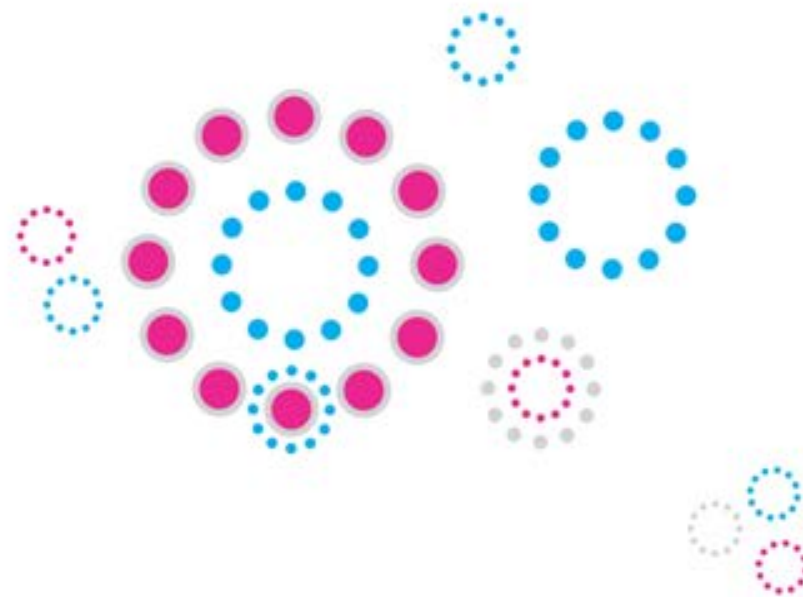


From Kitchen Table to National Entity

24 September 2013

Leila Picken
National Policy Officer, NOFASD Australia



The NOFASD Australia Story

- Not a new story to most people here – how to raise the visibility of people most affected?
- Not just a health issue
- Have we been successful?

The story...

- Parents – Sue and Tony Miers – small child, struggling
- Help seeking – no professional knowledge – assessments inclusive of ‘indulgent parenting’
- Change - seek information outside Australia and shift to educator role
- 1999 South Australia – small group of parents and supporters established NOFASARD in 1999
- 1999-2013 – played pivotal role in advocating for the recognition of FASD as an issue of concern in Australia and for those individuals and families living with FASD



1999...

- Volunteers lobbied, educated and trained others
- Too often felt intimidated by those who agreed to listen
- Expanded the support base and engaged with professionals who had technical authority



2008

- The Ministerial Council on Drug Strategy FASD Working Group, the Department of Health and Ageing and Drug and Alcohol Services South Australia held a FASD Workshop in Adelaide. The goal of the workshop was to identify potential future directions and strategies for responding to alcohol use in pregnancy.

2009

- Monograph submitted to the Intergovernmental Committee on Drugs Working Party on Fetal Alcohol Spectrum Disorders (updated version released in 2012)
- Review of National Alcohol Guidelines – recommended ‘no alcohol is the safest option in pregnancy and in breastfeeding’
- ‘Parliamentarians for the Prevention of FASD’ formed – a bipartisan federal government committee

2010-2012 – a Diagnostic Instrument for FASD in Australia

- Funded by the federal Department of Health and Ageing and led by Winthrop Research Professor Carol Bower from the Telethon Institute for Child Health Research and Professor Elizabeth Elliott AM from the University of Sydney
- An Australian FASD Collaboration was formed to conduct the project, including health professionals, researchers, consumer and community members [NOFASD Australia represented by Ms Sue Miers]

2011 – 2013 A National Inquiry

- A National Inquiry conducted by the House of Representatives Standing Committee on Social Policy and Legal Affairs – focus on prevention strategies, intervention needs and management issues
- NOFASARD (now known as NOFASD Australia) awarded 2 X 3 month interim funding grants

2012 – National Action Plan

- Plan developed by Foundation for Alcohol Research and Education
- Supported by experts including researchers, doctors, carers, communities and families, including NOFASD Australia.
- Launched with a 'Day of Action' at Parliament House

2012 – FARE National Action Plan

Plan costed at \$37 million and addressed five priority areas

1. Increase community awareness of FASD and prevent prenatal exposure to alcohol
2. Improve diagnostic capacity for FASD in Australia
3. Enable people with FASD to achieve their full potential
4. Improve data collection to understand the extent of FASD in Australia
5. Close the gap on the higher prevalence of FASD among Aboriginal and Torres Strait Islander peoples

2012

- NOFASARD successfully tendered for a three year federal government grant – 2 full-time staff members
- Formal acknowledgement as the national non-government peak body representing the interests of those who live with FASD
- Final report tabled in parliament, *FASD: The Hidden Harm – Inquiry into the Prevention, Diagnosis and Management of Fetal Alcohol Spectrum Disorders*

2013

- National Disability Insurance Scheme announced
 - Submission from NOFASD Australia
- NOFASD Australia invited to attend a Round Table to provide input into the development of a Commonwealth FASD Action Plan.
- Commonwealth Government responded to the National Inquiry final report – announces \$20 million over four years for a **national FASD Action Plan**

2013 Commonwealth Action Plan

1. Enhancing efforts to prevent FASD in the community - \$5 million
2. Secondary prevention targeting women with alcohol dependency - \$4.8 million
3. Better diagnosis and management of FASD - \$0.5 million
4. Targeted measures supporting prevention and management of FASD within Indigenous communities and families in areas of social disadvantage - \$5.9 million
5. National coordination, research and workforce support - \$4.0 million

2013

International FASD Awareness Day – 9 September 2013

- NOFASARD renamed NOFASD Australia
- A new logo
- A new website www.nofasd.org.au
- First Strategic Plan 2013-2016

Strategic Plan 2013-16

- 1. Information and support services for individuals and families** - provide current information and appropriate referral services to individuals and families living with FASD
- 2. Community engagement** - inform all sectors of the Australian community about the risks associated with fetal alcohol exposure and the lifetime implications of FASD
- 3. Education and Training** - develop and deliver high quality evidence-based and practice-based education and training resources to organisations that work with individuals and families living with disability

Strategic Plan 2013-16

4. **Policy and advocacy** - advocate on behalf of individuals and families affected by FASD for public policy reforms that will improve the lives of people living with FASD and prevent FASD in the future
5. **Building partnerships** - develop and foster national partnerships with individuals, non-government organisations and all levels of government.
6. **Research** - contribute a consumer perspective to FASD research and the development of best-practice in education and training and service delivery responses to FASD in Australia

Thank you

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Patron: Her Excellency Ms Quentin Bryce Governor-General of the Commonwealth of Australia.

