Towards
Multidisciplinary Diagnostic Services
for
Fetal Alcohol Spectrum
Disorder

2010

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Contents

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Executive Summary

The problem

If a woman consumes alcohol during pregnancy it can cause a wide range of negative outcomes for the fetus.[1] The resulting neurodevelopmental disabilities emerge throughout childhood and compromise adult function. When exposed to alcohol at critical times of fetal development, individuals with fetal alcohol syndrome (FAS) are more easily detectable because they exhibit growth retardation and the characteristic facial dysmorphology. However, when the sensitive and rapidly developing brain is exposed at *any* time during gestation, the neurodevelopmental damage can be less evident but equally limiting to the child's cognitive development and learning potential.

Both animal and human studies have shown that alcohol exposure during gestation is not limited to fetal alcohol syndrome but can result in a continuum of subtle through to severe disorders. Since 2004 the term fetal alcohol spectrum disorder (FASD) has been used to cover this variability of identifiable outcomes.

The neurodevelopmental disability of FASD spans the whole life course and places an avoidable burden on the individual affected, their family and society. The international prevalence of FASD has been estimated at 1% of the population, with more recent epidemiological studies showing this could be as high as 5% in some Western countries. New Zealand has a relatively high rate of drinking during pregnancy, but no studies have been done to ascertain the outcomes for children exposed to alcohol *in utero* and the likely prevalence in this country. As a result, New Zealand has yet to establish procedures for the comprehensive diagnosis of those affected by FASD, services specific to their needs, or protocols to protect the unborn child from disability caused by prenatal alcohol exposure.

The cost of not preventing and not responding adequately to those born affected is substantial. Diagnosis and specialist intervention, particularly in early childhood, are pivotal for preventing future children being born affected and have been shown to be a protective factor for reducing the likelihood of secondary disabilities − those disabilities the individual is not born with but that develop over time, when their needs have not been appropriately met.

[1] The words 'fetal' and 'fetus' in this document are spelt according to the original Latin, in preference to the etymologically inaccurate 'foetal' and 'foetus' (see Liggins Institute 2004).

The project

In 2008 a group of interested and experienced health professionals from the disciplines of paediatrics, psychiatry, psychology and speech–language therapy came together, with the support of Alcohol Healthwatch and a government grant, to develop FASD diagnosis in New Zealand as part of a project called Establishing Multi-disciplinary Diagnostic Services for Fetal Alcohol Spectrum Disorders in Aotearoa New Zealand: An Evaluated Process. This included becoming familiar with the international literature in the field and undertaking specialist training in the American and Canadian harmonised models of diagnosis. A series of multidisciplinary differential diagnostic assessments were included to enable these health professionals to recognise and consider the assessment process that results in a consensus FASD diagnosis, and how it could be applied in the New Zealand context.

The aim of the project was to ascertain the clinical elements required to establish a multidisciplinary approach to FASD diagnosis in New Zealand and to ensure clinicians and policy makers are better informed. This report reflects the results of the project. It takes the form of a discussion document so that the reader can gauge some of the scale and impact of the issues that are raised by the medical diagnosis of FASD as a developmental disorder. To provide the appropriate background it includes an overview of some of the emerging literature regarding the outcomes of prenatal alcohol exposure and diagnosis. It also includes discussion and analyses of the outcomes of undertaking the diagnostic processes, and the development of diagnostic knowledge and skills acquired as a result.

On this basis some conclusions and preliminary recommendations can be made. However, this document is not meant to be the definitive word on best practice in FASD diagnosis. Rather, it aims to stimulate a discussion of options and consideration of factors to help New Zealand establish a more comprehensive and robust approach to FASD identification and diagnosis, such as is occurring elsewhere in the world.

Conclusions

A multidisciplinary diagnosis of FASD is required to accurately assess the range of associated physical and neurodevelopmental deficits present in an affected individual. In addition to clinical assessment by a medical practitioner, neuropsychological testing is required for an accurate diagnosis. Because multiple domains of brain development are affected by prenatal alcohol exposure, it is necessary to measure more than general intellectual ability. Neuropsychological testing is also required to measure the level of

expressive and receptive language skills, academic achievement, memory (verbal and non-verbal), speed of information processing, executive functioning and adaptive behaviour, which tend to be more impaired than IQ.

Although this level of assessment can add to the time and cost of a diagnosis, the patient, the family and any health and social services providers involved are better informed. As a result, they are able to deliver more effective, evidence-based interventions, which can reduce the need for multiple visits for what amounts to ineffective therapy and treatment. This is particularly important early in life, so that educational interventions can be tailored to the individual's learning needs and ameliorate the risk factors that lead to secondary disabilities. Multidisciplinary diagnosis of FASD can be carried out in a stand-alone specialist clinic or incorporated into an appropriate child development outpatient clinic in a hospital.

Policy recommendations for the New Zealand context

1. Acknowledge that establishing FASD multidisciplinary diagnosis in New Zealand is urgent, justifiable and feasible.

2. Establish a training programme to enable future clinicians who are willing to work as a multidisciplinary team to do so effectively within their own organisation or region.

3. Ensure there is trained neuropsychological capacity to support effective multidisciplinary FASD diagnosis within the public health system.

4. Investigate the feasibility of establishing a specialist FASD diagnostic, training and research organisation to guide FASD diagnosis and treatment in New Zealand, and to ensure this develops and continues in a well-informed, consistent and supported manner.

5. Develop New Zealand-based FASD diagnostic guidelines based on international guidelines to enhance a standardised approach across multiple sectors.

6. Establish an education programme to ensure the workforce in community-based services know and understand FASD in order to screen, refer and respond more appropriately and cost-effectively to the needs of the affected individual and their family following diagnosis.

1 Introduction

> *[Fetal alcohol spectrum disorder] is under-diagnosed and unrecognised in official statistics and cost estimates of harm from alcohol. The task of raising a child who is avoidably disabled by alcohol consumption during pregnancy places a huge burden on families and the health and education systems. Later the burden can shift to our workplaces, courts and prisons. It is a lifelong burden for our society.* (Rt Hon Sir Geoffrey Palmer, President of Law Commission, address to the Alcohol Advisory Council Working Together Conference, 2009)

What is fetal alcohol spectrum disorder?

> *The impact of what happens at the very start of our lives is felt through the whole of our lives and into the next generation.* (Professor Peter Gluckman, Director of the Liggins Institute, University of Auckland, 2008)

Alcohol is teratogenic, which means it can harm the development of an embryo and fetus. The maternal consumption of alcohol during pregnancy is known to increase the risk of birth defects and neurodevelopmental disorders (Sampson et al 2000). This finding has been verified in the medical literature since 1968 in France[2] and 1973[3] in the USA (Lemoine 1997; Jones and Smith 1973), although the effect has been observed and documented throughout Western history. These studies identified the 'face' of fetal alcohol syndrome (FAS), which brought the effects of alcohol use during pregnancy to the attention of the world.

Since that time, both animal and human studies have shown that alcohol exposure during gestation is not limited to FAS but can result in a continuum from subtle through to severe disorders. Since 2004 the term *fetal alcohol spectrum disorder* (FASD) has been used to cover this variability in identifiable outcomes. As a result, FASD is usually defined in general terms; for example:

[2] Based on observations spanning more than a decade, a paper by paediatrician Dr Paul Lemoine from Nantes, France, describing 127 cases of the pattern of abnormality, was published in the 25 March 1968 issue of *L'Ouest Medical*, with an abstract in the *French Archives of Paediatrics* (no. 7, 1968). A 1957 French doctoral thesis by Dr Jacqueline Rouquette that described the effects had previously been ignored.

[3] Dysmorphologists Dr Kenneth Jones and Dr David Smith from Seattle, Washington, identified and named fetal alcohol syndrome in their publication on eight cases.

> *Fetal Alcohol Spectrum Disorder (FASD) is an umbrella term used to describe a range of effects that can occur in an individual whose mother drank alcohol during pregnancy. These effects may include physical, mental, behavioural, and/or learning disabilities with possible lifelong implications. The term FASD is not intended for use as a clinical diagnosis.* (CDC 2004)

FASD includes the following diagnostic categories developed by the US Institute of Medicine:

- fetal alcohol syndrome (FAS)
- partial fetal alcohol syndrome (PFAS)
- alcohol-related neurodevelopmental disorders (ARND)
- alcohol-related birth defects (ARBD) (Stratton et al 1996).

The term 'fetal alcohol spectrum disorder' replaces the previous descriptive term 'fetal alcohol effects' (FAE), which can still be found in earlier literature.

There appears to be a dose–response relationship between exposure to alcohol and the development of FASD, but no definite threshold has been found (Chudley et al 2005; Sampson et al 2000). Although debate may continue regarding the existence or otherwise of a universal threshold effect, there is a scientific consensus that measurable harm can occur from exposure to variable levels of alcohol concentrations throughout pregnancy, and that this is not confined to women who are affected by alcoholism.

How does alcohol affect the fetus?

Maternal consumption of alcohol during pregnancy can have a range of adverse effects on embryonic and fetal development, but it is the permanent damage to the brain and central nervous system caused by alcohol that has the most profound lifelong effects for the affected individual and their family. It is also the most hidden and under-recognised outcome of alcohol use during pregnancy (O'Malley 2007).

Prenatal alcohol exposure can cause structural brain damage or disruption of neurotransmitter development that results in a variety of cognitive, behavioural and neurological impairments. Studies using magnetic resonance imaging (MRI) provide insight into the extent and nature of this alcohol-induced brain damage. Structural

damage observed in this way has been found across the full spectrum of FASD and corresponds with a linear increase in dysfunction (Astley et al 2009).

As well as identifying general neural disorganisation, neuro-imaging techniques have detected specific structural abnormalities of the corpus callosum, cerebellum, caudate and hippocampus (Norman et al 2009). A recent neuro-imaging study using diffusion tensor imaging (an advanced MRI technique) to examine micro-structural differences of white and deep grey matter in children diagnosed with FASD revealed significant differences of diffusion parameters in several areas of the brain, reduced white and grey matter volumes, as well as reduced total brain volume in this group (Lebel et al 2008). These structural brain differences are permanent, affecting the individual for life.

FASD across the life span

> *Fetal alcohol syndrome is not just a childhood disorder; there is a progression of the disorder into adulthood, in which maladaptive behaviours present the greatest challenge to management.* (Streissguth et al 1991)

The damage that occurs to the fetus from alcohol exposure results in neurodevelopmental disability, which emerges throughout childhood and compromises adult function. When exposed to alcohol at a critical time of development, individuals with FASD are more easily detectable through growth retardation and the characteristic facial dysmorphology of short palpebral fissures (eye openings), flattened philtrum (the ridges running from the base of the nose down to the upper lip) and thin vermillion (of the upper lip). However, when the sensitive and rapidly developing brain is exposed at other times during pregnancy, the damage can be less evident but equally limiting to the child's cognitive development and learning potential.

We will be looking at the diagnosis of FASD in detail later. This section gives a brief introduction to some of the ongoing effects of prenatal alcohol exposure, along with some of the challenges for diagnosis and support.

Most research and practice related to FASD have been guided by a child development rather than a life-span development perspective. As a result, issues related to adolescence and adulthood have not been extensively explored, with a few notable exceptions (eg, Streissguth et al 1991; Copeland and Rutman 1996). Yet FASD encompasses a range of lifelong disabling conditions. A diagnosis, when it does occur, is usually made on individuals between the ages of 4 and 14 years, when the behavioural

and learning disorders become more apparent. However, many affected individuals may slip through the system undiagnosed, largely due to a lack of information about their disabilities and insufficient assessment. Unlike the facial features, which tend to become more normal as the affected child grows to adulthood, the associated cognitive and behavioural deficits persist, creating longstanding problems in many areas of life.

Chudley et al (2007) have identified several challenges for clinicians when considering an FASD-related diagnosis in an adult, including:

- the need to educate primary care physicians about the recognition and possibility of FASD in an adult so that they can be referred for diagnostic evaluation
- the availability of reliable prenatal alcohol exposure history and informative birth records
- raising awareness of secondary disabilities in individuals who have previously been diagnosed as children, so that they can receive the help and intervention needed.

The term 'secondary disabilities' was introduced by Streissguth et al (1996) in a longitudinal study on children and adults with FASD. Secondary disabilities are the disabilities the individual was not born with and that could be ameliorated through better understanding and appropriate interventions. Secondary disabilities are hypothesised to be the result of an interaction of behavioural and mental health problems with an adverse environment.

Secondary disabilities that arise as a result of FASD, or as a consequence of not receiving early intervention, include:

- an increased likelihood of psychiatric problems (94% of individuals with FASD may have at least one co-morbid diagnosis in adulthood: 54% are diagnosed with depression, 43% make suicide threats, 33% have panic attacks, 29% are diagnosed with psychosis, 23% make suicide attempts and 40% are diagnosed with ADHD[4]) (Connor et al 2009)
- defensive behaviour, which develops as a result of chronic frustration, trauma and/or failure

[4] Attention deficit hyperactivity disorder.

- becoming isolated and lonely
- reduced self-esteem
- being easily manipulated
- increased school drop-out rates
- inappropriate sexual activity
- unemployment and poverty
- drug and alcohol use
- an inability to achieve/maintain independence
- criminal activity and imprisonment (approximately 60% of individuals with FASD get into trouble with the law − see 'FASD and criminal justice', below).

As adults, vulnerability to mental health problems, conflicts with the law, drug and alcohol abuse, and problems obtaining and maintaining employment have been found to be significant (Nilsson 2008; Spohr 2006; Streissguth et al 1996).

The organic brain deficits caused by fetal alcohol exposure result in difficulty associating cause and effect, learning from experience, generalising to new situations, and internalising principles of behaviour. This results in inconsistent and erratic behaviour, and affects the ability of affected individuals to explain and justify their actions (Connor et al 2009).

Although there are no statistics on mortality in adolescents and adults affected by FASD, it is assumed that the mortality rate is high due to the social chaos (physical and mental abuse, poverty, unemployment, imprisonment), drug dependency, and high incidence of mental health problems these individuals face (Chudley et al 2007).

How prevalent is FASD?

> *Because of its common availability and usage, alcohol is more than just a teratogen; it is the most prominent behavioural teratogen in the world.* (Warren and Hewitt 2009)

FASD is described in the literature as the leading cause of non-genetic intellectual disability in the Western world (British Medical Association Board of Science 2007). Due to a range of factors, including a low level of screening and diagnosis, the full extent of FASD remains to be fully determined internationally. However, based on a range of

epidemiological and clinical studies, the international FASD incidence/prevalence rate set in the 1990s was 1 per 100, or 1% of live births (Sampson et al 1997). Since then, further epidemiological studies suggest this figure may be an underestimation (May et al 2009).

Studies estimating the prevalence of FASD in mainstream populations present a challenge to researchers. Three major approaches have been used in the past: surveillance and record review systems, clinic-based studies, and active case ascertainment. Of these, active case ascertainment approaches that provide clinical outreach, recruitment and diagnostic services in specific populations produce the highest estimates of prevalence (May et al 2009).

Selected results from a number of in-school studies in South Africa, Italy, Croatia and the US show that FAS and other FASDs are relatively more prevalent in school populations − and by implication the general population − than previously estimated. The studies' authors estimate that the current prevalence of FASD in populations of younger school children may be as high as 2 to 5% in some Western countries (May et al 2009; Petkovic and Barisic 2009).

Risk factors for FASD

Since the earliest studies there have been misconceptions that FASD is associated with ethno-cultural background (Chudley et al 2005). However, the most important risk factors for FASD are high alcohol consumption, the timing of the exposure during fetal development, and the pattern and frequency of use of alcohol (Chudley 2005).

Risk factors associated with high levels of prenatal alcohol exposure can include higher maternal age, low socioeconomic status and education, other substance use, paternal drinking at the time of pregnancy, reduced access to care, and poor nutrition. Women who receive little or no prenatal care, who are unemployed, who are socially transient, who have lost children to foster care because of neglect, or who have experienced abuse or abandonment are more likely to have high alcohol use patterns that could affect a pregnancy (Bertrand et al 2004).

It should not be concluded from this that FASD is solely related to parental alcoholism. For example, a master's thesis that qualitatively investigated the experiences of eight New Zealand women who had given birth to children affected by prenatal alcohol exposure found that only two of the eight women were considered to be 'alcoholic'

during their pregnancy, the others describing themselves as 'social drinkers' (Salmon 2007).

Protective factors for FASD as a disability

> *There is a pressing need for identification of FASD so that cross agency planning and intervention processes can be implemented for children and adults with FASD.* (Kim Crawford, Principal, Karratha Education Support Centre, West Australia, 2008)

Protective factors that emerged from a study of secondary disabilities (Streissguth et al 1996) were:

- living in a stable home
- being diagnosed before the age of 6 years
- never having experienced violence
- receiving developmental disability services
- being diagnosed with fetal alcohol syndrome rather than fetal alcohol effects.[5]

A further study of adverse life outcomes and protective factors indicated that the odds of escaping adverse life outcomes are increased two- to four-fold by being reared in a stable, nurturing environment and receiving a diagnosis at an early age (Streissguth et al 2004). The lack of early identification is a contributing factor for the likelihood of secondary disabilities and perpetuates the invisibility of the disorder in the community.

Bertrand et al (2009) point out that a common theme reported by families raising children with FASD is that clinicians and health professionals have been reluctant to diagnose their children because there are no known effective treatments. However, the results of a recent evaluation of several different interventions in diverse locations dispels this concern. The evaluation demonstrated that interventions, within a general framework, improve the lives of individuals with FASD and their families, with all participants showing improvement in the target behaviour or skills (Bertrand et al 2009).

[5] Fetal alcohol effects (FAE) is a historical term used to describe the range of developmental deficits relating to prenatal alcohol exposure that did not meet the criteria for fetal alcohol syndrome.

FASD and criminal justice

> *I was always puzzled and failed to understand that there is a good reason why, in the Pre-sentence Reports of the Probation Officers, my FAS clients seem to 'shoot themselves in the foot' … My FAS clients did not understand the vocabulary that lawyers, judges and probation officers use every day. My FAS clients were eager to please.* (David Boulding, Lawyer, excerpt from *Mistakes I Have Made with FAS Clients*)[6]

Addressing developmental disabilities such as FASD within the justice system is at a relatively early stage internationally. A groundbreaking study carried out in Canada found that 23.3% of youth remanded for forensic psychiatric inpatient assessment were identified as having fetal alcohol syndrome or related disorders (Fast et al 1999). US case law now contains over 100 reported federal and state decisions related to FASD (Kelly 2006).

The life-long neurological impairments found in people with FASD can increase their susceptibility to victimisation and involvement in the criminal justice system, which requires consideration at all stages in the legal process (Fast and Conry 2009). Dr Paul Connor, during his visit to New Zealand in 2009 to provide training, identified the following typical adolescent FASD behaviours related to committing crimes:

- easily led by more sophisticated peers
- engaging in frequent low-grade, impulsive and often nonsensical crime, such as stealing something of little or no value in situations with a high likelihood of being caught
- making guileless confessions, sometimes to crimes not committed
- waiving of rights on arrest
- showing no guilt or remorse
- a lack of appreciation of the magnitude of a crime.

The nature of the organic brain deficits results in difficulty associating cause and effect, learning from experience, generalising to new situations, and internalising principles of behaviour. This results in inconsistent and erratic behaviour and affects an individual's ability to explain and justify their actions and to participate adequately in court

[6] See Boulding 2001.

proceedings. What's more, by the time adolescence is reached there may be few outward signs of disability based on appearance.

Adverse experiences, such as having a dysfunctional family background, mental health problems and substance use disorders, are compounding factors. Having experienced physical, sexual or emotional abuse also increases the risk that these individuals will become involved in crime. When the implications of an underlying brain disorder associated with prenatal alcohol (or other teratogenic exposure) are not factored into the affected person's treatment, addressing these high and complex needs to prevent reoffending is less likely to be effective.

Early recognition of the disabilities associated with FASD may help reduce the over-representation of this group in the criminal justice system. A comprehensive medical-legal report, prepared by professionals experienced in FASD, can help judges and lawyers to understand the complex interactions among brain damage, genetics and the environment. Corrections workers and probation officers need to comprehend the significance of FASD and how it affects the offender's ability to understand and follow rules and probation orders. Caregivers and parents also need to be involved whenever possible (Fast and Conry 2009).

The financial burden of FASD

The cost of not preventing alcohol-exposed pregnancies − and not reducing the risk of subsequent adverse outcomes for the affected population − has been shown to be enormous. Econometric studies have been carried out in Canada and the USA. One US study estimated the lifetime health care costs for one individual with FAS at US $1.4 million (Lupton et al 2004). In Canada, using an estimated lifetime care cost of $1 million per person, FAS alone has been calculated to cost Canadian taxpayers an extra $4 billion every year across all systems (Clarren 2007). This figure is arrived at by using the annual Canadian birth rate and an FAS prevalence rate of 1 per 1000 live births (the prevalence of FAS is much lower than that of FASD).

The most recent econometric measure of FASD costs also comes from Canada (Stade et al 2009). Applying Canadian figures as a proxy for New Zealand, the extra annual cost per person affected from birth to age 53 years is estimated to be NZ$32,000 per annum. The severity of the individual's condition, their age and the relationship of the individual to the caregiver (biological, adoptive, foster) were found to be significant determinants of costs. Studies are now being undertaken to evaluate specific interventions, which, if

proven successful, could help to offset some of this cost burden. If New Zealand were to accept the international rate of FASD as 1% of live births, as the literature suggests, we could expect more than 600 babies to be born affected each year based on our current birth rate, with a collective lifetime cost of over $1 billion per annum.

By way of comparison, a comprehensive multidisciplinary diagnostic assessment of an individual, which studies suggest could offset some of this burden, was estimated to cost around $3,000 (Canadian) (Clarren 2007). The evaluation by Bertrand et al (2009) indicated that intervention following diagnosis is more cost effective than non-specific intervention.

2 The Situation in New Zealand

In part 2 we look at the situation in New Zealand, focusing on the issues that prompted the current project. We begin by looking at alcohol use during pregnancy − which is relatively high. We then discuss the level of knowledge about FASD among health professionals and the kinds of advice they are giving to New Zealand women, and conclude with an overview of the current practice of FASD diagnosis here.

Alcohol use during pregnancy in New Zealand

The effects of alcohol use during pregnancy have been mentioned in New Zealand public health literature for more than two decades. A significant concern to emerge over the last decade is the increased quantity and frequency of social drinking by women of childbearing age (Habgood et al 2001). Women's consumption of alcohol has been increasing over time across all age groups, but particularly among young women (Law Commission 2009).

Several independent studies over the last 15 years have indicated that the level of drinking before and during pregnancy by New Zealand women appears to be relatively high in relation to some other Western countries (Counsel et al 1994; Mathew et al 2001; Mcleod et al 2002; Ho and Jacquemard 2009; Parackal et al 2006; Ministry of Health 2007; Watson and McDonald 1999). The studies indicate that approximately 80% of pregnant women surveyed were drinking around the time of conception, and that between 25% and 36% continued to drink after their pregnancy was confirmed. One national survey of midwives indicated that 80% of teenage pregnancies are alcohol exposed (Mathew et al 2001). In the Ho and Jacquemard (2009) study of 100 women who had just given birth at the local hospital, 80% reported they had consumed alcohol prior to becoming pregnant, and 66% of these reported they consumed four or more drinks on an occasion (defined as binge drinking) before pregnancy recognition. While most reduced or stopped once the pregnancy was known, 28% continued to consume some alcohol during pregnancy.

These New Zealand studies continue to indicate that drinking during pregnancy is higher than in many other countries. For instance, in Croatia where the most recent epidemiological study of FASD has been carried out, the rate of drinking during pregnancy was reported as 15.47% (Petkovic and Barisic 2009). This is concerning, given

that the FASD prevalence rate in the Croatian population of children assessed was found to be as high as 4%. The New Zealand drinking rate, prior to and during pregnancy, also appears to be far higher than in the USA. The highest rate of drinking by women aged 18−44 in the 30 days prior to pregnancy was recorded for the state of Wisconsin, where 68% reported any alcohol use and 23.9% reported binge drinking (Centers for Disease Control 2009). The overall US figures for drinking during pregnancy are 12.2% for any alcohol and 1.9% for binge drinking.

By contrast, the most recent national figures from the 2007/08 Alcohol Use in New Zealand data indicate that 28% of women aged 18−44 reported drinking during pregnancy. This figure is consistent with the findings of Ho and Jacquemard in their Taranaki study. However, the national survey did not include data on the quantity consumed during pregnancy. Parackal et al (2006), in their national survey, found that 20% of women had binged on at least one occasion during pregnancy, the majority (17%) before they realised they were pregnant.

The high level of alcohol consumption by New Zealand women of reproductive age, coupled with the fact that New Zealand has one of the highest levels of unplanned pregnancy in the developed world, strongly suggests that New Zealand has a significant and preventable public health problem that needs urgent attention. Despite continual indications of high maternal risk factors, no follow-up studies have yet been undertaken in New Zealand to ascertain the outcomes for children prenatally exposed to alcohol.

Health care provider knowledge and practice

Although studies have provided a relatively clear picture of drinking levels before and during pregnancy by women of reproductive age, little has been known about what advice they are receiving from health professionals. A survey of New Zealand medical practitioners conducted over 11 years ago showed that fewer than half the doctors surveyed advised pregnant women to abstain from alcohol (Leversha and Mark 1995).

A recent survey of New Zealand primary health care professionals to gauge what they know and do about alcohol and other drug use during pregnancy indicates that a very mixed picture still exists when it comes to knowledge, belief and practice (Wouldes 2009). The survey revealed that:

- 78% of the health professionals reported routinely ‘screening’, but this usually only involved asking one question: ‘Do you drink?’; only 7% were currently using any form of standardised questionnaire

- 57% reported a need for training to assess the risks from alcohol use (81% for other drug use), and the vast majority reported they would find a short standardised questionnaire useful
- 33% of participants thought that health professionals were sufficiently aware of FASD, but only 23% were able to correctly identify all four major criteria for making a diagnosis of FAS (growth, face, central nervous system dysfunction, alcohol exposure), suggesting their awareness of FASD may not equate with detailed knowledge in every case
- two-thirds of clinicians in the survey believed that a diagnosis may lead to a child and family being stigmatised, yet the health professionals surveyed overwhelmingly agreed that an early diagnosis may improve treatment plans for the affected child.

Overall, there appears to be widespread inconsistency when it comes to knowledge and practice regarding the diagnosis of FASD in New Zealand. Disturbingly, this situation is reflected in the very literature health professionals might turn to. An international review of 81 leading obstetric textbooks showed inconsistent recommendations, with some choosing not to address the subject at all. Of the publications since 1991, only 25% recommended a zero alcohol intake during pregnancy (Sarkar 2002).

A common theme among families surveyed is the doctor's reluctance to diagnose because there are no known effective interventions (Bertrand et al 2009). Yet a recent systematic review of interventions for children with FASD showed that statistically significant improvement can be achieved in the targeted behaviour or skill area for all affected children in the evaluated programmes.

What's more, in a survey by Salmon (2008), the New Zealand birth mothers interviewed reported they did not feel stigmatised by the diagnosis. On the contrary, they fought hard to find a diagnosis for their affected child and reported their general dissatisfaction with the health system:

> *The medical and health support networks were viewed as a failure with many gaps being identified, the major one appearing to be a lack of diagnostic professionals and services – in particular, medical diagnosis and neurodevelopmental, behavioural and psychological assessment. Even where a service might exist, coverage and access [are] uneven and often [do] not extend to rural or remote communities.*

Research relating to health care professionals' knowledge and practice indicates that FASD remains under-recognised and inadequately managed in New Zealand and elsewhere in the world, and that the available training is minimal at best. If this situation continues it will have multiple public health implications, including limiting the opportunity to:

- reduce exposure to alcohol during pregnancy
- recognise and respond effectively to FASD when families present with problems that may be linked to prenatal alcohol exposure.

Diagnosing FASD in New Zealand

Not surprisingly, in light of the above research, the diagnosis of FASD has tended to be *ad hoc* in New Zealand. There is no systematic approach from health or social services professionals to screening, identification or follow-up interventions for children found to be affected. As a result, the opportunity to prevent and reduce harm through an accurate FASD diagnosis is undeveloped and under-utilised. This is more likely to result in negative outcomes for affected families and a heavy avoidable burden on our systems and services.

From what can be ascertained, where diagnosis has been taking place in New Zealand health services it is likely to be carried out by a solitary physician undertaking a basic examination under time constraints. The physician may not have access to a full history of the child and family, they may or may not have received any specific FASD diagnostic training, and they may or may not be guided by the diagnostic codes that are being applied internationally (see part 3). The other issue for solitary practitioners is that they will be constrained by their particular clinical scope of practice and skill base, which, in essence, will result in a partial, a 'possible' or no diagnosis of FASD.

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 inability to capitalise on an individual's potential and to access effective support may compound and prolong an already difficult situation for affected individuals and their families.

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. A key circuit-breaker here is to increase the knowledge, skill and confidence of health professionals to screen and diagnose FASD, thereby lifting it out of obscurity (Alcohol Healthwatch 2007).

Continued advocacy and dialogue in recent years has led to a change in the momentum to address this and other FASD prevention and intervention issues. In 2008 FASD and its associated needs were considered a priority action at a national policy level. Under the auspices of the Inter-agency Committee on Drugs (a cross-ministry committee of officials who report to the Ministerial Committee on Drugs), a working party of officials was established to develop a draft action plan entitled *Developing the Child and Maternal Health Action Plan on Alcohol and Other Drugs*. This was informed by an advisory committee of informed individuals and a subsequent systematic review of the literature (Elliott et al 2008).

3 Current Methods for Diagnosing FASD

> *The diagnosis of Fetal Alcohol Spectrum Disorder (FASD) is complex and guidelines are warranted. A multidisciplinary approach is necessary*. (Chudley et al 2005)

In part 3 we look at the main methods used internationally for diagnosing FASD, and the difficulties posed by the relationship between FASD and a range of psychiatric disorders. We also begin to tease out some of the crucial features of these various approaches, which were used in the clinical intervention part of the project and form the basis for the recommendations presented at the end of this report.

What are the international guidelines?

There are three main diagnostic tools currently used internationally:

- the 4-Digit Diagnostic Code
- the Canadian Diagnostic Guidelines
- the CDC Guidelines.

We will now look at each of these in turn.

The 4-Digit Diagnostic Code

Originally created in 1997, the most widely used clinical diagnostic protocol is the *Diagnostic Guide for Assessing Fetal Alcohol Spectrum Disorders: The 4-Digit Diagnostic Code* (third edition, Astley 2004). This has been developed by the University of Washington FAS Diagnostic and Prevention Network.

The guidelines recognise that diagnosing FASD presents challenges, but that these are not insurmountable. However, they do require professionals from a range of disciplines to accurately assess and interpret the array of outcomes that define and differentiate the diagnosis. The pattern and severity of outcomes are dependent on the timing, frequency and quantity of alcohol exposure, the details of which may not be known, and these factors are confounded by other adverse prenatal and postnatal exposures and events. The 4-Digit Diagnostic Code was developed to standardise identification of FASD by providing a quantitative measurement and reporting system that would eliminate, as far as possible, inaccuracies while representing the diversity and continuum of disability associated with prenatal alcohol exposure.

The four digits rate the magnitude of expression of the four diagnostic features of FASD – growth deficiency, FAS facial phenotype, central nervous system abnormalities and prenatal alcohol exposure – on a four-point Likert scale, with 1 being an absence of the feature and 4 being a strong presence of the feature. Also recorded are the other adverse pre- and postnatal risk factors taken into account in deriving the differential diagnosis, including any other condition or issue that could account for the central nervous system abnormalities found (see Figure 1 for an example).

Figure 1: An example of the use of the 4-digit code to diagnose FAS

4-Digit Diagnostic Code										
One Example of FAS										
				3	4	4		4		
Significant	significant	Definite	4		X	X		X	4	high risk
Moderate	moderate	Probable	3	X					3	some risk
Mild	Mild	Possible	2						2	unknown
None	None	Unlikely	1						1	no risk
Growth Deficiency	**FAS Facial Features**	**CNS Damage**		Growth	Face	CNS		Alcohol		**Prenatal Alcohol**

Source: University of Washington Diagnostic and Prevention Network. URL: http://depts.washington.edu/fasdpn/htmls/4-digit-code.htm

Individuals of any age can be rated, from a code of 1, 1, 1, 1, showing no features of FASD, to 4, 4, 4, 4, showing the full fetal alcohol syndrome, with severe growth deficiency, severe expression of FAS facial features, definite central nervous system damage and a high risk of prenatal alcohol exposure. After the diagnostic work-up is complete, the combined four-digit coding can then be converted into one of 22 unique clinical diagnostic categories (labelled A through to V), providing a clinical summary for a diagnostic report.

Standards against which to rate each of the four digits are provided in the form of normal anthropometric charts for palpebral fissure length (upper lip), inner canthal distance (between the eyes), height, weight and head circumference growth charts, as well as photographic lip and philtrum guides for Caucasians and African Americans.[7] Ranking of central nervous system damage is made according to the results of

[7] Lip/philtrum guides for other ethnic groups have yet to be developed.

standardised psychometric testing and neurological evidence. Prenatal alcohol exposure risk is ranked according to the certainty and pattern of maternal alcohol use.

The Canadian diagnostic guidelines

The Canadian guidelines were published in 2005 (Chudley et al 2005) after review, analysis and integration of current approaches to diagnosis, as well as broad-based consultation among experts to reach agreement on a standard for Canada. The recommendation was for a harmonising of the Institute of Medicine diagnostic terminology (FAS, partial FAS, ARND and ARBD, Stratton et al 1996) with the approach identified in the University of Washington 4-Digit Diagnostic Code, in order to describe, assess and objectively measure alcohol exposure, growth, facial features and brain damage.

The Canadian guidelines harmonisation approach has resulted in fewer diagnostic categories than those set out in the University of Washington's four-digit guide, as follows:

1. fetal alcohol syndrome − with confirmed alcohol exposure
2. fetal alcohol syndrome − without confirmed alcohol exposure
3. partial fetal alcohol syndrome − with confirmed maternal exposure
4. alcohol-related effects – with alcohol-related birth defects, which involve congenital anomalies, malformations and/or dysplasias and confirmed maternal alcohol exposure
5. alcohol-related neurodevelopmental disorder − with confirmed maternal alcohol exposure.

While this simplifies the diagnostic categories, the range does not easily accommodate the full range of diagnostic ranking using the 4-digit Diagnostic Code system that can be applied in any one case (22 in all), thereby posing a potential challenge to clinicians as to the most accurate diagnostic category to be used in each case.

The Canadian guidelines require a comprehensive history-taking and physical and neurobehavioural assessments for the medical FASD diagnosis to be made. To increase the certainty that neurobehavioural test results are consistent with brain damage caused by alcohol, they recommend a stringent cut-off of two standard deviations below the age mean for IQ score (ie, a significant impairment) across three domains of brain performance. Recommended central nervous system domains that should be assessed using standardised measurement tools are:

- cognition (IQ)
- communication (receptive and expressive)
- academic achievement
- memory
- executive functioning and abstract reasoning
- attention deficit/hyperactivity
- adaptive behavior
- a review of the history of hard and soft neurological signs and brain structure (using imaging, if available, or head circumference).

Adopting a higher rating (3 or 4 on the third digit of the 4-Digit Code) as evidence of substantial deficiencies across multiple areas of brain performance addresses the concern of over-diagnosis of FAS and ARND that may occur using the Institute of Medicine criteria.

Overall, the Canadian guidelines emphasise the importance of early diagnosis to allow access to interventions and resources that may mitigate the development of secondary disabilities, and to provide intervention that may prevent the birth of alcohol-affected children in the future. The Canadian guidelines also set out criteria for screening and referral.

The CDC guidelines

The comprehensive *Fetal Alcohol Syndrome: Guidelines for referral and diagnosis* (Bertrand et al 2004) was developed for the Centers for Disease Control (CDC) National Center on Birth Defects and Developmental Disabilities. The CDC were congressionally mandated to develop diagnostic guidelines for FAS in 2002, and this work was supported through the 2002 appropriations funding legislation mandated by the US Congress. It was acknowledged that FAS represents the tip of the iceberg and that there is a continuum of outcomes associated with prenatal alcohol exposure. The guidelines cover:

- a referral and diagnostic framework
- FAS diagnostic criteria – structural, neurological and functional
- a differential diagnosis guide
- an age-specific intervention services guide

- a maternal brief and early intervention/screening guide.

Key issues and recommendations that emerged during the development of the guidelines included:

- more information is needed on the neurodevelopmental effects of prenatal alcohol exposure
- screening for possible FAS should become routine
- interdisciplinary communication is needed to improve documentation
- eligibility for services needs to meet the needs of affected children/adults
- professional and public awareness needs to increase.

The CDC guidelines acknowledge there are gaps in the evidence to inform the provision of services.[8] Prevention, according to the guidelines, requires the involvement and co-operation of federal, state and local agencies, clinicians and researchers, educational and social service professionals and families, all working together. This was the kind of collaboration that was used to develop the guidelines in the USA.[9]

Multidisciplinary diagnosis

> *Because the observable physical manifestations of FAS (ie, facial abnormalities and growth deficits) generally disappear during puberty, FASD conditions are difficult to detect in adolescents and adults, even for physicians trained in dysmorphology. Consequently, it is generally accepted in the field that accurate diagnosis of individuals over the age of 12 must involve multidisciplinary analysis from multiple perspectives, with emphasis necessarily on the neurological and cognitive-behavioral symptoms of FASD in lieu of observable facial dysmorphology and growth deficits.* (FASD Experts Assessment Group)[10]

The various diagnostic guidelines discussed above all advocate a multidisciplinary diagnostic approach from a range of disciplines. Children and adult patients with FASD have a complex pattern of disabilities, and the assessments therefore need to be comprehensive and to involve the collaboration of a number of health professionals.

[8] Further study by Bertrand et al (2009) has worked to overcome this lack of information, as mentioned earlier.
[9] http://www.cdc.gov/ncbddd/fasd/index.html
[10] http://www.fasdexperts.com)

Because FASD is a medical rather than a mental health diagnosis, a registered medical practitioner is required to make the diagnosis first and foremost. However, given the neurobehavioural nature of the disability, the role of a clinical psychologist trained in neuropsychological testing is critical for an accurate diagnosis. Their role is to:

- identify the current strengths and weaknesses of the client
- determine consistency of the symptoms with research on FASD
- determine the timeline of cognitive deficits
- identify competing aetiologies
- determine evidence of cognitive difficulties alongside any competing aetiologies (the incidence of co-morbidity/concurrent conditions may be high in FASD; eg, ADHD, head trauma, substance abuse)
- provide an opinion on whether the criteria for FASD have been met, based on the CDC guidelines
- refer the information on to a medical specialist for a final medical diagnosis

(Connor et al 2009).

Because prenatal alcohol exposure affects so many regions of the brain, affected individuals exhibit a wide variety of disturbances over a range of cognitive domains. The Canadian guidelines recommend neuropsychological assessment of the following cognitive domains:

- general intellectual ability
- expressive and receptive language skills
- academic achievement
- memory (verbal and non-verbal)
- speed of information processing
- executive functioning, including attention (selective, divided and sustained), working memory, planning and organising abilities, initiating skills, and maintenance of cognitive set
- adaptive behaviour, social skills and social communication.

A domain is considered ‘impaired’ when, on a standardised measure, scores are two or more standard deviations below the mean, or there is at least one standard deviation between sub-domains. For areas where standardised measurements are not available, a

clinical judgement of 'severely abnormal' is made, taking into consideration that important variables (including age, mental health factors, socioeconomic factors and disrupted family/home environment) may affect development but do not indicate brain damage (Chudley et al 2005).

An individual with a below-average IQ often has particular problems with:

- arithmetic and calculation – both skills are important for independent living, such as managing finances (80% need help managing money)
- memory – low IQ individuals forget work obligations, leading to termination of employment
- decreased concept formation and poor problem-solving skills
- difficulty understanding or learning complicated activities
- trouble focusing and maintaining attention.

This leads to poor functioning and behavior in education, employment and social situations.

Although some research is emerging that shows fairly consistent patterns of impaired functioning across the cognitive domains assessed, alcohol is a non-specific teratogen and there is no neurocognitive profile specific to FASD. Demonstration of significant impairment − a severity score of 3 or 4 in the 4-Digit Diagnostic Code (see Figure 1), across at least three domains of cognitive functioning − is necessary for diagnosis. Individuals who demonstrate mild impairment (a severity score of 2) across three domains of cognitive function may or may not reflect brain dysfunction from prenatal alcohol exposure (Chudley et al 2005).

Speech−language assessment as part of a multidisciplinary team approach to diagnosis is able to test a range of communication impairments that may not be picked up by other standardised measures. Data from a study by Bodaly and Woodworth (2009) indicated that of the 186 individuals assessed as having FASD, 113 had a significant communication impairment, 43 had verbal IQ scores of less than 70 (normal is 100), and 15 had a performance IQ that was significantly higher than their verbal IQ. Of the 130 who were tested for verbal reasoning, 78 were found to be significantly impaired.

The Canadian guidelines suggest that the core team may vary according to the specific context. Primarily the core team should consist of a case management co-ordinator (with a nursing or social work background), physician, psychologist, occupational

therapist and speech–language therapist. To maximise the potential of the affected individual, the team needs to work in partnership with relevant community services and appropriate individuals who work with the child and/or family.

The relationship between FASD and other mental health disorders

There is a substantial overlap between FASD and psychiatric disorder across the life span (Streissguth et al 1996; O'Connor et al 2002; O'Malley 2007). Streissguth et al (1996) found that 94% of the 415 FASD subjects in their study had received a mental health disorder diagnosis, either as children or as adults, including attention deficit problems, depression, suicide threats and attempts, panic attacks and psychosis. In a sample of 23 children, O'Connor et al (2002) found that approximately 87% met criteria for a psychiatric disorder, with the majority (61%) being assigned a mood disorder diagnosis.

Prenatal alcohol exposure appears to be a good predictor of mental health disorder in adolescence and adulthood. For instance, a study undertaken over a decade ago examined the relative importance of alcohol exposure and a family history of alcoholism as a predictor of adolescent alcohol problems (Baer et al 1998). Using data from the University of Washington longitudinal prospective study population of over 400 affected individuals (Streissguth et al 1996), Baer and colleagues were able to reveal that prenatal alcohol exposure retained a significant predictive effect for alcohol problems in adolescence, even after adjustment for family history and other prenatal and environmental covariates.

Ten years later, a study of 1252 adolescents was undertaken to examine the relationship between alcohol exposure in pregnancy and conduct disorder symptoms in adolescence (Disney et al 2008). It was found that prenatal exposure to alcohol was associated with higher levels of conduct-disorder symptoms in offspring, even after statistically controlling for the effects of confounding variables.

It is worth noting that, in relation to diagnosing the psychiatric dimensions of FASD, O'Malley (2007, p 8) makes the point that 'the presence or absence of facial dysmorphology or growth features did not seem to be clinically correlated to the psychiatric presentation of this neurodevelopmental disorder'.

Neither of the current mental health diagnostic manuals, DSM–IV or ICD 10, acknowledges the neurodevelopmental or neuropsychiatric disorders resulting from

prenatal alcohol exposure. However, O'Malley (2007) notes that there is a general category called 'Mental Disorders due to a General Medical Condition', which can be used to describe FASD and its co-morbid psychiatric presentation, and that it is also possible to code the clinical symptoms under an 'Infancy/Young Childhood, Zero to Three' (1994) classification such as 'Regulatory Disorders of Sensory Processing'.

More attention would be paid to presenting co-morbidity if consideration were given to prenatal alcohol exposure as a feature of dual diagnosis. A number of authors have even pointed out that in the adolescent and adult years, rather than being assessed for co-morbid 'dual diagnosis', people with FASD can present features of a 'triple diagnosis' – co-morbid neuropsychiatric disorder, co-morbid alcohol or substance use disorder and co-morbid neurodevelopmental disorder (O'Malley 2007).

Building diagnostic capacity

Over the past decade the USA has set up numerous state-funded FASD diagnostic centres. For example, six have been established in New Jersey (Brimacombe et al 2005). All the New Jersey regional diagnostic centres use an adapted form of the 4-Digit Diagnostic Code and the FAS Facial Photographic Screening Tool, and staff receive training in their use. After the diagnostic work-up is completed, the patients are referred to appropriate services that have received training and workshops to develop regional resources and skills.

The centres have developed a comprehensive patient referral database, which enables data to be collected to improve understanding of referral patterns and information on cases of FASD. This in turn helps to improve understanding of the underlying epidemiology of cases and to identify risk factors and secondary patterns relating to the cases (Brimacombe et al 2005).

Work undertaken by the FASD stakeholders for the Ontario Diagnostic Working Group resulted in a report in 2006 that focused on issues relating to diagnosis (Guilfoyle 2006). The goal of the project was to identify the strengths and challenges faced by diagnostic teams and to create a foundation for diagnostic capacity. All seven of the established FASD diagnostic services in Ontario participated in the project. The working group examined a number of aspects of these services in the course of the project, addressing the following questions:

- How do the services operate?

- Who are their funders?
- Who make up their diagnostic teams?
- Who are their clients?
- What is their outreach?
- What is their training?
- What is their research?
- What are their assessment statistics?
- What lessons have been learned?

Three basic models emerged:

- hospital-based clinics that also provide community outreach
- community-based specialist clinics
- networking among team members using an existing service, and submitting test results to the physician for diagnosis.

The results of this project indicated that each model has it strengths and limitations. The ability of the different teams to learn from each other and to consider new ways of overcoming challenges was one of the positive outcomes from the project. What was learned from the process was that FASD diagnosis requires a highly organised and inter-disciplinary approach, supported by team meetings to discuss each client's diagnosis and optimal outcomes for families. Challenges identified included insufficient funding and a lack of trained clinicians. It was felt that the teams needed to use creative approaches to overcome these challenges, such as on-line and peer mentoring, special grants, and networking among teams to problem-solve and share resources, where possible.

4 Towards a Framework for FASD Diagnosis in New Zealand

In part 4 we first look briefly at the project that formed the basis for this current document (a fuller description is provided in Appendix 1, and Bennett and Bijoux [2009] provide an evaluation). The project involved getting together a multidisciplinary team, training them in best-practice techniques for FASD diagnosis, and then applying these techniques to a group of subjects in different clinical settings. The bulk of part 4 shows how this approach worked in practice, and includes three representative case assessments to illustrate the scope and context of multidisciplinary FASD diagnosis.

The project

In May 2008 the project entitled Establishing Multi-disciplinary Diagnostic Services for Fetal Alcohol Spectrum Disorders in Aotearoa New Zealand: An Evaluated Process received funding approval.[11] The overall aim of this project was to ascertain the clinical elements required for establishing a multidisciplinary approach to FASD diagnosis in New Zealand, and to ensure clinicians and policy makers are better informed to move the issue forward.

The major aims of the project were to:

- train clinicians (and other stakeholders, if appropriate) to form part of a multidisciplinary team to develop FASD assessment skills for application in the Youth Court sector and the general population
- establish a best-practice approach to FASD diagnosis in New Zealand
- apply this approach, in the first instance, to the Youth Court-directed psychiatric assessment process (section 333, Children, Young Persons and Their Families Act 1989[12]).

The project, rather than being prescriptive, was developmental in nature. The scope of the training and assessments for the project was not intended to be limited to those in the youth justice sector, but to allow other clinical assessments to be included as the

[11] For details of the application process, see Appendix 1.

[12] Section 333 of the CYPFA provides for a Youth Court to obtain a medical, psychiatric or psychological report to assist the Court to determine what sort of order or condition should be imposed on a young person, or indeed whether the young person is legally insane, or fit to stand trial.

opportunities arose. However, section 333 of the Children, Young Persons and Their Families Act, which covers court referral for the psychiatric assessment of youth offenders (aged 14−16), provides a practical way to readily assess cases where there is a higher-than-normal chance of an individual being affected by FASD. This emphasis ensured the minimal objectives for training and application could be met within the short timeframe allowed.

The following stages were completed as part of the project.

- External evaluators were identified to conduct key stakeholder interviews and facilitate the development of a programme logic model (see Appendix 2).
- Diagnostic training was arranged for clinicians in New Zealand, the US and Canada.
- Eleven FASD assessments were completed during the course of the project, spanning childhood, adolescence and adulthood.

The team that assembled for the project consisted of two psychiatrists, a paediatrician, three neuropsychologists, a speech−language therapist and a team co-ordinator, who were involved at varying times over the year of the project. Intensive training was provided at the Asante Centre in Canada, and Dr Paul Connor, visiting Auckland from the US, provided assessment guidance to the neuropsychologists. (The training and capacity development aspects of the project are covered more fully in Appendix 1.)

Putting the multidisciplinary approach into practice: The clinical findings

To help understand the scope and potential of the FASD diagnostic process in New Zealand, 11 cases were included for FASD assessment and discussion as part of this project. The ability to carry out a full multidisciplinary assessment of each case was limited due to circumstances and the availability of appropriate clinicians.

Fulfilling the requirements of the project, four youth on charges before the Youth Court, aged 15 or 16 years, were assessed for FASD under section 333 of the Children, Young Persons and Their Families Act 1989. Their diagnosis was conducted by a child psychiatrist working together with a neuropsychologist.

In addition, independent FASD assessments were carried out for three children aged 4, 8 and 13 years, two internationally adopted adolescents aged 16 years, and two adults. The three child assessments selected for inclusion were carried out consecutively over 3 days at the Child and Adolescent Centre, Taranaki Base Hospital, using a replication of

the Asante Centre / Canadian model of diagnosis, which included paediatric, neuropsychological and (for the two younger children) speech–language therapy assessments.

The two adopted adolescents aged 16 years were included for assessment; both received psychiatric and neuropsychological testing and assessments. However, no speech–language assessments were available for these assessments. The two adults, aged 22 years and 32 years, received neuropsychological assessments only, as no medical assessment was available at that time.

Of the eleven cases assessed, eight were found to have disorders consistent with a diagnosis of FASD using the University of Washington 4-Digit Diagnostic Code. However, in three of these cases, the diagnosis could not be confirmed due to either unconfirmed maternal alcohol exposure (the international adoptions) or, in the adult cases, because no medical assessment was available at the time (neuropsychological assessment only). (A brief outline of all the assessments included as part of this project is set out in a table attached in Appendix 3.)

The process of assessment required each clinician to conduct their part of the assessment process independently. The clinicians were able to come together as a multidisciplinary team in the child development outpatient setting, on the same day, to discuss their findings and formulate a consensus on differential diagnosis and treatment outcomes. This was followed immediately by a face-to-face meeting with the families to discuss the assessment results and recommendations. A final report was written after this meeting.

What follows is a selection of three of the eleven cases assessed[13] where an FASD-related assessment was able to be made consistent with the diagnostic guidelines available. These three represent the range of assessments that were able to be carried out in different settings and under different circumstances. Case assessment 3, of an adult, is an incomplete diagnosis in that it could not be confirmed by a physician at the time. However, it has been included as a useful example demonstrating the neuropsychological testing results of a young adult that appear to be consistent with prenatal alcohol exposure, and because the referral involved a birth mother, prenatal alcohol exposure could be confirmed using the diagnostic criteria.

[13] Due to the variable nature of the clinical reporting, not all cases are presented in the same format or contain the same level of detail. The descriptions used in these summaries have been abbreviated for this report and do not equate with any original clinical reports in each case.

Case Assessment 1: Child aged 4 years 8 months

Multidisciplinary FASD assessment by a paediatrician, neuropsychologist and speech–language therapist

Background

Boy accompanied by his maternal grandparents and mother, presenting with general concern with his development/speech and being less advanced than his 3-year-old sister. No history of intellectual disability in the family. The mother indicated he was hard to control in public, was loud, easily distracted, active and impetuous. He was described as: social (including following strangers), enjoys active play, but has had preschool behavior difficulties and is sometimes rough with other children. Some motor development delay, no sleep/eating concerns but wets bed at night.

Alcohol exposure

Mother was binge drinking significantly − more than weekly during the entire pregnancy.

Medical examination

History

Full term at birth. Birthweight 2650 g (just above 3rd percentile). Head circumference at birth: 33.5 cm (above 2nd percentile). Initial feeding difficulties, grommets, inguinal hernia, adenoidectomy.

Physical examination

- Weight below 3rd percentile.
- Height below 3rd percentile.
- Head circumference currently above 2nd percentile.
- Palpebral fissure length 21 mm bilaterally (below 3rd percentile). Intercantal distance 27 mm. Lip philtrum and thinness Likert scale 3. Slightly down-slanting eyes.
- Respiratory system clear.
- Cardiovascular system normal.
- Abnormalities observed: single palmar crease right hand; three café au lait spots; penoscrotal fusion. No other obvious abnormalities.

Speech–language therapy assessment

Child assessed using the Reynell Developmental Language Scales. Although only a screening tool, it was short and provided enough qualitative information to compare and correlate with the other assessments completed. The child was also assessed using the Assessment of Articulation as he presented with several pronunciation difficulties.

Converses in English and Māori. Assessed in English and encouraged to use Māori if appropriate (eg, colours, numbers, etc). Has a small mandible and some oro-motor difficulties, resulting in several pronunciation errors. Speech difficult to understand at times.

Speech–language assessment found:

- on the Comprehension Scale on the Reynell Developmental Language Scales III, score of equivalent 2:02 years age
- able to name objects, relate two named objects, but has some difficulty with clausal constituents, attributes and locative relationships
- score of 2:03 years age equivalent obtained on the Expressive Scale – able to use single words (nouns and verbs), but has difficulty with phrases
- able to identify some body parts (eg, facial features, hands, feet, etc), but not more complex ones (eg, elbow, knee)
- spontaneously uses several single words and occasional short phrases.

Finding of significant speech and language (understanding and talking) difficulty. May need to reassess in Māori to determine if there is any discrepancy between languages.

Neuropsychological assessment

Tests administered:

- Wechsler Preschool and Primary Scale of Intelligence-Revised (WPPSI-R)
- NEPSY Developmental Neuropsychological Assessment
- Adaptive Behaviour Assessment System-second edition (ABAS-II).

Observation and presentation

Child was assessed over a morning and afternoon session and was taken home for a sleep in the middle of the day because he tires easily. The child appeared happy, with no signs of normal reserve expected at this age with an unfamiliar adult. Focus was short and it was difficult to direct him to the required tasks.

Attachment to mother was secure and close and reassuring. No concussions or other significant injuries despite his overactive play.

Episodes of blankness were observed, with a fixed stare for up to half a minute. Mother reported that these are frequent and can last longer. Appeared very tired in afternoon. Mood labile. Easily overexcited but persevered with tasks. Preschool tasks suitable for children from 3 years of age were administered.

Intellectual functioning

The overall results of the WPPSI-R found functioning in the Extremely Low range intellectually for his age. Full-scale IQ was 49, with 100 being an average score – more than three standard deviations (SDs) below the mean.

Adaptive function

Preschool version completed by mother. The General Adaptive Composite Score was in the deficient range at 45, consistent with the obtained IQ. Comparative strengths in the areas of home living, self-care and social (though still two or more SDs below the mean). Areas of greater weakness were for communication, functional pre-academics, health and safety, leisure and self-direction.

Verbal abilities

Child scored below a 3-year-old level and showed no apparent understanding on the NEPSY Comprehension of Instructions task.

Performance abilities

Not able to complete tasks that did not rely on language. He could not make any simple patterns with blocks. However, he did show some evidence of learning on this task. Had significant difficulty taking meaning from pictures. Could not point to objects or identify what was happening in a book. Could not draw any simple shapes. In the area of numeracy score he was impaired for his age. Could identify some comparative terms of size, such as biggest and smallest, but did not appear to understand tallest, most or more.

Attention and memory

Child could not participate in simple attention and memory tasks. Could not repeat any simple sentences. Was unable to grasp and follow simple instructions. Could not name or colour-match colours required. No evidence of any learning on this task. Could not sustain attention without considerable external support and prompting.

Using the 4-Digit Diagnostic Code, patient ranked 3 on the third digit for central nervous system damage or dysfunction.

Diagnosis and outcome

Using the 4-Digit Diagnostic Code this child's assessment was coded 3, 3, 3, 4 – corresponding to partial fetal alcohol syndrome criteria (using the Canadian Guidelines for diagnosis) – with significant deficits across all central nervous system domains.

This child will learn and develop at a slower rate than his peers and will continue to have a significant level of disability due to neurological impairment. He will require special needs teaching at a school level. There will be significant safety risks because of his level of impulsivity and low level of understanding. It is important that he is not set up to fail in a school setting without adequate support, and he will require the ongoing support of both speech–language and occupational therapists. Caregiver burnout is a real possibility, requiring regular arrangements for respite care.

Case Assessment 2: 15-year-old male

Assessed pursuant to section 333 of the Children, Young Persons & Their Families Act by psychiatrist and neuropsychologist

Background

Young person referred by the Youth Court and charged with unlawful sexual connection (child under 12). He had been raised in a situation of domestic violence, with parental substance abuse. His gang-related father had been imprisoned. Young person himself had been the victim of physical and sexual abuse and had been in CYF[14] care for several years. No previous intervention had been provided despite a number of years of reported sexually inappropriate behaviour. His education was also not suited to his needs. A history of prenatal alcohol and drug exposure was confirmed.

Using the 4-Digit Diagnostic Code as a guide, the FASD assessments included the following.

Alcohol exposure

Mother reluctant to discuss but confirmed alcohol use during pregnancy but 'not hard out all the time'. Alcohol exposure achieved a rank of 3 (some risk), with use confirmed but level and pattern of use unknown.

Medical examination

Growth

Birthweight reported as normal (7 lbs 9 oz). Current weight between 3rd and 10th percentile and height at the 25th percentile. Obtains a diagnostic rank for growth of 2 (mild growth deficiency).

Facial features

Scored an A for palpebral fissure length (left + 1 SD, right −0.5 SDs), C for philtrum that was indistinct, and C for upper lip that was thin, yielding a 4-Digit Diagnostic Code rank for face of 2 − mild expression of FAS facial features.

Neuropsychological testing

Showed significant deficits (> 2 SDs below mean) in the domains of cognition, with an IQ score of 66, and 59 on adaptive function. Attention, executive and scholastic function were tested. Achieved a central nervous system (CNS) rank of 3 − significant dysfunction, probable evidence of CNS damage.

[14] Child, Youth and Family.

Diagnosis and outcome

Using the University of Washington 4-Digit Diagnostic Code for Fetal Alcohol Spectrum Disorders, this young person was coded 2, 2, 3, 3 – static encephalopathy (alcohol exposed). Using the Canadian guidelines, a rating of 2, 2, 3, 3 is termed alcohol-related neurodevelopmental disorder (ARND).

The assessment of this young person also found he has:

- conduct disorder (childhood onset type, severe)
- attention deficit hyperactivity disorder
- substance abuse disorder
- mild intellectual disablement.

There was no clear-cut indication that this young person was unfit to stand trial. A high and complex needs package of care and a SAFE[15] programme were advised.

[15] SAFE is a not-for-profit agency established in the early 1990s to break the cycle of sexual abuse. SAFE operates community-based professional treatment programmes in Aotearoa /New Zealand for both adult and adolescent sex offenders. See: http://www.safenz.org/index.htm

Case Assessment 3: 22-year-old adult male

Neuropsychological assessment only (see previous discussion)

Background

Born at 43 weeks' gestation, low−normal birthweight with fully dislocated hips, breech and stressed having swallowed meconium. Development showed slow attainment of usual developmental milestones and failure to achieve within the education system (hyperactivity and poor concentration).

Exhibited poor behavioural and emotional self-regulation skills throughout adolescence/adulthood; ie, impulsivity (unable to manage own financial affairs); poor judgement; mood lability (adolescent suicide attempt); maturity and living skills well below chronological age; drug (cannabis, speed, opiates, P) and alcohol abuse from age 15 years.

First criminal charges were laid when aged 13 years for use of a firearm. Subsequent criminal activity has included breaking and entering, burglary, DIC[16] and assault with intent to injure.

No history of traumatic brain Injury, concussion or neurological illness. Assessed by a paediatrician when aged 16 years, who considered client had enough criteria to qualify for a diagnosis of fetal alcohol spectrum disorder (FASD).

Alcohol exposure

A clear history (maternal report) of significant exposure to alcohol (binge drinking during first trimester) and a lesser intake of alcohol throughout rest of pregnancy.

Neuropsychological testing

- General intellectual ability: average ability range.
- Academic achievement: low average ability range.
- Expressive and receptive language skills: intact.
- Memory: verbal − average ability; non-verbal − > 3 SDs below average.
- Speed of information processing: average ability range.
- Executive functioning:
  - signs of impulsivity
  - working memory: moderate impairment
  - control of attention: severe impairment
  - planning and organising abilities: mild impairment

[16] Drunk in charge of a motor vehicle.

- Adaptive behaviour: GAC 60 (ABAS-11); ie, > 2 SDs below average.
- Psychological functioning: BSI: significantly elevated GSI score.

Neuropsychological outcome

Overall cognition was found to be within normal limits, but impairment (> 2 SDs below the mean) was found in the domains of executive control, adaptive function and visual memory. Using the Canadian guidelines for diagnosis of FASD, on the 4-Digit Diagnostic Code this client was ranked as 3 on the third digit for CNS damage or dysfunction showing probable CNS dysfunction, and 4 on the fourth digit for prenatal alcohol exposure.

5 Discussion and Recommendations

What follows in part 5 is a summary of what was learned and applied by the clinicians involved in the FASD diagnostic process, along with some preliminary recommendations. We hope the reflections that follow, together with the background data included in this report, go some way towards informing the development of a more fully integrated service for FASD diagnosis and follow-up care in the community.

Diagnostic challenges and considerations for the New Zealand context

Applying differential multidisciplinary team diagnoses for the first time was complex and time consuming, both for the health professionals conducting them and for the families involved. However, there were distinct advantages, and with some forward planning it was also possible to manage a series of individual diagnoses efficiently and without serious disruptions of time. For example, three multidisciplinary assessments in a hospital setting were arranged and carried out over three days, including a feedback meeting with the families. As one of the clinicians noted:

> *The Multidisciplinary Feedback session was useful, as any questions the families had could be answered immediately and with input from all professionals.*

Another advantage of immediate feedback and discussion with the family is the opportunity it presents to discuss the prenatal exposure to alcohol with the birth family, and to seek assistance that may help to prevent harm to future children:

> *One of the mothers we saw is a heavy alcoholic. She is pregnant. I hope that the diagnostic process she attended for her child will motivate her to stop drinking at least for the latter part of this pregnancy.*

The experience of assessing three patients over three consecutive days also enabled the resident paediatrician and the speech–language therapist to attend to other patients during the course of the three days while the more time-consuming neuropsychological testing was being done. Report writing was additional, completed afterwards and delivered to the families subsequently. This process compared well with the assessment observed at the Asante Centre in Canada, where one child was assessed over two days and the preliminary report was provided to the family after their feedback session.

Although a stand-alone specialist clinic based on the Asante Centre model would be ideal, and fully applicable to New Zealand conditions, the New Plymouth experience showed that an FASD clinic can be integrated within a hospital-based child development

service without disrupting other patients or staff, and that this can be achieved successfully with the inclusion of visiting clinicians.

A complete multidisciplinary differential diagnosis has the added advantage of potentially reducing the number of duplicated assessments that are currently taking place, as the following insightful reflection from one of the physicians involved illustrates.

> *I had an interesting situation a few years ago. I assessed a child (with psychologist input) and concluded that she didn't have FASD. Mum disagreed and I then referred for second opinion. That paediatrician then did think she had ARND. Looking back now I think we were both wrong. Neither of us had neuropsychology or speech language therapist input in the case and both our opinions were based on insufficient information. I would like to think that in-depth assessments could be cost and time saving in the long run. Otherwise these children are seen over and over for semi-assessments.*

The multidisciplinary assessment posed no particular challenges once the team were trained and available. It was useful for the speech–language therapist to compare results with the neuropsychologist's tests, because the receptive and expressive language findings often correlated with and supported the test findings, particularly for more complex levels such as executive functioning.

With the exception of the two adult cases included in the project, a consensus diagnosis involving two or more clinicians was able to be reached using the University of Washington 4-Digit Diagnostic Code. Assessing a 4-year-old who was developmentally delayed and functioning at a 2-year-old level or below in most areas provided some challenges, but was achievable. The diagnostic procedures could be followed, and the diagnosis could be as validly made in a young child as in an older child or teenager.

After applying the available diagnostic guidelines and procedures of assessment, not all cases resulted in an FASD diagnosis, despite confirmed alcohol exposure and the individuals presenting with significant problems. This showed that the process is robust enough to exclude FASD when the benchmark of diagnosis is not reached and to differentially diagnose another disorder: in one case this was a previously undiagnosed conduct disorder, and in another case the neuropsychological assessment was able to rule out any obvious mental disorder.

Implications for diagnostic practice

Some concerns, issues and solutions identified and considered over the year-long project are explored below.

The risk of over-diagnosis or incorrect diagnosis

The diagnosis reached using the University of Washington 4-Digit Diagnostic Code harmonised with the Canadian model of diagnosis includes detailed data independently collected by the medical specialist, neuropsychologist and speech−language therapist in order to form a differential diagnosis. When the team comes together to analysis their independent findings, data is compared with the external standards of FASD that have been scientifically established and validated overseas. The process is very stringent, based on the presumption that the patient is not judged to be affected unless there is a high benchmark of proof that can be quantified. There is little room for subjective decision-making, and the entire process, as observed at the Asante Centre, errs on the side of caution in diagnosis. This approach is very compatible with New Zealand conditions.

Medical, developmental and educational histories are collected, standardised physical measures (growth, face and exposure) are made, and neuropsychological tests are used across all domains of cognitive function. The medical examination involves looking for the typical markers of FASD and ruling out any other neurodevelopmental or genetic condition that could be causing the presenting difficulties.

The Canadian model, requiring deficits of two standard deviations or greater across three domains of central nervous system function, was found to be a preferable benchmark for any deficits to avoid false positive diagnosis. Deficits on testing across three domains excluded those with mild or more specific cognitive problems that might be the result of other conditions such as ADHD, traumatic brain injury, learning disability or autism spectrum disorder. Evidence for other causes of disability is ruled out before the FASD diagnosis is made. Importantly, the process also allows for concurrent and secondary conditions to be identified and described.

The confounding effects of other complexities

In practice, prior to training it was hard to tease out the multitude of factors that influence a child's development in order to gauge the effects of brain dysfunction caused by alcohol exposure prenatally, or any other later-acquired brain insult. These other factors include abuse, neglect, poor parenting, educational programmes not meeting a child's needs, school failure, and significant behavioural / mental health

problems. As the FASD training was put into practice, however, this issue became less problematic. After considering the FASD literature, it was evident that there is not an 'either/or' situation when it comes to a child's brain function. Cognitive function can be deleteriously affected in its ontogenesis by alcohol, and a child's development and learning can subsequently be compromised by many other factors. Both of these aspects need to be considered in the assessment process.

The FASD differential diagnosis includes a consideration and record of other prenatal and postnatal risk factors, as well as protective factors. It can be acknowledged in writing as part of the assessment that all of a child's presenting problems may not be solely attributable to FASD, but that it is an important component when considering follow-up treatment and support.

Unfortunately, many FASD children are born to parents who are not well equipped to provide them with optimal care. They may have their own addictions or mental health issues, they may be living in situations of violence or poverty without supports, and they may be prenatally alcohol-affected themselves. Due to brain damage, FASD children do not follow a normal course of development and they are not easy children to bring up.
This is a very vulnerable group of disabled children, easily harmed by parents and caregivers, who may be young, substance abusing, poorly skilled in parenting and unsupported, leading to sometimes tragic consequences. Such children may also be vulnerable in foster care when there is little understanding of how best to manage the presenting behavior of a child with FASD.

When individuals present with a complex array of problems, it may be professionally unacceptable to fail to diagnose FASD when indicated and thereby fail to provide the services required. Where a diagnosis of FASD is warranted, it needs to be pursued.

The benefits and risks of diagnosing in the absence of follow-up services

This is the chicken-and-egg dilemma. Until FASD is diagnosed and recognised in New Zealand as the pervasive and disabling condition that it is, there will be limited services provided and vulnerable people will continue to fall through the cracks, which will present other challenges and cost burdens. This pilot project was a response to that vicious circle − an attempt to act as a circuit-breaker. Those clinicians who travelled to Canada were able to see that this is not an insurmountable problem, and that despite experiencing similar issues, these are being systematically and appropriately addressed in other parts of the world. It was felt however, that New Zealand is 10 or perhaps 20 years behind in its response.

The cost of not addressing this problem is huge, and is already being paid by the health, justice, education, and Child, Youth and Family service sectors, not to mention those affected and their families. Recognising and treating FASD as a pervasive and disabling condition can only cost less. It is evident that early diagnosis and increased public awareness of the damage alcohol does to the unborn child are the keys to reducing suffering and future harm.

In this project, once FASD was diagnosed in the cases where it was warranted, some effective plans could be made, even without specific FASD resources. For example, two young people in youth justice were provided with care and treatment for their sexual offending that could be tailored to their needs due to the comprehensive assessments that were provided to the court. Two other teenagers were found not to have FASD: one was directed to conduct disorder services and the other to a SAFE mainstream programme. The diagnosis of the youngest child highlighted the extent of his disabilities and areas of strength, enabling the family and future services to plan more effectively for early interventions and to avoid further compromises to his life potential.

Can the fact that drinking in pregnancy has caused serious damage to a child's brain be addressed in a way that empowers rather than blames the mother?

In the Asante model of FASD diagnosis, the feedback meeting to present and discuss the findings with the family is critical and involves the whole team. Perhaps surprisingly, in practice these meetings did not prove a negative experience for the families in the study. It took professional courage, experience and training to raise and face this issue with families, but unless this was done they could not be fully informed about the nature of their child's disability and therefore could not know what to do about it.

In the three-day FASD clinic run at Taranaki Base Hospital, two of the three children assessed were diagnosed with FASD: one with partial FAS and the other with ARND. During the feedback session with the team, the first mother reported that she had always known in her heart that her drinking had damaged her son and she expressed gratitude that someone had finally come out and confirmed it. The exact nature and degree of her son's disability had been established and was discussed and explained at length. She reported that she could now seek help and make realistic plans for his future rather than not knowing why he had these problems and hoping, unrealistically, that they might just disappear. It was very evident that she was a good mother and that she had been disempowered by criticism that her parenting was the cause of her boy's global behavioural and learning problems. The New Zealand Birth Family study by Jenny Salmon (2009) confirms that this experience is common.

The second child was brought to the clinic by his mother, who was 5 months pregnant and still drinking, and his grandparents, who took him from her as a newborn when she was binge drinking and breastfeeding at the same time. The need for abstinence in subsequent pregnancies can be highlighted by the timely and careful diagnosis of FASD. In this case the mother remained quiet but the grandparents expressed gratitude to know what was wrong with their grandson and how to go about getting support. To have a report and a way to describe his problems would help the school know how best to support him, now and in the future. Unfortunately, in neither case could the team offer many appropriate services. However, it was evident that the diagnosis and reports would help both families understand the nature of the disability and seek out services for their affected children. Other, as yet unborn, children may have also been afforded some protection.

Is FASD relevant to the Youth Court process, and how can its recognition reduce re-offending?

Through this project it has become clearer that teenagers with FASD, especially when not diagnosed and compensated for through childhood, are a population greatly at risk for offending. They tend to be socially immature, limited in their reasoning powers, impulsive, and have impaired executive functions that would normally provide the young person with the skills to realise the likely consequences of their actions on others. Although often lacking ill intent, their actions can be dangerous because they tend to think about their own needs and not the effects of their behaviours on others. Actions can be erratic, unpredictable and illogical. Consequences have little effect, and they tend not to learn from their mistakes − or even to know when they make them.

Having FASD also places them at risk of substance abuse and of coming under the influence of other youth who are more sophisticated in their criminal offending. FASD offenders may be gullible and naïve, and require responsible adults to structure their lives to reduce opportunities to behave inappropriately. It was heartening to see in Canada that there are programmes directed solely to the needs of youth offenders with FASD, pitching interventions at their level of understanding.

Some youth offenders with FASD may have significant levels of intellectual disability and be deemed unfit to stand trial, and may therefore be eligible to receive support services and care through disability services. However, many more may not entirely lack the capacity to be held accountable for their actions or score in the retarded range intellectually, but may still have areas of significant cognitive deficit. Their level of disability may not be evident at first glance when arrested or appearing in court. A referral from the Youth Court for a section 333 psychiatric and neuropsychological

assessment is an opportunity to identify FASD or other neurodevelopmental and/or mental health conditions, and should provide some direction for the provision of services that can reduce their later offending.

Conclusions

In conclusion, it is clear that FASD may be an underlying cause of problems for many children presenting with complex cognitive and neurodevelopmental difficulties. Although FASD had previously been considered by the clinicians involved with this project, the training and practical application of a specific diagnostic process resulted in a more thorough and rigorous diagnosis being made by those involved, and positive ongoing changes to their assessment practice overall. As one clinician noted:

> *Through gaining of knowledge and experience in this complex field that included: reading and digesting of international literature; listening to experts working with FASD internationally; clinicians involved in Canada in diagnosis service provision and support for sufferers and their families as well as families who bravely shared their stories; I have been able to overcome my earlier concerns about FASD diagnosis and move forward in my practice.*

The critical factor in the diagnosis of FASD is the multidisciplinary evaluation, covering both medical and neurodevelopmental assessment, with access to and understanding of clinical testing tools. Ideally, a team would also include a speech–language therapist and, if warranted, an occupational therapist. These therapists are able to identify critical aspects of development not picked up by other testing. In addition, a co-ordinator who can liaise with the family and other services, gather data and provide support to the family before, during and after the assessment is invaluable for the smooth running of the process and for minimising the time needed by clinicians. However, if funding does not allow for a broad-based team, then a confident diagnosis can be made by a physician and a neuropsychologist working together, with access to and training in the use of appropriate FASD diagnostic tools.

The project has confirmed that FASD diagnosis can be validly and reliably made in New Zealand within reasonable means, and that training in multidisciplinary diagnosis is warranted. Doing so has benefits for the individual and their family, and for the clinicians, who are able to offer a credible diagnosis and provide valid information to enable effective interventions to be developed. A system to enable this to become standard practice is justifiable. It would be possible to integrate an interdisciplinary FASD diagnosis within existing services, which would enhance and complement these

services with little disruption. The provision of neuropsychological services is crucial to an accurate FASD diagnosis, which is fundamentally a brain-based disorder. However, the capacity of the public health system to provide neuropsychological services would need to be investigated further. The challenge, therefore, will be to resource further training, provide greater integration of neurodevelopmental assessment, and ensure there is sufficient knowledge in the wider health and social service sector to respond appropriately to the needs of the affected individuals.

FASD is often the hidden disability underlying a complex mix of health and social issues, and these collectively warrant taking a comprehensive and inclusive professional approach. This project has demonstrated that the cost of undiagnosed FASD is already a burden on existing systems, through repeated and potentially wasteful treatments that are inappropriate for the individuals' needs. Further investigation and investment in developing a framework for effective FASD diagnosis and follow-up service provision is not only warranted, it is essential.

By providing adequate FASD diagnosis, appropriate services can be directed towards harm reduction from the secondary disabilities that are so prevalent in this vulnerable group of affected children, adolescents and adults. The earlier in life this can be provided, the greater the opportunity there is for obtaining a sufficient level of support for the individual to attain and maintain their life potential and avoid the risk and heavy burden of secondary disabilities.

The added benefit of effective FASD diagnosis is to increase the protection of other children yet to be born. A diagnosis brings with it the opportunity to increase a family's awareness and knowledge of the risks of prenatal alcohol exposure, and for this to translate into a healthy pregnancy outcome in future. Viewed in this way, FASD diagnosis is preventive.

Policy recommendations for the New Zealand context

1. Acknowledge that establishing FASD multidisciplinary diagnosis in New Zealand is urgent, justifiable and feasible.

2. Establish a training programme to enable future clinicians who are willing to work as a multidisciplinary team to do so effectively within their own organisation or region.

3. Ensure there is trained neuropsychological capacity to support effective multidisciplinary FASD diagnosis within the public health system.

4. Investigate the feasibility of establishing a specialist FASD diagnostic, training and research organisation to guide FASD diagnosis and treatment in New Zealand, and to ensure this develops and continues in a well-informed, consistent and supported manner.

5. Develop New Zealand-based FASD diagnostic guidelines based on international guidelines to enhance a standardised approach across multiple sectors.

6. Establish an education programme to ensure the workforce in community-based services know and understand FASD in order to screen, refer and respond more appropriately and cost-effectively to the needs of the affected individual and their family following diagnosis.

Appendix 1: Establishing Multidisciplinary Diagnostic Services for Fetal Alcohol Spectrum Disorders in Aotearoa New Zealand: An Evaluated Process

Scoping the development of services

In March 2007 a visit to the Fetal Alcohol Drug Unit in Seattle, Washington, USA, initiated by Alcohol Healthwatch, provided the opportunity to engage directly with teams working in the area of FASD diagnosis and intervention and to explore opportunities with them to help New Zealand work towards building clinical knowledge and capacity. At that time the Seattle unit had developed a Legal Resource Centre,[17] where the emphasis was on diagnosing individuals with FASD within the criminal justice system. Evidence indicated that individuals with FASD were over-represented in this system, and that accommodating their disability was not well considered (Streissguth et al 1996; Fast et al 1999).

Subsequently, a legal resource team accepted an invitation to visit New Zealand to give a presentation on that topic at the December 2007 Youth Offending Conference, a cross-ministry initiative for the youth justice community in New Zealand. The visit to New Zealand by Judge Anthony Wartnik (retired) and Legal Resource Co-ordinator Katherine Kelly from Washington state provided an opportunity to engage with people in the wider health, social and justice sectors, including forensic and mental health clinicians. Attending an associated Auckland seminar on 'FASD and Justice' were two psychiatrists who had previously identified and diagnosed clients with FASD. With a view to investigating diagnostic approaches and potential training in New Zealand, the Alcohol Healthwatch Trust enabled these clinicians to attend an FASD conference in British Columbia, Canada, and to meet with multidisciplinary diagnostic teams in both British Columbia and Seattle, to learn from their approaches to diagnosis and forensic assessment. That investigative tour took place in March 2008.

The 2008 National Drug Policy Discretionary Grant Fund

The visit to Canada and the US in March 2008 coincided with the opportunity to seek short-term funding through the National Drug Policy Discretionary Grant Fund. The increased attention that had been generated for FASD at a national level by such things as the inclusion of FASD as a topic at the Youth Offending Conference and subsequent

[17] http://depts.washington.edu/fadu/

seminars had led to FASD being listed as a priority area under this 12-month funding grant scheme. The FASD-related priority proposals called for were for studies on:

- the prevalence, incidence, presentation and nature of harms related to individuals in the youth justice system
- effective intervention initiatives and the evaluation of existing services in New Zealand and internationally
- screening, diagnostic tools and identification of possible guidelines for health professionals to use for the diagnosis of FASD
- attitudes and behaviours towards drinking and substance abuse during pregnancy
- options for screening for FASD effects prior to school, and what these outcomes could mean for education plans.

Against this background, a proposal that met the criteria of the NDP Grant priority list for 2008/09 was developed and submitted.

The project, entitled Establishing Multi-disciplinary Diagnostic Services for Fetal Alcohol Spectrum Disorders in Aotearoa New Zealand: An Evaluated Process*,* proposed to examine the establishment of diagnostic approaches. This primarily − though not exclusively – was in relation to FASD as a disability affecting young offenders in the Youth Court. The grant application was submitted on 6 March and received approval on 2 May 2008.

About the project

Aims and objectives

The overall aim of the project was to ascertain the clinical elements required for establishing a multidisciplinary approach to FASD diagnosis in New Zealand, and to ensure clinicians and policy makers would be better informed to move the issue forward. The project aimed to:

- train clinicians (and other stakeholders if appropriate) to form part of a multidisciplinary team to develop FASD assessment skills for application in the Youth Court sector and the general population
- establish a best practice approach to FASD diagnosis in New Zealand

- apply this approach, in the first instance, to the Youth Court-directed psychiatric assessment process (section 333, Children, Young Persons and Their Families Act 1989).

The specific objectives for the project were to:

- develop capacity in multidisciplinary knowledge, skills and clinical practice to improve the diagnosis of FASD and follow-up interventions in New Zealand
- identify and train a team of clinicians based on international best practice adapted to fit the New Zealand context
- undertake multidisciplinary case-based assessments applying best-practice guidelines in the youth justice system
- carry out an external formative evaluation to track progress and to ensure the project met the expectations of key participants and stakeholders
- write and disseminate a report that included the evaluation findings and recommendations for New Zealand best practice guidelines and workforce development, including transition protocols and referral pathways across services.

The measurable outcomes for the project were considered to have been met when:

- an appropriate external evaluator had been identified and engaged following a call for expressions of interest or a request-for-proposal process
- at least six New Zealand-registered clinicians (including at least one paediatrician, one psychiatrist, one clinical psychologist and one speech–language therapist) had been trained in a team approach to multidisciplinary assessment of FASD
- at least four multidisciplinary FASD diagnostic assessments had been carried out in the youth justice sector
- an external formative evaluation process to guide and evaluate the effectiveness of the project, with a report to inform future development, had been completed.

The project, rather than being prescriptive, was developmental in nature. The scope of the training and applied assessments for the project were not intended to be limited to those in the youth justice sector, but to allow other clinical assessments to be included as the opportunities presented themselves. However, section 333 of the Children,

Young Persons and Their Families Act 1989, which covers court referral for the psychiatric assessment of youth offenders (aged 14−16), provides a practical mechanism to readily assess cases where there is a higher-than-normal chance of an individual being affected by FASD. This emphasis ensured the minimal objective for training and application could be met within the short timeframe allowed for the project.

Stages of the project

The following stages were completed as part of the project.

- External evaluators were identified to conduct key stakeholder interviews and facilitate the development of a programme logic model.
- Diagnostic training was arranged for clinicians, to be carried out in New Zealand, the US and Canada.
- Eleven FASD assessments were completed during the course of the project, spanning childhood, adolescence and adulthood.

Assembling and training the team

The diagnostic team

The team that assembled during the project consisted of two psychiatrists, a paediatrician, three neuropsychologists, a speech−language therapist and a team co-ordinator, who were involved at varying times over the year of the project. The three neuropsychologists, one psychiatrist and the team co-ordinator attended the Auckland-based training with Dr Paul Connor from Seattle. The paediatrician and two neuropsychologists and the team co-ordinator attended the Third International FASD Conference in Victoria, British Columbia, Canada, and the Asante Centre training in Maple Ridge, British Columbia. The two psychiatrists had previously trained in British Columbia and Seattle.

Asante Centre training

The visit in March 2009 to the Asante Centre in Maple Ridge consisted of 2½ days of intensive training for four of the project team. The training included a comprehensive introduction to the Asante Centre structure and contracted processes, the application of the Canadian guidelines to reach an FASD diagnosis, the full observation of a case-based assessment of an 8-year-old child, engagement with the process of reaching a multidisciplinary diagnosis, and observation of engagement with the child's family and

their social worker to convey the assessment findings and discuss the next steps. Training was conducted with Dr Ko Asante, Medical Director and developmental paediatrician, with 30-plus years' experience diagnosing children and adolescents with FASD; Dr Julie-Ann Conry, a registered psychologist with 20 years' experience; Kristal Bodaly, a speech–language pathologist who joined their team in 2006; the Executive Director of the Centre, Audrey Salahub; and other staff.

Adolescent and adult neuropsychological assessment training

Dr Paul Connor, a neuropsychologist specialising in forensic diagnosis of older adolescents and adults, provided the New Zealand neuropsychologists with assessment guidance based on his experience of 10 years of FASD assessment and research. He presented the model used by the FASD experts on his team, and provided a forum for discussing issues of diagnosis, such as competency to stand trial, FASD as a mitigating factor, appearance in court as an FASD expert witness, and applying sentences that reduce the chances of re-offending.

Dr Connor works in the US as part of the Seattle-based forensic diagnostic team (FASDExperts.com), which focuses on diagnosing FASD in serious offenders, some of whom have already been convicted for capital offences and face the death penalty. (The death penalty is excluded in the US for those with a proven disability.) Although the death penalty is not applicable in New Zealand, many of the issues that face FASD-affected offenders interfacing with the law are directly applicable to the New Zealand context.

The Third International FASD Conference

Four members of the team joined more than 1000 international delegates in Victoria, British Columbia, for four days of lectures and presentations on the theme 'FASD, Integrating Research, Policy and Promising Practice Around the World: A Catalyst for Change'. Leading experts in the field of FASD presented on a wide range of topics, including animal models, the latest imaging findings, FASD and post-traumatic stress disorder, international research collaborations, and child protection and public policy. There was an array of sessions presented by those working at the grassroots level providing support and services to FASD-affected individuals and their families, and in prevention. A panel of birth mothers, including a New Zealand representative, shared their stories and expertise.

Project evaluation

The project process and results were subject to external evaluation. The evaluation focused on project activities between February 2008 and April 2009, and interviews were conducted in two phases. Phase one included establishing a programme logic model (Appendix 2). The external evaluation found that up to the point of this final report the project had achieved its stated objectives.

For further information about this project contact:

Christine Rogan

Alcohol Healthwatch Trust

PO Box 99407 Newmarket

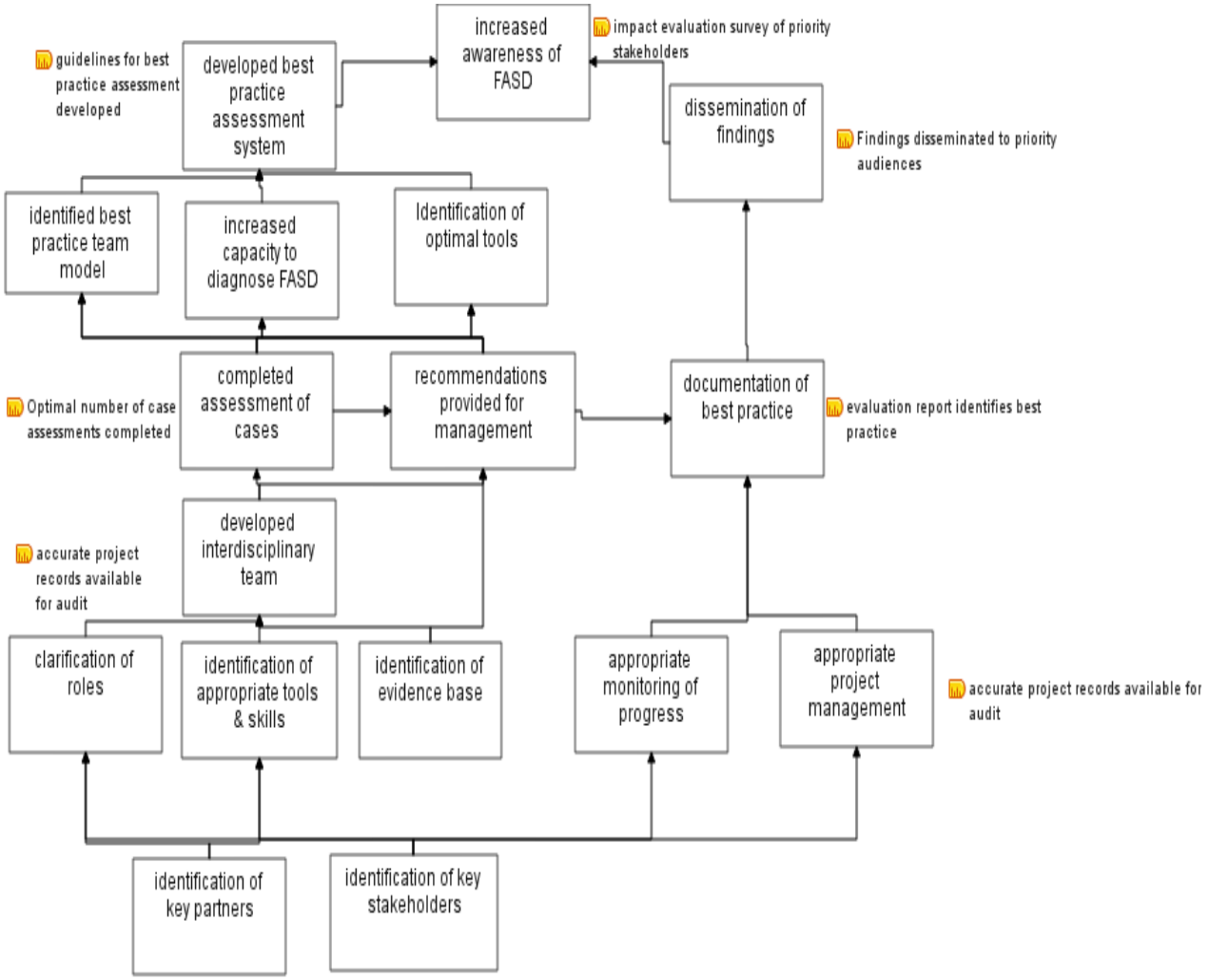
Auckland 1149

New Zealand

09- 520 7037

christine@ahw.org.nz

Appendix 2: The FASD Project Logic Model



Appendix 3: Summary of All Cases Assessed

CASE 1	**35-year-old female**
Referral service	An alcohol and drug service
History/presenting problems	• Maternal exposure reported but unconfirmed • Alcohol and drug abuse since 14 years • Forensic history and incarceration • Mental health • Psychosis • Unemployment
Assessment	Neuropsychological testing only of: • general intelligence • academic achievement • working memory – verbal/non-verbal • expressive/receptive language • information processing • adaptive function • psychological functioning.
Findings	Mild impairment not of clinical significance
Diagnosis/outcome	No fetal alcohol spectrum disorder (based on neuropsych testing results only). On the 4-Digit Diagnostic Code, client ranked 1 on code 3 (CNS damage/ dysfunction) and 1 on code 4 (prenatal alcohol exposure). Prenatal exposure cannot be ruled out as a contributing factor but symptoms are more likely the result of chronic substance abuse.
CASE 2	**22-year-old male**
Referral service	Private clinic

History/presenting problems	• Full-term but low birthweight • Slow attainment of milestones • Underachieved in education • Poor self-regulation • Alcohol and drug abuse from age 15 years • Forensic history • No history of head injury/neuro illness • Paediatric assessment of possible fetal alcohol effects age 16 years • Maternal exposure confirmed
Assessment	Neuropsychological testing of: • general intelligence • academic achievement • working memory – verbal/non-verbal • expressive/receptive language • attention • information processing • adaptive function • psychological functioning.
Findings	• Normal cognition • Two standard deviations below the mean for executive function, memory function and adaptive function.
Diagnosis/outcome	Alcohol-related neurodevelopmental disorder (based on neuropsych testing results only). On the 4-Digit Diagnostic Code for FASD code 3 − CNS damage/ dysfunction, rank of 3, and 4 for prenatal alcohol exposure. Significantly elevated GSI.
CASE 3	**16-year-old male**
Referral	Youth Court
History/presenting problems	• Unlawful intimidation, indecent acts, property offences • Previous court-ordered psychological assessment of possible limited intellect or neurodevelopmental disorder • Aggressive and non-compliant

	• Non-confirmed exposure to alcohol
Assessment	Medical and neuropsychological assessment Growth, face, CNS and maternal exposure assessed Neuropsychological testing of: • intelligence • verbal learning • verbal fluency wide range achievement • working memory and story memory • subtests • executive function • attention
Findings	• No growth deficiency • No facial dysmorphology • No significant cognitive deficits
Diagnosis/outcome	No fetal alcohol spectrum disorder. • On the 4-Digit Diagnostic Code for FASD: coded 1, 1, 1, 1. • No other mental health or neurodevelopmental condition. • Became more co-operative and able to discuss emotion. • Found fit to stand trial. • SAFE programme recommended.
Case 4	**16-year-old male**
Referral	Youth Court
History/presenting problems	• Unlawful sexual connection • Abuse/neglect • No intervention provided, despite exhibiting years of inappropriate sexual behaviour • Maternal alcohol exposure confirmed with other drug, plus domestic violence
Assessment	Medical and neuropsychological assessment.

	Growth, face, CNS and maternal exposure assessed. Neuropsychological testing of: • intelligence • verbal learning • verbal fluency wide range achievement • working memory and story memory • subtests • executive function • attention • adaptive behaviour.
Findings	• Mild growth deficiency – diagnostic rank of 2. • Mild expression of FAS facial features – diagnostic rank of 2. • Significant deficits (over two standard deviations below mean) in the domains of cognition (IQ 66), adaptive function (GAC 59), attention, executive and scholastic function – diagnostic rank of 3 for CNS (significant dysfunction, probable evidence of CNS damage). • Maternal alcohol exposure confirmed − diagnostic rank of 3.
Diagnosis/outcome	Alcohol-related neurodevelopmental disorder. On the 4-Digit Diagnostic Code for FASD − coded 2, 2, 3, 3. Also has: • conduct disorder (childhood onset type, severe) • attention deficit hyperactivity disorder • substance abuse disorder • mild intellectual disablement. Found fit to stand trial. Received high and complex needs package of care and SAFE programme.
CASE 5	**16-year-old male**

Referral	Youth Court
History/ presenting problems	• Charged with rape and theft. • History of serious behaviour and learning problems. • Behaviour consistent with conduct disorder. • Diagnosed with ADHD. • Maternal alcohol exposure confirmed.
Assessment	Medical and neuropsychological assessment (no further details available)
Findings	Neuropsychological assessment scored within very low range IQ of 62 (no further details available).
Diagnosis/outcome	Using the 4-Digit Diagnostic Code, young person met criteria for static encephalopathy alcohol exposed, code 1, 1, 3, 3 – alcohol-related neurodevelopmental disorder, using the Canadian guidelines. Found fit to stand trial.
CASE 6	**15-year-old female**
Referral	Youth Court
History/ presenting problems	• Charge of attempted murder • History of solvent use • History of sexual abuse • Diagnosed with a post-traumatic stress disorder, attachment disorder and severe conduct disorder • Maternal alcohol and toluene exposure confirmed • IQ of 62.
Assessment	Medical /neuropsychological (no further details available)
Findings	(No further details available)
Diagnosis/outcome	Using the 4-Digit Diagnostic Code, this young person met criteria for sentinel physical findings/neurobehavioural disorder (alcohol exposed), code 4, 1, 3, 4 − alcohol-related neurodevelopmental disorder (ARND) using the Canadian guidelines.

	Found unfit to stand trial (pursuant to section 4 of the Criminal Procedure [Mentally Impaired Persons] Act 2003) and intellectually disabled (pursuant to section 7 of the Intellectual Disability [Compulsory Care and Rehabilitation] Act 2003).
CASE 7	**16 year-old male**
Referral	Private
History/ presenting problems	• Adopted from Russia at 30 months. • Born full-term. • Delayed developmental milestones. • Academic underachievement, especially in maths. • Academic problems in language and maths. • Behavioural problems. • Known history of maternal alcohol consumption but quantities unknown.
Assessment	Medical assessments of: history, weight, height, face, physical exam (no further details available). Neuropsychological assessment of: • general intellectual function • adaptive function • verbal abilities • performance abilities • attention and memory • executive function • scholastic achievement. Exhibited high anxiety and was opposed to assessment, which may cast doubt on the validity of the results obtained.
Findings	• No growth deficiency. • Mild facial features of FAS. • Significant dysfunction of brain functioning – intact cognitive and behavioural functioning. • Knowledge of word meanings. • Receptive language skills. • Visuospatial and constructional skills. • Analysing and synthesising complex visuospatial information.

	• Non-verbal reasoning. • Reading accuracy. • Rate of processing simple visual information. • Working memory. • Attending to and processing aurally presented information. • Ability in shifting attentional focus. • Ability in seeing things from different perspectives when problem solving • Spatial planning, rule learning and inhibition skills. Cognitive and behavioural deficits: • verbal concept formation and higher-level verbal reasoning • expressive language skills • reading comprehension • calculation skills • learning and recalling auditory/verbal information • learning and recalling complex visuospatial information • focusing on two tasks simultaneously while under time pressure • planning and organising his approach to problem-solving tasks in everyday settings • ability with inhibiting impulsive responses • adjusting to changes in routine or task demands • emotional modulation and behavioural monitoring • initiating problem-solving or activity • organising his environment and materials • adaptive skills in the areas of expressive language, personal skills, domestic skills, interactions with others, use of play and leisure time, and responsibility and sensitivity to others.
Diagnosis/outcome	Static encephalopathy – alcohol exposed. Using the 4-Digit Diagnostic Code, young person ranked 1, 2, 3, 3. Canadian guidelines did not match a ranking of 1, 2, 3, 3 due to unknown alcohol exposure nor FAS facial phenotype. *Recommendations* • One-on-one assistance with reading comprehension and mathematics. • Best suited to practical work in the future (a trade) as visuospatial and constructional skills and non-verbal

	reasoning skills are areas of strength. • Problems with anxiety and low self-esteem – individual counselling recommended. • Complex tasks should be broken down into their component parts. • Coping with multiple cognitive demands very difficult so needs to focus on one task at a time. Needs to receive only one or two instructions at a time because he becomes rapidly overloaded with aurally presented information. • Needs plenty of structure and routine, and plenty of parental oversight and supervision.
CASE 8	**16-year-old female**
Referral	Private
History/ presenting problems	• Adopted from Russia age 3 years. • Premature birth. • Early parental neglect for 30 months. • Delayed developmental milestones. • Academic underachievement, especially in maths. • Known history of maternal alcohol consumption but quantities unknown. • Impulsive behaviour. Unable to predict possible consequences of her behaviour.
Assessment	*Medical and neuropsychological assessments* History, weight, height, face, physical exam. Neuropsychological testing of: • general intellectual function • adaptive function • verbal abilities • performance abilities • attention and memory • scholastic achievement • executive function.
Findings	• Mild facial features of FAS – 4-Digit Diagnostic Code 2. • Moderate growth deficiency – 4-Digit Diagnostic Code 3. • Significant dysfunction of brain functioning – 4-Digit Diagnostic Code 3 • Co-operative and worked hard on all tasks during formal testing.

	Intact areas of cognitive functioning: • knowledge of word meanings • receptive language skills • reading accuracy • rate of information processing in simple automatic tasks • attending to and processing aurally presented information • working memory • recalling recently learned auditory/verbal information from memory • learning and recalling complex visuospatial information • learning and recalling auditory/verbal information • performing tasks in an unfamiliar novel fashion • flexibility in thinking and problem-solving • planning and organising approaches to problem-solving • behavioural functioning in the school context. Cognitive deficits: • verbal concept formation and higher-level verbal reasoning • non-verbal reasoning • visuospatial and construction al skills when placed under time pressure • reading comprehension • understanding mathematical concepts and calculation skills • in everyday life – problems with impulsivity, initiating problem-solving or activity, planning and organising problem-solving approaches, organising her environment and materials, and monitoring her behaviour • adaptive functioning in the areas of expressive language, daily living skills, community participation and socialisation skills. Within the home there were significant behavioural problems: disruptive and uncontrolled behaviours, lying, nervousness and fearfulness, withdrawal, pessimism and sadness, health-related concerns, adapting to changing situations, decision-making, performing simple daily activities in a safe and efficient manner, receptive and expressive communication skills, maintaining attentional focus, emotional self-control, social skills and communicating with others.
Diagnosis/outcome	Sentinel physical findings /static encephalopathy. 4-Digit Diagnostic Code 3, 2, 3, 2. The Canadian guidelines for a FASD could not be applied because there was no confirmed alcohol exposure, nor clear FAS facial phenotype.

	Recommendations • One-on-one remedial assistance in reading comprehension and maths. • Ensure that information presented is readily understood. Tasks should be broken into their component parts so they do not appear overwhelming. • Plenty of structure and direction, and close supervision. • Encourage independence in activities of daily living to facilitate independent functioning in the future.
CASE 9	**4 years 8 months male**
Referral	Taranaki Base Hospital Child and Adolescent Unit
History/ presenting problems	Developmental delay. Speech, attention, impulsivity, rough play. Exposed to continual binge drinking.
Assessment	Paediatric/speech−language/neuropsychological assessment. Paediatric history, growth, face, other health issues, physical examination. Speech−language testing of comprehension, expression. Neuropsychological testing of: • cognitive function • attention • adaptive behaviour • memory • performance.
Findings	• Head circumference above second percentile. • Palpebral fissures below third percentile. • Height below third percentile. • Weight below the third percentile. • Lip/philtrum scale 3. • Speech−language comprehension and expressive language equivalent to 2 years. • IQ of 49. • Adaptive function of 45.

	• Significant deficits on performance, verbal, attention and memory tasks.
Diagnosis/outcome	Partial fetal alcohol syndrome − using the Canadian diagnostic guidelines criteria. Significant level of disability due to neurological impairment. *Recommendations* • Will require extra support and special-needs teaching at school though ongoing resourcing (ORRS funding). • High therapy needs requiring ongoing speech−language and occupational therapy. • Will learn slowly and it will be important to keep expectations at a simple level. • Needs may be better met within a specialised class or school. • Devoted and skilled mother but will need respite care to avoid burnout to give her (and the other children) time out.
CASE 10	**9-year-old male**
Referral	Taranaki Base Hospital Child and Adolescent Unit
History/ presenting problems	• Poor learning. • Poor concentration. • Concerns raised via the school – high score for hyperactivity, impulsivity and attention deficits. • Difficulty following instructions. • *In utero* alcohol exposure – 3 to 4 times a week, cask of wine on weekend and smoked.
Assessment	Paediatric/neuropsychology/speech−language therapy. • History, height, weight, head circumference, physical exam. • Wechsler Intelligence Scale for Children − fourth edition (WISC-IV). • California Verbal Learning Test: Children's Version (CVLT-C). • Wide Range Achievement Test of Memory and Learning (WRAML2); Finger Window, Working Memory and Story Memory subtests. • Rey Complex Figure Test. • D-KEFS Executive Function System, Trail Making Test, Verbal Fluency Test, Tower Test, Colour-Word Interference Test, Sorting Test. • Wide Range Achievement Test-3rd Revision (WRAT3). • Adaptive Behaviour Assessment System-second edition (ABAS-II).

Findings	• Birthweight 5 lb 9 oz. • Current weight 29 kg, 50th percentile. Height 132.7 cm, 25th–50th percentile. Head circumference 52 cm, between 2nd and 50th percentile. Palpebral fissure length both sides 27 mm, 50th percentile. Intercantal space 27 mm. Lip Likert scale 2, philtrum Likert scales. • Clinodactyly of both the fifth fingers. • All else normal physically. • General intellectual functioning – low–average range. Full-scale IQ was 84. • Adaptive score obtained lower than IQ at 70 (two standard deviations below mean). • Use and understanding of words was at the lower limit of age-appropriate, and social comprehension scored normal for his age. • On performance, did better on practical than verbal tasks. • Difficulty with visual motor integration. • Attention and memory – difficulty with visual motor integration and worked at a very slow rate. • Showed some early signs of concern in some areas of executive function. • Scored well below his age level in all scholastic achievement areas – scored at a 7.5-year-old level on the written maths task. Presented as a child who has become disheartened through school failure.
Diagnosis/outcome	Alcohol-related neurodevelopmental disorder. Using the 4-Digit Diagnostic Code, ranked as 3 on the third digit for CNS damage or dysfunction, showing probable CNS dysfunction (no further ranking details available). Overall, cognition within normal limits for age. He showed strengths when taking meaning from picture information and with practical tasks. Impairments (greater than or equal to two standard deviations below the mean for his age) were found in the domains of attention, executive function, adaptive function and scholastic achievement. *Recommendations* • Will qualify for extra educational support through the Ministry of Education's Moderate Needs funding. • In class would be best seated near the front away from noise and distraction. He may need repeated instructions and reminders. • Stimulant medication for attention deficits may improve focus and rate of school learning. Now that the nature of his difficulties has been clarified, support will need to be put in place so that he can experience success. Expectations will need to be realistic; ie, not expected to complete the same amount and level of work as his classroom peers who do not have a neurological condition. He will require a high level of praise for his efforts and

	acknowledgement that he has to work harder to achieve less than others in the class.
CASE 11	**13 years 6 months male**
Referral	Taranaki Base Hospital Child and Adolescent Unit.
History/ presenting problems	Concerns about behaviour and development, assault, stealing, drinking. Mother was 18 years and drank heavily on weekends.
Assessment	Paediatric and neuropsychological assessments. History, weight, height, face, physical exam. Neuropsychological testing of: • general intellectual function • adaptive function • verbal abilities • performance abilities • attention and memory • executive function • scholastic achievement.
Findings	• Normal birth and birthweight, normal healthy development. • Bilateral clinodactyly of fifth fingers, otherwise no dysmorphic features. • Co-operative and worked hard on all tasks during formal testing. • Insecure, low self-esteem, hypersensitive to feedback, liked to win and be in control. • IQ 97. • Adaptive score significantly lower than IQ at 61 (over two standard deviations below mean) – generally oppositional and antisocial rather than functional disability. • Excellent communication skills. • Above average on performance skills tests. • Attention and memory within normal limits. • Within normal limits on all executive function tasks. • Reading at a 12-year-old level, spelling at a 9.5-year-old level.
Diagnosis/outcome	No fetal alcohol spectrum disorder diagnosed. Although exposed to alcohol prenatally, patient showed none of the

	indicative cognitive deficits. Behaviours consistent with conduct disorder problems that are seriously disruptive. Possibly due to abuse or neglect and poor role modelling as a child. *Recommendations* • Intensive counselling and intervention from a specialist in treatment of conduct disorder. • Has all the resources needed to make positive changes with the right support. • If antisocial and abusive attitudes are not challenged and changed at this age, may go on to offend seriously in the future.

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