nofasard national organisation for fetal alcohol syndrome and related disorders

Sue Miers AM

www.nofasard.org.au sue@nofasard.org.au ph 0418 854 947 PO Box 323, Blackwood South Australia 5051





Fetal Alcohol Syndrome

- Specific pattern of facial features
- Pre- and/or postnatal growth deficiency
- Evidence of central nervous system dysfunction



Photo courtesy Teresa Kellerman







Fetal Alcohol Syndrome

Partial Fetal Alcohol Syndrome
 Alcohol Related Neuro- developmental disorder
 Alcohol Related Birth Defects



Fetal Alcohol Spectrum Disorder

Fetal alcohol spectrum disorder is the most common preventable cause of birth defects and brain damage in children. It is a lifelong disorder, caused by prenatal alcohol exposure.





Fetal Alcohol Spectrum Disorders

- Estimated Incidence Rate: 1/100 live births (Sampson et al, Teratology 56:317-326, 1997)
- Incidence rates surpass Down Syndrome and Spina Bifida (WHO)



Secondary Disabilities Individuals with FAS/FAE have a range of secondary disabilities – disabilities that the individual is not born with, and which could be improved with appropriate interventions.



Universal Protective Factors

- Living in stable home with nurturing parents and minimum of changes in household
- Diagnosis and the implementation of appropriate interventions before the age of six
- Protection from violence

Streissguth et al 1996



Diagnosis is Crucial

- Essential to improve the quality of life for the affected child
- Helps to stabilize the home and improve parenting
- Allows for early intervention, appropriate treatment and support.
- Helps families and support people understand behaviours as reflective of brain damage rather than being the result of poor parenting
- Is the key to preventing further affected births



FASD in Australia

- Assessment and diagnostic services not routinely available
- Doctors have received very little training in diagnosing FASD
- FASD is poorly understood by most health professionals and glaringly absent in policy in most areas where it should be receiving attention.







Neural Pathways

40 days post conception – 50,000 nerve cells form per minute. During this period, transient ethanol exposure can delete millions of neurons from the developing brain.

Mann et al – Florida Dept Health





FASD & Societal Expectations A poor fit!

Societal Expectations	Values	Assumptions	Interventions	Reaction
• Based on age and appeal- rance	 Age appropriate Conform Comply with rules Take responsibility for actions 	• Non- compliance equals laziness, recalcitrance, spoilt, stupid	 Imposing will, punishments 	• Disruptive behaviour, anger, acting out, anxiety, shutting down

Adapted from D Malbin FASCETS ©



Individuals with FASD CAN learn!!

We firstly have to make a huge paradigm shift

- Understand that the brain is the source of all behaviour
- Individuals with FASD have brain difference
- Brain difference = different behaviour = normal for them
- Accept as individuals who "can't do" rather than "won't do"



Fair doesn't necessarily mean same

- In order to be fair individuals with FASD may need to be treated differently
- This means giving them what they need so that they can experience success just as we do for individuals with more familiar disabilites



FASD impacts on all sectors of our community

- Education
- Health
- Family & Community Services
- Drug & Alcohol / Mental Health Sector
- Disability Sector
- Criminal Justice System



Failure to address FASD is a human rights issue

It is critical that FASD is acknowledged in public policy and receives appropriate support and service delivery that enhances the rights, capacities, choices, and dignity of affected individuals and their parents, families and carers.

