

University of Otago
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Fallen by the Wayside
Young People with Fetal Alcohol Spectrum Disorder (FASD) in
New Zealand's Youth Justice System

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Abstract

Young people with FASD are overrepresented in justice systems worldwide. There is an estimated 30,000 children and young people with FASD in New Zealand, many of whom will not have a formal diagnosis. The unique cognitive profile of a young person with FASD presents a challenge for the youth justice system. The brain damage caused by prenatal exposure to alcohol can lead to a series of cognitive difficulties manifested in a pattern of behaviour that can lead to criminal offending (such as impulsivity, suggestibility, and an inability to consider consequences). Compounding the difficulties faced by these young people is their vulnerability in a justice setting, and the likelihood of recidivism due to difficulties with learning and problems with memory. Currently in New Zealand there is no specific legislative or policy guidance on how to manage young people with FASD in the youth justice system. Given this absence, this thesis considered i) what are the common presentations of FASD and why do they present such a problem for the justice system; ii) why the current legislative and policy context is inadequate for young people with FASD; and iii) how can New Zealand's youth justice system be improved for young people with FASD?

This qualitative research focused on FASD as a lived experience, including family life, justice system involvement, and professional knowledge and attitudes. It included 39 participants, comprising: two young people, 12 parents, one teacher, one school principal, one education sector service manager, one psychologist, five paediatricians, four social workers, one Youth Aid Police officer, two Youth Court judges, one youth justice service provider practice manager, one director of a youth justice service provider, one youth forensic alcohol and other drug clinician, and six key stakeholders.

The New Zealand Disability Strategy and the United Nations Convention on the Rights of Persons with Disabilities require impairment and disability to be viewed through the lens of the social model of disability. Individuals are not to be defined or described in terms of deficits, but first and foremost by their strengths. This research found that young people with FASD are kind, creative, intelligent, and confident. It also found that for these young people and their families, the brain damage sustained by prenatal exposure to alcohol causes an extensive array of learning, behavioural, and parenting challenges. Compounding these challenges is a lack of awareness and understanding of the disability among professionals in the education, justice and health sectors in New Zealand, and a lack of formal support pathways in the justice system. The diagnostic process for FASD in New Zealand needs urgent, formal recognition through funding streams and training programmes, which would enable the early identification of FASD in children and reduce the risk of secondary disability (including criminal offending) among young people.

Recommendations from this thesis include developing formal diagnostic guidelines for FASD in New Zealand; incorporating formal training for FASD into the tertiary curriculums for teachers, and for all justice professions likely to have contact with young people, implementing a mandatory, robust screening service for FASD in the Youth Court, acknowledging FASD as a mitigating factor in sentencing legislation, and extending the legislative jurisdiction of the youth justice system to all young people aged 24 or below.

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List of Abbreviations

Action Plan	Taking Action on Fetal Alcohol Spectrum Disorder
ADHD	Attention Deficit Hyperactivity Disorder
Alcohol Healthwatch	Alcohol Healthwatch New Zealand
<i>Aravena</i>	<i>R v Aravena</i>
ARND	Alcohol Related Neurodevelopmental Disorder
ASD	Autism Spectrum Disorder
AUDIT-C	Alcohol Use Disorders Identification Test – Consumption
CAFS	Child, Adolescent and Family Services
<i>Caldwell</i>	<i>R v Caldwell</i>
CBA	Canadian Bar Association
CDC	United States Centre for Disease Prevention
CDS	Child Development Services
CJ	Chief Justice
CNS	Central Nervous System
CPMIP Act	Criminal Procedure (Mentally Impaired Persons) Act 2003
Crimes Act	Crimes Act 1961
CRPD	United Nations Convention on the Rights of Persons with Disabilities
CYFS	Child, Youth and Family
CYPTF Act	Children, Young Persons and Their Families Act 1989
DAP	Developmental Assessment Programme
DHB	District Health Board
DSM	Diagnostic and Statistical Manual of Mental Disorders
FANNZ	Fetal Alcohol Network New Zealand
FAS	Fetal Alcohol Syndrome
FASD	Fetal Alcohol Spectrum Disorder
FASD-CAN	Fetal Alcohol Spectrum Disorder Care Action Network
FGC	Family Group Conference
fMRI	Functional Magnetic Resonance Imaging
<i>George</i>	<i>R v George</i>
GP	General Practitioner

IDCCR Act	Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003
IQ	Intelligence Quotient
J	Justice
JA	Justice of Appeal
JJA	Justices of Appeal
MMR	Mixed Methods Research
MP	Member of Parliament
MYJP	Manitoba Youth Justice Programme
NCEA	National Certificate of Educational Achievement
NIA	National Interest Analysis
ORS	Ongoing Resourcing Scheme
OT Act	Oranga Tamaraki Act 1989
P	President
<i>Powderface</i>	<i>R v Powderface</i>
<i>Ramsay</i>	<i>R v Ramsay</i>
RTLB	Resource Teachers: Learning and Behaviour
SEG	Special Education Grant
SENCO	Special Education Needs Coordinator
T-ACE	Tolerance Annoyance Cut-down Eye-openers
Te Tiriti	Te Tiriti o Waitangi/The Treaty of Waitangi
The Disability Strategy	The New Zealand Disability Strategy
The guide	The Australian Guide to the Diagnosis of FASD
TWEAK	Tolerance Worried Eye-openers Amnesia Kut-down
UN	United Nations
UNCRC	United Nations Convention on the Rights of the Child
UPIAS	Union of the Physically Impaired Against Segregation
<i>VT</i>	<i>Police v VT</i>
WINZ	Work and Income New Zealand
YCJA	Youth Criminal Justice Act (Canada)

Chapter 1

Introduction

Jasper, a 14 year old boy, stands in the Youth Court. He is charged with theft and common assault. He does not understand the Court process, and does not know what is going to happen to him. He has not seen his mother since he was arrested the day before. He has spent the night in the Police cells. He is a first-offender, and his offending is low-level. Despite this, following his Court appearance, he will spend seven weeks in a youth justice residence, waiting for a psychological report to be completed. He will then spend six weeks in supported bail accommodation. There is nowhere else for him to go. At the youth justice residence he will learn that the staff there do not understand disabilities like his very well. He will be left alone in a corridor to shout and scream.

Jasper has Fetal Alcohol Spectrum Disorder (FASD), and his biggest hope is that other young people with FASD will not have to endure the justice system the way that he did. He is now back home with his family, determined never to set foot in a youth justice residence again. So how could his experience have been different? To what extent did the justice system acknowledge Jasper's disability and provide appropriate supports to enable him to participate effectively? Did the professionals engaging with Jasper understand his disability and communicate the justice process effectively to him? Did the final order by the Youth Court acknowledge his unique diagnostic and rehabilitative needs?

The issues raised by Jasper's experience are the focus of this thesis: the experiences of young people with FASD, their parents and caregivers, and the professionals engaging with them, as well as their views on how the justice system might better accommodate them. The research questions guiding this study direct an examination of New Zealand's diagnostic, policy and legislative background and compare it to the international context. They also lead the inquiry into the lived experiences of young people with FASD and their families. The research questions are:

1. What are the differences between intellectual disabilities (as defined in the Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003 (IDCCR Act)) and the symptoms of FASD and why are these differences significant in the youth justice context?
2. How is FASD acknowledged and taken into account in New Zealand's youth justice system?
3. What are the experiences of young people with FASD in the justice system, and parents and caregivers of children with FASD, and what are their views on how the justice system could better meet their needs? How do these experiences compare with the experiences of professionals from the health, education and justice sectors working with young people with FASD?
4. Drawing on the international context, how can legislative, diagnostic and community-based initiatives more effectively address the needs and rights of young offenders with FASD in New Zealand?

5. How should legislative, diagnostic and community-based initiatives be formulated to this effect for New Zealand?

I. Legal context

In New Zealand, the youth justice system is governed by the Oranga Tamariki Act 1989 (OT Act)¹ which sets out the process for managing young people, from their initial contact with a Police officer, through to their appearance in the Youth Court.² The principles of the OT Act dictate that any measures for dealing with a young person should, as far as it is practicable to do so, “address the causes underlying the child or young person’s offending”.³ This principle is supported by s 333 of the OT Act, which allows the Court to order a medical, psychiatric, or psychological report for a young person, to assist the Court in determining the type of order to make for the young person. This provision relies on the Court itself recognising that such an order is necessary, which implies that the Court, or more specifically, the judge, has an adequate awareness and understanding of the potential presentations of the various disorders that might be revealed by the making of such an order. If the results of the report indicate that a young person has FASD, there is currently limited legal recourse for redirecting young people, unless they satisfy the criteria for an intellectual disability or are found unfit to stand trial.

Recent amendments to the OT Act have strengthened the rights of young people to effective participation in justice processes and imposed mandatory obligations on the Court to ensure that these rights are fulfilled.⁴ The new principles and purposes of the Act also emphasise the need to carefully balance the rights of the offender against the interests of any victim and of society as a whole.⁵ While the research for this thesis was conducted prior to these amendments taking effect on 1 July 2019, they are highly pertinent to the discussion and recommendations made in Chapter 11, regarding additional support for young people with FASD and how that might be achieved through legislative amendment or policy changes.

The IDCCR Act codifies the process for dealing with offending by young people (and adults) with intellectual disabilities. Section 7 provides a restrictive definition for intellectual disability as an individual who has an intelligence quotient (IQ) measuring as 70 or below; an IQ higher than this precludes an individual from coming within the ambit of the Act. This exhaustive definition is problematic generally for correctly identifying individuals with intellectual disability which requires a more nuanced approach⁶, but particularly for young people with FASD. Although FASD has been cited as the leading known preventable cause of intellectual disability, the majority of individuals with FASD are likely to have an IQ above 70.⁷

¹ Previously known as the Children, Young Persons and their Families Act 1989 until July 2017 when the name was changed.

² Oranga Tamariki Act 1989 pt 4.

³ Oranga Tamariki Act 1989 s 208(fa).

⁴ Oranga Tamariki Act 1989, ss 4, 4A, 5, 10 and 11.

⁵ Oranga Tamariki Act 1989, s 4(1)(a)(i) and s 4A(2).

⁶ See for example Asa G Hilliard “Back to Binet: the Case Against the Use of IQ Tests in the Schools” (1990) 61(4) *Contemp. Educ.* 184 at 184.

⁷ Ann P. Streissguth and others *Understanding the Occurrence of Secondary Disabilities in Clients with Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Effects (FAE)* (Centers for Disease Control and Prevention, Grant No. R04/CCR006515, August 1996) at 20.

The Criminal Procedure (Mentally Impaired Persons) Act 2003 (CPMIP Act) stipulates the process for finding an individual (including a young person under the jurisdiction of the Youth Court) unfit to stand trial.⁸ The interpretation section describes unfitness in relatively narrow terms; in summary, limiting it to individuals who are unable to comprehend the legal proceedings to the extent that their effective participation is nullified.⁹

The first problem with New Zealand's legislative context is that if a young person has FASD, but does not have an intellectual disability, there is very limited legislative means for dealing with them outside of the mainstream justice system. The CPMIP Act is only likely to apply for a small number of young people with FASD, whose expression of the disability impacts on the specific cognitive abilities noted by the interpretation section. The second problem is that the IDCCR Act and the CPMIP Act are triggered late in the justice process, while the focus of the OT Act is to divert young people as early as possible.¹⁰ Thus if a young person with FASD commits an offence, the likeliest scenario is that they will be dealt with before they reach the Youth Court. For more serious offending that does reach the Court, the likelihood is that neither the IDCCR Act nor the CPMIP Act will apply. This doctoral research focuses on the cohort of young people falling through this gap.

II. Research

There is plentiful research on FASD generally, and the interaction between FASD and the criminal justice system specifically.¹¹ However, in New Zealand, there is a lack of qualitative research seeking the direct lived experiences of young people with FASD who have had contact with the justice system, and of their parents and caregivers in supporting them. This study focused on obtaining their insights regarding the ability of the youth justice system to adequately support young people with FASD, and their suggestions for how the system might be improved. Twelve parents and two young people shared their stories, providing a rich narrative of experiences of parenting, the frustrations of navigating a health system that is ill-equipped to recognise and diagnose FASD, and the pitfalls of a justice system that is not yet adequately supporting these young people.

Nineteen professionals were also interviewed, representing the health, education, and justice sectors, which allowed me to gain insight into the diagnostic process for FASD in New Zealand, the structure of youth justice service provision, disability support services in schools, and Police and judicial involvement with young people with FASD. The contribution of these participants also enabled a comparison to be made between the perspectives of the family members and the perspectives of the representatives from the

⁸ Criminal Procedure (Mentally Impaired Persons) Act 2003, ss 4 and 7.

⁹ Section 4.

¹⁰ See, for example, Oranga Tamariki Act 1989 s 208(a) and s 209.

¹¹ See, for example, Streissguth A.P and others "Risk factors for adverse life outcomes in fetal alcohol syndrome and fetal alcohol effects" (2004) 25(4) *J Dev Behav Pediatr* 228; Svetlana Popova and others "Fetal Alcohol Spectrum Disorder Prevalence Estimates in Correctional Systems: A Systematic Literature Review" (2011) 102(5) *Can J Public Health* 336; I. Freckelton "Expert evidence in fetal alcohol spectrum disorder cases" (2016) 2 *Ethics Med Public Health* 56; and Raymond R Corrado and Evan C McCuish "The development of early onset, chronic, and versatile offending: The role of fetal alcohol spectrum disorder and mediating factors" (2015) 8(2) *Int J Child Adolesc Health* 241.

professional sectors they were engaging with. This strengthened the dataset by providing additional insights into how the youth justice system might be improved.

Five key stakeholders also shared their perspectives from the justice, youth justice, child wellbeing and advocacy, alcohol harm prevention, and indigenous advocacy sectors. They provided a variety of suggestions regarding how the youth justice system might be improved, and how current systems and processes could be amended to better support young people with FASD.

III. Theory

This doctoral research is underpinned by a theoretical argument that draws on the concepts of autonomy, criminal culpability and neuroscience in relation to adolescent brain development.

Criminal culpability rests on an assumption that an individual was acting autonomously, and therefore it is appropriate (and, indeed, expected) for society to attribute blame and apportion punishment. Legal systems worldwide, however, have developed in ways that reflect the understanding that there will, at times, be circumstances in which an individual should not be held criminally culpable for their actions.¹² The legal concept of *mens rea*, considered as a required element of criminal offending, acknowledges that an individual must be established as not only having committed a guilty act, but also must have had a “guilty mind” when committing it.¹³ However, certain defences to criminal offending acknowledge that even if an individual had the requisite *mens rea*, it may be inappropriate to hold them criminally culpable for their actions because certain influences on their cognitive functions negate (or inhibit) the exercise of autonomy.

The neuroscientific evidence regarding adolescence has established that the brain development of young people is ongoing, and that crucial cognitive functions that enable the interplay between cognition and emotion, and the ability to make rational decisions, is inhibited until well into the 20s. While the ability of neuroscience to inform court processes may still be considered limited,¹⁴ this evidence is nevertheless reflected in New Zealand’s criminal justice system, whereby age is considered a mitigating factor in sentencing.¹⁵ Young people with brain damage (e.g., caused by prenatal exposure to alcohol) that affects crucial cognitive domains responsible for the interplay between cognition and emotion experience compounding pressures on their ability to make reasoned decisions.¹⁶ Therefore, the concepts of autonomy and criminal culpability, and the neuroscientific evidence regarding adolescent brain development, offer a starting point for the argument to be made

¹² Autonomous action exists in degrees and legal systems have somewhat developed to reflect the consequent varying degrees of criminal culpability: John Coggon “Varied and Principled Understandings of Autonomy in English Law: Justifiable Inconsistency or Blinkered Moralism?” (2007) 15 *Health Care Anal* 235 at 240.

¹³ Jan Broersen “Deontic epistemic *stit* logic distinguishing modes of mens rea” (2011) 9 *J Appl Logic* 137 at 137.

¹⁴ See Armin Alimardani and Jason M. Chin “Neurolaw in Australia: The use of neuroscience in Australian criminal proceedings” (2019) 12(3) *Neuroethics* 255 at 264 where the authors refer to an “ethic of caution” in relying on neuroscience evidence in criminal justice proceedings.

¹⁵ Sentencing Act s 9(2)(a) and Oranga Tamariki Act s 208(e).

¹⁶ Anne L Kramers-Olen “Neuroscience, moral development, criminal capacity, and the Child Justice Act: justice or injustice?” (2015) 45(4) *S Afr J Psychol* 466 at 471.

that young people with FASD have reduced criminal culpability that should be reflected in the law and processes of the criminal justice system.

IV. Personal background

During the latter stages of my undergraduate law degree at the University of Otago, I developed a keen interest in the youth justice system in New Zealand. I was particularly interested in the legislation's focus on addressing the underlying causes of offending in young people, and was interested in exploring how, in practice, this is achieved. In the final year of my undergraduate studies I wrote an Honours dissertation on the connection between disengaging from school and youth offending in New Zealand.

My interest became more focused as a result of volunteering as a child advocate for a care and protection secure residence in Dunedin. During my time as an advocate I became more aware of the alarming connection between cognitive dysfunction and youth offending, including the effects of early childhood trauma and FASD on the development of the brain and consequent learning and behaviour outcomes. It became apparent that the overrepresentation of young people with FASD in the justice system was a growing issue, and one that was not well-understood by the professionals involved in the care of these young people. I thus embarked on this research to identify where the knowledge gaps were in New Zealand, and to give a voice to the young people and their families in need of support. My aim in this study was to determine whether the current legislative, diagnostic and policy initiatives were in need of amendment to ensure young people with FASD in the justice system are adequately supported.

V. Structure of the thesis

To understand the implications that FASD has on criminal offending, the physiological effects of prenatal exposure to alcohol must first be examined. Chapter 2 outlines the medical and scientific understanding of the teratogenic effects of alcohol on the developing brain in utero and discusses the associated learning and behavioural traits that are exhibited as a result of this damage. This chapter also outlines the current diagnostic process for FASD in New Zealand and identifies the shortfalls of this system.

Chapter 3 considers the implications of the social and behavioural traits for criminal offending and how and why young people with FASD will be more vulnerable in a criminal justice context. As well, the key pieces of legislation in New Zealand (the OT Act, the CPMIP Act, and the IDCCR Act) are examined and consideration given to why this legislative context is inadequate. Several cases from the Youth Court are analysed and provide further evidence as to why the current legal landscape is in urgent need of amendment.

Chapter 4 turns to the international context, and examines the legislative, diagnostic and policy initiatives of Canada and Australia with respect to FASD. This provides a platform for comparing the support for FASD in these two jurisdictions and considers how New Zealand could learn from overseas developments to improve its own response.

The concepts of criminal culpability and autonomy are explored in Chapter 5, with a focus on how the criminal justice system has acknowledged the necessary interaction between

cognition and emotion. This chapter argues that for young people with FASD, the compromised nature of their brain structure and subsequent cognitive challenges results in reduced autonomy which should be reflected by a legal acknowledgment of reduced criminal culpability.

Chapter 6 discusses qualitative research and outlines the methods used for this small-scale research study, from initial recruitment to the coding and analysis of results. It also discusses ethical issues and sets out the final sample of family members, professionals and key stakeholders.

The next four chapters present my study findings. Firstly, Chapter 7 sets out nine family stories, written by compiling the interview data from the parents and the young people in the study. These family stories provide an important context for the thematically-oriented results chapters that follow, grounding the families' insights within each of their unique experiences growing up as, or parenting, a child with FASD.

Chapter 8 reports the experiences of the families, whose voices highlight the need for increased awareness of, and support for, FASD in New Zealand.

In Chapter 9, the knowledge, experiences and perspectives of the professionals and key stakeholders are outlined.

Chapter 10 integrates the interview data from families, professionals and key stakeholders to report their views on how New Zealand's youth justice system is not meeting the needs of young people with FASD. It also sets out their suggestions for how the system could be improved.

Finally, Chapter 11 discusses the study findings in the context of the diagnostic, legal, empirical, theoretical and international material explored in the early chapters of the thesis. A series of recommendations for legislative, policy and service delivery changes are also made.

Chapter 2

FASD: How is it Presently Understood?

I. Introduction

Fetal Alcohol Spectrum Disorder (FASD)¹⁷ is a diagnosis given to reflect a range of neurocognitive impairments that can occur in an individual as a result of prenatal exposure to alcohol. Overseas data, coupled with New Zealand's high rates of drinking, puts a prevalence estimate at around 5%, or between 1200 and 3000 babies born with FASD per year in New Zealand.¹⁸ The disorder is described as a spectrum because of the incredibly complex nature of the developing brain, and the consequential variety of effects alcohol exposure can have on the resulting child.¹⁹ The particular developmental period in which the brain is exposed, and the type and quantity of alcohol that is consumed by the mother during pregnancy, will dictate the exact nature of the developmental disruption and resulting social and behavioural traits in the child. This chapter will outline the physiological effect prenatal alcohol exposure has on various parts of the brain and will explain how the resulting brain damage affects behaviour. This chapter also notes that regardless of the particular nature of the damage and resulting needs of the child, early diagnosis is crucial to mitigate the effects of secondary disability.²⁰ Important developments in Canada have highlighted that streamlined national diagnostic services for FASD are possible and effective. This chapter discusses the early measures taken in New Zealand which are beginning to reflect the importance of early intervention to prevent young people in Aotearoa continuing to fall through the gaps.

II. Physiological and neurological effects of FASD

Alcohol is a teratogen that can cause permanent and devastating damage to an embryo or foetus.²¹ When a pregnant woman consumes alcohol, the developing embryo or foetus is exposed to the alcohol through the placenta. The resulting neurobehavioural effects have been found to be worse than the effects of cocaine, heroin or marijuana on the developing brain.²² The early stages of brain development during pregnancy are incredibly complex, and studies have found that exposure to alcohol can interfere with neuronal migration,²³ cell

¹⁷ Although in New Zealand the British spelling *foetal* is used in day-to-day language, the North American spelling *fetal* is the accepted spelling when referring to FASD in scientific literature and is therefore used for consistency throughout this thesis.

¹⁸ Norma Hayward "Fetal Alcohol Spectrum Disorder: Drinking for Two" (Brainwave Trust Aotearoa, 2012).

¹⁹ Hayward, above n 18.

²⁰ See for example: Alcohol Healthwatch "Towards Multidisciplinary Diagnostic Services for Fetal Alcohol Spectrum Disorder" (Alcohol Healthwatch, 2010) at 11; and Health Promotion Agency "Hawke's Bay District Health Board Developmental Assessment Programme FASD Assessment Pathway: Process Evaluation" (2015) at 41.

²¹ Ministry of Health *Taking Action on Fetal Alcohol Spectrum Disorder (FASD): A discussion document* (Ministry of Health, December 2015) at 3.

²² Ministry of Health, above n 21 at 3.

²³ Kazue Hashimoto-Torii and others "Combined transcriptome analysis of fetal human and mouse cerebral cortex exposed to alcohol" (2011) 108 PNAS 4212 at 4212.

proliferation²⁴ and hippocampal function.²⁵ It is difficult to obtain evidence regarding the link between the specific amount of alcohol consumed and its consequent effect on brain development due to the reliance on self-reporting and retrospective analysis in the research literature.²⁶ However, animal studies, coupled with an analysis of comparable human brain function and observable deficits in humans exposed to alcohol *in utero*, have provided a relatively comprehensive picture of the teratogenic effects of alcohol on brain development.²⁷

A. *The Cerebral Cortex*

The cerebral cortex in a human brain comprises the outer layer of the cerebrum, and plays an important role in consciousness and the processing of sensory and motor information.²⁸ A sensitive stage in human cerebral cortex development is between 15-18 weeks gestation, when a significant number of neurons migrate to the superficial cortical layers.²⁹ Results of a 2011 rodent study analysing fetal cerebral cortices suggest the molecular identities of some neuronal subtypes in each cortical layer are disturbed by alcohol exposure during this sensitive stage of development.³⁰ The particular disturbances are found to persist after exposure and are retained postnatally, reflecting the permanent nature of alcohol damage on a developing brain.³¹ Such disturbance of molecular identity can lead to functional impairments which may contribute to the neurological and psychiatric impairments seen in FASD patients.³²

A 2011 study involving 33 participants, aged between 6-30 years, examined the correlation between developmental cortical thickness and cognitive difficulties in individuals diagnosed with FASD.³³ The results confirmed that overall brain volume and mean cortical thickness was reduced in the FASD individuals compared with the controls.³⁴ The cortical thinning ranged in severity across different areas of the cortex, with significant differences in the left lateral temporal lobe.³⁵ The role of this region of the brain is predominantly in processing

²⁴ Anna Patten “Replenishing what is Lost: Using Supplementation to Enhance Hippocampal Function in Fetal Alcohol Spectrum Disorders” (PhD Thesis, University of Victoria (Canada), 2013) at 4.

²⁵ Patten, above n 24 at 23.

²⁶ Robert J. Sokol, Virginia Delaney-Black and Beth Nordstrom “Fetal Alcohol Spectrum Disorder” (2003) 290 JAMA 2996 at 2996.

²⁷ See for example: Kazue Hashimoto-Torii and others “Combined transcriptome analysis of fetal human and mouse cerebral cortex exposed to alcohol” (2011) 108 PNAS 4212; Scott E. Parnell and others “Chronic ethanol increases fetal cerebral blood flow specific to the ethanol-sensitive cerebellum under normoxaemic, hypercapnic, and acidaemic conditions: ovine model” (2007) 92.5 Exp Physiol 933; and Paul Shoemack “Drinking During the Third Trimester of Pregnancy: a Cause for Concern” (PhD Thesis, University of Otago, 2014).

²⁸ E. D Hirsch, Joseph F. Kett and Jame Trefil *The New Dictionary of Cultural Literacy* (3rd ed, Houghton Mifflin, Boston, 2002).

²⁹ Hashimoto-Torii, above n 23 at 4212.

³⁰ Hashimoto-Torii, above n 23 at 4215.

³¹ Hashimoto-Torii, above n 23 at 4215 - 4216.

³² Hashimoto-Torii, above n 23 at 4216. See “Social and behavioural traits of individuals with FASD” for full discussion on these impairments

³³ Dongming Zhou and others “Developmental cortical thinning in fetal alcohol spectrum disorders” (2011) 59 NeuroImage 16.

³⁴ Zhou, above n 33 at 18.

³⁵ Zhou, above n 33 at 20.

semantics in both speech and vision (including naming and verbal memory).³⁶ The study explained the cortical thinning by referring to the effects of alcohol on the mechanisms of neuronal activity, emphasising that exposure in early development can disrupt the formation of synapses leading to large-scale apoptosis (spontaneous cell-death).³⁷

B. The Prefrontal Cortex

A reduction in volume of the prefrontal cortex has been observed in human foetuses exposed to alcohol.³⁸ The prefrontal cortex is the region of the brain that has been identified as uniquely human, and is responsible for regulating the most complex human functions such as speech and language, abstract thinking, planning and deliberate decision-making.³⁹ Research conducted in 2001 used ultrasonographic examinations to assess the growth of the prefrontal cortex during pregnancy in 167 women.⁴⁰ The study was unique in that it assessed live foetuses *during* their development, rather than using retrospective post-birth documentation. The study relied on reported alcohol consumption at conception, using that data to predict likely alcohol consumption throughout the pregnancy and its subsequent effect on prefrontal cortex development.⁴¹ Although alcohol consumed at conception is a predictor of continued prenatal alcohol use, using only this data precluded the study from being able to pinpoint the exact time in the pregnancy at which the relevant brain development was affected.⁴² The results nevertheless suggested that prenatal alcohol exposure had a negative impact on the growth of the prefrontal cortex, with 46% of heavily exposed foetuses exhibiting a prefrontal cortex length below the 25th percentile.⁴³

C. The Hippocampus

Exposure to alcohol during the second trimester of pregnancy can alter neuronal migration, impair the timing of cell proliferation and reduce neuron and cell numbers in the hippocampus, a region of the cerebral cortex that focuses on learning, memory and executive function.⁴⁴ Deficits in cell numbers and synapse formation suggest pre-natal alcohol exposure can interfere with the neuronal circuitry that is necessary for the proper functioning of the hippocampus.⁴⁵ The three main regions of the hippocampus, when functioning properly, work together to encode spatial memory.⁴⁶ Impairments in spatial memory are commonly observed in both adults and children with FASD through the use of fMRI

³⁶ Ana Sanjuán and others “Dissociating the semantic function of two neighbouring subregions in the left lateral anterior temporal lobe” (2015) 76 *Neuropsychologia* 153 at 153.

³⁷ Zhou, above n 33 at 22.

³⁸ Zhou, above n 33 at 23.

³⁹ Bruce D. Perry and Maia Szalavitz *The Boy Who Was Raised as a Dog* (Basic Books, New York, 2008) at 22.

⁴⁰ Tara S. Wass, Wayne H. Persutte and John C. Hobbins “The impact of prenatal alcohol exposure on frontal cortex development in utero” (2001) 185 *Am J Obstet Gynecol* 737 at 738.

⁴¹ Wass, Persutte and Hobbins, above n 40 at 738.

⁴² Wass, Persutte and Hobbins, above n 40 at 741.

⁴³ Wass, Persutte and Hobbins, above n 40 at 741.

⁴⁴ Patten, above n 24 at 34.

⁴⁵ Patten, above n 24 at 29.

⁴⁶ Patten, above n 24 at 32.

(Functional Magnetic Resonance Imaging).⁴⁷ One possible explanation for these specific impairments is the impact of oxidative stress on synaptic plasticity.⁴⁸

Synaptic plasticity is the ability of synapses to strengthen or weaken depending on their required use and is incredibly important during the early stages of the developing brain.⁴⁹ A change in plasticity may contribute to the persistent effects seen in neurodevelopmental disorders such as FASD, and it is possible that an increase in oxidative stress is an explanation for decreased synaptic plasticity.⁵⁰ Alcohol exposure during pregnancy can cause oxidative stress.⁵¹ The ethanol in the alcohol can increase the generation of reactive oxygen and reactive nitrogen species, the over-accumulation of which can cause cell damage in the brain.⁵² Oxidative stress is particularly damaging to a foetus because developing cells do not possess the same levels of antioxidant that can be found in mature cells.⁵³ The apoptosis of such sensitive cells can also adversely affect the functioning of the surviving cells, and these oxidative stress-related imbalances correlate with FASD-related spatial learning deficits.⁵⁴

The successful functioning of the hippocampus is intrinsically linked to the effective functioning of other regions of the brain (for example, the prefrontal cortex).⁵⁵ If considerable cell loss occurs within the structure of the developing hippocampus, either as a result of oxidative stress or apoptosis caused by general ethanol exposure, it is reasonable to assume that cortical and subcortical areas linked to the hippocampus may also be affected.⁵⁶ An easy way to understand this relationship is to think of the brain as a symphony orchestra, and brain-dependent functioning as the resulting music; no single system is responsible for the sound of the ‘music’ you actually hear, and each individual component is connected to and interdependent on the others.⁵⁷ The third trimester of pregnancy represents a very specific temporal window of vulnerability for the developing hippocampus, and it has been observed that even a single incidence of binge alcohol exposure during this time can have long-lasting effects on hippocampal structure.⁵⁸ If a large loss of cells does occur in this region of the brain focused on learning and memory, subsequent loss of function in tasks dependent on hippocampal or interconnected structures may be observed in the child or adult as a result of prenatal alcohol exposure.⁵⁹

A New Zealand study conducted in 2014 is important because it identified that a single binge exposure to ethanol could have long-lasting effects on the development and functioning of

⁴⁷ Patten, above n 24 at 34.

⁴⁸ Patten, above n 24 at 45.

⁴⁹ Patten, above n 24 at 44.

⁵⁰ Patten, above n 24 at 45.

⁵¹ Katarzyna Mantha, Benjamin I. Laufer and Shiva M. Singh “Molecular Changes during Neurodevelopment following Second-Trimester Binge Ethanol Exposure in a Mouse Model of Fetal Alcohol Spectrum Disorder: From Immediate Effects to Long-Term Adaptation” (2014) 36 *Dev Neurosci* 29 at 38.

⁵² Patten, above n 24 at 20.

⁵³ Patten, above n 24 at 21.

⁵⁴ Mantha, Laufer and Singh, above n 51 at 38.

⁵⁵ Paul Shoemack “Drinking During the Third Trimester of Pregnancy: a Cause for Concern” (PhD Thesis, University of Otago, 2014) at 82.

⁵⁶ Shoemack, above n 55 at 28.

⁵⁷ Perry and Szalavitz, above n 39 at 22.

⁵⁸ Shoemack, above n 55 at 82.

⁵⁹ Shoemack, above n 55 at 82.

the brain.⁶⁰ The findings suggested that women who do drink during pregnancy usually do not drink in moderation on multiple successive days, but rather engage in binge drinking episodes spaced throughout the pregnancy.⁶¹ Studies that focus on the developmental effects of a single binge alcohol exposure during a particular time in the pregnancy are therefore more likely to accurately reflect the subsequent behavioural and social traits observed in individuals who were prenatally exposed to alcohol.

D. Summary

Prenatal alcohol exposure can have a negative, long-lasting impact on fetal development.⁶² Although significant, prolonged or heavy dose exposure can result in visible impairments in the resulting child such as impaired facial structure, damage to major organs or skeletal deformities, the source of the most serious damage is ‘hidden’ in the brain.⁶³ These hidden impacts have resulted in FASD being termed the “invisible disability”.⁶⁴ The brain is an incredibly complex organ and necessitates an equally complex pattern of early development. Exposure to alcohol can interrupt this pattern, resulting in a variety of developmental impairments. Difficulties in assessing exactly where, when and how these interruptions occur have not precluded numerous studies determining that ethanol exposure *in utero* has a permanent, devastating effect on brain development and subsequent functioning. The various behavioural and social traits exhibited in individuals with FASD certainly reflect many of the conclusions reached by studies examining the physiological effect of prenatal alcohol exposure.⁶⁵

III. Social and behavioural traits of individuals with FASD

The ‘hidden’ damage to the brain as a result of prenatal exposure to alcohol can lead to a raft of social and behavioural problems.⁶⁶ These problems will present differently in each individual, depending on the timing and severity of exposure, and the exact region of the brain affected. Some commonly recurring patterns of behaviour do, however, reflect the likely negative impact on several areas of the brain responsible for behaviours such as planning and coordination, social understanding, executive functioning, and learning from consequences.⁶⁷ As will be discussed in further detail in Chapter Three, some exhibited behaviours (such as confabulation) have a direct impact on youth offending and the escalation of behaviour in the context of police apprehension and subsequent court processes.⁶⁸

⁶⁰ Shoemack, above n 55 at 148.

⁶¹ Shoemack, above n 55 at 148.

⁶² Ministry of Health, Above n 21 at 3.

⁶³ Ministry of Health, above n 21 at 4.

⁶⁴ Fetal Alcohol Network NZ “Fetal Alcohol Spectrum Disorder” Fetal Alcohol Network NZ www.fan.org.nz

⁶⁵ See for example: Truman E. Coggins, GERALYN R. TIMLER and LESLEY B. OLSWANG “A State of Double Jeopardy: Impact of Prenatal Alcohol Exposure and Adverse Environments on the Social Communicative Abilities of School-Age Children with Fetal Alcohol Spectrum Disorder” (2007) 38 Lang Speech Hear Serv Sch 117 at 119.

⁶⁶ Ministry of Health, above n 21 at 4.

⁶⁷ Ministry of Health, above n 21 at 4.

⁶⁸ Valerie McGinn “Fetal Alcohol Spectrum Disorder and Confabulation” (May 2013) at 1.

A. General: Adaptive Behaviour

Adaptive behaviour refers to “real world competence” as a measure of ability, rather than focusing purely on IQ.⁶⁹ Adaptive behaviour includes communication ability, self-direction, maintaining health and safety, and participating in leisure and social activities.⁷⁰ The term evolved from a perceived over-reliance on IQ in measuring intellectual disability, which eventually came to be identified as an absence of three forms of intelligence: conceptual intelligence (IQ), practical intelligence (everyday living) and social intelligence.⁷¹ Social intelligence is particularly relevant when considering FASD, as the exercise of poor social judgement has the potential for legal consequences (whether as defendant or victim).⁷² As a result, measures of adaptive behaviour (which typically focus on the two prongs of social intelligence and practical intelligence) can be extremely valuable in assessing the competence of an individual with FASD, regardless of how high their level of intellectual functioning may be.⁷³

Most measures of adaptive behaviour use a “rating instrument” that lists certain activities involved in everyday life.⁷⁴ “Raters” (such as caregivers, teachers or doctors) are asked whether the individual being assessed can always, sometimes or never perform the particular task listed.⁷⁵ When considering the results of these measures for individuals with FASD, it is important to note that with individuals in the higher functioning range of intellectual impairment, there is typically a mixed pattern of functioning – while an individual may score strongly in some areas, they may be severely compromised in others.⁷⁶ The Vineland Adaptive Behaviour Scale⁷⁷ is one such measure that is widely used, including within the FASD programme at the University of Washington.⁷⁸ A study assessing the effectiveness of the measure in identifying FASD found that differences in adaptive functioning (such as exhibited impulsivity and insensitivity to social cues) for patients with FASD were more profound than the differences observed in IQ or achievement tests.⁷⁹ The important point to note in discussing adaptive behaviour is that individuals with FASD are likely to exhibit a range of behaviours which are not necessarily consistent with intellectual disability in every case.

A case study involving a child’s late-diagnosis of FASD provides a useful illustration of the discrepancy between intellectual ability and executive function.⁸⁰ In this case, the child’s diagnosis revealed that her level of executive functioning deficit was much more severe than

⁶⁹ William J. Edwards and Stephen Greenspan “Adaptive behaviour and Fetal Alcohol Spectrum Disorders” (2010) 38 *Journal of Psychiatry and Law* 419 at 420.

⁷⁰ Andi Crawford “Fetal Alcohol Spectrum Disorder, Adaptive Behaviour and Children’s Development” (May 2013) at 1.

⁷¹ Edwards and Greenspan, above n 69 at 422.

⁷² Edwards and Greenspan, above n 69 at 423.

⁷³ Edwards and Greenspan, above n 69 at 432.

⁷⁴ Edwards and Greenspan, above n 69 at 425.

⁷⁵ Edwards and Greenspan, above n 69 at 425.

⁷⁶ Edwards and Greenspan, above n 69 at 427.

⁷⁷ The Vineland Adaptive Behaviour Scale is a psychometric instrument used for children and young people with a variety of developmental disorders and delays.

⁷⁸ Edwards and Greenspan, above n 69 at 432.

⁷⁹ Edwards and Greenspan, above n 69 at 433.

⁸⁰ Edwards and Greenspan, above n 69 at 437.

her level of intellectual functioning would suggest.⁸¹ Based on the results of a rating scale similar to that discussed above, the child was found to: be highly impulsive; often act before considering consequences; have poor judgement in whom she trusts; be overly friendly with strangers; be too easily led by others (gullibility); need strong, clear commands because the fine points escape her; be unaware of the consequences of her behaviour (especially the social consequences); be very hyperactive; overreact to things; and be fearless and lack insight into potential danger.⁸² As was identified at the time, “a fuller and more accurate statement of the typical behavioural profile of someone with FASD [...] would be difficult to provide”, despite the child’s IQ being in the normal range.⁸³

B. Confabulation

Confabulation refers to an exhibited behaviour in which an individual produces fabricated or distorted perceptions.⁸⁴ It is distinct from lying, because the fabrication occurs without any conscious intention to deceive.⁸⁵ In the case of FASD, confabulation occurs because the individual concerned may not have the ability to base what they say in reality and to check it against the available evidence.⁸⁶ As a result, the individual producing the fabrication may completely believe what they say to be true, therefore appearing very convincing to an onlooker. This was evident in a 2008 study examining lie-telling in children with FASD, focusing on the children’s semantic leakage control – in other words, their ability to “cover up” their lie and keep their story consistent.⁸⁷ The study found that children with FASD were more likely to lie (94% lied compared with 72% of the controls), but were also more likely to provide a story consistent with their lie (58% compared with only 38% of the controls).⁸⁸ These findings support the contention that children with FASD tend to produce an answer they think is expected of them, regardless of whether they have evidence to support that response or not.⁸⁹ This issue is further discussed in Chapter Three in relation to its implication for youth offending.

C. Social Communicative Abilities/Language

In order for children to become competent communicators, there are three main processes they are required to develop and maintain: language, social cognition and higher order executive functions.⁹⁰ Language is important because it becomes the primary means by which older children establish and maintain relationships; social cognition is an essential tool for interpreting the social world; and executive functioning allows an individual to “plan, integrate and update his or her language and social cognitive abilities in accordance

⁸¹ Edwards and Greenspan, above n 69 at 437.

⁸² Edwards and Greenspan, above n 69 at 440.

⁸³ Edwards and Greenspan, above n 69 at 440.

⁸⁴ McGinn, above n 68 at 1.

⁸⁵ McGinn, above n 68 at 1.

⁸⁶ McGinn, above n 68 at 1.

⁸⁷ Carmen Rasmussen and others “Brief Report: Lie-telling in Children with Fetal Alcohol Spectrum Disorder” (2008) 33 *Journal of Pediatric Psychology* 220 at 221.

⁸⁸ Rasmussen, above n 87 at 223.

⁸⁹ McGinn, above n 68 at 1.

⁹⁰ Truman E. Coggins, Geralyn R. Timler and Lesley B. Olswang “A State of Double Jeopardy: Impact of Prenatal Alcohol Exposure and Adverse Environments on the Social Communicative Abilities of School-Age Children with Fetal Alcohol Spectrum Disorder” (2007) 38 *Lang Speech Hear Serv Sch* 117 at 119 at 118.

with the demands of the particular situation”.⁹¹ As such, executive functioning can be seen as the most important aspect of this model. The prefrontal cortex is the region of the brain that is responsible for executive functioning⁹², and as discussed above, its growth and subsequent functioning is likely to be adversely impacted by exposure to alcohol *in utero*.

i. Language

Effective language development has been found to be highly correlated to brain maturation, which is often disrupted in children with FASD.⁹³ Narrative analysis has been used as a practical method of assessing developmental deficiencies in children’s language abilities, and was used in a 2007 study to identify the utility of narrative analysis as a diagnostic tool in FASD.⁹⁴ The study, which assessed the narrative discourse of 32 school-aged children (half of whom presented clinical features consistent with FASD and half of whom were considered to be developing typically), acknowledged that narrative is an effective means of identifying children’s language abilities, as it provides a vehicle through which children can exhibit appropriate use of discourse within a wholly pragmatic context.⁹⁵ The study assessed the children’s abilities to keep entities and events distinct when creating narrative, and referred to “ambiguous nominal reference” to describe the narrative deficiencies exhibited by the FASD group.⁹⁶ Ambiguous nominal reference was said to occur when the story-teller chose a word that failed to either introduce or unambiguously reference a particular concept.⁹⁷ For example, a child may use the ambiguous phrase “a boy” to reference an already existing concept (*the boy*), or may “introduce” a new form as though it were already familiar (for example, “*the boy*” to introduce *a boy* or “*the shouting*” to introduce an event).⁹⁸ The children with FASD were far more likely to use such pragmatically inappropriate strategies for introducing or maintaining concepts in their stories and, as a result, these children were less likely to be able to distinguish between shared information and new information in stories.⁹⁹

ii. Social cognition

Social cognition refers to how children think about the social world.¹⁰⁰ Caregivers of children with FASD have consistently reported that the children seem unable to empathise and appear to have genuine difficulty anticipating the consequences of their actions.¹⁰¹ One specific aspect of social cognition that is considered of crucial importance is the ability to make inferences about what other people believe in a given situation.¹⁰² This skill is known

⁹¹ Coggins, above n 90 at 119.

⁹² Paul Tough *How Children Succeed: Confidence, Curiosity and the Hidden Power of Character* (Arrow Books, London, 2014) at 18.

⁹³ See Chapter 2, section II.

⁹⁴ John C. Thorne and others “Exploring the Utility of Narrative Analysis in Diagnostic Decision Making: Picture-Bound Reference, Elaboration, and Fetal Alcohol Spectrum Disorders” (2007) 50 *J. Speech Lang Hear Res* 459.

⁹⁵ Thorne, above n 94 at 460.

⁹⁶ Thorne, above n 94 at 469.

⁹⁷ Thorne, above n 94 at 469.

⁹⁸ Thorne, above n 94 at 469.

⁹⁹ Coggins, above n 90 at 119.

¹⁰⁰ Coggins, above n 90 at 119.

¹⁰¹ Coggins, above n 90 at 119.

¹⁰² Coggins, above n 90 at 119.

as “false-belief understanding” and children with FASD have been found to struggle with false-belief tasks, even when they are presented in a straight forward manner.¹⁰³ This deficiency may, in part, be due to FASD children having difficulties using language to describe their own state of mind let alone the states of mind of those around them.¹⁰⁴

iii. Higher order executive function

Higher order executive functions are what the brain engages at the beginning of a task or when confronted with a novel challenge.¹⁰⁵ Executive function encompasses behaviours such as abstract thought, planning and deliberate decision-making.¹⁰⁶ In the context of social communicative abilities, it is these higher order executive functions that allow a child to disengage from the immediate situation and reflect and reason about interpersonal goals.¹⁰⁷ It is the result of this reflection that will lead a competent communicator to adjust his or her language or social perception in accordance with what the particular communicative context demands.¹⁰⁸ Findings reveal that children with FASD have difficulties in concept formation, response inhibition and self-regulation, all of which reflect a general deficiency in executive function.¹⁰⁹ In the particular context of social communication, executive function deficits appear to constrain the amount of information children exposed to alcohol *in utero* can process, especially when confronted with more complex or unusual challenges.¹¹⁰

For children who do not have a neurodevelopmental disorder, or even for children who have intellectual disabilities but no FASD, social skills improve as the child matures.¹¹¹ However, the same skills, reliant on effective executive function, are seen to significantly *decrease* in children with FASD.¹¹² In New Zealand, this observed significant decrease could, in part, be attributed to the schooling system; children with additional learning needs are generally educated in mainstream schools. For primary school, in which the environment is relatively consistent and the main teacher remains the same, this does not pose significant problems – a child with FASD can be managed with structures and strategies to meet their needs.¹¹³ However, when a child transitions to high school, the environment becomes immediately more complex and stimulating, putting stress on a child’s executive functions that, in the case of a child with FASD, may not be adequate to cope with the demands of the transition.¹¹⁴ For a young person who finds planning, organising and social skills difficult, the new environment that high school presents can be particularly challenging and may lead to aggressive outbursts as a response to being unable to navigate its complexities.¹¹⁵ This form of acting out further reflects the executive function deficits mentioned above relating to impulse control and social communicative abilities.

¹⁰³ Coggins, above n 90 at 119.

¹⁰⁴ Coggins, above n 90 at 119.

¹⁰⁵ Coggins, above n 90 at 119.

¹⁰⁶ Perry and Szavalitz, above n 39 at 22.

¹⁰⁷ Coggins, above n 90 at 119.

¹⁰⁸ Coggins, above n 90 at 119.

¹⁰⁹ Coggins, above n 90 at 119.

¹¹⁰ Coggins, above n 90 at 119.

¹¹¹ Crawford, above n 70 at 2.

¹¹² Crawford, above n 70 at 2.

¹¹³ Crawford, above n 70 at 3.

¹¹⁴ Crawford, above n 70 at 3.

¹¹⁵ Crawford, above n 70 at 3.

D. Summary

The brain damage caused by exposure to ethanol *in utero* can have markedly different effects on social and behavioural traits depending on the nature of the individual's exposure. However, there are some exhibited behaviours that have become typical of a FASD profile; impulsiveness, fearlessness, poor judgement, an inability to link events with resulting consequences, and an inability to comprehend how their behaviour can affect others.¹¹⁶ The exhibition of these behaviours could be due to the likelihood that the cortex has been damaged through exposure, and the complex range of behaviours the cortex (and specifically the prefrontal cortex) is responsible for. As will be discussed in Chapter Three, an understanding of the commonality of these particular traits becomes incredibly important when considering youth offending, and the incidence of offending and recidivism among young people with FASD.

IV. The role of an adverse environment

Adverse childhood environments play a role in exacerbating the traits exhibited in young people with FASD. The effects of abusive or neglectful experiences during childhood can be described as trauma inflicted on the developing brain and can cause impaired organisation and function of important neural systems.¹¹⁷

As a child develops, their brain begins storing information based on previous experience; for example, if an infant approaches an elderly cat and gets hissed at, the infant's brain will store that information and will trigger a response (perhaps flinching or crawling away) next time an associated cue is experienced (for example, a cat's meow).¹¹⁸ Often, a response to a perceived threat will be triggered by the lower part of the brain, before the sensory input can even reach the higher cortical areas – the response will be subconscious.¹¹⁹ For infants and children growing up in an environment with pervasive threat, a set of mostly subconscious associations will be created between a raft of neutral cues and threats.¹²⁰ The cues may be as seemingly innocuous as a particular scent or a specific piece of music being played on the radio. When the child has been triggered by a neutral cue they are in a state of fear arousal, and their brain functions differently.¹²¹

The state of fear arousal is not necessarily a problem. After all, it is designed to prioritise functioning in the areas of our brain that will allow us to remove ourselves from the perceived threat or danger. However, when the state of fear arousal becomes persistent and pervasive, the organisation and functioning of the brain changes in a persistent and pervasive way.¹²² Use-dependent alterations in the brain's neurotransmitters become over-sensitised and dysfunctional, resulting in a set of maladaptive emotional, behavioural and cognitive

¹¹⁶ Timothy E. Moore and Melvyn Green "Fetal Alcohol Spectrum Disorder (FASD): A Need for Closer Examination by the Criminal Justice System" (2004) 19 C. R. 99 at 101.

¹¹⁷ Bruce D. Perry "Applying Principles of Neurodevelopment to Clinical Work with Maltreated and Traumatized Children" in *Working with Traumatized Youth in Child Welfare* (Guildford Press, New York, 2006) 27 at 29.

¹¹⁸ Perry, above n 117 at 33.

¹¹⁹ Perry, above n 117 at 32.

¹²⁰ Perry above n 117 at 34.

¹²¹ Perry, above n 117 at 34.

¹²² Perry, above n 117 at 36.

problems in the child.¹²³ The brain's stress response systems originate in the lower part of the brain, but help to regulate and organise the higher cortical areas.¹²⁴ If the lower parts of the brain are poorly regulated as a result of persistent stress, they will dysregulate the higher parts of the brain as well.¹²⁵

Unfortunately, children with FASD are disproportionately subject to negative or unpredictable caregiving environments, compounding their developmental difficulties.¹²⁶ The proportion of children with FASD having suffered from some form of abuse has been cited as high as 70%.¹²⁷ The socio-emotional difficulties experienced by children who have suffered trauma as discussed above may be exacerbated by existing communication deficits in the child.¹²⁸ As a result, a child with FASD may be particularly vulnerable to debilitating communication deficits as a result of "both the teratogenic effects of prenatal alcohol exposure and the erratic and atypical social interactive experiences that are associated with a maltreating environment".¹²⁹

V. *Diagnosis*

Diagnosis of FASD relies upon the identification of clusters of characteristics and a known or suspected history of prenatal alcohol exposure.¹³⁰ Accurate diagnosis of FASD is essential to mitigate "secondary disabilities" (such as mental health problems, defensive behaviour, isolation, unemployment and criminal activity)¹³¹ by putting in place targeted interventions and services.¹³² Access to diagnosis in New Zealand is difficult, and despite an attempt by Alcohol Healthwatch New Zealand (Alcohol Healthwatch) to standardise the approach in 2010, developments have been slow and funding is limited.¹³³ New Zealand still does not have a formalised guide for diagnosing FASD. The Canadian Medical Association published Canadian guidelines for diagnosis in 2005, streamlining their approach to diagnosing FASD nationwide (see Chapter Four).¹³⁴ Alcohol Healthwatch tried to follow suit in 2010, and recent training of health professionals in the sector suggests that New Zealand is recognising the importance of having a streamlined national approach. This is also reflected in the work already being undertaken in Hawke's Bay through their Developmental Assessment Pathway.¹³⁵

¹²³ Perry, above n 117 at 37.

¹²⁴ Perry, above n 117 at 38.

¹²⁵ Perry, above n 117 at 38.

¹²⁶ Coggins, above n 90 at 125.

¹²⁷ Craig Immelman "Fetal Alcohol Spectrum Disorder and Youth Justice in New Zealand" (Alcohol Action New Zealand 3rd Annual Conference 2012, University of Otago, Wellington).

¹²⁸ Coggins, above n 90 at 120.

¹²⁹ Coggins, above n 90 at 120.

¹³⁰ Margaret Mallinson Symes "The Legacy of Prenatal Exposure to Alcohol: Fetal Alcohol Spectrum Disorder, the New Zealand Situation" (PhD Thesis, Massey University, 2004) at 29.

¹³¹ Alcohol Healthwatch "Towards Multidisciplinary Diagnostic Services for Fetal Alcohol Spectrum Disorder" (Alcohol Healthwatch, 2010) at 11.

¹³² Albert E. Chudley and others "Fetal alcohol spectrum disorder: Canadian guidelines for diagnosis" (2005) 172 CMAJ s1 at 2.

¹³³ Alcohol Healthwatch, above n 131 at 21.

¹³⁴ Chudley, above n 132.

¹³⁵ Health Promotion Agency "Hawke's Bay District Health Board Developmental Assessment Programme FASD Assessment Pathway: Process Evaluation" (2015).

A. Alcohol Healthwatch Recommendations

In 2010, Alcohol Healthwatch, a charitable trust with the aim of reducing and preventing alcohol-related harm in New Zealand, produced a report recommending the development of diagnostic services for FASD.¹³⁶ The report highlighted the need for diagnosis as “pivotal” in preventing future cases of FASD and as working to provide a protective factor against secondary disabilities.¹³⁷ The recommendations emerged from a project that began in 2008 to establish a framework of diagnostic practice in New Zealand.¹³⁸ One of the main conclusions drawn from the project is broadly similar to that found in Canada: that a multi-disciplinary approach is essential to reflect the multifaceted nature of FASD.¹³⁹ The report begins by examining knowledge and practice of screening for FASD in New Zealand, before analysing current diagnostic options and concluding with recommendations for a streamlined national approach to be implemented throughout the country.

i. Knowledge and practice in New Zealand

An Alcohol Healthwatch survey of health professionals in 2009 sought to establish the level of knowledge of FASD in New Zealand and how it was being screened for.¹⁴⁰ Seventy-eight per cent of those surveyed reported “screening”, but most only to the extent that they asked a patient a single question: “do you drink?”¹⁴¹ Over half of the participants involved indicated that training was needed to be able to effectively assess the risks of alcohol.¹⁴² The overwhelming majority agreed that early diagnosis had the potential to make a significant positive impact in a child’s life, but a lot of participants felt diagnosis would be stigmatising.¹⁴³ Interestingly, a 2008 New Zealand survey assessing the experiences of birth mothers with children affected by FASD found the opposite.¹⁴⁴ The survey, which involved unstructured interviews with eight women who had nurtured or were still caregivers for their child with FASD, found that rather than feeling stigmatised, the predominant feeling post-diagnosis was relief.¹⁴⁵ Often the children had had multiple incorrect diagnoses before their diagnosis of FASD, and the mothers were pleased to have accurate knowledge about their child and an explanation for the child’s confusing behaviours.¹⁴⁶ The findings of this survey are consistent with the perception reflected in the Canadian Guidelines for Diagnosis, that “rather than labelling, a diagnosis provides a blueprint for early intervention”.¹⁴⁷

¹³⁶ Alcohol Healthwatch, above n 133.

¹³⁷ Alcohol Healthwatch, above n 133 at 5.

¹³⁸ Alcohol Healthwatch, above n 133 at 6.

¹³⁹ Alcohol Healthwatch, above n 133 at 6.

¹⁴⁰ Alcohol Healthwatch, above n 133 at 20.

¹⁴¹ Alcohol Healthwatch, above n 133 at 20.

¹⁴² Alcohol Healthwatch, above n 133 at 20.

¹⁴³ Alcohol Healthwatch, above n 133 at 20.

¹⁴⁴ Jenny Salmon “Fetal Alcohol Spectrum Disorder: New Zealand Birth mothers’ Experiences” (2008) 15(2) *Can J Clin Pharmacol* e191.

¹⁴⁵ Salmon, above n 144 at e202.

¹⁴⁶ Salmon, above n 144 at e202.

¹⁴⁷ Chudley, above n 132 at 14.

ii. Multidisciplinary diagnosis

Alcohol is a non-specific teratogen, which means there can be no consistent neurocognitive profile specific to FASD.¹⁴⁸ Alcohol Healthwatch acknowledges that all current diagnostic guidelines advocate for a multidisciplinary approach in diagnosing FASD.¹⁴⁹ With an understanding of the complexities of the disorder and the multiple regions of the brain that can be affected, it is readily apparent why this is the case. FASD is a medical, rather than a mental health, diagnosis and so a registered medical practitioner is a crucial component of any diagnostic team.¹⁵⁰ However, as outlined above, there is a significant neurobehavioural aspect to FASD, necessitating the involvement of a clinical psychologist.¹⁵¹ The psychologist's specific role may vary depending on the particular patient's presentation, but will generally include identifying strengths and weaknesses, determining cognitive difficulties and determining consistency of symptoms with research on FASD.¹⁵²

iii. Towards a framework for FASD diagnosis in New Zealand

The overall aim of the project conducted by Alcohol Healthwatch was to “ascertain the clinical elements required for establishing a multidisciplinary approach to FASD diagnosis in New Zealand”.¹⁵³ The team assembled for the project comprised: two psychiatrists, a paediatrician, three neuropsychologists, a speech-language therapist and a team co-ordinator.¹⁵⁴ Intensive training in FASD diagnosis was provided to the team at the Asante Centre in Canada, a not-for-profit organisation focused on providing services and support related to FASD.¹⁵⁵ Once training had been provided, the major focus of the project was to establish a best-practice approach to FASD diagnosis in New Zealand, and to apply this approach to the Youth Court-directed psychiatric assessment process.¹⁵⁶

Section 333 of the OT Act allows for the Court involved in a young person's proceedings to make an order for a medical, psychiatric or psychological report to be made available.¹⁵⁷ Alcohol Healthwatch did not intend to limit the project's scope to the youth justice sector, but used s 333 of the OT Act to focus their approach and ensure objectives were met within a relatively short time-frame.¹⁵⁸

Throughout the course of the project, 11 FASD assessments were completed, spanning childhood, adolescence and adulthood.¹⁵⁹ Four of the cases were young people on charges before the Youth Court, three were children, two were internationally adopted adolescents and two were adults.¹⁶⁰ Of the cases assessed, eight were found to have disorders consistent

¹⁴⁸ Alcohol Healthwatch, above n 133 at 29.

¹⁴⁹ Alcohol Healthwatch, above n 133 at 27.

¹⁵⁰ Alcohol Healthwatch, above n 133 at 28.

¹⁵¹ Alcohol Healthwatch, above n 133 at 28.

¹⁵² Alcohol Healthwatch, above n 133 at 28.

¹⁵³ Alcohol Healthwatch, above n 133 at 33.

¹⁵⁴ Alcohol Healthwatch, above n 133 at 34.

¹⁵⁵ The Asante Centre www.asantecentre.org.

¹⁵⁶ Alcohol Healthwatch, above n 133 at 33.

¹⁵⁷ Oranga Tamariki Act 1989 s 333.

¹⁵⁸ Alcohol Healthwatch, above n 133 at 34.

¹⁵⁹ Alcohol Healthwatch, above n 133 at 34.

¹⁶⁰ Alcohol Healthwatch, above n 133 at 34.

with a diagnosis of FASD using the 4-digit diagnostic code.¹⁶¹ Three of the four young people on charges before the Youth Court were included in this group.¹⁶² The assessments involved each clinician conducting their part of the diagnosis individually, and then meeting with the rest of the team on the same day to discuss their findings.¹⁶³ The team would form a consensus based on this discussion, and would present the results in a meeting with the patient's family.¹⁶⁴ A final report was written for each assessment after these meetings.¹⁶⁵

Three case examples were provided in the Alcohol Healthwatch report.¹⁶⁶ The examples are useful to illustrate the diagnostic process followed and how the results were reached in each case.¹⁶⁷ An example of the assessment of one of the young people facing charges in the Youth Court has been summarised below.

Case Example: 15 year-old male

This young person was referred by the Youth Court having been charged with unlawful sexual connection.¹⁶⁸ His background presented a profile all too common in the Youth Court: exposure to domestic violence, parental substance abuse, parental imprisonment, abuse, Oranga Tamariki (formerly Child, Youth, and Family) involvement, ineffective education and no prior intervention despite several years of inappropriate sexual behaviour.¹⁶⁹

Using the 4-digit diagnostic code as a guide, the assessment included an analysis of alcohol exposure, a medical examination and neuropsychological testing.¹⁷⁰ Alcohol exposure was given a ranking of 3 (some risk); exposure was confirmed by the mother, but the pattern of use or level of consumption remained unknown.¹⁷¹ The medical examination found mild growth deficit and a mild expression of the characteristic Fetal Alcohol Syndrome (FAS) facial features.¹⁷² The neuropsychological testing revealed significant deficits, with an IQ score of 66 and adaptive functioning score of 59.¹⁷³ The young person was given a Central Nervous System (CNS) rank of 3, representing significant dysfunction.¹⁷⁴

The diagnostic outcome for this young person, using the 4-digit diagnostic code, was 2-2-3-3, which constitutes an alcohol-related neurodevelopmental disorder according to the 2005 Canadian guidelines.¹⁷⁵ It was found, however, that there was not sufficient evidence to

¹⁶¹ Alcohol Healthwatch, above n 133 at 35. The 4-digit diagnostic code is a method of diagnosing FASD that attributes a score (1-4) to four diagnostic features of FASD (growth, facial features, central nervous system and prenatal alcohol exposure) to reflect the magnitude of expression and indicate a diagnostic category. After the Canadian Guideline to Diagnosis was updated in 2015, the 4-digit code and its associated diagnostic categories (Fetal Alcohol Syndrome, Partial Fetal Alcohol Syndrome, Alcohol Related Neurodevelopmental Disorders and Fetal Alcohol Effects) were no longer used in Canada or New Zealand.

¹⁶² Alcohol Healthwatch, above n 133 at 61-64.

¹⁶³ Alcohol Healthwatch, above n 133 at 35.

¹⁶⁴ Alcohol Healthwatch, above n 133 at 35.

¹⁶⁵ Alcohol Healthwatch, above n 133 at 35.

¹⁶⁶ Alcohol Healthwatch, above n 133 at 36.

¹⁶⁷ Alcohol Healthwatch, above n 133 at 36.

¹⁶⁸ Alcohol Healthwatch, above n 133 at 40.

¹⁶⁹ Alcohol Healthwatch, above n 133 at 40.

¹⁷⁰ Alcohol Healthwatch, above n 133 at 40.

¹⁷¹ Alcohol Healthwatch, above n 133 at 40.

¹⁷² Alcohol Healthwatch, above n 133 at 40.

¹⁷³ Alcohol Healthwatch, above n 133 at 40.

¹⁷⁴ Alcohol Healthwatch, above n 133 at 40.

¹⁷⁵ Alcohol Healthwatch, above n 133 at 40.

indicate the young person was unfit to stand trial, and so a high and complex needs package of care, and attendance at a Safe¹⁷⁶ programme, were advised.¹⁷⁷

iv. Summary

The project conducted by Alcohol Healthwatch demonstrated that providing in-depth assessment for FASD was possible within an integrated clinical setting, and that such an approach would save time and money long-term.¹⁷⁸ As one physician involved noted, if no diagnostic process for FASD is established, “these children [will be] seen over and over for semi-assessments”, and people will continue to fall through the cracks.¹⁷⁹ Importantly, the project also confirmed that the assessment process is robust enough to exclude individuals who fall short of the diagnostic criteria, which suggests there is little risk of over-diagnosis.¹⁸⁰

The report concludes with a list of policy recommendations for New Zealand, with an emphasis on developing New Zealand-based diagnostic guidelines for FASD.¹⁸¹ Recent developments signal that a standardised approach to diagnosing FASD in New Zealand has begun, and guidelines will be published in the near future.¹⁸² The Hawke’s Bay District Health Board (DHB) has already formulated an assessment pathway for identifying FASD in young people who present with symptoms of neurodevelopmental disorder, and has recommended nationwide adoption of its process.

B. The Hawke’s Bay District Health Board FASD Assessment Pathway

The Hawke’s Bay DHB has developed a Developmental Assessment Programme (DAP) which provides multidisciplinary diagnostic assessments of children who present with developmental or behavioural issues.¹⁸³ The DAP recognises the complexity of developmental disorders generally and so incorporates a training scheme within the programme.¹⁸⁴ Through the scheme, the programme offers training in developmental and behavioural conditions for people working in health, education and social services.¹⁸⁵ The FASD Assessment Pathway is one component of the DAP, and reflects aspects of both the Canadian guidelines for diagnosis and the recommendations made by Alcohol Healthwatch in 2010.

The FASD Assessment Pathway follows a two-stage approach: screening, followed by multidisciplinary assessment.¹⁸⁶

¹⁷⁶ Safe is a community-based provider of clinical assessment and intervention services for individuals with concerning sexual behaviour.

¹⁷⁷ Alcohol Healthwatch, above n 133 at 41. SAFE is a not-for-profit network in New Zealand focused on addressing harmful sexual behaviours: see www.safenetwork.org.nz.

¹⁷⁸ Alcohol Healthwatch, above n 133 at 45.

¹⁷⁹ Alcohol Healthwatch, above n 133 at 45.

¹⁸⁰ Alcohol Healthwatch, above n 133 at 46.

¹⁸¹ Alcohol Healthwatch, above n 133 at 52.

¹⁸² Personal Communication (Dr Valerie McGinn), 5 July 2016.

¹⁸³ Health Promotion Agency, above n 135 at 5.

¹⁸⁴ Health Promotion Agency, above n 135 at 5.

¹⁸⁵ Health Promotion Agency, above n 135 at 5.

¹⁸⁶ Health Promotion Agency, above n 135 at 13.

i. Screening

Screening occurs as a stop-gap measure for the FASD Assessment Pathway and will be triggered if a child has significant developmental or behavioural issues and FASD is a consideration.¹⁸⁷ The exact process the screening stage follows is dependent on whether the child is already under the care of Hawke's Bay DHB paediatrics or a new referral; however, the significant aspects remain the same.¹⁸⁸ Concerns are discussed with the family, a detailed history is taken including history of prenatal alcohol exposure, and data about growth, facial features and learning and behavioural problems is obtained.¹⁸⁹ At this point, the child is referred to the Child Development Service (CDS) for a more thorough assessment, and the formal diagnostic process begins.¹⁹⁰

ii. Multidisciplinary Assessment

The formal assessment process begins with a CDS allocation meeting, and ends with a report and feedback to the family.¹⁹¹ The process has been outlined below, to illustrate the way in which the Hawke's Bay DHB has closely followed the approach taken during the project conducted by Alcohol Healthwatch, as discussed above.

a) CDS Allocation Meeting

The CDS Allocation Meeting is held to allow a consensus to be reached among relevant individuals as to the best pathway to follow for the particular child being assessed.¹⁹² The meeting is attended by CDS and DAP representatives, paediatricians, Child, Adolescent and Family Services (CAFS), and Needs Assessment Services Co-ordinator service representatives.¹⁹³ The meeting is a collaborative process, and serves to provide sufficient information to inform either a referral on to DAP or to other services outside of the FASD Assessment Pathway.¹⁹⁴ Children who are referred onto DAP at this stage go on the FASD Assessment Pathway wait-list and are seen in turn.¹⁹⁵

b) Engagement (Initial Visit)

Once accepted into the programme from the wait-list, the child and their whānau are visited by the DAP co-ordinator.¹⁹⁶ The co-ordinator serves a vital role in the assessment process as a whole, connecting the family with the system and ensuring that what is expected of the whānau is within the limits of what they are able to cope with.¹⁹⁷ The co-ordinator reports back to the rest of the team and provides guidance on how best to deal with the family and what the best assessment process and mode of delivery is.¹⁹⁸ As part of the initial visit, the coordinator undertakes a holistic social assessment of the

¹⁸⁷ Health Promotion Agency, above n 135 at 13.

¹⁸⁸ Health Promotion Agency, above n 135 at 13.

¹⁸⁹ Health Promotion Agency, above n 135 at 13.

¹⁹⁰ Health Promotion Agency, above n 135 at 13.

¹⁹¹ Health Promotion Agency, above n 135 at 13-16.

¹⁹² Health Promotion Agency, above n 135 at 14.

¹⁹³ Health Promotion Agency, above n 135 at 13.

¹⁹⁴ Health Promotion Agency, above n 135 at 17.

¹⁹⁵ Health Promotion Agency, above n 135 at 14.

¹⁹⁶ Health Promotion Agency, above n 135 at 14.

¹⁹⁷ Health Promotion Agency, above n 135 at 14.

¹⁹⁸ Health Promotion Agency, above n 135 at 14.

family and provides support.¹⁹⁹ The support provided to the family includes information on FASD and behaviour management, advice regarding potential eligibility for services and linking the family to external services where appropriate (such as CAFS or the Ministry of Education).²⁰⁰

c) DAP Intake Meeting

The DAP Intake Meetings occur regularly, and once a child has been referred through to the FASD Assessment Pathway, specific team roles will be allocated for the child and a plan will be developed during the meeting.²⁰¹ The plan that is developed as a result of the meeting will be provided to the family.²⁰²

d) Assessment

Wherever possible, the assessments for each child are conducted at home, at the clinic and at school in order to get a full and accurate picture of the child's presentation.²⁰³ There are four distinct assessments completed during the process: a paediatric assessment, a speech-language assessment, a psychological assessment, and a social work assessment (gained over time).²⁰⁴ The multidisciplinary nature of the process reflects the guidelines and recommendations proposed by both Canada and Alcohol Healthwatch New Zealand.

The assessment process undertaken by the Hawke's Bay DHB is itself considered a form of intervention.²⁰⁵ The assessment involves the participation of individuals who play an integral role in the day-to-day life of the child, whether at home or at school.²⁰⁶ The therapeutic nature of the assessment process allows "those involved [...] to deepen their understanding of the child's needs and abilities and how best to respond to and work with the child".²⁰⁷

e) DAP Formulation Meeting

This step of the process is similar to the approach taken by Alcohol Healthwatch, in which the members of the team meet after their individual assessments to discuss their findings and reach a consensus.²⁰⁸ The purpose of the formulation meeting is to evaluate whether the particular child has met the diagnostic criteria.²⁰⁹ The outcomes relating to the diagnostic domains that were assessed are discussed and reviewed before a consensus is reached regarding the diagnostic status of the patient.²¹⁰ A diagnosis is then formulated, with accompanying recommendations.²¹¹

¹⁹⁹ Health Promotion Agency, above n 135 at 14.

²⁰⁰ Health Promotion Agency, above n 135 at 14.

²⁰¹ Health Promotion Agency, above n 135 at 14.

²⁰² Health Promotion Agency, above n 135 at 14.

²⁰³ Health Promotion Agency, above n 135 at 15.

²⁰⁴ Health Promotion Agency, above n 135 at 15.

²⁰⁵ Health Promotion Agency, above n 135 at 25.

²⁰⁶ Health Promotion Agency, above n 135 at 25.

²⁰⁷ Health Promotion Agency, above n 135 at 25.

²⁰⁸ Alcohol Healthwatch, above n 133 at 35.

²⁰⁹ Health Promotion Agency, above n 135 at 15.

²¹⁰ Health Promotion Agency, above n 135 at 15.

²¹¹ Health Promotion Agency, above n 135 at 15.

f) Comprehensive Report

A comprehensive, synthesised report is developed following the formulation meeting; it is written by one allocated team member, but follows a template that allows for input from each member of the assessment team.²¹² The report includes information on the assessment results for each step of the process, as well as the final diagnostic result and recommendations.²¹³

g) Feedback (family and school sessions)

The final aspect of the assessment process comes in the form of educating and supporting the family and school of the child.²¹⁴ The feedback sessions are delivered by at least two members of the assessment team: usually the paediatrician and another member of the team with an especially strong relationship with the family.²¹⁵ The sessions are educative in focus, and provide an opportunity for further discussion and clarification of the process and end result for all concerned.²¹⁶

iii. Review of the Hawke's Bay assessment process

A review of the Hawke's Bay DHB assessment process for FASD was conducted in 2015.²¹⁷ The report, commissioned by the Health Promotion Agency, found that the system constituted a robust multidisciplinary process with several important strengths.²¹⁸ The structure of the team (including key professional disciplines for FASD assessment), the vision and values of the programme, and the professional expertise of the individuals involved are three examples of the many positive aspects of the pathway identified in the report.²¹⁹ The report also examined the weaknesses of the approach, highlighting the significant time delay between referral and reporting back as an area particularly in need of improvement.²²⁰

The overwhelming conclusion reached by the report commissioned by the Health Promotion Agency was that similar programmes for FASD diagnosis should be developed throughout New Zealand.²²¹ The stakeholders interviewed as part of the report stated that "early detection and early intervention is essential".²²² It was acknowledged that the DAP FASD Assessment Pathway represented a best practice approach and provided a blueprint for other programmes to be developed.²²³ Additionally, it was noted that the "expertise now available within the DAP could provide invaluable support for further development" and that an extension

²¹² Health Promotion Agency, above n 135 at 15.

²¹³ Health Promotion Agency, above n 135 at 16.

²¹⁴ Health Promotion Agency, above n 135 at 16.

²¹⁵ Health Promotion Agency, above n 135 at 16.

²¹⁶ Health Promotion Agency, above n 135 at 16.

²¹⁷ Health Promotion Agency, above n 135.

²¹⁸ Health Promotion Agency, above n 135 at 23.

²¹⁹ Health Promotion Agency, above n 135 at 26-29.

²²⁰ Health Promotion Agency, above n 135 at 22.

²²¹ Health Promotion Agency, above n 135 at 41.

²²² Health Promotion Agency, above n 135 at 41.

²²³ Health Promotion Agency, above n 135 at 44.

of the programme was essential to reduce harm and promote health and wellbeing in children throughout New Zealand.²²⁴

A national diagnostic framework would align with the Government's goals outlined in the *White Paper for Vulnerable Children Volume I* (The White Paper).²²⁵ The White Paper called for approaches to be developed that identified, assessed, and linked vulnerable children with support services early and effectively.²²⁶ The Hawke's Bay FASD Assessment Pathway does just that by providing specialist services to vulnerable children and their families; however, it is a service that is currently not available to children and their families in all areas of New Zealand.²²⁷ Developing a framework and practice of diagnosing FASD in New Zealand should be a priority.

C. Recent diagnostic developments in New Zealand

From January 2016, over 40 clinicians nationwide in New Zealand began implementing their diagnostic training in FASD.²²⁸ The model used in New Zealand reflects that of the revised Canadian guidelines, with a focus on FASD as a diagnosis in itself, either with or without Sentinel Facial Features.²²⁹ Although currently the structure of the diagnostic teams vary, and do not reflect the diversity in discipline that is recommended as ideal by both the Canadian guidelines and the Alcohol Healthwatch recommendations, the emphasis is nonetheless on the multidisciplinary model of FASD diagnosis.²³⁰ Paediatricians and psychologists trained in FASD diagnosis collaborate to assess and follow-up with individuals affected by FASD, using the Canadian guidelines as a base model for diagnosis.²³¹

These recent developments are encouraging steps towards a fully recognised diagnostic service for FASD in New Zealand. Although the approach is currently under-funded and under-recognised, the clinicians involved have paved the way for a more formal diagnostic service being developed in New Zealand.

VI. Disability support in New Zealand

Disability support in New Zealand should be informed by the New Zealand Disability Strategy (the Disability Strategy)²³², released in 2016, and the United Nations Convention on the Rights of Persons with Disabilities (the CRPD). Together these documents require disability to be considered and understood through a social and rights-based model, where "disability is something that happens when people with impairments face barriers in society."²³³ The Disability Strategy therefore requires disability support in New Zealand to be developed consistently with the vision of a non-disabling society, where every human being is recognised as unique and where supports acknowledge that every individual's

²²⁴ Health Promotion Agency, above n 135 at 44.

²²⁵ Ministry of Social Development *The White Paper for Vulnerable Children Volume I* (Ministry of Social Development, 2012) at 3.

²²⁶ Ministry of Social Development, above n 225 at 9.

²²⁷ Health Promotion Agency, above n 135 at 42.

²²⁸ McGinn, above n 182.

²²⁹ McGinn, above n 182.

²³⁰ Personal Communication (Dr Valerie McGinn), 6 July 2016.

²³¹ McGinn, above n 230.

²³² Ministry of Social Development *New Zealand Disability Strategy 2016 – 2026* (Ministry of Social Development, November 2016).

²³³ Ministry of Social Development, above n 232 at 12.

experience of impairment will be different.²³⁴ The social model of disability is acknowledged in New Zealand’s inclusive approach to education, where schools must strive to eliminate the barriers to learning so that children with impairments can access education in a mainstream environment. Two approaches to fulfilling this goal are considered in this section: the Special Education Grant (SEG) and the Ongoing Resources Scheme (ORS).

A. The social model of disability

The first iteration of the Disability Strategy was published in 2001, and even then its focus was clear: disability in New Zealand should be understood according to the social model, which articulates the distinction between impairment and disability.²³⁵ While impairments are something individuals have (e.g., physical, sensory, neurological, intellectual), disability is what occurs when society is constructed around one group of people’s living situations, thereby creating barriers for all other individuals who differ from that group.²³⁶ This is distinct from the medical model of disability, which was historically the starting point for considering people with impairments, and which focuses on an individual’s impairment as something needing to be ‘fixed’ or ‘cured’.²³⁷ The medical model places the onus on the individual being different, rather than on society to cater for the differences that are an inherent part of being human.

The social model of disability evolved from the publication of the “Fundamental Principles of Disability” by the Union of the Physically Impaired Against Segregation (UPIAS) in the United Kingdom in the mid-1970s.²³⁸ The understanding articulated by UPIAS that society disables individuals with impairments, and that disability is “something imposed”, provided a catalyst for the disability rights movement, which had already achieved traction.²³⁹ Since then, the social model of disability has influenced law and policy worldwide, including in New Zealand, encouraging and requiring societies to adapt to cater for differences among the population, rather than requiring the individual to change who they are in order to participate effectively. The CRPD and the Disability Strategy are two examples of this movement that have relevance for young people with FASD in New Zealand.

²³⁴ Ministry of Social Development, above n 232 at 12.

²³⁵ Ministry of Health *The New Zealand Disability Strategy: Making a World of Difference Whakanui Oranga* (Ministry of Health, April 2001) at 7.

²³⁶ Ministry of Health, above n 235

²³⁷ Office for Disability Issues “History of disability in New Zealand” (8 December 2016) Office for Disability Issues www.odi.govt.nz/home/about-disability/history-of-disability-in-new-zealand/.

²³⁸ The Union of the Physically Impaired Against Segregation and the Disability Alliance “Fundamental Principles of Disability” (November 1976).

²³⁹ Above n 238 at 4.

B. The United Nations Convention on the Rights of Persons with Disabilities

i. History and establishment

On the 13th December 2006 the United Nations (UN) adopted the CRPD.²⁴⁰ It entered in to force on the 3rd May 2008 and represented a “great landmark” for the legal protection of human rights for people with disabilities.²⁴¹

The CRPD capitalised on a conceptual shift regarding persons with disabilities. The General Assmebly’s adoption of the Universal Declaration of Human Rights in 1948 established the core principle of equality for all.²⁴² Progress regarding international human rights norms followed, but disability was still conceptualised in the context of “rehabilitation, social protection, and welfare issues.”²⁴³ In 1950, several UN entities²⁴⁴ established standards for the education, training, treatment, and placement of persons with disabilities.²⁴⁵ These represented a first step in the shift in focus from people with disabilities as recipients of welfare to individuals entitled to exercise their rights in the same way as everyone else.²⁴⁶

In 1969 the General Assembly adopted a declaration calling for the protection, welfare, and full participation of persons with disabilities in society and, shortly afterwards, the concept that it is *society* that creates barriers to participation was born.²⁴⁷ Two international rights instruments were adopted in the 1970s²⁴⁸ and in 1981 the International Year of Disabled Persons promoted the full integration of disabled persons in society.²⁴⁹ 1981 represented a “pivotal year”²⁵⁰ for the advancement of rights for disabled persons, further cementing the understanding of disability from a social model perspective.²⁵¹ In 1982 the General Assembly adopted the World Programme of Action Concerning Disabled Persons “to achieve the goal of full and effective participation of persons with disabilities” and the UN ‘Decade of Persons with Disabilities’ followed.²⁵²

The CRPD has been described as a milestone document, with 81 states and the European Union signing at its opening ceremony on 30th March 2007.²⁵³ New Zealand ratified the CRPD on 25th September 2008 and made no reservations to the convention.²⁵⁴ It is the first legally binding human rights instrument that offers comprehensive protection for persons

²⁴⁰ Heather Stuart “United Nations Convention on the Rights of Persons with Disabilities: a roadmap for change” (2012) 25(5) *Curr Opin Psychiatry* 365 at 366.

²⁴¹ Stuart, above n 240 at 366.

²⁴² United Nations “The United Nations and Disability: 70 Years of the Work Towards a More Inclusive World” (United Nations, 23 January 2018) at 6.

²⁴³ United Nations, above n 242 at 6.

²⁴⁴ The International Labour Organisation, World Health Organisation, and United Nations Children’s Fund.

²⁴⁵ United Nations, above n 242 at 6.

²⁴⁶ United Nations, above n 242 at 6.

²⁴⁷ United Nations, above n 242 at 7.

²⁴⁸ The Declaration on the Rights of Mentally Retarded Persons (1971) and the Declaration on the Rights of Disabled Persons (1975).

²⁴⁹ United Nations, above n 242 at 8.

²⁵⁰ United Nations, above n 242 at 8.

²⁵¹ Stuart, above n 240 at 366.

²⁵² United Nations, above n 242 at 9.

²⁵³ Stuart, above n 240 at 366.

²⁵⁴ Ministry of Justice “Convention on the Rights of Persons with Disabilities” (11 May 2018) Ministry of Justice www.justice.govt.nz/justice-sector-policy/constitutional-issues-and-human-rights/human-rights/international-human-rights/crpd/

with physical or mental impairments, emphasising the social determinants of disability.²⁵⁵ The substantive provisions include both positive and negative rights, and people with developmental disabilities (a population often overlooked) are afforded broad protections.²⁵⁶

ii. Access to justice

Article 13 of the CRPD addresses access to justice and reads:²⁵⁷

1. States Parties shall ensure effective access to justice for persons with disabilities on an equal basis with others, including through the provision of procedural and age-appropriate accommodations, in order to facilitate their effective role as direct and indirect participants, including as witnesses, in all legal proceedings, including at investigative and other preliminary stages.

2. In order to help to ensure effective access to justice for persons with disabilities, States Parties shall promote appropriate training for those working in the field of administration of justice, including police and prison staff.

Paragraph one emphasises that access to justice needs to be *effective*, and the use of this word is significant. Federal Guidance provided for the American Disabilities Act 1990 articulates the meaning of the word effective, in the context of communication assistance for persons with disabilities:²⁵⁸

What does it mean for communication to be “effective”? Simply put, “effective communication” means that whatever is written or spoken must be as clear and understandable to people with disabilities as it is for people who do not have disabilities.

Interpreting the use of the word in the CRPD in a similar way, effective access to justice (which includes access to police, prisons, courts, tribunals, and “other instruments of justice”) needs to be as attainable for people with disabilities as it is for people without.²⁵⁹ The word ‘disability’ is described in the CRPD itself, and is consistent with a social model of disability:²⁶⁰

[Disability means] the interaction between persons with impairments and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others.

Article 13 is the only article in the CRPD in which the word “accommodations” is not limited by the word “reasonable.”²⁶¹ This suggests that a request for accommodation must be granted even if it imposed a disproportionate or undue burden – a suggestion that is

²⁵⁵ Stuart, above n 240 at 366.

²⁵⁶ Stuart, above n 240 at 367.

²⁵⁷ United Nations Convention on the Rights of Persons with Disabilities, art 13.

²⁵⁸ ADA Best Practices Tool Kit for State and Local Governments, Chapter Three: General Effective Communication Requirements under Title II of the ADA, available at https://www.ada.gov/pcatoolkit/ch3_toolkit.pdf (accessed 9 November 2018).

²⁵⁹ Kevin M. Cremin “What Does Access to Justice Require? – Overcoming Barriers to Invoke the United Nations Convention on the Rights of Persons with Disabilities” (2016) 2 *Front. Law China* 280 at 286.

²⁶⁰ Cremin, above n 259 at 287.

²⁶¹ Cremin, above n 259 at 287.

consistent with the understanding that access to justice is crucial in order for the remainder of the rights included in the CRPD to be more than mere “paper victories.”²⁶²

iii. New Zealand’s obligations under the CRPD

New Zealand ratified the CRPD in September 2008. Ratification refers to the formal binding action taken by a member state agreeing to be bound by the obligations contained within the treaty or convention.²⁶³ New Zealand constitutional practice precludes the Executive from changing the law (by entering an international treaty or convention, for example).²⁶⁴ Before a treaty or convention can be ratified it goes through a process called a National Interest Analysis (NIA), which establishes the reasons for entering the treaty or convention and examines domestic legislation and whether any changes need to be made.²⁶⁵ The NIA for the CRPD found the only changes required to domestic legislation were “minor and technical” and could be rectified through an omnibus Bill that was subsequently passed in 2008.²⁶⁶

As a state party to the CRPD, New Zealand has undertaken “to adopt all appropriate legislative, administrative, and other measures for the implementation of the rights recognised” in the CRPD.²⁶⁷ The inclusion of the general phrase “other measures” renders the obligations wide, and supports the adoption of the recommendations made and discussed in Chapter 11.

C. The New Zealand Disability Strategy

The Disability Strategy was developed to “guide the work of government agencies on disability issues from 2016 to 2026” and supports the implementation of the CRPD in New Zealand.²⁶⁸ It also emphasises the importance of reflecting the principles of both Te Tiriti o Waitangi and the CRPD in its implementation, and states that these principles are “a framework for building a positive relationship between disabled people and the Government.”²⁶⁹ Finally, the Disability Strategy ensures that disabled people are involved in decision-making that impacts them, recognising that they are “experts in their own lives.”²⁷⁰

The first approach that the Disability Strategy advocates is a “whole-of-life and long-term approach to social investment.”²⁷¹ This is aimed at ensuring that adequate support is provided early and is sustained throughout the life-span to facilitate meaningful and

²⁶² Cremin, above n 259 at 281.

²⁶³ Ministry of Foreign Affairs and Trade “International Treaty Making Guide” (August 2018) Ministry of Foreign Affairs and Trade www.mfat.govt.nz.

²⁶⁴ New Zealand Law Commission *International Law and the Law of New Zealand* (New Zealand Law Commission) at [43].

²⁶⁵ Sylvia Bell, Judy McGregor and Margaret Wilson “The Convention on the Rights of Disabled Persons: a Remaining Dilemma for New Zealand?” (2015) 13 *NZJPI* 277 at 281.

²⁶⁶ Bell, above n 265 at 282.

²⁶⁷ United Nations, above n 257, art 4(a).

²⁶⁸ Ministry of Health, above n 235 at 9.

²⁶⁹ Ministry of Health, above n 235 at 18.

²⁷⁰ Ministry of Health, above n 235 at 19.

²⁷¹ Ministry of Health, above n 235 at 20.

unencumbered participation in community and family/whānau life.²⁷² The second approach requires mainstream services and supports to be inclusive of and accessible to disabled people, and also for services to be developed that are specific to disabled people.²⁷³

The Disability Strategy approach to “whole-of-life” support is relevant for young people with FASD, where the impairments are permanent and will have a lifelong impact. The importance of identifying an individual’s needs and strengths early is fundamental, and ensuring that the agencies involved with them (including the justice system) are cognisant of the need for ongoing support to improve their ability to participate as equal and effective members of society.

D. Disability support in school

In New Zealand, support for students with impairments that may impact their learning is provided in the context of “inclusive education.”²⁷⁴ An inclusive school environment is one that strives to “increase the participation of students in the life of the school and its communities.”²⁷⁵ Article 24 in the CRPD requires States Parties to “ensure an inclusive education system at all levels” and this is further enshrined in domestic legislation through s 8 of the Education Act 1989:

People who have special educational needs (whether because of disability or otherwise) have the same rights to enrol and receive education at State schools as people who do not.

There are a variety of means through which mainstream schools are therefore provided with the tools to support learners with additional educational needs, including the Special Education Grant (SEG) and the Ongoing Resourcing Scheme (ORS).²⁷⁶

i. The SEG

The SEG is a grant given to schools based on their decile rating and their roll count.²⁷⁷ Once the grant has been provided to the school, the school board of trustees has the discretion to decide how it is used, but its purpose is to support students with ‘moderate educational needs’.²⁷⁸ This may include access to Resource Teachers: Learning and Behaviour (RTLB), specialised services (e.g., occupational therapy) or teacher aides.²⁷⁹ A criticism of the SEG is that it is based on the raw pupil numbers of a particular school, rather than on the numbers

²⁷² Ministry of Health, above n 235 at 20.

²⁷³ Ministry of Health, above n 235 at 21.

²⁷⁴ An inclusive school has been defined as “places where everyone belongs, is accepted, and supports and is supported by his or her peers and other members of the school community in the course of having his or her education needs met”: S Stainback, W Stainback and B Ayres. Schools as inclusive communities, in: W. Stainback and S. Stainback (Eds) *Controversial Issues Confronting Special Education. Divergent Perspectives* (2nd Ed) (Boston, MA, Allyn & Bacon, 1996), 31–43.

²⁷⁵ Alison Kearney and Ruth Kane “Inclusive education policy in New Zealand: reality or ruse?” (2006) 10 *Int J Inclusive Educ* 201-219 at 203.

²⁷⁶ Kylie Valentine “Special education overview” Kiwi Families www.kiwifamilies.co.nz

²⁷⁷ For example, the 2019 rate for a decile 1 school was \$78.24 per student, and for a decile 10, \$40.26: Ministry of Education *Operational Funding Rates 2019 & 2020*.

²⁷⁸ Valentine, above n 276.

²⁷⁹ Valentine, above n 276.

of pupils with additional educational needs.²⁸⁰ The reality is that more inclusive schools are likely to attract more children with additional educational needs, but the amount that school receives under the SEG will not reflect this higher demand for support.²⁸¹

ii. The ORS

The ORS provides individualised funding for students with “the very highest needs for learning support.”²⁸² ORS funding covers a variety of services and supports, including access to specialists (e.g., speech-language therapists), additional or specialist teachers, and teacher aides.²⁸³ Any student can apply for ORS funding, but to be eligible they must be able to show that one of nine criteria has been met.²⁸⁴

To meet ORS criteria, students must have either ongoing extreme or severe difficulty in any of the following areas:

- Learning
- Hearing
- Vision
- Physical
- Language use and social communication

Or moderate to high difficulty with learning, combined with very high or high needs in any two of the following areas:

- Hearing
- Vision
- Physical
- Language use and social communication

A strength of the ORS system and criteria is that it is based purely on need, according to the ORS criteria, and is not determined by specific diagnoses or measures of IQ. This acknowledges the fact that many children with additional educational needs (for example, students with FASD) will not have had access to a diagnosis, or may not meet diagnostic criteria, but nevertheless require learning support. However, grading children on a scale of need necessarily focuses on a deficits-based model of disability, where children are “evaluated always and only for their shortcomings, as if disability were exclusively a property of the individual and never a function of the environment.”²⁸⁵

²⁸⁰ Giovanni Tiso and Hilary Stace “Education is for Everyone Unless you are Special” (2015) 11(4) *Policy Quarterly* 42 at 45.

²⁸¹ Tiso, above n 280.

²⁸² “Overview of Ongoing Resourcing Scheme (ORS)” (7 October 2019) www.education.govt.nz. A limitation of the scheme is that it does not extend to learners with ‘moderate’ needs who do not otherwise qualify for the limited availability of alternative support through the SEG. The Ministry of Education recently published the Learning Support Action Plan 2019 – 2025 (July 2019) which lists “flexible supports and services for neurodiverse children and young people” as its fourth priority measure. It specifically acknowledges that this will be particularly important for those with ‘moderate needs’. This may serve to address this gap.

²⁸³ ORS, above n 282.

²⁸⁴ ORS, above n 282.

²⁸⁵ Tiso, above n 280 at 44.

E. Summary

The social model of disability has been accepted through formal measures as the appropriate approach to providing support for people with impairments in New Zealand. The New Zealand Disability Strategy, the CRPD, inclusive education policy and the Education Act reflect an acknowledgement that attitudes about how disability is viewed have shifted. While, in practice, the implementation of education support policy still has some way to go, understanding New Zealand's obligations and commitments to upholding the social model of disability is important in considering how young people with FASD should be supported both at school and in the justice system.

VII. 'Taking Action on Fetal Alcohol Spectrum Disorder: 2016-2019'

In 2016, the New Zealand Government released an action plan on FASD.²⁸⁶ The plan outlines four priorities of focus for the three-year time period from 2016-2019:

- Prevention
- Early identification
- Support
- Evidence

The two priorities most relevant to this research are early identification (regarding development of a diagnostic pathway) and support (regarding services targeted at young people with FASD).

Listed in the indicators of success for early identification is “a clinical pathway for FASD has been developed, tested, endorsed and implemented in all DHBs” and that “FASD diagnostic guidelines are embedded in clinical competencies”.²⁸⁷ This is a positive step forward for New Zealand, where previously there was no acknowledgment at Government level of the need for a systematic development of a best practice approach to diagnosing FASD.

As at April 2019, the Ministry of Health had tested a “minimum assessment protocol” for FASD.²⁸⁸ More detailed information regarding the exact nature of the protocol could not be found.

Under the Support priority in the Action Plan, indicators of success include that teachers report increased understanding of what FASD is and how they can best support children with FASD to achieve at school, youth justice professionals are able to adjust their approach to people with FASD and other neurodevelopmental impairments, and that people with neurodevelopmental impairments have improved access to child development services in

²⁸⁶ FASD Working Group *Taking Action on Fetal Alcohol Spectrum Disorder: 2016-2019: an Action Plan* (Ministry of Health, August 2016).

²⁸⁷ FASD Working Group, above n 286 at 5.

²⁸⁸ Ministry of Health “Priority Action Area 3: Support” (16 January 2019) Ministry of Health www.health.govt.nz

the health and education sectors.²⁸⁹ The Action Plan identifies that in ensuring access to services, an FASD-specific pathway across multiple agencies will need to be developed.

As at April 2019, the Ministry of Education had developed resources for teachers to improve knowledge and awareness of FASD and its effect on learning.²⁹⁰ The resources are available online and include a section on ‘understanding FASD’ and several sections targeting specific strategies for supporting students with FASD in the classroom.²⁹¹ The strategies for action are split into four sections:²⁹²

1. Identify needs and how to provide support;
2. support self-regulation and positive behaviour;
3. helpful classroom strategies years 1-8; and
4. helpful classroom strategies years 9-13.

Each section contains suggestions for implementing the strategy, including videos and additional resources.

Developing guidance for those working in the youth justice sector is described as ‘ongoing’ on the Ministry of Health website, but several resources have already been developed for frontline staff.²⁹³ Matua Raki, an organisation focused on the development of addiction workforces in New Zealand, is co-designing a project as part of the FASD Action Plan to increase knowledge and awareness of FASD among professionals in the justice sector.²⁹⁴

Published on the Matua Raki website is an “Essential Strategies” resource for frontline professionals. The resource is thorough, including a detailed list of skills recommended for each frontline worker to develop. The skills are indicated as either “essential” (applying to *all* frontline professionals, regardless of role, context, or level, and regardless of how frequently or not they encounter young people with FASD), “essential +” (skills that build on and are additional to the “essential” level and applies to those professionals working with young people with FASD in a more intensive or ongoing manner), or “essential leadership” (skills that apply to anyone who is leading, guiding, supporting, educating and resourcing the work of others either intermittently involved or involved in an ongoing way with young people with FASD).

The Matua Raki website also provides a free e-learning course on FASD, and information about face-to-face workshops in various centres around New Zealand (although at the time of writing, there did not appear to be any FASD workshops listed). Matua Raki’s involvement in implementing the goals of the FASD Action Plan appears to be positive so far, with thorough, considered resources being developed for frontline professionals. It will be interesting to watch for developments in this space, especially regarding how, in practice,

²⁸⁹ FASD Working Group, above n 286 at 6.

²⁹⁰ Ministry of Health, above n 288.

²⁹¹ Ministry of Education and Te Kete Ipurangi “Guide to FASD and Learning” Te Kete Ipurangi www.inclusive.tki.org.nz

²⁹² Ministry of Education and Te Kete Ipurangi, above n 291.

²⁹³ Matua Raki “Fetal Alcohol Spectrum Disorder (FASD): An evidence-based approach for the prevention, early identification and organisation of existing supports for those affected by FASD” (2019) Matua Raki www.matuaraki.org.nz

²⁹⁴ Matua Raki, above n 293.

the resources affect the day-to-day response of frontline professionals to young people with FASD.

Although the Action Plan represents a significant step forward from a government that has previously been silent on the issue, it is important to bear in mind the limitations of a document that has at least initially restricted itself to a helicopter view of the issue. Whether or not the Action Plan lives up to the promises contained within it remains to be seen, but in the meantime, we are still faced with a question: what can we do *now*, to help our young people successfully navigate the pitfalls of a society that is not *yet* functioning best to support them?

VIII. Conclusion

While research on FASD in New Zealand is currently limited, international studies have starkly illustrated the effects the disorder is having on a cohort of individuals in our society. The effects that prenatal alcohol exposure has on the developing brain are multi-faceted and difficult to pinpoint and, as a result, the physical or behavioural presentations in the individual affected will be different in each case. What is certain, however, is that the effects are permanent and pervasive, with implications for all facets of an individual's life. The damage to the prefrontal cortex, and resulting executive functioning difficulties, results in patterns of impulsive behaviour with little to no regard for consequence. This, coupled with difficulties in language and social communication, has significant implications for how an individual is received in society and how they interact with their peers and authority figures. While prenatal alcohol exposure will occasionally manifest physically, the majority of people with FASD will show no physical signs – the disability is 'hidden' in their brain. The hidden nature of FASD as a disability thus compounds the vulnerability of these individuals as they interact with the wider community.

The complex and varied nature of FASD makes it a disorder that requires expert skill to diagnose.²⁹⁵ However, the guidelines to diagnosis published in Canada in 2005 demonstrate that it is possible to create a nationwide streamlined approach to FASD diagnosis within a jurisdiction.²⁹⁶ The project conducted by Alcohol Healthwatch New Zealand, discussed above, illustrates that a similar approach could be possible in New Zealand, and the FASD Assessment Pathway currently being used in Hawke's Bay is an example of the form it could take. As a result of this progress, New Zealand has started to implement a nationwide programme for FASD assessment and diagnosis, but it has yet to receive adequate funding and recognition.²⁹⁷ As a result, children and young people are continuing to fall through the gaps and missing out on the necessary support networks.²⁹⁸ The Government's Action Plan for FASD goes some way, at least on paper, to addressing these gaps.²⁹⁹ It remains to be seen, however, whether the assessment protocol suggested by the Action Plan will be sufficiently robust to ensure thorough and accurate diagnoses are made.

²⁹⁵ Hayward, above n 18.

²⁹⁶ Chudley, above n 132. See Chapter Four for a detailed discussion on the Canadian Guidelines to Diagnosis.

²⁹⁷ McGinn, above n 182.

²⁹⁸ Alcohol Healthwatch, above n 133 at 21.

²⁹⁹ FASD Working Group, above n 286.

The first step in mitigating ongoing harm for young people with FASD is to establish a comprehensive diagnostic process for FASD in New Zealand. A streamlined, nationwide approach to diagnosing FASD ensures the disability is identified early and appropriate supports are established. This would support the mandate in the Disability Strategy to provide long-term and whole-of-life support to ensure individuals with impairments are not excluded from equal and effective participation in society.

Unfortunately, if early identification of FASD does not occur, the constellation of effects that alcohol exposure has on a developing brain increases a child's risk of falling within the ambit of the youth justice system. Currently in New Zealand, young people with FASD are dealt with through the mainstream youth justice system; and although it is hailed as being revolutionary and progressive, it is not appropriately equipped to deal with these particular young people.³⁰⁰ The unique challenge that FASD poses to New Zealand's youth justice system is discussed in Chapter Three.

³⁰⁰ Andrew Becroft and Sacha Norrie "Signed, Sealed – (but not yet fully) Delivered" (paper to be delivered at the "Healing Courts, Healing Plans, Healing People: International Indigenous Therapeutic Jurisprudence Conference", Vancouver, October 2014) at 5.

Chapter 3

FASD and Youth Offending

I. Introduction

The social and behavioural traits that are exhibited in an individual affected by FASD (such as impulsivity, suggestibility, impairment in affect regulation, lability of mood and an inability to grasp abstract concepts) can translate to offending behaviours. Unfortunately, this occurs relatively frequently³⁰¹ due to the specific neurological impairments of FASD often precluding the individual from accessing important mental functions that usually allow people to control the way they act and how they respond to situations. A compounding feature for many young people with FASD is the effect of an adverse or traumatic childhood environment.³⁰²

New Zealand's legislative context is relatively limited when it comes to young offenders with FASD. The CPMIP Act outlines the criteria by which an individual may be found unfit to stand trial.³⁰³ Although young people with FASD may, in certain circumstances, fit within its ambit, the limitations of this provision are discussed in this chapter. The OT Act is the primary piece of legislation concerning young people in conflict with the justice system in New Zealand, and several key sections of that Act are discussed in this chapter. The IDCCR Act is also relevant and is analysed in relation to how it can be used for offenders with FASD. The ways in which the IDCCR Act falls short of being able to offer adequate support, both to individuals with FASD and to the courts, are also addressed.

This chapter also analyses five New Zealand cases that have dealt with young offenders with FASD. A few of these provide examples of the ways in which the IDCCR Act can, and has been, used in the context of FASD, while others reflect the difficulty that arises when the IDCCR Act cannot apply. New Zealand's seminal FASD case *Pora v R* will be discussed in some detail.³⁰⁴ These cases provide strong evidence that the current diagnostic, legislative and policy guidance available to the New Zealand courts regarding young offenders with FASD is inadequate.

II. Social and behavioural traits of FASD and the connection to offending behaviours

As outlined in the preceding chapter, FASD presents a variety of complex social and behavioural traits in the individual affected. Unfortunately, many of these traits are associated with offending behaviours, lending some explanation for the overrepresentation of individuals with FASD in criminal justice systems.³⁰⁵ Attributes commonly seen in

³⁰¹ It has been found that 60% of individual's with FASD will have had contact with the criminal justice system: Streissguth A.P and others "Risk factors for adverse life outcomes in fetal alcohol syndrome and fetal alcohol effects" (2004) 25(4) *J Dev Behav Pediatr* 228.

³⁰² See Chapter Two: the Role of an Adverse Environment.

³⁰³ Criminal Procedure (Mentally Impaired Persons) Act 2003, s 4.

³⁰⁴ [2015] UKPC 9.

³⁰⁵ Svetlana Popova and others "Fetal Alcohol Spectrum Disorder Prevalence Estimates in Correctional Systems: A Systematic Literature Review" (2011) 102(5) *Can J Public Health* 336 at 339.

individuals with FASD such as impulsivity, reduced capacity to be aware of the consequences of their actions, inability to grasp the abstract concept of time, reduced ability to empathise, lability of mood and pseudo-sophistication all contribute to the increased likelihood of contact with the justice system and subsequent escalation of offending or recidivism.³⁰⁶ The following section expands on how these attributes play a part in criminal offending, and why individuals with FASD are particularly vulnerable as they pass through the justice system.³⁰⁷

The outcomes associated with FASD are complex. There are the direct neurocognitive outcomes associated with impaired brain development (as discussed in Chapter Two) such as impaired executive functioning due to frontal lobe damage. Then there are the secondary outcomes that occur because the neurocognitive deficits are not adequately supported or accommodated in society, such as substance use and criminal offending.³⁰⁸ These secondary outcomes are known as “secondary disabilities”. The relationship between FASD and offending has been described as neither simple nor direct, and depends to a large extent on the particular individual’s circumstances, and the environment in which they have been brought up.³⁰⁹ A study conducted in Canada involving a cohort of 514 young offenders sought to assess the role FASD played in early onset offending.³¹⁰ The researchers observed that the criminal behaviour of young people with FASD was not reported as being “instrumentally motivated” (e.g., planned with an understanding of the long-term consequences of the harm).³¹¹ Instead, for these young people, the neurocognitive deficits of FASD involving social inappropriateness and problems with impulse control were able to explain their offending.³¹² This finding gives weight to the argument (developed further in Chapter Five) regarding the reduced culpability of offenders with FASD, and has been used to justify considering FASD as a mitigating factor in sentencing in some courts.³¹³

A. Specific Attributes Related to Neurocognitive Deficits

The specific attributes of FASD that are relevant to a young person’s offending are varied and will depend on the specific facts of each case. However, it is possible to generally analyse some of the common traits found in individuals with FASD to better understand why offending behaviours occur more frequently in this group of individuals. Impulsivity is one such attribute commonly seen in individuals with FASD, reflecting their inhibited prefrontal cortex and subsequent executive functioning deficits as discussed in Chapter Two.³¹⁴ Unfortunately, this impulsivity has the unsurprising result of individuals with FASD

³⁰⁶ I. Freckelton “Expert evidence in fetal alcohol spectrum disorder cases” (2016) 2 *Ethics Med Public Health* 59 at 66.

³⁰⁷ Kaitlyn McLachlan and others “Evaluating the Psycholegal Abilities of Young Offenders With Fetal Alcohol Spectrum Disorder” (2014) 38 *Law Hum Behav* 10 at 10.

³⁰⁸ Raymond R Corrado and Evan C McCuish “The development of early onset, chronic, and versatile offending: The role of fetal alcohol spectrum disorder and mediating factors” (2015) 8(2) *Int J Child Adolesc Health* 241 at 242.

³⁰⁹ Corrado and McCuish, above n 308 at 243.

³¹⁰ Corrado and McCuish, above n 308 at 242.

³¹¹ Corrado and McCuish, above n 308 at 242.

³¹² Corrado and McCuish, above n 308 at 242.

³¹³ See for example *LCM v State of Western Australia* [2016] WASCA 164 at [35].

³¹⁴ Freckelton, above n 306 at 66.

engaging in spur of the moment, unthought through activities, which may, at times, be criminal in nature.³¹⁵

Individuals with FASD are also more likely to be easily led or manipulated by others.³¹⁶ This attribute, especially when combined with impulsivity, can significantly impact upon how they come to engage in criminal activity in the first place, and is an important trait for the courts to be aware of when considering whether an individual's FASD should be included as a mitigating factor in sentencing.³¹⁷

Executive functioning deficits in individuals with FASD can also exhibit as decreased ability for affect regulation, meaning an individual may be unable to display a normal emotional response to situations.³¹⁸ To an outside observer, problems with affect regulation in an individual may be interpreted as emotional bluntness, with limited outward displays of sympathy for their conduct.³¹⁹ Impairments in this subset of executive functions can also lead to a reduced capacity to empathise or engage in social perspective taking.³²⁰ This attribute is particularly problematic in the context of restorative justice proceedings, where the ability of an offender to engage in social perspective taking and display genuine empathy towards their victim is considered a cornerstone of the process.³²¹ New Zealand's youth justice system heavily relies on the principles of restorative justice, especially in regards to the restorative focused Family Group Conference.³²² This presents a problem for the youth justice system when faced with young people with FASD, who may not have the cognitive *capacity* to acknowledge their victim or show remorse for their actions.

Another common trait found in individuals with impaired brain function because of prenatal exposure to alcohol is an inability to grasp the abstract concept of time.³²³ Abstract thought, including the ability to understand and process abstract concepts, is again facilitated by the prefrontal cortex, which enables executive functioning to occur.³²⁴ An inability to grasp the concept of time has significant implications for employment, exacerbating the likelihood of secondary disability, as discussed below.³²⁵ It also has a direct impact upon the likely escalation of punitive sanction upon the individual, as a result of failing to attend court or probation meetings, or failing to punctually complete community-based sentences.³²⁶ If the individual concerned has not had their FASD identified or diagnosed by the court, or if there are no appropriate alternative actions available to the court, repeated punishment for non-compliance is possible, resulting in a futile cycle of imposing sanctions upon an individual who lacks the ability to comply.

³¹⁵ Freckelton, above n 306 at 66.

³¹⁶ Freckelton, above n 306 at 66.

³¹⁷ Freckelton, above n 306 at 66.

³¹⁸ Freckelton, above n 306 at 66.

³¹⁹ Freckelton, above n 306 at.

³²⁰ Freckelton, above n 306 at 66.

³²¹ Sandra Pavelka O'Brien "Restorative Justice: Principles, Practices, and Application" (2007) 14 *Prev Res* 16 at 17.

³²² Oranga Tamariki Act 1989 s 245. The Family Group Conference process is described in more detail on p. 31.

³²³ Freckelton, above n 306 at 66.

³²⁴ Bruce D. Perry and Maia Szalavitz *The Boy Who Was Raised as a Dog* (Basic Books, New York, 2008) at 22.

³²⁵ Freckelton, above n 306 at 66.

³²⁶ Freckelton, above n 306 at 66.

Lability of mood is an attribute seen in individuals with FASD that can increase irritability and lead to aggressive, violent outbursts.³²⁷ Unfortunately, outbursts can be triggered or exacerbated by the person being subject to increasing frustration, especially if confronted with situations demanding complex communication skills.³²⁸ The criminal justice system, with its complicated jargon such as “waive”, “appeal” and “quash”, and somewhat elusive processes, such as adjournments, is a prime example of a context demanding sophisticated communication skills. Unfortunately, individuals with FASD may have higher levels of oral vocabulary than actual comprehension, resulting in pseudo-sophistication that makes their communication deficits difficult to identify.³²⁹

B. Vulnerability in the Justice System

Most individuals with FASD will not have any easily observable physical traits, hence the term “invisible disability”.³³⁰ This fact, combined with pseudo-sophistication, has resulted in young offenders with FASD being identified as particularly vulnerable as they pass through the justice system.³³¹

A research study conducted in Canada in 2013 recruited 100 young offender participants, 50 of whom had been diagnosed with FASD, and 50 of whom were not suspected of having sustained prenatal alcohol exposure.³³² It aimed to assess the psycholegal abilities of the young offenders with FASD, to establish whether this cohort experienced greater vulnerability in the justice system.³³³

The study’s approach was twofold: firstly, the authors sought to measure the actual abilities of the young offenders with FASD, especially in regards to interrogation and adjudication.³³⁴ Secondly, they aimed to establish the participants’ own insights and confidence regarding their perceived psycholegal abilities.³³⁵ To measure the participants’ actual abilities, the young offenders engaged in a comprehension exercise to establish the extent to which they could understand their legal rights.³³⁶ The results showed that the participants with FASD achieved significantly lower scores across all four measures of the comprehension test, indicating their substantial difficulty in understanding and appreciating their rights.³³⁷ Similarly, the authors discovered that the FASD group consistently had more difficulty understanding elements of arrest and trial processes, appreciating their involvement and possible consequences of proceedings and adequately participating in their defence.³³⁸ Importantly, the study also found that for the FASD group, self-confidence judgements did not reflect actual levels of comprehension.³³⁹ This finding is particularly concerning, as it

³²⁷ Freckelton, above n 306 at 66.

³²⁸ Andi Crawford “Fetal Alcohol Spectrum Disorder, Adaptive Behaviour and Children’s Development” (May 2013) at 3.

³²⁹ Freckelton, above n 306 at 66.

³³⁰ Fetal Alcohol Network NZ “Fetal Alcohol Spectrum Disorder” Fetal Alcohol Network NZ www.fan.org.nz.

³³¹ McLachlan, above n 307 at 10.

³³² McLachlan, above n 307 at 12.

³³³ McLachlan, above n 307 at 11.

³³⁴ McLachlan, above n 307 at 11.

³³⁵ McLachlan, above n 307 at 11.

³³⁶ McLachlan, above n 307 at 15.

³³⁷ McLachlan, above n 307 at 15.

³³⁸ McLachlan, above n 307 at 17.

³³⁹ McLachlan, above n 307 at 16.

suggests that young people with FASD may believe that they understand their rights (for example), and may convincingly act as though they understand, even if they actually do not.

The suggestibility of individuals with FASD also compounds their vulnerability in the justice system, especially in the context of being questioned.³⁴⁰ This attribute is exhibited as a result of an incapacity for abstract thought, a tendency to interpret things entirely literally, and general cognitive rigidity.³⁴¹ When being questioned by someone in a position of authority (a Police officer, for example), an individual with FASD who does not understand the question or does not know the answer may confabulate, in order to appear deferential.³⁴² The implications of this particular vulnerability in the criminal justice setting will be further discussed below, in relation to the case *Pora v R*.

C. The Role of an Adverse Environment/Secondary Disability

As previously mentioned, the relationship between FASD and offending is neither simple nor necessarily direct, and it has been established that FASD is associated with a variety of negative outcomes that are not directly linked to their neurocognitive deficits.³⁴³ These outcomes are often referred to as “secondary disabilities” or “tertiary outcomes”, and refer to the social impact or manifestation of an individual’s brain impairment.³⁴⁴ Contact with the justice system is an example of a secondary disability experienced by individuals with FASD and studies have found that approximately 60% of people with FASD are likely to come into contact with the justice system at some point during their lives.³⁴⁵

The interplay between the cognitive effects of FASD and the particular secondary disability of criminal offending was articulated by Professor Douglas in a 2010 article published in the *Criminal Law Journal*.³⁴⁶

The cognitive, social and behavioural problems associated with FASD often bring sufferers to the attention of the criminal justice system. It has been estimated that approximately 60% of adolescents with FASD have been in trouble with the law. Impulsive behaviour may lead to stealing things for immediate consumption or use, unplanned offending and offending behaviour precipitated by fright or noise. As a result of their suggestibility, FASD sufferers may engage in secondary participation with more sophisticated offenders. Lack of memory or in not understanding cause and effect may lead to breach of court orders, further enmeshing FASD sufferers in the justice system. Impaired adaptive behaviour that results from brain damage is translated into practical problems such as trouble handling money and difficulties with day to day living skills. It may be difficult for FASD sufferers to understand or perceive social cues and to tolerate frustration. Inappropriate sexual behaviour is also common amongst FASD sufferers; in one study, about 50% of FASD sufferers had

³⁴⁰ Freckelton, above n 306 at 64.

³⁴¹ Freckelton, above n 306 at 64.

³⁴² Freckelton, above n 306 at 65.

³⁴³ Corrado and McCuish, above n 308 at 243.

³⁴⁴ Corrado and McCuish, above n 308 at 243.

³⁴⁵ *LCM*, above n 313 at [10].

³⁴⁶ Heather Douglas “The sentencing response to defendants with foetal alcohol spectrum disorder” (2010) 34 *Crim LJ* 221 at 223 and 224.

displayed inappropriate sexual behaviours. Canadian research has found that FASD is over-represented in prison populations of sex offenders.

The social effects of FASD are also compounded by exposure to an adverse environment, as discussed in Chapter Two. It is important to reiterate this point in the context of criminal offending specifically, to illustrate the detrimental pathway that can occur for many children and young people with FASD. They are more difficult to parent due to their challenging and often incredibly complex behaviours, resulting in high levels of caregiver stress.³⁴⁷ Additionally, it has been found that children with FASD are significantly overrepresented in state care.³⁴⁸

D. Summary

The neurological damage sustained by the developing brain because of prenatal exposure to alcohol leads to a range of exhibited social and behavioural traits that can be observed in the resulting child (see Chapter Two). Unfortunately, several of the commonly observed behavioural traits, such as impulsivity, affect regulation, suggestibility, inability to grasp abstract concepts and lability of mood, can lead to and escalate criminal offending. A further exacerbating factor for these children is exposure to an adverse childhood environment, which compounds their neurological difficulties and increases their susceptibility to secondary disability. It is important to understand the varied contributing factors when considering the best possible pathway for a young offender with FASD and to remember that the specific developmental and contextual history of each individual will be different and will require a nuanced approach.

III. The Criminal Procedure (Mentally Impaired Persons) Act 2003

For young people with FASD, the CPMIP Act will be triggered if there is an inquiry regarding a young person's fitness to stand trial.³⁴⁹ Section 4 outlines the criteria for being found unfit:

Unfit to stand trial, in relation to a defendant –

- (a) means a defendant who is unable, due to mental impairment, to conduct a defence or instruct counsel to do so; and
- (b) includes a defendant who, due to mental impairment, is unable –
 - a. to plead;
 - b. to adequately understand the nature or purpose or possible consequences of the proceedings;
 - c. to communicate adequately with counsel for the purpose of conducting a defence.

The term 'mental impairment' is not defined in the CPMIP Act but was a deliberate shift from the term 'mental disorder' which had previously been used.³⁵⁰ The justification for

³⁴⁷ Corrado and McCuish, above n 308 at 243.

³⁴⁸ Corrado and McCuish, above n 308 at 243.

³⁴⁹ This process will usually begin with an order for a medical, psychiatric or psychological report to be made available to the Youth Court: s 333 Oranga Tamariki Act 1989.

³⁵⁰ David Collins "The Dilemma Caused by Delusional Defendants" (2015) 46 *VUWLR* 811 at 815.

changing the term was to increase the ambit of the fitness provision to ensure that individuals with intellectual disabilities were not excluded.³⁵¹ Leaving the term undefined was a deliberate omission to avoid further unintended gaps being created by the legislation.³⁵² The amendment makes clear, therefore, that both individuals with ‘mental disorders’ and those with intellectual disabilities fall within the ambit of the provision, and leaves the door open for other conditions to be similarly included.

Case law³⁵³ and commentary by Professor Warren Brookbanks³⁵⁴ have established, however, that the scope of the term is constrained by the statutory disposal options of offenders. Kós J in *R v T* identified that in practice, a defendant will only be found to be “mentally impaired” if they fit the definition of intellectual disability as per s 7 of the IDCCR Act, or mentally disordered as per s 2 of the Mental Health (Compulsory Assessment and Treatment) Act 1992.³⁵⁵

The cases discussed later in this chapter are evidence that, at least in some circumstances, FASD is considered a mental impairment for the purpose of s 4 of the CPMIP Act.³⁵⁶ It does appear, however, that inquiries into their fitness to stand trial were predominantly triggered by the existence of an intellectual disability, where their additional brain damage as a result of prenatal exposure to alcohol was then only considered as further evidence of their unfitness.³⁵⁷ This is problematic, given that the majority of individuals with FASD do not have an intellectual disability.³⁵⁸

If a young person with FASD is found to have a mental impairment for the purpose of s 4 CPMIP Act, they still need to satisfy the relatively stringent criteria for unfitness. The cognitive functioning of young people with FASD will vary depending on the nature of the brain damage they sustained. While some young people may fit the criteria for being found unfit to stand trial, there is a significant cohort for whom the Court consider able to effectively participate in the justice process. For these young people, whose cognitive functioning has nevertheless impacted their behaviour and criminal offending, and which has ramifications for their vulnerability within the justice context, the CPMIP Act will not apply. The following discussion identifies two other possible means of legal recourse for these people, outlining the circumstances in which support is available, and identifying the remaining gaps.

IV. The Oranga Tamariki Act 1989

The OT Act is the governing piece of legislation for young people who offend in New Zealand.³⁵⁹ The introduction of the OT Act in 1989 brought with it a “radical and innovative”

³⁵¹ Collins, above n 350 at 816.

³⁵² Warren Brookbanks “Mentally Impaired Offenders: What’s in a name?” (21 February 2014) Auckland District Law Society www.adls.org.nz

³⁵³ *R v T* [2013] NZHC 2299.

³⁵⁴ Brookbanks, above n 352.

³⁵⁵ Mental Health (Compulsory Assessment and Treatment) Act 1992, s 2.

³⁵⁶ See, for example, *R v BMS*, *Police v VT*, and *Police v ZW*.

³⁵⁷ Warren Brookbanks *Fetal Alcohol Spectrum Disorders and the Criminal Justice System: Some Challenges and Solutions* (paper from presentation at the Australian & New Zealand Association of Psychiatry, Psychology and Law Conference, April 2012).

³⁵⁸ Streissguth, above n 7 at 20.

³⁵⁹ Part 4 Oranga Tamariki Act 1989 (Youth Justice).

way of dealing with young offenders that has since been analysed and copied by jurisdictions worldwide.³⁶⁰ At the heart of the legislation is the intention to limit the number of young people who end up entrenched in the justice system, preferring instead diversionary measures and restorative justice-focused Family Group Conferences (FGC).³⁶¹ The legislation tightly controls the circumstances in which a young person can be arrested by Police,³⁶² and for those who are arrested, the legislation focuses on keeping them out of the Youth Court.³⁶³

The youth justice FGC borrows principles and processes established by restorative justice approaches, where the victim and offender work together to mitigate the harm caused by the offending.³⁶⁴ The people entitled to attend a youth justice FGC include the young person, parents or guardians of the young person, any other family members of the young person, the youth justice coordinator, the Police, the victim to the offending (or their representative), the young person's youth advocate (usually only in arrest/court cases), the chief executive (in certain cases), and any other person the family wish to be there.³⁶⁵ The focus on involving the young person and their family at the core of the decision-making process in youth justice cases has been described as "innovative".³⁶⁶ It reflects an understanding that to discover the root cause of offending in a young person, it is crucial to give that young person and their wider whānau a voice.

Section 208 of the OT Act articulates the principles underpinning the legislation.³⁶⁷ Paragraph (a) and (b) reiterate the point made above: that proceedings should not be instituted against a child or young person if there is an alternative means of dealing with the issue and that criminal proceedings should not be used solely as a vehicle for providing welfare to the child or young person.³⁶⁸ Criminal proceedings should be a last resort.

Paragraph (d) states that age is a mitigating factor in determining firstly whether to impose sanctions, and secondly in determining the nature of any such sanctions.³⁶⁹ This reflects justice systems worldwide, where there is a growing understanding of the brain immaturity of children and adolescents to the extent that age is considered to mitigate criminal responsibility (see Chapter Five for further discussion on age and its implications for criminal responsibility).

³⁶⁰ Allison Morris and Gabrielle Maxwell "Re-forming Juvenile Justice: The New Zealand Experiment" (1997) 77 *Prison J* 125 at 125.

³⁶¹ Morris ad Maxwell, above n 360 at 126.

³⁶² The arresting officer must be satisfied, on reasonable grounds, that arresting the young person is necessary for the purpose of ensuring the appearance of the child or young person in court; preventing the commission of further offences; or preventing loss or destruction of evidence relating to the commission of a crime. An arrest can also be made if the young person has committed a serious offence (where the maximum penalty is life imprisonment or at least 14 years) or if the arrest is required for "public interest": Oranga Tamariki Act 1989, s 214.

³⁶³ Section 245 stipulates that proceedings cannot be instituted against a young person unless a Family Group Conference has already been held.

³⁶⁴ John Harris and Vicky White *A Dictionary of Social Work and Social Care* (2nd ed, Oxford University Press, 2018).

³⁶⁵ Oranga Tamariki Act 1989, s 251.

³⁶⁶ Morris and Maxwell, above n 360 at 125.

³⁶⁷ Oranga Tamariki Act 1989, s 208.

³⁶⁸ Section 208(a) and (b).

³⁶⁹ Section 208(d).

Paragraph (fa) highlights the move from a punitive system of justice to a more welfare-oriented system: “the principle that any measures for dealing with offending by a child or young person should so far as it is practicable to do so address the causes underlying the child’s or young person’s offending”.³⁷⁰ This principle will almost always be relevant in cases where the young person has a neurodisability: as discussed earlier in this chapter, the behavioural presentations of FASD often lead to antisocial or offending behaviours. Whether or not this principle can be followed however relies on the Court *knowing* what the underlying causes of a young person’s offending are. It relies on the Court knowing, for example, that a young person has FASD.

Section 333 of the OT Act is the most pertinent to this thesis – it allows the Court to order a medical, psychiatric or psychological report to be made available.³⁷¹ It is through this provision that the Court is most likely to establish whether a young person has FASD (unless the young person already has a diagnosis which is made available to the Court). The purposes for obtaining a report are listed in subs (2) as assisting the Court to determine:³⁷²

- (a) whether the young person is unfit to stand trial;
- (b) if the young person is ‘insane’ within the meaning of the Crimes Act 1961;
- (c) the type and duration of any order that the Court is empowered to make; and
- (d) the nature of any requirement that it might impose as part of, or as a condition of, any order that the Court is empowered to make.

Section 333 is primarily concerned with providing the Court with information about the young person. Unless a young person with FASD is also found to be unfit to stand trial, ‘insane’ within the meaning of the Crimes Act 1961 (Crimes Act), or have an intellectual disability, there is currently a limit to the practical recourse the Court has for dealing with the young person. This is partly due to the limited services for FASD in New Zealand, but also partly due to the lack of legislative acknowledgment of the significant impact neurodisability has on criminal offending.

A. OT Act 2019 Amendments

In July 2019, several important amendments to the OT Act took effect. Section 4 now outlines the purposes of the Act as including the establishment, promotion, or co-ordination of services that are centred on children’s and young persons’ rights, and provides for their participation in decision making that affects them.³⁷³ Another purpose concerns the advancement of positive and long-term health, educational, social, economic, or other outcomes. The focus on ‘long-term’ is consistent with the aims of the Disability Strategy and is particularly pertinent for young people with FASD in the justice system - the nature of the cognitive impairment seen in FASD requires sustained support if a successful outcome for the young person is to be achieved. Section 4(1)(f) commits to upholding Te Tiriti o

³⁷⁰ Section 208(fa).

³⁷¹ Section 333.

³⁷² Section 333(2).

³⁷³ This is consistent with New Zealand’s obligations under the UNCRP, where Article Seven requires States Parties to “ensure that children with disabilities have the right to express their views freely on all matters affecting them”.

Waitangi (Te Tiriti) by providing “practical commitment” to the principles of Te Tiriti – this will be relevant to any policy or legislative change directed for young people with FASD.³⁷⁴

Paragraph (i) directly addresses offending by young people and requires the response to offending to promote the rights, best interests, and needs of the child, while simultaneously balancing the rights and interests of victims, and holding the young person accountable. Section 4A reiterates this, by firstly establishing that the well-being and best interests of the child are the “first and paramount” consideration. For all matters relating to offending by young people, the four primary considerations are set out as:³⁷⁵

- (a) the well-being and best interests of the child or young person; and
- (b) the public interest (which includes public safety); and
- (c) the interests of any victim; and
- (d) the accountability of the child or young person for their behaviour.

The effective balancing of these rights and interests is vital to any justice proceeding involving a young person, but when the young person has a cognitive impairment that may impact their culpability, it can present a particular challenge for the courts.³⁷⁶

Section 5 outlines the principles of the OT Act and includes several elements that strengthen young people’s rights generally and are especially critical for young people with FASD. Paragraph (a) reiterates the right expressed in s 4 that young people must be “encouraged and assisted” to participate in and express their views about proceedings or decisions that affect them. This wording requires more than simply giving the young person an opportunity to be heard – the young person must be *assisted* so that their participation and expression of views are effective.³⁷⁷ Paragraph (b) again emphasises that the well-being of the child is at the centre of decision-making, and refers explicitly to both the UNCRPD and the UNCRC, requiring the rights outlined in both Conventions to be respected and upheld.

Sub-paragraphs (b)(vi) and (viii) are pertinent for this thesis. These paragraphs acknowledge the existence of disability and the importance of considering how disability affects a child or young person’s ability to exercise the rights outlined in earlier sections. Paragraph (vi) requires a holistic approach to be taken, that “sees the child or young person as a whole person” which includes the child or young person’s disability.³⁷⁸ Paragraph (viii) relates specifically to decisions made about a child or young person with a disability (for example, any kind of plan or order made for a young person through a youth justice FGC or in the Youth Court) and requires them to:³⁷⁹

³⁷⁴ Ngā mātaḡpono o Te Tiriti – the principles of the Treaty of Waitangi – were developed as a way to incorporate the Treaty of Waitangi into legislation while acknowledging that the text itself cannot be regarded as law (primarily due to the difference in meaning and interpretation between the English text and the te reo Māori text). The principles refer to a wide range of obligations and entitlements but can be summarised with reference to three broad headings: partnership, participation and protection.

³⁷⁵ Section 4A(2)(a)-(d).

³⁷⁶ See Chapter Five, “Balancing Interests”.

³⁷⁷ A young person with FASD for example may require a communication assistant to enable them to fully participate in the court process.

³⁷⁸ Section 5(b)(vi)(G).

³⁷⁹ Section 5(b)(viii) (A) and (B).

... be made having particular regard to the child's or young person's experience of disability and any difficulties or discrimination that may be encountered by the child or young person because of that disability; and support the child's or young person's full and effective participation in society.

Consistent with the UNCRPD and the Disability Strategy, the first part of paragraph (viii) acknowledges that individual experiences of disability will be different, and that responses need to be tailored to each child or young person. The second part leads into the strengthened rights to participation outlined in sections 10 and 11 of the OT Act.

Section 10 sets out the duty of the Court to explain proceedings to any child or young person appearing in either the Family Court or the Youth Court. Paragraph (a) requires the Court to explain, "in a manner and in language that can be understood by the child or young person", the nature of the proceedings and, in paragraph (b), to "satisfy itself that the child or young person...understands the proceedings". The same obligation to communicate in a manner that can be understood is prescribed in paragraph (c), relating to any orders that are made by the Court. The obligations in this section are mandatory and seem to assume that the Court will know the manner of communication required and the level of receptive language ability of the child or young person. For young people with FASD, their communication abilities may not be apparent merely by speaking with them. Section 10 appears to require the Court to conduct whatever investigation is necessary³⁸⁰ to establish the appropriate means and level of communication for that particular child or young person prior to the proceeding.

A young person's right to effective participation is further entrenched in section 11. This section reiterates the principle outlined in s 5 that a child or young person must be "encouraged and assisted" to participate and must be given "reasonable assistance" to do so effectively.³⁸¹ This section also requires a child or young person to be given the opportunity to freely express their views, and where "the young person has difficulties in expressing their views or being understood" support must be provided to enable them to achieve this. The views expressed by the child or young person must be taken into account.³⁸² Paragraph (e) ensures that this obligation is more than mere rhetoric, by requiring a written record to be made of the child or young person's views, and, if they are not followed, the reasons for not doing so. This is consistent with New Zealand's obligations under the UNCRC, where in Article 12 the Convention outlines children's rights to freely express their views. Paragraph two specifies that "the child shall in particular be provided the opportunity to be heard in any judicial proceeding...affecting the child".

While the data for this research was collected prior to these amendments taking effect, they are highly relevant to the recommendations made in Chapter 11. Any legislative amendments or youth justice policy changes will need to be made according to these new principles and purposes. The right to effective communication and participation in decision-making and court processes, and the obligations on the court to ensure that these rights are fulfilled provide a foundation for the argument that young people with FASD require additional support in the youth justice system. The amendments also emphasise, however, the critical issue of balancing the rights of the victim and society against that of the child or

³⁸⁰ For example, a thorough screening test prior to appearing in Court.

³⁸¹ Section 11(2)(a) and (aa).

³⁸² Section 11(2)(d).

young person who may have caused harm. Understanding the theoretical justification for reduced culpability³⁸³ and subsequent alternative means of dealing with a young person with cognitive impairment is therefore vital to reducing the risk of reoffending and enhancing the safety of the community.

V. The Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003

The IDCCR Act was enacted in 2003 and sought to bridge a “legislative gap” that had existed in New Zealand since 1992.³⁸⁴ It is an example of specific legislative acknowledgment that a cohort of individuals should not be held criminally responsible for their behaviour and should not be dealt with through mainstream justice systems. The primary purpose of the IDCCR Act is to provide the courts with assessment and rehabilitative options for offenders with an intellectual disability and to recognise and safeguard the rights of individuals subject to the Act.³⁸⁵ However, for young offenders with FASD, the IDCCR Act is an inadequate tool, due to its limited scope and lack of sufficient means for dealing with young offenders as distinct from adult offenders.³⁸⁶ The following sections discuss the process by which the IDCCR Act aims to satisfy its purposes, whether or not the Act is, in fact, achieving its goal, and why this piece of legislation is insufficient for young offenders presenting with FASD.

A. How the IDCCR Act works

The IDCCR Act provides the courts with an alternative means of dealing with offenders with an intellectual disability. Section 7 sets out the criteria that need to be met for an individual to be classified as having an intellectual disability.

If these criteria are met, the individual concerned may become a “care recipient” under the IDCCR Act.³⁸⁷ Care recipients will either be “special care recipients”, in which case they will be mandated to receive care in a secure facility; or “general care recipients”, making them eligible for supervised care (in a given place other than a secure facility).³⁸⁸

Under Part 3 of the IDCCR Act, a “needs assessment” is carried out for every care recipient who has been found unfit to stand trial, not guilty by reason of insanity, or convicted of an offence.³⁸⁹ The needs assessment establishes the kind of care the specific recipient requires, identifies which services may be utilised in providing that care, and formulates a care and rehabilitation plan for that recipient.³⁹⁰ The facilitation of the plan is overseen by a co-ordinator, an individual appointed to the role by the Director-General of Health.³⁹¹ The actual formulation and performance of the plan, however, is undertaken by the care

³⁸³ See Chapter 5 for a detailed discussion on cognitive impairment and criminal culpability.

³⁸⁴ (21 October 2003) 612 NZPD 9558.

³⁸⁵ Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003 s 3.

³⁸⁶ See for example Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003 s 7.

³⁸⁷ Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003, s 6.

³⁸⁸ Section 4.

³⁸⁹ Section 15.

³⁹⁰ Section 16.

³⁹¹ Section 140.

recipient's care manager. This is an individual who is designated for the role by the co-ordinator and must be either an employee or agent of a service.³⁹²

The IDCCR Act sets out the various procedural requirements to be followed, including the acknowledgment and respect of certain specific rights held by care recipients.³⁹³ The IDCCR Act also requires care and rehabilitation plans to be regularly reviewed, in order to ensure their continuing necessity and efficacy.³⁹⁴ In 2015, a doctoral thesis sought to analyse the lived experiences of care recipients under the IDCCR Act, to establish whether or not the legislation was, in practice, fulfilling its aims.³⁹⁵ The findings of this thesis will be used in the following section to analyse the workings of the IDCCR Act.

B. Has the IDCCR Act been effective?

Prior to the IDCCR Act coming into force, individuals with an intellectual disability were originally included in the definition of "mental disorder" in the Mental Health Act 1969 (which was linked to the Criminal Justice Act in 1985), but explicitly excluded from the ambit of the Mental Health (Compulsory Assessment and Treatment) Act 1992.³⁹⁶ Thus, between 1992 and 2003, a legislative gap existed through which offenders with intellectual disabilities would fall, often being inappropriately incarcerated or discharged into the community.³⁹⁷ The IDCCR Act reflected an understanding that the needs of offenders with intellectual disabilities "are different to those with a mental health diagnosis, and therefore a distinct legislative tract that caters for them is justified".³⁹⁸

The 2015 New Zealand doctoral thesis used a social constructionist methodology³⁹⁹ to analyse the operation of the IDCCR Act and the various discourses that have emerged as a result of its enactment.⁴⁰⁰ One discourse the author examined was the criminal discourse, to establish what effect on identity placement under the IDCCR Act had on offenders with intellectual disabilities.⁴⁰¹ The author argued that a "criminal subjectivity" may be a new one for some care recipients, emphasising that before the IDCCR Act came into force, the behaviour may not have been identified as criminal and the individual would not have been charged.⁴⁰² This point was reiterated by an employee of a service provider under the IDCCR Act, who stated:⁴⁰³

³⁹² Section 141.

³⁹³ See Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003, Part 5.

³⁹⁴ Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003, Part 6.

³⁹⁵ Amanda Smith "Experiences of the Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003: a Discourse Analysis" (DHSC Thesis, Auckland University of Technology, 2015).

³⁹⁶ NZPD, above n 384.

³⁹⁷ NZPD, above n 384.

³⁹⁸ Smith, above n 395 at 2.

³⁹⁹ Social constructionism proposes that events do not have meaning in and of themselves, but gain meaning through the context in which they are produced and the interactions that occur between individuals involved (Amanda Smith "Experiences of the Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003: a Discourse Analysis" (DHSC Thesis, Auckland University of Technology, 2015) at 6.

⁴⁰⁰ Smith, above n 395.

⁴⁰¹ Smith, above n 395 at 136.

⁴⁰² Smith, above n 395 at 136.

⁴⁰³ Smith, above n 395 at 140.

Because they've been charged and placed as a care recipient and then exited, [care recipients] appear more risky than a person who has similar offending or similar assaultive behaviours who has simply not been processed through the justice system.

Prior to the implementation of the IDCCR Act, the question directing drafting was “how does society protect people from harm to self and others whilst giving them full opportunity to live self-fulfilling lives?”.⁴⁰⁴ Following implementation, the foundational philosophy of the IDCCR Act remained one of least restrictive outcome for care recipients.⁴⁰⁵ However, tensions arose between this important philosophy and the practical necessity of risk management, combined with a growing discourse that established care recipients as “inherently risky and dangerous”.⁴⁰⁶ A number of participants involved in the 2015 study felt that the practical approach taken in implementing the IDCCR Act focused on the punitive element at the expense of the rehabilitative element.⁴⁰⁷ The author noted that if an intellectual disability and criminal discourse “continued to dominate”, then the rehabilitative focus may remain on over-containment, “resulting in continuing detainment and a lack of rehabilitative outcomes”.⁴⁰⁸ The author aptly noted that:⁴⁰⁹

Strategies are not only required for intellectually disabled offenders to be diverted from the criminal justice system; they are also required to ensure that care recipients are able to exit the IDCCRA.

The concerns articulated by Amanda Smith illustrate an emerging discourse of care recipients as inherently dangerous, with the care recipients themselves articulating a problematic focus on confinement.⁴¹⁰ It is important to acknowledge and address these concerns when considering any legislative drafting for young offenders with FASD. The preceding analysis of the functioning of the IDCCR Act exhibits a disconnect between the legislation’s purpose (to provide the courts with appropriate rehabilitative options for offenders with an intellectual disability) and what is occurring in practice (the construction of care recipients as inherently dangerous, with a focus on punitive containment).⁴¹¹

C. Why the IDCCR Act is insufficient for young offenders with FASD

There are several reasons why the IDCCR Act as a piece of legislation is insufficient for young offenders with FASD. Two of the more predominant are discussed next. Firstly, the IDCCR Act was not drafted with young people in mind, despite including several provisions relating to children and young people as care recipients under the legislation.⁴¹² Secondly, and most significantly, the IDCCR Act precludes individuals with an IQ of greater than 70 from coming within its ambit, a criterion that excludes a large proportion of offenders with FASD.

⁴⁰⁴ Smith, above n 395 at 197.

⁴⁰⁵ Smith, above n 395 at 197.

⁴⁰⁶ Smith, above n 395 at 197.

⁴⁰⁷ Smith, above n 395 at 197.

⁴⁰⁸ Smith, above n 395 at 197.

⁴⁰⁹ Smith, above n 395 at 197.

⁴¹⁰ Smith, above n 395 at 197.

⁴¹¹ Smith, above n 395 at 197; Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003, s 3.

⁴¹² See Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003, ss 12 and 33.

i. Young people

As early as 1997, it was identified that young offenders as a group may put pressure on the framework of intellectual disability legislation, due to a lack of alternative options.⁴¹³ This was predicted to occur despite the legislation being drafted to cater primarily for adult recipients.⁴¹⁴ It has since been established that youth are “an emerging group” for the IDCCR Act, with care recipients under 18 years of age comprising 6% of the total number of care recipients under the Act.⁴¹⁵

The legislation itself contains two notable provisions relating to young people. Firstly, s 12 which outlines the relevant principles governing decisions affecting children or young people.⁴¹⁶ Secondly, s 33 states that where the assessment is of a child or young person, “wherever practicable” a specialist assessor trained in child and adolescent disability must be involved.⁴¹⁷ These provisions, while acknowledging the likelihood that young people may fall within the ambit of the statute, do not adequately provide for the nuanced approach that is necessary in assessing, treating, and providing for young people as distinct from adults. For example, cognitive development continues at least until a young person reaches their early 20s; this means that reliably assessing a young offender’s IQ to establish whether they come within the ambit of the IDCCR Act is incredibly difficult.⁴¹⁸ Cognitive development during adolescence occurs differently in everyone, and is at least in part dependent on environmental factors or the young person’s prior experiences.⁴¹⁹ In assessing a young person therefore, their individual cognitive functioning needs to be considered and applying a broad brush approach is insufficient.

ii. Intellectual Disability

Section 8 of the IDCCR Act clearly stipulates that if a person does not have an intellectual disability, the provisions of the Act cannot apply to that person, “whether or not the person has any other disability”.⁴²⁰ Intellectual disability is exhaustively defined in s 7 of the IDCCR Act, which provides:⁴²¹

- 1) A person has an **intellectual disability** if the person has a permanent impairment that—
 - (a) results in significantly sub-average general intelligence; and
 - (b) results in significant deficits in adaptive functioning, as measured by tests generally used by clinicians, in at least 2 of the skills listed in subsection (4); and
 - (c) became apparent during the developmental period of the person.

⁴¹³ Smith, above n 395 at 198.

⁴¹⁴ Smith, above n 395 at 198.

⁴¹⁵ Smith, above n 395 at 198.

⁴¹⁶ Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003 s 12.

⁴¹⁷ Section 33.

⁴¹⁸ Anthony Duncan “The IDCCRA” in John Dawson and Kris Gledhill (eds) *New Zealand’s Mental Health Act in Practice* (Victoria University Press, Wellington, 2013) 353 at 360.

⁴¹⁹ Vishnu P. Murty, Finnegan Calabro, and Beatriz Luna “The role of experience in adolescent cognitive development: Integration of executive, memory, and mesolimbic systems” (2016) 70 *Neurosci. Biobehav. Rev* 46 at 47.

⁴²⁰ Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003, s 8(2)(a).

⁴²¹ Section 7.

- (2) Wherever practicable, a person’s general intelligence must be assessed by applying standard psychometric tests generally used by clinicians.
- (3) For the purposes of subsection (1)(a), an assessment of a person’s general intelligence is indicative of significantly sub-average general intelligence if it results in an intelligence quotient that is expressed—
 - (a) as 70 or less; and
 - (b) with a confidence level of not less than 95%.
- (4) The skills referred to in subsection (1)(b) are—
 - (a) communication:
 - (b) self-care:
 - (c) home living:
 - (d) social skills:
 - (e) use of community services:
 - (f) self-direction:
 - (g) health and safety:
 - (h) reading, writing, and arithmetic:
 - (i) leisure and work.
- (5) For the purposes of subsection (1)(c), the developmental period of a person generally finishes when the person turns 18 years.
- (6) This section is subject to [section 8](#).

The reliance by the IDCCR Act on IQ as a measure of, and determining factor for, intellectual disability is problematic not only for individuals with FASD. Although IQ tests have been routinely used to determine intellectual functioning since their inception in the early 1900s, this has not been without controversy.⁴²² There are issues of bias and fairness, due to the cultural context in which IQ tests are derived and administered – children who differ from the “norm” will not necessarily generate an accurate result.⁴²³ There are also questions regarding the pedagogical validity of IQ testing – even if the cultural biases and other issues of fairness are removed, the purpose of IQ testing appears to be focused on ranking, classifying, and labelling children, rather than on the benefit such a test could serve on their further education.⁴²⁴

In the context of criminal offending and justice, the Supreme Court of the United States was confronted with the issue of strict IQ cut-offs in *Hall v Florida*.⁴²⁵ Prior to that case, the Court had established that the eighth and fourteenth amendments to the United States constitution forbid the execution of individuals with intellectual disabilities.⁴²⁶ In *Hall*, the Court identified that Florida law, like the IDCCR Act, defines intellectual disability to require an IQ test score of 70 or below.⁴²⁷ The Court held that this “rigid rule” created an “unacceptable risk” that individuals with intellectual disabilities would be executed. The Court referred to the medical community’s acceptance that a diagnosis of intellectual disability could be made

⁴²² Asa G Hilliard “Back to Binet: the Case Against the Use of IQ Tests in the Schools” (1990) 61(4) *Contemp. Educ.* 184 at 184.

⁴²³ Lee Gunderson and Linda S. Siegel “The evils of the use of IQ tests to define learning disabilities in first- and second-language learners (2001) 55(1) *Read. Teach.* 48 at 49.

⁴²⁴ Hilliard, above n 422.

⁴²⁵ 572 U.S. 701 (2014).

⁴²⁶ *Atkins v Virginia* U.S. 304 (2002).

⁴²⁷ *Hall*, above n 425.

even if an individual had an IQ score above 70, considering the “substantial and weighty evidence” of limitations in adaptive functioning.⁴²⁸

The decision in *Hall* was significant not only for its implications regarding the use of the death penalty, but because it recognised that a person is “more than just a number”.⁴²⁹

Not only is an important constitutional protection against cruel and unusual punishment at stake, but also the rights of a group of individuals who have long suffered due to the stigma of their intellectual disabilities.

Reliance on IQ test scores as a cut-off point for receiving services or support, or in making legally significant decisions about whether an individual should be considered criminally culpable or not, represents an inappropriate focus on a person’s deficits without considering their personhood in its entirety. The approach adopted in s 7 of the IDCCR Act is contrary to both the New Zealand Disability Strategy and the CRPD, both of which require New Zealand to adopt the social model of disability.⁴³⁰ Subsection (5), where the IDCCR Act defines the developmental period of a person ending when the person turns 18 is also inaccurate – more recent developments in the field have established that brain development continues well into the 20s.⁴³¹ Section 7 of the IDCCR Act is therefore an inappropriate platform generally for determining whether individuals with intellectual disability should fall within its ambit, but is especially concerning as a vehicle for providing support for individuals with FASD.

Subsection 3(a) precludes an individual from coming within the ambit of the IDCCR Act if they have an IQ above 70.⁴³² This is problematic for individuals with FASD, because although FASD has been cited as the leading cause of intellectual disability, the majority of young people with FASD will be found to have an IQ within the normal range.⁴³³ The relatively normal intellectual abilities of people with prenatal alcohol exposure has been known for some time. In 1996, a study was conducted through the University of Washington with the purpose of examining the types and magnitudes of secondary disabilities that occur as a result of prenatal alcohol exposure.⁴³⁴ In order to understand the existence of secondary disabilities in the 473 participants with identified prenatal alcohol exposure, primary disabilities, including measures of IQ, were assessed.⁴³⁵ The average IQ was found to be well above the cut-off for intellectual disability (IQ of 70 or below), and over 85% of the participants, ranging in age from three to 51 years, had an IQ within the normal range.⁴³⁶

⁴²⁸ Hall, above n 425.

⁴²⁹ Courtney Johnson “‘Moore’ Than Just a Number: Why IQ Cut-offs are an Unconstitutional Measure for Determining Intellectual Disability” (2018) 91 *S. Cal. Law. Rev.* 753 at 768.

⁴³⁰ See Chapter 2, Disability Support in New Zealand.

⁴³¹ See for example: Sara B. Johnson, Robert W. Blum and Jay N. Giedd “Adolescent Maturity and the Brain: The Promise and Pitfalls of Neuroscience Research in Adolescent Health Policy” (2009) 45(3) *J Adolesc Health* 216; Martina Knezevic “When Do We Become Adults? Review of Theory, Research and Recent Advances from an Interdisciplinary Perspective” (2018) 27(2) *Psihologijske Teme* 267; Andrew J. Fuligni, Mirella Dapretto and Adriana Galvan “Broadening the Impact of Developmental Neuroscience on the Study of Adolescence” (2018) 28(1) *J. Res. Adolesc.* 150.

⁴³² Section 7(3)(a).

⁴³³ Streissguth, above n 7.

⁴³⁴ Streissguth, above n 7.

⁴³⁵ Streissguth, above n 7.

⁴³⁶ Streissguth, above n 7 at 4.

The findings of the 1996 study have since been confirmed in a number of other research projects, with authors establishing that although individuals with FASD may not have an intellectual disability, they almost all require some sort of assistance for significant adaptive behaviour deficits.⁴³⁷ Unfortunately, the IDCCR Act cannot provide such assistance for the majority of young people with FASD, rendering it largely unhelpful as a piece of legislation to support young offenders with FASD moving through the justice system in New Zealand.

D. Summary

The IDCCR Act filled a legislative gap in New Zealand, providing a wide range of options for courts to consider in deciding how best to deal with offenders with intellectual disabilities. Over the past 13 years, the IDCCR Act has provided for care recipients, ensuring that individualised needs assessments are carried out, and that care plans are tailored and regularly reviewed. However, the IDCCR Act is unable to provide for the majority of offenders with FASD, due to its focus on IQ and intellectual disability as a criterion of applicability. The IDCCR Act is in need of legislative amendment to ensure its criteria reflect the Disability Strategy, the CRPD, and recent scientific advances regarding brain development. In addition, in the years since the IDCCR Act took effect, the doctoral thesis published in 2015 and discussed above made findings that call into question the efficacy of a piece of legislation designed to avoid further victimisation and provide much needed support to members of a previously unacknowledged community.

I now turn to consider how the courts have thus far dealt with offenders with FASD in light of the relative lack of appropriate legislative guidance. This section also seeks to determine whether court action in the absence of legislative guidance has been adequate, or whether there is scope for specific legislative or policy amendment in order to provide courts and other agencies dealing with young offenders with FASD with appropriate tools for supporting this challenging group of individuals.

VI. Case analysis

Most court cases dealing with offenders with FASD to date have concerned individuals that fall under the IDCCR Act or the CPMIP Act.⁴³⁸ An analysis of these cases is nevertheless relevant, to determine what aspects of an offender's FASD are deemed relevant by the courts in an offending context. Cases in which the offender was not caught under either of these pieces of legislation are also reviewed.⁴³⁹ These provide a relevant foundation for commentary on the ability of the justice system generally and the youth justice system in particular to provide appropriate rehabilitative support for offenders with FASD.

⁴³⁷ Kimberly A. Kerns and others "Cognitive Deficits in Nonretarded Adults with Fetal Alcohol Syndrome" (1997) 30 *J. Learn. Disabil.* 685 at 685; Heather Carmichael Olson and others "Neuropsychological Deficits in Adolescents with Fetal Alcohol Syndrome: Clinical Findings" (1998) 22(9) *Alcohol. Clin. Exp. Res.* 1998 at 1998; M. Nelson and M. Trussler *Fetal Alcohol Spectrum Disorders in Adults: Ethical and Legal Perspectives* (Springer International Publishing, 2016) at 241.

⁴³⁸ See for example: *R v BMS* CRI-2010-288-000001; *Police v VT* [2015] NZYC 819.

⁴³⁹ See for example: *Police v ED* [2014] NZYC 122; *Pora v R* [2015] UKPC.

i. R v BMS

In 2009 in Whangarei, a 15 year-old girl (BS) was charged with murdering her sister.⁴⁴⁰ In early 2010, the issue of her fitness to stand trial was raised and two health assessors' reports were obtained under s 38 of the CPMIP Act.⁴⁴¹ The reports were prepared by Dr Craig Immelman, a Child and Adolescent psychiatrist, and Dr Valerie McGinn, a clinical neuropsychologist.⁴⁴² The health assessors were in agreement on BS's level of intellectual and adaptive behaviour functioning, finding that she had an IQ in the "extremely low" range and had "significantly impaired" adaptive functioning.⁴⁴³

With an IQ of less than 70, BS fell within the ambit of the IDCCR Act. The health assessors additionally put forward that BS was unfit to stand trial under s 4 of the CPMIP Act.⁴⁴⁴ After hearing the evidence from the health assessors, the Crown contended that although BS was mentally impaired, her impairment (focusing mostly on her level of intellectual functioning) was at the mild end of the spectrum and thus she was fit to stand trial.⁴⁴⁵ The Crown's argument in this case reflected a more traditional stance on mental impairment, reminiscent of terminology pre-1960s, in which measures of IQ were the sole focus in assessing ability.⁴⁴⁶ Since the 1960s and the increasingly widespread use of the term adaptive behaviour or adaptive functioning, a more holistic analysis of BS's impairment was more appropriate.

Judge Druce (himself a social worker and counsellor before becoming a judge), of the District Court in Whangarei, reflected in his reserved judgement an understanding of the importance of taking a holistic view of impairment.⁴⁴⁷ In reaching his conclusion that BS was, in fact, unfit to stand trial, the Judge took into consideration the entirety of the health assessors' findings.⁴⁴⁸ He discussed BS's intellectual functioning, but considered it in light of her additional brain damage resulting from prenatal exposure to alcohol, and the trauma she experienced as a child exposed to domestic violence.⁴⁴⁹ The Court broke down her impairments in terms of the attributes that could be linked with prenatal alcohol exposure (as discussed above), including lability of mood, language and comprehension, verbal reasoning and executive functioning.⁴⁵⁰ These impairments were found to be causally linked to her FASD, and exacerbated by her unstable home environment.⁴⁵¹

This case is important in illustrating the holistic view of impairment that is required in order to accurately assess a defendant's ability to stand trial. Since BS was found unfit to stand

⁴⁴⁰ *R v BMS* CRI-2010-288-000001.

⁴⁴¹ Section 38 gives power to the court to order that a health assessor prepares an assessment report on the individual concerned in order for the court to then establish fitness for trial, insanity, type and length of sentence to impose, or any conditions or requirements to be imposed as part of the ultimate sentence or order.

⁴⁴² *BMS*, above n 440 at [1].

⁴⁴³ *BMS*, above n 440 at [3].

⁴⁴⁴ Section 4 states that a defendant is unfit to stand trial if they are unable, due to mental impairment, to conduct a defence, including a defendant who is unable to plead, adequately understand the proceedings or communicate effectively with counsel.

⁴⁴⁵ *BMS*, above n 440 at [5].

⁴⁴⁶ Edwards and Greenspan, above n 69 at 421.

⁴⁴⁷ *BMS*, above n 440 at [41].

⁴⁴⁸ *BMS*, above n 440 at [20]-[40].

⁴⁴⁹ *BMS*, above n 440 at [41].

⁴⁵⁰ *BMS*, above n 440 at [23], [25], [27], and [28].

⁴⁵¹ *BMS*, above n 440 at [23].

trial under the CPMIP Act, the Court had recourse to legislation that could guide its steps in regards to how best to deal with and support the young offender. Her mild intellectual disability meant she could be directed to receive a needs assessment under the IDCCR Act.⁴⁵² Had the defendant's level of intellectual functioning been higher, she would not have had recourse to this piece of legislation, despite requiring significant support for her adaptive functioning deficits.

ii. *Police v VT*

The 2015 case *Police v VT* concerned a young man facing seven different charges, and an application made to have these dismissed on account of delay.⁴⁵³ The power to dismiss charges for delay is set out in s 322 of the OT Act which provides:⁴⁵⁴

A Youth Court Judge may dismiss any information charging a young person with the commission of an offence if the Judge is satisfied that the time that has elapsed between the date of the commission of the alleged offence and the hearing has been unnecessarily or unduly protracted.

At the time the Youth Court was considering the application to have the charges dismissed, the issue as to VT's fitness to stand trial under the CPMIP Act had also been triggered, and a s 333 report had been written by neuropsychologist Valerie McGinn.⁴⁵⁵ McGinn had outlined in her report, which had been written four months after the alleged offending, that a finding of unfitness to plead and unfitness to stand trial were likely, due to the cognitive impairments experienced by VT as a result of his FASD.⁴⁵⁶

The factors to consider in whether to grant a dismissal of charges were discussed in both *BGDT v Youth Court Rotorua & NZ Police* and *Attorney-General v Youth Court*.⁴⁵⁷ These cases established that s 322 granted a discretionary power to dismiss charges *if* the test of "unnecessary or undue" delay had been met.⁴⁵⁸ In *Attorney-General v Youth Court*, Winkelmann J helpfully set out relevant factors to consider in determining whether delay could be considered "undue", including prejudice to the accused.⁴⁵⁹

In *Police v VT*, prejudice to the accused was considered highly relevant due to VT's cognitive impairments.⁴⁶⁰ He was found to be functioning in the extremely low range intellectually, his understanding of vocabulary was about that of a 7-year-old, his verbal reasoning matched that of a 6-year-old, he had serious memory deficits, could not retain information and was easily overwhelmed.⁴⁶¹ The Court concluded that VT was therefore especially vulnerable not only because of his youth, but also because of his disability.⁴⁶²

⁴⁵² *BMS*, above n 440 at [45].

⁴⁵³ *Police v VT* [2015] NZYC 819.

⁴⁵⁴ Oranga Tamariki Act 1989, s 322.

⁴⁵⁵ *VT*, above n 453 at [5].

⁴⁵⁶ *VT*, above n 453 at [5].

⁴⁵⁷ *BGDT v Youth Court Rotorua & NZ Police* (High Court) M 119/99; *Attorney-General v Youth Court* CIV 2006-404-2202, High Court Auckland.

⁴⁵⁸ *BGDT*, above n 457.

⁴⁵⁹ *Attorney General*, above n 457 at [52].

⁴⁶⁰ *VT*, above n 453 at [27].

⁴⁶¹ *VT*, above n 453 at [27].

⁴⁶² *VT*, above n 453 at [28].

This finding resulted in the Court exercising its discretion under s 322, in light of VT's age and disability, especially in regards to the way in which his disability affected his memory.⁴⁶³

The prosecution in *VT* submitted that a prosecution leading to a finding of unfitness under the CPMIP Act would allow welfare services to be provided to the young person involved.⁴⁶⁴ The Court however referred to the principle in s 208(b) of the OT Act: that proceedings are not to be instituted against a young person solely to provide assistance or services to that young person. The Court further noted that:

[...] V is now receiving good care. He lives with his grandmother and receives support that is being provided at least partly as a result of the diagnoses contained in the reports provided in these proceedings.

This final direction by the judge highlights the importance of diagnosis as previously discussed in Chapter Two. The case itself is an important example of the way in which a young person's FASD may be taken into account in deciding whether discretionary powers are to be exercised.

iii. Police v ED

Police v ED concerned a 14 year-old boy with an extensive offending history.⁴⁶⁵ The offending began when ED was just 12 years old, with an aggravated robbery.⁴⁶⁶ Other offences committed by ED included assault with intent to injure (when ED was 13), theft, trespass, wilful damage and assaulting a Police officer.⁴⁶⁷ The case in 2014 arose due to ED's continual and repetitive breach of conditions imposed as a result of prior FGC, and additional failures to comply with subsequent more stringent orders.⁴⁶⁸

At paragraph five of the case, the Youth Court noted that:⁴⁶⁹

Given the impulsive, repetitive nature of his offending, his inability to comply with seemingly simple rules and instructions, and to engage appropriately in programmes, a neuropsychological assessment was ordered.

The assessment was carried out by neuropsychologist Valerie McGinn, with a psychiatric assessment also conducted by Dr Immelman.⁴⁷⁰ The joint assessment resulted in ED being diagnosed with FASD.⁴⁷¹ Interestingly, ED was also found to meet the diagnostic criteria for Attention Deficit Hyperactivity Disorder (ADHD), conduct disorder and substance disorder; however, while these three diagnoses had been made for ED in the past, it was the first time he had been diagnosed with FASD.⁴⁷²

⁴⁶³ *VT*, above n 453 at [30].

⁴⁶⁴ *VT*, above n 453 at [31].

⁴⁶⁵ *Police v ED* [2014] NZYC 122.

⁴⁶⁶ *ED*, above n 465 at [1].

⁴⁶⁷ *ED*, above n 465 at [1].

⁴⁶⁸ *ED*, above n 465 at [2]-[4].

⁴⁶⁹ *ED*, above n 465 at [5].

⁴⁷⁰ *ED*, above n 465 at [6].

⁴⁷¹ *ED*, above n 465 at [6].

⁴⁷² *ED*, above n 465 at [6].

The clinicians identified damage to ED's frontal lobe as a result of prenatal alcohol exposure as being highly relevant to his offending behaviours.⁴⁷³ Dr Immelman noted that the repetitive cycle of offending and breach of conditions reflected ED's inability to learn from mistakes or associate actions with consequences, a learned behaviour that relies on effective frontal lobe functioning.⁴⁷⁴ Dr McGinn noted that his FASD had triggered a variety of secondary behavioural traits, including immaturity, impulsivity, hyperactivity, and emotional and behavioural dysregulation.⁴⁷⁵ She also acknowledged that his intellectual functioning was in the borderline range, but above the level that would give him access to disability services, despite being significantly disabled.⁴⁷⁶

Police v ED is an example of a case in which the young person had significant deficits that were clearly having an impact on his offending behaviours, but because his intellectual functioning was above the cut-off for intellectual disability, the Court had limited recourse. In this case, the neuropsychologist stressed that a youth justice residence was not an appropriate environment for ED.⁴⁷⁷ She pointed out that youth justice residences are highly stimulating environments and that over-stimulation would put significant amounts of stress on ED and could increase his emotional volatility.⁴⁷⁸ Dr McGinn emphasised that even for a young person with a history of serious offending, punishment would not change behaviours that are brain-based, and has limited utility.⁴⁷⁹

Instead, the Court gave ED a supervision with activity order, with 12 months of mentoring, attendance at a MYND⁴⁸⁰ support programme, and involvement of the Youth Horizons Trust.⁴⁸¹ The Court acknowledged that although in the past a variety of orders had been unsuccessful, the new knowledge of ED's FASD gave the individuals and services working with ED additional information regarding how best to focus his treatment and care.⁴⁸² This case reflects the inherently flexible nature of the Youth Court's jurisdiction, but simultaneously highlights the importance of access to diagnosis and early intervention for young people with prenatal alcohol exposure. It should not take multiple court appearances for a variety of criminal offending and breaches of court orders for the flags to be raised that perhaps this young person requires support of a different kind.

iv. *Police v ZW*

In 2017 the Youth Court sought to determine whether ZW, facing a number of serious charges, was unfit to stand trial.⁴⁸³ Judge Hikaka referred to the health assessments provided by two clinicians who prepared a joint memorandum for the Court.⁴⁸⁴ The judge noted that

⁴⁷³ *ED*, above n 465 at [8].

⁴⁷⁴ *ED*, above n 465 at [8].

⁴⁷⁵ *ED*, above n 465 at [9].

⁴⁷⁶ *ED*, above n 465 at [9].

⁴⁷⁷ *ED*, above n 465 at [11].

⁴⁷⁸ *ED*, above n 465 at [11].

⁴⁷⁹ *ED*, above n 465 at [11].

⁴⁸⁰ Although MYND was originally an acronym, the organisation abandoned this several years ago. The programme is now simply known as MYND.

⁴⁸¹ *ED*, above n 465 at [14].

⁴⁸² *ED*, above n 465 at [14].

⁴⁸³ *Police v ZW* [2017] NZYC 942.

⁴⁸⁴ *ZW*, above n 483 at [9].

relevant to the Court's assessment of fitness were the diagnoses ZW had received: FASD, a mild intellectual disability, ADHD, and a language disorder.⁴⁸⁵ The Court in this case was mostly concerned with whether, with the help of a communication assistant, ZW might be able to actively participate in the legal process.

In coming to his decision, Judge Hikaka reflected on issues such as confabulation, suggestibility, and stress, and concluded that “[ZW]’s confabulation and his suggestibility are such that even if he had the aid of a communication assistant ... it would help with [ZW]’s communication but not with his reasoning, abstract thinking and problem-solving”.⁴⁸⁶ Judge Hikaka expanded on each point, referring back to the concerns articulated by the health professionals in their reports about the increased vulnerability of ZW, especially when placed under stress. He concluded that ZW was unfit to stand trial.

The judge also made some interesting comments about the nature of FASD and the support that is required. He commented that given the nature of FASD, there are “challenges to those caring for the people with that disorder” and that supportive input needed to be “intensive and well-informed, over a long period of time”.⁴⁸⁷ He said that if such an approach is adopted, “the chances of optimising positive movement forward are greatly enhanced”.

Ultimately the Court directed for inquiries to be made under s 23 CPMIP Act, and given the existence of a mild intellectual disability, to focus the inquiries through Part Three of the IDCCR Act.⁴⁸⁸ The case is mostly pertinent to this thesis for the comments regarding the intensive supervision required in FASD cases, and also to establish that findings of unfitness can be made based on the behavioural presentations of FASD.

v. *Pora v R*

In 2015, the United Kingdom Privy Council made a decision on an appeal by Teina Pora, a New Zealand man who had been charged and convicted in 1994 of the rape and murder of Susan Burdett.⁴⁸⁹ Pora was 17 years old at the time the crimes were committed, and thus fell outside of the ambit of the youth justice system. An analysis of the case is nevertheless relevant to acknowledge the role FASD plays in vulnerability in the justice context. The appeal largely concerned a series of confessions that had been made by Pora in relation to the crimes, with new evidence regarding FASD undermining the reliability of those confessions.⁴⁹⁰ The case is a harrowing reflection of the potential consequences of a justice system failing to recognise or acknowledge the effects neurodisability has on individuals’ conduct.

⁴⁸⁵ ZW, above n 483 at [12].

⁴⁸⁶ ZW, above n 483 at [15].

⁴⁸⁷ ZW, above n 483 at [28].

⁴⁸⁸ Section 23 of the Criminal Procedure (Mentally Impaired Persons) Act 2003 stipulates that where a finding of unfitness to stand trial has been made, the court must order for inquiries to be made regarding the most suitable method of dealing with the person; Part Three of the Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003 provides the framework for needs assessments and care and rehabilitation plans to be conducted and developed.

⁴⁸⁹ *Pora v R* [2015] UKPC 9.

⁴⁹⁰ *Pora*, above n 489 at [2].

How Pora became involved

In 1993, about a year after Susan Burdett had been murdered, Pora was arrested in relation to a stolen vehicle.⁴⁹¹ While being interviewed by the Police, he asked whether anyone had been apprehended for the murder of Burdett, and when the Police said no, he told them he knew who had done it.⁴⁹² The Police told him there was a reward for information that would lead to her killer, and that indemnity against prosecution could be available for anyone who was not a principal offender.⁴⁹³ The concept of indemnity and the circumstances in which it might be available were explained to Pora who, after initially failing to comprehend the explanation, claimed to understand.⁴⁹⁴

Over the following four days, Pora was interviewed by the Police a number of times in relation to the Burdett case.⁴⁹⁵ Each interview seemed to elicit further information regarding the crimes that had been committed; however, Pora's accounts were "strewn with inconsistencies, contradictions, implausibility and vagueness".⁴⁹⁶ Pora's answers to questions during the interviews were often "halting, hesitant, incoherent and bizarre".⁴⁹⁷ Although the confessions Pora made were incredibly inconsistent and contradictory, the combined effect was that of a graphic and detailed account of the rape and murder of Burdett.⁴⁹⁸ As a result, Pora was charged with her rape and murder, and faced his first trial in 1994.⁴⁹⁹

Initial treatment of the confessions

In the weeks approaching Pora's first trial in 1994, there was no mention of any issues regarding mental capacity.⁵⁰⁰ When Pora gave evidence in his first trial, he denied any involvement in the crimes, but was unable to explain why he had previously made such detailed and explicit confessions.⁵⁰¹ He was convicted and sentenced to life imprisonment.⁵⁰²

New evidence

The new evidence that was relied on in the 2015 appeal was largely in the form of a series of affidavits.⁵⁰³ The most relevant affidavits for the purpose of the current analysis are those from the medical and clinical witnesses: Professor Gisli Gudjonsson (a clinical and forensic psychologist), Dr Valerie McGinn, and Dr Craig Immelman.⁵⁰⁴

⁴⁹¹ *Pora*, above n 489 at [6].

⁴⁹² *Pora*, above n 489 at [6].

⁴⁹³ *Pora*, above n 489 at [6].

⁴⁹⁴ *Pora*, above n 489 at [6].

⁴⁹⁵ *Pora*, above n 489 at [7].

⁴⁹⁶ *Pora*, above n 489 at [7].

⁴⁹⁷ *Pora*, above n 489 at [7].

⁴⁹⁸ *Pora*, above n 489 at [14].

⁴⁹⁹ *Pora*, above n 489 at [15] and [16].

⁵⁰⁰ *Pora*, above n 489 at [16].

⁵⁰¹ *Pora*, above n 489 at [17].

⁵⁰² *Pora*, above n 489 at [17].

⁵⁰³ *Pora*, above n 489 at [22].

⁵⁰⁴ *Pora*, above n 489 at [22].

Professor Gudjonsson's evidence

Professor Gudjonsson was asked to comment on the reliability of the confessions Pora made during his initial interviews and subsequent conviction.⁵⁰⁵ He conducted a series of psychometric tests on Pora, including assessments of his intellectual and neuropsychological functioning.⁵⁰⁶ He found that Pora did have a variety of significant mental functioning deficits; however, in his reports provided to the Court, he overstepped his role as an expert witness when he “trenchantly asserts that Pora’s confessions *are* unreliable”, a matter for the Court to determine.⁵⁰⁷ As a result, his evidence was found to be inadmissible.⁵⁰⁸

Dr McGinn's evidence

Dr McGinn was asked to inquire into whether Pora had a neurodisability, and if so, what the nature of that disability was.⁵⁰⁹ Dr McGinn started by investigating whether Pora had FASD, and found that he met the diagnostic criteria for what was then known as Alcohol Related Neurodevelopmental Disorder (ARND).⁵¹⁰ As a result of this finding, Dr McGinn made a series of conclusions about Pora’s behavioural abilities.⁵¹¹

Dr McGinn stated that Pora had significant deficits in executive functioning, deficits in regulatory control, and was cognitively rigid.⁵¹² She also noted that because of these deficits, when in a complex situation, Pora was likely to act impulsively and with reduced capacity to consider the consequences of his actions.⁵¹³ As part of McGinn’s investigations, she considered Pora’s developmental history and noted that it was “entirely consistent with a child with an undiagnosed FASD”.⁵¹⁴ Dr McGinn also made two comments highly relevant to Pora’s confession history, which it is worth reproducing in full:⁵¹⁵

Due to brain limitation Mr Pora will tend to say and do what seems to his advantage at the time, without a realisation that he is doing this. This tendency can be perceived as manipulative and self-serving until the underlying brain damage is considered and it is appreciated that this is not wilful or intentional.

And:⁵¹⁶

People with FASD, most especially when they have memory and executive deficits are prone to confabulate; that is make up stories to fill in the gaps that are not in

⁵⁰⁵ *Pora*, above n 489 at [23].

⁵⁰⁶ *Pora*, above n 489 at [23].

⁵⁰⁷ *Pora*, above n 489 at [24].

⁵⁰⁸ *Pora*, above n 489 at [33].

⁵⁰⁹ *Pora*, above n 489 at [35].

⁵¹⁰ *Pora*, above n 489 at [36]. Now, Pora would be diagnosed with “FASD without Sentinel Facial Features” due to the updated Candian guide (followed by clinicians in New Zealand) that has condensed the diagnostic categories to two – see Chapter Four for discussion on the Canadian Guideline for Diagnosis.

⁵¹¹ *Pora*, above n 489 at [37].

⁵¹² *Pora*, above n 489 at [37].

⁵¹³ *Pora*, above n 489 at [37].

⁵¹⁴ *Pora*, above n 489 at [37].

⁵¹⁵ *Pora*, above n 489 at [37].

⁵¹⁶ *Pora*, above n 489 at [37].

keeping with the truth. This is different to lying as it is not intentional and is a feature of executive brain impairment.

The evidence provided by Dr McGinn's reports was considered reliable and useful, and was admitted as new evidence in Pora's 2015 appeal.⁵¹⁷

Dr Immelman's evidence

Dr Immelman's evidence, providing a psychiatrist's perspective, largely corroborated the evidence given by Dr McGinn.⁵¹⁸ Significantly, he found that Pora's intellectual functioning was within the normal range (and well above the cut-off for intellectual disability support).⁵¹⁹ However, Pora's performance on verbal memory tests indicated great difficulty understanding questions and remembering what those questions were when composing a reply.⁵²⁰ Dr Immelman also noted that Pora had "significant impairment" in executive function, and that these impairments led Pora to have a tendency to maintain a position even when it was shown to be "entirely untenable".⁵²¹

Dr Immelman emphasised that the particular deficits exhibited in Teina Pora's case of FASD meant that answers given to questions could be unreliable even in a non-coercive setting.⁵²² There were three reasons given to explain why this is the case:⁵²³

...uncertainty about what the "correct" answers might be; interpersonal trust that the interviewer's intentions are constructive and benign; and reluctance to admit uncertainty or lack of knowledge when the interviewees believe they should know, or are expected to know, the answers to the questions.

Dr Immelman's evidence in relation to Pora's neurodisability was also found to be admissible.⁵²⁴

Decision

In light of the evidence provided by the medical experts, the Court found that Pora's confessions could not safely be relied upon in upholding his conviction.⁵²⁵ At paragraph 58, Lord Kerr concluded:⁵²⁶

The combination of Pora's frequently contradictory and often implausible confessions and the recent diagnosis of his FASD leads to only one possible conclusion and that is that reliance on his confessions gives rise to a risk of a miscarriage of justice. On that account, his convictions must be quashed.

⁵¹⁷ *Pora*, above n 489 at [43].

⁵¹⁸ *Pora*, above n 489 at [44].

⁵¹⁹ *Pora*, above n 489 at [45].

⁵²⁰ *Pora*, above n 489 at [45].

⁵²¹ *Pora*, above n 489 at [45].

⁵²² *Pora*, above n 489 at [46].

⁵²³ *Pora*, above n 489 at [46].

⁵²⁴ *Pora*, above n 489 at [48].

⁵²⁵ *Pora*, above n 489 at [55].

⁵²⁶ *Pora*, above n 489 at [58].

Pora v R highlights the significance of FASD on offending behaviours. Although this case involved the adult criminal justice system, it is nonetheless useful to illustrate the difficulties individuals with FASD face in navigating the complex legal world.⁵²⁷ Teina Pora spent 20 years in prison before he was finally acquitted, and his eventual release heavily relied on several key advocates fighting on his behalf. Additionally, the Privy Council’s decision serves to demonstrate the changing attitudes of the judiciary regarding neurodisability and its intersection with justice, and the importance of considering neurodisability as a potential issue at all stages of the justice inquiry.⁵²⁸

VII. Conclusion

There is a rapidly developing body of literature that establishes the connection between the behavioural traits associated with FASD and offending behaviours. Impulsivity (as a result of damage to the prefrontal cortex) can lead to individuals engaging in spur-of-the-moment criminal offending; vulnerability to peer influence and suggestibility can exacerbate criminal involvement; and difficulties in communication and affect regulation can escalate situations of conflict.⁵²⁹ Once in the justice system, comprehension difficulties can compound a young person’s vulnerability⁵³⁰ and result in an inability to comply with court orders, further escalating the young person through the justice system.⁵³¹

This connection is further emphasised by the results of the scientific studies as discussed in Chapter Two, which identify the specific neurological impairments that are associated with the relevant behaviours. Despite this evidence, the legislative background in which young offenders with FASD are experiencing the justice system in New Zealand is ill-equipped to adequately provide for these young people and their disability. The youth justice cases to date illustrate the lack of uniformity in approach. While some courts (for example the Youth Court in *R v BMS*) have been able to provide for the specific young person’s needs by using the IDCCR Act for intellectual disability, or the CPMIP Act for unfitness, a cohort of young people with FASD remain who do not fall within the ambit of existing legislation. An example of this was reflected in *Police v ED* where the young person’s level of intellectual functioning was above the cut-off for intellectual disability support.⁵³² The Youth Court in that case could not rely on legislative support for ED and instead had to make an order of the kind that had been made for ED in the past without success.⁵³³ Without appropriate

⁵²⁷ The “swiss cheese” nature of the brain damage seen in FASD has been described, in the context of Pora’s case, as ‘deceptive’. Rodney Hansen QC, in his report for the Minister of Justice regarding Pora’s compensation claim, stated that the vulnerability of individuals with FASD in the justice system can come from them “seeming more capable on the surface than they really are” Hon Rodney Hansen CNZM QC *On Compensation Claim by Teina Anthony Pora* (report for Minister of Justice, 23 March 2016) at 31.

⁵²⁸ It is not only to questions of sentencing and culpability that FASD will be relevant – Teina Pora’s case highlights the need for justice professionals to “be alert to the potential impact of FASD upon answers given during the interrogation process”: Ian Freckelton QC “Fetal Alcohol Spectrum Disorders, Expert Evidence and the Unreliability of Admissions during Police Interviews” (2016) 23(2) *Psychiatr Psychol Law* 173 at 182.

⁵²⁹ Freckelton, above n 306 at 66.

⁵³⁰ McLachlan, above n 307 at 36; see also *Pora v R* [2015] UKPC 9, where Pora’s difficulties in comprehension (among other cognitive vulnerabilities) ultimately lead to his wrongful conviction and incarceration.

⁵³¹ See for example *Police v ED* [2014] NZYC at [8].

⁵³² *ED*, above n 465 at [9].

⁵³³ *ED*, above n 465 at [14].

diagnostic and policy structures in place, these young people will unfortunately continue to fall through the gaps.

Developments in support for FASD, both clinically and in the context of justice, are occurring rapidly in Canada and Australia. The following chapter identifies and analyses the diagnostic regimes and judicial responses to FASD and considers how New Zealand might learn from these international examples.

Chapter 4

International Context

I. Introduction

FASD in both Australia and Canada has been identified as “chronic and costly”, with justice systems absorbing a significant amount of the total financial burden.⁵³⁴ It has only been relatively recently that diagnostic guidelines have been developed for both these countries⁵³⁵, following acknowledgment of the need to increase consistency and capacity in diagnostic practice. Following this acknowledgment, both Australia and Canada employed comprehensive consultation to establish guidelines to diagnosis that were streamlined, thorough and effective for their respective populations. New Zealand still does not have a formal guide for diagnosing FASD.

The awareness of FASD and the impact it has on offending behaviours and issues related to culpability and sentencing has been growing among justice sectors in both Australia and Canada. Both countries have grappled with the issue of FASD in the courts, considering the implications neurodisability has on the principle of aggravating and mitigating factors in sentencing. Canada has made some progress in exploring how FASD should be accommodated in legislative change, with a Bill⁵³⁶ that sought to codify neuroscientific evidence regarding FASD as a unique disability with a causal relationship to offending behaviours, requiring a targeted legislative response. Canada is also leading the way in developing appropriate interventions and initiatives for youth offenders with FASD.

The existence of formal diagnostic guidelines in Australia and Canada, in addition to the close geographical and political proximity to New Zealand (Australia) and the significant progress made in the justice sector (Canada) make these two jurisdictions the most useful starting point for a discussion on international context for this thesis. Both Australia and Canada have justice systems comparable to New Zealand, with targeted responses for young offenders. The progress being made in these jurisdictions regarding the acknowledgment of the role FASD has in criminal offending among young people allows for consideration of how New Zealand might best adopt some of these practices for our own youth justice population. This chapter discusses the diagnostic process for FASD in Canada and Australia, before analysing one case example from each jurisdiction, their legislative progress, and their youth justice initiatives.

⁵³⁴ Doug Shelton and others “Responding to fetal alcohol spectrum disorder in Australia” (2018) 54 *J. Paediatr. Child Health* 1121; Nguyen Xuan Thanh and Egon Jonsson “Cost of Fetal Alcohol Spectrum Disorder in the Canadian Criminal Justice System” (2015) 22(1) *J Popul Ther Clin Pharmacol* 125.

⁵³⁵ 2005 for Canada, updated in 2015; 2016 for Australia.

⁵³⁶ Bill C-235 was introduced as a private members Bill to amend the Criminal Code to recognise FASD, and was defeated in December 2016.

II. Canada

A. Diagnosis

The original Canadian Guidelines for Diagnosis, published in 2005, were the result of a national survey inquiring into the knowledge and attitudes of health professionals towards FASD.⁵³⁷ The results suggested that a standardised approach to diagnosing was critical and thus a seven-category guideline was established.

In 2015, a revised set of guidelines for Canada was published.⁵³⁸ The revision identified several key points, as well as making some substantive changes to what was recommended in the initial document. Firstly, the revision identified FASD as a diagnostic term “describing the constellation of effects that result from prenatal alcohol exposure”⁵³⁹, something that had been explicitly rejected in the initial guidelines.⁵⁴⁰ Secondly, the revision emphasised that making a diagnosis of FASD required a multidisciplinary approach, and that the diagnostic process itself should not be performed in isolation.⁵⁴¹ Importantly, and relevant to the situation in New Zealand, the 2015 revision repeated that “diagnosis of FASD is critical to improve outcomes for affected individuals and families, and to inform pre-pregnancy counselling to prevent future cases”.⁵⁴²

The revision made several other changes, mostly refining and expanding on the initial recommendations of 2005. For example, the 2015 version includes specific guidelines for diagnosing different age categories, and provides recommendations for how the diagnostic team should vary depending on the age of the patient.⁵⁴³ The original set of guidelines, together with the revision, have established a solid platform for effective diagnosis of FASD in Canada and provide a framework for other countries to build on and adapt.

The guidelines are split into seven categories, outlining the process from screening and referral to diagnostic criteria and the harmonisation of two different diagnostic approaches.⁵⁴⁴ It is important to examine these categories, as the approach taken by Canada has been closely analysed by Alcohol Healthwatch New Zealand in developing their own recommendations, and by the Hawke’s Bay District Health Board in implementing a similar approach (see Chapter Two).⁵⁴⁵

i. Screening and referral

The guidelines for diagnosis recommend that all pregnant or post-partum women be screened for alcohol use.⁵⁴⁶ Screening should be conducted using validated screening tools

⁵³⁷ Chudley, above n 132 at 2.

⁵³⁸ Jocelynn L. Cook and others “Fetal alcohol spectrum disorder: a guideline for diagnosis across the lifespan” (2015) CMAJ 1.

⁵³⁹ Cook, above n 538 at 1.

⁵⁴⁰ Chudley, above n 132 at 1.

⁵⁴¹ Cook, above n 538 at 1.

⁵⁴² Cook, above n 538 at 1.

⁵⁴³ Cook, above n 538 at 4.

⁵⁴⁴ Chudley, above n 132 at 1.

⁵⁴⁵ Alcohol Healthwatch, above n 133 at 25.

⁵⁴⁶ Chudley, above n 132 at 4.

by healthcare providers.⁵⁴⁷ The examples of screening tools included as appropriate options are the TWEAK method and the T-ACE method.⁵⁴⁸ These two tools are similar, each involving a series of questions that are prompted by each letter in the acronym. The TWEAK method stands for:

- T - tolerance (how many drinks can you hold?/how many drinks can you have before you start to feel the effects?);
- W - worried (have close friends or relatives worried or complained about your drinking in the past year?);
- E - eye-openers (do you sometimes take a drink in the morning when you first get up?);
- A - amnesia (has a friend or family member ever told you about things you said or did while you were drinking that you could not remember?); and
- K - kut-down (do you sometimes feel the need to cut down on your drinking?).⁵⁴⁹

The T-ACE method is similar, with the most significant difference being the ‘A’ standing for annoyance (have people ever been annoyed by your drinking?) rather than amnesia.⁵⁵⁰

The guidelines direct that high-risk women be referred (to counselling, for example) and for abstinence to be recommended to all women during pregnancy.⁵⁵¹ Referral of individuals for a possible FASD-related diagnosis should be made in the presence of any of a variety of FASD-typical traits.⁵⁵² The traits listed include the presence of the characteristic facial impairments, known or probable prenatal exposure to alcohol and the existence of central nervous system deficits.⁵⁵³ The guidelines emphasise that referral does not equate with diagnosis, but rather serves to identify individuals and their caregivers who require additional support.⁵⁵⁴

ii. Physical examination and differential diagnosis

The second category expanded on in the guidelines provides detailed recommendations for the physical examination aspect of diagnosis, and the importance of differential diagnosis to exclude the possibility of alternate explanations.⁵⁵⁵ The physical examination should include both a general physical and a neurologic exam, to identify growth and head size, and to assess characteristic findings.⁵⁵⁶

⁵⁴⁷ Chudley, above n 132 at 4.

⁵⁴⁸ Chudley, above n 132 at 4.

⁵⁴⁹ Katherine A. Bradley and others “Alcohol Screening Questionnaires in Women” (1998) 280 JAMA 166 at 168.

⁵⁵⁰ Bradley, above n 549 at 168. T-ACE: T – tolerance; A – annoyed; C – cut-down; E – eye-opener.

⁵⁵¹ Chudley, above n 132 at 4.

⁵⁵² Chudley, above n 132 at 4.

⁵⁵³ Chudley, above n 132 at 4.

⁵⁵⁴ Chudley, above n 132 at 5.

⁵⁵⁵ Chudley, above n 132 at 6.

⁵⁵⁶ Chudley, above n 132 at 6.

iii. Neurobehavioural assessment

A neurobehavioural assessment is crucial for most cases of FASD in which the sentinel facial features of FASD will not be present and thus diagnosis may not be achievable in the first stage of physical examination.⁵⁵⁷ Neurobehavioural assessment includes an analysis of 10 neurocognitive domains:

1. Brain Structure/Neurology
2. Motor skills
3. Cognition
4. Language
5. Academic Achievement
6. Memory
7. Attention
8. Executive Function, including impulse control and hyperactivity
9. Affect Regulation
10. Adaptive behaviour, Social Skills or Social Communication

The broad list of domains reflects the nature of FASD as a disorder that presents differently in each individual and illustrates why a one-size-fits-all approach to diagnosis is inappropriate. The recommendations provide guidance as to what constitutes an “impaired domain”, and state that evidence of impairment across three domains is necessary for a diagnosis.⁵⁵⁸

iv. Treatment and follow-up

The treatment and follow-up section of the guidelines has a focus on ensuring the individual and their family are well-equipped to process the diagnosis. Recommendations include outlining the importance of educating the patient and their family on features of FASD, and emphasising that any psychosocial tensions should be discussed in a culturally-sensitive manner.⁵⁵⁹ The recommendations also highlight continuity as essential, by stipulating that the original diagnostic team is responsible for following-up outcomes of assessment and treatment plans.⁵⁶⁰ Importantly, the guidelines state that diagnosed individuals should be linked to resources and services, but that a lack of services should not be a reason to justify withholding diagnosis, because “often the diagnosis in the individual is the impetus that leads to the development of resources”.⁵⁶¹

v. Maternal alcohol history in pregnancy

The fifth category provides recommendations on documenting maternal alcohol use during pregnancy.⁵⁶² The guidelines state that prenatal alcohol exposure in an individual must be confirmed by alcohol consumption by the mother during the index pregnancy – either

⁵⁵⁷ Chudley, above n 132 at 9.

⁵⁵⁸ Chudley, above n 132 at 9.

⁵⁵⁹ Chudley, above n 132 at 11.

⁵⁶⁰ Chudley, above n 132 at 11.

⁵⁶¹ Chudley, above n 132 at 11.

⁵⁶² Chudley, above n 132 at 11.

through clinical observation or self-reports by the mother.⁵⁶³ The number, type and frequency of alcohol consumption should also be documented if available.⁵⁶⁴ The recommendations emphasise that hearsay, lifestyle, other drug use or a history of alcohol exposure in previous pregnancies cannot, in isolation, be informative of drinking patterns in the currently observed pregnancy.⁵⁶⁵

vi. *Diagnostic criteria*

A diagnosis of FASD may be made either with or without sentinel facial features. For a diagnosis of FASD with sentinel facial features, an individual must:⁵⁶⁶

- present with all three facial anomalies associated with FASD; and
- have confirmed or unknown exposure to alcohol prenatally; and
- have evidence of impairment in three or more of the neurodevelopmental domains.

For a diagnosis of FASD without sentinel facial features, an individual must:⁵⁶⁷

- have evidence of impairment in three or more of the neurodevelopmental domains; and
- have confirmed exposure to alcohol prenatally, with the estimated dose at a level known to be associated with neurodevelopmental effects.

The revised Canadian guide includes a third option which is not a diagnosis but a “designation”.⁵⁶⁸ If an individual has:⁵⁶⁹

- confirmed exposure to alcohol prenatally, with the estimated dose at a level known to be associated with neurodevelopmental effects; but
- they do not meet the criteria for central nervous system deficit,

they may be given a designation of “at-risk for neurodevelopmental disorder and FASD, associated with prenatal alcohol exposure”. For individuals given this designation there must be:⁵⁷⁰

some indication of neurodevelopmental disorder in combination with a plausible explanation as to why the neurodevelopmental assessment results failed to meet the criteria for substantial impairment (e.g., patient was too young; incomplete assessment).

The designation may also be used if the individual has the sentinel facial features but does not yet show evidence of meeting the criteria for three or more neurodevelopmental domains.

⁵⁶³ Chudley, above n 132 at 11.

⁵⁶⁴ Chudley, above n 132 at 11.

⁵⁶⁵ Chudley, above n 132 at 11.

⁵⁶⁶ Cook, above n 538 at 3.

⁵⁶⁷ Cook, above n 538 at 3.

⁵⁶⁸ Cook, above n 538 at 4.

⁵⁶⁹ Cook, above n 538 at 4.

⁵⁷⁰ Cook, above n 538 at 4.

vii. *Conclusion*

The Canadian guidelines were developed after several consultations with Canadian experts in FASD.⁵⁷¹ Some of the participants were already offering diagnostic services for FASD in Canada, but the authors recognised that due to the multiple ways FASD diagnosis could be approached, developing an integrated guide would ensure consistency nationwide.⁵⁷² The authors also noted that developing a streamlined approach would facilitate data collection for the purpose of establishing Canadian prevalence rates, which could subsequently be used to inform prevention and intervention services and programmes.⁵⁷³

B. FASD and justice

i. *Background*

The total cost of FASD in Canada is estimated at \$9.7 billion per year.⁵⁷⁴ The cost for FASD in the criminal justice system accounts for 40% of that figure, at \$3.9 billion per year (compared to health, which comes in at just 21%). In 2015, a systematic review of journal articles was undertaken to establish the prevalence of young people with FASD involved in the justice system.⁵⁷⁵ Of the four articles included in the final sample, prevalence rates ranged between 10.9 and 21%.⁵⁷⁶ Despite the range, all results reflected significant overrepresentation of young people with FASD in the justice system.⁵⁷⁷ The prevalence rates for aboriginal young people was higher still: between 19 and 35.6%.⁵⁷⁸ The authors of this study commented on the high rates of aboriginal overrepresentation, questioning the source of data:⁵⁷⁹

The apparent association between FASD and Aboriginal populations must be questioned. Given the wide disparity in reported rates between Aboriginal and non-Aboriginal youth, it is unclear whether the association between FASD and engagement with the criminal justice system is more accurately explained by criminalisation among Aboriginal youth in Canada, given their significant overrepresentation at each stage of the justice system [...] The relationship is also potentially confounded by other experiences of discrimination and disadvantage experienced by Aboriginal communities. Rates of FASD cannot be readily separated from intergenerational disadvantage, poor access to health care and risk of mental health difficulties.

The study concludes by acknowledging that the small sample size cannot be used to make generalised comments about the overrepresentation of young people with FASD in justice, but that the lack of evidence points to challenges in the assessment process for FASD.⁵⁸⁰

⁵⁷¹ Chudley, above n 132 at s2.

⁵⁷² Chudley, above n 132 at s2.

⁵⁷³ Chudley, above n 132 at s2.

⁵⁷⁴ Nguyen, above n 534 at 125.

⁵⁷⁵ Nathan Hughes and others “A systematic review of the prevalence of fetal alcohol spectrum disorders among young people in the criminal justice system” (2016) 3 *Cogent Psychology* 1.

⁵⁷⁶ Hughes, above n 575 at 5.

⁵⁷⁷ Hughes, above n 575 at 5.

⁵⁷⁸ Hughes, above n 575 at 5.

⁵⁷⁹ Hughes, above n 575 at 5.

⁵⁸⁰ Hughes, above n 575 at 6.

The authors note the general difficulty in assessing for FASD and comment that these difficulties “are amplified in youth justice systems that typically lack access to the necessary trained clinical practitioners”.⁵⁸¹

ii. *Legislative context*

In 2016, Labour MP Larry Bagnall introduced a private member’s Bill (Bill C-235) seeking to amend the Criminal Code and the Corrections and Conditional Release Act.⁵⁸² The Bill sought to: “establish a procedure for assessing individuals who are involved in the criminal justice system and who may suffer from a fetal alcohol disorder”.⁵⁸³ It also sought to require the court to consider any diagnosis of FASD to be a mitigating factor in sentencing.

Bill C-235 was defeated at the second reading, but the suggested legislative amendments and criticism they received provide a useful starting point for considering legislative amendment for New Zealand.

The Bill first requires s 2 of the Criminal Code to be amended to include a definition of “fetal alcohol disorder”.⁵⁸⁴

Fetal alcohol disorder refers to any neurodevelopmental disorder that is associated with prenatal alcohol exposure – the spectrum of these disorders being commonly known as fetal alcohol spectrum disorder (FASD) – and that is characterised by permanent organic brain injury and central nervous system damage that result in a pattern of permanent birth defects, the symptoms of which include:

- impaired mental functioning,
- poor executive functioning,
- memory problems,
- impaired judgment,
- impaired ability to control impulse behaviour, and
- impaired ability to understand the consequences of one’s actions.

The definition provided for fetal alcohol disorder acknowledges the varied and diverse presentations of FASD and highlights that in the context of criminal justice, presentation of one neurodevelopmental disorder may be enough to influence an individual’s behaviour and culpability. The definition also removes any doubt that the disorders caused by prenatal alcohol exposure are permanent. By including in the definition that FASD is characterised by “permanent organic brain injury” the definition provides clarity to any legal professional who may remain uncertain about the legitimacy of a FASD diagnosis and what it means in the context of criminal offending.

Bill C-235 also provides for the Court to order assessment for FASD and stipulates that application for assessment may be ordered by the accused, the prosecutor, or the Court.⁵⁸⁵

⁵⁸¹ Hughes, above n 575 at 6.

⁵⁸² Bill C-235 2016 (C-235) (Canada); Criminal Code RS C 1985 c 46; Corrections and Conditional Release Act S C 1992 c 20.

⁵⁸³ Bill C-235, above n 582 at ii.

⁵⁸⁴ Bill C-235, above n 582 at 1.

⁵⁸⁵ Bill C-235, above n 582 at 2 and 3.

Allowing for application to be made by the accused or the prosecutor as well as the Court increases the chance of FASD being flagged as a potential issue regardless of the level of knowledge and awareness of FASD held by the presiding judge alone. In New Zealand the relevant section of the OT Act is s 333, whereby the Youth Court may order a psychological assessment for the young person. The young person's youth advocate or the Youth Aid Police officer may raise the issue of FASD or voice their concern with the Court, but the legislation does not provide a formal avenue to trigger the process for assessment by anyone other than the Court itself.

The Bill includes a section that allows for evidence of maternal alcohol consumption to be presumed, lowering the threshold from that which is required for a clinical diagnosis:⁵⁸⁶

If the court is satisfied that there is good reason the evidence of alcohol consumption by the mother of the accused while she was pregnant with him or her is not available, such as in circumstances in which the mother has died or cannot be identified or found, the cause of the disorder of the accused may be presumed to be the maternal consumption of alcohol.

Including this section acknowledges the difficulty in confirming maternal alcohol consumption. Even if the birth mother is available, under-reporting is common due to the stigma of drinking during pregnancy and the fallibility of memory (often the pregnancy concerned happened over a decade prior to the assessment being done).⁵⁸⁷ Allowing a presumption of evidence in the context of criminal justice mitigates the risk of young people falling through the gaps merely due to the inability to confirm prenatal alcohol exposure (this issue was highlighted by the Banksia Hill project which is discussed later in this chapter).

Bill C-235 requires the court to consider evidence of a fetal alcohol disorder to be a mitigating factor in sentencing. The relevant section reads:⁵⁸⁸

Evidence that an offender suffers from a fetal alcohol disorder shall be deemed to be a mitigating factor if the disorder impairs the offender's ability:

- (a) to make judgments;
- (b) to foresee and understand the consequences or risks of his or her actions; or
- (c) to control impulse behaviour.

There are two important aspects to note about this provision. The first is that it is a mandatory consideration, that evidence of a fetal alcohol disorder *shall be deemed* to be a mitigating factor, leaving no room for discretion. The second is that the section directly links common presentations of FASD to criminal offending, ensuring that a diagnosis of FASD is not in itself enough to trigger the presumption, but that the FASD needs to be connected to the offending by the presence of the specific impairments listed in the section. This is consistent with the judicial comments provided by Martin CJ in *LCM v State of Western Australia*⁵⁸⁹ discussed below. The section also implicitly acknowledges that the abilities listed in (a) to

⁵⁸⁶ Bill C-235, above n 582 at 3.

⁵⁸⁷ Sokol, Delaney-Black and Nordstrom, above n 26 at 2996

⁵⁸⁸ Bill C-235, above n 582 at 5.

⁵⁸⁹ *LCM v State of Western Australia* [2016] WASCA 164.

(c) are important cognitive functions generally required to avoid criminal offending in the first instance and to benefit from criminal justice principles such as punitive deterrence in the second instance.

The Bill included the addition of a subsection to the Criminal Code that provides for an external support plan to be implemented for the individual concerned.⁵⁹⁰ Section 731(3) requires the Court, in the instance an individual has been found to have a fetal alcohol disorder, to include in the probation order an external support plan. The plan is established by the probation officer, and is to include:

any components that the probation officer considers necessary to ensure that the offender has the necessary support to facilitate his or her successful reintegration into society.

This section emphasises the importance of ongoing support for individuals with FASD. It does place a significant onus on the probation officer to thoroughly understand the individual's disability and needs. This relies on the assumption that such officers have been adequately trained in FASD.

Support for Bill C-235

In November 2016 the Canadian Bar Association (CBA) wrote to MP Larry Bagnall in support of Bill C-235.⁵⁹¹ The CBA is a Canadian-wide organisation representing 36,000 jurists across the country. Included in their primary objectives are “seeking improvement in the law and the administration of justice”. In their letter to MP Bagnall, the CBA considered Bill C-235 as upholding both these objectives.⁵⁹² The CBA acknowledged that the presentations of FASD resulting from the organic brain injury caused by prenatal alcohol exposure “often go against underlying principles of criminal law”.⁵⁹³ Namely, the normative assumptions that:

- individuals are responsible for their own actions;
- they can control their behaviours in keeping with societal expectations; and
- they can learn from and be deterred by previous experience.

In 2010, the CBA passed a resolution urging for improvements to be made to the criminal justice system to better accommodate individuals with FASD and followed up with further recommendations in 2013.⁵⁹⁴ Their recommendations focused on the allocation of additional resources for FASD, development of appropriate policy to support individuals with FASD, and the amendment of sentencing laws to better reflect the culpability of individuals with FASD.⁵⁹⁵ In their 2016 letter to MP Bagnall, the CBA emphasised that Bill C-235 “advances

⁵⁹⁰ Bill C-235, above n 582 at 5.

⁵⁹¹ Letter from the Canadian Bar Association to MP Larry Bagnall regarding Bill C-235 2016 (23 November, 2016).

⁵⁹² Canadian Bar Association, above n 591 at 1.

⁵⁹³ Canadian Bar Association, above n 591 at 1.

⁵⁹⁴ Resolution on Fetal Alcohol Spectrum Disorder in the Criminal Justice System 10-02-A (2010); Resolution on Accommodating the Disability of FASD to Improve Access to Justice 13-12-A (2013).

⁵⁹⁵ Resolution, above n 594.

several changes in line with previous suggestions made by the CBA”.⁵⁹⁶ They concluded their letter by urging Parliament to adopt Bill C-235 and stated:

The problem with incarcerating people with FASD is pressing and can no longer be ignored.

Criticisms of Bill C-235

Larry Bagnall’s Bill met with criticism and was ultimately defeated at the second reading, with a vote of 170 to 133.⁵⁹⁷ Prior to the second reading, MP Bagnall responded to the criticisms the Bill received, and emphasised that none of the criticisms, in his view, necessitated withdrawal of the Bill.⁵⁹⁸

MP Bagnall responded to eight identified criticisms that were put forward by a sub-committee of justice professionals from across Canada.⁵⁹⁹ For the purpose of this chapter, three of the most pertinent criticisms are discussed.

1. A more comprehensive approach is needed

To respond to this criticism, Larry Bagnall succinctly stated “more comprehensive means bigger, not smaller; it means this Bill plus other measures”.⁶⁰⁰ The MP went on to explain that he expected government agencies and organisations to implement other appropriate services and supports for individuals with FASD, but that Bill C-235 was a crucial “piece of the puzzle” to limit time spent in incarceration.⁶⁰¹

2. Bill C-325 specifically singles out FASD for special treatment in criminal law

MP Bagnall acknowledged this criticism by reiterating that that was indeed the exact purpose of Bill C-235. He justified this position by explaining “[FASD] is a scientifically identified and unique condition that needs special treatment in the Criminal Justice System”.⁶⁰² He also pointed out that singling out a disorder for special treatment was not setting new precedent, as the criminal justice system already singles out disorders for alternative treatment. This can be compared with the New Zealand criminal justice system, where individuals with intellectual disabilities for example are provided for with an entirely separate piece of legislation.⁶⁰³

3. There is no policy justification to single out one disorder to the exclusion of another

This concern is similar to that raised above and was the most cited concern regarding the Bill.⁶⁰⁴ To respond to this criticism MP Bagnall used quotes by two individuals who were

⁵⁹⁶ Canadian Bar Association, above n 591.

⁵⁹⁷ “Private Member’s Bill” (December 3 2015 – present) LEGISinfo www.parl.ca

⁵⁹⁸ Email from MP Larry Bagnall to Neil Skinner and others regarding arguments to refute criticisms of Bill C-235 (10 December 2016).

⁵⁹⁹ Email from MP Larry Bagnall, above n 598.

⁶⁰⁰ Email from MP Larry Bagnall, above n 598.

⁶⁰¹ Email from MP Larry Bagnall, above n 598.

⁶⁰² Email from MP Larry Bagnall, above n 598.

⁶⁰³ See the Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003.

⁶⁰⁴ Email from MP Larry Bagnall, above n 598.

in support of the Bill. One of those individuals was a lawyer from one of the governments whose officials brought the concerns forward, and it is worth reproducing the quote in full:⁶⁰⁵

The policy rationale in my mind is quite simple. There is no other disability where research has shown such a direct link between the neuro-cognitive disability and the potential for interaction with the criminal justice system. While there is not an abundance of research, there is emerging research, from three different offender populations, that shows the numbers of FASD affected individuals being between 10 and 23% in Canadian correctional institutions. To address this very precise concern is not exclusionary, but a concise reaction to a clear and concerning epidemic. To not address it, is both discriminatory and contrary to our Canadian value system. To not address a problem that is proven and results in diminished quality of lives is negligent.

Summary

Bill C-235 represents an important step forward in acknowledging the impact of FASD in the legal system. Despite failing at the second reading, the Bill raised significant awareness of FASD among politicians and legal professionals. The structure of the Bill and the specific amendments included will be helpful in considering the possibility of legislative reform in New Zealand, discussed in Chapter 11. The comments of support for the Bill and the criticisms of various aspects of it also contribute to a wider discussion around how best to support individuals with FASD in the justice system and lower the incidence of recidivism.

iii. Case Example - R v Friesen

R v Friesen is a 2016 Manitoba Court of Appeal case in which the appellant sought to reduce a sentence for manslaughter on account of his FASD.⁶⁰⁶ The appellant was initially sentenced to a period of detention of six years, but argued in his appeal that the sentencing judge erred in two respects.⁶⁰⁷

1. in his assessment of the accused's moral culpability by failing to give due regard to his partial FASD diagnosis; and
2. by discounting the prospect of rehabilitation due to his concern as to the risk of reoffending.

In his reasoning, Monnin JA emphasised, using prior case law, that “a link between FASD and a reduction of moral culpability is fact specific”.⁶⁰⁸ This is consistent with Bill C-235 and *LCM v State of Western Australia* discussed below, where a diagnosis of FASD alone is not sufficient to reduce moral blameworthiness.

In summary, an offender's moral blameworthiness may be reduced if he suffers from an FASD related diagnosis *and* there is a connection between the condition and the offence for which he stands charged.⁶⁰⁹

⁶⁰⁵ Email from MP Larry Bagnall, above n 598.

⁶⁰⁶ *R v Friesen* [2016] MBCA 50.

⁶⁰⁷ *Friesen*, above n 606 at [12].

⁶⁰⁸ *Friesen*, above n 606 at [23].

⁶⁰⁹ *Friesen*, above n 606 at [26] emphasis added.

In *Friesen*, Monnin JA considered the sentencing judge, in expecting the defendant to abstain from alcohol, “placed too high of an expectation on someone with his diagnosis”.⁶¹⁰ Monnin JA focused on the appellant’s impulsivity and limited ability to foresee the consequences of his actions in reasoning that his “lack of control when intoxicated was a factor in his unprovoked attack” and that “it should have been considered a mitigating factor”.⁶¹¹ This represents an interesting interplay between the concepts of choice, intoxication, and criminal liability, discussed in Chapter Five. The defendant’s diagnosis of FASD in this case served to mitigate the level of responsibility the Court was comfortable attributing to his decision to drink alcohol in the first place.

The sentencing judge chose a lengthier sentence for Friesen by reasoning that public safety concerns necessitated such an approach when rehabilitation was futile because of the FASD diagnosis.⁶¹² Monnin JA, in disagreeing with the sentencing judge’s approach, reasoned that:⁶¹³

Rehabilitation is not limited to the traditional view of correcting the accused’s attitude to prevent him from recidivating. It can also deal with finding a way to control and modify the behaviour.

Monnin JA referred to a 2011 case, *R v Kendi*, where the judge articulated that:

Rehabilitation in the context of a situation with an FASD offender is really about adjusting our expectations to their abilities, but also about setting up a situation which maximises his chances of being successful within the community, and that is all really about structure, support, and supervision.

Monnin JA considered the sentencing judge’s approach in not acknowledging Friesen’s rehabilitative needs was “inconsistent with the principles of sentencing”.⁶¹⁴ He concluded by stating that despite the seriousness of the offence, it would be “inappropriate to give up on the accused and park him in a penitentiary for an additional period of time on the basis of his diagnosis”.⁶¹⁵ The appeal was successful and the appellant’s sentence was reduced from six years to four years.⁶¹⁶ The conflict reflected in this decision between the sentencing judge and Monnin JA highlights the tension inherent in sentencing principles, especially aggravating and mitigating factors, when it comes to neurodisability. Monnin JA in this case put more weight on the mitigating effect of the defendant’s reduced capacity for impulse control than on the risk of the defendant reoffending in the future. Arguably this is the correct approach, adhering more closely with the wider goals of criminal justice: retribution, deterrence, incapacitation, and rehabilitation.

Summary

Although a case involving an adult offender, *Friesen* provides useful commentary on the current judicial attitude toward individuals with FASD in the justice system in Canada. The

⁶¹⁰ *Friesen*, above n 606 at [29].

⁶¹¹ *Friesen*, above n 606 at [29].

⁶¹² *Friesen*, above n 606 at [34].

⁶¹³ *Friesen*, above n 606 at [36].

⁶¹⁴ *Friesen*, above n 606 at [38].

⁶¹⁵ *Friesen*, above n 606 at [39].

⁶¹⁶ *Friesen*, above n 606 at [40].

case highlights the growing awareness among the judiciary of the impact of FASD on behaviour and how this can affect the level of culpability of the offender. Monnin JA did emphasise the importance of connecting the individual's specific diagnosis with the particular facts of the offending, an issue that is raised several times in this chapter. FASD as a mitigating factor in sentencing is emerging as a means of acknowledging reduced culpability and will be discussed as an option for New Zealand in Chapter 10.

iv. Youth Justice Initiatives

The Manitoba Youth Justice Programme

The Manitoba Youth Justice Programme (MYJP) was initiated in 2006 and involves the collaboration of three agencies: the Manitoba FASD Centre, the Manitoba Adolescent Treatment Centre and Manitoba Corrections.⁶¹⁷ The programme arose from an initial pilot programme (the Youth Justice Pilot Project) which aimed to:⁶¹⁸

- ensure that youth with FASD who have come into conflict with the law receive diagnostic services;
- provide recommendations to the judiciary regarding dispositions consistent with the sentencing principles of the Youth Criminal Justice Act (YCJA);
- build capacity within the family and community while enhancing supports and services; and
- implement meaningful multidisciplinary intervention and reintegration plans for youth post-custody.

The four objectives of the MYJP remained the same from the pilot, and the three agencies each contribute resources to pursue the goal. The Manitoba FASD Centre provides a developmental paediatrician and a geneticist for FASD clinics, the Manitoba Adolescent Treatment Centre offers psychological testing, and Manitoba Corrections provides office space and coordination and post-assessment follow-up services.⁶¹⁹

The MYJP uses a “red flag” screening tool to indicate need for referral. A young person is referred to the programme if they exhibit the following “red flags”:⁶²⁰

- repeated failure to comply;
- lack of empathy;
- trouble in school/dropout;
- difficulties with intuitions, compliance, and peer interactions;
- inability to connect actions with consequences;
- does not seem affected by past punishments; or
- follows rather than leads an FASD diagnosis in a sibling.

Referrals can come from a multitude of sources usually after the referrer has witnessed “a pattern of behaviours that are characteristic of FASD”.⁶²¹ Referrers can include (but are not

⁶¹⁷ S. Longstaffe and others “The Manitoba Youth Justice Program: empowering and supporting youth with FASD in conflict with the law” (2018) 96 *Biochem Cell Biol* 260 At 263.

⁶¹⁸ Longstaffe, above n 617 at 262.

⁶¹⁹ Longstaffe, above n 617 at 263.

⁶²⁰ Longstaffe, above n 617 at 263.

⁶²¹ Longstaffe, above n 617 at 263.

limited to): lawyers, judges, probation officers, corrections staff, social workers, caregivers, parents, or adolescents who have self-identified the symptoms.⁶²² The acceptance of referrals from such a wide range of sources is a strength of the MYJP. It mitigates the risk of a young person falling through the gaps due to insufficient knowledge and awareness of FASD among justice professionals. It also empowers the young person and their family to initiate the process themselves, rather than having to advocate for their needs to a professional who may not understand the legitimacy of their concerns.

Once a referral has been received, the young person is placed on a waiting list. There must be an available clinic, and four criteria need to be met before a young person receives an assessment:⁶²³

1. the young person must be involved in the youth criminal justice system;
2. the young person must reside in the service area;
3. there must have been prenatal alcohol exposure for the young person; and
4. the young person must consent to the assessment.

The MYJP acknowledges the barriers that are often encountered by young people and their families in the youth justice context, and provides appropriate support to overcome these:⁶²⁴

Throughout the assessment process, program coordinators work diligently to ensure that parents, caregivers, and youth are fully supported. This typically means giving reminders about all appointments, providing transportation to and from meetings, and arranging interviews at times and locations most convenient to the family. This accommodation usually means meeting in the homes of parents and caregivers.

The assessment team provides a report which includes recommendations for the management of the particular young person, based on their unique clinical profile.⁶²⁵ The recommendations are included in a report provided to the court to help ensure sentencing decisions are consistent with the principles in the YCJA.⁶²⁶

The programme utilises a “strength-based client-centred approach” in developing intervention and reintegration plans for the young person.⁶²⁷ This involves thorough investigation into the young person’s environment, sensitivities, needs, strengths, history of success, and caregiver or parental capacity.⁶²⁸ Crucial to success is “to allow for as much client direction in plan development as possible”.⁶²⁹

Since the beginning of the MYJP in 2006 through to 2017, there had been 1048 young people referred, with 332 young people assessed and 234 receiving a diagnosis of FASD.⁶³⁰ There has been a call by judges dealing with young people with FASD in Canada for capacity to

⁶²² Longstaffe, above n 617 at 263.

⁶²³ Longstaffe, above n 617 at 263.

⁶²⁴ Longstaffe, above n 617 at 263.

⁶²⁵ Longstaffe, above n 617 at 264.

⁶²⁶ Longstaffe, above n 617 at 264.

⁶²⁷ Longstaffe, above n 617 at 264.

⁶²⁸ Longstaffe, above n 617 at 264.

⁶²⁹ Longstaffe, above n 617 at 264.

⁶³⁰ Longstaffe, above n 617 at 264.

be developed for similar programmes across all areas of Manitoba, recognising the success of the programme and the benefit in extending its reach.⁶³¹

C. Summary

Canada is widely regarded as leading the way internationally in FASD research and response. Their national diagnostic guidelines have been used as the starting point for streamlining diagnostic practice in both Australia and New Zealand, and their innovative response to FASD in the youth justice sector provides a platform for other jurisdictions to follow. The Court in *Friesen* raises important points regarding the criminal culpability of individuals with FASD, and how justice systems might reflect diminished responsibility in sentencing. These developments provide a starting point for considering how New Zealand could improve its support for young people with FASD, outlined in detail in Chapter 11.

III. Australia

A. Diagnosis

The Australian Guide to the Diagnosis of FASD (the guide) was published in 2016 and was supported by funding from the Australian Government Department of Health.⁶³² The guide was developed following several years of literature review, evaluation of existing international guidelines and consultation.⁶³³

i. Background

In 2011, a survey conducted in Australia found that only 16% of health professionals could correctly identify the essential features of FASD.⁶³⁴ Although the prevalence of FASD in Australia is unknown, an Australian study in a selected high-risk population reported some of the highest rates of FASD in the world.⁶³⁵ Published in 2018, the study looked at prevalence rates for FASD in Banksia Hill Detention Centre, a youth detention centre in Western Australia.⁶³⁶ This study found a prevalence rate of 36%.⁶³⁷

The prevalence of FASD for vulnerable children in out-of-home-care and in the youth justice system is considerably higher than the general population.⁶³⁸

Ensuring appropriate measures and tests are used in diagnosis is fundamentally important and:⁶³⁹

⁶³¹ Longstaffe, above n 617 at 265.

⁶³² Bower C and Elliot E J, on behalf of the steering group. Report to the Australian Government Department of Health: “Australian Guide to the Diagnosis of Fetal Alcohol Spectrum Disorder (FASD)” (2016).

⁶³³ Bower and Elliot, above n 632 at 2.

⁶³⁴ Shelton, above n 534.

⁶³⁵ Shelton, above n 534 at 1122.

⁶³⁶ Carol Bower and others “Fetal alcohol spectrum disorder and youth justice: a prevalence study among young people sentenced to detention in Western Australia” (2018) 8(4) *BMJ Open* 1.

⁶³⁷ Bower, above n 636 at 1.

⁶³⁸ Shelton, above n 534 at 1122.

⁶³⁹ Shelton, above n 534 at 1123.

Under-assessing has significant diagnostic and treatment implications, particularly in the context of tightening health and disability service funding arrangements where there is a need to demonstrate improvement into the future as a consequence of investment.

Despite the importance of accurately assessing for and diagnosing FASD, there is a reluctance among health professionals in Australia to become involved.⁶⁴⁰ The predominant reason for the reluctance cited by professionals is the stigma associated with the diagnosis. Other concerns include:⁶⁴¹

- Is FASD an actual diagnosis in itself?
- What is the diagnostic accuracy of an FASD assessment?
- Is it better to focus on the functional issues of a child rather than the diagnosis?
- What's the point, it doesn't really change anything?

In contrast to the views of the health professionals concerned about stigma, caregivers reported the assessment “provided them with validation and understanding” and that “the process of FASD diagnosis was empowering”.⁶⁴² This response is consistent with a New Zealand study mentioned in Chapter Two, where the authors found the predominant feeling for caregivers post-diagnosis was one of relief.⁶⁴³ The potential guilt of a birth-mother is an issue that needs to be addressed with sensitivity throughout the diagnostic process but should not be an impediment to investigating the possibility of FASD or referring a child for diagnosis.⁶⁴⁴

Caregivers in Australia have reported frustration at the lack of awareness and understanding of FASD by professionals in the health and education sectors and the systemic discrimination of individuals with FASD due to it not being recognised as a disability.⁶⁴⁵ Doug Shelton et al conclude their article by recommending that training in FASD should include GPs, specialists, nurses, midwives and allied health professional, and that because FASD is “rarely addressed” at university, health professionals need to actively seek out further training.⁶⁴⁶ The authors of this article also pointed out that the Australian education system does not recognise FASD as a disability, and that in general:⁶⁴⁷

Policies need to adapt so that children with FASD are not discriminated against through the lack of recognition of FASD as a condition that necessitates access to funding and support.

ii. Consultation and development of guidelines

In 2013, recommendations were published from a consensus development workshop, attended by health professionals, researchers, and consumer and community representatives,

⁶⁴⁰ Shelton, above n 534 at 1123.

⁶⁴¹ Shelton, above n 534 at 1124.

⁶⁴² Shelton, above n 534 at 1124.

⁶⁴³ Salmon, above n 144.

⁶⁴⁴ Shelton, above n 534 at 1124.

⁶⁴⁵ Shelton, above n 534 at 1124.

⁶⁴⁶ Shelton, above n 534 at 1124.

⁶⁴⁷ Shelton, above n 534 at 1125.

with a view to developing guidelines for the diagnosis of FASD for Australia.⁶⁴⁸ Consensus was defined as agreement by at least 70% of the panel and by the final stage of review there was consensus reached on two aspects of screening and referral and five on diagnosis.⁶⁴⁹ These seven aspects together made up the final recommendations.

Table 1: Australian Development Workshop Recommendations 2013

Area	Recommendations
Populations screening	We do not recommend population-based screening for FASD (GRADE: strong recommendation low quality evidence)
Referral	We recommend the use of standard criteria for referral for specialist diagnostic assessment (GRADE: conditional recommendation low quality evidence)
Diagnostic categories	We recommend the diagnostic categories of fetal alcohol syndrome, partial fetal alcohol syndrome and neurodevelopmental disorder-alcohol exposed for use in Australia (GRADE: conditional recommendation low quality evidence)
Diagnostic criteria	We recommended that the diagnosis of fetal alcohol syndrome, partial fetal alcohol syndrome and neurodevelopmental disorder-alcohol exposed are based on the criteria summarised in Table 2 (GRADE: conditional recommendation low quality evidence)
Diagnostic assessment methods	We recommend standard diagnostic assessment based on the comprehensive interdisciplinary UW approach to assessment (GRADE: conditional recommendation low quality evidence)
Resources for implementation	We recommend the development of comprehensive resources to facilitate national implementation of standard diagnostic criteria and national case reporting (GRADE: conditional recommendation low quality evidence)

⁶⁴⁸ Rochelle E Watkins and others “Recommendations from a consensus development workshop on the diagnosis of fetal alcohol spectrum disorders in Australia” (2013) 13 BMC Paediatrics 1 at 2

⁶⁴⁹ Watkins, above n 648 at 4.

Consumer information and support	We recommend that information and support are provided for individuals and their parents or carers during the diagnostic process (GRADE: conditional recommendation low quality evidence)
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These recommendations helped to inform the eventual development of the Australian Guide to the Diagnosis of FASD which was published in 2016.

iii. The Australian Guide to the Diagnosis of FASD

In 2015, a draft version of the guide was trialled in clinical settings throughout Australia, and was deemed to be “informative, useful, and flexible”.⁶⁵⁰ This draft instrument utilised the recommendations above, including the recommendation for three diagnostic categories to be used: fetal alcohol syndrome, partial fetal alcohol syndrome, and neurodevelopmental disorder-alcohol exposed. In 2015, the revised Canadian guide to diagnosis of FASD was also published, which led to a last-minute review and modification of the Australian draft. In the final instrument, FASD was included as a diagnostic term, with two diagnostic sub-categories: FASD with three sentinel facial features, and FASD with less than three sentinel facial features.⁶⁵¹

The final diagnostic criteria included in the Australian Guide are as follows:⁶⁵²

Table 2: Australian Guide to the Diagnosis of FASD – Diagnostic Criteria

Diagnostic criteria	Diagnostic categories	
	FASD with 3 sentinel facial features	FASD with <3 sentinel facial features
Prenatal alcohol exposure	Confirmed or unknown	Confirmed
Neurodevelopmental domains <ul style="list-style-type: none"> - Brain structure/Neurology - Motor skills - Cognition - Language - Academic achievement - Memory - Attention - Executive Function, including impulse control and hyperactivity 	Severe impairment in at least 3 developmental domains	Severe impairment in at least 3 developmental domain

⁶⁵⁰ Bower and Elliot, above n 632 at 3.

⁶⁵¹ Bower and Elliot, above n 632 at 3.

⁶⁵² Bower and Elliot, above n 632 at 5.

<ul style="list-style-type: none"> - Affect Regulation - Adaptive Behaviour, Social Skills, or Social Communication 		
<p>Sentinel facial features</p> <ul style="list-style-type: none"> - Short palpebral fissure - Smooth philtrum - Thin upper lip 	<p>Presence of 3 sentinel facial features</p>	<p>Presence of 0, 1 or 2 sentinel facial features</p>

The diagnostic process

The guide is divided into three main sections which outline the process for assessing each of the three diagnostic criteria (prenatal alcohol exposure, neurodevelopmental impairment, and facial and other physical features of FASD). The guide emphasises the importance of differential diagnosis to exclude alternative explanations for neurodevelopmental impairment, including genetic disorders and prenatal exposure to other teratogens.⁶⁵³ The guide also describes best practice as utilising a multidisciplinary team to complete the diagnostic process.⁶⁵⁴ The authors acknowledge the limited resources for diagnosing FASD in Australia, and that a multidisciplinary team will not be available in all instances. In these circumstances, diagnosis can be made by clinicians “including, but not limited to” paediatricians, psychologists, speech and language pathologists and occupational therapists.⁶⁵⁵

Section A: Assessing maternal alcohol use

The Australian guide acknowledges the difficulty in assessing maternal alcohol use and states that it requires “clinical judgement and careful evaluation” of the information and evidence available.⁶⁵⁶ The guide outlines that evidence of prenatal alcohol exposure may include reports by the mother of alcohol consumption during the pregnancy; reports by others who had direct observation of alcohol consumption during pregnancy; or documentation in official sources (such as child protection or medical records) indicating alcohol consumption during pregnancy.⁶⁵⁷ The information needs to undergo an assessment for reliability, and where there is any doubt, alcohol consumption should be recorded as “unknown”.⁶⁵⁸

The Australian guide advocates the use of the Alcohol Use Disorders Identification Test – Consumption (AUDIT-C) questionnaire for identifying maternal alcohol consumption where there is adequate information about prenatal drinking.⁶⁵⁹ The questionnaire involves

⁶⁵³ Bower and Elliot, above n 632 at 7.
⁶⁵⁴ Bower and Elliot, above n 632 at 7.
⁶⁵⁵ Bower and Elliot, above n 632 at 7.
⁶⁵⁶ Bower and Elliot, above n 632 at 9.
⁶⁵⁷ Bower and Elliot, above n 632 at 9.
⁶⁵⁸ Bower and Elliot, above n 632 at 9.
⁶⁵⁹ Bower and Elliot, above n 632 at 9.

three questions about maternal drinking and offers a standardised method for scoring risk of prenatal alcohol exposure. The questions are:⁶⁶⁰

1. How often did the birth mother have a drink containing alcohol during this pregnancy?
2. How many standard drinks did the birth mother have on a typical day when she was drinking during this pregnancy?
3. How often did the birth mother have 5 or more standard drinks on one occasion during this pregnancy?

The risk categories produced by the AUDIT-C questionnaire are:⁶⁶¹

- No exposure (confirmed absence), no risk of FASD;
- unknown exposure (alcohol use is unknown);
- confirmed exposure; and
- confirmed high-risk exposure (high risk level for FASD).

The guide reiterates the importance of considering alternative explanations for neurodevelopmental impairment, including other possible prenatal and postnatal exposures.⁶⁶²

Section B: Assessing neurodevelopmental impairment

A positive diagnosis for FASD requires severe impairment (two or more standard deviations below the mean) in at least three of the 10 possible neurocognitive domains (See Table 2).⁶⁶³

Testing involves both direct and indirect assessment.⁶⁶⁴ An example of a direct assessment is the use of a standardised test to measure verbal reasoning on cognitive assessment, while an indirect assessment is the combination of clinical observation and evidence from other sources.⁶⁶⁵ Direct assessment is preferred, but in some cases (for example in testing Attention) a combination approach may be required.⁶⁶⁶

The guide outlines a series of factors to consider to ensure accuracy when conducting the neurocognitive assessment. Issues identified include the importance of differential diagnosis, the existence of comorbidities (for example ADHD), and the cultural and linguistic background of the child.⁶⁶⁷ The guide provides strategies and processes for mitigating the impact of each of these issues.

⁶⁶⁰ Bower and Elliot, above n 632 at 12.

⁶⁶¹ Bower and Elliot, above n 632 at 13.

⁶⁶² Bower and Elliot, above n 632 at 13.

⁶⁶³ Bower and Elliot, above n 632 at 14.

⁶⁶⁴ Bower and Elliot, above n 632 at 15.

⁶⁶⁵ Bower and Elliot, above n 632 at 15.

⁶⁶⁶ Bower and Elliot, above n 632 at 15.

⁶⁶⁷ Bower and Elliot, above n 632 at 16 and 17.

Section C: Assessing Sentinel Facial Features

The three facial features that occur as a result of prenatal alcohol exposure in the first trimester of pregnancy are:⁶⁶⁸

1. Small palpebral fissures (short horizontal length of the eye opening);
2. smooth philtrum (diminished or absent ridges between the upper lip and nose); and
3. thin upper lip.

The guide outlines the criteria for FASD sentinel facial features, which were developed by the University of Washington FAS Prevention and Diagnostic Network.⁶⁶⁹ The guide articulates that the assessment can be done either through direct measurement and clinical examination or using computerised analysis of a digital facial photograph.⁶⁷⁰

Section D: Growth assessment

The guide identifies the importance of assessing a child's growth and plotting results on an age-appropriate chart to measure percentile rank.⁶⁷¹ This is in the context of general paediatric assessment and the authors note that growth results are no longer diagnostic of FASD due to the range of factors that can influence disparity.⁶⁷²

Section E: Formulating a diagnosis

The results collected during stages A-C should be reviewed, ideally by a multidisciplinary team, to formulate a correct diagnosis.⁶⁷³ If neither a diagnosis of FASD with three sentinel facial features nor a diagnosis of FASD with less than three sentinel facial features is appropriate, the assessment team may decide to designate the child as at-risk and requiring further investigation.⁶⁷⁴

Section F: Discussing the diagnosis and developing a management plan

In this section, the guide outlines the best practice approach to sharing the diagnosis and organising appropriate follow-up with families and other relevant organisations. The guide suggests discussing the outcome with the family and providing a written report.⁶⁷⁵ As part of the discussion the assessment team should identify to the family the various services and organisations (for example the child's school) that the information could be shared with.⁶⁷⁶ As appropriate, individuals should be referred for support for alcohol use disorders.⁶⁷⁷

Section G: Reporting a FASD diagnosis

The final section of the guide notes that FASD is a notifiable congenital impairment in some states and provides online links for reporting.

⁶⁶⁸ Bower and Elliot, above n 632 at 31.

⁶⁶⁹ Bower and Elliot, above n 632 at 32.

⁶⁷⁰ Bower and Elliot, above n 632 at 32.

⁶⁷¹ Bower and Elliot, above n 632 at 35.

⁶⁷² Bower and Elliot, above n 632 at 35.

⁶⁷³ Bower and Elliot, above n 632 at 36.

⁶⁷⁴ Bower and Elliot, above n 632 at 36.

⁶⁷⁵ Bower and Elliot, above n 632 at 36.

⁶⁷⁶ Bower and Elliot, above n 632 at 36.

⁶⁷⁷ Bower and Elliot, above n 632 at 36.

Conclusion

The Australian Guide to the Diagnosis of FASD is the culmination of several years of investigation and consultation, starting with the recognition that:⁶⁷⁸

The lack of a nationally adopted diagnostic instrument, confusion about diagnostic criteria and perceived lack of evidence-based treatments are persisting barriers to early diagnosis and appropriate management and prevention of FASD.

The purpose of the guide is to assist clinicians in the diagnosis, referral and management of FASD and to recognise the importance of standardising the diagnostic process for FASD in Australia.⁶⁷⁹ The guide acknowledges the lack of resources for FASD in Australia and the limited specialist clinics available for assessment and diagnosis, but suggests a possible pathway for any team of clinicians to follow to ensure best practice and accurate results.⁶⁸⁰

B. FASD and justice

i. Background - prevalence

Recent publications from an extensive and ongoing project to establish the prevalence of young offenders with FASD in Western Australia provide the context for work in this area. The Banksia Hill Detention Centre project has a primary aim of establishing, for the first time in Australia, an estimated prevalence rate for FASD among youth in custody.⁶⁸¹ Secondary aims included developing a screening tool to be used for young people sentenced to detention, in the hope of improving the management and support of young people with FASD in custody.⁶⁸²

The study, which involved assessment of 108 young people, was conducted between May 2015 and December 2016.⁶⁸³ The participants were young people in custody at the Banksia Hill Detention Centre, the only youth detention centre in Western Australia, who ranged in age from 10 years to 17 years 11 months.⁶⁸⁴ Standardised forms were used to collect information from the participants, with the AUDIT-C questionnaire used to gather information on maternal drinking (where possible).⁶⁸⁵ Clinical assessments were conducted by a multidisciplinary team (paediatrician, occupational therapist, speech pathologist and provisional neuropsychologists with supervision) who did not have prior knowledge of prenatal alcohol exposure in the young people.⁶⁸⁶ Diagnoses included differential diagnosis to exclude other explanations for the clinical presentations and a diagnosis of FASD was made conservatively only when no other explanation could be found.⁶⁸⁷

⁶⁷⁸ Bower and Elliot, above n 632 at 2.

⁶⁷⁹ Bower and Elliot, above n 632 at 2.

⁶⁸⁰ Bower and Elliot, above n 632 at 7.

⁶⁸¹ Bower, above n 636.

⁶⁸² Hayley M Passmore and others "Study protocol for screening and diagnosis of fetal alcohol spectrum disorders (FASD) among young people sentenced to detention in Western Australia" (2016) 6 *BMJ Open* 1.

⁶⁸³ Bower, above n 636 at 2, 6.

⁶⁸⁴ Bower, above n 636 at 2.

⁶⁸⁵ Bower, above n 636 at 4.

⁶⁸⁶ Bower, above n 636 at 4.

⁶⁸⁷ Bower, above n 636 at 5.

Of 108 young people assessed, 36 were diagnosed with FASD.⁶⁸⁸ Only two of the 36 diagnosed had received a diagnosis prior to being involved in the study.⁶⁸⁹ The prevalence rate of 36% found by the Banksia Hill project researchers is “the highest reported prevalence of FASD in a youth justice setting worldwide”.⁶⁹⁰ Despite the high prevalence, the authors caution that it may in fact be an under-estimate, and provided several reasons for this:⁶⁹¹

- the team did not assess the neurological domain of affect regulation, which was added to diagnostic guidelines after the study was completed;
- they were unable to formally assess adaptive functioning (although the authors note that informally, “the fact of being in detention suggests impaired adaptive functioning”);
- they were unable to confirm prenatal alcohol exposure in 13 of the young people. Of these 13 young people, nine of them had impaired functioning in <3 of the required domains, meaning that confirmation of prenatal alcohol exposure may have resulted in a diagnosis of FASD; and
- neurology was only assessed clinically (there was no imaging done).

Aboriginal young people were overrepresented in both the sample and the final results (74% of participants were aboriginal) and the authors commented on the complex post-colonial issues that are raised when such a finding is made:⁶⁹²

The greater prevalence of FASD in Aboriginal populations corresponds with higher rates of high-level alcohol consumption in these populations, but this observation fails to acknowledge the complex reasons for higher alcohol use. Past colonial policies such as the removal of Aboriginal children from their families and resultant dispossession from land, community, and culture, as well as the historical role of the criminal justice system and Aboriginal incarceration are well documented. In addition, these policies have left a legacy: high levels of family violence, drug and alcohol misuse, mental health problems, poverty, disadvantage, marginalisation, trauma and incarceration have been well documented as traversing generations of Aboriginal families. High population rates of FASD in Aboriginal young people are likely to be directly responsible, in part, for the high rate of Aboriginal youth incarceration.

The authors of the study also noted that for many of the young people involved, this was the first time they had received a comprehensive clinical assessment, despite many of them having been involved in the education system or state care prior to being incarcerated.⁶⁹³ This represents missed opportunities for assessment and intervention and highlights the need for better policy and practice responses for these young people.⁶⁹⁴

⁶⁸⁸ Bower, above n 636 at 6.

⁶⁸⁹ Bower, above n 636 at 6.

⁶⁹⁰ Bower, above n 636 at 7.

⁶⁹¹ Bower, above n 636 at 7.

⁶⁹² Bower, above n 636 at 7.

⁶⁹³ Bower, above n 636 at 8.

⁶⁹⁴ Bower, above n 636 at 8.

ii. *Background – knowledge and awareness of FASD among custodial staff*

The Banksia Hill project included an offshoot study looking at the knowledge, attitudes, experiences and practices of the youth custodial workforce employed at Banksia Hill Detention Centre.⁶⁹⁵ The study was designed to recognise the fact that young people with FASD encounter difficulties at every stage of the justice process, and⁶⁹⁶

it is suggested that staff training does not adequately address how to recognise specific vulnerabilities among young people, resulting in behaviours relating to permanent brain damage being misinterpreted as noncompliant or wilfully defiant.

The study used a survey to gather information, which included a variety of questionnaire methods (Likert scale, yes/no questions, multiple choice, check box and open-ended questions).⁶⁹⁷ 112 correctional staff employed at the Banksia Hill Detention Centre responded to the survey.⁶⁹⁸ The results showed “substantial gaps” in the knowledge, attitudes, experiences and practices relating to FASD among youth custodial staff at Banksia Hill.⁶⁹⁹ Most of the respondents were unaware that the sentinel facial features do not appear on all individuals with FASD and many were also unaware that FASD can occur in any population that drinks alcohol, regardless of demographics.⁷⁰⁰

The results of this study reflect results of an earlier study (the Justice Project) looking at the knowledge, attitudes and practices of justice professionals generally (lawyers, Police officers, judges *and* custodial officers).⁷⁰¹ The Justice Project found that extensive training in FASD awareness and identification was needed for all professionals working in the justice sector.⁷⁰² However, it also found that among the justice professionals involved in the study, custodial officers showed the highest level of understanding of the condition and how it affects children and adults.⁷⁰³

The results of these two studies suggest that although awareness of FASD in Australia is growing, there is a need for further professional development and training, not only for custodial officers but for all justice professionals.

iii. *Case Example - LCM v State of Western Australia*

LCM v State of Western Australia involved an appeal from the Children’s Court of Western Australia, based on an argument that new evidence indicated an alternative sentence should be imposed.⁷⁰⁴ The defendant, a 15-year-old youth, was initially charged with the murder of

⁶⁹⁵ Hayley M Passmore and others “Fetal Alcohol Spectrum Disorder (FASD): Knowledge, attitudes, experiences and practices of the Western Australian youth custodial Workforce” (2018) 59 *Int. J. Law Psychiatry* 44.

⁶⁹⁶ Passmore, above n 695 at 45.

⁶⁹⁷ Passmore, above n 695 at 46.

⁶⁹⁸ Passmore, above n 695 at 46.

⁶⁹⁹ Passmore, above n 695 at 48.

⁷⁰⁰ Passmore, above n 695 at 48.

⁷⁰¹ Raewyn Mutch and others “Fetal Alcohol Spectrum Disorder: Knowledge, attitudes and practice within the Western Australian justice system” (2013) Telethon Institute for Child Health Research.

⁷⁰² Mutch, above n 701 at 39.

⁷⁰³ Mutch, above n 701 at 15.

⁷⁰⁴ *LCM*, above n 589.

his new-born son.⁷⁰⁵ The charge was downgraded to manslaughter when a guilty plea was offered, and the defendant was sentenced to 10 years detention.⁷⁰⁶ An appeal was lodged based on new evidence regarding the defendant's neurodisability: namely that he was given a diagnosis of FASD.⁷⁰⁷

This case is mostly useful to illustrate the attitudes of the judiciary regarding the state of awareness and support for FASD in the justice sector in Australia and the importance of acknowledging the part neurodisability may play in offending. The case is also significant for its comments on reduced capacity and mitigation.

Martin CJ: general comments

Chief Justice Martin made several comments in his judgment emphasising the relevance of the defendant's FASD diagnosis.⁷⁰⁸ He noted firstly that the defendant's "organic brain injury" compounded the effects of a traumatic childhood environment and resulted in deficits relevant to sentencing.⁷⁰⁹ The Chief Justice went on to identify the inadequacy of services to assess and manage offenders with FASD in Western Australia.⁷¹⁰ He described it as "remarkable" that given the knowledge of LCM's family's history of alcohol abuse, nobody involved in his care and protection thought to investigate the possibility of neurological damage.⁷¹¹ This oversight was seen as particularly incredulous when taking into account LCM's behavioural and learning problems.⁷¹²

The most significant oversight identified by Martin CJ, however, was in respect of the justice system after LCM had been charged with murder. He again described it as "remarkable" that neither LCM's defence counsel, the author of the pre-sentence report, the author of the psychiatric report, the author of the psychological report or the Court itself identified the "fairly obvious" possibility that LCM had FASD.⁷¹³ In fact, it was only by accident that LCM was even diagnosed, when he was sent to Banksia Hill Detention Centre while the Banksia Hill project was underway.⁷¹⁴

The Chief Justice concluded his statements by emphasising the inadequacy of the current assessment and management facilities and warned that:⁷¹⁵

Unless those arrangements are improved, not only will injustice be suffered by those who commit crime at least in part because of a condition which they suffer through no fault of their own, but also the opportunity to reduce the risk to the community by appropriately managing such offenders will be lost.

⁷⁰⁵ *LCM*, above n 589 at [28].

⁷⁰⁶ *LCM*, above n 589 at [29].

⁷⁰⁷ *LCM*, above n 589 at [30].

⁷⁰⁸ *LCM*, above n 589 at [2].

⁷⁰⁹ *LCM*, above n 589 at [2].

⁷¹⁰ *LCM*, above n 589 at [3].

⁷¹¹ *LCM*, above n 589 at [4].

⁷¹² *LCM*, above n 589 [4].

⁷¹³ *LCM*, above n 589 at [5].

⁷¹⁴ *LCM*, above n 589 at [5].

⁷¹⁵ *LCM*, above n 589 at [7].

The Chief Justice ultimately agreed with Mazza JA and Beech J in allowing the appeal against sentence.⁷¹⁶

Martin CJ: FASD and sentencing

Martin CJ also made interesting comments regarding the relevance of FASD in sentencing. Importantly, he emphasised the incredibly individualistic nature of FASD as a disability and stressed that a FASD diagnosis will be different for each individual and will have differing effects on their offending and sentencing.⁷¹⁷ It is not enough to simply point to a diagnosis of FASD as a mitigating factor in and of itself as the specific neurological deficits and resulting behavioural traits in the individual will need to be identified as relevant to their offending.

The Chief Justice referred to another Australian case in which FASD was considered as a mitigating factor in sentencing.⁷¹⁸ He referred specifically to the observations made by McMurdo P regarding reduced culpability and how that affects overall sentencing discretion.⁷¹⁹

The fact that the respondent had a mental age of nine years (that is, below the age of criminal responsibility) and had limited grasp of the consequences and moral blameworthiness of his actions at the time he committed the offences is highly relevant to the exercise of the sentencing discretion. It lessened his moral culpability for the offending so that the retributive, denunciatory and deterrent aspects of sentencing were less relevant than otherwise.

This acknowledgement will be discussed further in Chapter Five, where the theoretical argument guiding the current research is outlined and involves an analysis of the reduced culpability and capacity of offenders with FASD.

Mazza JA and Beech J

Mazza JA and Beech J provided a summary of the case to date, allowed the appeal and imposed an alternative sentence of seven years.⁷²⁰ The reasons for allowing the appeal were outlined by the justices in detail, with a focus on the defendant's various cognitive impairments.

Firstly, the defendant was identified as having significant deficits across five of the eight domains in which he was tested: cognition, executive functioning, language, academic functioning and motor skills.⁷²¹ The justices then referred to the evidence of Dr Mutch, a physician who had met with the defendant and examined him, in explaining the relevance of LCM's impairments with his subsequent offending behaviours.⁷²² Parts of the evidence

⁷¹⁶ *LCM*, above n 589 at [1].

⁷¹⁷ *LCM*, above n 589 at [8] and [9].

⁷¹⁸ *LCM*, above n 589 at [15]; *R v MBQ* [2012] QCA 202.

⁷¹⁹ *MBQ*, above n 718 at [44].

⁷²⁰ *LCM*, above n 589 at [37].

⁷²¹ *LCM*, above n 589 at [91].

⁷²² *LCM*, above n 589 at [104].

Dr Mutch provided in terms of the defendant's impairments and how they might relate to offending was produced in full:⁷²³

The post-mortem reports indicate that force and violence was applied to the victim. [The appellant] maintained he had 'accidentally' completed the events. [The appellant's] adherence to the term 'accidental' may reflect [the appellant's] genuine belief that his physical actions were accidental, this understanding held by [the appellant] is in keeping with [the appellant's] diminished ability to think and act 'deliberately' and reason through consequence of the action. So the assignation of 'deliberately' or 'violently' to [the appellant] may not necessarily reflect his actual cognitive ability and action. Also, [the appellant] may understand 'accidental' and may not be fully cognisant of the meaning of deliberate; [the appellant] possesses a combination of restricted core language skills equivalent to a person of aged 9 to 12 years. [The appellant] has diminished cognition, impaired (executive) function and proprioception impairment (that is a diminished ability to perceive his actual position in space); singularly and together each of these impairments warrants consideration as relevant to the sentencing.

Dr Mutch's evidence indicates further issues regarding the capacity and culpability of offenders with FASD and, in particular, whether an individual with a specific set of cognitive impairments (such as LCM) had the ability to form the requisite *mens rea* for the crime in question.

The Court found Dr Mutch's evidence regarding intention "cast doubt" on the earlier judge's findings, especially that the defendant acted deliberately and forcefully and showed no remorse.⁷²⁴ An additional point of relevance identified by the justices was that of deterrence, and the appropriate weight to be given to deterrence in sentencing.⁷²⁵ The Court here relied upon a 2005 Supreme Court of Western Australia case, *Thompson v The Queen*, in which it was emphasised that deterrence relies on rational analysis and reasoning.⁷²⁶ If illness affects an offender's ability to make the analysis comparing the likely gains of criminal behaviour with the likelihood and severity of punishment, deterrence should not be afforded the same weight as for an offender who is fully able to make the same analysis.⁷²⁷

Decision

In concluding that the defendant's FASD did make a material difference to the appropriate sentence to be given, the Court identified several specific reasons why LCM's diagnosis impacted on his offending:⁷²⁸

- it diminished his moral culpability for the offence;
- it moderated the weight to be given to personal and general deterrence;
- it diminished the adverse impact of the primary judge's findings that the appellant acted 'deliberately' and 'violently';

⁷²³ *LCM*, above n 589 at [104].

⁷²⁴ *LCM*, above n 589 at [117].

⁷²⁵ *LCM*, above n 589 at [122].

⁷²⁶ *LCM*, above n 589 at [122].

⁷²⁷ *LCM*, above n 589 at [122].

⁷²⁸ *LCM*, above n 589 at [128].

- it bore on whether and to what extent the appellant was to be seen as lacking remorse, and the weight to be given to that;
- it bore on the significance of the appellant's failure to call for treatment immediately after the offence, a matter on which the primary judge made an adverse finding; and
- the appellant's impaired language skills may well explain the appellant's persistent adherence to the position that his actions were an 'accident', a position which the primary judge regarded negatively.

The defendant's sentence was changed to seven years, with eligibility for release after serving half.⁷²⁹

Summary

LCM v State of Western Australia is likely to become a seminal case in the history of judicial decisions regarding offenders with FASD in Australia. For the purpose of this thesis and an analysis of New Zealand's judicial position, the case sheds light on the possible theoretical arguments to be made on culpability, capacity and sentencing. It also emphasises the shift in judicial attitudes regarding neurodisability and offending. The case highlights the importance of early diagnosis of, and intervention for, FASD, and identifies that current services are inadequate.

LCM v State of Western Australia confirms that currently the judiciary is unable to rely on legislative or policy guidance on how to treat offenders with neurological disabilities generally and FASD specifically.

C. Summary

Knowledge and awareness of FASD is growing in the justice sector in Australia. There is significant work being done, especially in Western Australia, to establish prevalence rates and develop more streamlined referral systems for young people in custody. However *LCM v State of Western Australia* and the Banksia Hill project highlight continuing gaps in support for young offenders with FASD, suggesting the need for further research, training of justice professionals and improved systems of support and services for young offenders with FASD in Australia.

IV. Conclusion

The diagnostic guidelines published by each of the jurisdictions discussed above were born from an acknowledgment of the lack of consistency in knowledge and awareness of, and support for, individuals with FASD. With Canada leading the world in developing comprehensive guidelines for diagnosis to be used nationwide, a minimum standard was set as a precedent for the rest of the world to follow. Australia acknowledged and accepted the justification for the process outlined in the Canadian guide and adopted the approach that had already been established in Canada for several years. Australia did, however, conduct

⁷²⁹ *LCM*, above n 589 at [143].

widespread consultation before establishing national guidelines in order to ensure the process was relevant and effective for the local population.

The criminal justice sectors in both Canada and Australia have intensively investigated the implication FASD has for criminal offending and principles of culpability, rehabilitation and sentencing. Bill C-235 in Canada reflects a bold move forward in codifying in statute what neuroscience has already established: the brain damage caused by FASD has a direct and unique impact on criminal offending and requires a direct and unique response by the criminal law. Although the Bill was ultimately defeated, other justice initiatives in Canada reflect an acknowledgement that individuals with FASD require a targeted response. Australia is not far behind, with extensive research into the prevalence of FASD in youth offending populations, and discussion actively happening regarding the best way to support these young people to transition out of the justice system.

New Zealand's approach to date in developing diagnostic guidelines, or at the very least a streamlined approach to diagnosis, falls short of the rigour evident in both Canada and Australia. The New Zealand Government's FASD Action Plan represents a first step in the right direction, but significantly more is required to meet the minimum standard set by the two jurisdictions discussed in this chapter. Additionally, although New Zealand's youth justice system is cognisant of the impact neurodisability has on criminal offending, there needs to be direct acknowledgment that FASD is a unique problem that requires a specific targeted approach.

The development of FASD diagnostic processes and the growing awareness of the impact of FASD in criminal offending in Australia and Canada provide a helpful context for grappling with these issues in New Zealand. The analysis of these two jurisdictions highlighted several factors as being particularly important:

1. that FASD may reduce culpability to the extent that it should be considered a mitigating factor in sentencing;
2. each diagnosis of FASD is unique and distinct, and for an individual's diagnosis to be relevant in criminal offending the nexus between their disorder and their behaviour must be established;
3. clear assessment and diagnostic pathways are critical in mitigating harm and reducing the incidence of secondary disability; and
4. current initiatives in Canada provide a framework for developing effective youth justice services and supports for FASD in New Zealand.

These four aspects will be developed and discussed in Chapter 11 in relation to potential ways forward for New Zealand.

Chapter 5

Neurocognition and the Criminal Justice System

I. Introduction

New Zealand's legal system generally does not hold individuals accountable for offending that is not the result of an autonomous decision on behalf of the alleged offender.⁷³⁰ Criminal responsibility (and culpability) presumes autonomy. The legal system acknowledges autonomy in the concept of *mens rea*, mitigating factors in sentencing, and through various defences relating to mental impairment and reduced capacity (e.g., insanity, duress and intoxication). The philosophical literature on autonomy describes it as a concept that exists in degrees: a person can be more or less autonomous and a particular decision can be strongly autonomous, weakly autonomous, or not autonomous at all.⁷³¹

This chapter analyses the conceptual basis for autonomy in criminal justice by unpacking the elements of an offence (*mens rea* and *actus reus*) and outlining four defences to criminal offending: insanity, duress, intoxication and diminished responsibility. The conclusions drawn from these five sections provide a theoretical basis for the argument that for young people in general, and young people with FASD in particular, the preconditions for an autonomous decision in the context of offending will not always be met. The still developing brain structure of young people calls into question their capacity for exercising reason and judgement, and for young people with FASD this chapter further argues that their impulsivity and inability to properly consider consequences results in, at least, reduced autonomy. The law in New Zealand mostly considers criminal capacity as a binary concept, treating an individual as either capable of (and therefore responsible for) criminal offending, or as incapable and thus falling within the ambit of the various pieces of legislation providing an alternative path through the justice system.⁷³²

The principle of considering mitigating factors in sentencing is one area of the law that allows for flexibility, acknowledging that culpability exists in degrees. The New Zealand legal system considers age to be a mitigating factor in sentencing, accepting the neuroscience evidence regarding the brain structure and consequent immaturity of adolescents.⁷³³ This chapter argues that the brain structure of young people with FASD compounds the issue: not only are their brains still developing due to adolescence, but crucial areas of development are completely absent due to prenatal alcohol exposure. The result is reduced autonomy, both from adolescence and the cognitive impact of prenatal alcohol exposure, which should be recognised by the justice system. FASD should therefore be considered a mitigating

⁷³⁰ See for example s 20 Criminal Procedure (Mentally Impaired Persons) Act 2003: not guilty by reason of insanity; and the common law defence of duress by threats.

⁷³¹ John Coggon "Varied and Principled Understandings of Autonomy in English Law: Justifiable Inconsistency or Blinkered Moralism?" (2007) 15 *Health Care Anal* 235 at 240.

⁷³² See for example the Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003; Criminal Procedure (Mentally Impaired Persons) Act s 8A (unfitness to stand trial) and subpart 2 (acquittals on account of insanity).

⁷³³ See the Oranga Tamariki Act 1989 s 208(e) and the Sentencing Act 2002 s 9(2)(a).

factor in sentencing. This solution gives the courts flexibility to consider autonomy (and thus criminal responsibility) as existing in degrees for these young people.

II. The elements of an offence: mens rea and actus reus

For an act to be considered a criminal offence, it will almost always need to be established that there was both a ‘guilty act’ (*actus reus*) committed by an individual, and that they had a ‘guilty mind’ (*mens rea*) in committing it.⁷³⁴ The *mens rea* element to criminal offending can be proven by the existence of several different states of mind, the predominant being:⁷³⁵

1. intention (the individual has the “conscious object” of engaging in the conduct and actively hopes that the outcome occurs);
2. knowledge (the individual is certain the conduct will lead to the outcome);
3. recklessness (the individual knows the outcome exists but engages in the conduct anyway); and
4. negligence (the individual is unaware of the consequences of his conduct but a “reasonable person” would have been aware).

A fifth category of *mens rea*, that of strict liability, is often included in discussions on the topic.⁷³⁶ Strict liability exists for offences that do not require the individual to have any particular mental state – it is enough that they engaged in the conduct. This category of offence is reserved for instances where, for example, an individual is engaged in work or activity that is inherently risky and thus any ill consequence of that work or activity is automatically considered to be the responsibility of the individual, regardless of their lack of intention, knowledge, recklessness, or negligence. Strict liability offences are therefore not pertinent to a discussion regarding autonomy and criminal culpability.

The existence of *mens rea*, and therefore some element of attributable *fault*, as a necessary element to criminal culpability is important, given the “moral turpitude associated with a criminal conviction”.⁷³⁷ *Mens rea* is helpful in establishing the moral blameworthiness of conduct – without which an individual is generally not culpable for criminal offending.⁷³⁸ Without the presence of *mens rea*, certain conduct may not be inherently wrongful, but is “capable of being made wrongful when done for certain kinds of reasons”.⁷³⁹

The function of *mens rea* has also been described as giving individuals “fair warning” that their actions hold consequences and may be punishable by law.⁷⁴⁰ By proving intention, knowledge, or recklessness, the individual can be shown to have *chosen* to conduct the *actus reus*, and “this, in turn, serves to ensure that [the individual] had (and rejected) the

⁷³⁴ Jan Broersen “Deontic epistemic *stit* logic distinguishing modes of mens rea” (2011) 9 *J Appl Logic* 137 at 137.

⁷³⁵ Broersen, above n 734 at 137.

⁷³⁶ Broersen, above n 734 at 137.

⁷³⁷ Winnie Chan and A P Simester “Four Functions of Mens Rea” (2011) 70(2) *CLJ* 381 at 381.

⁷³⁸ Chan and Simester, above n 737 at 385.

⁷³⁹ Chan and Simester, above n 737 at 386.

⁷⁴⁰ Chan and Simester, above n 737 at 388.

opportunity to avoid wrongdoing, and so to evade the attentions of the criminal law”.⁷⁴¹ This analysis of *mens rea* suggests that not only is it important for the individual to have knowledge (or intention or recklessness) to commit the act and foresee its natural consequences, but also to have some understanding of its implications under criminal law: to understand that not only is the act *morally* reprehensible, but that it is also *illegal*.

Another aspect of *mens rea* to consider is that it must be connected to the *actus reus* for the action to be considered a criminal offence. It is not enough for an individual to have knowledge or intent at some point outside of the actual commission of the act – the requisite *mens rea* must “actuate the physical conduct”.⁷⁴² One justification for this is that the *mens rea* element manifests the level of culpability of the individual, something referred to as *Insufficient Regard Theory*:⁷⁴³

The degree to which a particular action is culpable equals the degree to which that action manifests insufficient regard for others or their legitimately protected interests.

Another expression of this is that *mens rea* serves to “differentiate behaviour by degrees of culpability”.⁷⁴⁴ The degree of culpability attributable to the individual subsequently suggests the level of punishment appropriate. However, there are difficulties in assessing *mens rea* which often requires a fact finder (for example a judge or a jury) to “contemplate what a defendant was thinking”.⁷⁴⁵ If the individual provides an explanation of their own mental state, the fact-finder is still required to “weigh the credibility of the defendant’s confession against the fact finder’s own perception of the world”.⁷⁴⁶ Carroll highlights the problematic nature of this assessment when the individual concerned is a young person and the weighing process is inevitably conducted by an adult:⁷⁴⁷

Under this approach, all thought and thought processes are adult, and the proper analytic baseline for *mens rea* is an adult’s understanding of the world.

Carroll particularly notes that the definitions for the various forms of *mens rea*, as well as the guidance provided for analysing and assessing *mens rea*, are based on an adult’s understanding of the world. The neuroscience evidence regarding adolescent development suggests that this application of *mens rea* analysis is inappropriate and “undermines the purpose of *mens rea* when applied to juvenile offenders”.⁷⁴⁸

Carroll’s perspective serves to suggest that understandings of criminal culpability, as identified in the assessment of *mens rea*, “should be recalibrated” when it comes to young offenders.⁷⁴⁹ This argument will be substantiated over the course of this chapter, with an

⁷⁴¹ Chan and Simester, above n 737 at 390.

⁷⁴² Alexander F Sarch “Knowledge, Recklessness and the Connection Requirement Between Actus Reus and Mens Rea” (2015) 120 *Penn St. L. Rev.* 1 at 10.

⁷⁴³ Sarch, above n 742 at 11.

⁷⁴⁴ Jenny E. Carroll “Brain Science and the Theory of Juvenile Mens Rea” (2015) 94 *N. C. Law Rev* 540 at 540.

⁷⁴⁵ Carroll, above n 744 at 541.

⁷⁴⁶ Carroll, above n 744 at 541.

⁷⁴⁷ Carroll, above n 744 at 541.

⁷⁴⁸ Carroll, above n 744 at 541.

⁷⁴⁹ Carroll, above n 744 at 541.

analysis of sentencing jurisprudence (specifically the role that mitigating factors play) and the various defences to *mens rea* supporting an alternative approach for young people with neurocognitive disability. The cognitive development of young people generally and young people with neurocognitive disabilities are also discussed more fully later in this chapter.

III. Defences

The criminal law recognises that there are circumstances in which individuals should not be held responsible for criminal offending even though the *actus reus* and *mens rea* have been established. Various defences to criminal offending exist to acknowledge reduced capacity and therefore reduced autonomy of individuals in certain circumstances. The defences of insanity, duress and intoxication are discussed below as examples of this. The insanity and duress defences reflect the criminal law's hesitancy in attributing blame to an individual who acts due to something out of their control. Intoxication is discussed as an example where although the defendant's state of mind is called into question, the cause of the incapacitation was in the defendant's control and thus is not considered exculpatory. The following section demonstrates that in the case of an individual with FASD, the theoretical justification for the defences of insanity and duress are more comparable than that of intoxication.

A. Insanity

The following section unpacks the justification for the insanity defence (and its implications for our understanding of autonomous decision-making) and explains how this defence is consistent with society's understanding of culpability.

The defence of insanity in New Zealand is provided by the Crimes Act and applies when an individual is, at the time of the act or omission, "labouring under natural imbecility or disease of the mind" to the extent that the individual is:⁷⁵⁰

- incapable of understanding the nature and quality of the act or omission; or
- of knowing that the act or omission was morally wrong, having regard to the commonly accepted standards of right and wrong.

The wording of this section in the Crimes Act acknowledges that even when it can be established that an individual has committed a criminal offence, including having the requisite *mens rea* at the appropriate time, there will be circumstances that render it morally reprehensible to hold them accountable. The defence of insanity has been described as a "symbolic perspective" of society's basic values:⁷⁵¹

It symbolises the gap between the aspirations of a theoretically positivist and objective common law system (in which behaviour is allegedly animated by free will and is judged and assessed on a conscious level), and the reality of an indeterminate, subjective, psychosocial universe (in which behaviour is determined by a host of

⁷⁵⁰ Crimes Act 1961 s 23.

⁷⁵¹ Michael L. Perlin "Unpacking the Myths: the Symbolism Mythology of Insanity Defence Jurisprudence" (1989) 40 *Case W. Res. L. Rev.* 599 at 620.

biological, psychological, physiological, environmental and sociological factors, and is frequently driven by unconscious forces).

Historically, the test for insanity was that “a man must have no more understanding than an infant, brute, or Wild Beast”.⁷⁵² The test for establishing whether a defence of insanity is appropriate was developed beyond the “Wild Beast” test by a seminal case in 1843.⁷⁵³ The case of *M’Naghten* involved a man who believed he was being persecuted by the Tories in England and, in attempting to kill the Prime Minister, shot the Prime Minister’s secretary. *M’Naghten* was acquitted of murder after the Court found him “insane”.⁷⁵⁴

The jurors ought to be told that in all cases every man is presumed to be sane, and to possess a sufficient degree of reason to be responsible for his crimes, until the contrary be proved to their satisfaction; and that to establish a defence on the ground of insanity, it must be clearly proved that, at the time of committing the act, the party accused was labouring under a defect of reason, from disease of the mind, as not to know the nature and quality of the act he was doing, or, if he did know it, that he did not know he was doing what was wrong.

This test laid out by Judge Tindall in *M’Naghten* is the foundation for s 23 of the Crimes Act in New Zealand.

The justification for a defence of insanity reflects society’s understanding of degrees of culpability and what constitutes a fully autonomous decision, as discussed above.⁷⁵⁵ For a criminal justice system to be effective, punishment needs to “serve a purpose both to the individual and society as a whole”.⁷⁵⁶ To achieve this goal, certain principles are followed in determining an appropriate sentence: deterrence, retribution, rehabilitation and incapacitation.⁷⁵⁷ Societies worldwide are uncomfortable punishing people with certain mental disorders, largely due to the difficulty of applying the principles of deterrence and retribution to these individuals, given that their offending is “due to something out of their control”.⁷⁵⁸

The scope of mental disorders caught within the ambit of the insanity defence varies among jurisdictions. In South Australia and Tasmania, an additional arm (the “volitional arm”) is included within the defence to expand its ambit to include individuals who have difficulty controlling their impulses.⁷⁵⁹ There are difficulties to this extension of the defence, predominantly the difficulty in objectively determining whether the action is the result of

⁷⁵² Stephen Allnutt, Anthony Samuels and Colman O’Driscoll “The insanity defence: from wild beasts to *M’Naghten*” (2007) 15 *Australis Psychiatry* 292 at 292.

⁷⁵³ *R v M’Naghten* (1843) 8 E.R. 718.

⁷⁵⁴ *M’Naghten*, above n 753.

⁷⁵⁵ The insanity defence in the Netherlands not only recognises that an individual may be more or less culpable for criminal offending, but has five distinct stages of culpability: responsible, slightly diminished, diminished, severely diminished, and not responsible. While this has the benefit of being able to “fine-tune” the punishment or measure to the particular offender and the particular crime, consistently distinguishing between the stages may be challenging in practice: Gerben Meynen “Legal Insanity and Neurolaw in the Netherlands: Developments and Debates” in Sofia Moratti and Dennis Patterson (eds) *Legal Insanity and the Brain: Science, Law and European Courts* (Hart Publishing, United Kingdom, August 2016) 137 at 145-147.

⁷⁵⁶ Allnutt, above n 752 at 293.

⁷⁵⁷ Allnutt, above n 752 at 293.

⁷⁵⁸ Allnutt, above n 752 at 293.

⁷⁵⁹ Allnutt, above n 752 at 296.

“an irresistible impulse or an impulse not resisted”.⁷⁶⁰ It is however an important addition to be considered, especially in the context of assessing criminal culpability and neurological disorder (which will be expanded on later in this chapter). Individuals with FASD often have significantly reduced function of their prefrontal cortex and have difficulty controlling their impulses as a result. In the context of permanent brain damage, it would appear an action by an individual with FASD would constitute “an irresistible impulse” rather than “an impulse not resisted”. It seems inconsistent to exclude this additional arm to the defence purely on the basis that it is legally challenging to assess, when the purpose of the defence is to ensure the criminal justice system does not improperly punish or incarcerate individuals who act in the absence of autonomy.

Steve Matthews suggests that one way to ameliorate the difficulty regarding which mental disorders to include within the ambit of the defence is to change the focus; instead of looking at specific “diseases of the mind”, the test should instead focus on an individual’s *agency*.⁷⁶¹ He argues that where the question is whether an individual possesses sufficient mental capacity to be held responsible for criminal offending, “the only relevant question is whether the individual reaches a certain threshold for agency”.⁷⁶² It does not matter to Matthews’ argument what the cause of the failed agency is, only that the individual did not have agency at the time of the offending.

Another concern with the defence as created by *M’Naghten* is that procedurally, because it requires “such a radically delusional subject”, individuals will far more often be found either unfit to plead or unfit to stand trial: “the rule is thus guaranteed to have almost no effective scope”.⁷⁶³ By focusing on the individual’s cognition, the *M’Naghten* test excludes other conditions “in which the ordinary powers of control or volition fail”.⁷⁶⁴ Focusing on the concept of “competent agency” avoids this problem by assessing *capacity*, and thus whether criminal responsibility should be attributed.⁷⁶⁵ Matthews articulates three criteria for establishing competent agency:⁷⁶⁶

1. An individual must possess the capacity to direct their future behaviour through intentions, undertakings, plans etc;
2. their intentions must connect with their environment (e.g., not be the product of delusions); and
3. they must be capable of recognising that what they are doing is expressive of what they judge they have a reason to be doing.

This explanation of an alternative to the insanity defence focuses more directly on the concept of autonomy and autonomous decision-making. The third limb of Matthews’ test suggests that for a decision to be autonomous a person’s evaluative judgment must be engaged.⁷⁶⁷ In considering the consequences of a decision or action, the person must be able to attribute various goals, preferences, or desires (an affective attitude) to the outcome, in

⁷⁶⁰ Allnutt, above n 752 at 296.

⁷⁶¹ Steve Matthews “Failed agency and the insanity defence” (2004) 27 *Int. J. Law Psychiatry* 413.

⁷⁶² Matthews, above n 761 at 415.

⁷⁶³ Matthews, above n 761 at 418.

⁷⁶⁴ Matthews, above n 761 at 418.

⁷⁶⁵ Matthews, above n 761 at 419.

⁷⁶⁶ Matthews, above n 761 at 419.

⁷⁶⁷ Matthews, above n 761 at 420.

order for one consequence or outcome to be preferable to the individual over another.⁷⁶⁸ Autonomous decision-making is thus the interaction between *cognition* and *emotion*; it is not enough to simply understand the facts of the given situation, the individual must be able to “appraise the action and consequences in light of their preferences, desires, goals, values and standards (affective attitudes)”.⁷⁶⁹

In 2013, the Law Commission in the United Kingdom conducted a review of the insanity defence, recommending its abolishment and suggesting an alternative defence of “not criminally responsible by reason of recognised medical condition”.⁷⁷⁰ While this new defence included the traditional *M’Naghten* criteria, it added a third option, where an individual who “wholly lacks capacity rationally to form a judgement about the relevant conduct or circumstances” would satisfy the requirements of the defence.⁷⁷¹ Like Matthews’ test for competent agency, this third option focuses on the capacity for *practical reasoning*: an individual who knew that the act was morally and legally wrong would still satisfy the requirements of the defence if they wholly lacked capacity for practical reasoning.⁷⁷² This proposed new defence would still likely have limited applicability, as individuals who substantially (but not wholly) lack capacity would nevertheless remain in the prison system.⁷⁷³

The question of whether the defence of insanity requires amendment is beyond the scope of this thesis. Insanity defence jurisprudence agrees, however, that fundamentally the purpose of the defence is to recognise that some individuals cannot be considered criminally responsible for their actions. This is because, despite evidence of *actus reus* and *mens rea* being attributable to them, the individual has failed to satisfy crucial preconditions for autonomy; namely the interaction between cognition and emotion as it relates to decision-making. At the root of the defence is the concept of autonomy and what constitutes an autonomous decision: the conflict comes from determining how a legal system can reflect these concepts and ensure the individuals concerned avoid inappropriate sanction.

B. Duress

The defence of duress has been recognised by common law “for centuries”⁷⁷⁴ and has been codified in New Zealand by s 24 of the Crimes Act with the defence of compulsion:⁷⁷⁵

A person who commits an offence under compulsion by threats of immediate death or grievous bodily harm from a person who is present when the offence is committed

⁷⁶⁸ Matthews, above n 761 at 420.

⁷⁶⁹ Matthews, above n 761 at 420.

⁷⁷⁰ United Kingdom Law Commission *Criminal Liability: Insanity and Automatism* (UKLC Discussion Paper, 2013) at 19.

⁷⁷¹ UKLC, above n 770 at 20.

⁷⁷² The individual would still need to establish a causal link between the lack of capacity and the recognised medical condition: Lisa Claydon and Paul Catley “Abolishing the Insanity Verdict in England and Wales: A Better Balance Between Legal Rules and Scientific Understanding?” in Sofia Moratti and Dennis Patterson (eds) *Legal Insanity and the Brain: Science, Law and European Courts* (Hart Publishing, United Kingdom, August 2016) 207 at 230.

⁷⁷³ Claydon and Catley, above n 772 at 235.

⁷⁷⁴ Law Commission *Battered Defendants Victims of Domestic Violence Who Offend* (NZLC PP41, 2000) at 48.

⁷⁷⁵ Crimes Act 1961, s 24.

is protected from criminal responsibility if he or she believes that the threats will be carried out ...

Duress has previously been treated as negating *mens rea*.⁷⁷⁶ However, it is now considered that both *actus reus* and *mens rea* are established, but the “presence of duress prevents the law from treating what the defendant did as a crime”.⁷⁷⁷ The defence of duress represents another context in which the criminal law is uncomfortable holding an individual accountable for criminal offending, despite the existence of *mens rea* and *actus reus* and the *absence* of any sort of “disease of the mind”.

To understand the justification for the defence of duress, one must also understand the concept of voluntariness. Historically, voluntariness and intention have been considered in union – if an act is intentional, then it is voluntary.⁷⁷⁸ Under this conception, a defence of duress would have to be interpreted as negating *mens rea*, namely intention, for the criminal act. However, voluntariness has alternately been described as an ethical notion rather than a psychological one.⁷⁷⁹ An act is voluntary: “if it is due to choice as opposed to ignorance or compulsion”.⁷⁸⁰ Duress negates not *mens rea* under this conception, but voluntariness. The implication of the defence of duress in criminal law is that in addition to the effective interaction between cognition and emotion, an individual must have acted *voluntarily* in order for a decision to be considered truly autonomous.

The defence of duress involves an investigation into whether an individual acted truly voluntarily; whether they had a choice in acting as they did.⁷⁸¹ Understanding duress means “understanding the relationship between ability, possibility, and choice”.⁷⁸² The damage to the prefrontal cortex caused by prenatal alcohol exposure inhibits an individual’s ability to reason, and undermines the possibility of *choice* by negatively impacting impulse control and the ability to consider consequences. Similarly, if an individual acts to avoid serious harm, the act cannot properly be considered voluntary.⁷⁸³ The nature of choice in that circumstance depends on the nature of the threat and the “value of the interest sacrificed by giving way”.⁷⁸⁴ Just because an individual *could* have resisted, does not mean that in acting under threat they acted voluntarily.

The Court of Appeal in Ontario, Canada, grappled with these concepts in a 2015 case, *R v Aravena*.⁷⁸⁵ In determining the test for duress and whether it can apply in an accessory to a murder case, the Court referred to voluntariness as the “bedrock principle” in criminal law. Doherty and Pardu JJA explained that:⁷⁸⁶

Voluntariness reflects individual choice and with choice comes responsibility for one’s actions. Society can properly hold individuals to account if they choose to act.

⁷⁷⁶ Law Commission, above n 774 at 48.

⁷⁷⁷ Law Commission, above n 774 at 48.

⁷⁷⁸ Dennis Patterson “Rethinking Duress” (2016) 7(3) *Jurisprudence* 672 at 672.

⁷⁷⁹ Patterson, above n 778 at 673.

⁷⁸⁰ Patterson, above n 778 at 673.

⁷⁸¹ Patterson, above n 778 at 674.

⁷⁸² Patterson, above n 778 at 674.

⁷⁸³ Patterson, above n 778 at 674.

⁷⁸⁴ Patterson, above n 778 at 674.

⁷⁸⁵ *R v Aravena* (2015) ONCA 250.

⁷⁸⁶ *Aravena*, above n 785 at [46].

Where there is no choice, punishment of the actor is incompatible with individual autonomy and arguably serves no utilitarian value.

The Court goes on to discuss the issue of voluntariness in the context of duress and acknowledges that when an individual is threatened, there still exists a physical choice for the individual in whether or not to act. However, the Court distinguishes physical involuntariness from moral or normative involuntariness.⁷⁸⁷ The latter reflects “an acceptance of individual autonomy and choice as essential preconditions to the imposition of criminal liability”.⁷⁸⁸

The Court’s analysis of the principles of voluntariness, individual autonomy and criminal liability in *Aravena* reflect society’s general understanding of the purpose of criminal law, as discussed earlier in this chapter. When the Court in *Aravena* stated that punishing an individual for a choice made under compulsion “serves no utilitarian value”, it reflects the argument above regarding individuals with mental disorders. If an individual does not meet the preconditions for autonomous decision-making (namely the interaction between cognition and emotion, and the existence of true *choice* or *voluntariness*), punishing an individual will not serve the criminal justice goals of deterrence, retribution, rehabilitation and incapacitation. It lies contrary to society’s values and undermines the legitimacy of criminal law.

C. Intoxication

Intoxication is not a defence to criminal offending in New Zealand. However, the difficulty in reconciling the effect of intoxication with the required elements of criminal culpability (including *mens rea*) has been widely discussed. Certain academics have suggested that courts have “modified” fundamental elements of criminal liability to ensure individuals acting due to self-intoxication do not escape liability.⁷⁸⁹

Traditional notions of rational capacity, *mens rea* and *actus reus* have been adapted to meet immediate social policy demands.

Stuart Bugg, in a 1985 article exploring intoxication and liability, considered the concept of rational capacity to be an appropriate starting point.⁷⁹⁰ He reflected on fundamental notions of criminal liability, echoing the discussion above regarding autonomy and voluntary conduct when he stated that “criminal jurisprudence may fairly be said to rest upon the (rebuttable) presumption that the individual is possessed of a free will”.⁷⁹¹ Drunkenness was historically considered to “deprive men of the use of reason” and was described in terms akin to insanity: “[it] puts many men into a state of perfect, but temporary phrenzy”.⁷⁹² These observations rightly call into question the rational capacity of individuals acting while

⁷⁸⁷ *Aravena*, above n 785 at [52].

⁷⁸⁸ *Aravena*, above n 785 at [52].

⁷⁸⁹ Stuart Bugg “Intoxication and Liability: A Criminal Law Cocktail” (1985) 5 *Auckland U. L. Rev* 144 at 145.

⁷⁹⁰ Bugg, above n 789 at 145.

⁷⁹¹ Bugg, above n 789 at 145.

⁷⁹² Bugg, above n 789 at 145.

intoxicated, *but* “the voluntary nature of such madness is perceived as denying it any mitigatory power”.⁷⁹³

In most jurisdictions, requisite *mens rea* is imputed upon a defendant who was intoxicated at the time of criminal offending, on the grounds that the individual *would have been aware* had he been sober.⁷⁹⁴ The voluntary nature of the intoxication is crucial in justifying this approach: that the individual *chose* to intoxicate himself and the intoxication is the sole cause of the subsequent lack of *mens rea*. Husak argues that for this position to be tenable, it must be established that the culpable state of an individual who has chosen to intoxicate himself must be *as bad or worse* than the culpable state the law requires.⁷⁹⁵ People become intoxicated for different reasons and in different circumstances and Husak argues that “it is almost impossible to accept the claim that the act of becoming intoxicated is negligent, let alone reckless”.⁷⁹⁶

The courts have had to grapple with this issue, especially in regard to how intoxication affects the issue of recklessness and whether evidence of intoxication can negate *mens rea*.⁷⁹⁷ The House of Lords in *R v Caldwell* held that “reducing oneself by drink or drugs to a condition in which the restraints of reason and conscience are cast off is a reckless course of conduct and an integral part of the crime”.⁷⁹⁸ It appears, however, that in determining intoxicated individuals as fully accountable for criminal offending the courts are not employing “close-reasoned juristic inquiry” but are instead appealing to public policy concerns.⁷⁹⁹

The above-quoted passage from *Caldwell* offers an opportunity to draw an analogy with individuals with FASD. The neurological damage resulting from prenatal alcohol exposure (discussed more thoroughly below) can cause an individual to act without the “restraints of reason” (due to inhibited capacity for impulse control) and without “conscience” (due to an inability to consider consequences at the time of acting). The crucial difference between the two states (intoxication versus FASD) is that the intoxicated individual “reduces *oneself*” to this state, whereas the individual with FASD is entirely blameless. This suggests that the neurological impairments seen in FASD may be enough to negate *mens rea*, at least in regard to how it was approached in *Caldwell*. This issue will be considered again in the discussion on neurological disability and culpability later in this chapter.

Regardless of the means by which the courts are holding that intoxication does not negate *mens rea*, or at least criminal culpability, it seems the justification generally stems from individual responsibility and choice. Even if an individual is so intoxicated as to not know the nature of what they are doing, or to be unaware of the possible risks involved, they made a conscious choice prior to the act to consume alcohol or drugs to such an extent that they lost the ability to reason. In the context of criminal culpability and autonomy, the

⁷⁹³ Bugg, above n 789 at 146.

⁷⁹⁴ Paul H. Robinson “A brief summary and critique of criminal liability rules for intoxicated conduct” (2018) 82(5) *J. Crim. Law Criminol* 381 at 383.

⁷⁹⁵ Douglas Husak “Intoxication and Culpability” (2012) 6 *Crim Law and Philos* 363 at 365.

⁷⁹⁶ Husak, above n 795 at 368.

⁷⁹⁷ Warren Brookbanks *Intoxication and Recklessness* (New Zealand Legal Research Foundation, Occasional Paper 232, 1984).

⁷⁹⁸ *R v Caldwell* [1981] UKHL L0319-2.

⁷⁹⁹ Brookbanks, above n 797 at 22.

autonomous decision has simply shifted in time – the individual may not have had complete control over their mind at the time of the offence, but they made an autonomous choice in getting to that point.

Excluding intoxication from the ambit of acceptable defences at criminal law reflects the importance of the *cause* of the lack of responsibility or capacity. In the case of duress and insanity, the *cause* of the individual's lack of responsibility is something entirely out of their control – a third party exerting a threat of violence over them, or a 'disease of the mind' inhibiting rationality or reason. This distinction is pertinent to the issue of criminal culpability of young people and people with neurodisability, discussed below.

D. Diminished responsibility

Diminished responsibility is described as a partial defence in cases of homicide, reducing a charge of murder to a charge of manslaughter.⁸⁰⁰ This section briefly outlines the rationale for the defence but acknowledges that diminished responsibility is not accepted in New Zealand. The defence has been codified in England in s 2 of the Homicide Act 1957:

A person ("D") who kills or is a party to the killing of another is not to be convicted of murder if D was suffering from an abnormality of mental functioning which-

- (a) Arose from a recognised medical condition,
 - (b) substantially impaired D's ability to do one or more of the things mentioned in subsection (1A), and
 - (c) provides an explanation for D's acts and omissions in doing or being a party to the killing.
- (1A) those things are-
- (a) to understand the nature of D's conduct;
 - (b) to form a rational judgment;
 - (c) to exercise self-control.

The justification for the defence is to acknowledge that there will be circumstances in which an individual does not meet the criteria for legal insanity, but nevertheless has some form of mental incapacity that has affected their actions. If criminal justice systems are comfortable for individuals with total incapacity to be fully absolved of criminal culpability, it follows that the criminal culpability of individuals with partial incapacity should be reduced.⁸⁰¹ An "abnormality of mental functioning" was described by Lord Parker as including not only an impairment in the ability to form rational judgment, but also "the ability to exercise will power to control physical acts, in accordance with rational judgment".⁸⁰² The New Zealand Law Commission considered the ambit of the definition as "broad", referring to a New South Wales Law Commission discussion paper which considered it to include "psychosis, organic brain disorder, schizophrenia, psychopathy, epilepsy, hypoglycaemia, endogenous and reactive depression, post-traumatic stress syndrome, chronic anxiety and personality disorders".⁸⁰³

⁸⁰⁰ Law Commission, above n 774 at 34.

⁸⁰¹ Law Commission, above n 774 at 34.

⁸⁰² Law Commission, above n 774 at 34.

⁸⁰³ Law Commission, above n 774 at 35.

The defence has been considered in New Zealand but rejected for a variety of reasons: originally it was considered unnecessary after the abolition of the death penalty, later it was decided that the circumstances in which it would be used could satisfactorily be dealt with by way of mitigating factors in sentencing.⁸⁰⁴ The statutory wording of s 2 of the Homicide Act 1957, alongside the interpretation of the defence by Lord Parker and the New South Wales Law Commission, provide an opportunity to consider FASD. A young person with FASD may have “substantial impairment” in their ability to form rational judgment or exercise self-control due to the brain damage caused by prenatal alcohol exposure. As is discussed more fully later in this chapter, the prefrontal cortex is a region of the brain often significantly impacted in individuals with FASD and is the region responsible for executive functions like impulse control and the ability to make rational judgments.⁸⁰⁵ A defence like the partial defence of diminished responsibility could effectively acknowledge that capacity (and therefore criminal culpability) exists in degrees for young people with FASD.

IV. Young people and criminal responsibility

This section commences with an analysis of children and young people in the context of criminal justice and criminal responsibility, with reference to neuroscientific evidence that has influenced justice systems worldwide. It then explores how the existence of neurodisability, and in particular FASD, can affect the capacity for autonomous decision-making and therefore should limit criminal culpability.

The criminal incapacity of children is recognised through the notion of *doli incapax*: inability to do wrong.⁸⁰⁶ Justice systems internationally have reflected this principle by setting a minimum age of criminal responsibility, below which a child is presumed incapable of criminal offending.⁸⁰⁷ Article 40(3) of the United Nations Convention on the Rights of the Child (UNCRC) requires States Parties to seek to promote a minimum age of criminal responsibility, and its General Comment on children’s rights in juvenile justice recommends the “absolute minimum age” be set at 12 years.⁸⁰⁸ In New Zealand, the minimum age of criminal responsibility is 10 years if the offence is murder or manslaughter, 12 years for other serious offences, and 14 years for all offences.⁸⁰⁹ The following discussion therefore is in reference to those children and young people who are legally considered capable of criminal offending (in New Zealand, children aged 10 years or older).

The issue of the criminal capacity of children and adolescents is complicated by the fact their brain has not fully developed. This lack of brain maturation requires an analysis of which aspects of brain development and cognition are necessary for criminal capacity, or whether capacity can be established despite the lack of maturation.⁸¹⁰ While the concept of *mens rea* represents ‘fair warning’, an understanding of wrongfulness requires a child to

⁸⁰⁴ Law Commission, above n 774 at 38.

⁸⁰⁵ See Chapter 2.

⁸⁰⁶ Emily Watt *A History of Youth Justice in New Zealand* (Department for Courts, 2003) at 2.

⁸⁰⁷ *Children’s Rights in Juvenile Justice* UN Doc CRC/C/GC/10 (25 April 2007) at 30.

⁸⁰⁸ UN doc, above n 807 at 32.

⁸⁰⁹ Oranga Tamariki Act 1989, s 272.

⁸¹⁰ Anthony L Pillay and Clive Willows “Assessing the criminal capacity of children: a challenge to the capacity of mental health professionals” (2015) 27(2) *Child Adolesc. Ment. Health* 91 at 94.

understand that their behaviour is *illegal* rather than just naughty, which requires some degree of awareness of *consequence*.⁸¹¹

Adolescents pass through a period of development where risk-taking behaviour increases and the regions of the brain responsible for executive control and decision-making (predominantly the prefrontal cortex) have not fully developed.⁸¹² This results in a lack of impulse control, vulnerability to peer influence and increased risk-taking behaviours, all of which can lead adolescents to make decisions that are less well-reasoned than those of adults, with little to no regard for consequence.⁸¹³

Further studies have found that although adolescents aged 16 years and older appear to have the same logical competencies, intelligence, and reasoning as adults in *non-stressful* situations, their abilities are significantly compromised in situations of “high emotional arousal”.⁸¹⁴ In these high intensity situations, the lack of interface between regions of the brain responsible for rational decision-making and regulation of emotion (e.g., the interface between *cognition* and *emotion*) result in adolescents being particularly vulnerable to impulsivity and peer pressure.⁸¹⁵

Neuroscientific evidence directly addresses the discussion around the moral development of adolescents and their ability to rationally consider actions and their potential consequences. Moll et al. found that in the face of moral dilemmas, the prefrontal cortex is activated, regardless of whether or not a decision actually needs to be made.⁸¹⁶ This suggests that moral dilemmas “by definition evoke cognitive-emotional association complexes, where higher order cognitive functions operate within motivationally significant contexts”.⁸¹⁷ This is problematic in an individual who does not yet have the capacity to engage those higher order cognitive functions in order to reach the “right decision”.

Neuroscientific evidence has informed justice systems worldwide regarding how to deal with young offenders.⁸¹⁸ In New Zealand, both the legislation governing young offenders (OT Act) and the legislation governing sentencing in general (Sentencing Act 2002)

⁸¹¹ Pillay and Willows, above n 810 at 92; see also Kate Fitz-Gibbon and Wendy O’Brien “A Child’s Capacity to Commit Crime: Examining the Operation of *Doli Incapax* in Victoria (Australia)” (2019) 8(1) *IJCJ&SD* 18.

⁸¹² John B. Meixner Jr “Applications of Neuroscience in Criminal Law: Legal and Methodological Issues” (2015) 15:513 *Curr Neurol Neurosci Rep* 1 at 6.

⁸¹³ Anne L Kramers-Olen “Neuroscience, moral development, criminal capacity, and the Child Justice Act: justice or injustice?” (2015) 45(4) *S Afr J Psychol* 466 at 469; see also Elizabeth Scott and others “Juvenile Sentencing Reform in a Constitutional Framework” (2016) 88 *Temp. L. Rev.* 675 at 679 where the authors explain the “long-established doctrine” that individuals with reduced decision-making capacity (such as those brought about by the developmental stages of adolescence) are deemed less culpable; and Laurence Steinberg “Adolescent Development and Juvenile Justice” (2009) 16(3) *Annu. Rev. Clin. Psychol.* 47 at 52 where the author notes that “in theory at least, an offender who, by virtue of developmental immaturity, is impulsive, short-sighted, and easily influenced by peers should be punished less harshly than one who is better able to control himself, anticipate the future consequences of his behaviour, and resist the antisocial urgings of his friends”.

⁸¹⁴ Kramers-Olen, above n 813 at 471.

⁸¹⁵ Kramers-Olen, above n 813 at 471.

⁸¹⁶ Kramers-Olen, above n 813 at 472.

⁸¹⁷ Kramers-Olen, above n 813 at 472.

⁸¹⁸ See for example Armin Alimardani and Jason M. Chin “Neurolaw in Australia: The use of neuroscience in Australian criminal proceedings” (2019) 12(3) *Neuroethics* 255 at 263, where Alimardani refers to a subset of criminal cases involving the sentencing of young offenders. These cases refer to studies of developmental neuroscience which “explain the relationship between neurological development and behavioural tendencies such as risk-taking or impulsivity in adolescents”.

acknowledge the nature of the adolescent brain as immature. Section 208(e) of the OT Act identifies age as a mitigating factor in deciding whether to impose sanctions on a child or young person, and the nature of what those sanctions should be. Section 9 of the Sentencing Act 2002 outlines specific aggravating and mitigating factors the court must take into account at sentencing, with s 9(2)(a) specifically listing the offender's age as a mitigating factor.

Arguably legislation could go further. Given the acceptance of insanity as a defence to criminal culpability and considering the justification stemming from a lack of autonomy, an analogy can be drawn with adolescent brain immaturity. If the preconditions for autonomy include the effective interaction between *cognition* and *emotion*, and in cases of insanity it is accepted that these preconditions are absent, it follows that for an individual to be held criminally culpable they must have the capacity for this interaction. As discussed earlier in this section, neuroscience has established that the brain structure of adolescents inhibits the interaction between regions of the brain responsible for *cognition* and *emotion*. Under this conception of autonomy and criminal responsibility, young people should be entitled to a *defence* to criminal culpability at least until their brain has matured and is capable of the logical reasoning discussed above.

The limited development of crucial regions of the brain in adolescents has been established by neuroscientific evidence and has been accepted to some extent by New Zealand's youth justice system. The youth justice system acknowledges the adolescent brain's lack of maturation by identifying age as a mitigating factor and structuring the system around supporting the child to continue developing.⁸¹⁹ The jurisdiction of youth justice in New Zealand, however, ends at 17 years old, despite neuroscientific evidence indicating the brain is still undergoing significant development into the 20s.⁸²⁰ The District Court in Porirua, Wellington, is developing a trial project to consider 'young adults' aged 18-24 as a distinct group of young people requiring extra support.⁸²¹ This project acknowledges that although these young people are excluded from the jurisdiction of youth justice, the neuroscience surrounding the developing brain and the likely overrepresentation of neurodisability necessitate an alternative approach.

⁸¹⁹ Section 208 Oranga Tamariki Act 1989.

⁸²⁰ For example, for young adults (18-21 years), areas of the brain that regulate self-control and judgement are still not fully mature, especially in high-intensity situations. When confronted with an emotionally charged situation, young adults' "capacity to regulate their actions and emotions appear more like that of teens than adults in their mid-20s or older". This includes increased impulsivity and risk-taking behaviour: BJ Casey and others "How Should Justice Policy Treat Young Offenders?: A Knowledge Brief of the MacArthur Foundation Research Network on Law and Neuroscience" (2017) at 3; see also Laurence Steinberg "A social neuroscience perspective on adolescent risk-taking" (2008) 28 *Developmental Review* 78 at 79.

⁸²¹ Judge Jan-Marie Doogue and Judge John Walker "Proposal for a Trial of Young Adult List in Porirua District Court" (May 2019). See also: Jo Thomas, Claire Ely and Ben Estep *A fairer way: Procedural fairness for young adults at court* (Centre for Justice Innovation United Kingdom, April 2018) where the centre recommends adopting procedural fairness for young adult offenders in a move to acknowledge the unique needs of this cohort of offenders and to mitigate recidivism; Ineke Pruin and Frieder Dunkel *Better in Europe? European responses to young adult offending* (Transition to Adulthood Report, March 2015) at 57: the Netherlands includes young people up to the age of 23 in its juvenile justice system; and Vincent Schiraldi, Bruce Western and Kendra Bradner "Community-Based Responses to Justice-Involved Young Adults" (2015) 1 *New Thinking in Community Corrections* at 3.

In 2012, the United States Supreme Court found that mandatory sentences for life without parole for juvenile offenders constituted “cruel and unusual punishment”.⁸²² Meixner commented on the reasoning the Court used⁸²³ to come to this decision, noting “the reasoning could be applied to almost any level of biologically driven propensity for increased risk-taking behaviour, whether adolescent or not”.⁸²⁴ His comment appears to signal the possibility for courts to consider the impact of neurodisability in a similar manner to how adolescence has been accommodated.

V. Criminal capacity of people with neurodisabilities (ADHD, ASD and FASD)

A. ADHD

Robert Eme, in a 2014 paper published in the *Journal of Forensic Psychology Practice*, argued for Attention Deficit Hyperactivity Disorder (ADHD) to be acknowledged by the courts.⁸²⁵ He identified that criminal justice systems are already accepting neuroscientific evidence for the brain immaturity of adolescence, and argued that the impact of ADHD on an individual’s brain results in similar diminished capacity and therefore should be reflected in attributable criminal responsibility.⁸²⁶

ADHD is a neurodevelopmental disorder that results in impulsivity, inattention and hyperactivity.⁸²⁷ Impulsivity is a risk factor for antisocial behaviour and, like FASD, individuals with ADHD are overrepresented in criminal justice statistics.⁸²⁸ Eme emphasises an important distinction between diminished intelligence and diminished capacity in individuals with ADHD. The former refers to an individual’s ability to distinguish right from wrong (which individuals with ADHD can do), while the latter refers to an individual’s ability to *act* on what an individual knows is the ‘right’ choice’.⁸²⁹ This reflects the discussion above regarding adolescents’ inability to act on their moral knowledge in high stress situations, and again highlights the critical role of the prefrontal cortex in controlling executive functions and the brain’s capacity to effectively support the interaction between cognition and emotion.⁸³⁰

Eme argued for ADHD to be treated as a mitigating factor in the criminal justice system in the same way that adolescence is.⁸³¹ He notes that the justification for accommodating

⁸²² *Miller v Alabama* 567 U.S. 460.

⁸²³ The majority discussed the impact of adolescent neurodevelopment on behaviours such as impulsivity, and the failure to appreciate risk and consequence. (at [477]).

⁸²⁴ Meixner, above n 812 at 6.

⁸²⁵ Robert Eme “Attention Deficit Hyperactivity Disorder: A Mitigation of Criminal Responsibility?” (2014) 14 *J Forensic Psychol P* 221.

⁸²⁶ Eme, above n 825.

⁸²⁷ Eme, above n 825 at 222.

⁸²⁸ Eme, above n 825 at 223.

⁸²⁹ Eme, above n 825 at 225. See also *R v P* [2016] NZCA 128, where the young offender had suffered a traumatic brain injury and the Court quoted from the psychologist’s report at [44]: “Criminal responsibility is premised on the fact that a person can reason right from wrong and [choose] right from wrong in a given situation. In my opinion, although knowing right from wrong, P was significantly reduced in his capacity to choose right from wrong, due to his lasting brain impairments”.

⁸³⁰ Eme, above n 825 at 471.

⁸³¹ Eme, above n 825 at 224.

adolescence in criminal justice systems is not just because of the differences in behaviour between adolescents and adults, but rather because of where those differences stem from.⁸³²

The evidence indicated that the well-known adolescent behavioural immaturity was not simply due to poor choices or different values but that it was at least partly due to factors that were not entirely under their control.

The impulsivity seen in individuals with ADHD is caused by an impairment in their inhibitory control, which is an executive function controlled by the prefrontal cortex.⁸³³ Eme therefore argued that for individuals with ADHD, their impulsive behaviour is, at least, partly due to factors that are not within their control, the same as for adolescents. This again reflects the discussion on the insanity defence, which is argued as justifiable because the behaviour of the individuals affected is out of their control, and due instead to an inability of regions of the brain to interact with each other. Eme therefore argued that ADHD should be considered a mitigating factor due to the person's diminished capacity for self-control and noted three recommendations for forensic practice:⁸³⁴

1. Firstly, the court would need to be persuaded that neuroscience accepts ADHD as a biologically based disorder that inhibits self-control;
2. secondly, it would need to be established that the defendant has ADHD; and
3. thirdly, the Court would need to establish that the neuroscience evidence regarding self-control is actually relevant in the particular case.

B. ASD

Individuals with autism spectrum disorder (ASD) come to the attention of the courts relatively rarely,⁸³⁵ but the particular presentations of the disorder and how it impacts criminal culpability provide a useful comparison with FASD. Like FASD, ASD is a spectrum disorder, with “much variation in different aspects of the phenotype, both clinical and cognitive”.⁸³⁶ The challenge for the courts becomes one of identifying which aspects of the clinical and cognitive phenotype have implications for criminal culpability rather than simply accepting that a diagnosis of ASD in itself should dictate a particular judicial approach. Woodbury-Smith and Dein suggest that cognitive strengths and weaknesses should inform decisions regarding culpability, with the specific diagnosis set to one side.⁸³⁷ The Court of Appeal in New South Wales grappled with this issue in *R v George*, where the applicant was found to have the disorder “at the milder end of the spectrum”.⁸³⁸ The appellate Court found that although the applicant's disorder was mild, it was relevant “not only to the extent of the applicant's culpability, but also ... in explaining the applicant's

⁸³² Eme, above n 825 at 225.

⁸³³ Eme, above n 825 at 227.

⁸³⁴ Eme, above n 825 at 229 - 231

⁸³⁵ Ian Freckelton “Autism Spectrum Disorder: Forensic Issues and Challenges for Mental Health Professionals and Courts” (2013) 26 *J Appl Res Intellect* 420 at 420; Marc Woodbury-Smith and Kalpana Dein “Autism Spectrum Disorder (ASD) and Unlawful Behaviour: Where Do We Go from Here?” (2014) 44 *J Autism Dev Disord* 2734 at 2734; and *R v George* [2004] NSWCCA 247 at [44].

⁸³⁶ Woodbury-Smith and Dein, above n 835 at 2739.

⁸³⁷ At 2739.

⁸³⁸ *R v George* [2004] NSWCCA 247 at [25]. The applicant in this case had Asperger's Syndrome, a disorder which has subsequently been included under the umbrella of ASD. He had been convicted of manslaughter after his elderly mother died as a result of his negligence in her care.

apparent lack of remorse”.⁸³⁹ To the question of his culpability, the Court found that certain aspects of his cognitive impairment⁸⁴⁰ served to reduce the culpability of otherwise aggravating factors to the offence, something that the sentencing judge failed to consider.⁸⁴¹

The Court in *George* acknowledged that the focus of inquiry needed to be not on the applicant’s diagnosis exclusively (where the description was “mild”), but on how the particular presentation of ASD’s diverse symptomatology affected the criminality of his conduct.⁸⁴² Specifically, whether ASD is relevant to the question of criminal culpability will depend on:⁸⁴³

Whether the individual’s personal experience of ASD symptomatology is such as to materially impact adversely upon rational thinking processes or genuinely to generate what would otherwise be unaccountable perceptions of others’ conduct or intentions.

C. FASD

Canadian academics at the University of Saskatchewan explored the issue of diminished criminal responsibility specifically as it relates to individuals with FASD.⁸⁴⁴ Mela and Luther analysed the Canadian Criminal Code and noted that FASD does not fit nicely under the definitions of “disease of the mind” or “mental disorder”; nor does it fit with the demands of the statute that the accused did not understand the nature of the act as being wrong.⁸⁴⁵ This acknowledgment reflects the analysis by Kramers-Olen and Eme discussed in the passages above. The particular regions of the brain affected by adolescence, ADHD, ASD or FASD do not necessarily preclude an individual from understanding right from wrong. They may, however, have a significant impact on an individual’s ability to control their impulses and act on what they know to be the ‘right’ course of action.

FASD is a spectrum disorder and, like ASD, this presents a particular challenge for the courts in assessing criminal culpability. A diagnosis on its own is inadequate in providing the answer to whether an individual’s conduct should be deemed less criminally culpable.⁸⁴⁶

⁸³⁹ At [32].

⁸⁴⁰ For example, his lack of empathy, a tendency to take his mother’s instructions to not arrange home-care literally and at her word, and a lack of capacity for an emotional response to the pain and suffering of another.

⁸⁴¹ At [41].

⁸⁴² See also *R v Sokaluk* [2013] VSCA 48 where the appellate court found that the respondent’s specific presentations of ASD and intellectual disability had a bearing on criminal culpability following the intentional lighting of a fire during a fire ban, resulting in extensive loss of property and life. Although the sentencing judge found that the individual “must have known of the risk” in starting the fire, he also found that culpability was reduced because the individual “did not fully appreciate” the consequences [37]. The appellate court emphasised the importance of a nuanced approach to assessing criminal culpability and cognitive impairment and the importance of relying on thorough forensic reports.

⁸⁴³ Freckelton, above n 835 at 431.

⁸⁴⁴ Mansfield Mela and Glen Luther “Fetal alcohol spectrum disorder: can diminished responsibility diminish criminal behaviour?” (2013) 36 *Int. J. Law Psychiatry* 46.

⁸⁴⁵ Mela and Luther, above n 844 at 47. See also House of Representatives Standing Committee on Social Policy and Legal Affairs *FASD: The Hidden Harm. Inquiry into the prevention, diagnosis and management of Fetal Alcohol Spectrum Disorders* (Department of the House of Representatives Australia, Government Inquiry, November 2012) at 5.106 where the inquiry noted that the definition of ‘mental impairment’ differs across statutes in Australia, where one can be interpreted to include FASD, and the other to exclude it.

⁸⁴⁶ See Heather Douglas “Foetal Alcohol Spectrum Disorders: A consideration of sentencing and unreliable confessions” (2015) 23 *JLM* 427 at 432 where the author notes “the availability of a diagnosis does not provide

In *R v Ramsay*, the Alberta Court of Appeal held that “the degree of moral blameworthiness must be commensurate with the magnitude of the cognitive deficits attributable to FASD.”⁸⁴⁷ This approach is consistent with the understanding of FASD and criminal responsibility advocated for by Mela and Luther, who go a step further by articulating exactly which neuropsychological functions are required to be considered criminally responsible.

Mela and Luther noted the difficulty in considering criminal capacity as a binary issue for individuals with FASD and argued instead for justice systems to adopt a “graded view of responsibility”.⁸⁴⁸

The goal is to proverbially widen the net to include accused individuals whose appreciation of criminal acts may not meet the stringent knowledge test but by alternate definition involve individuals who are not ‘totally’ responsible either.

The authors referred to the conceptualisation of *mens rea* as similarly binary and absolute and pointed out the tension that arises when confronted with the nature of FASD as existing along a continuum.⁸⁴⁹ They also unpacked the idea of capacity as requiring more than just understanding and that it involves “some analysis of information to assist in decision-making”.⁸⁵⁰ They describe capacity in neuropsychological terms as the ability to:⁸⁵¹

- understand and retain information (understanding);
- believe it (appreciation);
- weigh it up in an analysis of pros and cons (reasoning); and
- arrive at a choice (choice).

This process relies on the optimum functioning of the brain domains responsible for information, focus, learning from experience, and short and long-term memory – the domains that are often significantly impacted by the presence of FASD.⁸⁵² Despite the neuroscientific evidence indicating the debilitating effect that FASD has on crucial domains of the brain, in an analysis of court cases Mela and Luther found that no “not criminally responsible” arguments were accepted for individuals with FASD.⁸⁵³

FASD patients are languishing in the criminal justice system especially in prison. Equated with incarceration of Down’s syndrome patients, the practice is at best appalling and disturbing for a free and liberal society.

a neat conclusion to a sentencing hearing”; and *R v Verdins* [2007] VSCA 102 at [13] where the Court acknowledged that “where a diagnostic label is applied to an offender ... this should be treated as the beginning, not the end, of the enquiry”.

⁸⁴⁷ [2010] ABCA 267 at [25]. See also *R v Powderface* [2014] ABPC 193 at [15] where the Court found the accused’s FASD-related deficits “significantly reduce” his blameworthiness.

⁸⁴⁸ Mela and Luther, above n 844 at 47.

⁸⁴⁹ Mela and Luther, above n 844 at 49.

⁸⁵⁰ Mela and Luther, above n 844 at 49.

⁸⁵¹ Mela and Luther, above n 844 at 50.

⁸⁵² Mela and Luther, above n 844 at 49.

⁸⁵³ Mela and Luther, above n 844 at 50.

VI. *Balancing interests*

Throughout the process of establishing an individual's level of culpability, as well as considering aggravating and mitigating factors, the principles of sentencing require the court to consider and respond to the harm the offender may have caused. This requires carefully balancing their degree of culpability with the seriousness of the crime.⁸⁵⁴ This is particularly challenging when the court is faced with a young offender with significant cognitive impairment, who has committed a serious crime with consequences for the victim and for society as a whole. The New Zealand case *R v DP* is one example where the Court was forced to confront this balance.⁸⁵⁵ In this case, the offender was a 13 year-old child with a traumatic brain injury that had not received adequate support or rehabilitative attention; he also likely had FASD, and had a traumatic childhood background that was "turbulent in the extreme".⁸⁵⁶ He moved schools frequently, and at the time of the offending was not engaged in formal education, regularly drank alcohol and was addicted to synthetic cannabis.⁸⁵⁷ He was charged with manslaughter, having fatally stabbed the owner of a dairy during an attempted robbery.

The Court acknowledged that DP's cognitive impairment, as a result of his traumatic brain injury and probable FASD, directly contributed to his actions at the time of the offending.⁸⁵⁸ It also acknowledged that the owner of the dairy, Mr Kumar, paid "the ultimate price" any victim of offending can pay – he lost "the ability to remain with his family for the duration of his lifetime".⁸⁵⁹ Mr Kumar's family were also victims, in that they permanently lost a loved one and were obliged to "endure the criminal trial process".⁸⁶⁰ The Court considered further implications of the offending, stating that "the ripples of this type of offending go wider".⁸⁶¹ Here the Court was making reference to the "circle of victims" beyond Mr Kumar's family, acknowledging that other small shop keepers will be anxious about this sort of event reoccurring and will take extra precautions.

The need to protect the community was considered paramount to the Court's sentencing decision and was balanced against DP's personal circumstances (including his cognitive impairment).⁸⁶² This case illustrates the complexity involved in cases where the individual's vulnerabilities and potential reduced culpability need to be considered in the context of the

⁸⁵⁴ Section 8, Sentencing Act 2002.

⁸⁵⁵ [2015] NZHC 1796.

⁸⁵⁶ *DP*, above n 855 at [12].

⁸⁵⁷ *DP*, above n 855 at [13].

⁸⁵⁸ *DP*, above n 855 at [16].

⁸⁵⁹ *DP*, above n 855 at [20].

⁸⁶⁰ *DP*, above n 855 at [21].

⁸⁶¹ *DP*, above n 855 at [22].

⁸⁶² *DP*, above n 855 at [35]. The High Court's imposition of a six-year prison sentence with a minimum period of imprisonment of three years and three months was overturned by the Court of Appeal in *P v R* [2016] NZCA 128. The Court of Appeal held that the sentencing judge erred in finding the appellant's cognitive impairment had been sufficiently acknowledged by the jury finding him guilty of manslaughter rather than murder, and, significantly, held that the protection of the community was best served in not imposing a minimum period of imprisonment, but in allowing for flexibility to focus on P's rehabilitative options. The Court thus considered the protection of the community "is better safeguarded through the successful reintegration of the child, rather than a punitive response": Nessa Lynch "Case Note: The Sentencing of Vulnerability" [2016] *New Zealand Criminal Law Review* 103 at 109.

harm caused by the offending. Any formal legislative or policy direction to acknowledge FASD and reduced criminal culpability will need to be cognisant of this balance.

VII. Discussion

Despite growing neuroscientific evidence, criminal justice systems appear reluctant to acknowledge neurodisability in general (and FASD specifically) as a possible cause for diminished responsibility or lack of criminal capacity. The ability of neuroscientific evidence to directly aid legislative reform and judicial decision-making may be limited due to it being considered still in its “formative stages”.⁸⁶³ However, the acceptance of the neuroscience of adolescent development in criminal justice systems, combined with established principles of criminal law such as *mens rea* and defences to criminal responsibility (e.g., insanity, duress, intoxication), signals a desire by the courts to understand the root cause of criminal offending and to only attribute full moral blameworthiness if an individual possesses adequate cognitive capabilities. The lack of acceptance of neurodisability in this sphere highlights an inconsistency that needs to be remedied if criminal justice systems are to fulfill their commitment to acknowledging the underlying drivers of criminal behaviour.

If criminal justice systems are to consider autonomous decision-making consistently, adolescence and particular forms or presentations of neurodisability should be considered a defence to criminal culpability. In instances where the elements of the offence (*mens rea* and *actus reus*) are established and attributed to the individual, criminal culpability should be excused *unless* the preconditions for an autonomous decision are met. The individual should have the neurological capacity to integrate *cognition* and *emotion*, and the action that precipitated criminal proceedings must have been a truly *voluntary* decision. For young people with FASD, not only is their ability to integrate cognition and emotion compromised because of their still developing adolescent brain, but some areas of cognitive functioning will be permanently disrupted because of their prenatal exposure to alcohol. The vulnerability of these young people in the criminal justice system is compounded and should be recognised by acknowledging their reduced culpability.

Alternatively, it is possible that the neurological presentations of FASD, especially when combined with the cognitive limitations of adolescence, negate *mens rea* altogether. The lack of impulse control, the inability to consider consequences and the subsequent increase in risk-taking behaviours can be analogised with the state of mind of an intoxicated individual. Courts grappling with how intoxication negates *mens rea* have accepted that, technically, an individual acting under the influence of alcohol or drugs may not have the requisite *mens rea* at the time the *actus reus* occurred. However, *mens rea* is generally imposed upon the individual due to the policy concern that if an individual inflicts upon *himself* the state negating *mens rea*, he should still be held criminally responsible. The same cannot be said for an individual with FASD who is born with this condition.

⁸⁶³ Alimardani and Chin, above n 818 at 264. The applicability of neuroscientific evidence to the criminal justice sphere is still uncertain, and legal actors have been advised to establish an “ethic of caution”. For example, the term “neuromania” refers to the effect whereby descriptions of psychological phenomena are more convincing for people with the addition of “irrelevant neuroscientific terms” (at 267). This is concerning when considering lay jurors, for example, who may place undue weight on neuroscience evidence (at 265).

Since the courts only treat adolescence as a mitigating factor in sentencing rather than as a full defence, a similar approach would likely be taken for neurodisability. The partial defence of diminished responsibility would recognise the diminished capacity of young people with FASD, taking into account both their adolescent brain development and the impact of prenatal alcohol exposure on their cognitive functioning. However, given the defence has been rejected multiple times in New Zealand, it may be more realistic to consider FASD as a mitigating factor in sentencing first. Principles of sentencing, and in particular the role of aggravating and mitigating factors in sentencing, reflect society's understanding of culpability in criminal offending. Aggravating and mitigating factors give the fact finder the flexibility to assign more or less punishment to an offender depending on his or her individual circumstances, even after *mens rea* and *actus reus* have been positively determined. Criminal justice systems are already comfortable accepting that an individual's age should be considered a mitigating factor because of the neuroscientific evidence regarding cognition, emotion and reduced capacity for exercising reason.⁸⁶⁴ Young people with FASD arguably deserve further recognition. If FASD is only considered a mitigating factor in sentencing, the extent to which culpability is mitigated should reflect both their adolescence and their neurodisability.

VIII. Conclusion

Considering criminal responsibility in its entirety, to determine the *intentions* of an individual, whether they were *morally* responsible, and whether they had the *capacity* to act differently, requires an analysis of cognitive ability.⁸⁶⁵ If such an analysis were to discover the individual concerned had FASD which impacted on their executive functioning and impulse control (for example), it would be appropriate to consider the capacity for autonomous decision-making in that individual.

The concept of *mens rea* and the defences of duress and insanity reflect the theoretical basis for acknowledging the role of autonomy in criminal culpability. For an action to constitute criminal offending, the individual must have the required state of mind at the appropriate time. The individual must also be acting voluntarily and be free from any "disease of the mind" that inhibits the interaction of cognition and emotion. If the individual brings upon himself a state of affairs (e.g., intoxication) to negate *mens rea*, the criminal law is comfortable imputing the required state of mind to ensure blame is appropriately attributed. A young person with FASD who commits an offence does so with reduced capacity for exercising reason, a physiologically determined lack of impulse control, and permanent damage to the brain domains responsible for information, focus, learning from experience, and short and long-term memory. The lack of recognition of reduced criminal culpability of

⁸⁶⁴ While neuroscientific evidence is interpreted as a mitigating factor in the context of adolescence (a phenomena that is relatively short-lived), courts may not interpret the neuroscientific evidence of permanent impairment as favourably. For example, in *R v McCann* [2012] NSWSC 1462, the sentencing judge acknowledged that the defendant's cognitive impairment and frontal lobe damage lessened his moral culpability, but added: "the irreversible condition of the frontal lobes and the brain generally, raises the question of his dangerousness in the future" (at 36). Neuroscientific evidence and its contribution to sentencing has been described as a "double-edged sword" because of this risk: see Alimardani and Chin, above n 818 at 263.

⁸⁶⁵ Ellie A. Page "The Criminal Mind: Neuroscientific Evidence as a Mitigating Factor in Sentencing in New South Wales, Australia" (2017) 26(3) *Wash. Int. Law Rev* 659 at 661.

young people with FASD represents an inconsistent approach taken by criminal justice systems in recognising reduced autonomy and in the appropriate attribution of responsibility.

Given that the effects of FASD compound the cognitive effects of general adolescence, it would be consistent for the criminal law to accept FASD at least as a mitigating factor in sentencing, if not a defence to *mens rea* completely. This would acknowledge the reduced criminal culpability of young people with cognitive impairments that impact upon capacity for reasoned decision-making. It would also reflect that autonomous decision-making exists along a spectrum, and that criminal responsibility should be similarly attributable.

Chapter 6

Method and Methodology

I. Introduction

A small-scale research study was undertaken to ascertain the experiences of families living with FASD in New Zealand and to gain insight from the perspectives of professionals engaging with young people with FASD. The research employed a qualitative methodology using a sample from across New Zealand. Semi-structured interviews were conducted with parents and caregivers of children with FASD, professionals from the health, education and justice sectors, and several key stakeholders. This chapter begins by discussing the nature of qualitative research and describes the growing appreciation of qualitative research as a valid study approach. Three examples of qualitative research (ethnographic, grounded theory and phenomenology) are mentioned with reference to the current doctoral research. The chapter then turns to examining research with young people and people with disabilities, before outlining the specific research methods that were engaged for this study.

II. Qualitative research

Qualitative research is used primarily in the exploration of “social phenomena” as experienced by individuals in their natural context.⁸⁶⁶ For the majority of the 20th century, social scientists focused primarily on the cause and effect relationships that were supposedly present (and paramount) in the social world.⁸⁶⁷ During the final years of the 20th century, researchers were instead encouraged to consider that the focus should be on “the meaning that human beings attach to activity in the social world, meaning that human beings, themselves, create through social interaction”.⁸⁶⁸

Quantitative research was historically considered the most valid form of research.⁸⁶⁹ It focuses on precise, objective measurements, producing results that are generalisable and predictable, with a causal explanation.⁸⁷⁰ An analysis of numbers is used to objectify the data that is produced.⁸⁷¹ Quantitative research works off the premise that the social world is made up of cause and effect relationships; but “even in our world of numbers some information is best collected and analysed utilising a qualitative research method.”⁸⁷²

In contrast, qualitative research works off the premise that the social world is not caused, rather it is constructed through an ongoing process that occurs within and across individuals.⁸⁷³ Studies are exploratory by nature and involve the open-ended collection of

⁸⁶⁶ Daniel H. Grosseohme “Research Methodology: Overview of Qualitative Research” (2014) 20 J Health Care Chaplain 109 at 109.

⁸⁶⁷ Robert Donmoyer “Can Qualitative Researchers Answer Policymakers’ What-Works Question?” (2012) 18(8) Qual Inq 662 at 663.

⁸⁶⁸ Donmoyer, above n 867.

⁸⁶⁹ Suzanne Campbell “What is Qualitative Research?” (2014) 27(1) Clin Lab Sci 3 at 3.

⁸⁷⁰ Campbell, above n 869.

⁸⁷¹ Campbell, above n 869.

⁸⁷² Campbell, above n 869870.

⁸⁷³ Donmoyer, above n 867 at 662.

data from which themes emerge.⁸⁷⁴ With the growing acceptance of qualitative research as a legitimate vehicle for study design, a new paradigm emerged.⁸⁷⁵ This new, constructionist paradigm for research design rejected the notion of causality, arguing that “the complexity of social life [...] could only be captured in the thick description provided by qualitative case study research.”⁸⁷⁶

A. Methods of inquiry

The starting point for qualitative research is to establish a topic or paradigm of inquiry, and to create a research design.⁸⁷⁷ Once this process is complete, the researcher must consider the method of inquiry he or she intends to undertake. The method or strategy of inquiry refers to “the skills, assumptions, enactments, and material practices that researchers-as-methodological bricoleurs use.”⁸⁷⁸

Three examples of qualitative research design are ethnographic, grounded theory and phenomenology.⁸⁷⁹ To create my study design I drew from aspects of all three of these established approaches.

i. Ethnographic research

Ethnographic research involves the presentation of a given group’s “conceptual world, seen and experienced from the inside”.⁸⁸⁰ The sampling is purposive, based on criteria set by the researcher at the outset.⁸⁸¹ The criteria describes the participant – for example “parents and caregivers of children with FASD” – and is not designed to elicit responses that are representative of the wider population.⁸⁸² Ethnographic research ideally seeks to observe members of the given group in their “natural setting” over a period of time (for example, through long-term case studies or observation).⁸⁸³ Although the current research, for most participants, involved single interviews, the purpose of the interviews was to ascertain the experience of the individual participant. There was no attempt to elicit responses that were representative of the wider population; the focus was on the described sample groups and their unique experiences.

ii. Grounded theory research

Grounded theory research requires an inductive approach where data is analysed throughout the collection process – the analysis is used to inform subsequent data collection.⁸⁸⁴ This strategy of inquiry can be particularly powerful for social justice research due to its flexible

⁸⁷⁴ Campbell, above n 869.

⁸⁷⁵ Donmoyer, above n 867.

⁸⁷⁶ Donmoyer, above n 867.

⁸⁷⁷ Norman K. Denzin and Yvonna S. Lincoln (ed) *The Sage Handbook of Qualitative Research* (5th ed, Sage publications, United States, 2018) at 554.

⁸⁷⁸ Denzin, above n 877 at 554.

⁸⁷⁹ Grosseohme, above n 866 at 112-119.

⁸⁸⁰ Grosseohme, above n 866 at 112.

⁸⁸¹ Grosseohme, above n 866 at 113.

⁸⁸² Grosseohme, above n 866 at 113.

⁸⁸³ Campbell, above n 869.

⁸⁸⁴ Grosseohme, above n 866 at 113.

nature, where “hidden unjust practices and policies” may be observed throughout the research process.⁸⁸⁵

The nature of the research questions is used to dictate the sample description; a method I employed at the outset of my research.⁸⁸⁶ For example, one of the research questions for this study was:

What are the experiences of young offenders with FASD and parents/caregivers of young people with FASD and what are their views on how the youth justice system could better meet their needs?

This research question dictated a sample description for the young people – that they have FASD and have had contact with the justice system – and the parents/caregivers – that they have been involved in the care of a child or young person with FASD.

Grounded theory research focuses on the action of the individual participant and the researcher is required to set their own ideas aside.⁸⁸⁷ The theory of research that is formulated through this design is therefore grounded participants’ responses and reactions.⁸⁸⁸

iii. Phenomenology research

Phenomenology research acknowledges the researcher’s role in the investigation and considers participants and the researcher as partners.⁸⁸⁹ Large samples are not required for phenomenology research – the “goal is to gather descriptions of their lived experience which are rich in detail and imagery”.⁸⁹⁰ To encourage richness of detail in the current study, interview questions were broad and the participants were free to speak at length without interruption. The process of analysis for phenomenology research design is also most similar to the thematic analysis I used for my research as interview transcriptions are read and re-read to get a sense of the whole, before the coding and categorisation of participant statements.⁸⁹¹ For each category, the meaning of the participant’s own words is spelled out, then each transformed statement of meaning is combined into a few thematic statements.⁸⁹²

⁸⁸⁵ Kathy Charmaz, Robert Thornberg and Elaine Keane “Evolving Grounded Theory and Social Justice Inquiry” in Norman K. Denzin and Yvonna S. Lincoln (ed) *The Sage Handbook of Qualitative Research* (5th ed, Sage publications, United States, 2018) 720.

⁸⁸⁶ Grossoehme, above n 866 at 114.

⁸⁸⁷ Grossoehme, above n 866 at 115.

⁸⁸⁸ Campbell, above n 869 at 3.

⁸⁸⁹ Grossoehme, above n 866 at 117.

⁸⁹⁰ Grossoehme, above n 866 at 117.

⁸⁹¹ Grossoehme, above n 866 at 118.

⁸⁹² Grossoehme, above n 866 at 119.

iv. *Triangulation*

Denzin defined triangulation as “the combination of methodologies in the study of the same phenomenon”⁸⁹³ and advocated for a mixed methods approach, where:⁸⁹⁴

The bias inherent in any particular data source, investigators, and particularly method will be cancelled out when used in conjunction with other data sources, investigators, and methods.

Triangulation is described as a “postpositivist methodological strategy” and although it received substantial criticism in the 1980s, it has more recently been accepted as a legitimate strategy to deepen understanding of the research phenomenon.⁸⁹⁵ Seen from this angle triangulation is not merely about validating research findings, but should be considered an extension of the research product, providing a “source of extra knowledge.”⁸⁹⁶

B. *Qualitative interviewing*

Interviewing as a form of data collection is relatively new, dating back only to the start of the 20th century.⁸⁹⁷ Although it is now considered a legitimate and even natural form of data collection, the success of the interview relies on a particular communicative process, which is the result of shared “cultural-historical practices” between interviewer and interviewee.⁸⁹⁸ Without this shared history, the concept of a stranger willingly imparting – often personal and sensitive – details about their life to a researcher may not seem so natural.⁸⁹⁹ It is important to acknowledge the context in which such information can be shared so freely and, as a researcher, to not take for granted the effectiveness of the contemporary interview process.

v. *Semi-structured interviews*

Semi-structured interviews are sometimes equated with qualitative interviewing generally, but they represent a middle ground between relatively structured qualitative interviews and relatively unstructured qualitative interviews.⁹⁰⁰ The benefit of a semi-structured interview format is that it allows the interviewer to follow-up on angles deemed important by the interviewee, while still retaining the control needed to focus the conversation on the research issues.⁹⁰¹ Brinkmann and Kvale succinctly describe the semi-structured interview as:⁹⁰²

⁸⁹³ Norman K. Denzin *The research act: a theoretical introduction to sociological methods* (2nd ed, McGraw Hill, United States, 1978) at 291.

⁸⁹⁴ Denzin, above n 893 at 14.

⁸⁹⁵ Denzin, above n 877 at 562.

⁸⁹⁶ Uwe Flick “Triangulation” in Norman K. Denzin and Yvonna S. Lincoln (eds) *The Sage Handbook of Qualitative Research* (5th ed, Sage publications, United States, 2018) 777 at 786.

⁸⁹⁷ Svend Brinkmann “The Interview” in Norman K. Denzin and Yvonna S. Lincoln (ed) *The Sage Handbook of Qualitative Research* (5th ed, Sage publications, United States, 2018) 997 at 999.

⁸⁹⁸ Brinkmann, above n 897 at 999.

⁸⁹⁹ Brinkmann, above n 897 at 1000.

⁹⁰⁰ Brinkmann, above n 897 at 1002.

⁹⁰¹ Brinkmann, above n 897 at 1002.

⁹⁰² Svend Brinkmann and Steinar Kvale *InterViews* (3rd ed, Sage publications, Thousand Oaks, CA, 2015) at 6.

An interview with the purpose of obtaining descriptions of the life world of the interviewee in order to interpret the meaning of the described phenomena.

This middle-ground of interviewing was employed in the current research, where participants were asked general, guiding questions, but had the freedom to raise issues that were tangential to those questions. This method allowed participants to speak freely of their own life experiences, and provide detail where they felt it was most important.

C. Research involving young people/people with disabilities

Qualitative research (especially when the data collection takes the form of interviews) focuses on eliciting stories in participants' own words.⁹⁰³ It allows for not only the collection of individual experience, but also the meaning that an individual ascribes to their experience.⁹⁰⁴

It is the story-telling nature of qualitative research that makes it such a powerful design for sharing the experience of people with disabilities:

It is often by telling stories that [...] the public at large, have come to understand the needs of persons with disabilities.⁹⁰⁵

Qualitative research acknowledges that the phenomena under study involves complexity and requires a nuanced approach to both the collection of data and its subsequent analysis.⁹⁰⁶ The form and content qualitative research takes is a vehicle for breaking up the voice of a single author (the researcher) and instead seeks to reflect the multiple voices of the participants' themselves.⁹⁰⁷

One of the primary characteristics of contemporary, postmodern qualitative research is the commitment to bring to the surface stories of those whose voices have not been heard, those who have been oppressed or disenfranchised.

Research involving people with disabilities falls into the category described by the quote above. It has been questioned whether the voice of children with disabilities requires representation distinct from children generally.⁹⁰⁸ Agencies responsible for advocating for children in New Zealand (e.g., the Office of the Children's Commissioner) tend to include children with disabilities alongside other children, consistent with the goal of a more inclusive society.⁹⁰⁹ This approach, however, risks missing issues that affect children with disability specifically, with their voices being lost along the way.⁹¹⁰ It is crucial therefore to not only be inclusive of children with disabilities, but to also hear from them separately

⁹⁰³ Grosseohme, above n 866 at 110.

⁹⁰⁴ Grosseohme, above n 866 at 110.

⁹⁰⁵ Marleen C Pugach "The Stories We Choose to Tell: Fulfilling the Promise of Qualitative Research for Special Education" (2001) 67 *Except Child* 439 at 439.

⁹⁰⁶ Pugach, above n 905 at 440.

⁹⁰⁷ Pugach, above n 905 at 443.

⁹⁰⁸ Jennifer Conder, Lydie Schmidt and Brigit Mirfin-Veitch *Listening to the Voices of Children with Disabilities in New Zealand* (Donald Beasley Institute, Literature Review, June 2016) at 7.

⁹⁰⁹ Conder, Schmidt and Mirfin-Veitch, above n 908 at 7.

⁹¹⁰ Conder, Schmidt and Mirfin-Veitch, above n 908 at 7.

“when the policy or practice is directly related to their needs.”⁹¹¹ This is consistent with the “twin-track approach” advocated by the Disability Strategy, and the current research reflects an understanding of this philosophy by engaging directly with young people with FASD.

If interviewing is the predominant method of data collection for research involving children with disabilities, it is important to build rapport with the child at the outset of the interview process.⁹¹² This then allows the researcher to “follow the child’s lead and build on their particular interests.”⁹¹³ Underwood et al. suggested that data collection methods are strengthened when more than one interview is conducted with the child, using the same researcher:⁹¹⁴

This provided time for additional rapport-building and trustworthiness in the qualitative research process.

The current research used semi-structured interviews as its method of data collection, and for the young people, three separate interviews were undertaken, each with the same researcher. Building rapport was evident throughout each interview, but was especially noticeable when the second and third interviews were conducted – the young person appeared more relaxed as she knew me by then and the “warm-up” questions referred to topics discussed at the earlier interview/s.

The research for this thesis involved not only the collection of data regarding lived experience of disability, but also the experiences of children and young people in particular:⁹¹⁵

What these adolescents have to say cuts to the heart of what is needed to improve the attractiveness and effectiveness of treatment for them.

Research with children or young people as participants requires a particularly nuanced approach, with careful consideration given to ethical issues – both in a procedural and in a practical sense.⁹¹⁶ An aspect of procedural ethics that requires attention when involving children or young people is the issue of consent, or willingness to participate. It is important to seek consent from the individual child even when their parents have already consented on their behalf - this emphasises to the child their sense of agency in participating, and ensures their inherent dignity is upheld.⁹¹⁷ The purpose of the research and the child’s role in participating should be explained, and it is helpful to use age- or development-appropriate language to aid their comprehension.⁹¹⁸ In the current research, the importance of this was acknowledged at the outset, with children and young people provided with alternative

⁹¹¹ Conder, Schmidt and Mirfin-Veitch, above n 908 at 7.

⁹¹² Conder, Schmidt and Mirfin-Veitch, above n 908 at 15.

⁹¹³ Conder, Schmidt and Mirfin-Veitch, above n 908 at 15.

⁹¹⁴ Kathryn Underwood and others “Understanding Young Children’s Capabilities: Approaches to Interviews with Young Children Experiencing Disability” (2015) 21(3) *Child Care in Practice* 220 at 225.

⁹¹⁵ Bram Soenen, Franky D’Oosterlinck and Eric Broekaert “The voice of troubled youth: Children’s and adolescents’ ideas on helpful elements of care” (2013) 35 *Child Youth Serv Rev* 1297 at 1297.

⁹¹⁶ Shanon K. Phelan and Elizabeth Anne Kinsella “Picture This ... Safety, Dignity, and Voice – Ethical Research With Children: Practical Considerations for the Reflexive Researcher” (2013) 19(2) *Qual. Inq* 81 at 82.

⁹¹⁷ Phelan and Kinsella, above n 916 at 82.

⁹¹⁸ Phelan and Kinsella, above n 916 at 82.

information sheets – both with simplified language, and the information sheet for the younger children in a larger size, ‘fun’ font type.

Ensuring the child understands they can withdraw their consent at any time is also important. This can be difficult if the child perceives the researcher to be similar to that of a teacher, where they, as the student, are eager to please and do their best.⁹¹⁹ This is particularly pertinent when considering children and young people with FASD, who may be even more likely to defer to authority in situations where there is an imbalance of power (see below). To ameliorate this risk, it is useful to provide the child with multiple opportunities to withdraw, by discussing at the outset what the interview will involve, asking them if it sounds okay, and checking whether they still want to participate or not.⁹²⁰ This method was used in the present research, where at the start of each interview the structure of the interview was explained to the child/young person, they were asked if that sounded okay and if they had any questions, and were reminded that they could choose to stop at any stage.

Another crucial issue when involving children and young people in research, especially when there are cognitive impairments present, is any power imbalance between the child and the interviewer.⁹²¹ The researcher must strike a careful balance between falsely appearing as the child’s “friend” and presenting themselves as an authoritative academic figure.⁹²² There are practical ways the researcher can achieve this balance:⁹²³

The language used, the clothes worn, the body language adopted, how one interacts with the child, and the context of the interview can each influence the balance of power in both negative and positive ways.

For example, dressing casually and using child-friendly language may decrease the risk of a power imbalance during the interview. This was a method employed in the current research, with the first few minutes of each interview spent on “ice-breaker” questions, designed to make the child or young person feel at ease, and to give the interviewer an opportunity to assess the communication abilities of the child and tailor questions accordingly.

D. Limitations of qualitative research

Given the nature of the involvement of the researcher in qualitative research methodologies (especially study designs that employ a more phenomenological approach) it is important to acknowledge the presence of bias.⁹²⁴ However, the inherent influence of the researcher does not devalue a study “but, in fact, enhances it”.⁹²⁵ One way of demonstrating reliability is to document the methodological decisions made along the way – deciding what questions to

⁹¹⁹ Phelan and Kinsella, above n 916 at 85.

⁹²⁰ Phelan and Kinsella, above n 916 at 85.

⁹²¹ Phelan and Kinsella, above n 916 at 85.

⁹²² Phelan and Kinsella, above n 916 at 85.

⁹²³ Phelan and Kinsella, above n 916 at 85.

⁹²⁴ Grosseohme, above n 866 at 111.

⁹²⁵ Grosseohme, above n 866 at 112.

ask and to whom.⁹²⁶ The documented decision-making process should be clear enough that another researcher can understand what decisions were made and why.⁹²⁷

For this doctoral research, monthly reports were written throughout the research process. These reports recorded the progress that had been made, any issues encountered, and plans for the following month (including steps to remedy any issues). As well as these reports, a written application for ethical consent was made to the University of Otago Human Ethics Committee, which included an explanation and justification for each decision. This was approved prior to contact with potential participants. An application was also made to the Judicial Research Committee which involved amendment of an interview schedule. The explanation for the amendment was included in the relevant monthly report. These written records provide evidence of the methodological decisions made and the reasons for each step in the process.

Generalisability is an issue often discussed in the context of quantitative research – the data collected must be a representative enough sample to be generalisable to wider populations.⁹²⁸ For qualitative research studies, lack of generalisability is often listed as a limitation of the study (due to small sample sizes). However, this approach is misguided and represents a misunderstanding of the purpose of qualitative study. Statistical probabilistic generalisability “is not a meaningful goal for qualitative research”.⁹²⁹ The goal of qualitative research is instead to examine people’s lives in “rich detail” to develop in-depth understanding of people’s experiences, and to achieve this, small samples are purposively selected:⁹³⁰

Rich knowledge and small samples purposefully chosen are thus unique *strengths* of qualitative research, not *weaknesses*.

III. Aims of the study

A key aim of this research was to ascertain the current experiences of young people with FASD within the youth justice system in New Zealand. I was primarily interested in the ability of the youth justice system to identify the specific needs of young people with FASD and to adequately provide for them. I also acknowledged that the experience of parents and caregivers living with a child with FASD would provide important context for the discussion with the young people and subsequent interviews with professionals and key stakeholders.

IV. Ethics

This research study was approved by the University of Otago Human Ethics Committee on 23rd November 2016, approval number 16/146.

⁹²⁶ Grosseohme, above n 866 at 112.

⁹²⁷ Grosseohme, above n 866 at 112.

⁹²⁸ Brett Smith “Generalizability in qualitative research: misunderstandings, opportunities and recommendations for the sport and exercise sciences” (2018) 10(1) *Qualitative Research in Sport, Exercise and Health* 137 at 137.

⁹²⁹ Smith, above n 928 at 138.

⁹³⁰ Smith, above n 928 at 138.

Each adult (parent, professional, key stakeholder, or young person) consented to their own participation in the study. If a child wanted to participate, separate consent forms were provided for the child and each of the child's parents.⁹³¹ In the final sample one young person and one child participated. The young person was over the age of 16 and therefore able to provide their own consent to participate. The child consented to their participation and consent was also sought and given by both parents.

In some instances, interviews were conducted with several members of the same family. Additionally, some professionals who came forward to be interviewed had worked directly with the parents and young people discussed in the family member interviews. I took extra care writing up the results of these interviews to ensure identities remained anonymous.⁹³² I have used pseudonyms for the names of parents, caregivers and children, and any mention of specific schools, agencies or other individuals involved in the child's life have been deleted. Quotes have been edited for ease of reading.

Personal information was collected from participants: demographic data was collected directly from each participant and background information about a child or young person was collected from their parent or parents. Each participant was informed, prior to giving consent, of the purpose for collecting this information and who it would be shared with.⁹³³ The information was stored on a password-protected computer that only I had access to. Original interview transcripts were labelled with code numbers that did not identify the individuals concerned. All participants were offered copies of their interview transcripts and were able to make corrections or amendments.

Given that the research focused on the experiences of vulnerable young people, I was aware of the potential for participants to become distressed, anxious, or upset during the interview process. I ensured that I was familiar with issues surrounding FASD as a disorder before conducting the interviews and was prepared to support participants and refer them for professional support if needed. None of the participants in the study required referral. Additionally, I was aware of the possibility of disclosure by a young person of sensitive views or information in respect of their experience with the justice system or their FASD that they had not discussed with their parent/caregiver.⁹³⁴ This situation did not arise, but if it had, I would have encouraged the young person to discuss the issue with their parent/caregiver and would have offered my support in doing so. If a young person had disclosed abuse or neglect, I would have agreed on a course of action in collaboration with my supervisors, with the safety of the young person as the paramount concern.

⁹³¹ Phelan and Kinsella, above n 916 at 82: seeking individual consent from a child even when their parents have consented on their behalf ensures their sense of agency and dignity is upheld.

⁹³² Privacy and anonymity is an essential ethical principal to adhere to throughout the research process: Marilyn Lichtman *Qualitative Research in Education* (SAGE publishing, United States, 2012) at 55.

⁹³³ Participants have a right to know they are being researched and the right to be informed about the nature of the research: Anne Ryen "Ethics and Qualitative Research" in David Silverman (ed) *Qualitative Research* (3rd ed, SAGE Publishing, 2011) at 418.

⁹³⁴ "Disclosures may be made when working with children with disabilities, and researchers need to consider their likely course of action in such an event": Monica Cuskelly "Ethical inclusion of children with disabilities in research" in Ann Farrell (ed) *Ethical Research with Children* (Maidenhead: McGraw Hill Education, England, 2007) 97 at 103.

V. Application to the Judicial Research Committee

I submitted an application to the Judicial Research Committee in September 2017 to obtain their approval to interview Youth Court judges as part of the cohort of professionals in my study from the justice sector. Their approval was received shortly afterwards, on 19th September 2017.

VI. Sample recruitment

A. Family members

I initially sought to recruit up to 10 young people and up to 20 parents/caregivers for my sample of family members. The study design included several criteria the family participants needed to meet in order to be eligible to participate. For the parents:

- they needed to be (or have been) the parent, guardian, or caregiver of a child with FASD.

For the young people:

- they needed to be aged 12-25;
- have FASD; and
- have had some experience of, or interaction with, New Zealand's youth justice system.

I did not require the children or young people to have received a formal diagnosis of FASD. This was to acknowledge the limited diagnostic capacity for FASD in New Zealand and the reality that many families are unable to access a diagnosis for their child. I accepted reports from parents that their child had FASD and in the interview process I asked whether they had experienced any sort of formal diagnosis or assessment for their child.

Recruitment

I began the recruitment process for family members in December 2016. I contacted the administrator for the FASD-CAN caregiver support Facebook page. She advertised my research on the page and included my contact details for parents to get in touch with me directly.

Upon receiving expressions of interest from parents (usually via email, although one was via a phone call), I emailed the parents a formal letter of invitation (see Appendix A) and an information sheet (see Appendix B). I invited them to contact me if they had any questions about the study or wanted to discuss their participation further. Once the parent confirmed they wanted to participate, we jointly agreed to a convenient time for their interview.

I also relied on a word-of-mouth snowball effect to recruit my sample of family members. Initially I had been planning to only recruit participants from the Wellington, Hutt Valley, and Dunedin regions to keep the time and cost of travel to a minimum. However, as recruitment progressed it became clear I would be unable to recruit a large enough sample from these regions alone.

In January 2017 I applied to the Ethics Committee to amend my application to include the Auckland and Nelson regions and in March 2017 I requested approval to recruit throughout the whole of New Zealand. Approval was granted both times, and my scope to recruit was therefore significantly increased.

B. Professionals

I sought professional participants from the health, education and justice sectors. At the outset of my research I sought up to 10 professionals from each sector and was aiming for a spread across the professions (paediatricians, psychologists, psychiatrists, social workers, youth advocate lawyers, Youth Court judges, Police officers, school counsellors, teachers and school principals).

Recruitment

I first contacted the FASD Centre Aotearoa to advertise my research through them. In February 2017 an article I wrote about my research was published in *Court in the Act*, the Principal Youth Court Judge's newsletter. The article included my contact details and a message stating I was currently recruiting participants. In March 2017 I was interviewed about my research for an article in the *Sunday Star Times*, including a similar message at the end. These two articles contributed significantly to the recruitment process.

Professionals got in contact with me via email. After expressing their interest to participate, I emailed each professional a copy of the information sheet (see Appendix C). I invited them to contact me if they had any questions or wished to discuss my research further. After they had confirmed their willingness to participate, we organised a time for an interview.

C. Key stakeholders

I sought up to 12 key stakeholder participants, from relevant child and youth sector agencies (Office of the Children's Commissioner; Ministries of Social Development, Health and Justice; Te Puni Kokiri; the Youth Justice Section of the NZ Law Society; Ara Taiohi; and the Tamaiti Whangai Academy).

I contacted each potential key stakeholder directly and emailed them a copy of the information sheet (see Appendix C). Three of the key stakeholder interviews were conducted in person, with the other two conducted via Skype. The duration of the interviews for the key stakeholders ranged from 20 minutes to 45 minutes.

VII. Administrative procedures

As each participant was recruited I kept a record of their name and contact details in a masterfile. Correspondence was kept, along with copies of the signed consent forms. The audio files from their interviews were labelled with a code and kept separately from the file recording each participant's name and contact details. The information was stored on a password protected computer to which only I had access.

VIII. Sample of family members

The final sample of family members included 12 parents/caregivers and two young people. Three couples were included in the sample and six individual parents. The couples chose to be interviewed together. In one family, both parents and their young person participated (the young person was interviewed separately). In another family, one parent and their young person participated (the parent was interviewed separately, while the young person was 'interviewed' via email, with the parent's involvement).

Only one parent was the birth mother of the child with FASD being discussed. The 11 other parents were either permanent foster parents or adoptive parents of their children.

Nine parents identified as being in the 51-60 age bracket, with one parent aged 61-70 years and one parent aged 41-50. One other parent was unable to be contacted for the purpose of gathering demographic data. The parents'/caregivers' occupations were varied and included artists, teachers, nurses, architectural designers and university academics. The identified ethnicity was predominantly New Zealand European (eight), with one parent identifying as both New Zealand European and of Tainui descent, one parent simply as "kiwi", one parent not identifying ethnicity and one unable to be contacted.

The parents who were interviewed had 10 children with FASD between them. The children ranged in age at the time of the parents' interviews from 11 – 26 years. Of the seven children who were old enough to participate and who had experienced contact with the justice system, two chose to participate in the study: one female, aged 18 years, and one male, aged 14 years.

IX. Sample of professionals

The total sample of professionals comprised 19 professionals: three from the education sector (one teacher, one school principal and one service manager); six from the health sector (five paediatricians and one psychologist); and 10 from the justice sector (four social workers, one Youth Aid Police officer, two Youth Court judges, one director of a youth justice service provider, one youth justice service provider practice manager and one youth forensic alcohol and other drug clinician).

The professionals ranged in age from their 30s to their 60s, with half (nine) identifying in the 41-50 age bracket. Fifteen professionals identified as either New Zealand European or European, two as a combination of both New Zealand European and Māori, one as Niuean, and one caucasian American.

X. Sample of key stakeholders

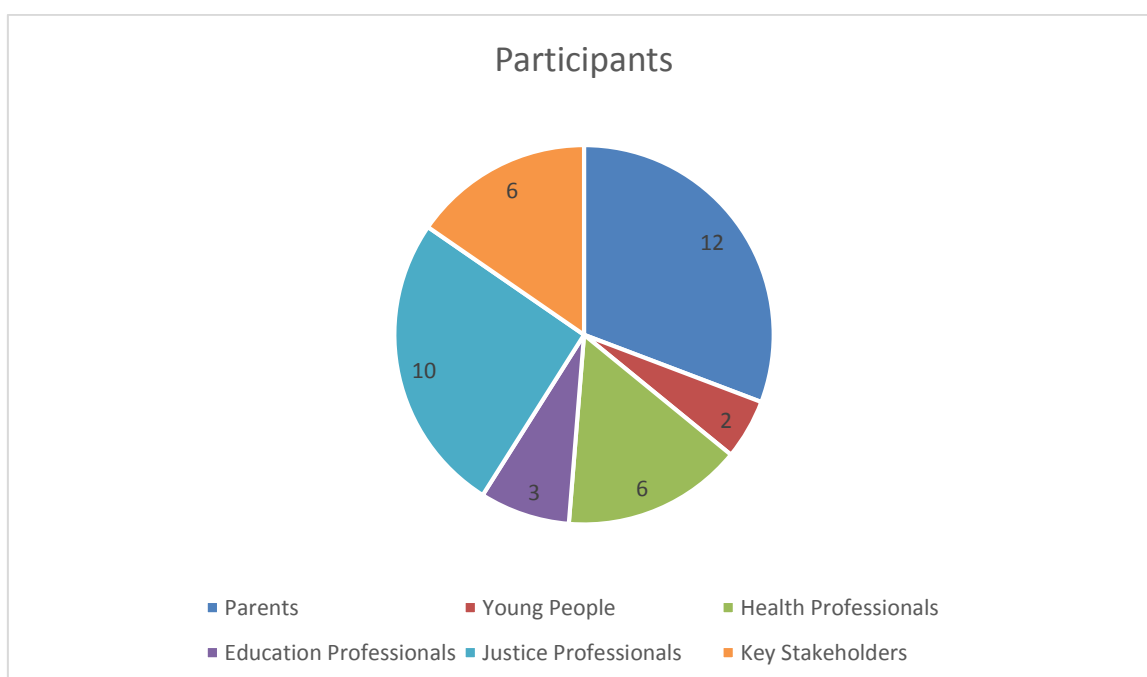
The total sample of key stakeholders comprised six participants (with two from the same agency). The following five sectors were represented by these participants:

- justice;
- youth justice;
- child advocacy;
- alcohol harm prevention; and
- indigenous advocacy.

XI. Total sample

The total sample of participants is depicted in Figure 1.

Figure 1: Study Participants



XII. Interviews

A. Family members

Once I received email confirmation from a parent that they were willing to participate, I emailed them to arrange a date, time and venue for their interview. At the beginning of each interview I talked the parents through the consent process and offered them a consent form to sign (see Appendix D). All parents were happy to sign the consent form. I also asked them if they had any questions before starting. These interviews used a semi-structured format (see Appendix E) to best allow for the parents' stories to be told and heard.

All parent interviews were audio recorded to ensure accuracy and to avoid the distraction of note-taking during the interview. I explained this to each participant prior to the interview starting and made sure they were comfortable with the use of the audio recorder. All parents gave their explicit consent to use of the audio recorder. Each recording was subsequently transferred to my password-protected computer as soon as practicable after the interview and the file labelled with the participant's code.

Parent interviews were conducted between January 2017 and March 2018. Interviews lasted between 33 to 64 minutes depending on the level of detail provided by the parent. I had informed the parents in advance to expect the interview to last around 45 minutes, but never rushed a participant if they wanted to add more detail to their story. There was no time limit given. Nine parents were interviewed in person, with three being interviewed via Skype. For the interviews in-person, five parents were interviewed in their own home, two in a café, one in a University of Otago study room and one at my home in Wellington.

The parent interview schedule (see Appendix E) focused on their experience living with and parenting a child with FASD. I asked about their experience of the diagnostic system in New Zealand and whether their child had had any interaction with the youth justice system. I finally asked parents about what advice they would give to youth justice professionals working with young people with FASD and what changes could be made to the system to improve support for these young people. My background of legal research into youth justice in New Zealand and my ongoing interest in this area allowed me to understand parents' stories when they had direct experience of the system, and I was able to ask appropriate follow-up questions as a result.

The first young person (young person A), aged 18 years, was interviewed on three separate occasions. The first interview was in January 2017 and the second interview was in March 2017. Both these interviews were conducted at the young person's home. The third and final interview was conducted in June 2017 via Skype. Before each of these interviews I explained the process of consent to the young person and emphasised that they could withdraw at any time. All interviews with the young person were audio recorded, with express consent sought and given for this each time.

The second young person (young person B), aged 14 years, was 'interviewed' via email in October 2018. At the time of the interview the young person was in a secure youth justice residence and was contacted via email through his mother. Consent was explained to his mother, who discussed it with him and explained to him the consent process and the consent form. Throughout the process of contacting his mother, I emphasised to her that her son could withdraw participation at any time. Consent was given by the young person (see Appendix F), and by both of his parents on his behalf (see Appendix G). Young person B chose to provide written responses to the questions in the first interview schedule (see Appendix H). While communication via email was not ideal, it was unavoidable in the circumstances, and the young person provided answers in their own words, with any clarification or elaboration provided separately by his mother. I was fortunate to have met and spoken with this young person prior to their detainment in a youth justice facility, so had a prior relationship and some understanding of their communication skills, which helped inform their ability to communicate effectively through email.

The interview schedule for the first interview with young person A focused on their experience living with FASD. I first asked about school and extra-curricular activities or hobbies to establish a comfortable rapport with the young person. The first interview also discussed the young person's experience living with FASD, including any experience of the diagnostic process for FASD. Finally, I asked about the young person's experience of the youth justice system in New Zealand.

At the end of the first interview I invited the young person A to work on a creative project for me between the first and second interviews, sharing their experience of the justice system in New Zealand. Arts-based research is a recognised qualitative research approach, which acknowledges that:⁹³⁵ “many factors are common to both qualitative research and the arts—primarily, valuing of the subjective nature of human experience.” By incorporating art forms in the research process, “it is possible to evoke emotional responses and to construct alternative forms of representation that promote dialogue and shared storytelling.”⁹³⁶ The purpose in offering art form through the creative project was to allow the young person to be fully in control of expressing themselves, in a manner they were comfortable with, and that would allow an “escape from the traps set by language.”⁹³⁷ I explained that the creative project could be anything they liked – a song, a painting, a blog post – and that we would discuss it together the next time we met.

The second interview with young person A started with some warm-up questions. I asked the young person about various things they raised in the first interview (for example the polytechnic course they had been enrolled in or the blog they had been developing). I then asked to see the creative project they had been working on. The young person had chosen to simply write bullet points outlining her experience of the youth justice system in New Zealand, which she read out to me. We discussed the bullet points in a bit more detail and I asked questions where I felt I needed clarification. At this interview I also asked the young person what advice they would give to another young person going through what they experienced, and what advice they might give to youth justice professionals working with young people with FASD.

The third interview focused on young person A's response to a vignette. The use of vignettes can provide a useful ‘icebreaker’, and short stories with “strong moral opinion” can prompt more confident discussions when interviewing children and young people.⁹³⁸ Ongoing discussion is then facilitated by the responses given to the vignette by the young person. I started the interview with some warm-up questions again, before explaining how this final interview was going to work. I then read the vignette out to the young person. I also emailed the young person a copy of the vignette so she could read it herself or refer back to it throughout the interview. The questions I asked the young person about the vignette were intended to establish her thoughts on how the youth justice system operates and whether FASD needed to be taken into consideration throughout the process. The questions about the vignette could have been a bit more free-flowing, more like the interview “prompts” for the semi-structured interviews. This may have facilitated a more relaxed discussion of the

⁹³⁵ Katherine M. Boydell and others “The Production and Dissemination of Knowledge: A Scoping Review of Arts-Based Health Research” (2012) 13(1) *FQS*.

⁹³⁶ Boydell et al, above n 935.

⁹³⁷ Conder, Schmidt and Mirfin-Veitch, above n 908 at 13.

⁹³⁸ Steven Walker “Consulting with Children and Young People” (2001) 9 *Intl J. Child. Rts.* 45 at 50.

issues, allowing the young person to dictate the issues they felt were most important and the length of time they were willing to engage in the activity. At the conclusion of the formal questions about the vignette I invited the young person to make any further comments about FASD and the youth justice system, and I asked whether they had any questions for me or about my research.

In October 2018 all family members were offered a copy of their interview transcript. Nine parents and one young person requested and were provided with a copy.

B. Professionals

Once I had received email confirmation that a professional was willing to take part, I emailed them to arrange a date, time and venue for the interview. Professional interviews were conducted between March and November 2017. Six interviews were conducted in-person (one health professional, three justice professionals and two education professionals) with the other 13 conducted via Skype. At the outset of each interview I explained the consent process and gave the participant a consent form to sign. For the interviews conducted via Skype I emailed copies of the consent forms for the participant to sign and return in advance of the interview. All interviews were audio recorded for the same reason given above. I explained the process and obtained express consent from each participant before starting the audio recording. I also indicated that the audio recording could be paused at any time and three participants took advantage of this (one who had to leave the room for a few minutes, one who received a phone call during the interview and one who wished to discuss an issue off the record).

I used a semi-structured format for all professional interviews, to encourage breadth of discussion. The content of the interviews varied slightly for each professional sector.

The interview schedule for health professionals (see Appendix I) focused on New Zealand's diagnostic process for FASD. I also asked the health professionals whether they had been involved in providing a report on a young person with FASD to the Youth Court. I ended the interview asking the health professionals about their perceptions on the connection between FASD and offending in young people and how they felt the current youth justice system could be improved.

The interview schedule for the education professionals (see Appendix J) focused on what supports existed (if any) for children with FASD at the educator's school. I also asked the education professionals about their perceptions on the connection between FASD and offending behaviours in young people and their views on the current youth justice system.

The interview schedule for the justice professionals (see Appendix K) focused on how the justice system copes with young people with FASD, specifically how FASD is identified in the youth justice system and what impact (if any) the presence of FASD has on the outcome of the case. I also asked justice professionals how they felt the system could be improved for young people with FASD.

I asked all professionals what advice they might give to their colleagues in each respective sector regarding dealing with a young person with FASD.

Interviews with the professionals ranged between 18 and 85 minutes, depending on the professional's experience and level of involvement in FASD in New Zealand. One participant was interviewed twice, with both interviews 98 minutes. This was due to a disruption at my end that required me to conclude the first interview prematurely. I contacted the participant concerned shortly after the first interview to apologise and to offer them a time to speak with me again, which they accepted. Two participants chose to be interviewed together.

In October 2018 all professionals were offered a copy of their interview transcript. Five professionals requested and were provided with copies. One professional made minor amendments which I then incorporated in to the transcript.

C. Key stakeholders

Once I received confirmation that a participant was willing to take part, I emailed each key stakeholder to arrange a date, time and venue for the interview. Three interviews were conducted in person, two occurred via Skype. For each interview I explained the consent process prior to starting and explained and obtained consent for the use of an audio recorder. Key stakeholder interviews were conducted between October and December 2017. The interviews ranged between 20 – 44 minutes depending on the stakeholder's level of involvement in FASD. The two participants representing the same agency were interviewed together.

The interview schedule for the key stakeholders (see Appendix L) focused on the role the agency had in advocating for young people with FASD. I also asked each key stakeholder about their perceptions on the connection between FASD and offending behaviours in young people and whether they felt the current youth justice system could be improved.

In October 2018 each key stakeholder was offered a copy of their interview transcript. Three participants requested and were provided with a copy.

XIII. Limitations of the research

There were two main limitations associated with the research. Firstly, I did not recruit the desired number of participants in the professional sectors. Those I did recruit also did not represent a particularly diverse spread across the professional disciplines. For the health professionals, I had hoped to recruit paediatricians, psychologists, psychiatrists and speech language therapists. The final sample of health professionals included five paediatricians and one psychologist. The implications for not having a representative speech language therapist could be that the findings are missing the voice of those professionals with the greatest understanding of communication difficulties for young people with FASD (generally and in the court setting).

For the justice sector, I had hoped to recruit judges, youth advocate lawyers, Police officers and social workers. The final sample of justice professionals included four social workers, two Youth Court judges, one Youth Aid Police officer and two 'other' justice workers. The most significant professional group missing from this sample is that of youth advocate lawyers. They act as a young person's bridge to the court process; not having any lawyers

in the sample of professionals means this crucial role and the impact it has for young people with FASD is not represented in the final findings.

Secondly, I had enormous difficulty recruiting a sample of young people and, ultimately, only two young people participated in the research. When planning my study I really wanted young people's voices to be highlighted in the results and recommendations sections of this thesis. The importance of this was reiterated to me when I attended the Adults and Adolescents with FASD Conference in Canada in April 2018, the slogan of which was "Nothing About Us Without Us." However, despite my best efforts I was unable to obtain the desired sample of up to 10 young people.

I first tried to recruit young people through the parents who came forward to be interviewed. The children of some of the parents I interviewed were either too young or too old to participate (my criteria for the young people were that they be aged 12-25 years). For the children who were the appropriate age, in one case the parents decided that it would not be appropriate to include their child. The other cases involved young people who were old enough to consent on their own behalf. For these young people, they had often disengaged completely from any apparent form or figure of authority as a result of their experiences and could not see any benefit to themselves in participating in the research.

I then tried to recruit young people directly through the youth justice system (by attending a Youth Court sitting and communicating with the professionals on the day). New Zealand's limited diagnostic capacity for FASD meant that when I tried to recruit young people this way many professionals suspected that their client had FASD, but did not know for sure. They were therefore unable to suggest to these young people that they contact me. Additionally, professionals were hesitant to pass on information about clients, or potential clients, who might be interested to take part and were unable to suggest alternative avenues of contact for me to try.

Finally, I attempted to recruit young people by reaching out to youth support agencies. There are no support networks for young people with FASD in New Zealand. However, there are support networks in several regions for parents and various clinical FASD networks for professionals. The lack of a centralised network for young people, or even adults, with FASD meant this potential recruitment avenue was also a dead-end.

The limitations discussed largely stem from, and are a result of, the lack of services and lack of awareness of FASD in New Zealand. Missing the voices of crucial professionals and not having the significant contribution of young people that I had hoped for limits the scope of my findings and the particular issues discussed. However, I was able to respond to this limitation in the thesis by using the missing voices as further impetus for recommending a better network of support for young people with FASD in New Zealand.

XIV. Data analysis

A. Transcription

Transcription has been described as “both an inevitable and problematic step” in qualitative data analysis.⁹³⁹ It involves a series of tasks done by the transcriber and the reader of the transcripts, who “bring their own habits, competencies and limitations to these tasks.”⁹⁴⁰ To reduce the impact of these limitations in the current research, all audio files were transcribed by me personally. This allowed me to preserve the complete anonymity of each participant and become very familiar with the data, especially given that I had also personally conducted every interview. Three audio files were difficult to hear. I managed to filter the background noise in one of them to the extent that I could adequately transcribe most of the interview. For the others, I listened to the file several times and transcribed what I could, with inaudible sections marked *(inaudible)* in the transcript and the main points summarised. For these transcripts, I shared the summarised points with the participant in question, to ensure their message had been conveyed accurately and to reduce the impact of inevitable selection and systematic bias.⁹⁴¹

B. Interpretation

Interpretation represents the stage of analysis that lies at “the heart of qualitative research.”⁹⁴² It is the stage in which the raw data – people’s experiences, thoughts, and feelings – is made meaningful by careful analysis and interpretation of its significance.⁹⁴³ Willig suggests that what the researcher is looking for will dictate the results of the interpretation, but that it is likely to fall into one of the following categories:⁹⁴⁴

- A better understanding of the author’s intended meaning (i.e. a clearer sense of what he or she was trying to express).
- A better understanding of the author’s unconscious (i.e. unintended) communication (i.e. an understanding of what may have motivated the author to say what he or she said or did even though he or she may not be aware of this motivation him- or herself).
- A better understanding of the social, political, historical, cultural and/or economic context which made it possible (or indeed necessary) for the author to express what he or she expressed.
- A better understanding of the social and/or psychological functions of what is being expressed (i.e. an insight into what is being achieved, in relation to other people or the self, by what is being expressed).

⁹³⁹ Sabine Kowal and Daniel C. O’Connell “Transcription as a Crucial Step of Data Analysis” in Uwe Flick (ed) *The SAGE Handbook of Qualitative Data Analysis* (SAGE Publications, United States, 2014) 64 at 65.

⁹⁴⁰ Kowal and O’Connell, above n 939 at 65.

⁹⁴¹ Kowal and O’Connell, above n 939 at 66.

⁹⁴² Carla Willig “Interpretation and Analysis” in Uwe Flick (ed) *The SAGE Handbook of Qualitative Data Analysis* (SAGE Publications, United States, 2014) 136 at 136.

⁹⁴³ Willig, above n 942 at 136.

⁹⁴⁴ Willig, above n 942 at 137.

- A better understanding of what the account may tell us about the nature and quality of a more general concept such as ‘human existence’, ‘social progress’ or ‘human psychology’.

The researcher’s assumptions about what is important will guide the interpretive process and will achieve different results depending on the ontological and epistemological position that was adopted at the outset.⁹⁴⁵

‘Empathic interpretation’ refers to a method in which the researcher’s goal is to “elaborate and amplify” the meaning that is already presented by the data, rather than uncover new meaning that is ‘hidden’.⁹⁴⁶ This is achieved by the researcher working with the data by “paying special attention to its features and qualities, by making connections between them and by noticing patterns and relationships.”⁹⁴⁷ I employed this method of interpretation in the analysis of the interview data, where themes and sub-themes were developed by reading through interview transcripts multiple times to identify similarities.

The coding categories I developed were based on my research questions and the main questions covered in the interview schedules. I worked through each transcript and coded all the data by copying and pasting relevant sections into separate word files, one for each code. I then read through each code, identifying relevant sub-themes based on issues that were raised by the participants. I created a new file for each code titled “sub-themes”. Each sub-theme was given a different colour and I used that colour to highlight text in the main coding document to identify which sections had been transferred to each sub-theme. I wrote up each sub-theme as soon as all the data relevant to it had been identified.

Soon after the coding was finished, I also wrote “family stories” where the interview data for each set of family members was combined to give a chronological account of the families’ experiences. This process not only presented a further opportunity for sharing the rich and varied experiences of the families, but also allowed me to become increasingly familiar with the interview data generally.

XV. Research questions

The research questions underpinning this study were:

- What are the differences between intellectual disabilities (as defined in the IDCCR Act) and the symptoms of FASD and why are these differences significant in the youth justice context?
- How is FASD acknowledged and taken into account in New Zealand’s youth justice system?
- What are the experiences of young offenders with FASD and parents/caregivers of young people with FASD and what are their views on how the youth justice system could better meet their needs? How do these experiences compare with the experiences of professionals from the health, education and justice sectors working with young people with FASD?

⁹⁴⁵ Willig, above n 942 at 137.

⁹⁴⁶ Willig, above n 942 at 138.

⁹⁴⁷ Willig, above n 942 at 138.

- Drawing on international precedents, how can legislative, diagnostic and community-based initiatives more effectively address the needs and rights of young offenders with FASD?
- How should legislative, diagnostic and community-based recommendations and initiatives be formulated to this effect for New Zealand?

Chapter 7

Family Stories

I. Introduction

This chapter outlines nine family stories, which were formed by combining the interview data from 12 parents and two young people. The process of writing these stories enabled me to become familiar with the families' experiences and better understand the events that had happened to them. It also meant that while some passages from their interview transcripts did not directly fit into a particular code or sub-theme, they were still able to be included in the thesis to provide important personal context to the results.

The first family story includes the perspectives of the mother, father and the young person. Five of the stories involve just one parent (four from the mother's perspective and one from the perspective of the father), one involves a mother and one of her sons, and the remaining two stories involve the perspectives of both parents but not the child or young person. The names of all individuals in these stories have been altered to protect their anonymity.

II. Ted, Amy and Jasmine (18)

Ted and Amy became permanent caregivers for Jasmine when she was a baby. The process was managed through Child, Youth and Family (CYFS)⁹⁴⁸ and the family have had continued contact with the agency throughout Jasmine's life.

Ted and Amy describe Jasmine's personality as infectious, saying she has a great sense of humour and is really good company. She is personable and confident, and used to be an excellent horse rider. Her parents attribute her riding skills to the fact that as a child and adolescent she had "no fear". She is good at cooking and working with computers, and has a creative streak. She taught herself ukelele and enjoys singing. Jasmine managed to get herself a job as an actress and did incredibly well in the role she was given.

Jasmine's parents describe her as intelligent and said "without the FASD she would've been quite gifted". Jasmine remembers when she was diagnosed with FASD the psychologist also talked about how high her IQ was and said that in the past she would have been considered "too bright" to have FASD. Jasmine remembers responding "that's awesome...good to know!"

When Jasmine was in early adolescence, home life became "dynamite". Ted and Amy struggled for support, being helped by various different agencies "in very unhelpful ways". Jasmine was frequently running away from home, getting in to drugs and getting raped. She had been caught shoplifting and was excluded from school. Jasmine said that when she felt stressed she could "lose the plot a bit" and decision-making became difficult. She also said that managing her mental health had been a challenge.

When Jasmine was about 14 she was placed in an alcohol and drug rehabilitation home for young people. It was while she was there that her parents finally got referred to a

⁹⁴⁸ Now Oranga Tamariki.

psychologist who specialised in FASD. The psychologist met with Jasmine while she was in the rehabilitation home and shortly afterwards she received a diagnosis of FASD. Jasmine remembered the psychologist being “absolutely lovely”.

Ted and Amy found the diagnosis incredibly helpful. They said the psychologist met with them as a family and explained the diagnosis, which gave Jasmine some insight into her behaviour so that she could stop “feeling like she was just bad”. Jasmine initially felt “kind of pissed off”, expressing “there *is* something wrong with me then isn’t there?” She eventually saw the positive side to the diagnosis as an explanation for her behaviour. Ted and Amy commented that before the diagnosis they had been experiencing a lot of conflict in the home and had been struggling to cope. After the diagnosis they could “stop searching for an answer”. They completely changed their parenting approach, and the clashing, combative home environment has significantly improved.

Ted and Amy have had reasonably positive interactions with the Police, who seem to know more about FASD “than the general public – than the health system!” They said having a diagnosis has helped pre-empt contact with the Police by informing their local station about Jasmine’s condition, so that they know what they are dealing with if and when a situation arises where she is stopped by the Police. Jasmine described the FGC process as a positive one for her, reflecting especially on the value of goal-setting and “reaching checkpoints”. Jasmine also felt her interactions with police had been relatively positive, saying that there is not much more they could have done to make the situation better.

Jasmine felt that “the whole system” needs to become more aware of FASD and ensure that the relevant professionals have all the facts. Ted and Amy both feel that professionals working in youth justice in New Zealand need to be educated about FASD and that the discrepancy between chronological age and developmental age needs to be taken into account. They are aware that Jasmine has benefited from an incredibly supportive home environment, and they are concerned about the young people with FASD whose families are unable to provide such intensive support.

III. Gloria and Jason (26)

Gloria remembers having problems with Jason even when he was a small baby. He had trouble sleeping and used to cry a lot. As he grew into a toddler he became a real “boysy boy”. Gloria can remember him before he could even walk, crawling across the room of the playgroup to “whack another kid on the head”.

Gloria says when Jason started daycare she soon developed a fear for the word “incident”. Jason was a boisterous, full-on boy who was always getting into trouble. Gloria said that she and Jason’s dad would sit him down and explain to him why his behaviour was inappropriate, but that it “felt like we were just hitting our heads against a brick wall”.

When Jason started school his behaviour got “worse and worse”. He started lighting fires and he got suspended several times from primary school. Gloria said she was practicing “positive parenting” with him, and that they used reward charts and other techniques suggested to them by parenting courses. But nothing worked. She remembers thinking “God, what is wrong with our kid?” She describes Jason as a generous boy, but said he had difficulty choosing appropriate friends.

Gloria and Jason lived in a small community and Gloria felt isolated trying to deal with her son's difficult behaviour without support. Gloria does acknowledge that the small primary school Jason attended "tried their hardest" but did not fully understand his needs.

Jason spent his 13th birthday in the Police cells and shortly afterwards had his first stay in a youth justice residence. Jason started displaying inappropriate sexual behaviours and was put on the STOP⁹⁴⁹ programme. The programme usually lasts for one year, but Jason took four years to complete it successfully. During this time Gloria says CYFS required her to give up custody of Jason so that they could fund the programme.

Gloria says she was having to educate the agencies involved with Jason about his needs and how best to support him. She described herself as a "mother on a mission".

When Jason was 17 he was back in a youth justice residence and Gloria said there were some "pretty dodgy things" going on in the residence. She says when she visited him there he told her that a staff member was supplying the young people with marijuana. She said it was difficult to know what to do, because she did not know what the repercussions would be and she felt like she could not trust anyone.

Gloria felt desperate to try something new for Jason. She took him in to the countryside, to a privately funded programme she had heard of. The programme was accessible only by boat and she said when Jason first got on the boat he was "just an angry kid". As the boat accelerated, Jason got splashed in the face and Gloria said he "was like a 3-year old again". The transformation made her realise how important environment is.

Gloria has had mixed experiences of the youth justice system. She said one judge was wonderful and even called her at home one day to check in with how Jason was doing. But on another occasion Jason had a Youth Court judge with "no compassion at all". Gloria feels it is crucial for youth justice professionals to be educated about FASD and to develop some empathy for these young people.

Gloria started to suspect Jason may have FASD relatively recently when she began working in the disability sector. The more she learned about FASD, the more she thought "this is him". She was only 21 when she became pregnant with Jason and for the first few months she did not know she was pregnant. She remembers one incident of drinking during those months – a friend's 21st birthday party, where Gloria got "really really drunk, so many spirits". She said she wishes someone had asked her about FASD earlier.

IV. Annabelle, Ben and Natasha (13)

Annabelle and Ben describe their daughter as bright, bubbly and creative. She loves drawing and music and is generally very creative. She is good at playing to her strengths, but if there is a task that requires her to be organised, structured and deliberate, "the wheels do tend to come off". Annabelle says Natasha is also very social and loves to be around people. Ben follows up that she is a very open and accepting child and that she does not see ability or disability, she only "sees the person".

⁹⁴⁹ STOP is an organisation that provides community-based assessment and intervention for children and adolescents with concerning sexual behaviour.

Ben and Annabelle have not managed to secure a formal diagnosis of FASD for Natasha. They said based on the conferences they have attended and the research they have done themselves, they are confident that she would meet the criteria for a diagnosis. Natasha has received an “at-risk” designation for FASD by a local paediatrician, but there are no local diagnostic services available.

Annabelle and Ben have tried to discuss FASD with Natasha, but Natasha is resistant to the label. She “idolises” her birth mother and does not want to accept that her difficulties may be due to her birth mother’s actions. Annabelle and Ben have so far managed to avoid formal contact with the justice system and they say they have achieved this by creating very tight boundaries around Natasha. They try to ensure she has no opportunity for acting on her impulse.

Natasha finds it difficult to interpret non-verbal communication like body-language, tone and inflection. She also appears to be unaware of her own body-language and how she might be interpreted by others. Natasha does not learn from experience and does not seem to understand concepts of property and ownership. She tends to confabulate a lot and will make up stories that are “really plausible”.

Annabelle and Ben said their parenting of Natasha had been based on their older children and they were trying to use consequences and reward as strategies to curb behaviour. But they found that nothing worked and every day was “Ground-hog day”. They said Natasha was an emergency foster care placement that became permanent. They were optimistic that they would be able to “break the cycle”. They now realise it is more complex than that and look back and think “how naïve we were”.

Since starting intermediate school Natasha has a bit more freedom and Annabelle and Ben have found it more difficult to contain her behaviour. There have been a couple of incidences of theft at school, where the school has initiated contact with the community constable. Annabelle and Ben said that the constable’s discussion with her was “like water off a duck’s back”.

Annabelle, Ben and Natasha were eventually connected with a Youth Aid Police officer, and Annabelle said they finally felt they were being supported as a family. The Youth Aid officer took the initiative to learn about FASD and try new techniques that may help with some of Natasha’s challenging behaviour. Despite this progress, Ben and Annabelle find it incredibly challenging to know what the best approach is regarding their parenting of Natasha.

Ben and Annabelle feel that professionals in the justice sector need to understand that FASD presents differently for each child. They need to “seek to understand that individual, their disability and what it means for them” and then respond on that basis.

V. Amanda, Richard (15) and Jasper (13)

Amanda and her husband are the adoptive parents of two boys with FASD, Richard and Jasper. The boys were adopted as pre-schoolers and Amanda describes them as active teenagers now.

Richard enjoys gymnastics and tennis and has recently become quite keen on speech and drama at school, particularly the acting component. He does well at school and enjoys focusing on academic pursuits. Amanda describes him as brave and tenacious and says he likes to do things differently. Jasper had a three-year interest in diving, which included participating in various competitions. He also plays water polo and tennis and has started enjoying his homework. Jasper is passionate about technology, volunteering at a phone shop after school and helping Amanda with her smart phone whenever she finds anything difficult – “every breath he takes is a technology breath”. Amanda describes Jasper as loyal, social and articulate.

Amanda says when they adopted the boys, they were more aware of potential issues than perhaps other parents would have been, given their professional backgrounds. But at that time FASD was only ever talked about in relation to the physical features that present in the face, and as such Amanda and her husband were not looking for “what we now know is a spectrum”.

As the boys grew up it was clear they were experiencing difficulties. Jasper was prone to “very distressed tantrums” which escalated when he started school. He described “lashing out” and explained that he does things that he does not always mean, and that he “doesn’t remember much about the situation afterwards”. The family sought support, and a paediatrician told them it was “probable fetal alcohol spectrum disorder”. Until then, health professionals had defaulted to telling them it was ADHD and that they were “doing a good job” as parents. Jasper still finds schoolwork hard and said that “teachers don’t understand about my learning and that I need to learn differently and in special ways”.

As the two boys became more aggressive, both to each other and to the rest of the family, Amanda demanded more help. A new paediatrician in the area happened to specialise in FASD and said that both boys were likely to meet the criteria for FASD. However, there were no professionals in the region able to provide the psychological assessment component to complete the diagnosis and so it was several years before the family received an answer.

During that time Amanda and her husband attended several parenting courses but the aggression in the boys continued to escalate. Amanda says that both boys struggle with impulsiveness and cannot link cause and effect. Richard finds receptive language difficult and often struggles to comprehend concepts like “before and after”. He confabulates a lot and always tries to say the right thing, “even if it gets him into further trouble”. Jasper’s difficulties seem to stem from sensory issues, with the tantrums from childhood becoming damage to property in adolescence.

Amanda contacted the local Police for help. Jasper had been kicking holes in the walls at home and Amanda said it was “getting too crazy”. They met with a local Police officer who talked with them for half an hour. He talked to Jasper about his FASD and the fact that he struggles to control his temper. He gave Jasper some suggestions for alternative expressions of anger. Amanda said the conversation was “quite helpful”.

Jasper has since been in contact with the justice system after some low-level offending. He said the justice system had not treated him well. He was remanded to a youth justice residence for seven weeks waiting for a psychological report to be completed, and then spent a further six weeks in supported bail accommodation. He remembers “not having a clue”

what was going on, and said the Police, the youth advocate lawyer and the youth justice residence staff did not understand about FASD. He said the Youth Court judge was “okay” and seemed to know a bit about FASD. Jasper said that the youth justice residences “don’t know much about disabilities” and were unable to support him with any effective “calming down strategies”.

Jasper felt it was crucial for young people to have the opportunity to have a youth justice FGC before going to a residence with no explanation. He also emphasised the importance of offering more support to young people with FASD, and ensuring professionals are trained in “how our brains work differently”. Amanda feels that education of professionals is crucial and that it needs to begin at tertiary level. She suggested that Police, judges and lawyers in training needed to be taught about FASD and how to respond appropriately. She also pointed to the current lack of services for FASD in New Zealand and suggested there needs to be more support, interventions and opportunities. Amanda stressed to her boys that they are in it for the long haul, but told me that without support, “I’m not going to survive the long haul”.

VI. Bruce and Jonti (17)

Bruce describes his son Jonti as a “lovely guy” and says he is the kindest person Bruce has ever met. He says Jonti has a “kinder heart” than his biological son and that he is incredibly giving and generous. Jonti is a hard worker. On his first shift at a new job he worked for 13 hours, and one of his colleagues said in 30 years in the industry he had never seen anyone work so hard. When he was younger Jonti said that he wanted to be a professional motor cross rider and a DJ.

Jonti’s birth mother was only 15 when she had him and Bruce and his partner at the time adopted him when he was a baby. When Jonti was nine months old and their biological son was two, Bruce’s partner left him and he raised the boys alone.

Jonti started playing up at school. Bruce says it was difficult because when the trouble kids would play up Jonti would join in and when the teacher turned around the other kids would all stop what they were doing. Jonti did not understand that was what you had to do and so he was always the one to get caught out. Jonti would “get angry and go off the rails” because he did not understand why the other kids were not getting into trouble.

Bruce says Jonti struggles to control his impulses and will tend to lash out and damage property without thinking about what he is doing. After the fact he expresses remorse, but Bruce says that in the moment there is “no time in his processing” to consider the consequences of his actions.

Over the last two years Jonti has “basically been locked up in every institution in the country”. It started when he kept running away and eventually it was decided that a secure residence was the only option. Jonti did not feel safe in residence and would intentionally lash out at the guards so that they would put him in isolation, where he felt safer. Bruce says he was getting a name as “a hard, hard boy”.

When Jonti was 14 he received a formal diagnosis of FASD but there were no services or supports available for him. Eventually a social worker became involved with Bruce and Jonti

and Bruce says she was amazing. She took the initiative to educate herself about FASD and has encouraged her colleagues to do the same. Bruce says while the rest of the community saw Jonti as “trouble” and “naughty” the social worker tried to focus on how to help him. She spent time with the local Police officers, educating them about FASD and giving them strategies to cope with Jonti when his behaviour escalated.

Bruce wants the government to acknowledge that FASD is an issue in New Zealand. He says that schools do not know about it and so when confronted with challenging behaviour they turn to CYFS. Bruce says CYFS do not understand FASD at all and the only reason he had any success at all was that he “never gave up”.

VII. *Kate and Henry (13)*

Kate describes Henry as an active boy whose passion is sport. He plays basketball and cricket and likes to take his scooter down to the skate park. Henry also enjoys anything to do with computers. Kate says the more they keep him moving the better things are, but if he’s kept idle “that’s when he can get a bit disruptive”.

Kate and her family became caregivers for Henry when he was six. Kate says he was “wild”. They could not take him into a supermarket without him pulling everything off the shelves. Over the next three years they managed to stabilise a lot of the disruptive behaviour and Henry accelerated hugely – “he was a completely different child”. Despite this progress there were difficulties that did not appear to be improving at all.

Henry was in a primary school that just saw him as a naughty child. The school was putting a lot of pressure on Kate and her partner as parents that they were not dealing with Henry’s behaviour adequately. Kate was trying to access support from various agencies and health professionals but was being “passed from pillar to post”.

Kate knew there had been maternal drinking and was trying to explore the possibility of FASD. Henry already had diagnoses of ADHD, Oppositional Defiance Disorder and Reactive Attachment Disorder but Kate was not happy that “those three meant nothing”. There were no diagnostic services for FASD available in her area. Eventually a local paediatrician and psychologist got together and managed to provide a diagnosis for Henry, with the oversight of an external psychologist who specialised in FASD. It was a lengthy process and Kate still would not say that diagnostic services were “available” in her area.

Kate said that prior to the diagnosis she had a paediatrician tell her there was no point getting it done. But she says it has made a huge difference to their parenting approach. Instead of thinking Henry is being deliberately unwilling, she instead tries to shift her thinking to “what is he stuck on? What help does he need to be able to do this?”

Henry is unable to link cause and effect or understand consequences. He also struggles with abstract concepts and has issues with sensory processing. He has limited social awareness and tends to “say it as he sees it”.

Henry now attends a high school that is incredibly understanding and supportive of his needs. The teachers have maintained regular contact with his parents and have set up systems of support around Henry to help him achieve as best he can. At the moment Henry enjoys going to school, which is something Kate says is a “huge, big thing for us to hear”.

Henry has not had any contact with the justice system because of the stringent circle of support Kate and her partner have created around him. However, she can “absolutely see how it would happen”. Henry has very simplistic thinking and a total lack of awareness of how other people might perceive a situation. He is tall and lanky, and likes to wear hoodies, baseball caps and black skinny jeans.

Kate feels that frontline staff need to have better awareness of FASD and what to look out for. She also said that the justice system needs to acknowledge the discrepancy between chronological and developmental age and that there needs to be better support systems in place for the whole family.

VIII. Margaret, John and Cameron (11)

Margaret and John describe Cameron as social and likeable, saying people will often “go the extra mile” for him. He is open and giving and will share his food with anyone. Cameron is good at problem-solving and when he is interested in something and left to his own devices, he can focus and complete a task. He enjoys lego and the trampoline and used to do motorcross riding. He stopped competing at motorcross when the gap between him and his peers got wider and wider. John said that mentally Cameron could not make the transition to get better, while the other kids continued progressing.

Margaret and John adopted Cameron when he was four weeks old and at that stage there was nothing to indicate there were any problems. They had specifically said they were unable to take a child with additional needs because they already had an older child at home. They started noticing something was wrong when Cameron was a toddler. As soon as he started kindergarten he was identified as having additional learning needs and was streamlined into the alternative education system.

Cameron was diagnosed with ADHD but was not responding to any of the usual management techniques. When he was about eight, the psychologist working with him went to a conference and presented on Cameron, hoping someone might be able to identify what he was missing. A woman approached him after the conference and suggested FASD. Cameron was later diagnosed with FASD, with seven out of the nine cognitive domains significantly affected and meeting the criteria for intellectual disability.

Margaret and John said the diagnosis was incredibly helpful and made sense of why the management techniques had not been working. They changed their parenting approach and felt more confident about how to manage Cameron’s behaviour.

Cameron is home-schooled by Margaret and they are part of a supportive extended home-school environment in the community. Margaret and John think that if he had stayed in mainstream school they would “have more issues with him”. They feel that home-schooling provides an environment in which Cameron has an opportunity to develop good self-esteem.

Cameron has had interactions with the Police on three separate occasions. All the incidents involved him running away and all of them occurred before he was diagnosed with FASD. Margaret and John said their interactions with the Police have been positive, but that probably has something to do with Cameron’s age – he was still a small child when each incident took place.

Margaret and John acknowledge that Cameron is vulnerable to being caught up in the justice system in the future. He has always struggled to make and maintain friendships and they say that if he felt there was something he needed to do to be accepted in a social group he would do it without hesitation. If he is put under pressure he will say whatever he thinks you want to hear and they have had problems with him confabulating in the past.

Margaret would like to see young people with FASD treated in a specialist court system and for any sanctions imposed to be community-based and rehabilitative. Both Margaret and John emphasised that FASD is predominantly a health issue and that the only reason justice becomes involved is because of the way the health issue manifests in antisocial behaviour. They feel there needs to be increased education and awareness about FASD for all professionals working in the justice sector.

Margaret also commented about the lack of support for families. She said respite services need to improve and the criteria for accessing support needs to change. It is “too much” for a family to cope with alone.

IX. Marnie and Tegan (11)

Marnie describes Tegan as loving, warm, sunny and happy. She says Tegan is very intelligent and is outgoing and independent. She is not afraid of anything and does not harbour resentments or hurts. She is a “vivacious, confident child”. Marnie says Tegan will give anything a go, but never puts in the effort to refine a skill or talent.

Marnie has been the foster parent for Tegan since she was three weeks old. She says that when she became a caregiver for CYFS she fantasised about taking children in and giving them an idyllic year or two on her and her husband’s rural farm property. The reality ended up being quite different.

Tegan was diagnosed with “probable fetal alcohol spectrum disorder” when she was 18 months old. Marnie’s husband died when Tegan was two years old. Since then she has been regularly assessed by health professionals but has not been through any formal assessment for FASD. Marnie recently attended a conference on FASD and said it was “precisely” on her experience and that she “could have written it word for word”.

Marnie says Tegan has a “constant need for attention”, lacks boundaries and social skills, is incredibly impulsive and lacks understanding of cause and effect. Marnie said she tried positive-parenting but it did not work. She said she started doubting herself and that people kept suggesting other approaches she could try. Marnie was relieved when she found out conventional parenting approaches did not work for a child with FASD.

Tegan has had problems with stealing, both at home and at school. She also confabulates, making up big stories “when the truth will do just as well”. Marnie has “no doubts” that Tegan will end up in the justice system. She says the behaviours will isolate her socially and she will turn to drugs and alcohol for a quick fix. Marnie says Tegan is already very vulnerable to the wrong influences and that it is a “no-brainer” that she will end up getting in to trouble.

Marnie would like all justice professionals to understand that young people with FASD are not “trying to be bad”. She says an alternative system for these young people would be a

different society, one that “accepted these children wholeheartedly”. Marnie feels that schools need to be better equipped to deal with FASD and there needs to be more funding in place to support teacher aides.

Marnie also emphasised the lack of support for families. She says being the permanent caregiver of a child with FASD has taken its toll on her. She is unable to sustain relationships and that the intensity of the responsibility is “relentless”. She feels there needs to be better access to respite for families caring for children with FASD and if more support was available “we’d all cope better”.

X. Lynne and Benjamin (20)

Benjamin is “a loving boy”, outgoing, articulate and inquisitive. Lynne describes him as intelligent, saying his reading level was three years above his age when he was at primary school. But from the age of 11, “everything started to go downhill”.

Benjamin got into trouble with drugs and alcohol and that was “the beginning of all his problems”. He has an extensive Police file and has been through the youth justice system multiple times. He is impulsive and lacks understanding of consequences. He is vulnerable to influence and has several times pleaded guilty to offences committed by other people.

When Benjamin was 14, Lynne paid for him to have an assessment for FASD. There were no diagnostic services available in their region, so they had to pay for an external assessment. He was diagnosed with “probable fetal alcohol spectrum disorder”. He was unable to be given a full diagnosis because they could not confirm whether there had been maternal drinking.

For one of Benjamin’s appearances in court, the court directed for a psychological assessment to be made. Lynne provided the court with the assessment they had already paid for that indicated he had probable FASD. The court did not accept this report, stating that because it had been paid for privately it could not be relied upon. Instead, they used a court-appointed psychologist who had no understanding of, or training in, FASD.

Lynne said that initially the Police were pretty good, but as Benjamin progressed through the system with repeated infringements, they “ran out of tolerance”. They said to Lynne they were just waiting for him to turn 17 so they could process him through the adult justice system.

Benjamin has particular difficulties complying with bail conditions. Lynne said that at the time the conditions were explained to him he always intended to comply and believed that he could, but “he just couldn’t see it through”.

Now that Benjamin is an adult he no longer allows Lynne to attend court with him. Lynne finds this incredibly frustrating and says it is impossible to talk logically with him about his vulnerability. Lynne says he does not appear to understand the gravity of his situation. She says he wants to join the army but does not understand how his criminal conviction history might impact his chances of being accepted.

Lynne says that a lot of Benjamin’s issues stem from his alcohol and drug use. She has tried to access support for his addiction but says there is a lack of continuity from service

providers. She also said that at one stage they were told Benjamin would need a conviction in order to access residential treatment for drug abuse.

Lynne would like justice professionals to understand that young people with FASD are not necessarily able to change their behaviour. She wants them to understand that FASD is a disability and that these young people were born with it. She said the system needs to stop blaming young people and their families and instead needs to focus on providing appropriate interventions. The interventions need to be aware of the limitations of young people with FASD and need to provide allowances for their impulsivity. Lynne also emphasised that the Police need to have “far greater awareness”.

XI. Conclusion

These stories depict the diverse range of challenges facing families living with FASD. Several common themes can, however, be seen emerging: seven families emphasised difficulties with school, either as a catalyst for escalating behaviour (Gloria and Jason; Amanda, Richard, and David; Bruce and Jonti), problems with theft at school (Ben, Annabelle and Natasha; Marnie and Tegan), or highlighting the lack of support for FASD in the education context (Kate and Henry; Margaret, John, and Cameron). Seven families also raised the challenges they faced parenting a child with FASD, specifically where conventional parenting approaches (such as ‘positive-parenting’, or parenting based on rewards and consequences) proved futile. Three of these families (Margaret and John; Kate; and Ted and Amy) said that they changed their parenting approach after their child was diagnosed with FASD. Some differences in experience are also reflected in these stories. While Ted and Amy spoke highly of their experience of the Police, Lynne felt they ran out of tolerance for Benjamin and emphasised the need for greater awareness across the frontline. All families reported the need for further training, education and awareness about FASD for all professionals coming into contact with these young people.

While this research was predominantly focused on the implications of these family experiences for the youth justice system, in sharing their stories the parents of these children raised important issues outside of the legal sphere. Writing the family experiences in narrative form allows these unique issues to come to the fore and provides context for how the parents and caregivers reported their subsequent experience of, or opinion about, the youth justice system. The themes emerging from these stories are expanded and elaborated on in the following chapters.

Chapter 8

FASD as a lived experience

I. Introduction

This chapter outlines the experiences of nine New Zealand families living with FASD. It considers the behaviours of children and young people with FASD as reported by their parents, including the implications of these for offending and youth justice engagement. The caregivers emphasised the many positive attributes of their children with FASD to ensure these strengths were at the fore. Family members also shared some of the challenges they faced in parenting a child with FASD and the difficulties they experienced accessing diagnostic services and support in New Zealand. The voices of two young people are also shared in this chapter. The insights and perspectives offered by these two reflect their bravery in opening up about their experience living with FASD and interacting with New Zealand's youth justice system. Their willingness to share their stories and contribute to this research illustrates their shared desire to ensure there is better support in New Zealand for young people with FASD in the future.

II. Family experiences

Parents and caregivers of children with FASD talked about their child's personality, including their positive attributes, hobbies and interests. Parents of older children also discussed their child's experience of employment, including the work ethic of young people with FASD. They shared their experiences of the difficult behaviour that often presents in children with FASD and the parenting challenges associated with it. They also identified the current lack of support services for FASD in New Zealand.

A. Personality/attributes

All the parents shared various aspects of their child's personality. Most described their child as confident or sociable and just over half identified their child as being intelligent, or academically confident. Some of these parents simultaneously acknowledged how that initially seemed incongruous with a FASD diagnosis since the "invisible" nature of FASD as a disability, can enable children to appear to be functioning like their neurotypical peers.

Several caregivers identified that their child could also be motivated and focused, if the task was something they were engaged in and felt confident with.

The parents also spoke of their children as being warm, loving, kind, articulate and generous:

He's a lovely guy, he's the kindest person I've ever met ... he's got a kinder heart than my [biological] son, he's really nice like that. ... If you'd have met him, you'd fall in love with the guy, he's got a beautiful smile. [Bruce, Father]

B. Hobbies/interests

The parents raised the various hobbies their children enjoyed. Creativity was emphasised as a strength, with parents talking about children engaging in hobbies relating to art or music. Several mentioned sport as a positive expression of energy for their child and a way to keep them engaged and physically active. Some identified their child's passion for, or interest in, technology or computers. Jasper also emphasised his interest in technology, reporting how much he enjoyed volunteering at a phone shop after school. Three of the parents mentioned Lego, explaining their children's aptitude for more mechanical-type problem solving.

While their children had the potential to pursue various hobbies, some parents acknowledged they encountered barriers to success including struggling to keep up with their peers, lack of motivation and an inability to understand the need for perseverance:

She's good at a lot of things but she's not, because she hates putting in any effort [...] She's capable, but she won't try, she won't put in the effort. [Marnie, Mother]

Jasmine personally related to this, saying that she found it "quite hard to be motivated".

C. Employment

Four of the parents had children who were old enough to have experienced some form of employment. Work ethic was emphasised, with Bruce describing his son Jonti (aged 17 years) as being "renowned as a hard worker". Jonti's determination had been recognised by an older co-worker who commented to the boss that "in 30 years he's never been that impressed with anyone".

The structuring of each employment relationship was described as an important factor in a young person's success. For Jasmine (aged 18 years), the job that worked best for her was well-structured and involved someone picking her up at the beginning of the day and dropping her home after her shift. Jasmine's parents described the role as being "the best structured job for somebody with FASD".

D. Parenting a child with FASD

Feeling isolated, being judged by other parents, and experiencing exhaustion and feelings of hopelessness were challenges faced by many of the parents. Lynne recalled being treated "pretty terribly for how bad a parent you are". Gloria described internalising this attitude, saying that after a while she started to think "I'm just obviously hopeless, I must be". Utilising traditional parenting strategies focused on reward and consequences also confronted these parents, who experienced repeated failures despite persevering with professional advice. Ben acknowledged the difficulty in trying to apply orthodox parenting approaches to a child with FASD by explaining that expecting Natasha (aged 13 years) to learn and change, meant they were "almost asking the impossible of her".

Kate had come to understand that in parenting Henry (aged 13 years) she needed to employ a "paradigm shift in thinking". Instead of interpreting difficult behaviour as deliberate defiance, Kate understood that "this isn't his unwillingness, this is what FASD is. What help does he need to be able to do this?".

E. Support for Families

Parents talked about the importance of support and explained how it is not enough to expect extended family to bear the responsibility of providing it. Families parenting a child with FASD need “someone external for the *whole* family”. They stated that the support available for children with an intellectual disability is “absolute rubbish” and, because the threshold is an IQ of 70, many children with FASD are ineligible anyway. Jasper also felt there needed to be more help offered to those with FASD, including targeted support services like mentoring.

A lack of information or support for families committed to permanent foster care or adoptive arrangements for children in state care was raised as an issue. Four parents said they had limited awareness of FASD at the time they committed to the role of permanent caregiver for their child. Annabelle and Ben thought “nurture would win out” when they took on permanent care of Natasha, but now saw “how naïve we were”.

III. Assessment and services

Family members discussed the reluctance of health professionals to diagnose FASD, the difficulties they experienced accessing diagnostic services for FASD in New Zealand and the impact a correct diagnosis can have on a family.

A. Reluctance to Diagnose

Health professionals were described by parents as being reluctant to diagnose FASD, with parents explaining this was primarily due to the professionals’ concern that a diagnosis would not make any difference. More specifically, some said the professionals justified their reluctance because “there’s no point in giving a diagnosis ‘cos there’s no services [for FASD]”. Trying to get professionals to lose the stigma associated with FASD and recognise the needs of children in an alternative education school is “an uphill battle”. Professionals are hesitating to investigate the possibility of FASD because “that’s a hard question to ask”. The experiences of these parents reflect that recorded in the literature, that despite a growing body of evidence relating to the positive effects of early diagnosis, health professionals remain hesitant.

Parents felt frustrated and powerless as a result of the health professionals’ hesitancy. Amy was told by a health professional that there was “no point” diagnosing Jasmine and she said she “felt like slapping her”.

B. Pre-diagnosis experience

Eight of the 12 parents had experienced a formal diagnosis of FASD for their child. Three of the other four had investigated the possibility and received some form of ‘at-risk’ designation for their child. The remaining parent has been unable to access a diagnosis for her son. All of them discussed the challenges they encountered before FASD became the likeliest explanation for their child’s difficulties.

i. Prior diagnoses

Children had often received multiple diagnoses before FASD was raised as a possibility. Gloria remembers Jason being diagnosed with Conduct Disorder, Oppositional Defiant Disorder and ADHD and “we still didn’t get to the point”. Health professionals appear “happy to label” these disorders but they “need to add the FASD”. Families ended up with “all these labels bobbling around” that described their children’s behaviour but really meant nothing, especially when the children did not respond to the management techniques prescribed for the diagnosed disorders.

ii. Multiple agency involvement

Prior to an assessment for FASD, many of the families had experienced being passed from “pillar to post” multiple times. They expressed frustration at the seeming inability of the health system to provide consistent and sustainable support for them and their child. Kate remembers the frustration she felt when none of the agencies she approached for help took responsibility: “it’s not [mental health service’s] problem, it’s paediatrics; it’s not paediatrics’ problem, it’s behavioural.”

A lack of continuity of care was described as a resulting issue. Lynne remembers five or six separate agencies being involved with Benjamin, but that “on the whole...there’s a lack of joining up, there’s a lack of continuity”.

iii. Implications for parenting/feeling judged

Almost all the parents (11 of 12) discussed the parenting challenges they faced in trying to manage their child’s behaviour in the face of an unidentified disability. Many said they felt “judged as shit parents” who were seemingly unable to cope with what appeared to be simple bad behaviour on the part of their child. This made them feel “hopeless” and as though they were “doing it all wrong”.

iv. Learning about FASD

When they first started learning about FASD, many of the parents articulated how it described their child “to a T”. For Kate, the more reading she did on FASD the more she felt it described Henry: “I just said, ‘that’s my child, that’s him!’”. Marnie attended a conference on FASD and just sat there thinking “I could have written this word for word. It was exactly, precisely, on my experience”.

v. Not asking the question

Gloria felt frustrated that no-one ever asked her if she drank during her pregnancy. She said there is “so much stigma” associated with FASD but that she wishes “someone just said ‘did you have a drink?’” The earlier the question is asked, the sooner appropriate interventions and support can be put in place for both the child and the mother.

C. Diagnosis in New Zealand

i. Effect of diagnosis

A diagnosis of FASD had both positive and negative effects for the families. Some parents felt they “could stop trying to search for an answer” and that the diagnosis provided an explanation for their child’s behaviour and the difficulties they had been experiencing as a family. Kate acknowledged that although Henry’s diagnosis had not “opened doors to support or services”, it had made a big impact on the adults around him (for example, school teachers and other parents). She said the diagnosis had “shifted thinking” about Henry’s behaviour and not only identified his weaknesses, but also highlighted his strengths for the adults working with him.

Lynne felt it was a “good thing just sort of knowing”, especially to have “some confirmation it’s not just your parenting”. However, she also said that “the negative is it’s a lifelong disability”.

ii. Child/young person’s response to diagnosis

The parents reported their children having a variety of responses to the diagnosis. Some children were too young, or too cognitively impaired, to really understand what it meant, but for the older children, the stigma of having a disability appeared to be a significant concern. Bruce remembered Jonti wanting to repeat the test, saying to Bruce: “I just said the things I thought she wanted to hear”. Bruce thought this was because “he didn’t want that label”.

Jasmine (aged 18 years) “was kind of pissed off at first” after receiving her diagnosis, seeing it as confirmation that there was “something wrong” with her. Eventually she recognised that the diagnosis provided an explanation for her behaviour and that was a “positive side of it”. Jasper remembered that the doctor involved in his diagnosis was “really cool” but acknowledged that “FASD affects my life”.

iii. Access to diagnosis/funding

The cost involved in diagnosing FASD and local workforce capacity were raised as issues impeding access for many families. Ted mentioned the capacity in Hawke’s Bay, but felt that throughout the country there needed to be “20 times the amount of people geared up to diagnose”. Most diagnostic services for FASD are not publicly funded, but private assessments can cost “up to \$8000 for a full assessment”. Margaret expressed concern for families who are unable to access private assessments and acknowledged that being a “cliché, white middle-class, educated” family had a positive impact on the funding they were able to secure for Cameron (aged 11 years).

D. Availability of Services/Not fitting criteria

Most parents raised the issue of their child not fitting certain criteria for accessing disability support services, often because they are deemed to be “not bad enough”. Amanda is trying to access respite services to help with feeling “overwhelmed”, but unfortunately, they are

“not fitting all the boxes”. She has been told that because her sons are adopted and not intellectually disabled, “they’re not getting as much help as they could do”.

IV. FASD and school

Parents and caregivers discussed the impact FASD had on their child’s schooling. Issues raised were disengaging from school, being labelled ‘naughty’ by teachers who did not understand or were not adequately trained in FASD, exclusion and suspension, and some strategies that could make a difference (including extra funding and support).

A. Disengaging from school

Disengaging from school or formal education is an unfortunate outcome for children struggling with unmet needs from an often unrecognised or unsupported disability. Some parents recognised that their child’s disengagement was specifically related to academic tasks and one mother chose not to turn it into a battle by letting her son leave school early.

The transition between school levels is also an issue that several families were confronted by as particularly problematic. Bruce said that while Jonti coped quite well at primary school with the same class, same teacher, and same routine, it became “too much” when he got to high school level. More senior school levels “start expecting the kids to self-manage” and require the children to have the ability to “organise themselves to get from one classroom to another and passed all these other social interference things like boys”.

Annabelle and Ben suggested possible pre-emptive measures that could, to some extent, mitigate the negative effects experienced by children transitioning school levels. With Natasha facing high school next year, they said they are “looking for a very specific high school” - an academic environment focused on achieving is “not going to be right for her” so they are instead looking for “the kind of school environment that’s going to be able to cater for her”.

Annabelle and Ben acknowledged the difficulty regarding whether to inform the school of Natasha’s FASD, or not. They were conscious of not wanting to stigmatise her as being “different” and wanted to “give her the opportunity to be who she is”.

B. Labelled naughty

Where a child had not yet received a diagnosis of FASD or where the diagnosis was not acknowledged or understood by the school, the child often ended up being labeled as naughty or bad. Kate remembers that for Henry, being in a school “that was telling him he was bad” resulted in Henry adopting that concept, believing that he was a bad child and “that is why this is happening”.

Margaret and John took Cameron out of the mainstream school system because he was starting to internalise this concept. He would say “I’m the naughty one, I’m the dumb one” and they were concerned about the impact this was having on him. They were hopeful that homeschooling will result in him being “not just a better person, but hopefully with more self-esteem”.

C. Exclusion/Suspension

Problematic behaviour by the children resulted in many of them being excluded either from the school entirely, or from the classroom. One child was put “in a filing cabinet room” to keep him isolated from the other children, while another parent reported that a child had to do his schoolwork in the principal’s office because his teacher “couldn’t cope”. Jason was suspended from primary school several times before Gloria had to attend a meeting with the board of trustees. Coming from a small town in a close-knit community, Gloria described the experience as “just horrendous”.

Margaret and John said the school’s management of Cameron’s needs was another reason they ended up home-schooling him. School staff “kept restraining him” and when Margaret talked to Cameron about what was going on, he told her, “I get angry and then I feel really sad”. Margaret felt the school poorly understood Cameron’s needs and that his reaction to being restrained was “really sad”.

D. Awareness of FASD/lack of training

The parents identified the general lack of adequate knowledge around FASD in the education sector as an issue of concern. Teachers were “not actually taught about it in training college” and while the responsibility should not fall to individual teachers to remedy this gap, they needed to “at least have some insight into what’s going on”. Jasper confirmed this, saying that in his experience teachers do not understand that he needs to learn in “special ways” and that this lack of understanding means that “school work is much harder” for him.

Just as parents faced challenges utilising traditional parenting strategies with their children with FASD, teachers applying “success-oriented teaching” were also said to be unlikely to effectively engage a child with FASD. Marnie felt frustrated that teachers “don’t know [FASD] doesn’t affect their intelligence” and that the teachers she had tried to educate about FASD did not really understand the implications, simply reassuring her that “I’m a good teacher”.

E. Teacher aide/extra support/funding

In Canada, each child with FASD is allocated \$18,000 worth of additional support, whereas in New Zealand, Marnie “can’t even get a teacher-aide for Tegan”. Parents said that the availability of one-on-one support in the classroom for children with FASD had a significant impact on the learning success for that child. When Henry enrolled in a new school he “immediately got put under the SENCO teacher, and she was just fantastic”. When he transitioned to college, “none of the information was lost from intermediate to college”. Kate said that as a result of the support made available for Henry, he was enjoying going to school “and that is a huge, huge, big thing for us”.

F. Strategies that help/possible alternatives

Despite the lack of formal, streamlined pathways to access support in schools for children with FASD, parents discussed various strategies that could help. These included open communication between home and school, acknowledging the academic limits of their child,

establishing support teams within the school and considering alternatives to mainstream education.

i. Communication

For some parents, open lines of communication between home and school were crucial in ensuring their child was provided with the best possible support: Annabelle said that her child's previous "teacher was very receptive, there was lots of email contact". Kate explained how helpful it was when the diagnostic team met with the school to explain what the disorder meant for Henry and what extra supports he would need, because "it is a really complicated disorder to understand".

In contrast, Annabelle and Ben expressed frustration that they had not had the opportunity to "go in and do a session about FASD". They wanted the school to "work with us rather than in isolation" but felt that was not happening.

ii. Picking your battles

Two parents noted that it was helpful to acknowledge their child's academic limits (and the limits of the family) and not push beyond that. Annabelle and Ben said they no longer did school-work at home "because it's not worth the price ... it just becomes a huge battle locking walls".

Similarly, three parents acknowledged that a useful strategy was to keep themselves somewhat removed from the issues that occurred at school. These parents let the school determine how best to deal with challenging behaviour without involving the parent every time.

iii. In-school strategies

A multidisciplinary team approach to supporting students with FASD in school was suggested as an option. One set of parents felt there ought to be a team of professionals providing support for the school – a social worker collaborating with the Police and public health. These parents felt that the issue of FASD in school needed to be approached by a multidisciplinary team and that the team could both provide support for the school and be the link for the families.

iv. Alternatives to mainstream school

Several families talked about the different pathways their young person had taken, after realising that mainstream school was no longer working.

Jasmine (aged 18 years) had enrolled at polytechnic to catch up on the school work she had missed, but acknowledged that "it's quite hard to stay focused on it". The correspondence nature of the course was a challenge for her and she found it difficult to stay motivated.

G. Challenging behaviour

i. Poor friend choices

Struggling to make and maintain positive friendships with their peers was a challenge most parents witnessed their children experiencing. Amy remembers the phrase ‘poor friend choices’ as seemingly innocuous, but from experience knows “poor friend choice means that you’re absconding from school, smoking at school, having sex at school and taking off”. For Gloria, she recalls Jason “not having the ability to filter who’s cool and who’s not” and being quite desperate to please people. Tegan (aged 11 years) will “make friends in an instant” but they “change throughout the day”. She has never had a consistent friend and never been invited to another child’s birthday party.

ii. Not thinking about consequences

Half the parents talked about their child’s inability to consider consequence, or link cause and effect. Kate describes Henry as not being about to link sequences or understand “that this is going to happen as a result of this”. Children were also described as being remorseful *after* the event, but not having an awareness in the moment that what they are doing will have a negative effect – “almost not understanding why he did it”. Jasper described this as “lashing out” without meaning to, and then “not remembering much about the situation afterwards”.

On a more positive note, Ted and Amy felt that Jasmine has “come huge ways in her thinking”. While she used to act impulsively and often dangerously (for example getting in to cars with strangers), she now “realises consequences much more and looks back on those days and realises how at-risk she was”. Jasmine reflected that her actions “caused unnecessary worry” and that she had been “so consumed in what I was doing in my life” that she had not considered at the time about how it was affecting the other people in her life.

iii. Anger and aggression

Being quick to anger, out of control, aggressive and having “major meltdowns” were problematic behaviours described by the parents. Amanda described her two boys as becoming more aggressive as they get older, throwing things at the rest of the family and threatening them: “that was difficult”. When Jasmine was younger, dinner time was a particular battle, throwing things at the wall and having meltdowns. Jasmine described “losing the plot” when she felt stressed, and having difficulty managing her mental health. Ted and Amy reflected that if they had had the diagnosis of FASD earlier, “we could have managed them [the meltdowns] much better”.

iv. Confabulation

Parents/caregivers commonly reported children engaging in confabulation. The child’s subconscious creates convincing stories to fill the gap when the child does not know the answer or cannot remember. Children will not necessarily confabulate purely to avoid trouble but, because of its subconscious nature, they will “lie when the truth will do just as

well”. Confabulation seems to increase if the child feels under pressure or “backed into a corner”. Ted and Amy emphasised the importance of not “bullying” them into a corner, because “they will just tell you what you want to hear”.

v. *Impulsivity*

Cameron acted so unpredictably that Margaret and John had trouble pre-emptively setting boundaries. He would “just do something so random”, acting without thinking “and that’s the concern”. Annabelle and Ben talked about Natasha being “absolutely genuine in her remorse and her apology” after an incident, but that “within 5, 10, 15, 20 minutes she’ll do it again”.

vi. *Other issues*

Families also reported their experiences of children misunderstanding body language, being unable to learn from experience, not understanding personal boundaries, having sensory issues and difficulties grasping abstract concepts.

Annabelle and Ben discussed the distinction between receptive and expressive language. They described Natasha as “very articulate, from an extremely early age” but said her level of comprehension was lower than it should be for her age. “She can parrot it, but comprehension – it’s not there”.

vii. *Effect of behaviour on wider family*

The challenging behaviours exhibited by the children had implications for the rest of their family – parents, but also other siblings living in the household, extended family, and friends. Natasha’s issues with stealing and confabulating had led Annabelle and Ben to “contain” as much as they can, “because we keep losing relationships with people”. Amanda said her neurotypical daughter “struggles a wee bit” with her brothers’ “relentless abuse”.

Jasmine experienced a turning point on her 15th birthday. She was in a rehabilitation home at the time and said she “didn’t really respect the kind of effects I was having on the other people in my life”. She spent time reflecting on her past behaviour and when her parents took her out for her birthday, she realised that despite the difficulties they had with her, she could “still feel this love from my family ... it was really special”.

V. *FASD and offending behaviours*

Some parents had direct experience of their children being involved in the justice system. Others shared their opinions on how behaviours they observe in their child could potentially translate to offending behaviours as the child grows older and the parents are less able to control their environment.

A. *Stealing*

Stealing was raised as a significant issue and was linked by the parents/caregivers to some of the behaviours described above, such as confabulation and impulsivity.

Two families had problems with their children stealing food. Annabelle and Ben said that for Natasha, “a lot of what she takes is based around food”. Similarly, Amanda said that if her and her partner were not pre-emptively restricting access, Richard (aged 14 years) would “raid the cupboard entirely”. While Natasha was younger, her problem with stealing was restricted to the home environment. However, when she started intermediate school it became more serious, with “things going missing from outside the home”.

More serious stealing described by the parents include shoplifting, stealing cars and stealing from friends. Marnie said Tegan’s stealing was almost compulsive, “she steals constantly, she cannot help herself”. How property and ownership is understood by young people with FASD can be problematic: “they understand what’s mine is mine, and what’s yours is mine too”. For those who have spent time in state care “their sense of ownership is different, because they’ve never had belongings”.

Natasha used to walk to school with a friend, but then money went missing and her shoes: “that relationship is now over”. A friend of Annabelle’s used to help out by picking the children up from school, but Natasha stole her purse so now she is unable to use that friend: “we keep losing relationships with people”.

Kate was pleased that Henry had managed to stay away from the justice system so far, but she could certainly see how he might end up getting into trouble. She cited an example of Henry (a tall 13-year-old who likes to wear a baseball hat and a black hoodie) choosing a snack in the supermarket and immediately putting it in his pocket. When she asked him what he was doing and pointed out the security cameras, he assured her he just “needed to see that it would fit in my pocket” and not to worry about the cameras because he would explain to the security staff that he was just “trying it for size”.

B. Running away

While not an ‘offending behaviour’, many parents discussed their child’s running away as an issue that had required Police involvement. At the extreme end, it even necessitated Jonti, aged 14 years at the time, being committed to a “youth facility” to keep him safe.

Cameron ran away on three separate occasions before he received his FASD diagnosis. On the third time, Margaret and John remembered him running away in the middle of the night, dressed in camouflage and carrying a kitchen knife. He was trying to replicate a “Bear Grylls” type of adventure. Their most serious concern with each of these incidents was that Cameron “didn’t really get it” - he did not understand the danger he was putting himself in. When Margaret tried to explain to him that he needed to be really careful, he reassured her, “it’s all good, I picked up a piece of glass and had it in my pocket”.

C. Sexualised behaviour

Inappropriate sexual behaviour by children with FASD toward others led one family to confront another adult about the importance of open communication. It led another mother to relinquish custody of her son for four years to attend a STOP programme.

When Natasha became “very cuddly” with one of the boys on a sleepover, the responsible adult chose not to talk to her parents and instead “deal with it within the group”. Annabelle

and Ben explained that the problem is the two children involved attend the same school and are connecting there, “so we need to know”.

When Jason was 13 he was sent to a residential school where his inappropriate sexual behaviour became apparent. In order for CYFS to fund his attendance at a STOP programme (a community based assessment and intervention service for harmful sexual behaviour), Gloria was required to transfer custody to the state.

D. Alcohol and other drug use

Susceptibility to addiction and using alcohol and other drugs as a way to self-medicate against social isolation were issues experienced, or raised, by several parents.

Benjamin’s offending started with alcohol-related offences and escalated until he was involved with multiple agencies to address his “proneness to alcohol”. Marnie talked more hypothetically about Tegan, who she felt certain was “going to end up a juvenile delinquent”. Her problematic behaviours will “isolate her socially” and she will turn to alcohol and drugs as a “quick fix”.

VI. Family experience of the current youth justice system: positive reflections

Several families with experience of the youth justice system discussed the importance of professional advocates, some positive examples of youth policing, the effectiveness of youth justice residences that were receptive to learning about FASD and the probation and forensic assessment services.

A. Professional advocates

Two families talked at length about the difference it made having a professional work alongside them and advocate for them and their child. Bruce described Jonti’s social worker as “an amazing woman”, who refused to abandon his case even after he “tried to light her office on fire”. Bruce and Jonti lived in a small community where the local Police just saw Jonti as trouble. Jonti’s social worker sat the local Police down and explained to them about what FASD was. She went “way beyond her brief” to help Jonti.

Both families acknowledged the professional working with them had no prior knowledge of FASD but took the time to educate themselves in order to provide the best support. Annabelle remembers that for the Youth Aid Police officer working with Natasha, “FASD was very new to her” but that she made an effort to educate herself about it “and was quite a big support”.

B. Positive interactions with Police

When asked about interactions with the justice system, many parents spoke positively about their experience with Police officers.

Bruce recalls one particular Police officer who was on duty when Jonti ran away from the house looking for a fight. When the officer got there, he calmly engaged Jonti by talking to

him about his interests: “what he was doing was treating Jonti not as a criminal, but a kid who was not on medication and needed to be brought back down ... that blew me away”.

Similarly, Amanda recalled a Police officer suggesting alternate expressions of aggression for Jasper (aged 13 years). Instead of punching a hole in the wall, the officer worked with Jasper “and asked him what sort of strategies he could use, like going for a run”.

The age of the child or young person at the time of the Police encounter was a relevant factor for some families. Lynne acknowledged that the more positive experiences with the Police occurred when Benjamin was younger, but that they had lost patience as he got older. Margaret and John said their interactions with the Police had been “really good”, but also acknowledged that it “could be an age thing”. Cameron was only a child (aged seven or eight years) when each of his running away incidents occurred.

Jasmine spoke positively of her interactions with Police officers and felt that “they couldn’t have done much more to make the situation better”.

C. Youth justice residences

By the age of 17, Jonti had been “locked up in every institution in the country”. Although Bruce had “nothing nice to say” about his experiences in three New Zealand cities, he did acknowledge that the residence in one provincial town was very accommodating of Jonti’s FASD. He had a case worker there who was “on to it” and the programme at the residence allowed Jonti to “blossom”. The young people were allowed to leave the residency, go fishing, swimming, or play volleyball with other young people. Bruce said “it was the best place for Jonti”.

D. Forensic assessments

The Youth Court can order, through s 333 of the OT Act, a medical, psychiatric, or psychological report to be done for a young person. Lynne already had a diagnosis of FASD for Benjamin, which came with a detailed report outlining his cognitive abilities. For his various Youth Court appearances, Lynne remembers the Court requesting a psychological report. For some of these occasions, Lynne tried to provide the Court with the copy of the diagnosis she already had, but they refused it. In one case, however, she said the Court psychologist “was really good”; the difference this time being the psychologist was aware of the diagnostic report, “acknowledged the report ... and didn’t try to do anything else herself. She was wonderful”.

E. Probation Service

Lynne also spoke positively about her experience with the Probation Service and the way they acknowledged Benjamin’s vulnerability. They had tried to find an alternative to community service because “we don’t want him mixing with those people”. Lynne was especially thankful because a lot of Benjamin’s issues in the past “have been because he’s been influenced by other people”.

VII. Conclusion

Parents described their children in various positive ways, emphasising their creativity, kindness, and intelligence. The children were also described as sociable and confident, engaging in a wide variety of hobbies and sporting interests. The parents acknowledged that these attributes initially appeared incongruous with a serious disability and highlighted the need for greater awareness of the presentations of FASD among professionals.

The current lack of support for FASD in New Zealand was emphasised by parents and young people. Difficulty obtaining a diagnosis, lack of awareness of FASD among health and education professionals, and a lack of formal support services targeted at FASD were raised as issues contributing to the challenges faced by these families. The hesitancy of health professionals to diagnose FASD exacerbated feelings of hopelessness and despair in parents and caregivers and reflects the inadequate state of professional training in FASD in New Zealand. Teachers perceiving children with FASD as 'naughty' emphasises the urgency with which professionals in the education sector need to be trained: the self-esteem and identity of these young people are suffering in the meantime.

The challenging behaviours observed by parents/caregivers (such as confabulation, impulsivity, aggression, and stealing) had, in some cases, led to their child becoming involved in the youth justice system. For parents/caregivers of younger children, they expressed concern that without adequate support (for example teacher aides in schools, or professional advocates working with the child and their family), their children may offend as adolescents. While support for young people with FASD is limited, parents/caregivers and young people acknowledged some good work that is happening in the youth justice sector in New Zealand (such as professional advocates, empathetic Police officers, innovative approaches taken by particular youth justice residences and forensic screening in the Youth Court). The following chapter reiterates many of these issues, from the perspective of several key stakeholders, and professionals from the health, education and justice sectors.

Chapter 9

FASD in New Zealand: Insights from Professionals and Key Stakeholders

I. Introduction

This chapter presents the insights of 19 professionals from the health, justice and education sectors, and six key stakeholders, on FASD in New Zealand. Assessment and services for FASD are considered, including the issue of health professionals' reluctance to diagnose, raised by the parents in Chapter Eight. The current diagnostic process for FASD in New Zealand is outlined and professionals share their views on the efficacy of the system.

Professionals from all three sectors and several key stakeholders commented on the experience of young people with FASD in school. Like the parents, these participants raise issues regarding students' exclusion, lack of adequate additional support and suggest some alternative options. This chapter includes a section on professionals' understanding of FASD, including what training, if any, the participants have experienced. It concludes with a section on FASD and offending behaviours, with professionals and key stakeholders identifying the connection between FASD and offending, and discussing some positive aspects of New Zealand's current youth justice system.

The chapter opens with an insightful commentary on New Zealand's drinking culture and its link with the subsequent challenges faced by the young people living with FASD and their families. Although this was not an issue that participants were asked directly about, many professionals raised it and spoke passionately about the importance of acknowledging and rectifying the damage that alcohol causes in our society.

II. New Zealand's drinking culture

Look at the way alcohol is just completely saturating society. [Paediatrician]

Certain types of drinking were said to have become so normalised as to not be considered harmful by the individuals affected. An attitude of apathy was encouraged regarding the dangers of alcohol:

In the 80's supposedly post-feminist women discovered a form of individualism where getting drunk was part of being, doing woman. [Service Manager, Education]

A social worker in the justice sector also commented that particular eras were more prone to problematic drinking and identified the issue of alcohol outlets targeting low socio-economic areas: "where's the cheapest booze around? It's the low socioeconomic areas".

The health professionals mostly raised this issue to emphasise the collective responsibility on New Zealand as a society in addressing FASD and to remove stigma and blame from individual mothers: "no-one here's blaming you". They felt that responsible drinking needed to be modelled by New Zealand's political leaders and at the moment that is not happening.

A psychologist commented that at political functions “they’re always standing with glasses in their hands” and that “we need to stop normalising alcohol as part of our culture”.

Alcohol lobbyists were considered part of the problem, marketing alcohol consumption as “glamorous”. But “you watch people drinking, there’s nothing glamorous about it ... Five minutes they’re happy and then they’re aggressive and then they’re sad”.

One paediatrician summarised her concern that ultimately, as a society, we need to do more:

Until our country really steps up and recognises we have a massive problem with alcohol, and until the Government leads the way in doing something about that, I just don’t think it’s going to change.

III. Assessment and services

Professionals discussed impediments to the diagnosis of FASD in New Zealand (including the reluctance of health professionals to refer or assess children for FASD), the diagnostic process, availability of support services and the difficulty of narrow entry criteria for accessing supports.

A. Reluctance to Diagnose

Like the parents, professionals from the health, education and justice sectors raised the issue of health professionals being reluctant to diagnose FASD. Some health professionals felt frustrated that their colleagues “don’t even seem to want to go there”. They raised possible reasons for the hesitancy, including laziness, misinformation and lack of confidence: “I don’t understand what they’re all afraid of”. Professionals from the justice sector also expressed frustration at their colleagues in the health sector being unwilling to diagnose FASD and said they “are being gun shy and they should do their job”.

In contrast, three participants (one from each professional sector) expressed their own concerns about the efficacy of a diagnosis. A school principal said that a diagnosis comes with “fear and uncertainty” and that “it doesn’t necessarily help”. The concerns expressed by these three participants are consistent with some of the concerns expressed by professionals to the parents that were interviewed. For two out of these three professionals, their hesitancy came from the lack of services and supports currently available for FASD in New Zealand, with one stating “a diagnosis of FASD is relatively meaningless at this point in time, in terms of support.”

B. Pre-diagnosis experience

i. Prior diagnoses

Professionals reported that children had often received multiple diagnoses before FASD was raised as a possibility, but “none of them will quite fit”. This phenomenon has led some professionals to describe children with FASD as “alphabet kids” due to the number of diagnostic acronyms that get assigned to them before their underlying disability (FASD) is identified.

Several of the professionals had encountered this in their experience with young people with FASD. A Youth Court judge said that he often saw “conventional types of diagnoses” (for example ADHD and Conduct Disorder) attached to the young people he is dealing with “where, in actual fact, the proper and most important diagnosis would be the FASD”.

ii. Implications for parenting

Some professionals also identified the difficulties faced by parents of children with undiagnosed FASD, who often struggled at home for a long time before the child first presented at a clinic for assessment. A service manager from the education sector said that parents are often “so exhausted” and resented being sent to “another bloody parenting course” that had a low likelihood of being successful.

iii. Not asking the question

Stigma is a potential impediment to FASD being raised as a potential issue or area of concern requiring further investigation. A justice sector participant felt it was crucial for other professionals to confront a potentially difficult conversation to ensure that children and their mothers are assessed and supported earlier. She was concerned that “so many mums have never been asked” and emphasised the importance of early intervention to avoid a difficult conversation preventing support being put in place: “It’s a shame these questions aren’t getting asked earlier”.

C. Diagnosis in New Zealand

i. Effect of diagnosis

Like the parents in Chapter Eight, several professionals discussed the positive impact a diagnosis can have on a family, and the practical ways a diagnosis can help parents manage their child. One paediatrician explained that the diagnostic process is “a therapeutic process” and represents the first stage of intervention. This clinic also offers a follow-on service:

We have a counselling psychologist that can work with families for up to six months post-diagnosis. ... She goes into the home, and she spends time with the caregivers, and explains things. She’s doing psychoeducation for FASD and teaching about strategies and how to manage the kids. [Paediatrician]

Diagnosis involves a “feedback session” where the diagnostic team meet with the child’s parents, school and other important adults to offer “a bit more support after a diagnosis”.

A diagnosis of FASD can have a positive impact on a child’s self-esteem, as noted by several parents in Chapter Eight. A social worker agreed that a diagnosis can “help them understand themselves better” and change their thinking from “I’m dumb” to acknowledging they have some strengths and some areas where they need additional support.

ii. Access to diagnosis/funding

Lack of funding and lack of workforce capacity were raised by the professionals as impediments to accessing diagnosis for FASD in New Zealand.

Gateway assessments were developed by the Ministry of Education, the Ministry of Health and CYFS to support children in state care (or at risk of coming into state care). The process is designed to collect detailed information about a child's health, social, and education needs so that the relevant agency can provide support where necessary. However, if a professional involved in a Gateway assessment flags FASD as a potential issue, "there's no-one within the actual DHB that the Gateway clinician can refer to for a FASD assessment" (Paediatrician).

One paediatrician emphasised the lack of formal funding streams for the diagnosis of FASD. The psychological and speech therapist components of the diagnosis is about "18 hours' worth of face-to-face time ... it's on par with \$4000 or \$5000". Most diagnostic teams for FASD rely on referrals from Oranga Tamariki who then "pick up the bill" for the assessment. Private referrals "are not cheap" because "there's no funding currently for these types of assessments".

iii. The diagnostic process

Six of the 18 professionals had been actively involved in the diagnosis of FASD in New Zealand: five professionals from the health sector (four paediatricians and one neuropsychologist) and one service manager from the education sector.

Establishing diagnostic capacity

Most of the professionals involved in diagnosing FASD in New Zealand are not officially supported or funded through the New Zealand Government. They identified this gap, independently sought further training or professional support, and began diagnosing without official recognition or support: "we just quietly got on with it". The exception was the diagnostic pathway in Hawke's Bay developed as part of that region's DHB's DAP.

Multidisciplinary team approach

All six professionals described New Zealand as following the diagnostic process outlined in the revised Canadian Guidelines, with a focus on the need for a multidisciplinary approach: "it's very much a working together process".

The referral pathways

The referral pathway the professionals described differed slightly depending on the organisation employing the professional. Usually the child or young person would enter the pathway due to presenting with "severe behaviour" and/or learning difficulties.

Involving the family

Several professionals mentioned the importance of involving the family in the diagnosis. This was emphasised as being especially important before the diagnostic process was triggered, to ensure the process was open and that families understood what was being assessed and why. A practitioner might say: "okay, so you drank when you were pregnant, it would be really good if we could explore how that's impacted on your child's growth and development". A paediatrician said that involving the family "also gives the opportunity to explain to a mum that no-one here's blaming them for this."

Post-assessment

The professionals involved in diagnosis often described a post-assessment component, involving feedback sessions for the family and/or the child's school and a list of recommendations regarding how best to manage the child and their FASD disability. This step was reported as crucial: "the recommendations were what they [the schools] loved though". It ensured that every adult around the child had a good understanding of "their needs and strengths".

The assessment

The assessment process was described in broadly similar terms. A paediatric assessment would be made (including differential diagnosis) and a psychological assessment of the child or young person's neurocognitive domains would be conducted, before the team came together to formulate a report and possible diagnosis.

Importance of thorough diagnosis

The diagnostic process and resulting report and recommendations need to be thorough to ensure an accurate picture of the child is created.

Although "going deep" with an assessment may seem incongruous with the education sector (which tends to advocate for a "non-intrusive approach")⁹⁵⁰, a service manager acknowledged that, for FASD, it is important to "do a comprehensive assessment".

The Government-released FASD Action Plan advocates for the establishment of a "minimum assessment protocol" for FASD. Unfortunately, "there's no such thing as having minimum FASD". One psychologist felt strongly that it was inappropriate to "just do a little screen and jump from there to some conclusions". She stated: "we don't do that with cancer, so why should we do it with FASD?"

A member of the judiciary raised this issue in the context of s 333 OT Act reports for the Youth Court and reached similar conclusions:

There's been a concern raised about how long it's been taking to get those reports, But where the mental impairment is FASD or another neurodisability, you can't do a three-week, five page assessment. If you're going to take half the time and pay half the attention, you get a half-rate report. [Youth Court Judge]

D. Availability of services/not fitting criteria

A diagnosis of FASD is not enough for families to meet the criteria to access support: "even if you do have a diagnosis of FASD, there's nothing there for you" [Paediatrician]. The difficulty is there is "no streamlined way forward ... to address it in a meaningful fashion once the diagnosis is sorted" and again it comes down to funding. FASD is a long-term disability that requires long-term investment and "that's the long-term focus that politicians and accountants don't have".

⁹⁵⁰ Ministry of Education *Learning Support Action Plan 2019-2025* (Ministry of Education, Action Plan, July 2019) at 29.

i. Insights from service providers

Keeping task groups small and working within a young person's abilities were two practical strategies employed by a social worker from a service provider for young people engaged in the justice system. The staff at the service provider used physical activity to gradually increase attention span – keeping their expectations at a minimum:

It'll go from two minutes to five minutes, every week we're increasing it, without the kid knowing that's what we're doing. [Social Worker]

Ensuring that the staff working with the young person were adequately supported and had a good understanding of the young person's complex set of needs was also raised as an important factor. This involved “making sure that communication is transparent between ... our management team versus the staff that are on the frontline”. The director of the service provider emphasised that each young person will present differently (which reflects the importance of a thorough and individualised diagnosis to inform justice workers) and staff need to be well-equipped with strategies to use with each young person.

Like the issues identified by the paediatrician quoted above, the director of this service expressed frustration at the lack of understanding from other agencies about the long-term nature of progress in these young people:

They say, “oh, you guys didn't work”. Well, look at who we're dealing with. And you expect a silver bullet to change everything? It doesn't work that way” [Director, Youth Justice Service Provider]. A service provider for young people with alcohol and other drug issues is circumventing the problem of young people with complex neurological disorders not fitting stringent entry criteria. A social worker from this provider explained how their service was more accessible for some young people with FASD because “we have a low threshold around criteria”. Additionally, he talked about the importance of advocating for these young people and ensuring they understood what they were experiencing. The social worker has experienced young people “saying ‘yes’ to things not knowing what they're saying yes to or getting ‘coerced’ into youth AOD residential treatment without any real idea of what they're signing up for as part of their plans”.

IV. FASD and school

Professionals from all three sectors discussed the impact of FASD on a child's schooling, from disengagement to formal exclusion or suspension.

A. Disengaging from school

The issue of children disengaging from school when their needs were left unmet was raised by parents, professionals and key stakeholders.

Like the experience of the parents reported in Chapter Eight, the professionals noted the particular difficulties experienced by children with FASD as education increases in difficulty, and the gap between them and their peers grows larger. One of these professionals emphasised the danger in a child's learning needs being unrecognised and unsupported for too long. This social worker described how a 12-year-old was referred to their service

because of a drug issue. It became apparent that the child had learning needs and upon further assessment an intellectual disability was diagnosed. If the child had not been referred for an incidental drug issue, he would have “transitioned onto high school with no assessment, no identified learning needs, and would have just very quickly disengaged”.

One key stakeholder identified transience as a barrier for children remaining engaged in school. He talked about the Police stopping children as young as nine with “three years not in school” and asked “why haven’t we got a system to identify transience?”

A teacher reported feeling disappointed when the school was not made aware of a student’s needs. She shared her experience of only finding out at Year 12 level that the student had FASD due to the caregiver’s fear of stigma: “It’s probably prevented a whole lot of support that could’ve been there”. Her final message to the parents and caregivers of these children was to “lose the stigma and get the support”.

B. Labelled naughty

A health professional said that parents often learn to manage their child’s behaviour at home and although they get criticised for “not having guidance and boundaries in place”, it is because they have learned that “that doesn’t work for their child”. However, schools “can’t do that, schools don’t do that” and so the children end up “standing out more and more in the classroom.” Because schools are unable or unwilling to be flexible, the children get labelled as naughty.

C. Awareness of FASD/lack of training

Low levels of awareness of FASD and a lack of formal training among professionals in the education sector were indicated as areas of concern for participants. The key stakeholders expressed doubt about the availability of school policy on FASD and identified the education sector as requiring widespread training.

One teacher acknowledged that training and resources for teachers about FASD is limited – “you have to go hunting a little bit more” - and emphasised the need to take initiative to ensure better understanding of students with the disability: “you have to look for good information to support the student”. In contrast, a school principal acknowledged that awareness is limited, but did not feel there was much to be gained in raising awareness due to the lack of funding for FASD in New Zealand. This reflects the experiences of parents dealing with professionals in the health sector who are hesitant to assign a ‘label’ to a child with no perceived immediate benefit.

D. Teacher aide/extra support/funding

One of the health professionals echoed the sentiment expressed by the parent in Chapter Eight espousing the benefits of a SENCO teacher being made available for her son. The professional emphasised how important it was for a child to have adequate support in the school environment. She acknowledged that most children with FASD will not be eligible for funding for a teacher aide, but the “kids with teacher aide funding with someone sitting alongside them in the classroom do much, much better”.

The allocation of extra support for students with higher learning needs had a focus on inclusion and avoiding isolation and stigma for students. In one school, the supports “are never classified around conditions”. Instead, the needs of the entire classroom are assessed and teacher aides allocated according to that holistic assessment. When the teacher aide is allocated, the “students see the teacher aides as support for the whole class, but the teacher aide knows there’s five targeted students for them” [SENCO teacher].

There are difficulties ensuring children with FASD are provided adequate support because of limited funding and narrow eligibility criteria. One teacher explained that the school receives \$19,000 to share across all students with extra learning needs, but they spend about \$105,000. There is no funding for their student with FASD. This participant also raised an important point about FASD, echoing the paediatrician quoted above, that support for FASD needed to be long-term: “you can’t drop off the attention that you’re giving”.

Two other professionals acknowledged the difficulty in securing adequate funding and support for students with FASD, consistent with the experience of most of the parents who raised this issue. Despite the child requiring “significant adaptation”, they just “don’t have the supports”. Unless they meet the criteria for an intellectual disability (IQ below 70), “they are reliant on people understanding”.

One of the key stakeholders also acknowledged the gap in support for students with FASD in schools, by stating generally that:

School isn’t catered very well for kids with neurodevelopmental disabilities, including FASD. [Key Stakeholder, Child Advocacy Sector]

E. Strategies that help/possible alternatives

i. Communication

Like some of the parents in Chapter Eight, an education professional emphasised how important it was for the families to keep the school informed about their child’s needs, especially as the child’s needs change over time. Having open lines of communication between home and school ensures consistency in the care and support the child receives between both environments.

This teacher also felt it was important for the lines of communication to extend to other members of staff within the child’s school and for everyone around the child to be aware of and to understand their extra needs. This encourages the “base knowledge across schools” to continue to grow. Additionally, if the student is stronger in one subject area, keeping open lines of communication between teachers means: “the food technology teacher can share what strategies they use with the maths teacher”.

Opportunities for support could be lost if a family chose not to share information about their child’s disability with the school. A teacher referred to an example mentioned above where a family had waited until their daughter was in year 12 before telling the school she had FASD and would likely be transitioning out of school early. If the parents had informed the school earlier, “her academic course instead of being based on external examinations at the end of the year could have been structured around her doing internal examinations during the year, where she had more time and more support and she would have got her credits”.

Open lines of communication between home and school give the school the option of altering a student's curriculum to better meet their academic needs.

Another professional from the education sector shared the SENCO teacher's message of the need for the information to be shared among a wide network of people. Sharing strategies and recommendations from the diagnostic team was vital with "not just the team around the child, [but also] the whole school" [Service Manager, Education].

One of the key stakeholders (Alcohol Harm Prevention) also acknowledged that regardless of whether a child or young person is at school or in another environment, it is crucial for the people around them to be aware of FASD and to understand its implications.

ii. Advocates

Several professionals raised the importance of the child having a committed advocate and the difference this made in the accessibility of support for that child. This reflects the issue discussed above, where the limited awareness of FASD in New Zealand can lead to children missing out on available supports. When the level of awareness of FASD in a foster family is low "and therefore if that advocacy hasn't come through from home", the information the school receives is limited. The information that families have "and are prepared to relay and advocate for that student at a school is really important".

iii. In-school strategies

Three of the professionals spoke at some length about in-school strategies that worked for children with FASD. One teacher recounted the experience she had with a child with FASD and what had worked well for that child. Having small, measurable goals for completing tasks was important, as was sharing those goals with the student as this "puts a little bit of expectation on him, not too much, but enough to bring commitment to it" [SENCO Teacher].

This teacher also suggested that finding the young person's passion or strength was a way of channelling their focus and allowing them to achieve success. Finding the strengths of a child with FASD can be an incredibly effective method of mitigating attention deficit and self-esteem problems:

This student has got good basketball skills ... and it's given him a role where he can be a leader. Whereas in education, he's never a leader. [SENCO Teacher]

The other two professionals (from the education and health sectors) spoke more generally about approaches that could be taken to engage children with FASD in school, including developing secure relationships.

iv. Alternatives to mainstream school

The importance of supporting a young person through transitioning from school to work, especially if they have a neurodisability like FASD, was emphasised. This is similar to the parents in Chapter Eight articulating the difficulty their children had in transitioning between school levels. Many transition services have eligibility criteria that do not fit with a diagnosis of FASD and it falls to the young person's advocate to convince the service to make an exception:

We'll find someone like Work Bridge, who do transitions for people with mental health and convince them maybe, that this one fetal alcohol child, even though it's not mental health, could do with a mentor to help the employers understand that you will have to keep an eye on them. [Service Manager, Education]

This same professional suggested how to make mainstream school more accessible for children with FASD, reflecting the idea of identifying a child's strengths and creating a more flexible education framework around them: "there needs to be alternatives for kids who find mainstream school aversive". Instead of focusing on schools as a rigid concept, she suggested that education should be provided flexibly through "a space for learning that meets needs".

A teacher felt that a formalised buddy or mentor programme could hugely improve the school experience for children with FASD by increasing engagement and independence. She cited an example of a student with FASD with a close friend who has "a stabilising influence on her behaviours" [SENCO Teacher].

This same teacher emphasised the need to fundamentally change the way mainstream schools currently operate, to improve the rates of children with disabilities remaining engaged in school. It is important to acknowledge that some children will not be able to engage in the purely academic side of school, and that instead, coming back to school level and putting in some "vocational courses and taking out some of the academic courses would be a good start".

V. Professionals' understanding of FASD

A. Early awareness/understanding

Several of the professionals reported their understanding of FASD with reference to how it had been presented to them early on in their professional career, or by reference to the fact that nobody had spoken about it at all.

One of the key stakeholders said that if it had not been for her line of work as a youth advocate lawyer, she would not have any awareness at all: "as a person or a lawyer in society ... I had no idea".

Misunderstanding that the presentation of FASD is identified in the physical appearance of an individual's face was common among the professionals, until relatively late in their careers where they had the opportunity for additional training: "Up until that training, I was always looking for those facial features, when 70% don't present with it" [Youth Aid Police Officer].

B. Training

Seven of the professionals had received formal training in FASD at some point in their career.

The training varied, with some attending workshops and seminars presented locally. One of the health professionals had received training in FASD as part of his formal medical training. Two of the professionals had been to Canada and the United States to receive training. One

had received formal training in FASD in Australia and discussed similar plans for training for the team he worked with locally. The format and content of the training received varied, depending on the location and presentation style.

Four other participants mentioned that although they had not received formal training in FASD, they had either received informal training, or had educated themselves by reading widely and consulting colleagues.

C. Presentation

Most professionals (15 out of 19) and all key stakeholders discussed what they understood the commonly observed presentations of FASD to be. The professionals largely discussed the presentations in the context of whichever sector they were from.

In the context of education, a SENCO teacher described warning signs as seeing a student perhaps falling behind their peers academically. In the context of youth justice, if a young person was continually breaching bail that would constitute a red flag for one Youth Court judge. The judge reflected the issue regarding understanding of consequences: “where there are obviously increasing consequences, but still the behaviour is continuing unabated” [Youth Court Judge].

There were also common strands across the education, health and justice sectors, where professionals consistently identified certain behavioural traits. Planning and organisation, impulsiveness and attention, aggression and general behavioural difficulties, and executive functioning deficits were mentioned by participants across sectors. Like the experience of most parents in Chapter Eight, a paediatrician focused on the “disconnect between thinking about what they do and then the consequences of that”. She also identified young people with FASD as having “poor judgement [and] poor reasoning”. A practice manager for youth offenders agreed, focusing on young people’s “lack of awareness of those around them [and] how their decisions might affect them”.

The issue of confabulation was raised and the description given by a service manager from the education sector echoed the descriptions given by many of the parents. Confabulation is distinct from lying as the young person is simply trying to “link two events together to make sense”. The young person may have the “A” and the “C” and will “connect the A and C with a B which happens to be what other people call a lie”.

A health professional identified the ‘swiss cheese’ nature of FASD as a disability, explaining how the various presentations may not appear consistent with each other:

At the age of 12 they might read like an 11-year-old but have the emotion regulation abilities of a three year-old and perhaps the attention abilities of a five year-old ... it’s quite unpredictable. [Paediatrician]

One key stakeholder emphasised the varied nature of the disability and explained that regardless of the presentation, it required accommodation in society:

Anyone who is fully diagnosed on that fetal alcohol spectrum has severe difficulties in areas of brain development. We don’t see the disability because it’s hidden deep

in the brain but we have to accommodate it differently just like we do with other disabilities. [Key Stakeholder, Alcohol Harm Prevention]

D. Multifactorial

Presentations of FASD were likely to be influenced by several factors, including the child or young person's environment, genetics, or family history: "you've got a mixture, a real cocktail". This is particularly relevant in the context of youth justice, where the court will need to determine a link between a young person's disability and their offending behaviours and establish the best path forward to address the young person's needs: "really hard in some of these cases to work out what to try and deal with first" [Youth Court Judge].

The multifactorial nature of the presentations of FASD emphasise the need for thorough diagnosis, discussed earlier in this chapter. A diagnosis of FASD offers a description of individual needs. A FASD diagnosis is not just a label, but is a "picture of where this child's strengths are, what we can teach to, what we can treat to, intervene to, and what parts of the child we need to accept, for now" [Service Manager, Education].

VI. Susceptibility to offending

Professionals were asked about their views on how the presentations of FASD could lead to antisocial or offending behaviours. The professionals raised several issues, including some antisocial behaviours they would expect to see (stealing, anger and aggression, and alcohol and other drug misuse), but also factors affecting a young person's susceptibility to offend in the first place (such as poor friend choice) and their vulnerability within the justice system (such as communication difficulties).

A. Offending behaviours

i. Stealing

Like the parents, many professionals identified stealing as a problem they had seen in young people with FASD. A paediatrician used an example of a young person with FASD who had been involved in burglaries. This young person ended up identifying over 30 houses to Police, many of which had not been burgled at all, because "every time he pointed at a house, he got praise...he just thought he was doing the right thing".

A Youth Court judge told the story of a young person trying to sell stolen goods back to the original owner, using the reasoning that he knew the owner would need them.

ii. Anger and aggression

Young people with FASD can have difficulties controlling anger, with the emotion manifesting in sometimes uncontrollable aggression. The professionals raising this issue talked about the nature of FASD as a disability and the reasons why behaviours may escalate rapidly in situations of conflict.

The sub-cortical regions of the brain dominating over the prefrontal cortex is one explanation for seemingly excessive reactions. For example, if a child with FASD is working hard on a task and someone knocks their desk, their reaction could be to "upturn the desk,

run out of the classroom, and then spend the next half an hour running around”. A SENCO teacher explained that this reaction would likely occur time and again, regardless of how many times they tried to work out alternative ways of dealing with the situation: “it would still go back to the immediate flight fright response”.

One paediatrician explained that children with FASD reflect emotion, so when they are confronted with a negative response (someone getting angry at them for not listening or not doing a task correctly) they are likely to respond negatively without thinking:

And then you cycle down into your spiral of offending behaviour. They’re existing in a ticking bomb. Because one day something’s going to happen, and it’s going to explode. [Paediatrician]

A social worker from the justice sector linked aggressive behaviour in young people with FASD to an inability to connect cause and effect, explaining that “they’re constantly carrying knives. But they can’t see the link between the knives and maybe hurting somebody”.

iii. Alcohol and other drug use

Like some of the parents discussing issues their child had with alcohol and drug use, six professionals (one education professional, two justice professionals and three health professionals) also acknowledged the co-existence of alcohol and other drug problems for young people with FASD.

The intergenerational nature of dependency and harm caused by drugs and alcohol was raised by professionals from the health and justice sectors, and a key stakeholder. Intergenerational alcohol abuse means that for many of these children, “probably the parents have got FASD issues themselves”. The key stakeholder emphasised this issue, referring to the intergenerational nature of the harm and how early substance dependence can begin.

B. Susceptibility to offend/vulnerability in justice

Many participants discussed specific types of offending behaviours seen in young people with FASD (see discussion above). Most also made comments about the connection of FASD to offending which focused on the neurological or physiological reasons behind young people with FASD coming into contact with the justice system and how these reasons make young people vulnerable within the youth justice context.

Some of the issues raised by participants included:

- the impulsivity of young people with FASD;
- poor friend choices;
- age and communication difficulties;
- difficulty learning; and
- confabulation.

i. Impulsivity, cause and effect, and consequence

Consequences and impulsiveness were issues raised by several of the professionals and key stakeholders. One social worker described a young person as “the most compulsive person” she had ever met. The implication for offending was that he “couldn’t walk down the street with a load of cars parked in it without trying every handle”. She described him as a “delightful young man” but said that his offending was never clever and was always “spur-of-the-moment”.

A key stakeholder from the alcohol harm prevention sector described crimes committed by young people with FASD as “not sophisticated”, echoing the social worker quoted above. She emphasised the limited capacity for executive functioning in these young people and explained that the offending is very impulsive and “with that impulsivity comes the inability to apply their executive functioning at the time it’s needed”.

ii. Poor friend choices

This sub-theme can be broken down into two issues that were raised by participants: young people with FASD are generally more vulnerable to influence and they are more likely to “take the rap” for something they didn’t do, or more likely to be the ones who get caught.

Vulnerable to influence

Two professionals from the education sector made general comments about the vulnerability of young people with FASD: “they’ll be easily led”. The four other professionals raising this issue were from the health sector and linked vulnerability with criminal involvement. Young people with FASD are “very easily led, and so come into crime by more experienced young people and adults who are involved in criminal activity” [Paediatrician].

The key stakeholder discussing this vulnerability did so in the context of emotional immaturity and developmental delays in young people with FASD. Delays to the development of maturity in these young people “makes them naïve and gullible” which increases their vulnerability to more sophisticated peers. It “makes them susceptible to manipulation and suggestion”. This vulnerability, coupled with “their willingness to please”, often results in young people with FASD very quickly “radiating towards the wrong influences”.

‘Taking the Rap’

Young people with FASD appear to be more likely to ‘take the rap’ for something they have not actually done, or alternatively are most likely to be the ones that get caught (in a group offending situation). This reflects both an eagerness to please and an inability to consider the consequences of their actions. Cognitively, they are “least able to change their pathway and do something different”. They are also “most likely to be caught holding the thing they’ve stolen or standing next to the person they’ve assaulted” [Paediatrician].

iii. Age and communication abilities

Some participants raised the discrepancy between chronological age and developmental age in young people with FASD and the implications for communication and comprehension in

the justice system: “they’re vulnerable to being misunderstood because they’re presentation verbal” [Service Manager, Education]. Young people with FASD are likely to be “least able to communicate what has happened, or answer any of the questions that the courts place or while being interviewed by policemen”.

iv. Difficulty learning

Professionals and key stakeholders talked about the difficulties young people with FASD have with learning: “they don’t seem to learn in the same way”. Some participants raised this issue in the context of learning from past behaviour or consequence – “they don’t seem to learn from their behaviours” - others raised it in the context of education. A practice manager for youth offenders noted that when behaviours are repeated regardless of consequences, “you start to realise that they’re not in control of this whatsoever ... it’s like pressing a reset button”. One social worker described young people with FASD as escalating “further and further into the system”, emphasising the importance of identifying FASD and providing suitable interventions as early as possible.

v. Confabulation

Like the parents, professionals raised the issue of young people with FASD confabulating, telling convincing stories to fill the gaps where their brain is unable to understand or remember: “they’ll probably get believed when they’re not telling the truth” [Service Manager, Education].

The three professionals (one from each sector) also focused on the vulnerability aspect, linking confabulation to the likely existence of communication or language disorders in young people with FASD. This reiterates the issue discussed above, where young people appear to be compliant and understand the situation, when they are “not really understanding what they are agreeing to” [Social Worker].

VII. Reports for the Youth Court

Professionals involved in providing medical or psychological reports for the Youth Court under s 333 of the OT Act talked about the report process, feedback they received and the purpose of providing such reports.

A. Process

Three professionals (two health professionals and one justice professional) had direct experience writing reports for the Youth Court on a young person with FASD. Three additional participants (one social worker, one paediatrician, and one key stakeholder) had indirect experience of these reports and were able to comment on the process by which these reports come about.

Usually the referrals came from the Child and Adolescent Mental Health Service forensic team and included instructions for the health professional about what the Court required.

A health professional emphasised the importance of getting these reports done so that the Court has accurate information about the young person to inform their decision. She

reiterated the importance of thorough and accurate diagnosis of FASD and used the example of a boy who had “never been assessed for [FASD]” but that the courts had been presuming it: “next thing he’s in [a Youth Justice Residence] awaiting multiple charges. It’s not good enough for a court to presume a child has FASD. It must be properly assessed for. Because no proper plans can be made unless you know for sure” [Psychologist].

The process of finalising a s 333 report is “really laborious” due to the regional youth forensic service editing the reports and requiring the health professional to make changes. A paediatrician questioned the efficacy of this requirement, especially given “there’s just not enough resource for that”.

The key stakeholder that discussed the process of reports on FASD for the Youth Court similarly commented on the laborious nature of it as it stands and questioned the costs involved. This participant said that the reports require two independent health professionals to assess a young person for FASD and that the limited capacity for assessment impacted upon cost. He described the process as “quite long and quite convoluted”, with various agencies “arguing about ... who’s going to pay for travel? Which DHB’s going to pay for the report?”.

B. Feedback

Professionals involved in providing s 333 reports for the Court raised the issue of not receiving feedback from the Youth Court regarding the outcome of their report, or what had happened as a result of their recommendations.

Two professionals felt that this was “very unsatisfying”. A professional working in the justice sector acknowledged that she did not receive feedback on her reports but said that the courts “own the report” and her role was simply in raising the red flag.

After being asked whether she knew the outcome of a specific case she had provided a report on, one health professional explained that she would only expect feedback on her report if there was a difference of opinion. She also stated that although she rarely receives feedback, in her experience the courts are likely to take heed of the recommendations:

The judges, especially the youth court judges take it very seriously. And they absolutely try to follow the right processes, because it’s going to be more effective.
[Psychologist]

C. Purpose

There are reported differences between general or clinical diagnostic reports on FASD and reports that are made specifically for the Youth Court.

A key stakeholder discussing this issue summarised it and stated that the courts did not require the same level of detail as a general diagnostic report would contain.

In contrast, two of the health professionals felt that this approach was problematic. They emphasised that diagnosis was often the “first stage of intervention for managing these kids”, and that the courts were missing this opportunity by focusing so narrowly on the legal implications. If the courts did not have someone specifically trained in FASD to “come in

and then help that young person that's been diagnosed through a court report", the whole process was "a bit of a waste of time" [Paediatrician].

Another health professional identified this difference in focus between general diagnostic reports – "we write in developmental language" - and reports for the Youth Court, by talking about a colleague who is responsible for providing s 333 reports: "she writes in court language".

A participant working in the justice sector summarised it simply:

This [court work] is a different world. [Alcohol and Other Drug Youth Forensic Clinician]

VIII. Current youth justice system effectiveness

One participant described New Zealand's youth justice system as "second to none in the world" [Paediatrician]. The following section acknowledges this accolade by reporting the ways in which professionals and key stakeholders felt the youth justice system was discharging its duty to young people with FASD effectively.

A. Professional advocates

Two professionals talked about instances in which they took initiative to learn about FASD and support a family who had come to them for help. A social worker described a local community as referring to her client as "naughty J" and the steps she took to educate them about his disability and his needs: "it was around working with the local police ... and educating the Youth Court judge as well".

The Youth Aid Police officer talked about the extra training she sought out after learning about the child's FASD. She wanted to educate herself about the disability in order to know how best to support the family.

B. Positive feedback on police

Like many parents, one professional (from the education sector) and a key stakeholder emphasised the quality of New Zealand's youth Police:

I have the biggest praise for the youth justice officers out there. There are some really amazing youth police. [Service Manager, Education]

C. Structure of the Youth Justice System

Several participants talked about positive aspects of the youth justice system in general. In particular, the structure of the Youth Court and the youth justice system in New Zealand and how they are working well for young people with FASD was raised:

I have had uniformly positive interactions with the Youth Courts. [Paediatrician]

The specific issues raised by participants in the context of this general sub-theme were:

- the limited resources available;

- youth justice residences;
- the multiple voices present in the youth courts;
- screening/forensic presence;
- the focus on underlying needs of the young person;
- crossover lists;
- opportunity for intervention;
- the efficacy of working with a diagnosis; and
- the attitude of youth justice professionals.

i. Limited resources

One participant from the education sector focused on the limited resources the youth justice system had to work with. When I asked her what her thoughts were regarding the effectiveness or ineffectiveness of the justice system for young people with FASD, she said:

I think it could be better, but I think it does a bloody good job considering it gets very limited funding. [School Principal]

ii. Youth justice residences

The screening and assessment tools that are utilised at youth justice residences was raised as a strength of the youth justice system. Within the first seven days of being at a residence, “all the kids have been seen by a doctor and screened for a number of things” [Key Stakeholder, Child Advocacy]. In addition, “usually the youth forensic team” will also do an assessment for mental health concerns. After the assessments are completed, the health teams work with the floor staff to “help them have the best way of responding to these kids”.

iii. Multiple voices

Involving a variety of agencies about how best to proceed with a young person in the Youth Court was raised as an important issue and a distinguishing factor of New Zealand’s youth justice system. In the context of this issue, the fact that so much of the youth justice process is specialised was also emphasised as a strength of the system: “young people who offend in New Zealand are very likely to be seen by specialist social workers, specialist police, specialist judges ... who understand the issues pretty well” [Paediatrician].

In a practical sense this can have huge implications for a young person’s outcome. Where previously (prior to the current structure of the Youth Court) if a young person had not made progress on their plan the default would be to increase their sanctions, “all of a sudden there were these other voices that wouldn’t ever normally be heard - the forensic mental health service people, the social worker - who’d start saying ‘look, if you’re willing to be patient, you’ll be able to see those things falling into place’. And it was almost always exactly right” [Youth Court Judge].

As well as the multiple professional voices involved in the court process, one key stakeholder pointed to the effect of involving the victim in youth justice processes. In this example, a dairy owner had been burgled by a young person. At the FGC he learns that the young person’s dad is in prison and his mum has “real issues”. The boy is in the care of his

grandfather. The dairy owner tells the young person “if you follow your grandad, you go to college, I’ll give you a Saturday job at my dairy” [Key Stakeholder, Justice Sector].

iv. Screening/forensic presence

Like the issue mentioned above regarding screening of young people at youth justice residences, several participants pointed to the forensic screening that occurs in the youth courts. It is “mandatory for the forensic nurses to go down and do a screen” for all young people appearing in the Youth Court [Key Stakeholder, Youth Justice]. The young people are screened for “any behaviours” or any red flags that suggest the need for further assessment. At that point, the screening team will refer for a s 333 report or a comprehensive alcohol and drug report.

v. Focus on underlying needs

One of the justice professionals identified a strength of the youth justice system was the focus the legislation puts on recognising and addressing the underlying needs of the young person:

The mandate is not only to address the offending, but to acknowledge the young person’s needs, to address the underlying causes of offending, to explain what’s going on in a manner and language that’s understood, to encourage them to participate. [Youth Court Judge]

vi. Crossover lists

The use and efficacy of “crossover lists” (information on young people who are involved in both the family courts and the youth courts) in the youth courts was raised. The “whole point” of the lists is to give “practical effect to information sharing”. Prior to the crossover lists there was no way for the Youth Court to know whether a young person had been through the family court system. This was problematic, because “the family files are just covered in red flags about things the Youth Court has to know about”. The crossover lists allow the Youth Court to recognise, for example, “the effect trauma has on behaviour”, and to be able to “make sensible bail decisions”.

vii. Opportunity for intervention

One participant focused on the youth justice system as an opportunity for intervention for young people with FASD who might have been missed in the past. This social worker commented particularly on the “intensive structure and routine” offered by the justice system, and that young people with FASD may have better “access to positive activities through mentoring”.

viii. Working with the diagnosis

Incredible results can be seen if a correct diagnosis of FASD is made and the justice system works to accommodate the diagnosis and support the individual.

A professional from the justice sector used an example of a case he had been involved in to illustrate this point. In this example, the young person was back before the court having previously offended and was finally assessed as having FASD. The FGC plan incorporated the recommendations from the assessment, including lots of structure, support and supervision. The young person's strength was in mechanics and working with cars and so he attended a programme where young people are involved in working to put together a V8 race car. The individual managing the programme came to the Youth Court because he wanted to let the judge know that "he'd never had a kid like this before". The young person had been diligent in his work since starting the programme and the director was blown away by his commitment and work ethic.

The judge commented on how working with the diagnosis had changed this young person's trajectory: "the plan continued, and the progress continued, and what had happened by the end is this young guy's trajectory had completely changed." The judge noted that if they had approached things "in the conventional way" by imposing more sanctions they would not have seen success in this young person. But by "recognising the signs, getting the diagnosis right, and following the recommendations, which weren't really complicated or expensive to introduce ... it was jaw dropping. You think, 'this is like a miracle' [Youth Court Judge].

A professional from the health sector also raised this issue. In this example the man was in the adult justice system, but the participant used it to illustrate how court proceedings generally could be incredibly effective for individuals with FASD. For this man, once the diagnosis was made known "the whole legal process changed". This psychologist said that all the legal professionals made an effort to speak more simply and worked together to come up with a plan that would be effective. This participant concluded this example by emphasising the "cost of the assessment to the court is quite insignificant compared to the cost of what they were planning which was to incarcerate him. It can make a big impact" [Psychologist].

ix. Attitude of Youth Court judges

The attitude of youth justice staff, and especially Youth Court judges, toward young people with FASD and other neurodevelopmental disability was identified as a positive factor in the system.

Youth Aid Police officers were described as being "really open to learning" about FASD and neurodisability. Youth Court judges were singled out as being particularly knowledgeable and open to understanding FASD. A paediatrician commented generally on the willingness of youth justice professionals to seek advice where needed and "take it on board and make judgment with that added information". He felt that this was "definitely a strength of the youth justice people".

D. Practical Strategies

The youth justice system is already employing several practical strategies to help improve outcomes for young people with FASD. Strategies raised by the participants included:

- communication style;
- considering alternative programmes or interventions;

- educating the team around the young person;
- ‘structure, support, and supervision’; and
- supporting the whole family.

Four professionals (one paediatrician, one Youth Court judge and two social workers) raised the issue of communication style. These participants emphasised that the way you spoke to a young person with FASD could have a significant impact on their ability to engage with the youth justice system. One paediatrician said that if a court plan is put in simple language with realistic timeframes it creates much better outcomes for the young person.

For young people with FASD, the likelihood is that alternative strategies will need to be employed. A justice sector professional used an example of a young person with FASD who was in the Youth Court, and explained how the Court dealt with the young person’s management:

It meant that there was no point just putting this person in a mainstream group programmed to do something. It needed special design of any intervention that could occur. [Youth Court Judge]

The importance of educating the whole team of justice professionals around the needs of one young person was emphasised by a social worker. The young person in her care could not tell the time and so professionals learned to ensure he had alarms for appointments set on his phone. This exemplifies the importance of educating the team around a young person that because they are unable to change their behaviour, the responsibility lies with the adults around them to modify their approach: “by the time we got to the end, people were really modifying their behaviour ... it educated a lot of people. What he has, and what needs to change to make it successful. He’s my success” [Social Worker].

Another professional focused on the importance of structure, support and supervision. A young person was sent to supervision with residence for six months and the change in him following that intensive period of support was described as “miraculous” [Youth Court Judge].

There are certain practical strategies that can be engaged to address the core issues underlying offending in young people. There is a need to support the whole family in order to enable success in the young person. In an example given by a key stakeholder, the young person’s mother was struggling for support and had been unable to secure financial assistance to fix various problems around the house. Eventually she was provided with support to attend a WINZ (Work and Income New Zealand) appointment and the issues were resolved. The key stakeholder said this provided impetus for the young person to feel a sense of ownership and confidence, suggesting to his mother that perhaps “we can get people to take their shoes off at the door now we’ve got new carpet”. The key stakeholder explained that empowering the whole family is “real youth justice. It’s turning them around” [Key Stakeholder, Justice].

IX. Conclusion

Professionals from the health, justice and education sectors shared their insights on the current state of support for young people with FASD in New Zealand. They all

acknowledged that early, thorough and accurate diagnosis should be a priority in supporting young people with FASD. Health professionals are working hard to establish diagnostic capacity for FASD in New Zealand but are struggling against limited funding options and reluctance from their colleagues. Health professionals need to receive adequate training in FASD diagnosis to recognise that it is a manageable diagnostic process to learn and that there is value in giving a diagnosis despite the current lack of support services for FASD in New Zealand.

Formalised training would also benefit the education sector. Several participants discussed the challenges faced by young people with FASD in the school system who are often labelled as “naughty” by professionals who do not understand their disability. Participants highlighted the current lack of extra support available for FASD in schools. Children and young people with FASD often do not meet the stringent criteria for accessing extra support in the classroom and schools are left to share limited resources across a large body of children with extra needs. Participants shared their ideas on mitigating these issues, including establishing a wider range of vocational courses aimed at children and young people who struggle to engage academically.

The Government’s role in adequately acknowledging FASD was emphasised by professionals. Formal funding streams need to be developed so that diagnostic capacity throughout the country can be established, and formalised training programmes and specific support services developed.

All participants recognised the connection between FASD and offending behaviours. The vulnerability of young people with FASD – both through peer influence and the disparity between chronological and developmental age – was emphasised. Professionals involved in providing psychological reports for the Youth Court commented on the efficacy of the process, suggesting that the courts needed to focus more on the opportunity for intervention.

Although specific services and supports for FASD in New Zealand are limited, participants commented on the strategies already being used by professionals in the justice sector to help improve outcomes for young people with FASD in the justice system. Communicating in a manner the young person could understand was an example of a practical strategy that had positive effects and participants emphasised the importance of assuming communication difficulties when interacting with a young person with FASD in the justice system. Participants further noted that the youth justice system already had positive aspects that were working well for young people with disabilities: the multiple voices present in the Youth Court, the forensic screening process, the open-minded attitude of youth justice professionals (especially Youth Court judges) and the efficacy of working to a young person’s diagnosis were raised by participants as positive aspects of New Zealand’s youth justice system.

The following chapter expands on this discussion, reporting the concerns participants have with New Zealand’s youth justice system, and sharing their ideas for how it might be improved.

Chapter 10

New Zealand's Youth Justice System: Current Issues and New Ideas

I. Introduction

Participants across all three sample groups (family members (including young people), professionals and key stakeholders) raised issues about the current youth justice system regarding the way it deals with young people with FASD. This chapter opens by examining these issues, including: a lack of awareness and training among professionals; the limited diagnostic capacity for FASD in New Zealand; variability of service provision; and the limited interface between the youth justice and care and protection sectors.

This chapter also reports on the various solutions offered by participants to improve the experience of people with FASD in the youth justice system, including: adopting a paradigm shift in attitude; better cross-agency collaboration; simplifying the court process; acknowledging the issue as health rather than justice; and providing alternate paths to justice for these young people.

II. Awareness and training

Families

All the parents and both young people felt there needed to be more awareness of FASD among individuals working in the justice sector and that widespread training was important.

One family had a positive experience with a Youth Aid Police officer who made the effort to learn about FASD and suggested more professionals (specifically Police officers) should take similar initiative. In contrast to this family's experience, the general lack of understanding and awareness among frontline staff was notable and parents wondered whether Police officers perceived that there was little that could be done at that early stage.

Two parents identified strategies the Police could employ to make a difference. One mother explained that "a bad situation can become an awful lot worse if the person doesn't recognise this *could* be FASD". She said it comes down to how Police officers "deal with them" and knowing that "what they say can set them off". The other parent agreed, saying it is important that Police "understand how to deal with them" to avoid escalating violence.

Oranga Tamariki was identified by one father as not having "any understanding of FASD at all." When he first contacted them for help and support, they replied: "well, it's got nothing to do with us."

Formal training of professionals needed to start early, ideally being incorporated into tertiary education for people "going into any form of work in youth justice systems" (Mother). Two parents, when asked what advice they would give to youth justice professionals coming into contact with young people with FASD, summed this up succinctly: "Just to learn about it".

The young people echoed this sentiment and felt that people in the justice system needed to have access to accurate information about FASD. One young person reflected on his experience that “the Police did not know about FASD ... the lawyer definitely did not know about FASD ... [and] my social worker does not get FASD at all.”

Professionals

Most professionals (13 of 18) also raised the lack of awareness and training about FASD.

The lack of knowledge about FASD among justice professionals concerned professionals from the health sector who emphasised the importance of spreading awareness to mitigate harm to young people.

Justice sector participants commented that more training was essential and that this needed to be practical and job-specific “not only about what [FASD] is” [Director, Youth Justice Service Provider].

The professionals were asked whether they thought there was a place for FASD-specific training for justice professionals, and one social worker said it should be mandatory for “pretty much everybody who works in the system”.

In contrast to the above, one Youth Aid Police officer was not convinced that further training would necessarily make much difference because the Police are already trained in de-escalation, which is what they would employ at first contact regardless of the presence of disability. This participant simultaneously acknowledged, however, that the training they have independently sought for FASD is great, “because it provides staff here, in Police, and agencies a chance to actually understand”.

Key Stakeholders

All five key stakeholders felt that further training and awareness about FASD was necessary. FASD currently only becomes an issue to the Court if the young person’s youth advocate picks up on it “and that’s not frequent” [Key Stakeholder, Youth Justice Sector]. There are still barriers to recognising FASD in the health sector because health professionals are not taught about brain injury as distinct from mental health. They work to the Diagnostic and Statistical Manual of Mental Disorders (DSM) which “describes a symptom, it doesn’t identify that there’s underlying brain damage causing [it]” [Key Stakeholder, Alcohol Harm Prevention]. This same key stakeholder felt that education of each group within the justice sector needed to be nuanced, and, like the views of parents already discussed, felt that training should happen early.

The lack of knowledge among Police officers, and the implications this potentially had for offering diversionary or alternative actions, was raised by a key stakeholder from the justice sector. This participant expressed concern that if an inexperienced Police officer chose to divert a young person and that young person had FASD, their disability and underlying needs may be missed. The importance of early intervention in these scenarios was highlighted, with one key stakeholder emphasising that training and awareness was needed for those outside the justice sector as well.

III. Diagnostic capacity in youth justice

When participants were asked about how the current youth justice system could better support young people with FASD, most raised diagnostic capacity as a significant issue. They identified several issues with the current diagnostic capacity for FASD in the youth justice system, including: a lack of workforce capacity; the missed opportunity for early assessment and intervention; the lack of adequate screening in the Youth Court; the lack of a clearly defined pathway from the courts to assessment; and the delays inherent in the legal process for obtaining assessment.

A. Lack of workforce capacity

Families

Government funding for FASD diagnosis was a focus for two parents, who suggested “a lot more people [should be] geared up to diagnose”. These parents recognised that diagnosis represents the first step in intervention and support and that if New Zealand had “20 times the amount” of professionals able to diagnose FASD, “then a lot of these kids wouldn’t get into trouble in the first place”.

Professionals

The lack of workforce capacity was suggested by one paediatrician to be related to clinicians’ hesitancy to diagnose a disorder that does not come with any services or support. If the Government formally recognised FASD as a disability and if a “FASD diagnosis came with funding to support the young person and their family, people would make that diagnosis!”

A psychologist stressed the need for diagnostic capacity to be increased among youth justice staff, but emphasised that proper training in FASD diagnosis was crucial: “you can’t just leap to being an expert when you’ve never done any assessments”.

Like the key stakeholder above, a Youth Court judge acknowledged that because mental health clinicians are generally trained in diagnoses contained in the DSM FASD is often missed. Although FASD is included in the most recent edition of the DSM, “it’s only there as something needing more research and development”.

The lack of capacity to diagnose FASD within the justice sector was a reason given for the entire process being too slow. A justice sector participant said that increasing capacity to diagnose would “speed up the process”, but first there needed to be “more resources [and] more people skilled in that field” [Director, Youth Justice Service Provider].

A Youth Aid Police officer lamented the lack of diagnostic capacity in the region as FASD is “not even looked at” by her colleagues. This participant also reiterated there was little point in further training in FASD for Police officers until diagnostic capacity was improved.

B. Early assessment and intervention

Families

If a young person was diagnosed as soon as they first encountered the justice system, one parent felt this might prevent years of people “just saying this is bad behaviour”. The issue of diagnosis as the first step for intervention was emphasised again: “even without services or supports being available to us ... the earlier the diagnosis, the better” [Mother].

Professionals

A paediatrician emphasised that early diagnosis, “along with a nurturing environment free from violence” was a protective factor against offending. A Youth Aid Police officer identified a similar issue, pointing to the number of incarcerated people with unaddressed mental health issues. If this population had “received proper support and help back in their youth, and their mental health was diagnosed and treated then ... our prison population would actually be lower”. Another justice sector professional explained that diagnosis contextualises the issues experienced by justice professionals working with young people, making it “much easier to interact” with them.

Justice professionals need to be aware of the warning signs for FASD before young people become entrenched in the system. Often by the time an assessment was ordered, “these kids have had a lot of years doing what they’re doing. It’s a shame we don’t ask those questions way back” [Youth Forensic Alcohol and Other Drug Clinician].

C. Lack of adequate screening

Ten participants talked about the lack of adequate screening in the youth justice system. Some of these participants talked about the Youth Court specifically, while others suggested the need for screening to occur much earlier in the system.

Families

The parents who raised the issue mentioned above regarding increasing diagnostic capacity in New Zealand also said it would mean that “all kids that come to Court would get some sort of screening”.

Professionals

The professionals acknowledged that the youth courts in New Zealand already have a forensic presence and that regular screening should already occur. They focused on the fact that forensic staff needed to be trained specifically in FASD and that the screening needed to be thorough enough to flag relevant issues. One psychologist felt that the forensic staff currently doing screenings are not spending enough time with the young people and that there needs to be “proper screening and a proper system put in place”.

Key Stakeholders

These concerns were echoed by a key stakeholder who said that forensic staff “do a quick assessment on the day of the Court ... they’re only spending minutes with them [young people]” and that “quick is not easy with FASD”. The inconsistency of current screening

practices was raised by a key stakeholder from the youth justice sector who said that the “screening is quite random [even though] they’re meant to be mandatory”. Even if screening is occurring, the clinicians are not trained in identifying FASD, it is “a pretty basic screen”.

Another key stakeholder suggested that there needed to be an assessment tool provided to frontline workers earlier, before the young people reach the Court.

D. Clearly defined pathway

Six professionals and two key stakeholders believed there should be a clearly defined pathway within the youth justice system for assessment for young people with FASD.

Professionals

There is no formal pathway for identifying young people with FASD and one psychologist said she mostly only received referrals “when people are jumping up and down saying we need an FASD assessment”. She felt that FASD needed to be recognised in the justice setting because “the legal process is important” – young people are being held to account for behaviour and “if they’ve got an underlying neurodisability that needs to be recognised properly”.

Trying to identify a young person’s needs had become an incredibly convoluted process for a Youth Justice Service Provider as often they must push for an assessment, when it should be the responsibility of the Courts, the judge, the social worker, or the young person’s lawyer. This participant felt the responsibility got passed around because no-one wanted to claim the financial burden and that young people were falling through the gaps as a result: “that’s the gap that needs to be closed. Recognising it and identifying it”.

A Youth Court judge noted that obtaining a full neuropsychological assessment for FASD involved “great difficulty” and after the diagnosis the Court was faced with the question “well, what now?” In contrast, one of the psychologists felt that the Youth Court could, and should, be assessing far more frequently and that health professionals could be trained in forensic assessment relatively simply.

The comments by the Youth Court judge were somewhat inconsistent with the parents’ opinions reported in Chapter Eight, as they felt that even without services and supports, a diagnosis was very helpful for their child.

Key Stakeholders

A key stakeholder from the youth justice sector felt there needed to be a mechanism for identifying young people with FASD “right at the start” before they reached the youth justice system. Often young people involved in the justice system will have been involved in state care years earlier: “there needs to be some mandatory process or specific direction around FASD at that point. There’s a missing link”.

E. Delays

Two professionals and one key stakeholder were concerned with the delays inherent in the legal process for obtaining a psychological assessment. One young person also noted this as an issue.

Professionals

The length of time it takes for an assessment to be completed is an issue that one participant said resulted in “young guys being needlessly incarcerated for long periods of time ... just waiting” [Social Worker]. This social worker recalled an example where a young person spent two years with their service before the Court finally found him unfit to plead due to FASD: “it’s taken a bloody long time”.

Key Stakeholders

In contrast to the professionals discussing the importance of thorough diagnosis in Chapter Nine, one key stakeholder questioned whether the Courts needed “a very detailed report” as the courts do not need to know “what colour shoes and socks you’re wearing.” The reports should instead focus on “whether they’re fit to plead, and whether they understand the process”.

Families

One young person commented that he “was left” in a youth justice residence waiting for a s 333 report to be chased up. He recalled being there for five weeks without hearing any update.

IV. Variability

Nine participants discussed the variability in current services provided by the youth justice system.

Families

For one parent, the variability related to the response of the staff at youth justice residences to his son’s FASD diagnosis. When asked whether the residences knew about his son’s diagnosis, the parent responded: “yes, but nothing was done about it except in one residence” [Father].

The variability in arrest and charging practices of local Police and how this can cause difficulties for parents of young people with disabilities was also raised as an issue. Some Police officers will respond to a call and help de-escalate the situation, but will not press charges, whereas in other localities charges will be laid. This is “quite hard as a parent” to know what to do: “[one friend’s] philosophy is ‘don’t ever let your child get anywhere near the youth justice system regardless’. Better to let them get away with it” [Mother].

Professionals

Local skill availability and the inability of Oranga Tamariki to “write decent briefs about understanding kids’ underlying needs” were cited by professionals as reasons for the variability in the capacity to provide support to young people with FASD in the justice system.

Interpretation of legislation was another area of concern, with a professional from the justice sector stating, “we see a difference of interpretation all over the place” [Director, Youth Justice Service Provider].

Key Stakeholders

One of the key stakeholders expressed concern about the Police's youth justice alternative action policy as "with discretion comes inconsistency". This participant also questioned the validity of removing the oversight of the judiciary: "now we've got Police doing alternative action – who's doing the oversight?"

Similar to professionals above with concerns about the variability in interpreting legislation, one key stakeholder referred to the principles provision of the OT Act that requires any measures for dealing with the young person to be designed to strengthen whānau, hapu and iwi. He recalled an example of a young woman who had "been in the system for years" and said that "all the agencies have touched her, [and none of them] could tell her what her ethnic background was ... what her tribe or iwi was". He questioned the care that was being taken with these young people if "we don't even know a fundamental thing like that".

Another key stakeholder provided a response to this concern, with reference to new legislation that strengthens the mandate to engage whānau, hapu and iwi with "three new pou, or principles, in it: mana tamaiti, whakapapa and whanaungatanga". The new principles should provide "more of a mandate" for youth justice service providers to try to engage, or "at least give opportunities for wider hapu and iwi to be involved in the plan for the young people".

V. Youth justice vs care and protection

The interface between New Zealand's youth justice and care and protection systems was raised by professionals as an area of concern.

Professionals

Section 208(b) of the OT Act states the principle that criminal proceedings should not be instituted against a young person on care and protection grounds. A professional from the education sector expressed concern at the separation of these two sectors. She felt that "they need to think carefully about having youth justice separate from care and protection" because the care and protection needs of the young person are often lost in the justice process.

A Youth Court judge acknowledged this issue when he said, "historically we have not done a good job of coordinating what happens for the young people in the Youth Court who are in the care and protection system" [Youth Court Judge]. This judge reflected on the intentions of the legislation regarding the interface between youth justice and care and protection compared to the reality of practice. He stated that the OT Act always intended for there to be an interface, but in reality "it was not at all unusual for young people entering the Youth Court to be bailed to a home they'd been removed from on care and protection grounds in the Family Court, because nobody in the Youth Court knew they were in the Family Court. There was no way of sharing the information".

This problem has been mitigated to a certain extent with the "crossover lists" discussed in Chapter Nine, but this judge emphasised the importance of doing better by these young people: "we need to do a much better job of tapping into the information that's available to us".

VI. Strategies to improve the system

In the context of the problems discussed above, participants were asked for their ideas about how the youth justice system might be improved for young people with FASD. Their suggestions are reported in the following five sections: the need for a paradigm shift in attitude; the importance of cross-agency collaboration; simplifying the court process; acknowledging the issue as health rather than justice; and providing alternate paths to justice for these young people.

A. Paradigm Shift

All those conceptions they [justice professionals] have about appropriate behaviour and social norms and expectations, you can just take them all off the table. [Mother and Father]

Several participants across all three participant groups suggested there needed to be a “paradigm shift” in attitudes to FASD in the justice sector. This involved three distinct, albeit linked, ideas: the vulnerability of young people with FASD in the justice system (including developmental age versus chronological age, and ability to comprehend proceedings); the importance of acknowledging FASD as a disability; and the importance of investing early.

i. Vulnerability within justice

Families

Young people with FASD are generally more vulnerable in the justice system. Parents explained that their young people were particularly susceptible to peer influence and abuse in a custody setting.

Parents suggested the justice system needed to take account of the difference between chronological age and developmental age in young people with FASD. Justice professionals dealing with young people with FASD needed to “change their thinking from ‘this is an 18-year-old’ to ‘this is a nine year-old’ ... [they need to] use language and terminology that they would understand if they were nine years old” [Mother]. One parent highlighted that the implication of the developmental age versus chronological age discrepancy is the young person’s level of comprehension is significantly lower than what might otherwise be expected.

This parent suggested employing some simple strategies to aid comprehension by making it “very clear at the end what the expectations are”. She added that it was important to check that the young person had understood by asking them to clarify what they think they need to do (in their own words).

Professionals

Like some of the parents cited above, a health professional expressed concern that people with FASD were potentially more vulnerable to the influence of peers and can end up being held responsible for crimes they did not commit. A school principal echoed this concern and said that young people with FASD would “follow people that they think are going to be nice to them” regardless of the potential consequences.

The justice professionals felt that young people's vulnerability in youth justice residences could result in intentional misbehaviour to secure time in isolation. There is a lack of resources to support young people with FASD in youth justice residences and so this participant explained that "security is the safest place to put them" [Social Worker].

Like some parents, the issue regarding the discrepancy between chronological age and developmental age as a factor in vulnerability was raised by a psychologist who suggested the youth justice system needed to consider this discrepancy: "these are very immature [young people], so they should be managed under youth jurisdiction for longer. Even at 20 they're still going on 8 or 10 in their thinking". A justice sector participant agreed, recommending that "while they may look like an 18 year-old, you need to mentally envision you're talking to a nine or 10 year-old".

Another two professionals raised the problem of comprehension within the justice system generally and the difficulties faced by young people with FASD. A social worker referred to "the languaging of literature" in Court and said that understanding things like bail conditions "isn't a youth-friendly process, let alone youth-friendly with learning disabilities".

If justice professionals assumed that everyone entering the system had a cognitive disability, a paediatrician suggested that some of the difficulties faced by young people trying to comprehend the justice system could be ameliorated. This participant recommended that justice professionals should approach the situation on the basis that the young person's reaction may be reflecting a disability, rather than just being bad behaviour. She said that professionals are not communicating well "with people who deserve better from us" and felt the responsibility lay with the adults. As professionals, "we should be coming to them with appropriate means of communication, not expecting them to get up to our level".

Key Stakeholders

Like the social worker quoted above, the general inaccessibility of the justice system was identified by a key stakeholder who questioned "what chance has a young person got?". This participant identified both age and difficulties in comprehension as compounding factors and suggested increasing the age of the Youth Court jurisdiction: "what about anyone up to 25? What about anyone up to 35?"

ii. Acknowledge FASD as a disability

None of us chooses what happens to us when we're in the womb. [Youth Justice Practice Manager]

Several participants raised not only the importance of acknowledging FASD as a disability, but also of accommodating it as a disability within the justice system.

Participants focused on the importance of identifying FASD, understanding it as a disability and recognising that the offending behaviours are an expression of the disability. The next step is to find:

supportive ways to accommodate them to be well-supervised. I think it's that understanding and then you can move on to a whole different paradigm of

accommodation. Working on their strengths. [Key Stakeholder, Alcohol Harm Prevention]

Several of these participants noted that the justice system already accommodated other disabilities and that including FASD was simply expanding on this practice:

Just as we have to communicate differently for a person who's deaf, or a person who's blind! [Key Stakeholder, Alcohol Harm Prevention]

iii. Investing early

Participants across all three sample groups raised the issue of investing early. Some emphasised the need to identify and diagnose FASD earlier, while others focused on the economic benefits of investing early.

Families

The misallocation of funding was an issue raised by one parent, who said that in New Zealand a significant amount more is spent on justice than on health. She said it was “frustrating that the Government has no choice but to pour all this money into care and protection, and to youth justice, and the justice system thereafter”. This parent pointed out that each individual incarcerated cost the Government “a huge amount, far more than if they put intervention and diagnosis right at the beginning”.

Professionals

One professional from the education sector identified a need to prioritise resources and ensure underlying issues are identified early. Like the mother quoted above, a paediatrician highlighted the economic benefit to investing early in these young people. His message was “not so much for justice, but for the economic minister” and noted that the choice is either to invest early and have “a workforce of people who are willing, able and enthusiastic” or to avoid early investment and “put them in jail [where they are] a detriment to the financial bottom line”.

One Youth Court judge acknowledged that the justice system should not be the vehicle for intervention, but that identification of FASD should be happening far earlier: “We’re doing the best we can in the Youth Court, but the Youth Court isn’t the solution to it” [Youth Court Judge].

A service provider for young people in the justice system also expressed frustration at the apparent attitude of waiting too late to intervene. This participant explained that to be eligible for their service, young people needed to have exhausted every other option, but by that stage it is often too late: “why wasn’t the work done a lot earlier?” [Director, Youth Justice Service Provider].

If disability was identified and supported earlier, the likelihood is our incarceration rates would be lower. A Youth Aid Police officer said that if the resources were there to intervene earlier, “we won’t see them in prison later on” [Youth Aid Police Officer].

Key Stakeholders

One key stakeholder reiterated the problem with using the justice system as a means for intervention and emphasised the importance of taking advantage of early opportunities for intervention:

What's everybody off doing before this kid got to Court? Should we really be celebrating the fact that we have to wait for these kids to commit crime, and then go 'yay, we can get an assessment'? Is that really what we're about? [Key Stakeholder, Alcohol Harm Prevention]

B. Cross-agency collaboration

Cross-agency collaboration was a strategy suggested by participants as a means of mitigating harm to young people with FASD in the justice system.

Parents

Two parents focused on the fact that the justice system was just part of the equation and that support for young people with FASD needed to be “a community approach”. They suggested having a social worker onsite at each school “just as you have public health nurses and dental nurses in schools”. The social worker would collaborate with “the Youth Aid Police officers and maybe public health as well”. The importance of providing support for parents was emphasised, when the parents explained that this multidisciplinary team would “be a link for families”.

The lack of continuity in service provision was emphasised by one parent who shared the experience she had with her son's interaction with the justice system and trying to access rehabilitative services for drug and alcohol addiction. He was eventually referred for drug and alcohol rehabilitation through the DHB, but by that time he had already been seen by multiple different agencies. His mother felt “there's a lack of joining up and there's a lack of continuity” with the agencies involved in his care.

Professionals

Two professionals from the justice sector said that the Government ministries are not communicating well enough together and are “working in silos”. Another justice sector professional recounted an example of a young person involved in youth justice, lamenting that “once he turns 17, very little of his information or history is going to follow him to Court”.

In contrast, one justice professional acknowledged that New Zealand's youth justice system allows for a collaborative approach to be taken in the courtroom, something that is absent in the adult justice system. This Youth Court judge reiterated that the Youth Court approach means a variety of voices are heard, including someone from the forensic service, the education sector and social workers.

One health professional commented on the Government-released FASD Action Plan which promises a cross-agency collaborative approach. This psychologist said that the plan is “supposed to be cross-ministry” with the Ministries of Education, Social Development,

Health, Justice and the Department of Corrections working together to achieve the targets set out in the Action Plan. However, it is unclear what progress has been made since 2016. When this psychologist talked about the Ministry of Justice's involvement, she said: "we're just not hearing what's happening ... or if anything is happening in that space".

Key Stakeholders

Like the psychologist quoted above, a key stakeholder described the Action Plan as a "helicopter view" of the issues. While acknowledging the Action Plan was a "whole of Government document", this participant also said it was a "bit of a mystery" as to what progress has been made: "I'm still waiting to see what, if anything, they're doing" [Key Stakeholder, Alcohol Harm Prevention].

Another key stakeholder said that FASD necessitated a "multi-faceted approach" and that a crime prevention framework "across the whole of Government" is in line with the collaborative approach the Action Plan recommended.

The importance of cross-agency collaboration generally was emphasised by key stakeholders. It is important for people not to be overwhelmed by "the system", but to be empowered by the fact that "systems are just people". To help improve support for young people with FASD in the justice system, the agencies concerned simply needed to "join forces and communicate".

A key stakeholder from the youth justice sector identified the lack of information sharing between health services and the Youth Court. Young people's interaction with mental health services was not automatically made available to the Youth Court and the various agencies were not talking to each other.

The issue was also summarised by a key stakeholder, who said:

There needs to be far greater openness and sharing across sectors than there has ever been before. FASD does not sit anywhere in isolation. We're still way too siloed in our approach to this. There's not nearly enough trust and communication going on across agencies. And I don't think there's enough connection between the people with expertise who can help, and the people who are dealing with the systems and running them. So I want to get a collaboration and engagement. I also want to see families at the decision-making table, and that's something that has not been at the fore enough. [Key Stakeholder, Alcohol Harm Prevention]

C. Simplify the Court process

In response to being asked how the youth justice system could be improved for young people with FASD, participants talked about the complexity of the Court system. Several specifically identified the difficulty young people with FASD have complying with Court order conditions or conditions of bail. Participants suggested that simplifying the process, even just in the way conditions are communicated to young people, could improve outcomes.

Families

One mother spoke of her son who had been given a discharge without conviction, but did not understand one of the conditions associated with the sentence: “he was discharged, but if anything happened in the next six months ... he didn’t understand the ‘if anything happened in the next six months’ part”.

This same parent identified a particular problem with bail conditions. Her son had difficulty understanding the conditions and would continually break curfew. While this participant could see this was as a result of his neurological disability, “the Police just saw it as defiance and lack of respect”.

Professionals

A social worker raised this issue in a general way by identifying that the “language of literature” in court is not “youth-friendly” regardless of the added presence of a neurological disability.

Several participants from the justice sector suggested some practical ways this issue could be mitigated. One Youth Court judge focused on how he communicated with young people and tried to ensure the young person had understood what their responsibilities were. He believed it was important for justice professionals to have expert advice on hand and referred specifically to the wording of bail conditions were “bad enough anyway for even a person without FASD” when they used words and phrases like ‘reside’ and ‘not to associate’.

One social worker spoke about a specific young person she had worked with and the strategies they used for him. Justice professionals were provided with a “tip sheet” on how to communicate best with her client. Simple things like “use short sentences” and waiting patiently for a response, even if it takes a few minutes. More practical strategies included always using the same courtroom and have the client stand in the same place to avoid the young person feeling disoriented and stressed.

Key stakeholders

One of the key stakeholders also referred to the issue of bail and conditions and suggested that the justice system needed to make some accommodations for these young people. Simplifying the language of bail conditions or taking account of a young person’s difficulties when drafting them could avoid significant recidivism in young people with FASD. The current practice of compounding punitive sanctions was not working: “It’s not teaching them. It’s teaching them how to fail” [Key Stakeholder, Alcohol Harm Prevention].

D. Treat as a health issue

Two professionals from the justice sector suggested that young people with FASD who offend should be the responsibility of the health sector, not justice. These participants pointed out that the law works too slowly for these young people, and also that the health system is able to be more flexible regarding treatment options: “This young person needs treatment, not punishment” [Social Worker, and Director, Youth Justice Service Provider].

The issue of funding and resources supported the argument for young people with FASD sitting predominantly under the health umbrella. The professionals from this youth justice

service provider said they were getting the young people “on the smell of an oily rag” compared to organisations funded through the health system that were getting “so many resources available to them”. They described the offending of young people with FASD as being driven by the diagnosis and that FASD was “actually a health problem, not a justice problem”.

They also felt the justice system was too restrictive regarding the amount of time a service provider could work with a young person. The health system works with an individual for the length of time treatment is needed, whereas youth justice service providers are part of the restrictive, punitive element of a young person’s order. When they tried to “fight” to work with young people for longer, they “get restricted”. They said the Courts told them that “in terms of law you’ve done enough, [the] punitive element is finished.”

Finally, these two professionals pointed to the adult justice system as evidence to support a change of approach being needed. They emphasised the number of illiterate adult prisoners and suggested that as young people those individuals should have been swapped into the health system and offered the support and treatment they required. For young people with FASD specifically they suggested getting “the diagnosis done asap is what I say, and swap the system, tag into health” [Social Worker and Director, Youth Justice Service Provider].

E. Alternatives

Participants were also asked whether they had any suggestions for an alternative pathway for young people with FASD in the justice system. Responses varied, from specific suggestions like specialising Courts and residences, to more general comments regarding the detrimental nature of incarceration.

i. Prison is not the answer

We can’t lock them away forever, amen. [Director, Youth Justice Service Provider]

Thirteen participants (six parents and seven professionals) emphasised that incarcerating young people with FASD was ineffective despite acknowledging the conflict faced by the justice system regarding the importance of accountability for one’s actions. They emphasised it was the manner by which young people with FASD were held to account that needed to be different.

Families

One parent talked specifically about the experiences his son had in youth justice residences throughout the country and the damaging nature of peer relationships for young people with FASD during incarceration. Their suggestibility often resulted in behaviour becoming worse as they try to “fit in” with the other young people in the residence, to the extent that they start to believe their offending defines them: “Every time I’d talk to him, his goal was: ‘I wanna live in Auckland and I’m a crim’” [Father].

Professionals

The justice system’s focus on accountability was suggested as not necessarily being the best approach. One education professional identified that the legislation required young people

to “have an opportunity to learn”, but emphasised that this would not be provided or fulfilled “in doing meaningless community hours”.

The default for young people with FASD seemed to be incarceration simply because there were no alternatives. A Youth Aid Police officer said that “it seems a shame to incarcerate them in a youth justice facility”, but questioned “what else is there?”

Similarly, two professionals working for a youth justice service provider focused on the importance of providing an environment for productivity and learning. They emphasised the need to work with these young people in the community because “at the end of the day they’re going to be somewhere in the community”. The primary issue was to ensure the young people were taught basic transferable living skills, because eventually “they are going to be adults”.

ii. ‘Box-ticking’ is ineffective

In looking at what needed to be improved in the current youth justice system, three professionals pointed out the ineffectiveness of formal ‘box-ticking’ exercises. One social worker had experienced young people “muddling their way through” a Court order and being signed off without ever really engaging or addressing the underlying causes of their offending.

These professionals described the risk of rushing a young person into services or programmes because if the young person was not ready and did not engage “you’re burning bridges with the course ... and the young person retracts further because they’re just being isolated again” [Director, Youth Justice Service Provider].

iii. The importance of advocates

Participants said that having an advocate for, or mentor track with, the young person could make a significant difference to their outcome, especially in the justice system.

Family members

Jasper specifically mentioned mentoring as an option that he felt would be effective in providing better support to young people with FASD in the justice system. He had personal experience with a mentor and found it incredibly helpful.

Professionals

Professionals talked specifically about the effectiveness of good role models for young people with FASD. One paediatrician suggested that there should be “some form of youth programme set up specifically for offenders” where they have the opportunity to be “mentored with positive role models”.

Two professionals spoke about the youth justice programme they ran and the care they took in formulating peer groups for the young people to work in. They said it was important not to exclude the young people “otherwise they’ll feel isolated” and instead worked to get their “strongest peer supporter in there [with the young person], they can do it together”.

A SENCO teacher suggested ways the education system could extend its current support systems to include a mentoring programme for young people with FASD. She talked about the Ongoing Resourcing Scheme (ORS) that supports young people transitioning out of school and said that if this was available to FASD students, “it would give the student, family and school someone else to act as that ‘friend’ to grow the person, build the relationship and mentor transition. Nothing like this exists for any student unless they are ORS” [SENCO Teacher].

Another professional talked about this issue in the context of the intensive amount of support and supervision young people with FASD need and the difficulty this presents in a society where there are no support services.

Key Stakeholders

Like the professionals above, the key stakeholders agreed that young people with FASD needed good role models and adequate levels of support and supervision. They went one step further and specified that in the youth justice context these young people needed advocates to help them comprehend legal proceedings: “they’ve got to have somebody alongside of them, an advocate to interpret what’s going on and help them understand it” [Key Stakeholder, Alcohol Harm Prevention].

The other two key stakeholders raised a separate issue in the context of advocacy for young people in the youth justice system when they expressed concern at how late in the process a young person is assigned a legal representative (youth advocate lawyer). When a young person is interviewed by a Police officer, “there’s no mandatory requirement that you have to ring a youth advocate”. Their particular concern with this issue was that an interview between a young person and a Police officer was “a pretty unequal playing field”. They referred to a “little fluffy piece of law” which allows Police officers to “essentially facilitate a breach of the young person’s rights” by interviewing them without a youth advocate present.

Both key stakeholders referred to s 231(1)(d) of the OT Act, which allows a Police officer interviewing a child or young person to nominate a third party to support the child. The nominated third party is not legally trained and one key stakeholder expressed concern that young people should be entitled to legal representation “from the get-go”.

The key stakeholder from youth justice was particularly concerned about the effect this legislation had on the treatment of young people with FASD and other neurodisabilities in the justice system and said that it was “entrenching or encompassing the institutionalised view that people subject to this disorder should just be dealt with in an arbitrary manner”. They concluded that a young person’s representation “should be a lawyer”.

iv. Sustained support

Participants emphasised that any support provided by the justice system for young people with FASD needed to be sustainable, with a longer-term focus than current programmes.

In this context, several participants (from across all three sample groups) explained that for young people with FASD, the behaviour associated with the brain damage was not necessarily able to be changed.

Families

One parent showed how these issues are related, by first acknowledging that the behaviour was not able to be changed and then suggesting practical ways to support these young people nonetheless. Instead of requiring the young person to change, the justice system needed to first understand that “that’s actually a big ask, because it is a disability”. Secondly, the justice system needed “to be asking everybody around them [the young person] to change, and accommodate, and offer support and services”.

Professionals

A Youth Aid Police officer had experienced first-hand the necessity for sustained support. In her work with a young person with FASD, she said the young person would acknowledge the behaviour during discussion, but would “leave the room and just do it again”.

Like the parent above, one of the health professionals said that despite the behaviour being difficult or impossible to change, it did not mean there was nothing to be done to support these young people. It is crucial not to give up hope on these children, but rather to adjust expectations and be more flexible in what constitutes an acceptable outcome:

It doesn’t matter how careful you are, they’re still going to behave inappropriately. But it’s the response to that, and the guidance that’s provided that will lead to better outcomes ... it won’t necessarily stop them ever reoffending. [Psychologist]

This psychologist also emphasised the importance of the support being ongoing: “The problem is the minute they leave care, and they leave the oversight of people who know what to do, then they’re left to their own devices and then they’re offending and coming to prison”. She recalled that young people she had been involved with as children were “now coming out into adulthood at Mt Eden [Prison]”.

A Youth Court judge acknowledged that historically in the Youth Court, repeated offending behaviour “we just used to see as evidence of naughtiness, or badness”. He spoke about young people with brain damage being unable to learn lessons in one context and apply them in another. The efficacy of the programmes young people are sent to rely on this ability and he commented that while the programmes were “gold standard”, they were “pitched at the functioning of a normal person!” When young people were consistently ‘failing’ at these programmes, the Youth Court “just decided we needed to ramp up the sanctions”.

The professionals raising the importance of sustained support referred specifically to the time constraints currently faced within the justice system. This reflects the issue discussed above regarding the limited time available for youth justice service providers to work with young people. The providers of a support service for young people in the justice system said that “it takes time” and that providing care for these young people “shouldn’t be time bound in terms of level of support”.

One health sector professional also felt that because young people with FASD “absorb” the people they are around, in order to become “really strong and resilient” they needed to experience positive affirmations from supportive individuals. However, “that level of care ... operates in a long-term fashion”. He explained that for support services to be effective,

they need a foundation “that’s got a 50-75-year mission ... a visionary idea that allows for the agency to operate with a very, very long-term focus” [Paediatrician].

v. *Specific services for young people with FASD in the justice system*

Participants across all three sample groups identified the current lack of targeted services in the justice system for young people with FASD.

Families

A parent felt that drug and alcohol rehabilitation services were “not geared up for people with FASD”. The services needed to be more aware of the impulsivity of young people with FASD and to have “some sort of allowance ... for the time it takes them to adjust and to understand”. Jasper also suggested that support needed to be targeted to young people with FASD, including the development of “courses explaining legal processes and possible consequences for different offences”.

Professionals

Most professionals discussed this issue. They suggested a variety of specific support services that the youth justice system needed to utilise or to develop specifically for young people with FASD, such as substance abuse support, transition services and enhanced support in schools.

One health professional singled out the issue of substance abuse: “a lot of these young people are already struggling with substance abuse” and suggested that the courts needed to “recognise that and try to put something in place” [Paediatrician].

The development of FASD-specific support services, including transition and supported living services was suggested, as young people in the justice system needed “to be transitioned [from the youth justice system] into some kind of adult services that provide oversight ... some kind of supported living arrangements” (Psychologist, Auckland). General youth justice support services that focus on reward charts and level systems “probably work for well-adjusted, Pākehā children” but are “not equipped to deal with [FASD].”

One professional suggested that the services that are provided should be mindful of stigma and that offering support for young people with FASD should not happen in isolation from their peers. In contrast to several professionals quoted above, this professional suggested that providing FASD-specific services was not necessarily the best approach. She said that “all young people want is to be seen to be the same” and that instead of developing new services, the focus needed to be on adapting the services that currently exist to manage young people with FASD in addition to neurotypical young people.

The education system’s ORS, which provides specific funding to schools to support students with additional learning needs, was raised as a possible service the justice system could utilise. Young people with FASD are not automatically eligible for ORS funding, but a teacher suggested a similar scheme needed to be available to support students who are currently missing out. The Ministry of Education and the Court system needed to “get their heads together” to develop a system of support in collaboration with schools, families and foster carers.

This teacher also suggested there needed to be collaboration between schools and workplaces and that students needed to engage in something they could see success in. She talked about an initiative led by the Warehouse called the “red shirts” whereby young people are offered work at the Warehouse as part of an NCEA programme. The Warehouse does not necessarily employ the young person afterwards, but they do offer references, and it makes the young people “feel like a million bucks”. This participant emphasised how effective this programme was at raising self-esteem in young people and “lets them think they are employable”.

The “red shirts” programme only starts at Year 11 (15 and 16-year-olds), but this teacher felt that similar initiatives that focused on vocation rather than academia needed to start earlier to avoid children disengaging. Often by Year 11, “we have lost these kids’ drive and energy to succeed” due to their needs being left unsupported for too long. Programmes targeted at children who do not thrive in an academic environment needed to be “early and ongoing” and they needed “funding and commitment”.

Like the justice professionals quoted earlier in this chapter, several professionals articulated that it is not the justice system that is lacking, but rather the health system’s responsibility to prioritise these young people and provide support services to which the justice system can refer them. One paediatrician felt strongly that it was “not a problem of the youth justice system which is excellent. It is a problem with the health system which has not prioritised these young people”.

The consequences of inadequately supporting young people with FASD, or removing the supports, is that they “drop to the bottom of society”. One psychologist explained that with support, young people with FASD can function at a high level. If that support is removed, they become prone to “victimisation and offending as a sort of desperate means to get money”. The paediatrician explained that young people with FASD are too often left to “fall by the wayside, in the ruinous trenches of society”.

Key Stakeholders

The key stakeholders who raised the issue of support services framed it in a variety of ways.

One spoke generally about what young people with FASD needed and again reiterated that it comes down to the adults around the young person being aware of their needs. Instead of expecting the young person to gain insight into their behaviour, the adults around them needed to ask “how do we accommodate them better? And how can we help them divert their behaviour on to a positive path?” [Key Stakeholder, Alcohol Harm Prevention].

Like the professionals quoted above, another key stakeholder felt that it was not the justice system that should be wholly responsible for these young people. The education system and the health system served as points of contact to these young people, and actually “the first point of contact – it’s health!” [Key Stakeholder, Justice].

A key stakeholder from the child advocacy sector agreed with the professionals above who emphasised the importance of FASD-specific supports and services. She referred to the current lack of workforce capacity as an impediment and said that working effectively with families is “quite a skill” that requires specific cultural knowledge and sensitivity. She

explained that currently there is a lack of capacity and capability in the workforce “to actually provide what is needed”. The answer was to “slowly grow and build capacity”.

The final key stakeholder who raised this issue also identified the importance of acknowledging the significance of culture in support services and of ensuring a wraparound service of support. More is needed “than just to throw money at one part of the issue”. Instead, targeted support should be available “to fund Rangatahi programmes that connect to cultural identity” and to ensure that every aspect of these complex issues is addressed. Services should also be flexible enough to target additional issues “as they present” [Key Stakeholder, Māori Advocacy].

vi. Focus on strengths

The effectiveness of focusing on a young person’s strengths was discussed by participants across all three sample groups. This was raised in response to several different questions during the interviews, but the following participants specifically raised it in the context of the youth justice system.

A paediatrician noted that there are many things that young people with FASD are good at that can be missed by those who are unaware of the importance of these skills:

People don’t hear about the fact that these people are really great caregivers to older folk, to younger kids, to pets ... they’re really good with their hands. They’re hard workers when they’re given a task and they know what they need to do. They’re very organised with respect to small-scale repeated activities. They’re very expressive, they usually have some form of an artistic bent, one way or the other. They’re extraordinarily positive and pleasant when they’re seeing positive and pleasant reflected to them. They don’t know any strangers, they’re usually the best greeters in the world, they’re enthusiastic, they don’t hold grudges. ... There are lots of positive things about someone with FASD. The problem is, those aren’t things that are prized in society with respect to getting ahead, getting a job, ‘making it’. Those are seen as passive skills, that someone’s got to do because someone can’t do something more. And that’s a sad way to think about it as well. Because folks with FASD don’t see it that way. [Paediatrician]

vii. Specialising

Nine participants (two parents, six professionals and one key stakeholder) talked about the possibility of specialising aspects of the youth justice system for young people with FASD. Specialist courts were suggested for young people with neurodisabilities, like the Drug and Alcohol Courts that currently exist.

Others talked about the difference it made having specialist staff working in the justice sector. In the context of youth justice, it is only relatively recently that judges have been able to specialise. Previously, judges were often only doing youth work about 10% of their time. One Youth Court judge questioned “what person could you think of in any other walk of life who you would think a specialist if you found out they were only doing that 10% of their time?”.

Four participants raised specialism specifically in the context of youth justice residences as they are currently ill-equipped to manage this cohort of young people. One social worker explained that there is no process to treat young people with FASD any differently and said “there is a complete lack of an understanding within residences from staff”. This reflected one of the parent’s experiences reported in Chapter Eight, where his son had experienced multiple youth justice residences with only one of them acknowledging his disability. One of the young people confirmed this with his experience that “in the youth justice residences they don’t know much about disabilities”. To mitigate this issue, a practice manager for youth offenders suggested that one of the four youth justice residences should be tailored to young people with FASD and it “should be designed to feel welcoming to an 8 or 9 year-old”.

A key stakeholder suggested that the justice system is aware of this issue and is investigating possible alternatives, like “whether we need a youth justice residence that just specialises in kids that are very vulnerable”.

This participant also raised the possibility of ‘remand homes’ becoming more tailored to specialist groups of young people. She emphasised the importance of specialist staff trained in looking after young people with neurodisabilities working in the ‘remand homes’, so that they can have access to “good support and good activities and good structure” [Key Stakeholder, Child Advocacy].

VII. Conclusion

The most significant issues with the current youth justice system’s ability to provide for young people with FASD were discussed by participants from all three sample groups. New Zealand’s lack of diagnostic capacity for FASD was highlighted as a central issue by parents, professionals and key stakeholders alike, as well as the need to train health, education and justice workforces to recognise and manage FASD in young people. Both young people also reported the lack of awareness of FASD as an issue that needed to be rectified and suggested that the main solution to this problem was for professionals to “learn about it” and develop some FASD-specific support services. Family members emphasised the need for justice professionals to engage in a paradigm shift of accommodation and understand that the young person in front of them is manifesting their disability, not being wilfully obstructive. Professionals and key stakeholders emphasised the importance of moving beyond the point of identification to develop a streamlined process for young people to access diagnostic services and targeted supports and interventions.

For young people with FASD to successfully cycle out of the justice system, all participants felt it was vital for agencies to develop better lines of communication and information sharing. Professionals felt that the Youth Court should have automatic access to relevant records for the young person concerned and that the agencies involved with the young person (whether it be mental health, alcohol and other drug misuse agencies, or Oranga Tamariki) should have a system of sharing information. A simple manifestation of this suggestion suggested by a parent would be a multidisciplinary team present in each school (including a representative from Police, Oranga Tamariki and health).

It was also suggested that young people with FASD who offend should be dealt with primarily through the health system, acknowledging the cause of their antisocial behaviour

as a health issue rather than as an issue for the justice system. Falling short of this, participants felt that aspects of the justice system should at least become specialised for young people with FASD. Youth justice residences could tailor their response assuming that the majority of young people have some sort of neurodisability, or one of the four residences could become a focused FASD-residence. A specialised neurodisability Youth Court was also suggested as an option. Specialising youth justice processes could mitigate the delays inherent in the current system, an issue that was raised by several participants. One of the young people had experienced this first-hand, with a long remand period at a youth justice residence waiting on the results of a s 333 psychological report. This young person emphasised how difficult it had been waiting for the report with no information and no update as to how long it was likely to take.

While the importance of positive role models or advocates was emphasised by the professionals and key stakeholders, this was much less evident in the perspectives of the parents. Interestingly however, one of the young people also emphasised this as an option that could have positive effect. Similarly, while professionals and this same young person articulated in detail their ideas for specific services for young people with FASD, the parents did not go further than agreeing that support services needed to have an understanding of, or allowance for, young people with FASD.

The final chapter discusses these suggestions within the national and international contexts, together with the current state of knowledge on FASD, to articulate a set of recommendations for New Zealand.

Chapter 11

Discussion, Recommendations and Conclusions

I. Introduction

FASD is a growing problem for New Zealand's youth justice system. The physiological effect of prenatal alcohol exposure on the developing brain results in a constellation of behavioural difficulties and learning challenges.⁹⁵¹ Young people with FASD present with a variety of symptoms that are not always easy to identify, but that can be used to characterise a particular type of youth offender. Young offenders with FASD tend to be opportunistic and impulsive, easily led by their peers, and they often commit poorly planned offences (such as in broad daylight in view of witnesses). They are also often recidivist offenders who do not learn from their mistakes and they fail to comprehend the impact of their offending on themselves or others.⁹⁵² This doctoral research therefore makes a unique and timely contribution by highlighting the lived experiences of young people with FASD, parents and caregivers and the challenges they face in general and in the youth or criminal justice systems in particular. Their insights illustrate the enormity of the difficulties and barriers they encounter in their daily lives and in their interactions with health, education and justice professionals. The perspectives of professionals and key stakeholders are also shared and their suggestions, together with those of the family members, to improve diagnostic, legal and judicial responses are worthy of serious attention if New Zealand is to truly offer young offenders with FASD a just and supportive outcome.

This chapter firstly considers the scope of the problem that FASD presents for the justice system and focuses on the New Zealand context where a poorly supported workforce and a lack of formalised targeted interventions are currently commonplace. It then discusses four priority areas for action and further research: pre-justice involvement in pre-emptive measures (diagnostic capacity and support in schools); training for professionals; youth justice policy; and legislative change. These four priorities confirm the significance of FASD as an urgent problem that New Zealand must address to ensure the response to young offenders with FASD is improved.

II. FASD: the problem

The effects of prenatal exposure to alcohol can be devastating: a child can be born with significant, permanent brain damage that manifests slowly over time through a series of complex learning and behavioural challenges.⁹⁵³ Compounding the difficulty faced by these individuals and their families is the fact that the disability is 'hidden' in the child's brain – it is not a disability that can be recognised or identified by looking at a person, talking to them, or even observing them over time:⁹⁵⁴ FASD is therefore known as the "invisible

⁹⁵¹ Hayward, above n 18.

⁹⁵² Craig Immelman "Fetal Alcohol Spectrum Disorder and Youth Justice in New Zealand" (Alcohol Action New Zealand 3rd Annual Conference 2012, University of Otago, Wellington).

⁹⁵³ Ministry of Health, above n 21 at 4.

⁹⁵⁴ Ministry of Health, above n 21 at 4.

disability”.⁹⁵⁵ The Ministry of Health, in its Discussion Document on the proposed FASD Government Action Plan (Taking Action on Fetal Alcohol Spectrum Disorder), acknowledged that “the most serious” damage caused by prenatal alcohol exposure is hidden in the brain.⁹⁵⁶ One of the research questions underpinning this study asked what the differences are between intellectual disability (as defined in the IDCCR Act as an IQ below 70) and the symptoms of FASD, and the Fetal Alcohol Network NZ (FANNZ) reiterated the invisible nature of FASD by explaining that the cognitive functioning of people with FASD is often much lower than their IQ or physical appearance would suggest.⁹⁵⁷ The findings of this research are consistent with this: 92% of the parents interviewed in this study described the challenges they experienced parenting in the face of an unidentified disability, with peers and professionals alike often judging them as “shit parents”.⁹⁵⁸ The professionals also reported having misconceptions about being able to identify FASD in a person’s face, not understanding until late in their careers that the majority of individuals with FASD will show no physical signs at all.⁹⁵⁹

So how should a justice system be expected to cope with a cohort of young people with a disability that is almost entirely hidden, but that has significant implications for culpability, recidivism and rehabilitation? The first and most crucial step is to reveal the disability by being aware of the signs and providing thorough and effective diagnosis. Children with FASD often receive multiple incorrect diagnoses before an assessment for FASD is completed, due to the presentations of the disorder appearing similar to other conditions (such as ADHD or Conduct Disorder).⁹⁶⁰ In a New Zealand Youth Court case, a 14 year-old boy had prior diagnoses of ADHD, Conduct Disorder and substance disorder, but it was not until he was assessed through the Youth Court that he was found to have FASD.⁹⁶¹ Salmon commented, in the results of a 2008 New Zealand survey, that not only is it crucial to correctly identify FASD so that proper support can be put in place, but also that receiving multiple, incorrect diagnoses for a child is incredibly frustrating for the families.⁹⁶² The findings reported in this thesis showed how families with a child with FASD are often passed “from pillar to post” before a correct diagnosis is made. This culminates in the child having multiple, incorrect diagnoses that may describe the behaviour, but do not facilitate the provision of effective support or management techniques.⁹⁶³

In order to avoid children with FASD being misdiagnosed and subsequently mismanaged, early identification of, and assessment for, FASD is crucial. While some health professionals are hesitant to diagnose the condition for fear of attributing stigma to the family, the 2008 survey by Salmon confirmed that the predominant feeling for mothers post-diagnosis was one of relief, because “as well as knowing what was wrong with the child, it also made sense of confusing behaviours they had ... thought were the consequences of their own poor mothering skills”.⁹⁶⁴ The findings of the current research reflect this sentiment, with parents

⁹⁵⁵ Fetal Alcohol Network NZ, above n 64.

⁹⁵⁶ Ministry of Health, above n 21 at 4.

⁹⁵⁷ Fetal Alcohol, Network NZ, above n 64.

⁹⁵⁸ See Chapter 8, page 146.

⁹⁵⁹ See Chapter 9, page 166

⁹⁶⁰ Ministry of Health, above n 21 at 4.

⁹⁶¹ *ED* above n 465 at [6].

⁹⁶² Salmon, above n 144 at e202.

⁹⁶³ See Chapter 8, page 145.

⁹⁶⁴ Salmon, above n 144 at e202.

expressing how the diagnosis meant they could “stop searching for an answer” and how it was helpful having confirmation that the source of their child’s challenging behaviour was “not just your parenting”.⁹⁶⁵

Work being done internationally supports the importance of early identification of FASD. An article examining the diagnostic context in Australia reported that, contrary to professionals’ perceptions, caregivers described the diagnostic process as empowering.⁹⁶⁶ The Canadian Guidelines for Diagnosis similarly emphasise that a diagnosis of FASD is not a stigmatising label, but rather “provides a blueprint for early intervention”.⁹⁶⁷ Locally, the Hawke’s Bay DHB DAP for FASD recognises this, describing their model as “a therapeutic intervention rather than being a solely diagnostic process”.⁹⁶⁸ The current research confirms this position, with health professionals describing the diagnostic process as “therapeutic” and emphasising the importance of early intervention.⁹⁶⁹ To mitigate the potential harm caused by an “invisible disability”, the first step in the process is to identify and diagnose FASD so that individuals with the disability can be provided appropriate support.

For New Zealand to be reflecting international practice in identifying and diagnosing FASD there needs to be, firstly, a mechanism to provide for referral and diagnosis nationwide, as well as more professionals trained in recognising the signs and subsequently assessing and diagnosing the condition. An invisible disability will remain invisible unless the professionals interacting with these young people (and in the justice sector that includes youth advocate lawyers, Youth Court judges, social workers, youth justice FGC coordinators and Police officers) are adequately trained. Shelton et al., in Australia, recommended that training in the health sector needed to extend to GPs, specialists, nurses, midwives and allied health professionals.⁹⁷⁰ Canada has been farsighted enough to provide specific training in FASD through the Asante Centre; a not-for-profit organisation offering intensive training in FASD for professionals worldwide.⁹⁷¹ The call for extensive training among health, justice and education professionals was near unanimous by the participants I interviewed, with 100% of the family members and key stakeholders and 70% of the professionals raising the issue.

With the problem identified, the question then becomes, “well, what now?” – as was articulated by a Youth Court judge in my study. Young people with FASD present a unique problem for the Youth Court: they are often articulate and intelligent, so do not fall within the ambit of the intellectual disability legislation, nor do they obviously satisfy the criteria for being found unfit to plead or stand trial.⁹⁷² And yet their pervasive and permanent brain damage results in a pattern of behaviour that cannot be ignored. Their impulsiveness and inability to consider consequences increases their risk of offending behaviours; their communication difficulties and reduced developmental age compounds their vulnerability in the justice system; and their poor memory precludes the efficacy of conventional

⁹⁶⁵ See Chapter 8, page 147.

⁹⁶⁶ Shelton, above n 534 at 1124.

⁹⁶⁷ Chudley, above n 132 at 4.

⁹⁶⁸ Health Promotion Agency, above n 135 at 25.

⁹⁶⁹ See Chapter 9, page 159.

⁹⁷⁰ Shelton, above n 534 at 1124.

⁹⁷¹ Asante Centre, above n 155.

⁹⁷² See Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003, s 7; Criminal Procedure (Mentally Impaired Persons) Act 2003, s 4.

rehabilitation programmes. Canadian academics, Mela and Luther, argue that to be held criminally responsible for offending, an individual must possess the cognitive ability to “analyse information to assist in decision-making” – something that individuals with FASD often do not have.⁹⁷³ The findings from the current research establish that for young people with FASD, “all those conceptions [justice professionals] have about appropriate behaviour and social norms and expectations, you can just take them all off the table.”⁹⁷⁴

To effectively address the problem of FASD in the justice system, the concepts of autonomy and criminal capacity must be acknowledged. As previously discussed in Chapter Five, if an individual does not possess the neurological capacity to integrate cognition and emotion, they should not be held fully accountable for criminal offending.⁹⁷⁵ This concept is reflected through the accepted defences of insanity and duress.⁹⁷⁶ Criminal justice systems, including both the adult and the youth justice systems in New Zealand, also acknowledge that the developing adolescent brain inhibits this capacity and support for young people is therefore reflected in the principles of the OT Act.⁹⁷⁷ For young people with FASD, they are faced with the compounding issue of adolescent brain structure and permanent brain damage through prenatal alcohol exposure, and for these young people, there is no support. To consistently acknowledge the role autonomy plays in criminal responsibility, New Zealand’s youth justice system must go further to ensure these young people are acknowledged and supported as they move through the justice system.

Four key themes have emerged from this research that unfortunately highlight just how far New Zealand lags behind Canada and Australia in providing support for young people with FASD and how urgent change is needed. These four issues, discussed in detail below, are: the importance of pre-emptive measures, including a formalised diagnostic process and support in schools; widespread training for professionals in the health, education and justice sectors; implications for youth justice policy; and finally legislative changes to ensure young people with FASD are provided with adequate support in the justice system. The following discussion provides answers to the final two research questions of this study: drawing on the international context, how can legislative, diagnostic and community-based initiatives more effectively address the needs and rights of young people with FASD in the justice system; and how should legislative, diagnostic and community-based initiatives be formulated to this effect for New Zealand?

The ensuing recommendations are made on the premise that in developing any new policy or legislation, young people with FASD are an integral part of the process. Article 12 of the UNCRC⁹⁷⁸ requires States Parties to “assure to the child” the right to express their views on all matters affecting them, and for those views to be given “due weight”.⁹⁷⁹ This is consistent with the new principles of the OT Act, specifically s 5(1)(a) requiring a child or young person to be encouraged and assisted to participate in any process, proceeding or decision affecting them. The New Zealand Disability Strategy articulates that one of the three

⁹⁷³ Mela and Luther, above n 844 at 49.

⁹⁷⁴ See Chapter 10, page 186.

⁹⁷⁵ See Chapter 5, page 110.

⁹⁷⁶ See Chapter 5, page 94 and 97.

⁹⁷⁷ Section 208.

⁹⁷⁸ To which New Zealand is a party, having ratified it in 1993.

⁹⁷⁹ See also: Office of the Children’s Commissioner “Children’s participation” www.occ.org.nz/our-work/childrens-participation/.

cornerstone principles of the document is that disabled people are involved in decision-making that impacts them and one of the listed outcomes of the strategy is that “we have choice and control over our lives”.⁹⁸⁰ This includes that as children, their views will be considered “when choices are made about what supports and services we receive and what things work best for us”.⁹⁸¹ Any changes that are made in the best interests of young people with FASD must be made in collaboration and consultation with those young people, acknowledging that they are “experts in [their] own lives”.⁹⁸²

III. Pre-emptive measures

Prenatal alcohol exposure leads to permanent brain damage affecting neurocognitive functioning (such as impaired executive functioning due to frontal lobe damage).⁹⁸³ This kind of damage is known as the “primary disability”, the harm that is a direct result of the exposure to alcohol. There are also harms that occur when the primary disability (the neurocognitive impairment) is not adequately supported and accommodated in society and these harms are known as “secondary disabilities”.⁹⁸⁴ Secondary disabilities include, for example, substance abuse and criminal offending.⁹⁸⁵ There is an opportunity here to intervene, by identifying and acknowledging the primary disability and providing adequate supports to prevent the individual from experiencing secondary disability (in the context of this thesis, criminal justice involvement).

The distinction between primary disability and secondary disability was an issue reflected in the findings of this research, with participants acknowledging the importance of providing support *before* a young person becomes involved in the criminal justice system.⁹⁸⁶ The consequence of the primary disability being left unidentified and subsequently unsupported is that young people with FASD will “fall by the wayside, in the ruinous trenches of society”.⁹⁸⁷

A. Diagnosis

The 2015 review of the Hawke’s Bay DAP for FASD acknowledged that early identification and assessment for FASD was critical to mitigate the risk of secondary disability and that a diagnosis constituted a protective factor against additional secondary harms.⁹⁸⁸ Alcohol Healthwatch New Zealand, in their 2010 report recommending a multidisciplinary approach to diagnosing FASD in New Zealand, similarly identified early diagnosis as “pivotal” to reducing the likelihood of secondary disabilities.⁹⁸⁹ The importance of early diagnosis is

⁹⁸⁰ Ministry of Health, above n 235 at 36.

⁹⁸¹ Ministry of Health, above n 235 at 36.

⁹⁸² Ministry of Health, above n 235 at 38.

⁹⁸³ See Chapter 3, page 35.

⁹⁸⁴ Corrado, above n 308 at 242.

⁹⁸⁵ Corrado, above n 308 at 242.

⁹⁸⁶ See Chapter 10, page 188.

⁹⁸⁷ See Chapter 10, page 197.

⁹⁸⁸ Health Promotion Agency, above n 20 at 8.

⁹⁸⁹ Alcohol Healthwatch, above n 133 at 5.

recognised internationally, with the Canadian Guideline for Diagnosis itself describing a diagnosis as a “blueprint for early intervention”.⁹⁹⁰

The findings of the current research support the argument that early diagnosis is crucial for providing support for young people with FASD. Health professionals involved in diagnosing FASD in New Zealand describe the process as “therapeutic” and articulate that it represents the first stage of intervention.⁹⁹¹ Importantly in the context of avoiding secondary disability, the effect of a diagnosis was reported as improving young people’s self-esteem.⁹⁹²

Despite the evidence, both in New Zealand and internationally, showing that early assessment for, and diagnosis of, FASD constitutes a protective factor against secondary disability (including criminal offending), health professionals appear hesitant to diagnose FASD. A 2009 New Zealand survey of health professionals found that *even though* the overwhelming majority of participants acknowledged that early diagnosis was a protective factor, they were still concerned with the potential stigmatising effect a diagnosis could have.⁹⁹³ A survey of Australian paediatricians in 2004 found similar results. The professionals in that study were hesitant about diagnosing FASD for a variety of reasons (including a hesitancy regarding the legitimacy of the diagnosis), the most predominant being the perceived stigma associated with it.⁹⁹⁴ Health professionals in Australia were also reportedly concerned about the value of a diagnosis in the context of limited supports and services for individuals with FASD.⁹⁹⁵

Health professionals’ hesitancy regarding diagnosing FASD was a consistent theme emerging from the findings of this doctoral research. Parents and caregivers reported that their health professionals resisted investigating FASD as a possible diagnosis for their child because they perceived there was “no point”.⁹⁹⁶ Consistent with the results of the studies discussed above, the parents also perceived the health professionals as avoiding any investigation of FASD because of the stigma associated with the disability: “that’s a hard question to ask”.⁹⁹⁷ This theme also emerged from the interviews with professionals and key stakeholders. Health professionals who were actively involved in diagnosing FASD in New Zealand were frustrated that their colleagues appeared to be afraid of diagnosing FASD and justice professionals felt that the health sector were being “gun shy”.

The problem of health professionals being reluctant to diagnose FASD is not isolated to New Zealand. However, the current research has shown that, internationally, work has been done to actively mitigate the misconceptions held by health professionals about FASD diagnoses. Australia and Canada both engaged in widespread consultation to establish the need for formalised guidelines to diagnosing FASD, with the intention that a streamlined diagnostic process would be established.⁹⁹⁸ Canada published its first guidelines to diagnosing FASD in 2005, with an updated guideline published 10 years later. Australia

⁹⁹⁰ Chudley, above n 132 at 4.

⁹⁹¹ See Chapter 9, page 159.

⁹⁹² See Chapter 9, page 159.

⁹⁹³ Alcohol Healthwatch, above n 133 at 20.

⁹⁹⁴ Shelton, above n 534 at 1124.

⁹⁹⁵ Shelton, above n 534 at 1124.

⁹⁹⁶ See Chapter 8, page 145.

⁹⁹⁷ See Chapter 8, page 145.

⁹⁹⁸ See Chapter 4.

followed suit in 2016, recognising that a formalised process for diagnosing FASD was critical to mitigate the barriers to accessing support, including “confusion about diagnostic criteria and perceived lack of evidence-based treatments”.⁹⁹⁹

The findings of this research suggest that the steps New Zealand has taken to date to encourage the confident, consistent diagnosis of FASD by health professionals does not match the standard set internationally. In 2016 the Government released an Action Plan on FASD with several priority areas of focus for the three-year time period 2016-2019.¹⁰⁰⁰ Indicated in the “early identification” focus area was the goal to establish a “minimum assessment protocol” for FASD.¹⁰⁰¹ It remains to be seen exactly what the Government envisaged when they proposed a *minimum* assessment protocol, but response from the participants of this research indicates it is not enough. Participants emphasised the importance of the diagnostic process for FASD being thorough, articulating that there is “no such thing as having minimum FASD”.¹⁰⁰² This approach is reflected in the guidelines to diagnosing FASD in both Australia and Canada, where the diagnostic process is outlined in a series of detailed and thorough clinical steps.¹⁰⁰³

Thorough best-practice diagnosis for FASD is occurring in some parts of New Zealand. The Hawke’s Bay DAP (run through the DHB) follows an assessment process that reflects the detailed nature of FASD diagnosis recommended in the international guidelines.¹⁰⁰⁴ Similarly, the FASD Centre Aotearoa in Auckland is providing diagnostic services for FASD following the recommendations outlined in the Canadian guidelines.¹⁰⁰⁵ Independent clinicians have also received training in FASD diagnosis (following the Canadian guidelines) and are implementing their training throughout New Zealand.¹⁰⁰⁶ The difficulty for these professionals is that there is no formal, Government-funded initiative to support the development of these diagnostic services: “we just quietly got on with it”.¹⁰⁰⁷ With the exception of the Hawke’s Bay DAP, clinicians diagnosing FASD predominantly rely on referrals from Oranga Tamariki to fund assessments, or they practice privately.¹⁰⁰⁸ Private assessments for FASD come at great cost to families - “it’s on par with \$4000 or \$5000” – making it inaccessible for the majority of New Zealand families who would benefit from the process.¹⁰⁰⁹

B. School support

Early identification of FASD through thorough diagnostic services is a crucial first step in mitigating the risk of secondary disability. Once the primary disability has been identified, it is then important to alter the environment around the child or young person to support

⁹⁹⁹ Bower and Elliot, above n 632 at 2.

¹⁰⁰⁰ FASD Working Group, above n 286.

¹⁰⁰¹ FASD Working Group, above n 286.

¹⁰⁰² See Chapter 9, page 161.

¹⁰⁰³ See Chapter 4, pages 63 and 80.

¹⁰⁰⁴ See Chapter 2, page 22.

¹⁰⁰⁵ McGinn, above n 230.

¹⁰⁰⁶ See Chapter 2, page 25.

¹⁰⁰⁷ See Chapter 9, page 160.

¹⁰⁰⁸ See Chapter 9, page 160.

¹⁰⁰⁹ See Chapter 9, page 160.

their needs. A child's school represents a significant environmental influence and should therefore be a focus when a child is diagnosed with FASD.

Andi Crawford, in her 2013 article examining adaptive behaviour and general development of children with FASD, identified increasing difficulty at school as a particular problem for young people.¹⁰¹⁰ The primary school environment can often cater quite well for children with FASD, even those who do not yet have a diagnosis. Usually a child will be in the same classroom with the same teacher and the child's day will be well-structured with a predictable routine. As the child moves through the school system however, the cognitive demands become more complex, and for a child with FASD, this results in a growing gap (both behavioural and academic) between them and their peers.¹⁰¹¹

The findings of the current research are consistent with Crawford's article: parents identified that the transition between school levels was a problem for their children, when the schools started expecting the children to "self-manage".¹⁰¹² Given the significance of the influence school has on a child and their potential to succeed (or not), diagnostic services for FASD often include a specific "feedback session" for the child's school. The guidelines for diagnosis in Australia recommend sharing information with the child's school, the Hawke's Bay DAP include this as an important step in the diagnostic process and the health professionals in the current research discussed the importance of including the school in the ongoing management of the child post-diagnosis.¹⁰¹³

Education professionals in the current research reflected the importance of open communication and information sharing. Sharing a child's diagnosis was described as crucial to enable the school to best support that child – one teacher emphasised that communication should extend to all staff throughout the school so that the "base knowledge" across the school could continue to grow.¹⁰¹⁴

The extent to which schools in New Zealand are able to act on that knowledge, however, is currently limited. Access to disability support in schools is still confined to relatively narrow eligibility criteria (e.g., for ORS funding) or relies on individual schools apportioning funding from the more flexible, albeit limited, SEG.¹⁰¹⁵ The findings of the current research are that schools in New Zealand are "not catered very well for kids with neurodisabilities, including FASD".¹⁰¹⁶ The Australian education system appears to have a similar problem, with Shelton et al. reporting that FASD is not recognised as a disability in schools and that by not recognising FASD as a condition that "necessitates access to funding and support" these children are being discriminated against.¹⁰¹⁷

Support systems that have the potential to be effective for children with FASD already exist, they simply need to be more widely available. Although the criteria for accessing disability support through ORS or the SEG are not confined to a specific diagnosis, the parents interviewed in the current research encountered significant barriers in trying to establish

¹⁰¹⁰ Crawford, above n 70.

¹⁰¹¹ Crawford, above n 70.

¹⁰¹² See Chapter 8, page 148.

¹⁰¹³ See Chapter 4, page 82, and Chapter 9, page 160.

¹⁰¹⁴ See Chapter 9, page 164.

¹⁰¹⁵ See Chapter 2, page 30.

¹⁰¹⁶ See Chapter 9, page 164.

¹⁰¹⁷ Shelton, above n 534 at 1125.

appropriate in-school support for their children. This perhaps suggests that there is variability and inconsistency in the provision of support across different schools or that the communication between the school and the parents regarding the supports that are available needs to improve. The teacher aide programme for example was described by professionals and parents in the current research as incredibly beneficial to children with FASD – “kids with someone sitting alongside them in the classroom do much, much better” – but parents often struggled to access that support.¹⁰¹⁸ The findings of the current research also suggest that an environment that focuses purely on academic achievement is not going to allow children with FASD to flourish.

C. Summary

Diagnosing FASD represents a crucial first step in mitigating the risk of secondary disability, namely criminal offending, in young people. New Zealand has not yet done enough to establish robust diagnostic services, or to provide support in the school environment. The following recommendations aim to identify the steps that need to be taken to ensure New Zealand is following best-practice guidelines and keeping up with its international counterparts.

D. Recommendations:

The New Zealand Government should support widespread consultation on, and subsequent development of, formal diagnostic guidelines for FASD in New Zealand. Consultation should consider the guidelines developed in Australia and Canada, while ensuring care is taken to adapt the guidelines to suit the New Zealand context.

Formal funding streams should be developed to ensure health professionals are supported to provide diagnostic services in FASD through local DHBs so that early assessment and diagnosis is accessible for families.

The eligibility criteria for accessing disability support in schools should be expanded so that more students have access to the individualised and sustained support provided by ORS. School curriculum should be amended so that there is an option for students to follow a less academic, more vocational path if it is established that this is the best option to enhance their self-esteem and possibility of success.¹⁰¹⁹ This option should be available to students early (by Year 9) to mitigate the risk of disengagement.

IV. Training

The ability to a) recognise that a child may have FASD and refer them appropriately; and b) diagnose a child with FASD, requires the professional working with the child to have adequate awareness of, and knowledge about, the disability.

¹⁰¹⁸ See Chapter 9, page 164.

¹⁰¹⁹ See for example the “Red Shirts” initiative, Chapter 10, page 196.

A. *Recognising that a child may have FASD*

There are several points of contact in a child or young person's life at which a professional has the opportunity to recognise that the child may have FASD and to then intervene appropriately. The first point of contact is a child's school. As previously mentioned, children spend a significant amount of time at school and, therefore, the environment of the school can have a major impact on a child and represents an important vehicle for providing support. Unfortunately, the contributions of the participants in the current research suggest that at least some teachers are not taught about FASD during their university studies, do not necessarily understand the presentations of FASD (for example that it often does not affect a child's intelligence) and that consequently children with FASD are labelled as "naughty" or "bad".¹⁰²⁰ This has significant implications firstly in terms of missing the opportunity to identify a child's difficulties as stemming from a neurological disability and secondly in attributing further harm to a vulnerable child's self-esteem.

The New Zealand Government's Action Plan for FASD has recognised this shortfall and has included the desirability of teachers having an increased understanding of FASD as a goal under the 'support' priority listed in the Action Plan.¹⁰²¹ As outlined in detail in Chapter Two, the Ministry of Education has developed a variety of resources aimed at providing teachers with specific strategies for supporting children with FASD in the classroom. Although the resources are thorough, it is not clear whether there is a formalised process for teachers to access and understand the material or whether it is relying on teachers taking the initiative. The findings of the current research suggest that at least until now, teachers were expected to take the initiative and "go hunting" for information to support students with FASD in the classroom.¹⁰²²

The second point of contact is in the context of youth justice engagement. Justice professionals (from frontline workers such as Police officers, to members of the judiciary) coming into contact with young people should have a level of awareness of FASD adequate to recognise the signs and alert relevant individuals of the need for referral. The Australian case of *LCM v State of Western Australia* highlights the importance of justice professionals being cognisant of FASD.¹⁰²³ In that case, five representatives of the justice system had been involved with the young defendant before his case was brought to appeal: his defence counsel, the author of the pre-sentence report, the author of the psychiatric report, the author of the psychological report and the Court itself. None of them considered the "fairly obvious" possibility that LCM had FASD.¹⁰²⁴

Another example from Australia that highlighted the need for further training among justice professionals was the Banksia Hill project, which looked at knowledge of, and attitudes towards, FASD among custodial staff.¹⁰²⁵ Consistent with the findings of the appeal court judge in *LCM*, the Banksia Hill project concluded that there were "substantial gaps" in the

¹⁰²⁰ See Chapter 8, pages 148 and 149.

¹⁰²¹ FASD Working Group, above n 286 at 6.

¹⁰²² See Chapter 9, page 163.

¹⁰²³ *LCM*, above n 589.

¹⁰²⁴ See Chapter 4, page 86.

¹⁰²⁵ See Chapter 4, page 83.

knowledge of custodial staff in the Banksia Hill youth detention centre, including misapprehensions about the common presentations of FASD.¹⁰²⁶

The current research has produced similar results: as mentioned above, professionals reported misunderstanding the common presentations of FASD until late in their careers and 100% of the family member participants and key stakeholders felt that justice professionals needed extensive training in FASD in order to adequately support young people in the justice system.¹⁰²⁷ Currently, FASD only becomes an issue for the New Zealand courts if the young person's youth advocate lawyer picks up on it and suggests to the Court the need for a s 333 psychological report.¹⁰²⁸ If the youth advocate does not have an adequate understanding of the presentations of FASD there is a risk that the young person will escalate through the justice system without recognition of their disability. The Manitoba Youth Justice Programme (MYJP) in Canada, a programme aimed at providing young offenders with FASD with additional support in the justice system, has a system to mitigate this issue.¹⁰²⁹ Referrals to the programme can come from a variety of sources including lawyers, judges, probation officers, corrections staff, social workers, caregivers, parents, or adolescents who have self-identified the symptoms. Formally accepting referrals from such a wide variety of sources acknowledges the issue that at present, training and awareness of FASD among justice professionals is inadequate in ensuring young people are identified early and provided support.

The New Zealand Government's FASD Action Plan has acknowledged this issue by including as an indicator of success that youth justice professionals are able to adjust their approach to people with FASD and other neurodevelopmental impairments.¹⁰³⁰ The work in the justice context is described as "ongoing" but several resources have been developed to aid increasing awareness of FASD among justice professionals.¹⁰³¹ Similar to the developments in the education sector mentioned earlier in this section, it is not immediately clear whether there is a formal process for rolling out training programmes, or whether it will be left to the initiative of individual professionals to seek out the resources that have been made available. The findings of the current research are that training for justice professionals needs to be extensive, job-specific and provided early (ideally incorporated into tertiary education programmes).¹⁰³² Relying on individual professionals to seek out further training and resources on their own initiative is not adequate.

B. Diagnosing a child with FASD

The 2009 survey of New Zealand health professionals found that over half of the participants indicated that further training was necessary.¹⁰³³ In Australia, Shelton et al. recommended further training in FASD was needed, acknowledging that FASD was "rarely addressed" at tertiary level training.¹⁰³⁴ Similarly, in Canada, the diagnostic guidelines were published

¹⁰²⁶ Passmore, above n 695 at 48.

¹⁰²⁷ See Chapter 10, page 179.

¹⁰²⁸ See Chapter 10, page 180.

¹⁰²⁹ See Chapter 4, page 73.

¹⁰³⁰ FASD Working Group, above n 286 at 6.

¹⁰³¹ See Chapter 2, page 33.

¹⁰³² See Chapter 10, page 179.

¹⁰³³ Alcohol Healthwatch, above n 131 at 20.

¹⁰³⁴ Shelton, above n 534 at 1124.

partly in order to establish streamlined diagnostic practice nationwide, but also to address the need for professional training of health practitioners.¹⁰³⁵ The findings of the current research indicate there is an ongoing problem in New Zealand, with parents suggesting that if there were “20 times more people geared up to diagnose” then a lot of young people would avoid justice system involvement altogether.¹⁰³⁶

Young people with FASD receiving incorrect diagnoses prior to a diagnosis of FASD was an issue that emerged from this research and was mentioned briefly at the start of this chapter. Parents and caregivers from the current research described health professionals as “happy to label” children with diagnoses of ADHD, Conduct Disorder and Oppositional Defiant Disorder but they seem reluctant to “add the FASD”.¹⁰³⁷ A possible explanation for the reluctance emerged through the interviews with the professionals, who suggested health practitioners lacked the confidence to diagnose FASD and were “misinformed” about what the diagnostic process entailed.¹⁰³⁸ This is similar to the findings of the Australian study reported by Shelton et al. where health professionals indicated a lack of understanding about FASD diagnosis.¹⁰³⁹ In that study, health professionals questioned whether FASD was a diagnosis in itself, the diagnostic accuracy of an FASD assessment and whether there was any point in diagnosing FASD when there were limited supports available.¹⁰⁴⁰

The question regarding whether FASD is a legitimate diagnosis possibly reflects the method of training health professionals currently receive. The findings of the current research emphasised that because health practitioners work to the DSM, they are not taught about brain injury as distinct from mental health.¹⁰⁴¹ The current edition of the DSM does mention FASD, but only as “something needing more research and development”.¹⁰⁴²

Of the professionals interviewed in this research who were involved in diagnosing FASD, only one had received training in FASD as part of their formal medical training.¹⁰⁴³ The rest had used their own initiative to seek out further training, usually overseas.¹⁰⁴⁴ Increasing workforce capacity for the diagnosis of FASD in New Zealand should not be a significant problem, provided there is adequate support for professionals and formal funding streams available for training. If there are health professionals who are confident and able to diagnose other disorders (such as ADHD, Conduct Disorder, or Oppositional Defiant Disorder), they should be able to diagnose FASD with relative ease. However, formal training is essential: “you can’t just leap to being an expert when you’ve never done any assessments”.¹⁰⁴⁵

¹⁰³⁵ Chudley, above n 132 at 2.

¹⁰³⁶ See Chapter 10, page 181.

¹⁰³⁷ See Chapter 8, page 145.

¹⁰³⁸ See Chapter 9, page 158.

¹⁰³⁹ Shelton, above n 534 at 1124.

¹⁰⁴⁰ Shelton, above n 534 at 1124.

¹⁰⁴¹ See Chapter 10, page 180.

¹⁰⁴² See Chapter 10, page 181.

¹⁰⁴³ See Chapter 9, page 166.

¹⁰⁴⁴ See Chapter 9, page 166.

¹⁰⁴⁵ See Chapter 10, page 181.

C. Summary

The results of this research indicate that the level of awareness and understanding about FASD among professionals from the health, education and justice sectors is insufficient to mitigate the risk of secondary disabilities. Extensive training of professionals is crucial to ensure children and young people with FASD are identified early. The Government's FASD Action Plan indicates there is an awareness of this issue but is not clear enough about how widespread awareness and understanding of FASD will be rolled out. The following recommendations aim to provide greater clarity about the steps New Zealand needs to take to increase capacity among professionals to identify, diagnose and manage FASD.

D. Recommendations

Formal training about FASD needs to be incorporated into the tertiary curriculum for students training to become teachers and specific training programmes should be implemented for currently registered teachers to ensure all teachers in New Zealand can identify FASD and have strategies to manage children with FASD in the classroom. This could be achieved through workshops and seminars on FASD that teachers would be required to attend as part of their professional development.

Formal training about FASD should be incorporated into the tertiary curriculum for all disciplines where contact with young people in the justice system is possible, including social workers, lawyers and Police officers. The Government should roll out specific additional training for all currently registered social workers, youth advocate lawyers and Police officers to ensure these professionals can recognise the signs of FASD and have strategies to support and manage young people with FASD in the justice system. Workshops and seminars would be an effective means for this cohort as well, providing the content is discipline-specific and includes strategies for individual professional sectors to manage young people with FASD.

Training programmes should be developed for current youth justice service providers that are job-specific and offer practical strategies to manage young people with FASD in the context of youth justice, rather than simply an overview of what the condition is. This training should extend to youth workers in all youth justice secure residences, remand homes and custodial officers working in youth units in adult prisons.

A nationwide training programme for health professionals (paediatricians, nurses, clinical psychologists, speech language therapists and psychiatrists) in the diagnosis of FASD should be developed. In the absence of a New Zealand guideline for diagnosing FASD, training of these professionals should follow the best-practice approach currently used in the Hawke's Bay DHB's DAP and the FASD Centre Aotearoa.

V. Youth justice policy

The best outcome for young people with FASD is that their disability is recognised early, they are referred for assessment and diagnosis, and support is put in place to prevent future justice system involvement. The reality is, however, that there are significant numbers of young people currently in New Zealand's justice system, and until there is widespread training of professionals and a streamlined diagnostic service available nationwide, that is

unlikely to change. It is therefore important to ensure the justice system is well-equipped to manage this cohort of young people to avoid recidivism and their escalating involvement in higher-tier courts and institutions.

A. Screening

The MYJP, discussed in Chapter Four, recognises the overrepresentation of young people with FASD in the justice system and has established a process for identifying and supporting them.¹⁰⁴⁶ Crucial to the success of the programme is its robust screening process: a young person is referred to the programme if they exhibit a series of “red flags” identified as being suggestive of FASD. In New Zealand, all young people coming to the Youth Court should receive a forensic screen by a trained health professional, a strength of New Zealand’s youth justice system.¹⁰⁴⁷ However the findings of this research suggest that it is not happening consistently, and when it does, the screening is “pretty basic”.¹⁰⁴⁸ Forensic staff at the Youth Court may conduct a “quick assessment” on the day of a young person’s court appearance, but they are not adequately trained in FASD and are not spending enough time with the young person to allow for the “red flags” of FASD to be identified.¹⁰⁴⁹

The Banksia Hill Project in Australia supports the argument that robust screening of young people coming into the justice system is critical.¹⁰⁵⁰ Secondary to establishing prevalence rates of FASD among young people in custody, that project aimed to develop a screening tool for FASD to be used for all young people sentenced to detention.¹⁰⁵¹ As at May 2019 the results of that aspect of their study were not publicly available, but the work was due to be completed soon.¹⁰⁵² The findings of the current research suggest that such a screening tool should be developed for use in the Court and adapted for use by frontline workers (such as Police officers) as well.¹⁰⁵³

B. Referral

If a young person is flagged by the MYJP screening tool, they are then referred for a full assessment. A strength of this programme, as highlighted in Chapter Four, is that referrals can come from a wide variety of sources, including the young person themselves, or members of their family. In New Zealand, if a young person is flagged through a forensic screen, the Court will order a s 333 psychological report to be completed.¹⁰⁵⁴ However, the formal process for requesting a s 333 report requires the Court itself to action the referral. One of the emerging themes from this doctoral research which has already been discussed in this chapter is the lack of awareness of FASD among professionals, including those in the justice sector. Relying solely on the abilities of the forensic practitioner completing the screen to identify the possibility of FASD and direct the Court to order a report is resulting in young people with FASD falling through the gaps. The findings of this research indicate

¹⁰⁴⁶ See Chapter 4, page 73.

¹⁰⁴⁷ See Chapter 9, page 174.

¹⁰⁴⁸ See Chapter 10, page 183.

¹⁰⁴⁹ See Chapter 10, page 182.

¹⁰⁵⁰ See Chapter 4, page 83.

¹⁰⁵¹ See Chapter 4, page 83..

¹⁰⁵² Personal Communication (Dr Rochelle Watkins), 7 February 2019.

¹⁰⁵³ See Chapter 10, page 183.

¹⁰⁵⁴ See Chapter 3, page 43.

that a “proper system” needs to be put in place in order to ensure these young people are identified as soon as possible.¹⁰⁵⁵

C. Report

Once a young person has been assessed and diagnosed with FASD under the MYJP, a report is provided to the Court which includes recommendations for managing the particular young person (and their unique clinical profile) and to ensure sentencing decisions are appropriate.¹⁰⁵⁶ The purpose of the s 333 report in New Zealand is similar: to inform the Court with information about the young person to assist in making an appropriate decision regarding a young person’s sentence.¹⁰⁵⁷ The findings of the current research however suggest that in the context of FASD, the Court is focusing too narrowly on the legal implications of a young person’s diagnosis rather than considering it an opportunity for intervention.¹⁰⁵⁸ Additionally, unless the Court is able to direct the young person and their whānau to someone trained in FASD to help explain to them the implications of the diagnosis and how to manage it, the whole process is “a bit of a waste of time”.¹⁰⁵⁹

This sentiment is echoed by the focus the MYJP put on appropriate support and follow-up after a youth justice assessment for FASD. The programme utilises a “strength-based client-centred” approach which encourages the young person to be actively involved in the development and management of their plan. This approach relies on a thorough investigation into the young person’s environment, needs, strengths, history of success, and caregiver or parental capacity. The depth of information garnered from this comprehensive approach is in stark contrast to the legally focused reports provided through s 333 of the OT Act.

D. Action

One of the research questions this thesis aimed to answer was how is FASD taken into account and acknowledged in New Zealand’s youth justice system? Currently, in the Youth Court, if a young person has a prior diagnosis of FASD or is diagnosed through a s 333 report, the Court has no ability to divert them through an alternative path away from the mainstream justice system. If the young person does not meet the criteria for intellectual disability, insanity, or unfitness, the options for the Court are limited. In *Police v ED* the Youth Court was faced with exactly this issue.¹⁰⁶⁰ The Court acknowledged the recommendation made by the psychologist that a youth justice residence would be inappropriate for *ED*, so he was instead sentenced to a supervision with activity order. *ED* had been ordered to engage in similar youth justice support programmes in the past and had been unsuccessful. The Court was optimistic that with his new FASD diagnosis, the youth justice service providers would be in a better position to manage his care.

The findings of the current research suggest that the professionals working in the youth justice service providers may not be adequately trained or supported in managing young people with FASD and that keeping them in the justice system is not necessarily the right

¹⁰⁵⁵ See Chapter 10, page 182.

¹⁰⁵⁶ See Chapter 4, page 75.

¹⁰⁵⁷ See Chapter 3, page 43.

¹⁰⁵⁸ See Chapter 9, page 172.

¹⁰⁵⁹ See Chapter 9, page 172.

¹⁰⁶⁰ See Chapter 3, page 54.

course of action.¹⁰⁶¹ Youth justice service providers are working to support these young people “on the smell of an oily rag” and many feel that the justice system is ill-equipped to deal with young people whose offending is driven by a health condition.¹⁰⁶²

New Zealand’s IDCCR Act recognises that in some cases, offending should be managed primarily through the health system.¹⁰⁶³ This Act was passed to provide courts with an alternative means of dealing with individuals with intellectual disabilities, but also to recognise the special vulnerability of this group of individuals, especially in the mainstream justice system. The vulnerability of young people with FASD was a theme that emerged from this research and was emphasised by parents, professionals and key stakeholders.¹⁰⁶⁴ Communication difficulties, susceptibility to peer influence, and the disparity between developmental and chronological age were issues that were highlighted by participants as compounding a young person’s vulnerability.

Research conducted in Canada in 2013 similarly highlighted the vulnerability of young people with FASD in the justice system.¹⁰⁶⁵ McLachlan et al. found that young people with FASD had difficulty comprehending the legal process and understanding their legal rights, but their self-confidence judgements were inconsistent, meaning they *believed* they understood. An article written by Ian Freckelton QC in 2016 further explored the vulnerability of individuals with FASD in the justice system and noted that, when questioned by authority figures (such as Police officers), young people may confabulate in order to appear deferential.¹⁰⁶⁶

Communication and comprehension difficulties represent a particular source of concern in the youth justice context. Coggins et al explained that executive function deficits can limit the amount of information a young person with FASD can process, especially in situations that are particularly complex or unusual.¹⁰⁶⁷ The findings from this research are similar, in that the “linguaging of literature” in the Youth Court presents a complex and unusual challenge for young people generally, let alone young people with a neurodisability like FASD.¹⁰⁶⁸ Family members, professionals and key stakeholders specifically mentioned the difficulties young people with FASD have complying with conditions of bail.¹⁰⁶⁹ This may be partly due to difficulties with memory but, in large part, is likely to be because bail conditions use complicated words and phrases like ‘reside’ and ‘not to associate’.¹⁰⁷⁰

Creating new legislation to divert young people with FASD out of the justice system and into the health system would allow them to be managed according to the symptoms of their disability (the root cause of their offending). Arguably this would simply be extending the cover already provided by the IDCCR Act – acknowledging that individuals with particular vulnerabilities should be managed through the health system rather than the justice system.

¹⁰⁶¹ See Chapter 10, page 191.

¹⁰⁶² See Chapter 10, page 191.

¹⁰⁶³ See Chapter 3, page 45.

¹⁰⁶⁴ See Chapter 9, page 169.

¹⁰⁶⁵ McLachlan, above n 307.

¹⁰⁶⁶ Freckelton, above n 306 at 65.

¹⁰⁶⁷ Coggins, above n 90 at 119.

¹⁰⁶⁸ See Chapter 10, page 191.

¹⁰⁶⁹ See Chapter 10, page 190.

¹⁰⁷⁰ See Chapter 10, page 191.

Alternatively, the justice system needs to adapt in order to accommodate young people with FASD and ensure their vulnerability is not exacerbated.

E. Summary

Effective screening, referral, assessment and disposition of young people with FASD in the justice system is critical to mitigate the risk of recidivism and ensure the underlying cause of their offending is addressed. The themes emerging from this research suggest that although there are policies in place for screening in the Youth Court, and legislation providing a means for referral and assessment, the process in New Zealand is insufficiently robust. The following policy recommendations aim to improve the efficacy of current screening and referral protocol and suggest alternatives to mainstream justice for young people diagnosed with FASD.

F. Recommendations:

Mandatory, robust screening needs to be established for all young people coming to the Youth Court. The screening needs to be FASD-specific, and professionals conducting the screens need to be trained in FASD and need to allow sufficient time for the screening prior to a young person's Court appearance. Conducting the screen on a separate day and time to a young person's Court appearance would help mitigate the risk of the screen being rushed and the professional conducting the screen missing the warning signs of FASD.

A young person flagged at a Youth Court screen should be immediately referred for an FASD assessment. A clear pathway from screening to assessment needs to be established, without relying on the Court alone for referral. The assessment report should include detailed recommendations regarding the young person's management and should not be limited to the legal implications regarding fitness.

Standard Court processes should be adapted to accommodate young people with communication and comprehension difficulties. Standard bail conditions should be reworded with simple, plain language and should include a pictorial element. Young people should be allowed a support person nearby at all times, with whom they can communicate and who has a voice in the Court process.

VI. Legislative amendments

The final priority issue concerns the need for legislative amendments to better support young people with FASD in the justice system, acknowledging their unique cognitive profile and how this affects their criminal culpability.

A. FASD as a mitigating factor in sentencing

The seminal Australian case *LCM v State of Western Australia* involved an appeal argument that the young defendant's sentence should be reduced to reflect his diagnosis of FASD.¹⁰⁷¹ The Court held that reducing LCM's sentence from 10 years to seven years was appropriate, taking into account his reduced moral culpability, specific cognitive impairments and the

¹⁰⁷¹ *LCM*, above n 589.

futility of relying on principles of deterrence.¹⁰⁷² The judge emphasised the importance of the particular cognitive impairment being causally linked to the offending, explaining that a diagnosis of FASD on its own will not constitute a mitigating factor.¹⁰⁷³ Legislative developments in Canada reflect this approach, with MP Bagnall's Private Member's Bill recommending that FASD be codified as a mitigating factor in sentencing.¹⁰⁷⁴

In New Zealand, both the Sentencing Act 2002¹⁰⁷⁵ and the OT Act¹⁰⁷⁶ stipulate relevant mitigating factors for the courts to consider. Both pieces of legislation include the age of the defendant as a relevant mitigating factor, echoing the literature on neuroscience and adolescence, discussed in detail in Chapter Five. Meixner, in a 2015 article examining the role of neuroscience in criminal law, described adolescents as passing through a period of brain development where impulsive, risk-taking behaviour increases due to the limited development of the prefrontal cortex.¹⁰⁷⁷ The prefrontal cortex is the region of the brain that has been described as being "uniquely human" and is responsible for our most complex cognitive functioning.¹⁰⁷⁸ The prefrontal cortex is significantly impacted by prenatal exposure to alcohol and the findings of this research are that for young people with FASD who engage in impulsive offending behaviours, with that impulsivity comes "the inability to apply their executive functioning at the time it's needed".¹⁰⁷⁹ Adolescent brain development combined with the neurocognitive effects of prenatal exposure to alcohol result in a spectrum of learning and behavioural effects that should be reflected in a graded view of criminal culpability. Short of a partial defence of diminished responsibility, acknowledging and accepting FASD as a mitigating factor in sentencing is the appropriate response.

International developments in both Canada and Australia suggest that justice systems are recognising the similarity between adolescence and FASD in terms of the cognitive impact and relationship to criminal offending. By recognising FASD as a mitigating factor in sentencing, these jurisdictions are applying theories of culpability consistently, acknowledging the role brain damage from prenatal exposure to alcohol plays on a defendant's autonomy and ability to control their impulses and engage executive functioning. New Zealand legislation has codified the neuroscience of adolescent brain development by recognising age as a mitigating factor in sentencing but is inconsistently holding offenders with neurodisabilities wholly accountable for criminal offending that may in part be due to their limited cognitive capacity.

B. Recognition of vulnerability

The disparity between chronological and developmental age in young people with FASD was an emerging theme in the findings of this research. A New Zealand Youth Court case example illustrates this issue. In *Police v VT*, although the defendant was a teenager appearing in the Youth Court, his comprehension of vocabulary was assessed as being that

¹⁰⁷² *LCM*, above n 589 (*LCM*) at [122].

¹⁰⁷³ *LCM*, above n 589 (*LCM*) at [8].

¹⁰⁷⁴ Bill C235, above n 582 at 5.

¹⁰⁷⁵ s 9(2).

¹⁰⁷⁶ s 208(e).

¹⁰⁷⁷ Meixner, above n 812 at 6.

¹⁰⁷⁸ Perry, above n 39 at 22.

¹⁰⁷⁹ See Chapter 9, page 170.

of a seven-year-old and his verbal reasoning matched that of a six-year-old.¹⁰⁸⁰ The findings of the current research are consistent with professionals describing the “swiss-cheese” nature of FASD as a disability, where a young person may have a chronological age of 12, but “the emotion regulation abilities of a three year-old and perhaps the attention abilities of a five year-old”.¹⁰⁸¹

This disparity has significant implications in the context of criminal justice. Firstly, it has implications for comprehension ability and subsequent vulnerability in justice proceedings. The findings of this research suggest that youth justice proceedings should be amended to reflect the fact that the young person is likely to be developmentally significantly younger than they appear and that justice professionals should “change their thinking from ‘this is an 18-year-old’ to ‘this is a nine year-old’ ... [they need to] use language and terminology that they would understand if they were nine years old”.¹⁰⁸² Secondly, it has implications for the jurisdiction of the youth justice system generally: “these are very immature [young people], so they should be managed under youth jurisdiction for longer. Even at 20 they’re still going on 8 or 10 in their thinking”.¹⁰⁸³

The developmental age of young people with FASD also calls into question the legitimacy of holding them to account for criminal offending at all. New Zealand recognises the concept of *doli incapax* by setting the absolute minimum age of criminal responsibility at 10 years.¹⁰⁸⁴ A minimum age of criminal responsibility acknowledges the fact that the brain development of a child younger than a certain age precludes them from having sufficient cognitive capacity for rational decision-making and regulation of emotion.¹⁰⁸⁵ Canadian academics, Mela and Luther, argue that the cognitive impairment caused by prenatal alcohol exposure also results in an inability to effectively analyse information to assist in decision-making and that individuals with FASD should be recognised as having at least reduced capacity for criminal offending.¹⁰⁸⁶

Applying a blanket principle whereby any individual with FASD is automatically considered to have reduced capacity for offending is not, however, an appropriate response, given the diverse symptomatology of the disorder. As discussed above regarding FASD as a mitigating factor in sentencing, an individual’s cognitive impairment must be causally linked to the relevant offending behaviours. There are specific aspects of impairment that will be particularly relevant for assessing culpability. Not only does the degree of moral blameworthiness need to be “commensurate with the magnitude of cognitive deficits”¹⁰⁸⁷, but the particular cognitive impairments need to have a direct impact on the ability to process information, focus, learn from past behaviour and consequences, and exercise short and long-term memory.¹⁰⁸⁸

¹⁰⁸⁰ VT, above n 453 at [27].

¹⁰⁸¹ See Chapter 9, page 167.

¹⁰⁸² See Chapter 10, page 186.

¹⁰⁸³ See Chapter 10, page 187.

¹⁰⁸⁴ Oranga Tamariki Act 1989, s 272. See also Chapter 5, page 91.

¹⁰⁸⁵ See Chapter 5, page 102.

¹⁰⁸⁶ Mela and Luther, above n 844.

¹⁰⁸⁷ *R v Ramsay*, above n 847.

¹⁰⁸⁸ Mela and Luther, above n 844.

The existence of FASD should call into question an individual's level of culpability. It should also direct justice professionals to consider vulnerability at all stages of the inquiry. *Pora v R* acknowledges and applies the fact that "FASD can impact powerfully upon what would otherwise be the fairness of criminal investigations and subsequent decisions of criminal guilt".¹⁰⁸⁹ The findings of the current research are consistent with Freckelton's remarks about Pora's vulnerability. Young people with FASD are "susceptible to suggestion"¹⁰⁹⁰ and eager to please, especially when deferring to an individual in a position of perceived authority. Communication abilities compound this issue, such that the "swiss-cheese" nature of brain damage can deceive justice professionals into assuming they are communicating with a cognitively-able young person.¹⁰⁹¹

Teina Pora was 17 years old at the time of the first police interview and was therefore treated as an adult for the purpose of the subsequent criminal investigation and trial. The first police interviews occurred over the course of three days without any legal representation for Teina. Had Teina been younger, he would have fallen within the ambit of the OT Act and been afforded the supports and rights contained within it. Acknowledging the 2019 amendments, the focus of that Act is clear: the rights of children and young people must be upheld, justice processes must be adapted to ensure full and effective participation, and any disability must be acknowledged and supported, in a manner that is individualised and long-term.¹⁰⁹²

C. Summary

The New Zealand legal system acknowledges the neuroscience regarding adolescent brain development and the impact this has on criminal capacity. The Sentencing Act 2002 and the OT Act require courts to consider age a mitigating factor in sentencing. The findings of the current research suggest that jurisdictions internationally are beginning to recognise that the impact of prenatal alcohol exposure on the brain results in similar reduced capacity for criminal offending and that recognising FASD as a mitigating factor in sentencing is an appropriate response. The vulnerability of young people with FASD, including the disparity between chronological and developmental age, requires an analysis of whether ending the youth justice system's jurisdiction when a young person turns 18 is appropriate. The following recommendations aim to bring New Zealand in line with its international counterparts in acknowledging the role FASD plays in criminal culpability and capacity to effectively participate in justice proceeding.

D. Recommendations:

i. FASD as a mitigating factor in sentencing

Section 9 of the Sentencing Act 2002 and s 208 of the OT Act should be amended to include FASD as a mitigating factor in sentencing. Legislative drafting should be careful to ensure that an individual's diagnosis is only a mitigating factor in circumstances where the particular nature of their impairment has a direct link to the offending behaviour in question. The amendment should also include a requirement to draft and implement an external

¹⁰⁸⁹ Freckelton, above n 528.

¹⁰⁹⁰ See Chapter 9, *susceptibility to offend/vulnerability in justice*.

¹⁰⁹¹ Hansen, above n 527; McLachlan, above n 307.

¹⁰⁹² See Chapter 3, page 43.

support plan for the individual, based on the specific cognitive impairments that led to their offending. Drafting an entirely separate piece of legislation for young people with FASD is unnecessary. The OT Act already caters for vulnerable young people in the justice system, so amending s 208 to include FASD as a mitigating factor in sentencing would enhance the consistency of the justice system in recognising the special vulnerability of these young people.

The most likely criticism of this recommendation would be that there are many neuro-cognitive impairments that may have similar implications for vulnerability and culpability in the justice system. Why should FASD be singled-out and codified as a mitigating factor in its own right? The policy rationale is threefold:

1. There is no other disability where research has shown such a direct link between the neuro-cognitive impairment and criminal justice involvement¹⁰⁹³;
2. Although there is currently no prevalence data for New Zealand, robust international data coupled with New Zealand's high rates of alcohol consumption and unplanned pregnancy would indicate that young people with FASD are likely to be significantly overrepresented in the justice system;¹⁰⁹⁴ and
3. Not addressing the issue runs contrary to the obligations enshrined in domestic legislation and international law.¹⁰⁹⁵

Including FASD as a specific mitigating factor in sentencing is therefore not exclusionary, but rather “a concise reaction to a clear and concerning epidemic”.¹⁰⁹⁶ Requiring the courts to consider FASD and acknowledge the role it may play in reducing criminal culpability will serve to remove any doubt that FASD is a serious and life-long disability that has direct ramifications for the justice system. Forcing the courts to formally apply principles of mitigation and assessments of moral blameworthiness will also direct the inquiry toward the aspects of the young person's behaviour that need the most support. Those neurological impairments that are causally linked to offending behaviours and an individual's capacity for the executive functioning required to link *cognition* and *emotion* can be identified on the basis of a FASD diagnosis, providing the court with a detailed and individualised report on a young person's functioning. Such a report will identify the areas in which the young person needs the most support and should be taken into consideration for the drafting of an external support plan, and any orders or probation obligations that are imposed on the young person.¹⁰⁹⁷

ii. Extend the jurisdiction of the youth justice system and Youth Court

The jurisdiction of the youth justice system (including the Youth Court) should be extended. To acknowledge the discrepancy between chronological age and developmental age in

¹⁰⁹³ Email from MP Larry Bagnall, above n 598; See also Chapter 3.

¹⁰⁹⁴ Bower, above n 636 where the prevalence rate of FASD in a youth detention centre in Australia was found to be 36%; Hughes, above n 575 where prevalence rates in youth justice in Canada are cited at somewhere between 10 and 21%; and Streissguth and others, above n 301 where it is reported that 60% of individuals with FASD have had contact with the justice system.

¹⁰⁹⁵ See for example Chapter 3, *OT Act 2019 Amendments* (page 43) and Chapter 2, *Disability Support in New Zealand (UNCRPD)* page 26.

¹⁰⁹⁶ Email from MP Larry Bagnall, above n 598.

¹⁰⁹⁷ As an example of how this might work, see section 731(3) Bill C-235, above n 582.

young people with FASD, it would seem appropriate to extend the jurisdiction of the Youth Court to all individuals with a developmental age of 17 or below, regardless of their chronological age. This would reflect the particular vulnerability of a young person whose physical appearance and chronological age suggest greater sophistication than they are cognitively capable of. The potential difficulty with this approach, however, is that it assumes there are predictable “norms” of development rather than an acknowledgement that each individual child develops differently, with or without the presence of neurological impairment. Strictly defining what satisfies the criteria of a developmental age of 17 will be difficult and may result in some young people being excluded from the youth justice jurisdiction because of an arbitrary determination of “average” development. The jurisdiction of the youth justice system should therefore be extended to cover all young people up to the age of 25. This would include the cohort of young people with FASD whose chronological age falls outside of the ambit of the current youth justice system, but for whom the adult justice system does not afford appropriate support. Including all young people under 25 within this recommended extension would also recognise the cognitive development trajectory of all young adults, and the potential presence of disability, early childhood trauma, or adverse environmental pressures for some. This extension is consistent with the New Zealand legal system’s understanding of criminal culpability, and how brain development (and cognitive impairment) will impact upon an individual’s level of moral blameworthiness.

Kramers-Olen identified that important advancement in brain development continues until the early to mid-20s for young people without any brain injuries or cognitive impairments.¹⁰⁹⁸ When considering how brain development affects impulsive, risky behaviour, it can be difficult to draw a line between “adolescence” and “adulthood”. Steinberg noted that rates of risk-taking are high among young people aged 18-21. In some jurisdictions this group may be classed as adolescents, whereas in others they would be considered adults.¹⁰⁹⁹ In New Zealand these young people would all be dealt with in the adult justice system. Steinberg did consider that, “as a general rule”, adolescents *and* young adults are more likely than adults over 25 to engage in risky behaviour, including criminal offending.¹¹⁰⁰ The results of the current research are consistent with Steinberg and Kramers-Olen’s perspectives, where a key stakeholder from the justice sector questioned why the jurisdiction of the Youth Court could not be extended to include anyone up to the age of 25.¹¹⁰¹

The youth justice system in New Zealand allows the response to offending by young people to focus on the underlying causes of the behaviour and assumes that with appropriate intervention, the behaviour can be avoided. It also acknowledges the reduced criminal culpability of young people, by redirecting the options available to the Court (for example) away from punitive sanctions in favour of a more welfare-oriented approach. This includes the priority of avoiding young people becoming entrenched in the justice system, and, where possible, preferring diversionary measures for dealing with offending.¹¹⁰² This is incredibly important for young people with FASD, who are particularly vulnerable to negative

¹⁰⁹⁸ Kramers-Olen, above n 813 at 470.

¹⁰⁹⁹ Steinberg, above n 820.

¹¹⁰⁰ Steinberg, above n 820.

¹¹⁰¹ See Chapter 10, page 187.

¹¹⁰² See Chapter 3, page 41.

influences and for whom punitive outcomes are unlikely to be effective.¹¹⁰³ The youth justice system also acknowledges the likely presence of disability and the impact of early childhood trauma and environmental stresses and provides mechanisms by which the Court can order diagnostic reports and subsequent recommendations to inform how best to manage the young person.

The importance of acknowledging vulnerability up to the age of 25 has already been recognised in a trial project in Porirua, Wellington. The project is creating a separate list as part of the District Court that specifically caters to young people aged 18-24.¹¹⁰⁴ The proposal document for the trial first outlines the process of youth justice in New Zealand, highlighting the presence of the multidisciplinary team in the Youth Court and identifying the provisions of the OT Act that dictate that:¹¹⁰⁵

Accountability, instilling a sense of responsibility, promoting safety of the community, are not compromised by recognition of the needs of a young person.

The proposal goes on to acknowledge the overrepresentation of neurodisability among young offenders, including the increasing rates of FASD. The presence of neurodisability compounds the “under-developed brain” and the associated traits (impulsivity, high susceptibility to peer pressure, reward-seeking behaviour) “do not conclude at 17 or 18”.¹¹⁰⁶ Crucially, the proposal identifies that all individuals who come to Court before the age of 25 will have “the cognitive shortcomings that the current brain science tells us about” and that sanctioning them as fully mature adult offenders “could have life-long consequences that harm the young person and communities and negatively impact on public safety”.¹¹⁰⁷

The Centre for Justice Innovation in the United Kingdom similarly noted that there are several significant factors that result in young people under the age of 25 being overrepresented in the justice system – the top two of these being brain development in maturation and the presence of neurodisabilities.¹¹⁰⁸ In their 2018 report they developed a method of procedural fairness to mitigate the gap through which young people were falling.¹¹⁰⁹ The United Kingdom and New Zealand are not alone in recognising that young people require assistance and support beyond that which adult justice systems can offer. In April 2014 the Netherlands codified a series of recommendations influenced by extensive research into young adult offenders to extend the reach of their juvenile justice system up to 23 years.¹¹¹⁰ A United States paper on justice-involved young adults also recommended the consideration of young adults under an alternative system of justice, but emphasised that this new model “aims to promote opportunity as much as public safety”.¹¹¹¹

The OT Act amendments require any dealings with offending by young people to closely consider the impact of offending on the victim and society as a whole. Although the presence

¹¹⁰³ See Chapter 10, page 192; see also *ED*, above n 465 at [11].

¹¹⁰⁴ Doogue and Walker, above n 821.

¹¹⁰⁵ Doogue and Walker, above n 821 at 4.

¹¹⁰⁶ Doogue and Walker, above n 821 at 9.

¹¹⁰⁷ Doogue and Walker, above n 821 at 9.

¹¹⁰⁸ Thomas, Ely and Estep, above n 821.

¹¹⁰⁹ Thomas, Ely and Estep, above n 821.

¹¹¹⁰ Pruin and Dunkel, above n 821 at 57.

¹¹¹¹ Schiraldi, Western and Bradner, above n 821 at 4.

of FASD may reduce an individual's blameworthiness and consequent culpability for offending (as in *Powderface* and *Ramsay*),¹¹¹² young people with FASD sometimes commit horrendous crimes with significant and far-reaching implications. One of the four primary considerations in dealing with offending by young people required by the OT Act amendments is the public interest, which includes public safety.¹¹¹³ Enhancement of public safety is achieved when the opportunity for recidivist offending is minimised. The outcome for dealing with a young person with FASD should therefore be focused on whatever is most likely to redirect the young person away from offending in the future. Although the means of achieving this will differ for each young person, the current research has identified consistent messages regarding the outcomes that will be ineffective:

1. Incarceration of a young person with FASD is ineffective. The vulnerability of young people with FASD to manipulation or suggestion increases the likelihood they will be indoctrinated during their time in incarceration and are more likely to reoffend upon release;¹¹¹⁴ and
2. outcomes focused on deterrence do not acknowledge the impact FASD has on the cognitive domains responsible for learning from mistakes and being able to consider consequences.

Outcomes should be focused on providing a young person with structure, support and supervision, in an environment that can identify and work with the young person's strengths. A Youth Court judge in the current research identified how effective this approach can be in redirecting a young person with FASD's trajectory and emphasised the flexible nature of the youth justice system in tailoring outcomes to the needs of individual young people.¹¹¹⁵ This approach was reinforced in *P v R* where the Court of Appeal explicitly acknowledged that the protection of the community would be best served in adopting a flexible approach that was dictated by P's particular circumstances, the impact of his neuro-impairment and the progress he was making.¹¹¹⁶

Extending the jurisdiction of the youth justice system to include all those under the age of 25 recognises this cohort of young people as a distinct group and has the additional benefit of addressing the specific vulnerability of young people with FASD. The still-developing cognitive functions, compounded for some by the impacts of neurodisability, early childhood trauma or adverse environments necessitate an alternative approach for young people aged 18-24 years. It is likely, however, that this recommendation may encounter policy and political barriers and resistance from the public. The current evidence, as discussed above justifies, at the very least, extending the jurisdiction of the youth justice system to young people with neurodisabilities, and especially FASD, where they would otherwise be dealt with in the adult justice system. This would allow young people with FASD to be dealt with by recourse to the principles and purposes outlined in the OT Act. It would allow outcomes to be tailored to individual young people, where the focus is on supporting their needs (including the presence of disability) which, in turn, will reduce the risk of reoffending in the future. This approach is consistent with the way the New Zealand

¹¹¹² *Powderface* and *Ramsay*, above n 847.

¹¹¹³ Section 4A.

¹¹¹⁴ Immelman, above n 952.

¹¹¹⁵ See Chapter 9, page 176.

¹¹¹⁶ *P v R* [2016] NZCA 128.

legal system considers criminal responsibility and blameworthiness, acknowledging the role cognition plays in regulating conduct.

VII. Conclusion

This thesis focused on the experiences of young people living with FASD and their families and examined the gaps in support for young people with FASD in New Zealand's youth justice system. Although there is a significant amount of research on FASD and its implications for offending and justice sector involvement internationally, there is a notable absence of such research in the New Zealand context. There is a particular lack of qualitative research that seeks to ascertain and understand the lived experiences of individuals with FASD and their families and their views on how the youth justice system could provide better support for those young people with FASD who unfortunately come within its ambit. This thesis is intended as a promising beginning to filling that gap.

The qualitative nature of the methodology allowed me to directly explore the answer to the research question: what are the experiences of young people with FASD in the justice system, and parents/caregivers of young people with FASD, and what are their views on how the justice system could better meet their needs? Parents and caregivers of children with FASD shared their stories, providing a powerful narrative about the challenges of parenting a child with an underrecognised neurodisability. Their experience highlighted the importance of support from professionals and the urgent need for these professionals to receive extensive training in FASD. The professionals and key stakeholders similarly provided valuable insights about the need for further attention to be given to FASD in New Zealand to ensure young people are supported to live positive lives free from offending. Two young people bravely opened up about their experiences of New Zealand's youth justice system, understanding that while their personal experience cannot be changed, their input to this thesis has the potential to improve how young people with FASD are impacted in the future from contact with the justice system. It is the experiences and insights of young people that needs to inform policy and legislative change in the youth justice sector.

Despite the aim of this doctoral research to provide a platform for the voices of young people with FASD to be heard, recruitment was difficult in the context of a disability that is invisible, unsupported and stigmatised in New Zealand society. Work needs to start with recognising FASD on a nationwide basis and ensuring professionals are thoroughly trained in identifying, diagnosing and managing FASD. With support from the professional sectors, individuals with FASD will hopefully feel more secure in sharing their experiences and fighting for change. Future research should focus on collecting the insights of young people directly, in order to inform the development of a more supportive, inclusive youth justice system.

New Zealand's youth justice system is hailed worldwide as revolutionary and professionals, key stakeholders and family members discussed the varied and significant positive aspects of the current system. Its understanding of young people as inherently vulnerable, its focus on addressing the underlying causes of offending and the multiple voices encouraged to participate in the process are strengths of the system deserving of such praise. However, there is no room for complacency and greater efforts should be made to support all young people passing through the youth justice doors by the most effective means possible. The

next phase for the youth justice system in New Zealand, established by the findings of this thesis, should be a greater focus on young people with neurodisabilities by improving and standardising their forensic screening, referral for diagnosis and management. Youth justice processes should be inclusive of young people with neurodevelopmental disabilities and the jurisdiction of the youth justice system, including the Youth Court, should apply to young people according to their cognitive and developmental abilities by extending the age limit to include young people up to the age of 25.

In the end, the key message to emerge from this thesis is relatively simple and was aptly summarised by one of the young people with FASD who I interviewed. His quote needs to resonate loudly with policymakers and professionals throughout New Zealand:

Offer more help to those with FASD. Get professionals to understand how our brains work differently. Get more knowledge about FASD. Give young people with FASD more support, like mentoring, courses on offending, courses on explaining legal processes and possible consequences for different offences because it might teach you and your brain not to do offending. I just did some bad stuff and I did not know the consequences and no-one explained to me that if I did bad stuff I might end up in Youth Justice residence. If I am in here too much longer I might go insane.

[Jasper, aged 14 years].

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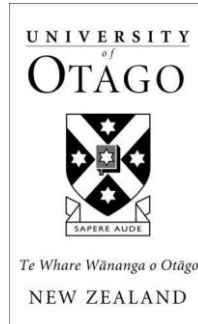
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Appendix A

Letter to Parents/Guardians/Caregivers

[Reference Number 16/146]
[23 November 2016]



Young People with Fetal Alcohol Spectrum Disorder (FASD): Are We Doing Enough?

Dear Parent(s), Guardian(s) or Caregiver(s),

Research Project about Young People with FASD in New Zealand

Thank you for showing an interest in the research I am undertaking for my PhD at the University of Otago under the supervision of Associate Professor Nicola Taylor and Professor Mark Henaghan. You must be/have been the caregiver of a young person between 12 and 25 years who has FASD. I am very grateful to you for giving me your time and considering whether just you, or you and your young person, would like to take part in this research. It may be that a support organisation that you or your young person consults with has sent you details of the research of my behalf, or you have heard about the research and have asked me for more information.

I believe it is really important to hear from families and young people about their experiences of living with FASD. I would like to ask you about your experience of raising a young person with FASD, your perception of the connection between FASD and offending behaviours, how effectively you think the youth justice system caters for young people with FASD, and whether there are any improvements that could be made. This will be an important part of my research in considering whether the law needs to be changed.

I have enclosed information that gives details of my study and am inviting you to consider taking part in an interview with me of around 30-45 minutes duration. I would also like you to consider whether your child or young person might be able to participate in the study too.

The interviews can take place at your home or at another place suitable for you or your young person. Please note that what I am told will be confidential and will not be passed onto any professional, individual or organisation.

Strict guidelines regarding confidentiality will be observed so that information from participants will never enable them to be identified. If you agree to take part I will ask you to sign a consent form, and to agree to your young person's participation by signing a separate consent form on their behalf (unless they are old enough to consent on their own). I will also check before I interview your young person that he or she is happy to take part – they have a consent form to sign too.

This study has been approved by the Human Ethics Committee at the University of Otago.

Please phone or email me if you would like to take part or if you have any questions.

I appreciate your consideration of my request.

Yours sincerely

Kesia Sherwood, PhD student

Contact:

Kesia Sherwood

and/or

Associate Professor Nicola Taylor

Phone: xxx xxx xxxx
Otago

Children's Issues Centre, University of

Email: kesia.sherwood@otago.ac.nz
479 5038

University Telephone Number: (03)

nicola.taylor@otago.ac.nz

Email

Address:

Appendix B

Information Sheet for Parents / Guardians / Caregivers

[Reference Number 16/146]
[23 November 2016]



Young People with Fetal Alcohol Spectrum Disorder (FASD): Are We Doing Enough?

Thank you for showing an interest in this project. Please read this information sheet carefully before deciding whether or not to participate. If you decide to participate we thank you. If you decide not to take part there will be no disadvantage to you and we thank you for considering our request.

What is the Aim of the Project?

My name is Kesia Sherwood and I am undertaking this project as part of my PhD study on young people with FASD and their involvement in the youth justice system. I would really like to hear from parents, caregivers or guardians of young people with FASD about what their experience has been. Your young person does not necessarily need to have had contact with the justice system – I would still like to hear your thoughts on FASD generally. I want to find out the perspectives of people who have experience living with and managing FASD to better inform my research and to help me provide advice on how to improve diagnostic, policy and legal initiatives in New Zealand.

What Type of Participants is Being Sought?

1. **Professionals (health, education and justice).**
2. **Family Members**
3. **Key stakeholders**

What will Participants Be Asked to Do?

Should you agree to take part in this project, you will be asked to participate in a taped interview of around 30-45 minutes with me. The interview will be conducted at a time and venue convenient to you.

If your young person is also taking part in the study, the interview with you will also provide a good opportunity for our first introduction. The initial interview with your young person will then be arranged for another date.

What are the Topics of Discussion?

Young People and Family Members

With your consent where necessary (if your child is under 17 years of age), I would like to speak with your young person (aged between 12 and 25 years). If possible, I would also like to first speak with you, either alone or jointly with another caregiver. Discussions with you will focus on your perspectives of living with and managing FASD, and the implications FASD has for offending behaviours. I will also ask you a few questions about what you think of the youth justice system in terms of how effectively it is able to meet the needs of young people with FASD. This will either be based off your personal experience of having a young person who has had interaction with the justice system, or based off your knowledge of and experience of FASD more generally. It doesn't matter if your particular young person has not had interaction with the justice system – I still want to hear your thoughts.

Discussions with the young people I hope to interview will take place over the course of three separate interviews, with a break of 3-4 weeks between each interview. These discussions will focus on interactions the young person has had with the justice system, including the level of acknowledgement given to the young person's FASD, the support offered to ensure the young person understood the process and any alternative rehabilitative pathways that were suggested for the young person. Discussions with the young person will be generated several different ways, including giving the young person the opportunity to complete a creative project to portray their experience. Discussion in the final interview with the young person will be centred around a hypothetical scenario, which I will read out to the young person and then ask them some questions about what they think about it. For these interviews, the young person needs to have had some contact with the justice system, whether formally or informally.

I am aiming to speak with up to 10 children and 10-20 parents/guardians/caregivers in the Wellington, Hutt Valley, Dunedin, Auckland and Nelson areas.

What Data or Information will be Collected and What Use will be Made of it?

The information to be collected will be your responses to the questions about FASD and youth justice, together with brief demographic data regarding your gender, ethnicity, age-range and locality. With your agreement the research interview will be taped so that key themes can be identified, and relevant quotes and examples of practice can be retrieved, for inclusion in the doctoral thesis and journal publications.

Only myself and my supervisors will have access to the information you and the other participants provide. The data collected will be securely stored in such a way that only they

will be able to gain access to it. Data obtained as a result of the research will be retained for **at least 5 years** in secure storage. Any personal information held on the participants [such as contact details and audio tapes after they have been transcribed] will be destroyed at the completion of the research even though the data derived from the research will, in most cases, be kept for much longer or possibly indefinitely.

An overview of the key themes emerging through all the interviews with participants will be analysed. Anonymous quotes and examples of practice will also be included to illustrate these themes. No individual or their location will be identified without their consent.

The results of the project may be published and will be available in the University of Otago Library (Dunedin, New Zealand), but every attempt will be made to preserve your anonymity.

You will be offered a copy of your interview summary and will have the opportunity to correct or withdraw any information you provide at any time in the period following the interview and prior to conclusion of the thesis or publication of any journal articles.

At the conclusion of the project, I will be pleased to provide you with a copy of a summary of the research findings and any journal articles written.

Can Participants Change their Mind and Withdraw from the Project?

You may withdraw from participation in the project at any time and without any disadvantage to yourself of any kind.

What Participants Do if They Want to Take Part or Have any Questions?

If you would like to take part or if you have any questions about the project, either now or in the future, please feel free to contact:

Kesia Sherwood

and/or

Associate Professor Nicola Taylor

Phone: xxx xxx xxxx
Otago

Children's Issues Centre, University of

Email: kesia.sherwood@otago.ac.nz
479 5038

University Telephone Number: (03)

nicola.taylor@otago.ac.nz

Email

Address:

This study has been approved by the University of Otago Human Ethics Committee. If you have any concerns about the ethical conduct of the research you may contact the Committee through the Human Ethics Committee Administrator (ph 03 479 8256). Any issues you raise will be treated in confidence and investigated and you will be informed of the outcome.

Appendix C

Information Sheet for Health / Education / Justice Participants

[Reference Number 16/146]
[23 November 2016]



Young People with Fetal Alcohol Spectrum Disorder (FASD): Are We Doing Enough?

Thank you for showing an interest in this project. Please read this information sheet carefully before deciding whether or not to participate. If you decide to participate we thank you. If you decide not to take part there will be no disadvantage to you and we thank you for considering our request.

What is the Aim of the Project?

Kesia Sherwood is undertaking this project as part of her PhD study on young people with FASD and their involvement in the youth justice system. There are three principal aims:

1. To consider the current knowledge and practice of professionals in dealing with young people with FASD.
2. To consider the experiences and views of young people with FASD who have had contact with the justice system, and parents/guardians/caregivers of young people with FASD.
3. To consider whether the law and policy on youth offenders with FASD is satisfactory or needs amendment.

What Type of Participants is Being Sought?

1. **Professionals (health, education and justice).**
2. **Family members.**
3. **Key stakeholders.**

What will Participants be Asked to Do?

Should you agree to take part in this project, you will be asked to participate in a taped interview of around 30-45 minutes with Kesia Sherwood. The interview will be conducted at a time and venue convenient to you.

Organisations who support young people with FASD are also invited to pass on information about the study to families they consider might be interested in participating in it. An information sheet for parents and a separate one for young people will be provided which can be passed onto families. An advertisement flyer is also available which we would appreciate being placed in your waiting room or office.

What are the topics of discussion?

Professionals

The discussion will explore your understanding of FASD and your experience of dealing with young people with FASD (whether it be through screening or diagnosis as a health professional, representation as a youth advocate, or contact with a young person in the education context). The questions will also enquire into any issues and concerns relating to the treatment of young people with FASD in the justice system, either based on your perceptions, or through your direct experience with these processes.

Young People and Family Members

With the consent of a parent/guardian/caregiver where necessary, Kesia would like to speak with **young people aged between 12 and 25 years**. If possible, she would also like to first speak with one or both of the young person's parents/guardians/caregivers who have been involved in raising the young person. She is also interested in speaking with parents/guardians/caregivers of young people with FASD, even if their particular young person has not had contact with the justice system. Discussions with the adults will focus on their perspectives of FASD, and how the youth justice system might better meet the needs of this group of young people. Discussions with the young person will take place over the course of three separate interviews, and will focus on the interaction/s they have had with the justice system, including the level of acknowledgement given to the young person's FASD, the support offered to ensure the young person understood the process and any alternative rehabilitative pathways that were suggested for the young person. Discussions with the young person will be generated several different ways, including giving the young person the opportunity to complete a creative project to portray their experience. Discussion in the final interview with the young person will be centred around a vignette. Kesia is aiming to speak with up to 10 young people and 10-20 parents/guardians/caregivers in the Wellington, Hutt Valley and Dunedin areas.

Key Informants

Discussion will explore the legislative, regulatory, policy and practice contexts regarding young people with FASD in the justice system.

What Data or Information will be Collected and What Use will be Made of it?

The information to be collected will be your responses to the questions about FASD and youth justice, together with brief demographic data regarding your gender, ethnicity, age-range, locality, and your role and length of professional experience. With your agreement, the research interview will be taped so that key themes can be identified, and relevant quotes and examples of practice can be retrieved, for inclusion in the doctoral thesis and journal publications.

Only Kesia and her supervisors will have access to the information you and the other participants provide. The data collected will be securely stored in such a way that only they will be able to gain access to it. Data obtained as a result of the research will be retained for **at least 5 years** in secure storage. Any personal information held on the participants [such as contact details and audio tapes after they have been transcribed] will be destroyed at the completion of the research even though the data derived from the research will, in most cases, be kept for much longer or possibly indefinitely.

An overview of the key themes emerging through all the interviews with participants will be analysed. Anonymous quotes and examples of practice will also be included to illustrate these themes. No individual or their location will be identified without their consent.

The results of the project may be published and will be available in the University of Otago Library (Dunedin, New Zealand), but every attempt will be made to preserve your anonymity.

You will be offered a copy of your interview summary and will have the opportunity to correct or withdraw any information you provide at any time in the period following the interview and prior to conclusion of the thesis or publication of any journal articles.

At the conclusion of the project, Kesia will be pleased to provide you with a copy of a summary of the research findings and any journal articles written. In addition, she is very willing to attend any professional development seminars to discuss the findings with professional audiences.

Can Participants Change their Mind and Withdraw from the Project?

You may withdraw from participation in the project at any time and without any disadvantage to yourself of any kind.

What Should Participants Do if They Want to Take Part or Have any Questions? If you would like to take part or if you have any questions about the project, either now or in the future, please feel free to contact:

<i>Kesia Sherwood</i>	and/or	<i>Associate Professor Nicola Taylor</i>
Phone: xxx xxx xxxx		Children's Issues Centre, University of Otago
Email: kesia.sherwood@otago.ac.nz		University Telephone Number: (03) 479 5038

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Address:

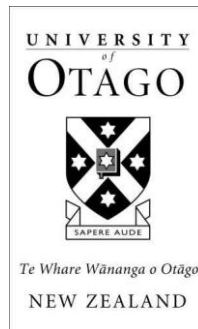
nicola.taylor@otago.ac.nz

This study has been approved by the University of Otago Human Ethics Committee. If you have any concerns about the ethical conduct of the research you may contact the Committee through the Human Ethics Committee Administrator (ph 03 479 8256). Any issues you raise will be treated in confidence and investigated and you will be informed of the outcome.

Appendix D

Consent Form for Adult Participants

[Reference Number 16/146]
[23 November 2016]



Young People with FASD: Are We Doing Enough?

I have read the Information Sheet concerning this project and understand what it is about. All my questions have been answered to my satisfaction. I understand that I am free to request further information at any stage.

I know that:-

1. My participation in the project is entirely voluntary;
2. I am free to withdraw from the project at any time without any disadvantage;
3. Personal identifying information [e.g. audio-recordings] will be destroyed at the conclusion of the project, but any raw data on which the results of the project depend will be retained in secure storage for at least five years;
4. The results of the project may be published and will be available in the University of Otago Library (Dunedin, New Zealand) but every attempt will be made to preserve my anonymity.

I agree to take part in this project.

.....

.....
(Signature of participant)

(Date)

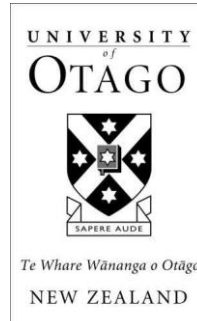
This study has been approved by the University of Otago Human Ethics Committee. If you have any concerns about the ethical conduct of the research you may contact the Committee

through the Human Ethics Committee Administrator (ph 03 479 8256). Any issues you raise will be treated in confidence and investigated and you will be informed of the outcome.

Appendix E

Interview Schedule for Parents / Guardians / Caregivers

[Reference Number 16/146]
[23 November 2016]



Young People with FASD: Are We Doing Enough?

BACKGROUND

Tell me about what your child/young person is like, in particular their personality.

Prompts:

- How old is your child now?
- What are some things they like doing in their spare time?
- What would you say are your child's particular strengths?

FASD:

Can you tell me about your child/young person's experience with FASD?

Prompts:

- How old were they when they were first assessed/diagnosed for FASD? What led to the diagnosis? Who did the diagnosis/assessment? How did it work?
- What effect did the diagnosis have on you as a family?
- Are there specific behaviours you can observe in your child/young person that reflects their diagnosis of FASD?
- Has your child/young person had any contact with the justice system?
- IF YES: can you tell me about what that was like?
 - a. Was their FASD a known factor throughout the process?
 - b. Did you feel they were adequately supported to understand the process?

- c. Did you understand the process?
 - d. Are there any aspects of the process that could have been improved for your particular child/young person, in regards to their FASD?
- IF NO: What is your perception on the connection between FASD and youth offending?

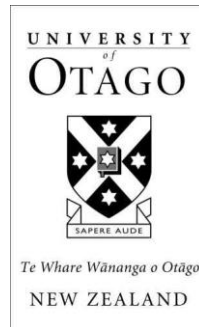
Prompts:

- What behaviours commonly seen in FASD do you think might translate to offending behaviour?
- Do you think New Zealand's youth justice system should acknowledge a young person's FASD and adjust the consequences of their offending to reflect their disability?
- How do you think the youth justice system could be improved for young people with FASD?
- If you could give advice to justice professionals working with young people with FASD, what would it be?

Appendix F

Consent Form for Young People

[Reference Number 16/146]
[23 November 2016]



Young People with FASD: Are We Doing Enough?

I have been told about this study and understand what it is about. All my questions have been answered in a way that makes sense.

I know that:

1. Participation in this study is voluntary, which means that I do not have to take part if I don't want to and nothing will happen to me. I can also stop taking part at any time and don't have to give a reason.
2. Anytime I want to stop, that's okay.
3. Kesia will audio-record me so that she can remember what I say, but the recording will be erased after the study has ended.
4. If I don't want to answer some of the questions, that's fine.
5. If I have any worries or if I have any other questions, then I can talk about these with Kesia.
6. The paper and computer file with my answers will only be seen by Kesia and the people she is working with. They will keep whatever I say private.
7. Kesia will write up the results from this study for her University course. The results may also be written up in journals and talked about at conferences. My name will not be on anything the researchers write up about this study.

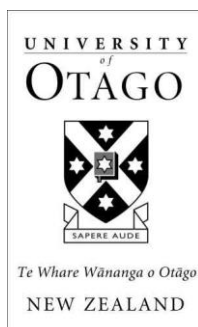
I agree to take part in the study.

.....
Signed

.....
Date

Appendix G
Consent Form for Parents / Guardians on Behalf of their Child
(aged 12 – 16 years)

[Reference Number 16/146]
[23 November 2016]



Young People with FASD: Are We Doing Enough?

I have read the Information Sheet concerning this project and understand what it is about. All my questions have been answered to my satisfaction. I understand that I am free to request further information at any stage.

I know that:-

1. My child's participation in the project is entirely voluntary;
2. I am free to withdraw my child from the project at any time without any disadvantage;
3. Personal identifying information, such as audio-recordings will be destroyed at the conclusion of the project but any raw data on which the results of the project depend will be retained in secure storage for at least five years;
4. The results of the project may be published and will be available in the University of Otago Library (Dunedin, New Zealand) but every attempt will be made to preserve my child's anonymity.
5. The researcher will contact me prior to my child being interviewed.

I agree for my child to take part in this project.

.....

.....
(Signature of parent/guardian)

(Date)

Name:..... Ph:

Address:..... Email:.....

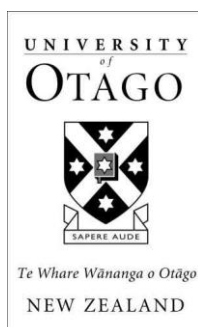
Name of Child:.....

This study has been approved by the University of Otago Human Ethics Committee. If you have any concerns about the ethical conduct of the research you may contact the Committee through the Human Ethics Committee Administrator (ph 03 479 8256). Any issues you raise will be treated in confidence and investigated and you will be informed of the outcome.

Appendix H

Interview Schedule for Young People

[Reference Number 16/146]
[23 November 2016]



Young People with FASD: Are We Doing Enough?

Interview One

Hi, I'm Kesia Sherwood. I am studying at the University of Otago in Dunedin. I am talking with young people aged between 12 and 25 years, and their families, about FASD and their experience of the justice system. What this means is when you were arrested by the Police or appeared in the Youth Court, did they know about your FASD and did you understand what was happening?

Your Mum/Dad/other adult has said that it is okay for me to ask you if you would like to help me with my study. I'll also be talking to your Mum/Dad/other adult but I think it is really important that young people get to have their say about it all too. So that's why I want to talk to you – so I can find out what you think and what your experience was. That way we may be able to help adults like police, youth advocate lawyers and judges do more to make things better for other young people.

Everything you say to me will be private, just between you and me, and I won't tell Mum, Dad, or anyone else in your family what you tell me. Also, I will not tell your doctor, lawyer or anyone else that you see. I will be talking to the people I work with about what we talk about but they won't know your real name, because you can choose a fake name. What I want to know is what *you* think and what *your* experience was so there are no right or wrong answers, and if there are any questions that you don't want to answer just tell me. Sometimes young people have a lot to say about some things and nothing to say about other things so you can say as much or as little as you want to and it's okay if you don't have answers – just say you don't know. You don't have to talk to me if you don't want to and you can tell me if you want to stop at any time and we will.

What you and everyone else tell me will be written in a report that others can read. This will not have anyone's names, and nobody will know it was you who said anything in the report because I'll use your fake name. It is okay if you change your

mind after you talk with me. If that happens before the report is written I will not use anything you have said.

[Ask young person if they are happy to talk to you. Ask young person what fake name they would like. Show young person the consent form and ask them to sign it. Explain that we are going through a consent process. This is them agreeing to taking part in my study. Explain about the audio recorder and give young person the option of turning it off if they want to and being in control of starting it.]

Warm up questions-

1. How old are you; where were you born; what school do you go to; what do you like to do after school and at weekends; who lives with you in your home [these questions will vary based on the young person's particular circumstance (eg they may not be at school or live at home)].
2. What jobs or responsibilities do you have at home / school / in the workplace?

FASD:

I'd like to talk to you about your FASD. Tell me about what it was like when you first found out you had FASD?

Prompts:

3. How old were you, do you remember?
4. Do you remember the doctor or psychologist you saw? What were they like?
5. How do you think FASD affects you in your life? Are there some things that you think are harder for you than for other children/young people?

Justice:

The next thing I want to ask you about is your experience of the justice system. If you're happy to talk to me about your experience, I have a few questions. For example, can you tell me what was it like when you were arrested by the Police/in the Youth Court/in a Family Group Conference?

Prompts:

6. Did the lawyer/police/judge know about your FASD?
7. Did anyone give you extra support for your FASD?
8. Did you understand what was happening at the time?
9. Do you remember any parts of the process that were helpful?
10. Were there any parts of the process that were especially challenging?

Thanks so much for sharing your experience with me, it's really helpful. If you want to help me understand your experience even better from your perspective, I have a suggestion for a creative project you could do. For example, you could draw or paint a picture, or if you like music you could compose a piece or make a playlist of songs that reflect what your experience was like. You can take a few weeks to think about this

and create something, then we can meet again and you can tell me about what you have put together.

Interview Two

Warm up questions:

11. What have you been up to; have you done anything interesting at school/work recently; how is it going with your sport/music/extra-curricular activities?
12. Have you thought of anything else to tell me about FASD or the justice system since we last met?

Personal experience:

I'd like to talk to you about your experience of the youth justice system again. Would you like to share with me the work you have created?

13. Can you explain how this reflects your experience? [This question will vary depending on the particular medium they have chosen. I will be able to ask more specific questions once I am looking at/reading/hearing their work].

Personal perceptions:

I'd like to ask you a few questions about how you think the process could be better.

14. Can you think of what advice you might give to another young person with FASD who is about to go through what you went through?
15. Do you have any advice for police/lawyers/judges about how they might treat young people with FASD better?
16. If you could change something about the system for young people with FASD, what would it be?

Interview Three

Warm up questions:

17. What have you been up to; have you done anything interesting at school/work recently; how is it going with your sport/music/extra-curricular activities?
18. Have you thought of anything else to tell me about FASD or the justice system since we last met?

The next thing I want to do is to just get your opinion on a scenario. So I'm going to read out a short story of a young person with FASD, and then ask you a few questions about what you think about it. There are no right or wrong answers, I just want to hear your thoughts!

Vignette

This story is about a 14-year old boy with FASD. Because of his different brain structure, he has difficulty understanding normal ideas about property – for example, he doesn't understand that it is wrong to take something that doesn't belong to you. He also finds it difficult to communicate his feelings in stressful situations – for example, if he is being told off by his parents or teachers he will tend to get angry very quickly and lash out, because his brain stops him from being able to organise his thoughts into words.

One day the boy goes into a café to get a drink of water. He is on his way home, and it is a hot day. He has quite a long way to walk and is already feeling pretty tired. On his way out of the café he sees a handbag sitting on the floor of the café next to a table. There isn't anyone sitting at the table. He picks up the handbag and walks out, thinking there is probably some money in it that he could use to catch a bus home.

A few minutes later the boy gets stopped by a policeman. The policeman says “did you just steal a handbag from that café?” The boy feels nervous and stressed about being stopped by the policeman, and says “No” and starts running away. The policeman runs after him and catches him and says “I can see that you have a handbag. Is that your handbag?” The boy says “Yes”. The policeman starts getting a bit angry, and tells the boy to stop lying. The boy doesn't understand and doesn't know how to explain to the policeman that there was no-one with the handbag when he took it. Instead, he shouts “Get off me!” and hits at the policeman's arm to try to make him let go.

Questions:

19. What do you think might happen next? What *should* happen next?
20. Has the boy's FASD affected the way he acted? If so, in what way?
21. What might be different if the boy didn't have FASD? Might he still have taken the handbag and/or hit the police officer? Why/why not?
22. Do you think the policeman knows the boy has FASD? Why/why not?
23. If the policeman did know the boy had FASD, how do you think the policeman could have acted differently?
24. Let's say this boy goes to a Family Group Conference – should this FGC take his FASD into account? How? What should he be expected to do to make up for his offending?
25. What if the boy ends up going to the Youth Court because of his offending? Should the Youth Court take his FASD into account? How? What do you think the judge should do? Would your answer be different if the boy didn't have FASD? Why/Why not?

Conclusion:

Thank you so much for sharing your thoughts about this story – it is really helpful! Do you have any general questions for me about my research project, or about anything we have talked about over the last few weeks? Are there any changes you would like to suggest that could really make a difference? Do you have any advice for other young people facing similar situations to what you have been through? Do you have any final comments you'd like to make about FASD, or the youth justice system, or anything else?

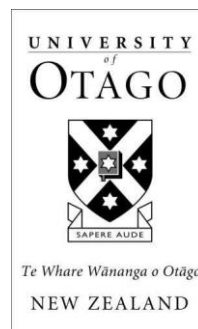
Thank you for participating in my study. I have really enjoyed talking with you!

[

Appendix I

Interview Schedule for Health Professionals (Paediatricians, Psychologists, Psychiatrists and Speech Language Therapists)

Reference Number 16/146]
[23 November 2016]



Youth Offenders with FASD: Are We Doing Enough?

Background:

Tell me about your understanding of FASD?

Prompt:

- When/how did you first become aware of the disorder?
- What do you understand to be the key/commonly observed presentations of the disorder?
- Have you had any formal training regarding FASD? If so, what did it involve?
- Describe the diagnostic process for FASD in New Zealand, how you understand it to be?

Personal experience:

Have you ever been involved in the assessment, diagnosis or treatment of a child or young person with suspected FASD?

Prompts:

- Describe the last patient you had for whom FASD was a central issue?
- How was FASD raised as a possibility?

- What was the assessment/diagnostic/treatment process in that particular case?
- What advice would you give to other health professionals in New Zealand or internationally regarding the treatment of young people with FASD?

Have you ever been involved with providing a report for the Youth Court on a young person with FASD?

- What did the process involve?
- Do you know what the outcome of the case was?
- How do you perceive the experience to have been for the young person?
- How satisfied were you with the process?

Personal Perceptions:

What are your perceptions on the relationship between FASD and youth offending?

Prompts:

- How do the specific brain impairments caused by alcohol exposure *in utero* affect behaviour?
- How would the particular behavioural patterns observed in a young person with FASD lead to antisocial/offending behaviours in particular?
- Is there a specific type of offending you might expect to see in a young person with FASD? Why?

What are your perceptions on the current youth justice system's effectiveness or ineffectiveness in dealing with young offenders with FASD?

Prompts:

- Can you give an example of an aspect of the system that works well for these young people?
- Can you give an example of an aspect of the system that doesn't work for these young people?
- Do you have any views on what changes to either the law or policy might make the system more responsive to these young people?

Demographics:

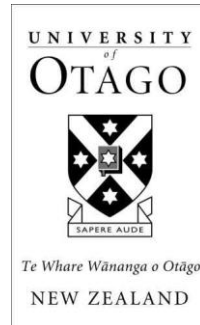
- What are your gender, ethnicity, age-range (30-40; 41-50; 51-60; 61-70; 70+), professional title and length of professional experience?

Appendix J

Interview Schedule for Education Professionals (School Principals (or nominee), Teachers and School Counsellors)

[Reference Number 16/146]

[23 November 2016]



Youth Offenders with FASD: Are We Doing Enough?

BACKGROUND

Tell me about your understanding of FASD?

Prompts:

- When/how did you first become aware of the disorder?
- What do you understand to be the key/commonly observed presentations of the disorder?

Personal Experience:

Have you encountered a child or young person with FASD during your career as an educator?

Prompts:

- Can you describe the most recent experience you had with a young person with FASD at school?
- How was the issue of FASD raised/made aware to you?
- In what context was the issue raised? Was the child/young person experiencing difficulties?
- Are there any extra supports for children with FASD at your school?
- Do you have any advice to give to other education professionals regarding supporting children with FASD at school?
- Do you think there is a need to raise awareness of this issue? Why?

Personal Perceptions:

What are your perceptions on the relationship between FASD and youth offending?

Prompts:

- What are some common behaviours seen in children with FASD?
- How do you think these behaviours could translate to antisocial/offending behaviours?
- What are your thoughts on the youth justice system regarding the way it deals with young people with FASD?
- Do you think there are any aspects to the law or policy surrounding youth justice that could be improved for young people with FASD?
- Is there anything else you would like to raise about FASD generally or in the context of youth offending in particular?

Demographics:

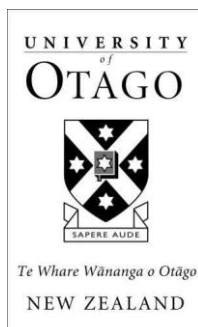
- What are your gender, ethnicity, age-range (30-40; 41-50; 51-60; 61-70; 70+), professional title and length of professional experience?

Appendix K

Interview Schedule for Justice Professionals (Youth Advocate Lawyers, Police, Youth Court Judges)

[Reference Number 16/146]

[23 November 2016]



Youth Offenders with FASD: Are We Doing Enough?

BACKGROUND

Tell me about your understanding of FASD?

Prompts:

- When/how did you first become aware of the disorder?
- What do you understand to be the key/commonly observed presentations of the disorder?
- Have you had any formal training regarding FASD in the course of your professional development?

Personal Experience:

Have you encountered a child or young person with FASD during your career as a youth advocate/judge/member of police?

Prompts:

- Can you describe the most recent interaction you had with a child or young person with FASD during your role as a [justice professional]?
- How was the issue of FASD raised/made apparent to you?
- What impact did the existence of FASD have in the way you approached the situation/interacted with the young person?
- Did the young person's FASD have a material impact on the outcome of the case? What was the outcome of the case?

- What advice would you give to another [justice professional] regarding working with a young person with FASD?

Personal Perceptions:

What are your perceptions on the relationship between FASD and youth offending?

Prompts:

- What are some common behaviours seen in children with FASD?
- How do you think these behaviours could translate to antisocial/offending behaviours?
- What are your thoughts on the youth justice system regarding the way it deals with young people with FASD?
- Do you think there are any aspects to the law or policy surrounding youth justice that could be improved for young people with FASD?
 - a. Do you think there needs to be specific legislative amendment to provide an alternate pathway through the justice system for young people with FASD? If so, what do you think such an alternative might look like?
- Do you think there is a place for further training for [justice professionals] in regards to working with young people with FASD?
- Is there anything else you would like to raise about FASD generally or in the context of youth offending in particular?

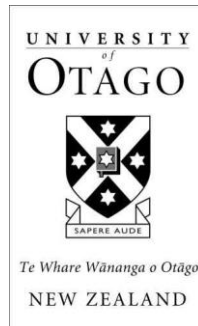
Demographics:

- What are your gender, ethnicity, age-range (30-40; 41-50; 51-60; 61-70; 70+), professional title and length of professional experience?

Appendix L

Interview Schedule for Key Stakeholders

[Reference Number 16/146]
[23 November 2016]



Youth Offenders with FASD: Are We Doing Enough?

BACKGROUND

Tell me about your understanding of FASD?

Prompts:

- When/how did you first become aware of the disorder?
- What do you understand to be the key/commonly observed presentations of the disorder?

Personal Experience:

What kind of involvement have you, or your organisation, had regarding the issue of young offenders with FASD?

Prompts:

- What is your agency's role in raising awareness and facilitating discussion of this issue with parents and young people, justice, health and education professionals and the wider community?
- Do you think there is a need to raise awareness of this issue? If so, how should it be done?

Personal Perceptions:

What are your perceptions on the relationship between FASD and youth offending?

Prompts:

- What are some common behaviours seen in children and young people with FASD?
- How do you think these behaviours could translate to antisocial/offending behaviours?
- What are your thoughts on the youth justice system regarding the way it deals with young people with FASD?
- Do you think there are any aspects to the law or policy surrounding youth justice that could be improved for young people with FASD?
- Is there anything else you would like to raise about FASD generally or in the context of youth offending in particular?

Demographics:

- What are your gender, ethnicity, age-range (30-40; 41-50; 51-60; 61-70; 70+), professional title and length of professional experience?