

A Call to Action from Australian & New Zealand Parents

“Our Common Voice”

18 November 2013

In the 40th anniversary year of the formal naming of Fetal Alcohol Syndrome (FAS) in Washington State, USA in 1973, a meeting of 35 parents and carers of children living with Fetal Alcohol Spectrum Disorder took place on the 18th November in Brisbane. This was the first ever opportunity for parents and carers to meet, share, connect and support each other across Australasia. The collective was united in their loud and clear common voice. ‘No one can tell us more than we know’ about FASD, said one parent. As parents we are angry, frustrated, scared, worried, isolated, disbelieved, patronized, overlooked, and dismissed and want change.

Recognition

1. FASD must be officially recognized and understood as a disability. This is critical in order to be able to access services.
2. FASD must be recognized by Governments (systems and services sector).
3. Every decision-making forum that relates to FASD must have parent/ carer representation
4. FASD must be acknowledged as a serious consequence of alcohol use. It is too often unrecognized when alcohol-related harms are discussed in public policy.
5. Recognition of the cost burden to families. The cost burden to both families and services doesn't make sense versus cost of prevention.
6. A national media campaign aimed at primary and secondary prevention.
7. Equitable distribution of Government funds. Currently funds are biased towards disabilities such as Autism.

Education and training

8. Community-wide education undertaken and followed up at regular intervals to encourage tolerance and understanding across the community.
9. FASD must be included in all training modules for professionals who work with children and adults who may have an FASD. The group placed a particular emphasis on better training for the education system.

Redefining community expectations

10. Community expectations and understanding of ‘success’ for those living with FASDs must be reframed to acknowledge the strengths of individuals living with FASD.

Birth parents

11. Birth parents do not want to be treated differently, they want respect and they want the truth. All professionals, particularly health professionals, must lose the stigma, ask questions and provide honest answers.

Diagnosis

12. Individuals and families need child and family support services across the lifespan.
13. Diagnosis across the lifespan.
14. Assessment processes must be delivered by professionals familiar with the characteristics of FASD.

Signed: 35 parents of children living with FASDs