



COMMONWEALTH OF AUSTRALIA

PARLIAMENTARY DEBATES



HOUSE OF REPRESENTATIVES

PROOF

MOTIONS

Foetal Alcohol Spectrum Disorder

SPEECH

Monday, 22 August 2011

BY AUTHORITY OF THE HOUSE OF REPRESENTATIVES

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Questioner
Speaker Mr SIDEBOTTOM

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(Braddon) (NaN.NaN pm)

Mr SIDEBOTTOM (Braddon) (12:41): I second the motion. I thank the member for Murray and my other colleagues the member for Moore and the member for Blair for supporting this motion, as it was supported in the Senate. I also acknowledge the Foetal Alcohol Spectrum Disorders Group in the parliament, which is determined to advocate action on FASD and to promote far more public acknowledgement of this insidious disorder, which is so little understood. We hope that we can progressively reverse that.

Foetal alcohol spectrum disorders, or FASD, is an umbrella term for a range of disabilities resulting from prenatal alcohol exposure. The syndrome was first described in 1973 by two paediatric dysmorphologists in the USA, Kenneth Jones and David Smith. That study and further research of FAS has identified three additional less severe syndromes known as FASD, or foetal alcohol syndrome disorders. These are: foetal alcohol effects, foetal alcohol related birth disorders and alcohol related neurodevelopment disorders.

The true prevalence of FASD in Australia is unknown, as the member for Murray pointed out earlier, and is believed to be chronically underreported in part due to the lack of agreed clinical guidelines and also a lack of understanding among both medical professionals and the general population about the risks of consuming alcohol during pregnancy. Indeed, there is an ambiguity to it. We have heard evidence from people who have spoken to our support group that some medical practitioners, for example, believe it is still okay to have some alcohol whilst being pregnant. Most of the evidence is clearly indicating that no alcohol is the preferred desired behaviour, but it is a message that is only slowly being taken on board even by the medical profession itself. We know that a lot of work is being done with midwives, for example, in trying to fully understand and explore this insidious disorder.

Data suggests that prevalence rates of FAS in Australia are between 0.06 and 0.68 per 1,000 live births in the general population. I know my friend the member for Blair has far more detailed information on this, but among Indigenous Australians it is between 2.76 and 4.7 per 1,000 births. Most accept these rates are under ascertained due to poor and ad hoc information, and indeed the limited skills and capacities in detection and

diagnosis and the multiple barriers faced by women seeking help.

If I may, I would like quote from NOFASARD, a publication dealing with FAS, from June 2011. It quotes a research papers under the heading, 'Australia's first screening and diagnostic service for children with alcohol related birth defects could be up and running by the end of the year.' It goes on to state:

Elizabeth Elliott, Professor of Paediatrics and Child Health of the Children's Hospital, said it was hard to know exactly how many children were affected by FASD because of lack of research and diagnostic clinics. However, she estimates that at least two per cent of all Australian babies are born with FASD each year.

She states:

That is likely a significant underestimate because doctors are not recognising it and are not asking women about alcohol use in pregnancy.

It is as simple as that; they are not even asking. The consequences of that are absolutely considerable on all levels. If it does not register in terms of health and the social consequences, it will and would on the economic level, because they are very considerable.

It is estimated that FASD affects one per cent of all live births in the USA, for example, and FAS specifically affects between 0.5 and two per 1,000 births in the USA. The prevalence of FAS is much higher in terms of rates in some other countries such as South Africa, where it is quite extraordinary and is estimated to affect between 68 to 89.2 per cent per 1,000 children in Cape Province, for example. The same publication I noted earlier states South Africa has the highest recorded rate of foetal alcohol syndrome in the world, affecting more than one million residents, and is being urged to take action against the preventable medical condition, the impact of which has been labelled as devastating as HIV. HIV is recognised and known now. What we are talking about is something as prevalent and yet unknown or greatly misdiagnosed. The country has the highest recorded rate of foetal alcohol syndrome in the world that we know of. The country's leading experts estimate more than one million South Africans have

been damaged by their mother's drinking while they were pregnant.

That leads us to this undeniable fact, that FASD are preventable but are incurable and require a lifetime of care and support. So, FASD, as I mentioned, are preventable, it is incurable and it is a lifetime sentence. That is a significant statement about a behaviour that we can get rid of or we can stop. It really does beggar belief that we allow this to continue. Our support group demonstrated this in this chamber today, and many others are working towards eradicating this. This is just totally and utterly unacceptable. FASD are a leading cause of preventable non-genetic birth defects and intellectual disability in Australia—and I will repeat it—preventable non-genetic birth defects and intellectual disability, but it does not even officially rate as a disability. Our motion calls on our government—indeed all parties—to support this and recognise it as a disability.

While FASD is a leading cause of non-genetic intellectual disability, another major issue of concern is that the majority—that is, 75 per cent to 80 per cent of people—living with an FASD actually have a normal IQ but struggle with everyday living skills making accessing developmental disability services very difficult. Foetal alcohol syndrome is often considered to be the most serious of the disorders within the spectrum. A person living with FAS will have a brain injury, impaired growth, neurological deficits and facial dysmorphism. The difficulties experienced by people with FASD can include difficulty with mathematical concepts; time and handling money, thinking things through and learning from experiencing, understanding consequences of their actions or the concepts of cause and effect, difficulty with social skills, difficulty storing and retrieving information, including following instructions, and finally impulsivity and distractibility—all basic living skills and all behavioural issues that we can affect. By not drinking during pregnancy we can bring this to a halt.

I will conclude by just pointing out as I did earlier that foetal alcohol spectrum disorder does not have a disability status in Australia. The situation relegates this condition to the status of non-entity; minimises public perception and service provider perception of the real scope of the problem, perpetuates belief in the limited risks posed by lower doses of alcohol, and fails to acknowledge the rate of incidents that has been contrasted to other non-genetic causes. Having it registered as a disability in Australia brings credibility to at least four decades of contemporary knowledge and research on alcohol as both a teratogen and a substance toxic to healthy foetal development. (*Time expired*)