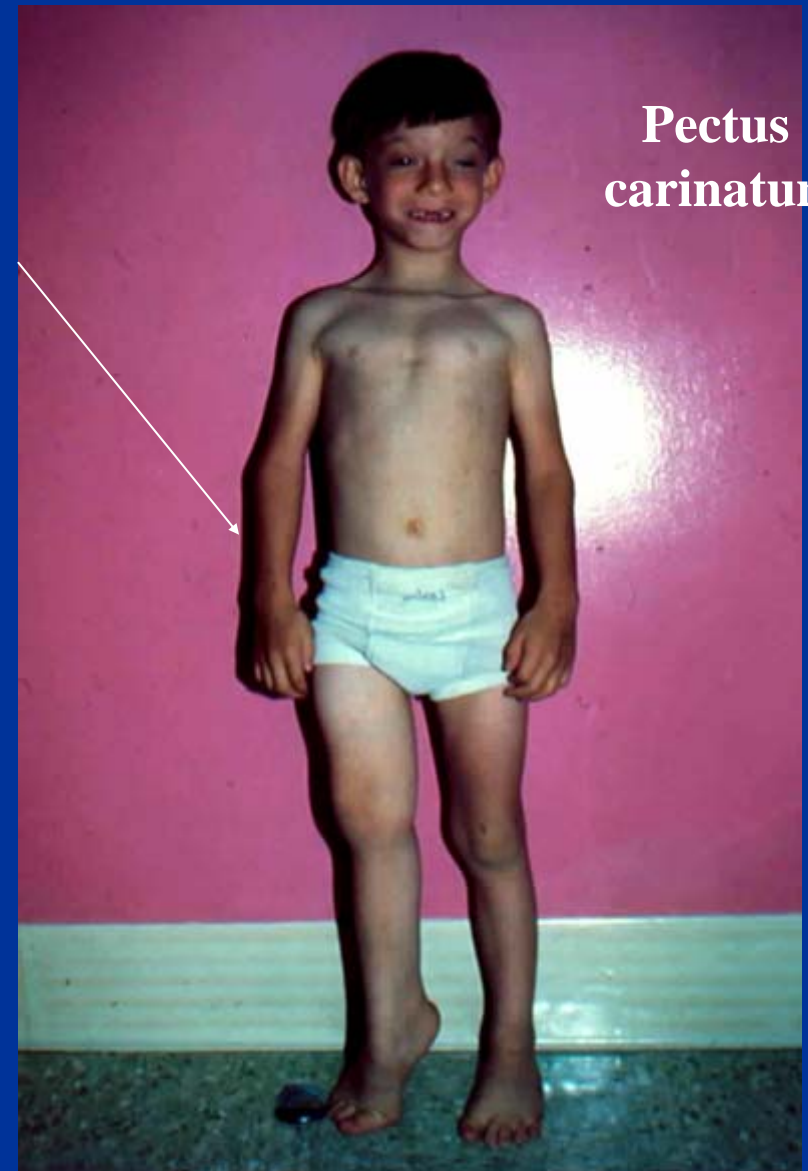
or

- 2 or more minor anomalies e.g. clinodactyly, hypoplastic nails, hockey stick palmar creases, pectus carinatum/excavatum

Hoyme. A practical approach to diagnosis of fetal alcohol spectrum disorders. Pediatrics 2005;115:39-47.

Fetal alcohol syndrome

Limited pronation, supination at elbows
Joint contractures



Pectus
carinatum

Courtesy: Ken Jones

Other features following prenatal alcohol exposure

- Clinodactyly 5th digit
- camptodactyly
- “Hockey stick” upper palmar crease



Courtesy Ken Jones

Alcohol related neurodevelopmental disorder

Confirmed maternal alcohol exposure

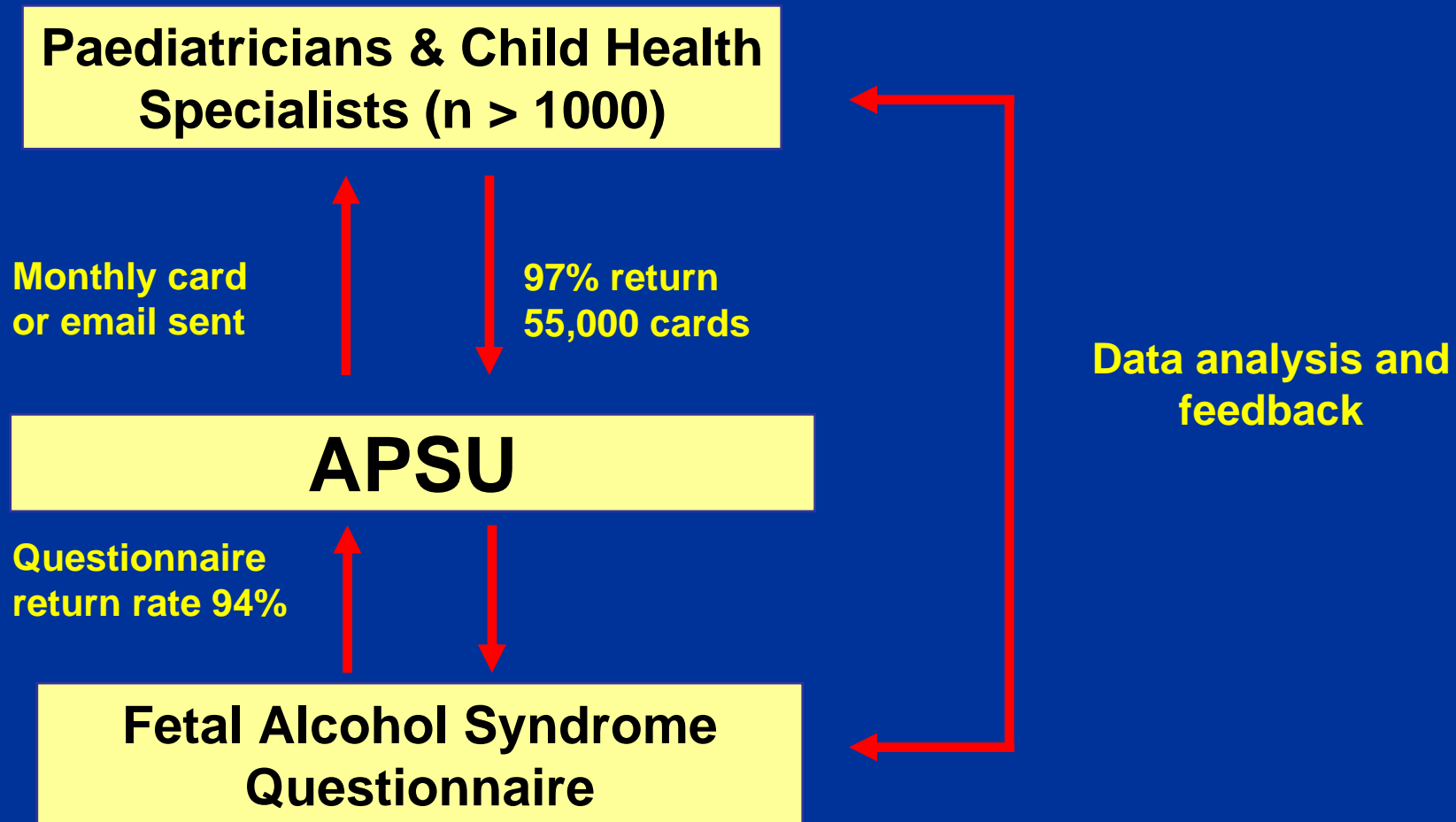
- Normal face, growth, no birth defects
- 1 or more of
 - deficient brain growth or development
 - Characteristic complex pattern of behavioural or cognitive impairment

For all categories, other genetic and malformation syndromes must be excluded.

Hoyme. A practical approach to diagnosis of fetal alcohol spectrum disorders. Pediatrics 2005;115:39-47.

FAS in Australia (FASD??)

Australian Paediatric Surveillance Unit*



- active, monthly, national surveillance of selected rare diseases
- Elliott E, Payne J, Bower C, Haan E. Arch Dis Child 2007, In press.

FAS in Australia

Australian Paediatric Surveillance Unit: 2001- 4

- 92 newly diagnosed 4 y (25 exclusions)
- Significant increase over time (doubling)
- 65% low birth weight (<2.5 kg)
- 36% preterm
- 64% Indigenous (~2%)
- 60% in out-of-home care
- 51% has an affected sibling
- 53% Microcephaly (present at birth in 56%)

Elliott E, Payne J, Bower C, Haan E. Arch Dis Child 2007, In press

Australia n=92. Congenital Abnormalities (24%)

Cardiac	VSD, ASD, PDA, PS, PFO
Skeletal	Cervical rib, proximal placement thumbs, pectus carinatum, thoracic kyphosis, talipes, spina bifida occulta, large patent fontanelles
Vascular	Vascular ring, haemangiomas
Renal	Horseshoe kidney, renal dysplasia, vesico-ureteric reflux
Cleft palate	Pierre Robin sequence
Ocular	Microphthalmia

Elliott E, Payne J, Bower C, Haan E. Arch Dis Child 2007, In press

FAS in Australia: 2001-2003 (n=92)

Developmental problems

60% Speech and language disorder

50% Fine motor delay

49% Intellectual impairment

42% Behavioural problems

36% Gross motor delay

5% Hearing loss (sensorineural)

4% Visual impairment

Elliott E, Payne J, Bower C, Haan E. Arch Dis Child 2007, In press

FAS in Australia

Australian Paediatric Surveillance Unit: 2001- 4

- 92% high risk exposure
(>4/sitting/week or binge >5 in first trimester)
- 75% exposed \geq 1 drug plus alcohol
(nicotine, marijuana, heroin, cocaine, amphetamine, glue)
- 7% diagnosed at birth
24% <12 months; mean 3.26 y (0-11)
- Multiple physical, developmental, behavioural, problems
- High health, education, community service usage

Behavioural phenotype (n=92)

Externalising problems

Oppositional defiant disorder 24 (26%)

Attention/hyperactivity 34 (37%)

Internalising problems

Anxiety 16 (17 %)

Depression 1 (1%)

Other 10 (11%)

School problems (absenteeism, bullying), autistic spectrum disorder, self injury, abnormal eating behaviour, inappropriate sexual behaviour

Why make a diagnosis?

Referral woman

Referral child for
assessment

Early intervention

Prevent 2^o disability

Prevent FASD in
subsequent children



Diagnosis requires

- Acknowledgement of cause
 - community
- Index of suspicion
 - Information about alcohol use in pregnancy
- Knowledge of features
 - health professionals
- Willingness to make diagnosis
 - stigmatisation
- Specialised services and staff training
 - e.g. diagnostic clinic

Paediatrician Survey

- 45% routinely ask about alcohol use in pregnancy
- 19% know FAS diagnostic features
- 2% very prepared to deal with FAS
- 70% concerns about 'labelling,' stigmatising
- 36% think parents might refuse referral
- 83% want educational resources

Elliott et al. JPCH 2006,42:698-703.

Women's survey

- Health Canada survey (CATI)
- 1103 Australian women aged 18 to 45 years (69%)
- 15% usually drank at risky levels (≥ 5 /sitting)
- 34% drank during last pregnancy
- 32% would drink during future pregnancy
- one third knew about potential adverse effects

Health Professionals' role

Agree (%)
(n=1103)

Health professionals should ask pregnant women about alcohol 96.9

Health professionals should advise women how many standard drinks are safe to drink during pregnancy 96.9

Health professionals should advise women to give up drinking alcohol during pregnancy 90.7

Intention To Drink Alcohol During A Future Pregnancy

- Previous risky drinking behaviour
- Smoker
- Tertiary education
- Previous pregnancy
- Knowledge alcohol may cause lifelong disability
- Tolerant attitude to alcohol in pregnancy

Health professionals don't know what to advise

- 87% 'consider not drinking'
- 44% think women should abstain
- 33% 'don't get intoxicated'
- 22% provide information on consequences
- 12% give information consistent with NHMRC guideline



Australian Alcohol Guidelines for Indigenous Communities

Guideline 3

- If you are pregnant or thinking about having a baby, it is safest for both you and your baby if you do not drink alcohol at all
- If you are breastfeeding, it is safest not to drink alcohol at all

(DHA, 2004)

A sobering lesson for boozing mothers-to-be



Education of health professionals and community:



NHMRC Alcohol Guideline 11 (2001)

Women who are pregnant or might soon become pregnant

11.1 may consider not drinking at all;

11.2 should never become intoxicated;

11.3 if they drink, should have less than 7 standard drinks over a week,

AND no more than 2 standard drinks per day

www.nhmrc.gov.au/publications/synopses/ds9syn.htm

NHMRC Draft Alcohol Guideline 3

For women who are pregnant or planning pregnancy

- “Not drinking is the safest option”
- *The risk of harm to the fetus is:*
 - highest with high, frequent, maternal alcohol intake
 - likely to be low if a woman has consumed only small amounts of alcohol before she knew she was pregnant or during pregnancy
 - hard to predict in the individual

Evidence

4 systematic reviews

- Only pregnancy, early infant outcomes
- Methodological flaws
- Inconsistent results
- No 'safe' lower limit established

NHMRC Draft Alcohol Guideline 3

For women who are breastfeeding

- “Not drinking alcohol is the safest option”
- Women should avoid alcohol in the first month after delivery until breastfeeding is well established
- After that time women should:
 - Limit alcohol to no more than 2 standard drinks/day
 - Avoid drinking alcohol immediately before breast feeding
 - Consider expressing milk in advance if they wish to drink

Evidence

Average weight, 2 drinks 3.07 hours to clear
1 systematic review

- At >2 drinks per day infant outcomes
 - Decreased lactation (milk ejection reflex, milk production, milk consumption)
 - Earlier cessation of breastfeeding
 - Deficits in psychomotor development
 - Disrupted infant sleep-wake behavioural patterns

Mothers-to-be told not to drink at all as official UK NHS advice is revised



Daily Mail March 19, 2007

American Academy of Pediatrics:

- Because a 'safe' level for alcohol consumption during pregnancy is not established, ***AAP recommends abstinence*** in women who are pregnant or considering pregnancy

Maternal determinants of risk

- Pre-existing drinking problem
- Timing; level of alcohol intake
- Unplanned pregnancy
- Poor nutrition
- Genetics
- Indigenous background
- Low SES
- History of physical/sexual abuse
- Environment/ psychological indicators

(Chambers 2003, Astley 2000)

Pregnancy warnings overkill, say winegrowers

UK will label bottles

- “Know your limits”
- “Avoid alcohol if you are pregnant or trying to conceive”
- Application lodged** to Food Standards Australia New Zealand for warning labels on wine bottles.

The industry is opposed

OBSERVER March 20, 2007

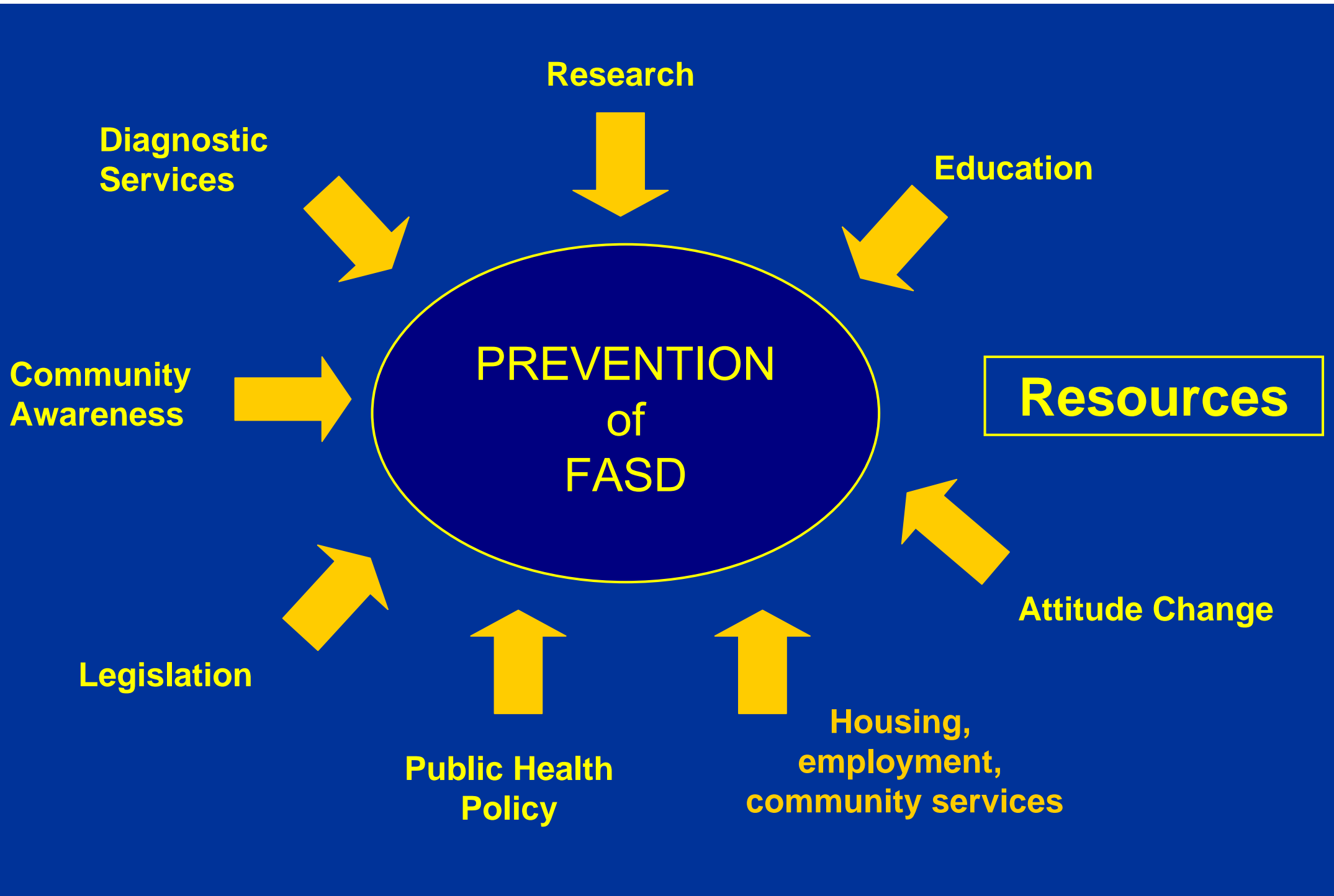


Revealed: how alcopops lure the young



SMH, August 6, 2007

“You don’t necessarily know you’re drinking alcohol and that’s a conscious effort to make those drinks more appealing to young people.”



Acknowledgements

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