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Putting Fetal Alcohol Spectrum Disorder (FASD) on the Map in New Zealand: A Review of Health, Social, Political, Justice and Cultural Developments

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The damaging effects of alcohol intake have long been recognised as an issue for New Zealand society since the introduction of alcohol by early settlers. In the mid-1990s, New Zealand began to acknowledge the distinct set of impairments that result from prenatal alcohol exposure that is now known as fetal alcohol spectrum disorder (FASD), which affects all facets of an individual's life, including having individual impairments as well as secondary disabilities arising from those impairments. In New Zealand, a collaborative, multidisciplinary and multiagency approach has been necessary in order to offer the best support for individuals and families who are living with FASD. In this article, the developments within New Zealand's health, justice, social and cultural sectors are traced and the work of many individual trailblazers who have put FASD on the map is acknowledged. The story of putting FASD on the map in New Zealand is one of determination, hope and opportunity, as well as recognition that there is still a long way to go.

Key words: disability; FASD; fetal alcohol spectrum disorder; health; justice; medical; New Zealand; race; social.

Introduction

Fetal alcohol spectrum disorder (FASD) is a term that describes a range of permanent brain-based disabilities resulting from prenatal exposure to alcohol, which is a teratogen. In New Zealand over half of all pregnancies might have involved alcohol exposure (Health Promotion Agency, 2015b; Ministry of Health, 2015). The advice from all sectors is that there is no safe limit for alcohol consumption during pregnancy. Although not all alcohol-exposed pregnancies will result in FASD, conservative estimates are 1 in 100 for New Zealand (Ministry of Health, 2015). Internationally, and where communities experience higher rates of alcohol use, the

prevalence rates climb to 1 in 20 (May et al., 2014). For New Zealand, this means that 570 or more children are born every year with a preventable disability. Early research both in New Zealand and internationally completely underestimated the prevalence of FASD (Buxton, 2004; Leversha & Marks, 1995; May et al., 2014), mainly because it was not yet a recognised disability. Rather, fetal alcohol syndrome (FAS) was recognised, with some emphasis on identifying a particular set of facial features, which it is now known occurs in only 4% of diagnosed cases of FASD (Clarren et al., 2015). The true prevalence rates of FASD in New Zealand are unknown because, to date, no thorough study

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has been undertaken; however, action is planned on a number of fronts through a recently launched FASD action plan (FASD Working Group, 2016a, 2016b).

FASD is a profound lifelong neurodisability with significant central nervous system impairments and in some cases significant physical impairments. However, for the vast majority of FASD sufferers and their families, the greatest harm arises as a result of secondary disabilities, i.e. those harms which are inflicted upon individuals and families by wider society – exclusion, intolerance, stigma, and a failure to be accommodated in education, medical and legal systems. The social, behavioural and cognitive impairments of FASD are well documented (Popova, Lange, Burd, & Rehm, 2016; Streissguth et al., 2004), and include impairments in attention, memory, cognition, language and communication, motor skills, emotional regulation, age-appropriate behaviour, and life skills. Children with FASD stand the best chance of a positive outcome if they are assessed and diagnosed before the age of 6 years (Buxton, 2004; Streissguth et al., 2004). Sadly, in New Zealand the majority of those with FASD go undiagnosed and unacknowledged (FASD Working Group, 2016a). According to robust international guidelines on diagnosing and assessing FASD (Cook et al., 2016), children with FASD need to be assessed by members of a well-trained multidisciplinary team of at least a medical doctor (often a paediatrician or psychiatrist) and a psychologist. Since the mid-2000s New Zealand diagnostic teams have used international guidance to implement diagnosis and assessment services.

This article begins with a brief overview of the early work of FASD champions in getting FASD on the map, and then explores the broader health, social, political, justice and cultural developments that have led to greater FASD awareness and action in New Zealand, from the mid-1990s to the present day, ending with some thoughts as to future developments.

Early Days

It has taken a long time for FASD to be recognised in New Zealand, in spite of the advent of advocacy and awareness campaigns from the early 1990s – and arguably before that. One of the key champions in New Zealand was and is Christine Rogan, who – in her role as health promoter and FASD project coordinator, working for Alcohol Healthwatch – has campaigned tirelessly to raise awareness of the harm caused to unborn children by alcohol consumption during pregnancy. Rogan has authored influential fact sheets (Alcohol Healthwatch, 2006), briefing papers and reports (Alcohol Healthwatch, 2007; Rogan, 2010), consensus statements (Alcohol Healthwatch, 2014), and book chapters (Rogan & Crawford, 2013), as well as playing a key role in getting professionals and politicians to listen, facilitating networking between researchers and practitioners, initiating training, giving presentations and workshops, applying for grants, and giving support to families. Since 1996, Rogan has provided regular communications specifically focused on building knowledge and awareness of the nature of FASD and its impact, as well as for the need to cease drinking alcohol during pregnancy. She joined advocates from other nations to host the inaugural International FASD Awareness Day on 9 September 1999 and she has ensured that New Zealand has participated every year since. She has raised money for and facilitated the first diagnostic team training and development in New Zealand (see below), and she started the Fetal Alcohol Network (<http://www.fan.org.nz>) to inform and connect service providers and families. It is fair to say that without this level of consistent activity, very few of the developments mentioned in the subsequent sections of this article would have been initiated or achieved.

Another key champion from the mid-1990s was Shirley Winikerei, a grandmother from Hamilton who tirelessly advocated for her adopted daughter and granddaughter,

both of whom were suspected to have FASD (Bidios, 2000; Buxton, 2004). Winikerei set up New Zealand's first FASD family support trust in 1997 (known as FAST), but a lack of funding led to it closing down in 2007 (Collins, 2007). She also petitioned the courts and the government to get FASD recognised as a disability long before it was widely recognised (Grade, 2014; New Zealand House of Representatives, 2004). She received a civic award for her work in 2010, and although she is now in her seventies she is still supporting new initiatives. Alongside Winikerei, there have been many other grandparents, caregivers, and birthparents who have fought for their grandchildren and fostered, adopted and birth children with compassion and tenacity in order to have FASD better acknowledged and treated.

A more recent and pivotal media campaign and story, which dominated the media during 2014/15, was that of Teina Pora, a 17-year-old Māori male with undiagnosed FASD who had spent 21 years in jail for crimes he did not commit. Pora was released in 2014, and his convictions were overturned by the privy council in 2015. Pora was diagnosed with FASD in 2014 by Drs Valerie McGinn and Craig Immelman (Bennett, 2016; Freckelton, 2016; Young et al., 2016), and FASD was viewed as the most significant factor in his original conviction – his inability to explain himself, his willingness to agree that he had committed terrible crimes, his false ‘confessions’ to police, and his young developmental age at the time of conviction. This put FASD on the map in the wider public arena, establishing that a failure to recognise it in the legal process had led to a gross miscarriage of justice, and could do so again in the future.

In the early days of getting FASD on the map, many Canadian and United States researchers and experienced practitioners were invited to New Zealand to share their expertise and valuable insights into working with people with FASD. These visitors have supported professionals, carers and families

in New Zealand, many of whom have travelled overseas to learn, with the aim of developing capacity in their own regions. Auckland, Northland, Taranaki, Hawkes Bay and Gisborne were the first regions in the North Island to have skilled clinicians who were able to assess and diagnose FASD, and more recently Nelson, and Dunedin have begun to develop capacity in the South Island. As early as 2003, Dunedin had professionals undertaking research about the experiences of birth parents of children with FASD (Salmon, 2007). Dunedin's first trainer from Canada arrived in 2007, and more research about the needs of – and services for – people with FASD ensued (Bagley, 2013). Research and conversations with families, particularly those who had adopted children from overseas, highlighted the need for a multi-perspective understanding of FASD, and a multidisciplinary and multi-context response to creating services and FASD-tailored responses (Fetal Alcohol Spectrum Disorder in the Youth Court, Part 1, 2010; Fetal Alcohol Spectrum Disorder in the Youth Court, Part 2, 2010; Gyde, 2013; O'Driscoll, 2011; Parsonson, 2015; Rogan & Crawford, 2013; Salmon, 2014; Symes, 2004). New Zealand's approach to getting FASD on the map has involved all sectors, families, researchers, health and welfare professionals, Judges and other legal professionals, and international friends.

Health and Medical Developments

FASD is a medical disorder that results in needs across a range of sectors, including health, mental health, disability, education, care and protection, and justice. It has taken time internationally for FASD to be accepted as a medical disorder (Shankhar, 2015), and in New Zealand some health professionals remain poorly informed, despite the range of medical literature available. FASD cases may be diagnosed as attention deficit hyperactivity disorder (ADHD) or other mood or behavioural disorders, as well as attachment

difficulties, which are common comorbidities (Peadon & Elliot, 2010; Popova et al., 2016; Young et al., 2016). The influence of robust scientific evidence on the harm caused to the developing brain by alcohol – as well as by trauma, neglect and other substances (Center on the Developing Child, 2012; 2016) – has influenced the way in which clinicians and other professionals view the world of neuro-disability and motivated them to become better versed on neuroscience at a basic level, along with *brain-based* interventions (Bagley, 2013; Malbin, 2011). But, for far too long FASD has been the invisible disability (Brown & Mather, 2014), with families being turned away by uninformed health and medical professionals (Salmon, 2014; Whitehurst, 2012).

The Ministry of Health, Alcohol Healthwatch, the Health Promotion Agency and many other researchers, professional groups, and FASD advocates have promoted consistent messages of alcohol cessation during pregnancy (Ako Aotearoa, 2012; Alcohol Healthwatch, 2006; Ministry of Health, 2007, 2010; Royal Australasian College of Physicians, 2016; Royal Australian and New Zealand College of Psychiatrists, 2016). Other studies have highlighted the lack of knowledge that professionals have about FASD, as well as the need for FASD-specific diagnostic and other services (Bagley, 2013; Blair, 1997; Salmon, 2007; Symes, 2004; Wouldes, 2009). For Christine Rogan of Alcohol Healthwatch, the key to action on FASD is to develop FASD diagnostic capacity and not just undertake awareness raising:

The lack of any systematic and comprehensive multidisciplinary approach to FASD diagnosis represents a significant missed opportunity for implementing appropriate follow-up care and prevention. [...] The development of diagnostic services has been limited in New Zealand for a number of reasons. Leading among these, a lack of prevalence data on the affected population has often been cited as a reason for the lack of progress in developing a systematic

approach to FASD at a national level. This has resulted in a situation where a lack of FASD diagnosis leads to a lack of data, which leads to a lack of resources to strengthen workforce development and responsiveness. (Rogan, 2010, pp. 21–22)

When a proposed government FASD action plan failed to get off the ground in 2008, and with the recognition of FASD by Youth Court judges growing, Rogan joined forces with a handful of committed medical professionals to explore other avenues to address the lack of FASD diagnosis and intervention. With a successful grant bid, Alcohol Healthwatch initiated a new project with these health professionals to explore the introduction of a multidisciplinary diagnostic capacity to New Zealand and to ascertain which diagnostic protocols provided the best fit for the New Zealand context (Rogan, 2010).

Key people in this first phase include Drs Craig Immelman (child and adolescent psychiatrist) and Valerie McGinn (neuropsychologist), both of whom had already completed their training in the United States and Canada for assessing and diagnosing FASD in 2007 and 2008, respectively. They began undertaking New Zealand's first FASD assessments in 2008. They identified the previously hidden impact of prenatal alcohol exposure on the development of children and young people in trouble with the law, and gave evidence to the New Zealand courts. This initiative was positively supported by the Principal Youth Court Judge of New Zealand, Andrew Becroft, along with two other Youth Court judges – Fitzgerald and O'Driscoll – who also travelled to Canada to gain more knowledge about FASD at this time. Since undertaking training, McGinn in particular has completed over 400 FASD neuropsychological assessments, of which 300 have been confirmed as FASD, and she has proactively trained other health and welfare professionals. Her neuroassessments have proved extremely helpful to judges in both the youth and adult courts of New Zealand. In 2012, she set up the FASD Centre Aotearoa, with

Dr Zoe MacLaren (paediatrician), New Zealand's only private but not-for-profit FASD diagnostic and treatment service.

Thanks to another grant, diagnostic training of the first district health board (DHB) teams began (Taranaki, Hawkes Bay and Auckland). This included training from Dr Albert Chudley, a pre-eminent FASD researcher and geneticist from Manitoba, as well as a visit to the Asante Centre in British Columbia (Bagley, 2013; Health Promotion Agency, 2015a; Rogan & Crawford, 2013). In 2011, 13 New Zealand clinicians attended the biannual international FASD conference in Vancouver. The three teams set about taking referrals from 2011 in three districts, with Hawkes Bay being the most advanced, as their specialist team includes a social worker, a speech and language therapist, access to occupational therapy, a neuropsychologist, and a consultant paediatrician (Health Promotion Agency, 2015a). The expansion of the trained teams has continued, and there are now seven assessment and diagnostic services up and running in the North Island, with two emerging ones in the South Island. However, all of these services – bar the FASD Centre Aotearoa – focus on child/youth assessment, and are not equipped to offer the much-needed post-diagnostic intervention services (these are just beginning, as is discussed below).

In 2008, the Ministry of Health funded an extensive systematic literature review (Elliot, Coleman, Suebwongpat, & Norris, 2008), which explored primary, secondary and tertiary prevention strategies to reduce the harm caused from alcohol exposure. Much of this material explored useful screening practices, and in 2010 the Ministry of Health and Alcohol Healthwatch produced a helpful guide entitled *Alcohol and Pregnancy: A Practical Guide for Health Professionals* aimed at GPs, midwives, and other helping professionals to discuss alcohol and pregnancy, and the risks of continuing to drink while pregnant (Ministry of Health, 2010). In 2011, Christine Rogan for Alcohol Healthwatch, along with

researchers from the University of Otago, helped to implement a project funded by the Ministry of Health that resulted in an online educational resource for health professionals. Hosted by Massey University's continuing education Ako Aotearoa platform (<https://ako.aotearoa.ac.nz/projects/pact>), the resource includes modules about alcohol use and its effects on the foetus and subsequent FASD, and practical information about screening and prevention.

In 2014, Alcohol Healthwatch once again gathered key professionals, researchers, FASD-impacted families and advocates for a symposium hosted by Auckland University's Department of Population Health, Centre for Addiction Research, and this resulted in a Consensus Statement that called for:

Urgent strengthened efforts to improve the lives of individuals with Fetal Alcohol Spectrum Disorder (FASD) and their families and prevent this brain-based disability. FASD demands shared responsibility with committed cross-government and cross-sector policy and service delivery working together in a coordinated, funded and effective strategic direction. (Alcohol Healthwatch, 2014, p. 1)

After years of gathering much material and research, campaigning and advocacy from families, the Ministry of Health supported the setting up of an FASD working group, and cross-party committee, involving a range of disciplines from the health, social development, corrections, and education sectors, as well as representatives of families and non-governmental organisations (NGOs) working in the area. A discussion document was issued in December 2015, and after 150 submissions the FASD working group produced New Zealand's first three-year action plan (FASD Working Group, 2016a, 2016b). A key person driving the plan forward was Catherine McCulloch, a senior policy advisor in the Ministry of Health, who worked passionately to get representation and commitment from the main ministries in New

Zealand: those of health, social development, justice, and education. The plan was supported by Hon Peter Dunne, the Associate Minister of Health, who in the opening statement of the plan emphasised the need for collaboration across sectors and communities to reduce the harm caused by alcohol use. He also emphasised that New Zealand's approach to dealing with FASD needs to focus on agencies and communities working together for the duration of the lifespan of people with FASD, thus acknowledging the lifelong impacts of the disability. The plan itself focuses on prevention, evidence-gathering, early diagnosis and support for people and their families, and NZ\$12 million has been set aside to support the initiatives mentioned – most of it for investigative and preventative work. During 2016, the Ministry of Health also took submissions on a new 10-year disability strategy, changes to special education, and respite services, all of which have indirect relevance in terms of interventions and support for families for whom FASD is an issue. The disability strategy (Ministry of Social Development, 2016) is underpinned by principles from the Convention on the Rights of Persons with Disabilities (Convention on the Rights of Persons with Disabilities, 2008), notably respect, participation and inclusion. Even though FASD has previously been 'hidden' it is now firmly part of the disability agenda in New Zealand.

In the following sections, developments in the social, political, educational, justice and cultural contexts which have influenced the FASD map of New Zealand are reviewed.

Social, Political and Educational Developments

FASD is beginning to emerge as a social issue in New Zealand, as more is learned about the significant harm that alcohol causes to the brains of unborn children. Historically, the ills of alcohol in relation to entire populations is well established, but only since FAS was first documented in 1973 has it begun to

become clear that its impairment effects on the brain and behaviour of children are profound and lifelong. In New Zealand, the first children with FAS were identified in 1995 (Leversha & Marks, 1995). Since then, while numerous reports have been published, reinforced by changes to the alcohol laws and campaigns to raise awareness, the rates of drinking are still alarming – particularly in young women, who in recent years have begun to catch up with men in terms of problematic drinking behaviour (Slade et al., 2016; Superu, 2015). The costs of FASD have been known for a while, but only recently quantified. The overall annual cost, including the use of services and support, to New Zealand is estimated as at NZ\$690 million, around NZ\$15,000 for every individual with FASD (Ministry of Health, 2015). Easton, Burd, Rehm, and Popova (2016) have also estimated the annual loss to economic productivity due to FASD to be around the NZ\$200 million mark. If 'unseen costs' such as those associated with the social, health and financial impacts on family members are also included, along with the cost of finding alternative or extra education, getting legal help, and paying for extra medical expenses and assessments or interventions, then the burden of FASD increases even further.

That alcohol misuse and its consequences are a major social problem in New Zealand is accepted; yet money is poured into promoting its use. Alcohol's damaging effects costs the nation billions every year (Law Commission, 2009). For Māori, the intergenerational impact of colonisation – loss of identity (whakapapa), loss of land and connections, poverty, violence and alcohol misuse – has left its mark, with much higher numbers of Māori in care, in prison, and in poor health (Law Commission, 2009; Simpson, Adams, Oben, Wicken, & Duncanson, 2015; Stanley, 2016).

The media has played an increasing role in highlighting the tragedies of FASD. There have been stories of grandparents fighting for better deals for their young ones, stories of

young people with FASD in court facing serious charges, stories of pregnant women drinking alcohol, stories of research findings, responses to government initiatives, and many more (Bidios, 2000; Channel 39 News, 2016; Collins, 2007, 2008; Grade, 2014; New Zealand Herald, 2015; Satherley, 2016; Savage, 2015; Taylor, 2015). The media has had a clear role in influencing how this disability is viewed, and whether or not it is presented as a serious public issue (Eguiagaray, Scholz, & Giorgi, 2016). FASD is getting more attention in all forms of the media – and with the coverage comes both hope and stigma, as unfortunately there are no guarantees that the media coverage of any issue will be a force for good (Bell et al., 2015; Eguiagaray et al., 2016).

Research and professional bodies like the Addictions Research Centre at Auckland University and the colleges of health professionals have also helped to shape the discourse on alcohol-related harm and FASD (Alcohol Healthwatch, 2014; New Zealand College of Midwives, 2016; Royal Australasian College of Physicians, 2016; Royal Australian and New Zealand College of Psychiatrists, 2016). The FASD discussion document (Ministry of Health, 2015) received 150 written submissions from professionals and individuals (FASD Working Group, 2016b). Submissions advocated more awareness raising, screening, diagnosis and action aimed at preventing children in New Zealand being born with FASD, as well as supporting families and individuals coping with the impairments arising from living with FASD.

Individual researchers from around New Zealand have noted the damaging effects of FASD on families and young people, as well as the continued lack of capability in the health, education, welfare and justice professions with regard to acknowledging, assessing and helping to deal with FASD (Bagley, 2013; Blair, 1997; Manning, 2016; Salmon, 2007, 2014; Symes, 2004). A number of these researchers have proactively supported local initiatives to help families, train professionals, and raise funds to promote acceptance and

awareness of FASD. Dr Ruth Napper of Otago University (Gibb, 2010), who specialises in exploring the effects of alcohol on the brains of rats, has been a determined advocate for families with an FASD in Dunedin, and has helped raise funds to set up Dunedin's first assessment and diagnosis team.

Individual champions, caregivers, young people with FASD and support groups have contributed substantially to awareness raising and demand for recognition and services. Early campaigners included families of adopters, both internationally and locally (Buxton, 2004; Gyde, 2013). A number of parents who adopted children from Russia, in particular, were aware of the likely effects of prenatal alcohol exposure. Claire Gyde describes her family's journey from 1999, when she and her husband Paul adopted their son Jakob from Pskov, Russia. Gyde worked with Rogan and others to offer online support and FASD-awareness training, and in 2013 this led to the setting up of the charitable trust FASD-CAN Inc. (www.fasd-can.org.nz), which aims to support caregivers, parents and families, as well as individuals with FASD, and to educate New Zealanders more generally about FASD (Gyde, 2013). FASD-CAN now has over 80 members, and many of these parent and caregiver advocates were consulted and made submissions to the FASD action plan as it was developed. FASD-CAN is focused on maintaining and further developing relationships within the government and having an influence at the policy level so that the concerns of parents and caregivers are heard. FASD-CAN is a charity and relies entirely on donations. It has successfully partnered with Alcohol Healthwatch and the Health Promotion Agency to host a number of parent workshops. The charity also hosts an online support network, with a number of regions having also established support meetings.

Political Developments

Families and advocates, as previously outlined, have all raised awareness of the

dangers of alcohol intake and subsequent FASD, and have attempted to get FASD onto the political agenda, alongside the lobbying work of Alcohol Healthwatch. Shirley Winikerie was well known as an activist for FASD recognition in political circles during the 1990s and early 2000s (Buxton, 2004). She petitioned the government in 2004, with 478 others, to move that FASD be made a notifiable disability and gain greater recognition (New Zealand House of Representatives, 2004). Her petition was supported by the Labour MP for Hamilton East, Dianne Yates. The petition resulted in some new recommendations being made around data collection and monitoring, but FASD was not recognised as a notifiable disability; the committee felt that the notification would result in stigmatisation and reduced numbers of women reporting alcohol consumption. The stigma for birth mothers and children is very real, in a society where alcohol is socially accepted yet mothers are blamed for the harm caused to their unborn children (Bell et al., 2015; Salmon, 2007).

Other parents and grandparents have continued to lobby local and national MPs and ministers in parliament, especially to support the recognition FASD as a cross-party issue that is in need of cross-party support and multi-ministry involvement. Two MPs, in particular, have been supportive of FASD activities, resulting in the three-year action plan (FASD Working Group, 2016a). Tim McIndoe (Winikerie's local National MP) and Hon Peter Dunne (of United Future) who is the Associate Health Minister, have written and voiced their support:

FASD is not solely a concern for women of child-bearing age, it is an issue for all of us [...]. Communities need to work together to create a context and culture that supports families and whanau to have healthy, alcohol-free pregnancies. (McIndoe, 2016, p. 2)

The three-year action plan on FASD is just one aspect of the challenge ahead to

reduce the harm caused by excessive alcohol intake. Peter Dunne, MP, in his foreword to the three-year action plan, notes that the stigma associated with FASD needs be reduced and the barriers to accessing help and support need to be removed (FASD Working Group, 2016a). In a recent media article, Labour's MP Hon Jacinda Ardern has specifically supported changes to the criminal justice to avoid wrongful imprisonments like that of Teina Pora (Ardern 2016).

Politically, FASD is not going to be a vote winner, yet with the economic and other costs now being calculated, and with the need for all sectors to be involved in dealing with the impacts of FASD, it is vital that it remains on the political priority job list. The need to focus on neurodisabilities in the prison and care population (see below; see Lynch, 2016) and on children's well-being is receiving more attention from the political parties, as well as the Office of the Children's Commission (Becroft, 2016). New Zealand is currently undergoing a radical reshaping of its child protection services and legislation, some of which is aimed at improving the lives of young people in care or who might end up in care, where neurodisabilities like FASD are a significant issue. This period of reshaping makes for an opportune time to ensure that children and young people with an FASD are identified, assessed, given a voice, and assisted to reach their potential – physically, socially, culturally, and vocationally.

Educational Developments

From an educational perspective, the aforementioned issues, people and initiatives have all added to the raising of awareness of FASD and its impacts. Nevertheless, one of the most tragic impacts of FASD is noticed directly at school. Gyde's (2013) story of her son's exclusion and alienation from both school and his peers is repeated over and over throughout New Zealand, with lifelong damage resulting from being misunderstood by teachers and educational workers. Families

have long campaigned for FASD to be recognised as a disability in order to *attract funding* to support their children at school – but this has still not occurred. There has been some excellent work done recently, alongside the three-year FASD action plan, developed with families and through the Ministry of Education Inclusive Education website (<http://inclusive.tki.org.nz/>). While it is good that the resources on FASD can be accessed directly by teachers, there appears to be an assumption that teachers will go online and educate themselves; no time or money has been set aside to purposively introduce the materials and give teachers quality professional development time or training to use them.

Other educational contributions to the FASD story in New Zealand include a small review of educational interventions that might help children with FASD at school (Gunn, 2013), and a more extensive literature review by Parsonson (2015), which notes the significant challenges that children with FASD face in the classroom. This review also offers insights on educational strategies that would be useful for teachers and other educational professionals to use. Additionally, in 2015, Rose Hawkins – a regional disability advisor from Child, Youth and Family – created a *pack of FASD cards* as an educational resource to be used by practitioners and caregivers in order to better understand and help young people with FASD. She has developed other resources, along with Dr McGinn, to inform Child, Youth and Family social workers nationwide about the special needs of children with FASD who are in care.

Justice and Legal Developments

Recognition of and advocacy for individuals with FASD in the justice sector has been developing in New Zealand over the last decade. The impetus has come from the FASD health and neurological assessments provided by Dr McGinn and Dr Immelman at all levels of the courts since 2008, which has resulted in FASD being increasingly accepted

as a mitigating factor both at sentencing and when considering fitness to stand trial and be accommodated in legal processes. Communication assistance is also being provided to defendants with FASD to ensure that they can participate adequately in the courtroom and when communicating with counsel (Kedge & McCann 2016).

In 2006, Judge Andrew Becroft – Principal Youth Court Judge at the time – identified the growing incidence of neurological disabilities in the youth justice context and recognised that FASD is a significant contributor to this cohort of young offenders (Fetal Alcohol Syndrome & Youth Justice 2006). Also in 2007, Judge Tony Wartnick from Seattle visited a youth justice conference in Wellington, speaking about the significance of FASD in relation to the justice system. Issue 24 of *Court in the Act* published extracts of information on FASD sent to the sector from Christine Rogan of Alcohol Healthwatch (Fetal Alcohol Syndrome & Youth Justice 2006). Following this publication, early in 2007, Judge Becroft came in ‘for a bit of flack’ on New Zealand TV for suggesting that youth offending ‘might begin prenatally’ (Letter to the editor 2007). Rogan wrote a letter to the editor of *Court in the Act* defending Judge Becroft’s statements, emphasising that there was a ‘growing body of evidence’ to support his statements (p. 12).

In the same letter to the editor of *Court in the Act* in 2007, Rogan attached two emails with information from and researchers in Canada. The messages highlighted the likely prevalence of FASD in justice systems, and emphasised the importance of developing programmes to deliver appropriate preventative education messages to women and wider society about the dangers of drinking alcohol during pregnancy (Letter to the editor 2007). The judges also point out that the problems are ‘easy to miss’ due to the majority of FASD sufferers exhibiting no physical signs of disability, warning that these individuals do not see cause and effect, thus significantly limiting the efficacy of most justice sanctions

that are largely based on principles of deterrence and rehabilitation (Letter to the editor 2007).

In 2007, two groups – the government-appointed Youth Justice Independent Advisory Group (chaired by Judge Becroft) and a group of Youth Court judges – became increasingly concerned regarding inadequate services for the purpose of diagnosing and responding to FASD in the youth justice system, and it was submitted that there is a clear need to provide proper resourcing to the Youth Court to carry out its statutory mandate in particular. Both groups met separately and regularly, first with Associate Minister of Health Hon Damien O'Connor (Labour Government) and later with his replacement, Associate Minister of Health Hon Peter Dunne (National-led Government), to share their concerns. These groups have consistently sought more resourcing for FASD assessment and targeted action in order to help young people coming through the courts who might have FASD.

In 2010, through the *Court in the Act* 50 and 51 editions (Fetal Alcohol Spectrum Disorder in the Youth Court, Part 1 and Part 2, 2010). Judge Becroft – together with Judge Stephen O'Driscoll, a district court judge with a Youth Court designation – combined the growing body of knowledge of FASD to produce a two-part series on FASD and justice. Issue 51 stresses the importance of justice professionals being aware of FASD, of ensuring individuals who are suspected of having FASD are well represented by an advocate throughout the justice proceedings, and that leading questions should be avoided due to the suggestibility of young people with FASD and their eagerness to please. Judge O'Driscoll continued to discuss the issue of FASD in 2011, in an article highlighting how specific parts of New Zealand legislation might be applied to help offenders with suspected FASD (O'Driscoll, 2011). In the December 2015 issue of *Court in the Act*, Judge Tony Fitzgerald (Fitzgerald, 2015) reiterated the significance of neurodisabilities in

general, and FASD in particular, in the youth justice context. Judge Fitzgerald highlighted the needs of young offenders with FASD and other neurodisabilities, and emphasised the importance of providing different treatments to offenders with neurodisabilities, as compared to their neurologically-typical counterparts (Fitzgerald 2015).

Other organisations and people have been instrumental in encouraging an increase in awareness of FASD in the justice system. One such organisation is JustSpeak, a non-partisan network of young people aiming to raise awareness of issues across the criminal justice system in New Zealand (<http://www.justspeak.org.nz>). In its 2012 submission on the Youth Crime Action Plan, JustSpeak urged for 'universal screening' for FASD in the Youth Court (JustSpeak, 2012). In 2013, the organisation published an article on the links between FASD and offending on its website, further raising awareness of the issue. More recently, in 2016, JustSpeak has been highly vocal in its support of extending the jurisdiction of the Youth Court to include 17-year-olds (Kenner & Bruce, 2016). This is a pertinent issue for all advocates for individuals affected by FASD due to the implications of involving a young person with a chronological age of 17 but the developmental age of a much younger child in the justice system (Malbin, 2011; Streissguth & Kanter, 1997). Dr Ian Lambie, of the University of Auckland, has also been vocal regarding the issue of including 17-year-olds in the youth justice system (Lambie, Ioane, & Best, 2014). Lambie has a background in clinical psychology, as well as tertiary education, and is a member of the Youth Justice Independent Advisory Group. Lambie et al. (2014) explore the extension of the age of youth coming into the Youth Court's jurisdiction – and at the time of writing, the Government of New Zealand has just announced that it plans to raise the age of youth justice to 18 years (Kirk, 2016).

Lambie, Best, Ioane, Becroft, and Polaschek (2016) have also recently published an

article regarding the use of s333 reports in the Youth Court (part of the Children, Young Persons and Their Families Act 1989). This provision gives the judge scope to order a medical, psychiatric or psychological report to be made available to the court (s333). Lambie et al. (2016) focus on the overrepresentation of neurological disorders in the youth justice system, including the likely prevalence of FASD. They make several recommendations regarding how best to utilise this provision, including making reports available at the earliest point of engagement with the justice system, and suggesting that perhaps judges are not the professionals best placed to make a discretionary judgement as to whether or not a report should be requested (Lambie et al., 2016).

One of the most significant developments in the area of FASD and the justice system in New Zealand is the seminal case of *Pora v Queen* (2015). Teina Pora was charged with the rape and murder of Susan Burdett in 1994, and convicted (Freckelton, 2016). At the time of the alleged offending, Pora was 17 years old. His conviction was largely based on a series of incriminating statements that he made to police officers investigating the crime, as a result of being interviewed several times in the space of a few days. Having served 21 years in prison, Pora's case was appealed to the United Kingdom Privy Council in 2014, with a judgement given in early 2015. The Privy Council quashed Pora's convictions on the basis of evidence given by neuropsychologist Dr Valerie McGinn and psychiatrist Dr Craig Immelman. The combined evidence of these two professionals established that Pora suffered from FASD, and the Privy Council held that in light of this evidence, his 'confessions' could not be considered reliable. Without Pora's confessions being deemed reliable, there was very little evidence on which to uphold his conviction, and he was subsequently acquitted, and later awarded compensation (*Pora v Queen*, 2015).

The work of several key justice professionals has been instrumental in raising

awareness of FASD and its likely prevalence in New Zealand's justice system. However, there is a significant amount of work yet to be done in order to ensure that individuals with FASD who come into contact with the justice system are adequately represented at all stages of the process, fully able to understand their legal rights, and have adequate programmes and services available to them to aid in rehabilitation and reintegration. The case of *Pora v Queen* (2015) has paved the way for the lower courts of New Zealand to take FASD into account and to ensure that neurodisabilities are adequately considered. The work of Dr Nessa Lynch at Victoria University, Wellington has also been valuable in bringing awareness to the issue of neurodisabilities and justice through the publication of a report detailing how vulnerability intersects with youth justice in New Zealand (Lynch, 2016).

Cultural and Race Developments

FASD occurs in every society in which alcohol is readily available and consumed heavily. However, internationally, a pattern of research into FASD has developed in which 'at-risk' populations have been targeted, resulting in potentially biased prevalence results (Ontario Federation of Indian Friendships [OFIFC], 2013). The indigenous populations of Canada and Australia and have been found to incur a higher incidence of FASD than the non-indigenous populations; however, some academic commentary suggests that this is less a result of culture or race, and more a result of structural discrimination and research bias (Pacey, 2009).

Several studies have emerged in both Canada and Australia in the last five years suggesting that the focus on prevalence studies of FASD in indigenous populations may be misguided (Hayes, D'Antoine, & Carter, 2014; OFIFC, 2013; Pacey, 2009; Tait, 2003). In 2003, a Canadian study examining the links between FASD and residential schools acknowledged that issues of alcohol

abuse 'should be understood as a problem of certain individuals and sub-populations, rather than a problem of *all* Aboriginal people' (Tait, 2003, p. xv). The study goes on to emphasise that the difficulty in targeting Aboriginal communities to study because of alcohol abuse issues means that comparison with other populations becomes 'difficult, if not impossible' (p. xx).

In 2009, Michael Pacey – with the National Collaborating Centre for Aboriginal Health in Canada – published a review of the prevalence of FASD (Pacey, 2009). Focusing on previous studies of the epidemiology of FASD, he notes that epidemiology is 'not well-equipped to provide explanations that incorporate historical precedent or unmeasurable dimensions of socioeconomic status' (Pacey, 2009, p. i). This point brings to light the possibility that at-risk populations are possibly more likely to evolve from a history of discrimination and oppression, or from within a wider context of social deprivation, than from accepted cultural norms.

In 2013, the Ontario Federation of Indian Friendships (OFIFC) reiterated the above point, stating that FASD is 'rife with misconceptions', including that it is 'a product of modern Aboriginal culture' (OFIFC, 2013, p. 3). The 2013 paper identified that children with FASD are overrepresented in state care, and that this corresponds with an overrepresentation of Aboriginal children in state care (OFIFC, 2013). However, the paper emphasises that the overrepresentation of Aboriginal children in state care is also the result of 'colonial issues of deprivation' rather than an issue of culture or race (OFIFC, 2013, p. 16).

These studies have relevance in the New Zealand context due to a similar history of colonisation and an indigenous population that has suffered decisions being made *for* them rather than *by* them (Ministerial Advisory Committee for the Department of Social Welfare, 1988). The majority of children taken into state care in New Zealand are Māori, despite Māori comprising less than 15% of the general population of New

Zealand (Office of the Children's Commissioner, 2016). Similarly, it is estimated that FASD affects upwards of 50% of the children in state care in New Zealand, reflecting a similar landscape to that found in Canada (Buxton, 2004; FASD Working Group, 2016a).

In 2009, Keriata Stuart published a thesis on Māori women drinking alcohol during pregnancy (Stuart, 2009). Stuart acknowledges that Māori society was one of the few that did not discover the process of alcohol production before colonisation, and thus had no culturally-developed methods of regulating or managing its consumption. As a result, the introduction of alcohol to Māori was 'integrally related to colonisation' (Stuart, 2009, p. 30). Stuart notes that Māori women drink less often than their European counterparts, but are more likely to drink at dangerous levels when they do. Stuart explicitly acknowledges that the 'longest established contributing factor for FASD is socio-economic status and social deprivation' and that race is not an independent risk factor (p. 41).

Stuart's (2009) thesis reflects the international sentiment discussed in the preceding paragraphs that there is perhaps a tendency to focus on the ethnicity of perceived at-risk populations, rather than determining and focusing on the root cause of overrepresentation. An example of this potential bias is demonstrated in an Australian study which found that Aboriginal women were over 10 times more likely to be given an alcohol-related diagnosis (Hayes et al., 2014). In the New Zealand context, structural discrimination and bias can be seen coming through in the justice system, where in 2007 young Māori were six times more likely to be apprehended than their non-Māori counterparts (Workman, 2011).

This section highlights the importance of establishing the root cause for an overrepresentation of FASD in a particular population, rather than hastily drawing conclusions based on race or culture. However, while the Māori in New Zealand are likely to be overrepresented in the FASD prevalence rates due to

the connection with social deprivation, it is crucial to establish culturally-sensitive strategies for reducing the incidence of FASD. Currently, general diagnostic services for FASD are extremely limited in New Zealand, and this will need to be addressed in order for a culturally-competent workforce of diagnosticians to be established (OFIFC, 2013).

Current Developments and Future Hopes

The story of putting FASD on the map in New Zealand has been one of determination, hope and opportunity, and it has reached an important stage of acknowledgement at this time, strengthened by the advent of the provision of robust services to help families in need. The last 20 years have seen huge awareness-raising efforts on the part of a multitude of amazing professional champions and individual caregivers and families. The point where a positive difference is made for every family affected by FASD is still a long way off – but for some, the arrival of diagnostic services and the recognition of FASD as a disability in the action plan represents great gains. The next few years will see the implementation of the action plan, and this last section briefly focuses on current developments and future prospects.

The three-year FASD action plan includes action for the prevention of FASD, as well as early identification, support and evidence gathering (FASD Working Group, 2016a). A new appointment to oversee these priorities began in March 2017. Research activities that have already started include: a prevalence study using a well-known longitudinal study that is already underway in New Zealand; a stocktake of clinical competencies for assessing, diagnosing and managing FASD; and a general stocktake and gap analysis of FASD interventions, services and supports. With only NZ\$12 million allocated directly to the plan, all the new initiatives will need to seek alternative sources of funding. At the local level, Dunedin is pooling resources (skill sharing in particular) from across agencies and

incorporating family member input, as well as benefiting from individual donations of significant amounts of money. This will lead to the launch of an NGO and private-practice-led FASD assessment and diagnostic service. In Nelson, professionals and families have been active since 2015, and the District Health Board is supportive of further development of assessment and diagnosis services. Currently, 15 diagnostic teams (all North Island) have been trained to undertake FASD assessments, and although only seven of these are actually undertaking assessments, it is hoped that this number will rise. In Hawkes Bay, where a well-established diagnostic team already exists, work is focused on providing post-assessment intervention services, and the FASD Centre Aotearoa, is also making this a priority, as there are now several hundred individuals who have been diagnosed with FASD, and they all need ongoing support. Alcohol Healthwatch, with the support of the Health Promotion Agency and members of the FASD Centre Aotearoa, will continue to offer training and awareness-raising workshops, as will countless others in different locations throughout New Zealand. The Ministry of Health – in launching its action plan – is quite clear that it should be action focused, so that in 2019 it will be possible to clearly define what has been achieved, which in turn will accurately inform where future focus and prioritisation is best placed. It is also hoped that support will also be given to teachers as a consequence of the launch of the Inclusive Teaching website (<http://inclusive.tki.org.nz/>). In order for children with an FASD to be fully included in education, teachers need to be trained and given the space to increase their knowledge and skills. The focus for professionals across all sectors will be to consolidate a shared understanding of FASD, and to work cooperatively using existing strengths. By working with families, taking a case-coordinated approach and adopting a key-worker model (Bagley, 2013), more tailored-made interventions can be provided.

Finally, when thinking about the future of FASD in New Zealand, efforts need to be

focused on a child-centred approach which draws on the rights-oriented frameworks of conventions like the United Nations Convention on the Rights of the Child and the United Nations Convention on the Rights of Persons with Disabilities (Convention on the Rights of the Child, 1989; Convention on the Rights of Persons with Disabilities, 2008). *No child with an FASD chose to be born with permanent brain damage and lifelong impairments*. It is totally unacceptable therefore to blame or stigmatise these individuals when their disability impacts upon their ability to relate to others and fully participate in all aspects of New Zealand society. FASD has been firmly put on the map in New Zealand, but the children need to be put at the centre of how all the facets of the impacts of FASD are addressed. Help needs to be provided to individuals in the creation of specialist FASD prevention, diagnostic and intervention services, and children and young people with this disability need to be accommodated within all sectors, including education, medical, justice and welfare. A well-trained professional workforce who 'get' FASD is needed, whereas currently so few professionals are well versed in a brain-based way of working (Malbin, 2011). And the intergenerational impact of colonisation upon Māori whānau and how this links to the impact of FASD within Māori communities needs to be acknowledged. The pioneers of FASD have come a long way, but there is still a long way to go.

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