Dear Members & Supporters,

Welcome to our April newsletter.

Over the last month, NOFASARD has turned its attention to the impact of FASD on the criminal justice system and the issue of justice reinvestment, or putting justice system monies back into the community to address the root causes of offending behaviour.

Earlier this year NOFASARD was invited to make a submission to the Senate Standing Committee on Legal and Constitutional Affairs Inquiry into the value of a justice reinvestment approach to criminal justice in Australia. Please have a look at the Of Special Interest section below for links to NOFASARD’s submission and submissions from other likeminded organisations. Some of the issues canvassed include the possible link between FASD and high recidivism rates, the vulnerability of people with FASD in the criminal justice system, issues regarding culpability, the need for alternative sentencing options for people with FASD, and the need for investment in FASD prevention and early intervention to reduce the likelihood of offending behaviour.

Over the last month NOFASARD CEO, Vicki Russell, attended the 5th International Conference on FASD and two Training of Trainer workshops. Please see the National News and Media section for a copy of Vicki’s report.

We are always interested to receive your news and personal stories. The deadline for articles for our May newsletter will be 30th April 2013 (contact Leila@nofasard.org.au). You may be interested to read a personal story we received this month from a parent about preparing their child for school. Also, I would like to draw your attention to Vicki’s ‘Topic of the Month’ where she poses a question about the experience of people with FASD. We are keen to hear your thoughts and would like to encourage conversation.

We are always keen to expand our network so please encourage your family, friends, and colleagues to join NOFASARD and support FASD prevention in Australia.

Until next time, happy reading!

Warm regards,

Leila Picken
National Policy Officer
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Aboriginal Child Health Workshop, Perth: 2.00-5.00pm, 28 May 2013
2nd Aboriginal Maternal and Child Health Conference, Perth: 29-30th May 2013
2013 Special Education Expo, Adelaide: 8-10 July 2013
Australian Association of Special Education National Conference, Adelaide: September 29 – 1 October 2013
Australasian Fetal Alcohol Spectrum Disorders Conference, Brisbane: November 19 – 20, 2013

International

National Awareness Conference and Presentation of Current Research Information on Fetal Alcohol Spectrum Disorders (FASD), Accra, Ghana: June 6 – June 8, 2013
Consensus Development Conference on Legal Issues of FASD, Edmonton, Canada: September 18 – 20, 2013
First International Conference on Prevention of FASD, Edmonton, Canada: September 23 - 25, 2013
NOFASARD Submission to the Senate Standing Committee on Legal and Constitutional Affairs
Inquiry into the Value of a Justice Reinvestment Approach to Criminal Justice in Australia
NOFASARD welcomes the invitation to make a submission to the Senate Standing Committee on Legal and Constitutional Affairs regarding the value of a justice reinvestment model. NOFASARD focused on providing information to the inquiry regarding the impact of FASD on the criminal justice system. This included the link between FASD and the risk of criminal behaviour, as well as high rates of reoffending. NOFASARD also discussed the vulnerability of people with FASD in the criminal justice system, the need for alternative sentencing options (in particular the need for alternatives to traditional cognitive behavioural approaches) and investment in FASD prevention and early interventions to reduce the likelihood of offending behaviour. To read the NOFASARD submission click here and to read other submissions made to the inquiry click here.

National News and Media

NOFASARD CEO Report March 2013
Vicki provides an update on her recent travels to Canada and America. Some food for thought is Vicki’s ‘Topic of the Month’: I liked a comment I heard whilst overseas which went something like – “If an individual has average intelligence, then there is self-awareness of personal deficits and weaknesses.” I wondered how fetal alcohol is experienced by those who live in a world where their experience is unrecognised. Are they angry and frustrated in the world or withdrawn or acquiescent? What does it mean to not ‘fit’ in? We are interested to hear your comments or feedback. Read Vicki’s report

Advice from a parent – Preparing your child for school
A parent of a child with FASD shares their experiences in preparing their child for school and working with the child’s school and classroom teacher to ensure an adequate level of support is in place. Read more.

Foetal alcohol syndrome linked to binge drinking by mums
This article from The Advertiser (Adelaide) discusses the increasing problem of binge drinking among women of child-bearing age and work underway in the South Australian education sector to address FASD. Read more

National Disability Conference Initiative 2013-14 – Funding to assist people with disability to attend disability conferences in Australia
Funding is provided to assist people with a disability to attend disability conferences with a national focus held in Australia planned for 2013-14. Organisations may apply for up to $12,000. Read more
Register events/activities for Drug Action Week
Drug Action Week (DAW) will be officially launched on Wednesday 12 June with the theme of “Drugs, Communities & Families!” Supporting daily themes for DAW 2013 which will run from 16 to 22 June focus on "Illicit Drugs/ Stimulants/ Inhalants" on 17 June, “Alcohol/ Tobacco” on 18 June, “Pharmaceuticals (both script & non-script)” on 19 June, “Families/ Youth Issues” on 20 June, and “Building Resilience” on 21 June. Registrations are scheduled to close on 31 May. To register an event or activities for DAW 2013.

Nominations now open for 2013 National Drug and Alcohol Awards
A feature of Drug Action Week (DAW) 2013 will be the presentation of the 2013 National Drug and Alcohol Awards (NDAAs) in the Great Hall at Parliament House in Canberra on Thursday night, 20 June. The categories are NDAA Honour Roll, the Prime Minister’s Award, Law enforcement, Prevention and Community Education, Creating Healthy Sporting Communities, Research, Services for Young People, School Drug Education, Treatment and Support, and Media Reporting. Nominations are now open for the Awards and are scheduled to close on 30 April. To lodge a nomination.

International News & Media

The American Academy of Pediatrics web-based FASD Toolkit
The American Academy of Pediatrics (AAP), with the support of the Centers for Disease Control and Prevention’s (CDC) and the National Center on Birth Defects and Developmental Disabilities (NCBDDD) has developed a comprehensive, web-based FASD toolkit for primary care providers. The aim of the tools and resources is to raise awareness, promote surveillance and screening, and ensure that all affected children receive appropriate and timely interventions. The toolkit includes: General information about FASD; resources for identification, diagnosis, management and referral including general information and a more detailed algorithm for evaluation of FAS and FASD in the medical home and a provider checklist; patient and practice management resources, including care plans, evidence-based interventions and information on therapies. Access the toolkit.

‘Hey Teacher’ – NZ Resource for teachers of children with FASD
This fact sheet presents teachers of children with FASD some basic information about how children with FASD can be best supported to learn and develop in the classroom. The fact sheet also draws attention to specific behavioural issues and explains how the brain works differently for people with FASD. To access the resource click here.

Australian Research

Fetal Alcohol Spectrum Disorder: Knowledge attitudes and practice within the Western Australian justice system
Lead investigator: Dr Raewyn Mutch. Investigators: Dr Rochelle Watkins, Ms Heather Jones, Winthrop Research Professor Carol Bower, Telethon Institute for Child Health Research, The University of Western Australia, Perth, Australia, April 2013.
This study found that up to 85% of staff in the Western Australian justice system are required to respond to the needs of people with FASD in the course of their work. The report recommends
better training and education for justice workers, greater awareness of the issue of FASD and effective alternate sentencing options. Read the full report or click here for a short summary.

Development of a reliable questionnaire to assist in the diagnosis of fetal alcohol spectrum disorders (FASD)
This research formed part of the the Lililwan Project in the Fitzroy Valley. The research team developed and tested a questionnaire for use in collecting health information to diagnose FASD. The questionnaire developed can be used in remote Aboriginal communities around Australia and elsewhere. Read more

Maternal Alcohol Use and Sudden Infant Death Syndrome and Infant Mortality Excluding SIDS
Children whose mothers are diagnosed with an alcohol disorder in pregnancy, or within a year after giving birth, are three times more likely to die from Sudden Infant Death Syndrome (SIDS), compared with infants whose mothers do not have an alcohol disorder, a new study finds. 3% of non-SIDS infant deaths are also attributed to maternal alcohol use. Read more

International Research

Diffusion Tensor Imaging Correlates of Saccadic Reaction Time in Children with Fetal Alcohol Spectrum Disorder
Courtney R. Green, Catherine Lebel, Carmen Rasmussen, Christian Beaulieu, James N. Reynolds, Alcoholism: Clinical and Experimental Research, Article first published online: 2nd April 2013, DOI: 10.1111/acer.12132
This research looks to provide further explanation as to why impaired oculomotor control (tested using eye movement tasks) can be linked to structural and functional brain impairment identified in neurodevelopmental disorders. In particular, this research looks at the neuroanatomical substrates that are the underlying cause of impaired oculomotor control, identifying cerebellar dysfunction as a contributing factor. Read more

Towards Identifying a Characteristic Neuropsychological Profile for Fetal Alcohol Spectrum Disorders – Analysis of the Motherisk FASD Clinic
This study looks at 170 children who were seen by the Motherisk FASD Clinic between 2005 and 2009, 109 of whom had received a FASD diagnosis. Children with a FASD diagnosis were found to have neuropsychological profile characterised by clear weaknesses in verbal reasoning, memory, language function and mathematical reasoning and calculation. The two groups of children did not differ on measures of attention and executive functioning and the research team sites possible reasons for this, noting that this is not in keeping with other previous studies. The findings of this research will be used to inform best practice for diagnosis and treatment. Read more
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National

Focus on FASD Prevention in WA featuring Nancy Poole (Canada) – Perth: 9.00am-3.00pm, 15 May 2013
This workshop will be run by the WA Drug and Alcohol Office, Child and Youth Health Network and the Telethon Institute for Child Health Research. Nancy Poole from the British Columbia Centre of Excellence for Women’s Health, Canada will present on FASD prevention approaches as applied to her Canadian work. Local stakeholder presentations will relate to prevention campaigns, multi-sector implementation of the WA FASD Model of Care and workforce development. To register for the event (back)

Aboriginal Child Health Workshop – Perth: 2.00-5.00pm, 28 May 2013
This pre-conference Aboriginal Child Health Workshop is to be held on 28th May 2013, the day before the Aboriginal Maternal and Child Health Conference. The pre-conference workshop is a free event of interest to professionals working with Aboriginal children and their families. The workshop will be held at the Duxton Hotel, 1 St Georges Terrace, Perth. For further information please contact the Aboriginal Child Health Project on (08) 9224 1359 or to register click here (back)

2nd Aboriginal Maternal and Child Health Conference 29-30th May
The theme of the conference is Working together to Close the Gap – Building on success for the future. The conference will take place from 29-30 29–30 May 2013, Duxton Hotel, Perth WA. For more information please email amssu@health.wa.gov.au or phone (08) 9340 1555. (back)

2013 Special Education Expo – Adelaide: 8-10 July 2013
The expo will consist of over 60 workshops across 3 days with presentations covering: curriculum; differentiation; inclusive technology; communication; wellbeing/ mental health; learning difficulties; and disability. Special Education Resource Unit (SERU) and Adelaide West Special Education Centre will host sessions on Monday 8th July 2013. Sessions on Tuesday 9 and Wednesday 10 will be held at Education Development Centre Hindmarsh. Please check this link for updates (back)

Australian Association of Special Education National Conference, Adelaide: September 29 – 1 October 2013
The theme of the conference is ‘The Door is Open: Repertoires of Practice’. The conference will welcome both national and international speakers to provide information and current research on inclusion, differentiation and collaboration and to discuss national issues such as the Australian curriculum and the disability standards. Professor Barry Carpenter will be a keynote speaker at the event. Professor Carpenter is the author of ‘Educating Children with Fetal Alcohol Spectrum Disorders’ and will release another book in 2013 entitled ‘Fetal Alcohol Spectrum Disorders: Interdisciplinary Perspectives’. For further information and to submit an abstract click here (back)
Australasian Fetal Alcohol Spectrum Disorders Conference, Brisbane: November 19 – 20, 2013
Please save the date for the 2013 Australasian FASD Conference. The conference will take place at the Royal Brisbane and Royal Women’s Education Centre from 19-20 November 2013. The call for abstracts is now open and submissions close on 21 June 2013. For further information and to submit an abstract click here.

The National Indigenous Health Conference will be held at the Hotel Pullman Cairns International on November 25-27, 2013. Further information and registration

International

In 2013, the national day of health prevention in France will focus on alcohol and pregnancy. This conference will bring together both national and international experts to discuss issues relating to the prevention and diagnosis of FASD and effective interventions. English/ French translation will be provided. Registration closes on 30 April 2013. Read more

National Awareness Conference and Presentation of Current Research Information on Fetal Alcohol Spectrum Disorders (FASD), Accra, Ghana: June 6 – June 8, 2013
The theme for this conference is Highlighting National awareness on Fetal Alcohol Spectrum Disorders (FASD) in Ghana: A Silent Creeping Health Menace. Abstract submissions close on 30 April 2013. For more information about the conference

Consensus Development Conference on Legal Issues of FASD, Edmonton, Canada: September 18 – 20, 2013
This conference is a 3-day juried hearing of evidence and scientific findings that allows for the engagement and collaboration of citizens, decision makers in government, and the justice system in addressing a specific set of key questions on legal issues of FASD. Read more

First International Conference on Prevention of FASD, Edmonton, Canada: September 23 - 25, 2013
Professor Elizabeth Elliott from Westmead Children’s Hospital will be one of the guest speakers at this first international conference to address the primary, secondary, and tertiary prevention of FASD. The conference will serve as an international knowledge exchange and networking forum for those interested in FASD prevention, bringing together key experts from around the globe. Abstract submissions have now closed. Further information

NOFASARD CEO Report March 2013

I am pleased to advise that the Network membership has almost reached 700 members. Our membership base indicates a wide spectrum of interest – parents and carers; professionals; and para-professionals. We thank you for your ongoing support and expect to be in touch over the next few months as we streamline our database so that we can send you resources and seek your opinion
on a range of issues relevant to your experience. I am also introducing a little section in this report called ‘topic of the month’ and I invite you to tell me your thoughts. I have plenty of thoughts about topics for discussion but your ideas for future editions would also be welcome. We’ll print these in our newsletter so remember to be respectful, responsible, reciprocal and relevant.

March was a busy month most of which was spent in North America as I attended the International FASD Conference in Vancouver and then travelled to Madison, Wisconsin to participate in a 5 day training of trainers offered through the University of Wisconsin Division of Continuing Education in collaboration with the Great Lakes FASD Regional Training Center. Following this event, I travelled to Portland, Oregon where I participated in a 4 day training of trainers with Diane Malbin, FASCETS on a neurobehavioural approach. I am hopeful that in my time with NOFASARD I can share the training with others so that we might have many more skilled people able to effectively prevent the incidence of FASD and to have a greater capacity to support individuals and families who are managing this condition on a day to day basis. Please make contact with us if your organisation or community is interested in learning more (admin@nofasard.org.au).

### The 5th International Conference on FASD

The conference program began with a pre-conference event on a Law and FASD and provided the opportunity to present a short overview of the important components of work and practice issues. Presenters were from Australia and New Zealand, Canada and the United States. The following are brief notes and highlights from this important conversation. A full report will soon be available from Kathryn Kelly, University of Washington as each presenter has been asked to submit a review of the recorded information. This will include all Australian presenters including my own offering.

The International Conference was informative and choosing which concurrent sessions to attend was difficult. However, two sessions stood out for me: (1) the evening forum on prevention which differed as the audience participated and a group of speakers offered brilliant insight into alternative examples of prevention policy and practice; and (2) a meeting chaired by Lorian Hayes, Marilyn van Bibber and Keiran O’Malley. In the latter FASD was described as an environmentally induced disability and questions were posed like how we might shift the power base as academia has its bibliography and family has their stories. There were points made about how research presents a one dimensional view and that it should strive to be based in respect, responsibility, reciprocity and relevance; that FASD is a story of power and there is a question of shift in understanding the importance of nation and country; that there is dominance of culture, of gender, of academia, of financial status, of location, of justice, of age and of eligibility; and that FASD has a story of who is defining violence as this is experienced by others. Audience members were invited to approach the microphone and make comments and some important issues were raised. Quite a few people were parents or carers. I had a sense that there was unanimous agreement in the room that a ‘one-world’ format would place this discussion group in the centre and the conference delegates listening.

You will be advised of the conference proceedings as soon as these become available.

### Wisconsin Training of Trainers

This opportunity was offered to NOFASARD for free and this generosity was much appreciated. Thanks are extended to Georgiana Wilton and Kristi Obmascher for the invitation. As one of the group of 10, I also had the chance to meet and spend this time with some wonderful people from Wisconsin and other states. As can be appreciated, the course covered a wide range of topics including screening and the application of brief intervention with girls and women at risk for alcohol use in pregnancy; the biological effects of alcohol use on the developing fetus and screening,
Fetal Alcohol and Other Neurobehavioural Conditions – Training of Trainers

Having completed previous training in this approach (2005 and 2011) I have to admit bias towards this model. The Training of Trainers program covered orientation and framework; developing an understanding of the approach; paradigm shifts; values and value clashes; application of the neurobehavioural approach; healing and health.

For me, the approach offers a different way of thinking about behaviours as symptoms of a physical brain based condition and with misunderstanding of the source of the behaviours, the person is labelled wilful, lazy, aggressive and difficult. In effect, not understanding behaviour as symptomatic results in attempts to ‘fit’ a person in a box that is called ‘like us.’ Compliance whether by force or coercion has no place for those challenged by a physical brain-based condition and just because it cannot be seen, does not mean it does not exist.

Topic of the month

I liked a comment I heard whilst overseas which went something like – “If an individual has average intelligence, then there is self-awareness of personal deficits and weaknesses.” I wondered how fetal alcohol is experienced by those who live in a world where their experience is unrecognised. Are they angry and frustrated in the world or withdrawn or acquiescent? What does it mean to not ‘fit’ in? We are interested to hear your comments and feedback. Please contact admin@nofasard.org.au

Regards,

Vicki

Advice from a parent – Preparing your child for school

I am a foster parent and happily share the following information about our experience in preparing our daughter for school and how it went. This might be helpful for other parents. It’s taken a while to get back to you but I thought it would be best to see how she went to see if anything I did was of any
value to share...I had the support of my case manager and an education consultant and their psychologist.

We set up meetings with the school to exchange information. I gathered all reports on our daughter from the OT, speech therapist, doctors, early intervention preschool etc. I also went in armed with NOFASARD links and names of books that may be of interest to the teacher/staff. I had fact sheets on FASD and highlighted certain things that gave examples of typical behaviour from a child with FASD, including the information I got from the training in Tasmania with Dianne Malbin. We also arranged for extra orientation sessions to help our daughter with the transition and to hopefully make the teacher more aware of her needs.

The attitude at this stage from the school was let's just wait and see I'm sure we will manage she seems fine. Well, three weeks in and they are finally getting what I am talking about, our daughter is having trouble saying goodbye in the mornings, is telling me she does not like school and her behaviour is getting worse at home (all signs of stress).

Up until yesterday however the teacher was still smiling in the afternoon and telling me our daughter was fine. During class one of the boys took something from our daughter so she bit him and of course ended up in time out and asking the teacher what did she do wrong. Of course when I got there it was made worse again for her to have to tell me what she did wrong that day. Of course her reply was "I don't remember".

The teacher is now saying I will be pushing for all the help I can get for our daughter as I can see she really does need it. Yay finally! So my suggestion to parents with children starting school would be go in armed with as much information as possible. Be prepared to be treated like an over bearing parent who is more of a problem than the child. Allow the "experts to be experts" they will soon see it differently. Be patient with both the system and your child to see how things go, although don't allow the situation to get to the point where your child is being adversely affected.

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