

# Neuropsychological Aspects of Prevention and Intervention for Fetal Alcohol Spectrum Disorders in Australia

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**Abstract** The term fetal alcohol syndrome (FAS) was coined in 1973 to describe children with characteristic facial features, growth disorder and developmental delay associated with prenatal alcohol exposure. Yet, it was not until almost 20 years later that Australian researchers published on the public health significance of the range of conditions by then collectively termed fetal alcohol spectrum disorders (FASD). Similarly, the response to FASD within the government and various sectors of Australian society has been variable. Barriers in addressing FASD in the Australian context include a heavy drinking culture and large populations living in regional or remote communities and addressing FASD in high-risk populations such as juveniles in detention, some Aboriginal communities and “fly in-fly out” mining communities. Early Australian research was epidemiological, documenting notifications of FAS to birth defect registries and pediatric surveillance systems. The past decade has seen a rapid growth in Australian research into the full spectrum of FASD. Australian FASD diagnostic guidelines have recently been developed, a national FASD Action Plan has been endorsed, national and population-based data on FASD prevalence has

been reported and large FASD intervention and prevention studies are underway within a National Centers of Research Excellence framework. In recent years, there has been a greater focus on neuropsychological aspects of FASD in diagnosis and intervention, with pediatric neuropsychologists playing a key role. A multidisciplinary model in the implementation of FASD prevention, diagnosis and therapy approaches is considered best practice. A key challenge for Australian clinicians, policy makers and researchers is to collaborate on a coordinated, national response to FASD that is data-driven and aligned with international guidelines and study protocols.

**Keywords** Fetal alcohol spectrum disorders (FASD) · Neuropsychology · Epidemiology · Prevention · Intervention · Child development

## Introduction

Alcohol is a teratogen and causes damage to the central nervous system and other organ systems, and it may impair prenatal and postnatal growth and cause a characteristic syndrome of mid-face abnormalities (Astley and Clarren 2000; Fitzpatrick et al. 2015a). Disorders characterized by these features are collectively termed fetal alcohol spectrum disorders (FASD). Australian diagnostic criteria have recently been developed (Bower and Elliott 2016) and closely align with diagnostic terminology of Canadian guidelines including FASD with sentinel facial features and FASD without sentinel facial features (Cook et al. 2016). There has been an emerging level of awareness within Australia concerning the existence and potential ramifications of FASD. The publication of revised guidelines by the Australian National Health and Medical Research Council in 2009 that recommended no alcohol consumption was the safest option during pregnancy represented

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a key turning point within Australia regarding perceived acceptability of drinking alcohol in pregnancy (Australian Guidelines to Reduce Health Risks from Drinking Alcohol 2009). As well as population-level messaging, it has become increasingly clear that bio-psycho-social and ethical frameworks are required to understand and address the adverse impact of FASD at an individual, family and societal level (Meurk et al. 2014). While FASD occurs within all cross sections of society (Elliott et al. 2008b), its high prevalence in certain high-risk groups such as some remote Australian Aboriginal communities and children in care poses unique challenges due to complex historical, cultural, geographical, psychosocial and political factors (Gooda 2010). Additionally, the neuropsychological, social/emotional and behavioral sequelae related to FASD often contribute to the involvement of affected individuals in the criminal justice system, adding an additional layer of complexity (Fast and Conry 2009). Rather than taking a deficit approach through a focus on populations at high risk for FASD in Australia, it is in fact these communities (e.g. Aboriginal and Torres Strait Islander, foster carers) and sectors (justice, child protection) that have led the call for understanding and action relating to FASD in Australia. For this, mainstream Australian society, where most cases of FASD will reside, can be thankful.

### Orientation to the Australian Demographic

In 2016, Australians number some 24.1 million people, representing around 35 countries of origin (Australian Bureau of Statistics Census of Population and Housing 2016). Today, two thirds of Australians live in or near a major coastal city. The remaining one third of Australians live in regional centres (population 100,000–200,000) or remote and very remote communities. Our cities are relatively small by world standards—with Perth in Western Australia home to 2 million, and Sydney in New South Wales home to 4.5 million people. Australia's annual population growth rate is 1.3 %, with new migrants to Australia in the order of 150,000–180,000 people per year accounting for around 50 % of Australia's population growth. The main countries of origin of contemporary migrants to Australia are the UK, New Zealand, China, India, the Philippines and Vietnam (Australian Bureau of Statistics Census of Population and Housing 2016). It must be borne in mind that Europeans first settled in Australia in 1788, arriving by boat from Britain, and were the first true migrants. Indigenous populations, Aboriginal and Torres Strait Islander peoples, have continuously formed societies in Australia for some 60,000 years and numbered around half a million people at the time of British settlement.

In 2011, the estimated Aboriginal and Torres Strait Islander population was 669,900 people, representing 3 % of the total Australian population (Australian Bureau of Statistics Census of Population and Housing 2016). Their population

distribution is characterized by a high proportion of young people, with around 35 % being aged less than 15 years. Higher than average population growth among Aboriginal and Torres Strait Islander peoples suggests that their population will increase as a proportion of the Australian population over time. Important historical factors including dispossession of land and culture and contemporary adverse health and social factors contribute to a population distribution of Australia's first peoples that more resembles a developing nation, than a developed one.

Yet, Australia is a developed country, average weekly earnings are around \$1500AUD (~\$1200USD) and the unemployment rate is 5.7 % (Australian Bureau of Statistics Census of Population and Housing 2016). While most Australians enjoy access to high-quality universal health and education services, there are pockets of disadvantage influenced by people's geography and demography. These areas are generally in the outer metropolitan areas of major cities and in remote and very remote communities. The first Australians and the newest Australian immigrants are heavily represented in disadvantaged populations.

### Epidemiology of Prenatal Alcohol Use in Australia

Australians have what can be considered an “unhealthy relationship with alcohol,” with annual per capita (>15 years of age) consumption of pure alcohol of 10.4l (Global status report of alcohol and health 2014). In some very remote Aboriginal communities, these rates of consumption are up to five times the national average (Boulton 2008).

Alcohol consumption is common among Australian women, including women of childbearing age. National survey data suggests that about 50–60 % of Australian women drink in pregnancy (2013 National Drug Strategy Household Survey detailed report 2014; Colvin et al. 2007). However, there is an encouraging trend emerging in data from the National Drug Strategy Household Survey: in 2007, only 40 % of women abstained from alcohol use in pregnancy (2010 National Drug Strategy Household Survey report 2011), while in 2013, 53 % of women abstained (2013 National Drug Strategy Household Survey detailed report 2014). Most pregnant women report ceasing drinking alcohol once they find out that they are pregnant (2013 National Drug Strategy Household Survey detailed report 2014). However, one in four continue to drink even once they know they are pregnant, and of these, 96 % report drinking one to two standard drinks (defined as 10 g of ethanol) on a typical drinking occasion (2013 National Drug Strategy Household Survey detailed report 2014). Although data from a large national survey indicate that only 20 % of Aboriginal Australian women drink in pregnancy, it has also been reported that a greater proportion of Aboriginal women who drink do so at risky levels determined over the lifetime (on average drinking

more than two standard drinks per day) and based on single occasion risk (had more than four standard drinks monthly) (2013 National Drug Strategy Household Survey detailed report 2014).

While alcohol use in pregnancy is ubiquitous in Australia, Aboriginal Australians are a most highly researched population, and much data in this field comes from their communities. This unfortunately contributes to the ongoing characterisation of these communities from a 'deficit' perspective. Yet, it should also be seen as testimony to the fact that these communities have often led the way in acknowledging and seeking deeper understanding of these issues, for the betterment of their communities. Most of our understanding of prenatal alcohol exposure patterns in Australian Aboriginal women comes from Western Australian data. In a cohort of 274 urban Australian Aboriginal mothers surveyed in Perth in the mid-1990s, 44 % reported consuming alcohol during pregnancy (Eades 2003). About 15 % of the study cohort consumed alcohol at 'high-risk' levels (not defined) during pregnancy, although no validated tool was used. In this cohort, high-risk alcohol use was associated with preterm birth and/or low birth weight (Eades 2003), though no neurodevelopmental follow-up was conducted.

In Australian Aboriginal communities who initiated and participated in the Lililwan Project FASD prevalence study (Fitzpatrick et al. 2012), high-risk prenatal alcohol exposure patterns have been quantified using the Alcohol Use Disorders Identification Test-Consumption subset (AUDIT-C) (Bush et al. 1998). This population-based study, among 127 predominately Aboriginal women living in remote northwestern Australia, found that 55 % of women drank alcohol during pregnancy, with 95 % of those who drank doing so at risky (AUDIT-C score 4–5) or high-risk (AUDIT-C score 6–12) levels (Fitzpatrick et al. 2015b). A high proportion (88 %) drank in the first trimester and 50 % drank throughout pregnancy. Of women who drank, 71 % consumed greater than ten standard drinks on a typical occasion. Half of the women who drank consumed greater than ten standard drinks either two to four times per month or two to three times per week, and one in ten women who drank consumed greater than ten standard drinks daily or almost daily while pregnant (Fitzpatrick et al. 2015b).

## Epidemiology of FASD in Australia

In Australia, most estimates of FASD prevalence are thought to be an underestimate due to limited capacity for FASD screening or diagnosis and lack of a mechanism for reporting (R. C. Mutch et al. 2015; Peadon et al. 2008). Under-ascertainment is compounded by limited knowledge about FASD among health professionals. For instance, in a survey of 1143 Western Australian health professionals (Aboriginal health workers, general practitioners, allied health clinicians, community nurses and obstetricians), fewer than 50 %

routinely asked about alcohol use during pregnancy and as few as 12 % knew the diagnostic features of fetal alcohol syndrome (FAS) (Elliott et al. 2006; Payne et al. 2005). The only national study of the birth prevalence of FAS, utilising monthly reporting by specialist paediatricians, reports a birth prevalence of 0.06 per 1000 live births, with significantly higher rates in Australian Aboriginal populations (Elliott et al. 2008a). Regional birth prevalence has been reported as 0.01–0.03 per 1000 live births in Victoria (Allen et al. 2007), 0.27 per 1000 live births in Western Australia (WA) (Mutch et al. 2014) and 0.68 per 1000 paediatric inpatients in the Royal Darwin Hospital, Northern Territory (NT) (Harris and Bucens 2003).

Only one population-based study of the prevalence of all diagnoses on the FASD spectrum has been conducted in Australia (Fitzpatrick et al. 2015a). Called the Lililwan Project, and initiated by Aboriginal community leaders in the remote Fitzroy Valley communities of northwestern Australia, this study used active case ascertainment among all children born in 2002 and 2003, living in the Fitzroy Valley in 2011. The study required extensive travel to remote Aboriginal communities and the use of clinical assessments that reduced bias by culture and language. Applying Canadian FASD diagnostic criteria for FASD diagnosis that included categories of FAS, partial FAS and neurodevelopmental disorder-alcohol exposed (Table 1) (Chudley et al. 2005), a prevalence of FAS/partial FAS (pFAS) of 120.0 per 1000 children aged 7 to 9 years was identified (Fitzpatrick et al. 2015a).

A more detailed review of Australian studies follows, highlighting the varied study methodology and population sampling and providing a context for the wide variation in reported prevalence rates. Notifications to the Western Australian Birth Defects Registry and Rural Paediatric Service between 1980 and 1997 recorded a FAS prevalence of 0.18 per 1000 live births, with rates 100 times higher in the Aboriginal population (Bower et al. 2000). However, the authors concluded that this was likely an underestimation due to under-ascertainment and under-reporting. An update of the review of FAS notifications to the Western Australian Birth Defects Registry to include notifications up until 2010 indicates a FAS prevalence of 0.26 per 1000 live births, with 90 % of notified cases being Aboriginal (Mutch et al. 2014). This increase in notifications from 0.18 per 1000 live births for the period 1980 to 1997 is likely due to health promotion activity relating to FASD, increasing awareness of FAS and FASD among health professionals leading to increased diagnosis and notification, and the development of a Model of Care for FASD by the Western Australian Department of Health (Western Australian Fetal Alcohol Spectrum Disorder Model of Care 2010).

In the NT, a retrospective review of medical records for children born between 1990 and 2000 in Royal Darwin Hospital estimated the overall prevalence of FAS to be 0.68 per 1000 children and 1.87 per 1000 for Aboriginal children

**Table 1** Diagnostic criteria and central nervous system domains assessed in the Lililwan Project FASD prevalence study (J. P. Fitzpatrick et al. 2015a)*Fetal alcohol syndrome*

- Growth deficiency (weight or height  $\leq$ 10th percentile at any age) *and*
- Three characteristic FAS facial features: short palpebral fissure length ( $\geq$ 2 SD below the mean), thin upper lip, and smooth philtrum (rank 4 or 5 using the University of Washington Lip-Philtrum guide *and*
- Evidence of abnormality/impairment in 3 or more of the central nervous system (CNS) domains listed below
- With or without confirmed alcohol exposure

*Partial fetal alcohol syndrome*

- Two of the characteristic FAS facial features described above *and*
- Evidence of abnormality/impairment in 3 or more of the CNS domains listed below *and*
- Confirmed alcohol exposure

*Central nervous system domains assessed*

- CNS structure including microcephaly or other structural CNS abnormality
- Hard and/or soft neurological signs; seizure disorder; gross and/or fine motor functioning (+/- articulation, phonology and motor speech)
- Cognition—cognitive delay and/or uneven cognitive profile
- Memory—auditory and/or visual
- Executive functioning and abstract reasoning
- Communication—expressive and/or receptive language
- Attention deficit/hyperactivity (+/- other behavioural problems +/- sensory function)
- Visual motor integration
- Adaptive behaviour/social skills/social communication
- Academic achievement

(Harris and Bucens 2003). However, this study was limited by inconsistent medical record entries, poor information on prenatal alcohol exposure, absence of standardised neurodevelopmental assessment and use of only one of three facial features to render a diagnosis of FAS (Harris and Bucens 2003). In the state of Victoria, authors of an audit of the Victorian Birth Defects Registry between 1995 and 2002 reported a prevalence of FAS between 0.01 and 0.03 per 1000 live births. Nonetheless, under-reporting, limited data on alcohol use and selection of cases based on microcephaly (which is not present in all cases of FAS) again limit the validity of these data (Allen et al. 2007).

The first prospective study of FAS prevalence in Australia involved paediatricians notifying cases of FAS to the Australian Paediatric Surveillance Unit (APSU) between 2001 and 2004 (Elliott et al. 2008a). A birth prevalence of 0.06 per 1000 live births over the study period was found, with significantly higher rates in the Aboriginal population (Elliott et al. 2008a). Limitations of this study include inconsistent diagnostic criteria used by paediatricians, possible confusion about the definition of FAS and pFAS, likely under-

diagnosis by paediatricians and lack of paediatric services to high-risk populations, resulting in many cases not being ascertained. A follow-up national surveillance study is currently being conducted by the APSU.

The Lililwan Project, the first Australian population-based study of FASD using active case ascertainment, was conducted at the request of participating communities and involved a cohort of 127 children aged 7 to 9 years, living in the remote Aboriginal communities of the Fitzroy Valley, WA (Fitzpatrick et al. 2012). During the study period (April 2010–November 2011), 127/134 (95 %) consenting parents/caregivers participated in diagnostic interviews and reported on pregnancy exposures including prenatal alcohol use and birth and child development history. Medical records of mothers and children were reviewed. Neurodevelopmental outcomes were assessed through interdisciplinary assessments in 108 children (81 % of those eligible to participate) by a paediatrician, psychologist, occupational therapist, speech pathologist and paediatric physiotherapist. FASD diagnoses were assigned using modified Canadian FASD guidelines (Chudley et al. 2005). Using conservative case definitions for FAS facial features, microcephaly and neurodevelopmental impairment, 1 child received a diagnosis of FAS and 12 received a diagnosis of pFAS, giving a population prevalence of FAS/pFAS of 120.0 per 1000, among the highest rates reported internationally (Fitzpatrick et al. 2015a). Data relating to the prevalence of the entire spectrum of FASD diagnoses in this cohort is currently under review for publication.

### Neurocognitive, Academic and Psychosocial Deficits in Children with FASD from Australian Studies

To date, the Lililwan Project is the only Australian study to report the neurocognitive outcomes of children with FASD (Fitzpatrick et al. 2012). Community consultation was conducted to inform the assessment battery and ensure cultural relevance while aligning clinical reporting with local school and health service support eligibility criteria. The central nervous system (CNS) domains recommended in the Canadian FASD Diagnostic Guidelines were included in the assessment process (Chudley et al. 2005). Neurodevelopmental impairment was defined as structural abnormality and/or functional impairment in three or more domains (Table 1).

This study was designed in the context of several challenges specific to working in remote Aboriginal communities (Fitzpatrick et al. 2012). Firstly, assessments were conducted using measures standardised in non-Australian and non-Aboriginal populations due to a lack of availability of suitable tools with appropriate norms. For this reason, a conservative approach to diagnosis was adopted (i.e. where standardized scores were available, using the cutoff for impairment as less than two standard deviations below the mean, or less than the third percentile). When standardized scores were not

available, a cautious approach to assigning impairment was taken, drawing upon additional sources of information (such as school records, parent interview information) to inform decision making. Secondly, the majority of participants spoke English as a second or third language. To reduce bias by language and culture, the novel role of ‘Community Navigator’ was established. These were local Aboriginal community members trained in research techniques who assisted with interpreting during assessments. Where possible, non-verbal measures were used. For instance, the cognitive assessment battery included the Universal Nonverbal Intelligence Test (Bracken and McCallum 1998) and the Children’s Color Trails (Llorente et al. 2003). The speech language assessments were conducted in Kimberley Kriol and were designed in consultation with local community interpreters (Salter 2013). Thirdly, significant logistical challenges were encountered in conducting multidisciplinary assessments in geographically remote locations. Assessments were conducted on site in remote community schools or health centres, and an efficient method of multidisciplinary assessment, case conferencing and reporting was developed.

Data relating to neurodevelopmental impairment for children in the Lililwan Project across all diagnoses on the FASD spectrum is currently being reviewed for publication. Detailed descriptions of neurocognitive outcomes for those children diagnosed with FAS and pFAS have been described (Fitzpatrick et al. 2015a). The mean age at assessment was 8.7 years (range 7.5–9.6 years). A diagnosis of FAS ( $n=1$ ) or pFAS ( $n=12$ ) was made in 13 of 108 children assessed. All 13 children diagnosed with FAS/pFAS were prenatally exposed to alcohol (80 % in the first trimester, 50 % in all trimesters), all being exposed at high-risk levels using the AUDIT-C scores (Bush et al. 1998; Fitzpatrick et al. 2015b). Of children with FAS/pFAS, microcephaly was recorded in 69 %. The mean number of domains of abnormality/impairment in CNS structure and/or function was  $4.7 \pm 1.8$  (range 3–8). The most common functional impairments were attention deficit hyperactivity disorder (ADHD) with or without sensory dysfunction (69 %), academic achievement (62 %), communication (54 %), cognition (50 %), memory (50 %) and executive functioning (50 %) (Fitzpatrick et al. 2015a).

### Description of How the Australian Government Conceptualizes FASD

The Australian government has attempted to respond to advocacy from consumers, the medical community and researchers to better address the needs of families affected by FASD. These efforts have included a federal parliamentary inquiry into FASD in 2011 which recommended the establishment of a National Action Plan and FASD Reference Group to

advise on national initiatives to prevent, identify and manage FASD in Australian communities. Such initiatives included the following: (a) promoting awareness and training in guidelines to reduce health risks from alcohol in the health sector; (b) obtaining and recording consistent data regarding maternal alcohol consumption; (c) a public awareness campaign as well as considering health warning labels on alcoholic beverages and pregnancy testing kits and (d) supporting community-led alcohol management plans. In 2012, the Australian National Health and Medical Research Council made a call for research relating to FASD and targeted approximately \$3 million AUD into specific research projects. Further research funding has been awarded for FASD-related trials involving prevention and intervention. In June 2014, the Australian government released an announcement pledging funding of \$9.2 million AUD under a National FASD Action plan 2013–2017 (Commonwealth Action Plan to reduce the Impact of Fetal Alcohol Spectrum Disorders (FASD) 2013–2017 2014). Formal advice has been provided directly to the Australian Government regarding FASD through two mechanisms: the Australian FASD Technical Network and the Australian National Advisory Council on Alcohol and Drugs. In response to concerted formal advice and direct advocacy from advocacy groups and clinicians, in 2016 the Australian Government announced \$10.5 million AUD over 4 years in FASD-specific programs including the following: (a) to support a national FASD clinical network, including clinicians who work with children affected by FASD; (b) to establish a national FASD information hub to directly support diagnosis of and data collection about FASD and (c) to roll out evidence-based FASD prevention models with the benchmark being the successful Fitzroy Crossing Marulu FASD Prevention Project (taking more action to prevent Fetal Alcohol Spectrum Disorders 2016; Bruce et al. 2016). While these represent important initiatives and demonstrate a degree of political attention on the issue of FASD, there remain considerable gaps and ongoing challenges in resourcing and coordinating an appropriate response to FASD within Australia.

### Description of How the Medical Community and Mental Health Services Conceptualizes FASD

An alcohol and pregnancy and FASD research program was initiated through a collaboration between Telethon Kids Institute in Perth, WA, and at the University of Sydney, New South Wales (NSW), in 2001. Since then, strong research collaborations have emerged across multiple States and Territories, enabling an Australian collaboration on FASD research of national relevance. This research has included important projects relating to epidemiology and surveillance, prevention, diagnosis, interventions and workforce development.

As highlighted above, Australian FASD prevalence figures are generally lower than international estimates and a likely underestimate of FASD cases within Australia, due to issues related to inadequate screening and reporting, the lack of a standard nationally coordinated diagnostic approach and insufficient clinical pathways with specialist multidisciplinary assessment experience and resources. The heterogeneous nature of the physical and neuropsychological features of FASD, and the fact that facial features are not always present, further complicates differential diagnosis (Watkins et al. 2014). This situation has propelled the development of consensus recommendations for Australian-specific FASD screening and diagnostic guidelines, based on the current Canadian guidelines (Watkins et al. 2013, 2014; Cook et al. 2016). Australian FASD diagnostic guidelines, which harmonise with the recent update of Canadian guidelines, have recently been endorsed, and their use promoted among medical, psychology and allied health practitioners (Bower and Elliott 2016). It is recognised that a nationally standardized approach to FASD diagnosis will enable better documentation of the prevalence of FASD with Australia, including within high-risk cohorts such as out-of-home care settings and the justice system.

Australian researchers continue to argue that awareness and communication between doctors, health professionals and pregnant women need to be improved to ensure that accurate information about alcohol use in pregnancy is being provided and that expectant mothers understand the risks (Crawford-Williams et al. 2015; Peadon et al. 2010). Furthermore, Australian surveys of medical specialists and allied health staff have consistently demonstrated poor awareness of FASD and diagnostic criteria, suggesting a need for additional psychoeducation and resources to be provided to improve prevention and identification (Payne et al. 2011a, b). In our experience, some clinicians are also reluctant to explore the possibility of FASD due to concerns regarding stigma and blame, and potentially alienating their patients, as well as the perception that there is a lack of suitable interventions available.

Within Australia, there is a need for greater awareness and training to improve the screening and diagnostic capability of medical practitioners and other allied health staff in metropolitan, rural and remote regions. In addition to the importance of prevention, early diagnosis is crucial, as it (a) helps to reduce the impact of cognitive, social/emotional and educational difficulties; (b) reduces the impact of co-morbidities as the child matures; (c) helps carers, teachers and family members better understand the child's difficulties and brings about a paradigm shift in their understanding; (d) facilitates more appropriate and targeted interventions and (e) potentially prevents the child from disengaging from school or engaging in anti-social and criminal behaviour (Carmichael Olson and Montague 2011; Dudley et al. 2015).

As well as improved awareness and understanding of nationally and internationally accepted diagnostic criteria, there is a need for improved capacity for health professionals to accurately diagnose FASD using a nationally standardised evidence-based approach. While the situation in Australia is improving with the emergence of specialist teams in Queensland, WA, the NT and NSW, there is still an urgent need to build capacity across metropolitan, regional and remote locations across Australia. The recent formation of a national FASD clinical network represents an attempt to coordinate, expand capacity and standardise an approach relating to FASD referral, diagnosis and management in Australia. The terms of reference of this network include the following: (a) to provide collegiate support in establishing and expanding FASD diagnostic services; (b) to standardise an approach to assessment, diagnosis, data management and therapy; (c) to provide the opportunity for national and international collaboration in clinical research; (d) to standardise the definitions of training related to FASD education and continuing professional development; (e) to provide support for the development of continuing professional education tools for use by health professionals in Australia; (f) to support the national accreditation of continuing professional development in FASD; (g) to support workforce development in FASD assessment, diagnosis and therapy; (h) to contribute to research in FASD assessment, diagnosis and therapy and (i) to contribute to the development and maintenance of regional and national FASD databases. Through this network of clinics, Australia's first national, multisite FASD intervention trial is being planned.

## Description of How Schools Conceptualize FASD

The adverse effects that the neuropsychological sequelae of FASD can have on academic achievement has been well documented by overseas researchers (Rasmussen and Bisanz 2009; Tamana et al. 2014), although there is a need for more Australian research in this area. It is apparent from our clinical perspective that the cognitive deficits associated with FASD, especially difficulties with attention, working memory and executive functioning, have significant effects on the student's ability to learn and achieve at an age-appropriate level (Peadon and Elliott 2010). Similarly, social pragmatic, emotional regulation and adaptive functioning problems often experienced by children with FASD further hinder their educational achievement. These children are vulnerable to premature disengagement from school and at risk of truancy, suspension and expulsion due to the nature of their behavioural difficulties. The neuropsychological impairments caused by FASD are also often further exacerbated by disrupted attachment and trauma as well as socio-economic disadvantage and placement in out-of-home care settings, which

further heightens the educational needs of these children (Vasilevski and Tucker 2015; DeGregorio and McLean 2013; Ospina and Dennett 2013).

One Australian study (O’Leary et al. 2013a, b) of 4714 non-Aboriginal children born in WA between 1995 and 1997 linked the birth and educational records of 80 % of these children at ages 8 to 9 and found that alcohol exposure at binge and heavy levels increased the risk of specific learning problems. In particular, children exposed to first-trimester heavy alcohol exposure had test scores below national benchmarks for reading, and those exposed to occasional binge drinking during pregnancy performed below minimum expected standards on writing tests. Low-to-moderate prenatal alcohol exposure was not found to be associated with academic under-achievement, although the authors cautioned against over-interpretation of this result due to the retrospective nature of the data collection which may have reduced their ability to identify an association at lower levels of alcohol exposure.

There appears to be a growing awareness about the educational implications of FASD within Australian schools. This has been particularly encouraged by consumer organisations such as the National Organisation for FASD (NOFASD). Nonetheless, further efforts are still required not only to improve awareness and understanding but also to conduct research exploring the neuropsychological sequelae and efficacy of interventions within Australia. It is promising that the Australian National Disability Insurance Agency (NDIA) recently identified FASD as an important category of disability for consideration within the National Disability Insurance Scheme (NDIS), and hopefully this will enable more affected individuals to access treatment services (Dudley et al. 2015). Conversely, FASD is currently not recognised as an official disability on the Australian Government-funded Centrelink ‘List of Recognised Disabilities’ or fully recognised as a disability within Australian educational systems. This is partly because these children often have IQ scores that are not within the intellectually disabled range (Streissguth et al. 1991; O’Leary et al. 2013a, 2013b) or they do not meet criteria for other disability categories (such as autism, physical disability or global developmental delay) which are eligible for funding. Eligibility criteria for school-based funding vary between Australian States/Territories. Broadly speaking, no existing education funding systems recognise FASD. Furthermore, most criteria for educational funding require diagnosis (e.g. of global developmental delay) prior to entering kindergarten or first grade (Department of Education Funding for Students with Disability 2016). Many children with FASD have not been recognised as displaying developmental delay or behavioural problems by this age and as such will not have received a diagnosis. Thus, individuals with FASD are often not able to receive dedicated funding for treatment, resources and the support of teaching and learning adjustments within educational settings, such as individually allocated educational

assistants. This can be a frustrating situation for the child, family, school personnel and clinicians.

### Description of How the Justice System Conceptualizes FASD

As is the case overseas, there has also been increasing community and government concern regarding the forensic implications of FASD (Freckelton 2013; Douglas 2010), as the neuropsychological sequelae can potentially affect all aspects of the court process, such as fitness to plead, capacity to stand trial and ability to participate in interviews and give credible evidence (Freckelton 2012). This issue led the Canadian and American Bar Associations to pass resolutions for governments to avoid ongoing criminalisation of individuals with FASD and prevent their continual over-representation within the justice system (American Bar Association 2012; Canadian Bar Association 2010). Within Australia, a House of Representatives Standing Committee on Aboriginal and Torres Strait Islander Affairs in 2011 identified an association between FASD and involvement of young people within the criminal justice system. Other parliamentary inquiries, such as the Education and Health Standing Committee, 2012, and House of Representatives Standing Committee on Social Policy and Legal Affairs, 2012, have also highlighted the vulnerability of youth affected by FASD and called for specialised programmes and policies to better identify and address their unique needs.

Furthermore, researchers have recognised the need for education and training programmes to be targeted at all levels of the justice system, including police, correctional officers, lawyers and judges (Mutch et al. 2013). Mutch et al. (2013) emphasised the need for cross-sector collaboration and access to services and programs for diagnosis, treatment and management to prevent repeated engagement with the justice system (Mutch et al. 2013). Currently, the prevalence rate of FASD among detained youth within Australia is unknown; however, an NHMRC-funded research study is underway in WA to determine the prevalence of FASD in a juvenile detention centre and develop a validated screening tool so that affected individuals can be identified earlier. Youth will be assessed by a multidisciplinary team using measures appropriate for the Australian context.

### The Role of the Paediatric Neuropsychologist

While the diagnosis of FASD is a medical one, a multidisciplinary approach to assessment is ideal although not always feasible due to a lack of available trained staff with adequate resourcing and funding. This is especially the case in regional centres around Australia where access to resources and

clinical services, especially registered psychologists, is limited. Consequently, there continues to be a need for specialist FASD training and funding within Australia to upskill trainees, psychologists and their allied health counterparts so that they can better identify and address the needs of individuals and families affected by FASD.

The role of a paediatric neuropsychologist is particularly important in educational, clinical and forensic settings. A paediatric neuropsychological assessment not only informs a FASD diagnosis in relation to functional central nervous system criteria (Watkins et al. 2012, 2013) and whether the cognitive and social/emotional profile is in keeping with FASD but also facilitates the identification and impact of other common co-morbid disorders, such as ADHD and specific learning disorders. The establishment of a profile of strengths and weaknesses across domains that affect cognitive, social and behavioural functioning is also crucial given the heterogeneous nature of FASD. This not only serves to establish a baseline to monitor progress but also provides guidance regarding the development of appropriate educational goals (Miller 2010), intervention options, compensatory strategies and case management.

The neuropsychologist is in a good position to establish the functional implications of a child's unique profile to inform psychoeducation and facilitate a better understanding of the child's functioning, with the opportunity for ongoing review and assessment as the child develops. Such assessments are typically multifaceted and require an understanding of the complex neuropsychological, clinical, forensic and educational implications of neurodevelopmental conditions, often within a cross-cultural context. Also required is an understanding of how trauma and disrupted attachment affects development, as these youth often come from impoverished and disenfranchised backgrounds with transgenerational trauma (Pestell and Paul 2015).

Cross-cultural factors are an important issue for Australian neuropsychologists given the multicultural nature and ethnic diversity of Australian society (Bouma 2015). Assessing children from non-English speaking backgrounds, particularly Aboriginal children, is especially challenging. The significant diversity among Australian Aboriginal communities is also worth highlighting, despite popular media attempts to portray them as a homogenous group (Dudgeon 2000). Furthermore, as neuropsychological assessment theory has historically been developed in North American and European contexts, there is a lack of evidence base as well as professional and cultural competency frameworks relevant to the Australian context (O'Connor et al. 2015).

Past consultations with Aboriginal people has revealed widespread scepticism, fear and distrust regarding Western-style psychological services which complicates engagement and rapport building (Vicary and Bishop 2005; Garvey et al. 2000). It has also been found that many Aboriginal

community members perceived psychologists to be lacking in appropriate cultural knowledge and tending to stereotype Aboriginal clients (Ranzijn et al. 2007). Communication challenges were described and attributed to the psychologists' lack of understanding and skills, as well as application of suitable communication strategies and protocols for working with this population (Ranzijn et al. 2007).

It has been found that the possession of certain professional skills and personal characteristics will improve the effectiveness of the psychologist in working with Aboriginal people, and these include personal and clinical credibility, relationship centrism, contextual understanding, a holistic approach and flexibility (O'Connor et al. 2015). A model for how to engage with Aboriginal youth has also been developed and incorporates several steps which are pertinent to neuropsychological assessments. These include choosing suitable locations for the psychological service, being aware of the importance of non-verbal body language, introducing yourself the Aboriginal way (i.e. contextualising self in relation to your land/country), addressing cultural or gender differences, negotiating limits to confidentiality and engaging at the cultural level by acknowledging their belief system (Westerman 2010). The Australian Psychological Society has developed guidelines for providing psychological service for, and conducting research with, Aboriginal and Torres Strait Islander people of Australia (Guidelines for the provision of psychological services for, and the conduct of psychological research with, Aboriginal and Torres Strait Islander People of Australia 2008). The guidelines provide a framework for how to accommodate literacy issues and language differences, acknowledge different value systems and authority structures and collaborate with Aboriginal and/or Torres Strait Islander colleagues.

An additional challenge is that paediatric neuropsychologists working in this area are restricted by a lack of culturally appropriate tests with adequate norms. While neuropsychological testing is not contraindicated in children with Aboriginal backgrounds, it is recommended that tests be interpreted cautiously and that more weight is given to what the child can do rather than what they cannot, with an emphasis on more qualitative and 'process' aspects of their clinical presentation and test performance. It is also recommended that psychometric tests are chosen that rely less on acquired knowledge and are more non-verbal in nature, provide a practical context (i.e. use of pictures), involve spatial processing, are not timed and that verbal tests are linked with spatial or visual items (Westerman 2010). Consideration also needs to be given to the functional central nervous system criteria pertinent to FASD diagnostic criteria used in Australia, with adequate assessment across multiple domains (i.e. cognition, memory, language, executive functioning, attention/activity level/sensory processing, adaptive behaviour/social skills/social communication, academic achievement, motor functioning). It is important to base the assessment on multiple sources



of data and use an interpreter and cultural consultant wherever feasible.

Another challenge that psychologists within Australia face in relation to FASD assessments is that they are often required to manage expectations from referral sources and the judicial system that there is a ‘one size fits all’ approach to assessment (i.e. the assumption that all psychologists have the expert specialist skills of a forensic psychologist or neuropsychologist and are skilled in neuropsychological test administration and interpretation). This is often not the case, and there is a risk that psychologists conducting FASD assessments (particularly within disability, school and justice systems) might unwittingly act outside their level of expertise and training, with potentially significant adverse ramifications for the child as well as the psychologist, agency and/or court (Pestell and Paul 2015). It is thus essential that all psychologists working in this area undertake relevant professional training regarding FASD diagnostic guidelines within an Australian context and work in conjunction with other clinicians, particularly medical specialists such as paediatricians.

There are also important considerations regarding giving a diagnosis of FASD, as this can have significant repercussions within a family system due to potential stigma, guilt and blame. This is a particularly complex issue within the justice system as providing assessment feedback is usually contraindicated within a medico-legal context. Ideally, provision of an FASD diagnosis should be conducted by treating clinicians who have developed rapport and have an ongoing clinical relationship with the family.

## Description and Review of Prevention Efforts Unique to Australia

Australian efforts to prevent prenatal alcohol exposure and FASD have to date been based around raising awareness of FASD and establishing national guidelines (2009) that advise women who are pregnant, or planning to become pregnant, that not drinking is the safest choice (Australian Guidelines to Reduce Health Risks from Drinking Alcohol 2009). Much of the groundswell for FASD prevention in Australia came from community-based advocates represented by NOFASD, the peak national non-government organisation providing information and support to carers. As part of a national FASD action plan endorsed by the Australian Government (2013–2017), a national awareness raising program ‘Women Want to Know’ has been launched, as a project to develop FASD prevention resources through the Australian network of Aboriginal Community Controlled Health Services (Commonwealth Action Plan to reduce the Impact of Fetal Alcohol Spectrum Disorders (FASD) 2013–2017 2014).

At the community level, there are a number of promising FASD prevention programs underway. An innovative

community-designed antenatal education program, delivered since 2008 by the Ord Valley Aboriginal Health Service in the Kimberley region of Western Australia, documented cessation of drinking during the index pregnancy in all women receiving FASD education over a 12-month period (Bridge 2011); however, the size of this cohort, and the effectiveness of this program, has not been formally evaluated and published in scientific literature. Complementing community-led strategies, the Western Australian government has developed a FASD Model of Care and funded the WA Drug and Alcohol Office’s evidence-based FASD prevention program, Strong Spirit Strong Future (SSSF) (Strong Spirit Strong Future: Promoting Healthy Women and Pregnancies project 2014). SSSF has included statewide media campaigns (television, radio), health workforce training and resource development and a small grants program to fund community-based FASD prevention initiatives.

Two high-quality FASD prevention projects are underway in remote communities of the Fitzroy Valley (pop ~ 4500) and Pilbara (pop ~ 40,000), in Western Australia. The Marulu FASD Prevention strategy (Marulu means ‘precious’, worth nurturing in the local Bunuba language) in the Fitzroy Valley is a response to very high rates of prenatal alcohol exposure and FASD in the Fitzroy Valley (Fitzpatrick et al. 2015b). The Marulu FASD Prevention Strategy is led by Nindilingarri Cultural Health Services and the Marninwarntikura Fitzroy Women’s Resource Centre, along with research partner Telethon Kids Institute (Bruce et al. 2016). The strategy builds on the Canadian four-part FASD prevention model developed by Nancy Poole of the University of British Columbia (Poole 2008). Four elements of activity have been implemented: (a) an FASD mass media campaign via television and radio advertisement and social media, (b) targeted health promotion among high-risk communities and women of childbearing age and their partners, (c) intensive antenatal support provided by community midwives and (d) postnatal support through increasing child development service activity and early intervention capacity. Crucial to the Marulu Strategy have been supportive alcohol policy, introduced through community-led restrictions on alcohol takeaway sales and the establishment of regular FASD diagnostic clinics through the multidisciplinary Paediatric Child Health and Education Services (PATCHES) model [www.patches-paediatrics.com.au](http://www.patches-paediatrics.com.au) (Fitzpatrick and Kinniburgh-White 2014). While Marulu FASD prevention study data are not yet published, rates of drinking in the first trimester of pregnancy have decreased from over half of women drinking to less than one fifth of women drinking, between 2010 and 2015 (Bruce et al. 2016). Concomitant with reduced alcohol use in pregnancy, very high levels of community awareness of FASD has been documented in a Knowledge, Attitudes and Practice survey conducted in over 400 community members. Data from this promising model of FASD prevention will soon be published

and is currently being implemented across the entire Pilbara region, home to almost 40,000 predominately Aboriginal people.

### Description and Review of Intervention Efforts Unique to Australia

There has been an increasing number of FASD-targeted evidence-based treatment studies published across the world in recent years (Bertrand 2009), although it is beyond the scope of this paper to review them in depth. It is worth emphasising, however, that many of these intervention programmes show considerable promise although there continue to be gaps in the literature prompting the need for ongoing research. Key findings to date include the importance of parent education, explicitly teaching skills that typically developing children may automatically learn by observation and integrating individualised interventions into existing treatments within home, school or community environments (Bertrand 2009).

While two reviews of FASD interventions have been published by Australians (Peadon et al. 2009; Reid et al. 2015), there is a dearth of research exploring the efficacy of interventions within an Australian context. Reid et al. (2015) conclude in their systematic review that there is growing evidence for interventions that improve outcomes for early to middle childhood, although a lack of research exists for individuals not within the school age range. Of note is the lack of evidence-based data for treatment with infants and young children, which is of concern given the potential benefits of early intervention. Furthermore, there is a need for interventions targeting adolescents and adults as these cohorts are especially vulnerable because of the potential adverse consequences of secondary disabilities (such as challenging ‘at risk’ behaviours). Reid et al. (2015) also suggest targeting interventions towards multiple domains of functioning and considering how individual characteristics interact with the ecological context of the individual and family with FASD.

A recent Australian report that reviewed FASD interventions highlighted the following key principles when planning access to services and supports for individuals on the FASD spectrum, based on assessment that guides tailored and individualised support (Dudley et al. 2015): (a) a multidisciplinary approach to accommodate the changing needs for interventions depending on the number, type and severity of secondary FASD problems; (b) support for a coordinated family, school and therapy partnership which enables access to multiple interventions, especially when these are provided across settings and include multiple agencies; (c) family centred ‘wrap-around’ care to strengthen and build capacity for families to support children and to support the person into adult life through maximizing participation in everyday life; (d) build on caregiver and child strengths and provide

emotional support for caregivers that reduce FASD-related stigma or ‘blame/shame’; (e) reframe FASD for caregivers and professionals involved with the child (e.g. describing behavioural difficulties as ‘brain-based’, requiring environmental accommodations); (f) facilitate respite and self-care opportunities for carers, to support their own mental health and to address substance misuse problems where relevant; (g) provide risk assessment and monitoring for children within the caregiving setting; (h) the plan for the transition to adulthood for individuals with FASD should be viewed as a transition to ‘interdependence’ rather than necessarily a transition to independence and (i) cultural security for Indigenous and ethnically diverse communities: embedding programs and resources in community-controlled health organisations and employing Indigenous and culturally diverse people in intervention teams.

Dudley et al. (2015) also emphasise that functional impairment may become more apparent at key transition times during the developmental period, such as on entering primary or high school or when leaving school and entering the workforce. It is hoped that providing intervention early, and at adequate consistency, intensity and frequency, will improve neurodevelopmental and functional outcomes and reduce social and mental health problems later in life. Determining the appropriate intervention is dependent on a coordinated approach to assessment and diagnosis. A process of a referral, assessment, intervention, review and re-assessment with ongoing case coordination is recommended.

The Dudley et al. (2015) report has contributed to the Australian government response to FASD by including the impairments seen in FASD as eligibility criteria for therapy funding through a National Disability Insurance Scheme. This ground-breaking policy decision will enable access to much needed therapy funding and increase the drive for clinicians to diagnose FASD, knowing that funding for support will be able to be accessed.

There are a number of FASD intervention studies underway in Australia and a strong national collaboration working towards a national multisite randomised controlled trial. The most ambitious FASD intervention study currently underway is a randomised comparison trial of the Alert Program® (Williams and Shellenberger 1996) to improve self-regulation and executive functioning, among 250 school-aged children in nine schools in the remote Fitzroy Valley region. Following the impactful model of community-led research partnerships, this study is being implemented by Bree Wagner, a PhD student at Telethon Kids Institute and former teacher from the Fitzroy Valley, and her Aboriginal community research colleague Sue Cherele, a Gooniyandi woman from the remote Muludja community in the Fitzroy Valley. This study is being done ‘by’ the community, not ‘to’ the community. Preliminary data from a pilot of the study in 26 children during 2015 indicate a significant improvement in

measures of executive functioning on carer and teacher reports using the Behavioural Rating Inventory of Executive Functioning (Gioia et al. 2000), and reduction in problem behaviour using the Eyberg Child Behavior Inventory and Sutter-Eyberg Student Behavior Inventory (Eyberg and Pincus 1999). The full study will be implemented during 2016–2017. Concomitantly, a parent support/therapy randomised controlled intervention study across schools in the remote WA Pilbara region is being delivered during 2016–2018, which will involve ~200 school-aged children and carers receiving the Alert Program®. Through the Australian FASD Clinical Network, a national multisite randomised controlled trial of the Families Moving Forward (Bertrand 2009) plus Alert Program® is intended to be delivered across four clinics in WA, NSW and QLD, which would commence in 2017. It is anticipated that intervention studies will form a significant part of FASD research in Australia over the next decade, and international collaborations to increase study scale and international impact are being pursued.

## Conclusions and Future Directions

Alcohol consumption by women during pregnancy continues to be a common occurrence in Australia (2013 National Drug Strategy Household Survey detailed report 2014; Colvin et al. 2007). While an encouraging trend is emerging that more women are abstaining from drinking during pregnancy (2010 National Drug Strategy Household Survey report 2011), it is still an important health issue facing Australian communities. Additionally, Australian FASD prevalence figures are lower than international estimates and a likely underestimate, due to issues related to inadequate screening and reporting, the lack of a standard nationally coordinated diagnostic approach and insufficient clinical pathways with specialist multidisciplinary assessment experience and resources (Mutch et al. 2015; Peardon et al. 2008). Consequently, there is a need for further research on the prevalence of FASD in Australia, particularly in high-risk cohorts such as out-of-home care settings and the justice system (Streissguth et al. 2004; Popova et al. 2011).

Since 2001, strong collaborations have emerged, enabling national collaboration on FASD research, including the development of consensus recommendations for Australian FASD screening and diagnostic guidelines (Watkins et al. 2013, 2014; Bower and Elliott 2016), and culminating in the award of a prestigious Australian Centres of Research Excellence grant from the National Health and Medical Research Council (2016–2020). To meet the demand for FASD diagnosis in Australia, there is a need for funding and training to improve the screening and diagnostic capability of multidisciplinary diagnostic teams, ideally within existing general child development services. Further research to elucidate the

neuropsychological sequelae, impact of disrupted attachment and trauma and the efficacy of interventions is clearly required, particularly in relation to the cross-cultural issues unique to the Australian context.

This article has highlighted the crucial role that paediatric neuropsychologists' play in relation to FASD across educational, clinical and forensic settings within a cross-cultural context. A particular challenge is that paediatric neuropsychologists working in this area are restricted by a lack of culturally appropriate tests with adequate norms, and there is a need for the development of more culturally appropriate measures for non-English speaking populations. It is also essential that all psychologists working in this area undertake relevant professional training regarding FASD diagnostic guidelines within an Australian context and work in conjunction with other clinicians, particularly medical specialists such as paediatricians, as well as cultural consultants. Paediatric neuropsychologists have an important role to play in terms of informing appropriate interventions depending on the individuals' unique profile and promoting the concept of scaffolding and structure to support executive functioning and emotional and behavioural regulation.

We have seen that many FASD intervention programmes show considerable promise, although there continue to be gaps in the literature prompting the need for ongoing research. Of note is the lack of evidence-based data for treatment with young children, which is of concern given the potential benefits of early intervention. Key findings to date include the importance of parent education, explicitly teaching skills and integrating individualised interventions into existing treatments within home, school or community environments (Bertrand 2009). A recent Australian report that reviewed FASD interventions highlighted several key principles when planning access to services and supports for all individuals on the FASD spectrum (Dudley et al. 2015) and include a strength-based multidisciplinary systemic approach across family, school, therapy and community settings that incorporates psychoeducation, risk assessment and monitoring and ensuring cultural security. Combining a 'domain general' approach with a 'domain specific' approach will be more effective than isolated intervention approaches. Coordination and case management based on a key worker model allows an interagency collaborative approach and facilitates communication while simplifying the service milieu for families.

Australian FASD prevention strategies are among the most advanced internationally and have in many instances been led by Aboriginal communities, in partnership with research institutes (Gooda 2010; Bruce et al. 2016). The current FASD prevention strategies in the WA Kimberley and Pilbara regions are being conducted in collaboration with researchers from the USA and Canada (Bruce et al. 2016). A strengthening of the links between Australian and international research groups is enabling translational research in FASD prevention to take

pride of place in international FASD research fora. It is expected by the authors that for the next decade the international field of FASD research will move strongly into prevention and intervention studies. This indicates the maturing of a field, only 30 years young, where early research was committed to documenting the teratogenic effects of FASD and attempting to estimate prevalence through epidemiological studies.

The Australian government has begun to respond to pressure by consumers, the medical community and researchers to better address the needs of families affected by FASD, including through a federal parliamentary inquiry in 2011, targeted FASD research funding, the establishment of a National FASD Action Plan, an Australian FASD Clinical Network and Technical Network and \$10.5 million funding in the 2016 budget to prevent, identify and manage FASD in Australian communities (Parliament of Australia House of Representatives Inquiry into Foetal Alcohol Spectrum Disorder 2011; Commonwealth Action Plan to reduce the Impact of Fetal Alcohol Spectrum Disorders (FASD) 2013–2017 2014; Taking more action to prevent Fetal Alcohol Spectrum Disorders 2016). However, the scale of the problem of FASD in Australia requires strengthening of policy and resourcing to target FASD and the prevention of alcohol use in pregnancy. Barriers to moving forward have included a lack of data on the prevalence of prenatal alcohol exposure and FASD, limited awareness among health professionals of FASD and a delay in establishing Australian guidelines for the diagnosis of FASD.

A most important shift in Australian health and disability service policy is the recognition of FASD as a category of eligibility for disability funding (Dudley et al. 2015). Hitherto, the eligibility criteria have restricted access to dedicated funding for treatment, resources and interventions throughout the life span. As is the case overseas, there has also been increasing community and government concern regarding the forensic implications of FASD and the vulnerability of these youth in the justice system, with the need for specialised programmes and policies to better identify and address their unique needs (Mutch et al. 2013). Furthermore, despite increasing efforts to address FASD within Australia, there remain ongoing gaps in the awareness and knowledge of health professionals about FASD, in turn affecting the delivery of diagnostic and clinical services. Consequently, targeted strategies for research and funding to better address prevention, diagnosis and intervention across the country are still required to improve the lives of individuals affected by FASD.

Overwhelmingly in Australia, there is great hope that the preventable tragedy of FASD can be overcome. Many community FASD prevention initiatives have been progressed to ‘Make FASD History’ in Australia. The Australian Government has recognised FASD as a priority area; Australian FASD diagnostic guidelines have recently been

endorsed; large trials of intervention are underway and a critical mass of community advocates, researchers and clinicians are committed to do as Gandhi would have advised: “To apply the Law of Love, with scientific precision”.

#### Compliance with Ethical Standards

**Conflict of Interest** Dr. Fitzpatrick is Director of PATCHES Paediatrics, and Dr Fitzpatrick and Dr Pestell provide clinical services through PATCHES Paediatrics.

**Human and Animal Rights and Animal Consent** This article does not contain any studies with human participants or animals performed by any of the authors.

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