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Social cognition, executive functioning and IQ. What are the important influences on adaptive functioning in children with Fetal Alcohol Spectrum Disorder?

|   |   |
|---|---|
| He mokopuna He taonga                           | A child, a treasure   |
| Ko taku tamaiti e noho mai<br>nei kei te kōpū   | My child who lies within the<br>womb  |
| I te huaki pouri                                | On the edge of darkness, come<br>forth  |
| Nau mai, haere mai                              | Come forth into the world   |
| He wahine, he whenua, ka<br>ngaro ai te tangata | Women and land both provide<br>sustenance and nourishment and<br>without them the myriads of<br>descendants are lost <sup>1</sup> |

Andrea May Crawford

2018

A thesis submitted in fulfilment of the requirements for the degree of Doctor of Philosophy (PhD) in Psychology, University of Auckland, New Zealand.

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<sup>1</sup> This whakataukī was given by Te Wāhanga Hauora Māori (Māori Health Service), Hawke's Bay DHB, on completion of this thesis.



## Abstract

Fetal Alcohol Spectrum Disorder (FASD) is one of the leading causes of intellectual disability and learning difficulties around the world. International research suggests a higher prevalence of FASD in Indigenous populations, however, this must be considered within the context of colonisation and historical trauma having direct effect on the health of Indigenous populations. This research was supported by a strong partnership with Te Wāhanga Hauora Māori (Māori Health Service) and findings are discussed with regard to both the psychological literature, colonised history of Aotearoa New Zealand and Te Ao Māori worldview.

Children with FASD often have extremely low adaptive behaviour due to the severity of brain impairment, sometimes lower than expected given their level of intellectual functioning. Impairments in executive functioning (e.g. planning, cognitive flexibility and self-regulation) are thought to underlie many difficulties in adaptive functioning. Recent findings suggest children with FASD may also have difficulties with social cognition (e.g. emotion recognition, theory of mind social problem-solving). This research project aimed to investigate which factors (IQ, executive functioning, social cognition and Adverse Childhood Events, ACEs) predict adaptive functioning in children (8-12 years) with FASD. A comparison group was included which was matched on age, gender, ethnicity, maternal education and deprivation index. Findings were also considered within the context of psychosocial complexity that exists for children with FASD in this study, including implications for required support services.

Children in the FASD group performed significantly below the comparison group, on all cognitive tasks and all measures of adaptive functioning, and demonstrated severe neurological impairment. Although IQ, executive functioning, social cognition and ACEs were significantly correlated with teacher-rated adaptive functioning for the FASD group, when multiple linear regression analyses were performed, social cognition, especially recognising

emotions on adults' faces, was the only significant independent predictor of teacher-rated adaptive function, even after including for IQ, executive functioning and ACEs in the model. This is important from a Te Ao Māori perspective as Māori society is built upon whakapapa and whanaungatanga which requires highly developed social and emotional skills.

In addition, children with FASD have limited contact with tertiary level health and education services despite experiencing severe neurological impairments, often in the context of significant psychosocial issues. These systems are an example of institutional racism where systems benefit the dominant race and penalise minority groups. Solutions are discussed which aim to; build skills in the child, build support in the whānau, develop solutions that are holistic and culturally responsive.

## Acknowledgements

To all the children involved in this study I thank you. They have taught me that strength comes in a variety of colours and textures. You face so many challenges but I am amazed by what you do to live and just be in this world. To the brave and remarkable birth mothers who shared their stories, you have astonished me with your ability to face the past in order to have your child understood.

To all these whānau<sup>2</sup> who want the best for these children, thank you for your love, care and willingness to understand your child and FASD. These children and whānau did not need to take part in this research project, but all professed a desire to share knowledge to help others. The generosity of people still astounds me. Likewise all the comparison children and their whānau that gave up time and energy to help create a deeper understanding. I thank you.

A PhD is a process and, I admit that for me, this process has been terrifying. What started as a tidy neuropsychological scientific PhD soon morphed into a reflection of the history of Aotearoa New Zealand for both Māori and Tauīwi (Non-Māori). My supervisors Associate Professor Lynette Tippett and Senior Lecturer Dr Elizabeth Peterson showed the openness and understanding that I hope is reflected in all academic departments. Whilst holding me to high standards of academic rigour they accepted the need to create and reflect the context that is the reality for the children and whānau in my study. Thank you for your guidance, wisdom and intellect.

To the Wāhanga Whakapakari Tamaiti (Child Development Service). I could not have undertaken this project without the support of the whole team. My Clinical Team Leader Jeanette Frechtling gave me the mandate to conduct research within the service and supported

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<sup>2</sup> This includes non-kin caregivers.

me with untold support, admin, study leave and much needed coffee. Dr Kate Robertshaw (Consultant Neurodevelopmental paediatrician) was an expert advisor for my PhD research. Dr Robertshaw read my work, assisted with my ethics, presented with Laurie Te Nahu and myself at the 7<sup>th</sup> International conference of FASD, listened to my worries and even gave flowers when required. Thank you. Thanks also goes to Vic Gollner who worked tirelessly to ensure I had the numbers for my study. To the rest of the team Andrea Hannah, Vicki Nettlingham, Anne McLeod, Megan Pickering, Nicky Ridley and Claire Benton, thank you for your support in so many ways.

Te Wāhanga Hauora Māori (Māori Health Service) have supported and guided my journey to deepen my Te Ao Māori knowledge. Laurie Te Nahu and Querida Whatuira-Strickland have both been exceptional in their role they played in ensuring the research process was mindful of tikanga Māori and that findings were interpreted with sensitive regard to the history of Aotearoa. Querida's support was fundamental in the beginning to ensure the consent and information collection were sensitive to whānau needs. Laurie provided me with direction and knowledge, through books and kōrero, to understand Māori society and philosophy uncovering many strengths that I was previously unaware of. Both Querida and Laurie have amazed me with their openness, and patience I'm sure, in their willingness to join me on this journey. Likewise kōrero with Kaumatua furthered my understanding and enabled a sharing of ideas. I also give acknowledgement and thanks to Tracee Te Huia and Patrick LeGeyt for trusting me and their staff to support this project.

I am also extremely fortunate to have friends who have guided me with their own, academic and real world knowledge and experience of both Māori and Pākehā worlds. They have sat when I have wept over the history of Aotearoa, inspired me with their own accomplishments, and encouraged me in moments of self-doubt to continue. Always holding

me to a standard of the highest integrity thank you - Monica Stockdale, Aria Graham, Helen Lenihan, Shayne and Rachel Walker, Helen Rouse and Jen Margaret.

Dr Valerie McGinn, Neuropsychologist, was another expert advisor. She has the most experience of FASD in New Zealand and works tirelessly, to assess, treat and advocate for children and whānau experiencing FASD. I am so grateful for her unrelenting support of me and this research. She has never let me forget who this research is for (the children and whānau) and has pushed me to advocate strongly and clearly. Likewise Christine Rogan from Alcohol Health watch has been on this journey for many years and her ongoing formal and informal support has been so appreciated.

The Hawke's Bay Medical Research Foundation (HBMRF) has also supported this research from the beginning through student scholarships and providing extra funding in my final year. This funding greatly eased the financial burden of studying as a distance student. The HBMRF sees research as being an important contributor to the health of the Hawke's Bay community and for this I am extremely grateful.

So many people in Hawke's Bay helped me find comparison subjects. But special mention has to go to Dr Meg Wilson, friend and GP in Flaxmere, who found a number of comparison whānau for me. Principals and SENCO's in many Hawke's Bay primary schools also supported this project with finding comparison group participants and giving space for assessments in the school. Special mention goes to Pat Wilson (Camberly School), Ricardo Fox and Kate Medlicott (Mayfair School), Megan Adams and Tim White (Frimley School).

And then my own whānau. To my Mum and Dad who have always believed I can do anything, thank you. I realise how much of a privilege it is growing up with people who have enabled me to dream big. My father in-law Dr Robert Crawford has inspired my clinical practice and I am grateful for his wealth of knowledge in the field of addiction. To my children

Isla and Molly, you keep me grounded in your craziness and love, and never let me forget I am first and foremost a mother. I also could not have completed this PhD without the wonderful Mary Hodgson who cares for my girls like they are her own grandchildren. To my husband Geoff. There are no words to adequately describe how your rock solid belief that this will be done, and done well, has helped when I have stumbled. You make me a better person.

## Letter of Endorsement

# Corporate Services



24 October 2017

Ms Andi Crawford  
Developmental Psychologist  
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Hastings

Tēnā koe Ms Crawford,

On behalf of the Te Wāhanga Hauora Māori (Māori Health Service), it is our pleasure to transmit these few words as an endorsement for your PhD research titled 'Fetal Alcohol Syndrome Disorder (FASD) within Matau a Maui (Hawke's Bay)'.

Through your work we have come to understand that children and adolescents diagnosed with FASD have severe neurological difficulties and brain impairments, and contributes to problems in adapting to environments in school, in the home and in the community. A diagnosis of FASD increases the risk of learning problems, trouble with the law, mental health issues, alcohol and drug misuse, and later on in life, contributes to employment difficulties and a decreased ability to live independently.

The high prevalence of Māori in your current study demonstrates the importance of using Māori models in the development of prevention and intervention programmes for our population. You understand one's connection to culture is advantageous to Māori health, but is also important to Indigenous health in the international arena. Western models of health, especially Tertiary Service Delivery tend to be driven by diagnosis whereas, Māori models of health employ a more holistic view of wellness and wellbeing.

Prior to this research, a relationship between the Child Development Service (CDS) and Te Wāhanga Hauora Māori was established. This started as a conversation about raising FASD awareness in health professionals and in the community. Together presentations went out to iwi, health and social organisations and health providers throughout the district. This led to a presentation at Tū Kaha - Māori Regional Health Conference 2014 to promote discussion around prenatal alcohol exposure.

In 2017, Te Wāhanga Hauora Māori and the CDS co-presented a 90 minute workshop "*Developing Collaboration between Clinical and Indigenous Frameworks in FASD Practice to address current Inequalities in Service Provision*" to the 7<sup>th</sup> International Conference on

Fetal Alcohol Spectrum Disorder in Vancouver Canada. Presenters included yourself and fellow CDS Paediatrician Dr Kate Robertshaw, and Laurie Te Nahu of Te Wāhanga Hauora Māori. Indeed, the participants acknowledged our unique blend of cultural and clinical partnership that the team were endowed with a standing ovation.

What a respectful show of teamwork as a result of the cooperative nature of this partnership. In particular, your support for Māori Health and Ngāti Kahungunu Rohe has been noted. Therefore,

*“Ko ngā kupu, Ko te Rourou iti a Haere “  
“these words are a small basket of food, the donor of a gift sometimes modestly  
describes it in this manner”*

Nāku noa, nā



Patrick LeGeyt  
Acting General Manager  
Te Wāhanga Hauora Māori

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## Glossary

Most definitions derived from [www.Māori Dictionary.co.nz](http://www.Māori Dictionary.co.nz) with contributions from Hawke's Bay District Health Board Te Wāhanga Hauora Māori.

| <b>Te Reo Māori</b>        | <b>English</b>   |
|----------------------------|--|
| Aotearoa                   | Land of the long white cloud, New Zealand.   |
| Aroha                      | Affection, sympathy, charity, compassion, love, empathy.   |
| He Taumata Rangahau        | Māori Research & Investigations.   |
| He Wakaputanga o te        | The Declaration of Independence 1835.  |
| Rangatiratanga o Nu Tirene |  |
| Hapū                       | Tribe, subtribe, clan  |
| Hapu                       | To be pregnant, conceived in the womb.   |
| Iwi                        | Collective kinship group, tribe, nation.   |
| Kahunungunu                | Tribal group from the East Coast of the North Island.  |
| Kaitakawaenga              | Cultural mediator/facilitator within the District Health Board.  |
| Kaitiaki                   | Guardian/protect/conserve/watch-over/preserve.   |
| Kaitiakitanga              | Guardianship, stewardship, trusteeship, trustee, protector, conservator.   |
| Kaiwhakahaere              | Māori Manager  |
| Kaumātua                   | Tribal elder, leader, a person who has waded through life  |
| Kaupapa                    | Foundation/issue at hand   |
| Kawa                       | Protocols or etiquette, customs and behaviours on the Marae, particularly those related to formal activities such as pōhiri, speeches, mihimihi, tangihanga. |

|               |  |
|---------------|--|
| Kāwanatanga   | Government, authority, governorship of a province.   |
| Koha          | Gift, present, offering, donation, contribution - especially one maintaining social relationships and has connotations of reciprocity. |
| Kōhanga Reo   | Māori language nest, preschool.  |
| Kōrero        | Talk/to speak/converse   |
| Koroua        | Elderly man.   |
| Kuia          | Female elder, leader, a person who has waded through life  |
| Kura Kaupapa  | School operating under Māori custom and using the Māori language as the medium of learning and instruction.                            |
| Māori         | Natural/normal, the Indigenous People of Aotearoa  |
| Mana          | Prestige, authority, control, power, influence, status, spiritual power, charisma.   |
| Mana Motuhake | Autonomy/Independence  |
| Mana whenua   | Territorial rights, power from the land, authority over land or territory, jurisdiction over land or territory.                        |
| Manaakitanga  | Hospitality, kindness, generosity, support - the process of showing respect, generosity and care for others.                           |
| Pākehā        | Pale, White. New Zealander of European descent.  |
| Papatūānuku   | Earth, Earth mother and wife of Rangi-nui - all living things originate from them.   |
| Pou Ārahi     | Pillar/beacon/illuminating.  |
| Pūrākau       | Myth, ancient legend, story.   |
| Rangatira     | Of Chiefly descent/leader/diplomat   |

|                         |  |
|-------------------------|--|
| Rangatiratanga          | Chieftainship, right to exercise authority, chiefly autonomy, chiefly authority, ownership, leadership of a social group, domain of the rangatira, noble birth, attributes of a chief. |
| Taha Hinengaro          | Mental and emotional well-being.   |
| Taha Tinana             | Physical well-being.   |
| Taha Wairua             | Spiritual well-being.  |
| Taha Whānau             | Family and social well-being.  |
| Tamariki                | Children.  |
| Tangata Mātauranga      | Knowledgeable person.  |
| Tangata Whenua          | Of the Land, hosts, Indigenous people of a place.  |
| Taonga                  | Treasure, anything prized - applied to anything considered to be of value including socially or culturally valuable objects, resources, phenomenon, ideas and techniques.              |
| Tauīwi                  | Non-Māori, non-indigenous New Zealanders.  |
| Taumata Rangahau        | Research/search the horizon  |
| Te Ao Māori             | Māori lens and view of the world   |
| Te Reo Māori            | Māori language.  |
| Te Reo                  | Language/voice   |
| Te Tiriti o Waitangi    | The Treaty of Waitangi.  |
| Te Wāhanga Hauora Māori | Māori Health Service.  |
| Kaitiaki                | To guard, keep, to look after, care, protect, conserve, save.  |
| Tika                    | Correctly, directly, fairly, justly, straight - indicates a direct path.   |

|                     |  |
|---------------------|--|
| Tikanga             | Correct procedure, custom, habit, lore, method, manner, rule, way, code, meaning, plan, practice, convention, protocol - the customary system of values and practices that have developed over time and are deeply embedded in the social context. |
| Tino Rangatiratanga | Self-determination, sovereignty, autonomy, self-government, domination, rule, control, power.  |
| Tohunga             | Priestly leader/an expert/reader of natural signs  |
| Wairua              | Spirit/spirituality/two waters   |
| Waitangi Tribunal   | Reconciliation Committee to settle Māori claims against the Crown  |
| Wānanga             | Seminar/place of learning/discussion group.  |
| Whānau              | Family group including extended members.   |
| Whanaungatanga      | Immediate relationships/links/ties   |
| Whangai             | Adopt (a child)/literally from the spittle of my mouth   |
| Whakapapa           | Genealogy/Biological blood lines/to lay one upon the other.  |
| Whakataukī          | Proverb, significant saying, formulaic saying, cryptic saying, aphorism.   |
| Whakawhanaungatanga | Broader, wider family connections  |

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## Chapter One: Introduction

Exposure to alcohol during pregnancy causes neurological damage to developing brains that significantly impacts general health and wellbeing (Baer, Sampson, Barr, Connor, & Streissguth, 2003; Streissguth, Barr, Kogan, & Bookstein, 1996; Streissguth et al., 2004). The term Fetal Alcohol Syndrome (FAS) and more recently Fetal Alcohol Spectrum Disorder (FASD) has been described as one of the key causes of developmental disability (Jones, Smith, Ulleland, & Streissguth, 1973; O'Leary et al., 2012; Riley, Infante, & Warren, 2011). The FAS phenotype includes growth impairment, facial dysmorphia with associated central nervous system impairments, whereas the wider spectrum (FASD) (which includes FAS) acknowledges the presence of neurological impairments without requiring the presence of physical characteristics of growth and facial dsymorphology (Astley, 2004; Chudley et al., 2005; Cook et al., 2016). For the purposes of this study the broader term FASD will be used to represent the spectrum of diagnoses connected with prenatal alcohol exposure.

Children exposed to alcohol prenatally, who are diagnosed with FASD, show severe central nervous system impairment in at least three of the following domains: “*motor skills; neuroanatomy/neurophysiology; cognition; language; academic achievement; memory; attention; executive function, including impulse control and hyperactivity; affect regulation; and adaptive behaviour, social skills or social communication*” (Cook et al., 2016, p. 193). Intellectual ability, measured by intelligence quotient (IQ), constitutes one domain of impairment (cognition) in FASD. Adaptive functioning, a second domain is severely affected by FASD even when individuals have higher IQ (Astley et al., 2009c; Streissguth et al., 1996).

Impairments in adaptive functioning (communication skills, independence and social skills) may be more important than IQ when determining strengths, difficulties and areas that

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require support for a person with FASD. Research suggests that adaptive functioning difficulties typically remain even after accounting for IQ (Fagerlund et al., 2012; Jirikowic, Kartin, & Olson, 2008; Kully-Martens, Treit, Pei, & Rasmussen, 2013; Quattlebaum & O'Connor, 2013), and low cognition may even be a protective factor against adverse life outcomes as those people who have significantly lowered cognition may be more likely to access services (Streissguth et al., 2004).

Difficulties in adaptive functioning may, however, be due to impairments in executive functioning skills (e.g. planning, cognitive flexibility, and self-regulation (Davis, Gagnier, Moore, & Todorow, 2013) rather than general intellectual functioning or IQ (Edwards & Greenspan, 2010; Greenspan et al., 2016). Additionally, some more recent findings suggest that children with FASD may have particular difficulties with social cognition in the areas of emotional understanding and recognition (Greenbaum, Stevens, Nash, Koren, & Rovet, 2009; Kerns, Siklos, Baker, & Müller, 2016; Petrenko, Pandolfino, Quamma, & Olson, 2017) and theory of mind (i.e. understanding another person's perspective) (Lindinger et al., 2016; Rasmussen et al., 2009; Stevens, Dudek, Nash, Koren, & Rovet, 2015). In addition, children with FASD often experience a range of additional adverse psychosocial influences which may further impact their adaptive functioning difficulties (Coggins, Timler, & Olswang, 2007).

It is critical that we understand better the basis of the impairments in adaptive functioning in FASD so that early interventions can be developed that target the fundamental difficulties. The overall aim of this research was to investigate whether impairments in social cognition, in addition to executive functioning difficulties and adverse childhood experiences, were better predictors of everyday independence (adaptive functioning) than IQ in a group of children with FASD, alongside a group of typically developing children.

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This current study intended to reflect the general Hawke's Bay child population. However, in the group of children who presented at our Wāhanga Whakapakari Tamaiti (Child Development Service) for assessment for FASD, and consented to be part of this study, Māori were overrepresented. This study therefore has the responsibility of recognising the historical context that Māori experience, which includes trauma, in the form of loss of land and destruction of traditional Māori society. It is important in FASD research to not only focus on the individual but to also recognise the historical, social and ethical processes that impact the prevalence, assessment and service provision for children and whānau experiencing FASD (Meurk, Lucke, & Hall, 2014).

This chapter will review the prevalence of FASD and give a historical context of Aotearoa New Zealand with particular attention given to the process of colonisation and subsequent socio-political influences and systematic racism that impact Māori today. Following this Chapter Two will review the current research literature with respect to adaptive functioning, IQ, social cognition and executive functioning in the field of FASD and will outline the aims and hypotheses of the research. Chapter Three details the research partnership process of this study. In Chapter Four, the research methodology used in this research is described and Chapter Five contains the results. Chapters Six and Seven comprise discussion of the research findings with regard to the psychological literature (Chapter Six), and a Te Ao Māori perspective (Chapter Seven). Finally Chapter Eight discusses implications and solutions for service delivery and interventions.

### **Fetal Alcohol Disorder Prevalence**

Current international prevalence estimations for FAS are at approximately 0.4-1.2% whereas the full FASD spectrum may be as high as 2-5 % of the general population (May et al., 2011; May et al., 2014). A recent meta-analysis of FASD found a global prevalence of 7.7 per 1000 population, but results varied between countries (95% CI 4.9-11.7 per 1000

## CHAPTER ONE

population) (Lange et al., 2017). In particular, there have been reports of higher prevalence in communities where heavy binge drinking occurs within the context of poverty and geographic isolation (Fitzpatrick et al., 2017; May, De Vries et al., 2017). Although there is no safe amount of alcohol exposure during pregnancy, increased risk of FASD is associated with higher quantities in an episodic or ‘binge’ type pattern (May, Blankenship et al., 2013).

Aotearoa New Zealand does not have FASD prevalence data, but many pregnancies may be exposed to alcohol due to an increased culture of ‘binge’ in young New Zealand women (Law Commission, 2009) and high levels of unplanned pregnancies (Mallard, Gray, & Houghton, 2012; Mallard, Connor, & Houghton, 2013). Although many women in Aotearoa New Zealand reduce their alcohol consumption after pregnancy recognition, others continue to drink at high risk levels (Cheung, Timmins, & Wright, 2015; Ho & Jacquemard, 2009; Mallard et al., 2013; Morton et al., 2010).

Alcohol consumption patterns may also vary between different levels of socioeconomic status (SES). The 2011/2012 Zealand National Health Survey found that people living in deprived areas were less likely to drink alcohol, but if they did drink they were more likely to have hazardous drinking patterns, and hazardous drinking was increasing in deprived areas for women, but not for men (Ministry of Health, 2013). Moreover, disadvantage and lower socioeconomic status has been found to be associated with either abstaining or binge drinking during pregnancy whereas women from higher SES backgrounds consume alcohol at more moderate to low levels during pregnancy (Cheung et al., 2015; Zuccolo et al., 2013).

Many women who consume alcohol during pregnancy also experience other psychosocial complexity. Contextual factors must be recognised as women who have been exposed to trauma; childhood abuse (physical, emotional, neglect or sexual) and/or intimate partner violence, report more risky alcohol consumption during pregnancy regardless of their

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pre-pregnancy drinking patterns (Choi et al., 2014). In women who give birth to a child with FASD there is also a high prevalence of poverty (May et al., 2008), low maternal education and mental health difficulties (May et al., 2008; May, Tabachnick et al., 2013; Singal et al., 2017) and research has suggested that drinking during pregnancy may be a coping mechanism for significant stress and trauma (Stuart, 2009; Watt et al., 2014).

International research suggests a higher prevalence of FASD in Indigenous populations (Popova, Lange, Probst, Parunashvili, & Rehm, 2017; Roozen et al., 2016) however, this must be considered within the context of colonisation and historical trauma having direct effect on the health of Indigenous populations (Paradies, 2016). There has been criticism towards FASD prevalence research and some have proposed that prevalence is less about culture or race and more of the result of structural discrimination and research bias (Pacey, 2008). In fact, in terms of prevalence, it may be more important to focus on the intergenerational effects of colonising activities such as residential schools and corresponding abuse, rather than directly associating FASD with Indigenous (Canada) populations (Hunting & Browne, 2012; Tait, 2003). Moreover, children with FASD are overrepresented in state care (Astley, Stachowiak, Clarren, & Clausen, 2002). This is particularly relevant to Aotearoa New Zealand because children in state care are overrepresented with children of Māori descent (Office of the Children's Commissioner, 2015).

Alcohol use in Indigenous populations varies greatly and as Tait (2003) noted in Canada FASD may be better “*understood as a problem of certain individuals and subpopulations, rather than a problem of all Aboriginal (Indigenous, Canada) people*” (Tait, 2003, p. xv). Moreover, an overrepresentation of FASD in Indigenous populations may relate to increased prevalence of depression and trauma leading to higher levels of alcohol abuse due to the colonisation process, rather than an underlying issue with race or culture. The Ontario Federation of Indian Friendship Centres (2013) in Canada state:

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*“Aboriginal (Indigenous, Canada) communities are often heavily affected by FASD not through cultural predisposition, but rather as a result of the disproportionate hardship that they experience in relation to the social determinants of health.....discrepancies in the health outcomes that continue to plague urban aboriginal (Indigenous, Canada) communities are the reflection of a disconnection from Aboriginal (Indigenous, Canada) culture, rather than the culture itself.” (p. 3).*

The international commentary regarding the importance of recognising the impact of colonisation on wellbeing and development must also be applicable to Aotearoa New Zealand. In Aotearoa New Zealand risk factors for an alcohol exposed pregnancy have been found to include women, who are Māori, with no secondary qualification and where the pregnancy was unplanned (Cheung et al., 2015; Mallard et al., 2013; Morton et al., 2010). As with other Indigenous populations Māori in Aotearoa New Zealand have also experienced trauma due to colonisation and subsequently experience greater levels of inequity than Non-Māori (Tauwiwi) (Durie, 2001; Hawke's Bay District Health Board, 2014; Marriott & Sim, 2015; Ministry of Health, 2015).

The recognition that FASD prevalence is associated with experiences of abuse and trauma through residential schools may not be unique to Canada. Aotearoa New Zealand also has a history of a ‘state care’ system where maltreatment, multiple care placements, damaging institutional cultures,” (p. 58) increased the likelihood of experiencing time in custody (Stanley, 2017). Although many children experience maltreatment prior to state care, the system continues to fail them through ‘placement instability, further ‘violent victimisation’ and the ‘criminalisation’ of trauma based behaviour (Stanley, 2017). The trajectory from ‘care to custody’ also involves the increased incidence of alcohol and drug issues and we can speculate this to also include FASD.

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The remainder of this chapter will review historical context of Aotearoa New Zealand to outline the causes of inequity and ongoing trauma that may influence prevalence of FASD for Māori.

### **Tamariki, Whānau and Te Ao Māori**

Before the arrival of Pākehā, Māori shared common characteristics of social organisation. Individuals living in kindred groups belonged to a whānau (family), families from the same ancestor belonged to a hapū (clan), and clans with shared ancestry belonged to an iwi (tribe). There were also common values and protocols for behaviour, the most relevant to Māori society being those supportive of the health and safety, harmony, power and prestige of the clan. Children were thought of as taonga (treasures) and were protected and nurtured (Walker, 2004).

Collectively Māori whānau (families) including children, parents and grandparents often living in close vicinity from each other. Every clan member had responsibility and obligations for parenting/ child rearing (Heuer, 1972; Taonui, 2010).

The writings and letters of early Pākehā such as; William Colenso, George Angas, and Samuel Marsden, describe how the whānau embodied these values and both males and females were seen to care and protect children and infants.

*‘Their love and attachment to children was very great, and that not merely to their own immediate offspring. They very commonly adopted children; indeed no man having a large family was ever allowed to bring them all up himself – uncles, aunts and cousins claimed and took them, often whether the parents were willing or not. They certainly took every physical care of them; and as they rarely chastised (for many reasons) of course, petted and spoiled them. The father, or uncle, often carried or nursed his infant on his back for*

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*hours at a time, and might often be seen quietly at work with the little one there snugly ensconced* [William Colenso, 'On the Māori Races of New Zealand,' TNZ Inst I, 30]

*'Both parents are almost idolatrously fond of their children; and the father frequently spends a considerable portion of his time in nursing his infant, who nestles in his blanket, and is lulled to rest by some native song... The children are cheerful and lively little creatures, full of vivacity and intelligence. They pass their early years almost without restraint, amusing themselves with the various games of the country'* [Angas, 1847:313-4]

*'I saw no quarrelling while I was there. They are kind to their women and children. I never observed either with a mark of violence upon them, nor did I ever see a child struck'* [ed. Elder, J.R., The Letters and Journals of Samuel Marsden, 128]

These early writings reflect the observations that Māori demonstrated exceptional kindness and nurturing for their people, especially their children, which was at a level probably not observed in Victorian England. In the present day the media tends to focus on negative aspects of Māori and there is much attention on violence and male Māori perpetrators (Rankine et al., 2008; Taonui, 2010). In general there is a general failure to not only acknowledge positive news stories but to also acknowledge that the negative, e.g. Issues of family violence and addiction, have occurred in Māori society after the arrival of Pākehā and as a direct result of colonisation.

Traditional Māori society was based on tikanga which is defined by Durie (2016) as the application of Māori knowledge "to human survival, safety, engagement and relationship building. It is "derived from the word 'tika' which means right or correct". Within tikanga sits

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Māori values such as Kaitiakitanga, Manaakitanga, and Whanaungatanga. Kaitiakitanga describes the protection of people, places and objects in accordance with tikanga. Manaakitanga refers to respect and kindness of others and to give of oneself to help and assist people. Whanaungatanga refers to the connections and relationships which can be traced through the bloodlines of genealogy and was extremely important in Māori society. These values form the basis of tikanga and provides a foundation to establish the common 'lore' there is much a Māori law, as there is a Māori language. Māori have a well-established system of epistemology which formed the basis for the structure and governance of society.

The following section will explain how inequities have arisen, from this previous place of strength and order, due to the process of colonisation.

### **The Impact of Colonisation**

In the early days of colonisation Māori established themselves as formidable entrepreneurs especially in fishing and agriculture and "this early period of foreign contact was characterised by economic welcome" (Walker, 2004, p. 70). However, the arrival of Pākehā brought not only economic opportunity but other influences such as alcohol and lawlessness (Cullen, 1984; Hutt, 1999). The relationship between Māori and Pākehā was formalised in 1835 with He Wakaputanga o te Rangatiratanga o Nu Tirene (the Declaration of Independence of New Zealand) and then with Te Tiriti o Waitangi in 1840 with the aim to manage land transactions and lawlessness that was abound.

However, Māori did not relinquish sovereignty in these agreements and therefore many Māori continue to advocate for Tino Rangatiratanga, absolute sovereignty for their own affairs. The years after 1840 offered little protection for Māori and many acts of violence were committed against Māori through colonial wars and subsequent confiscation of land.

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For Māori, land is more than property to be used for economic purpose (Ministry of Justice, 2001). Papatūānuku is earth mother within Māori mythology and “the earth was loved as a mother is loved” (Walker, 2004, p. 70). Land forms the basis of identity, whanaungatanga and whakapapa and the loss of land through the land wars and other government processes was a crucial factor that led to fragmentation of traditional Māori society and values (Rangihau, 1988).

*“For us as Maori, we lost many things, but I believe the most damaging was the loss of our land. With the dispossession of our ancestral lands our access to those spiritual ties with papatūānuku were taken away, cutting us from our spiritual sustenance.”*  
(NiaNia, Bush, & Epston, 2016, p. 20).

A dislocation from ancestral land created the beginning of a loss of identity and an inability to pursue economic endeavours that became the basis of Pākehā prosperity (Walker, 2004).

The current study was based in Hawke’s Bay so in reviewing Hawke’s Bay’s history the Waitangi Tribunal found that a *“mindset prevailed that saw Māori eking out only a subsistence rural lifestyle, supplemented by employment as wage labourers. To that extent, the Crown made no concerted effort to ensure that Māori were left with sufficient land to participate in pastoral farming alongside Pākehā”* (The Waitangi Tribunal, 2004, p. xxxvi).

In Hawke’s Bay and across Aotearoa New Zealand, the loss of land and the introduction of new systems based on capital also meant a marginalisation of previous industrial aspirations. The Native Land Court system which instituted individual titles meant Māori *“were stripped of autonomous government, their legal basis for solidarity, their social and spiritual being”* (Rangihau, 1988, p. 60). The introduction of a cash society meant traditional bartering mechanisms were no longer available. Unemployment and commercial disadvantage led

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Māori to experience poverty and social disadvantage (Rangihau, 1988; Walker, 2004). The health and well-being of Māori decreased and in the post-colonial era Māori experienced dramatic decrease in population due to disease, malnutrition, war and loss of access to resources (Saggers & Gray, 1998). By the turn of the century Māori population had declined from an estimated 120-150,000 to approximately 46,000 (Walker, 2004).

The government recognised suffering and deprivation by Māori and tried to “*assimilate Māori fully into the benefits of Pākehā, education, health and culture*” (Rangihau, 1988, p. 61). However, this participation was regulated and based within a dominant Pākehā culture that did not recognise the impact of the loss of traditional Māori society and values. Active suppression of Māori culture and identity occurred through banning Te Reo Māori and tikanga in schools and wider governmental institutions (NiaNia et al., 2016; Walker, 2004). The Tohunga Suppression Act 1907 prohibited traditional Māori healing and delegitimised wider Māori wisdom and knowledge in the areas of arts, environment and spiritual connections (Durie, 2001).

Māori were given representation in government through institutions such as the Māori Land Councils (1900), The Department of Native Affairs (1906), The Native Trustee (1920), the Māori Purposes Fund Board (1924) and tribal Trust Boards. These institutions were established to reduce Māori deprivation however this paternalistic method “also contained special restrictions that reinforced the Māori’s unequal status” (Rangihau, 1988, p. 62). Although the government continued to try to improve Māori social economic status with further legislation such as the Native Trustee Act (1920), it wasn’t until the Treaty of Waitangi Tribunal Act in 1975 and the Waitangi Amendment Act 1985 were Māori given a “*proper constitutional base for the redress of grievance over land and other matters.....a forum in which we can stand as of right and have our people’s case be heard*” (Rangihau, 1988, p. 66).

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### **More Recent Effects of Socio-political Changes**

In Aotearoa/New Zealand social disadvantage increased in the 1980's with economic reform and changes to state structures such as the disestablishment of the Māori Affairs department. *“The loss of the Māori housing program for needy families led to overcrowded houses in urban centres and substandard living conditions in rural areas of Northland. In South Auckland meningitis and rheumatic fever rose to epidemic proportions”* (Walker, 2004, p. 288). Social disadvantage increased for many Māori during the political environment of the 1980's which imposed economic reforms based on free market principles. These economic reforms caused increased stress and hardship for many including unemployment and poor general health (Ajwani, Blakely, Robson, Tobias, & Bonne, 2003).

Results of economic reform could be seen in Hawke's Bay with the closure of freezing works: first Whakatu in 1986 and then Tomoana in 1998 where thousands were made redundant. Results of an eight year follow-up of workers from Whakatu found increased incidence of admission to hospital for serious self-harm or mental health diagnosis when compared to a cohort of workers from a neighbouring meat processing plant (Keefe et al., 2002). Closure of the plant had a wide ranging effect on the community including financial strife, loss of a 'way of life', breakdown of relationships and increased use of alcohol to handle stress (Keefe et al., 2002; Keefe-Ormsby, 2005).

Today Māori continue to experience socioeconomic disparity and higher rates of poverty (Durie, 2001; Hawke's Bay District Health Board, 2014; Marriott & Sim, 2015; Ministry of Health, 2015). Socioeconomic status is associated with overall health indicators although it is important to recognise that it is not the only factor in the burden of disease and ill health. For example, one longitudinal study in Christchurch Aotearoa New Zealand found that the strongest predictor of later mental health issues in adolescents 16-18 years was

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connected to the immediate social environment (e.g. parental characteristics, childhood adversity, school success)(Horwood & Fergusson, 1998).

*“There is seldom a single causative explanation for any illness or accident; instead health outcomes reflect complicated combinations of past and present, individual and group, home and nation”*(Durie, 2001, p. 35).

### **Colonisation and Alcohol**

There is no indication that before 1800, and the presence of Pākehā, Māori had any systematic production or consumption of alcohol as part of their society (Hutt, 1999; Mancall, Robertson, & Huriwai, 2000). Many documents in the early 1800's report Māori had an aversion to alcohol when introduced and when Māori started consumption it was in a moderate way at hui (Mancall et al., 2000). By the mid 1800's there were some reports of alcohol abuse by Māori (Mancall et al., 2000) but the prevalence of European abuse was reported to be much greater (Cullen, 1984). As early as 1830 Māori chiefs were calling for universal laws to control the use of alcohol (Saggers & Gray, 1998). Government was concerned that alcohol and tobacco were contributing to the decline of the Māori population and thus the Sale of Spirits Ordinance was passed in 1847 limiting Māori but not Pākehā consumption and trade. This passing occurred despite there being fewer records of early alcohol abuse for Māori and clear evidence of alcohol abuse by Tauīwi (Non-Māori) drinkers, including numerous convictions for drunkenness (Cullen, 1984).

The Ordinance Act gave Tauīwi the sole control of the production and sale of alcohol and has thus been criticised for providing *“a convenient way to cut Māori out of the economic benefits that the sale of alcohol could have brought to some of them, as well as limiting their ability to develop effective strategies to manage the social impact of alcohol”* (Mancall et al., 2000, p. 131). The law was difficult to police and alcohol was still consumed by Māori in parts

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of the country (Hutt, 1999). Robertson et al. (2002) suggested that the introduction of these laws prevented Māori from making positive efforts in managing alcohol related problems. In addition it is important to recognise the diversity of responses between iwi. Some iwi certainly wanted to prohibit the supply of alcohol whereas others wanted to have the same political and economic rights of Tauīwi (Mancall et al., 2000).

However, alcohol use certainly increased after the land wars and this has been attributed to the subsequent hardship, dispossession, and loss of cultural and social supports (Cullen, 1984; Hutt, 1999). Many reports also indicate that alcohol was used as a tool to assist in the confiscation of land. Māori were required to register ownership of their land which was in itself a foreign concept to a culture based on community ownership. They travelled to the Land courts where they were then sold alcohol and goods whilst waiting for their case to come up. These debts were unable to be paid and so land was confiscated in payment for the debts (Hutt, 1999; Sorrenson, 1956; Walker, 2004).

Other explanations of increased alcohol use have been attributed to alcohol being used as status symbol and exposure due to the daily ration of rum when Māori fought on the side of the crown (Hutt, 1999). The urbanisation of Māori and the adoption of Pākehā practices (e.g. consumption of alcohol) may have also been facilitated by the need to build social connectedness in substitute for traditional values and social structure that would have been provided by the Marae (Ebbett & Clarke, 2010) and alcohol issues are often associated with social factors such as unemployment, poverty and stress (Huckle, You, & Casswell, 2010; Saggars & Gray, 1998).

Documents from the 19th century suggest that there is little clear connection between the introduction of alcohol and immediate abuse of it by Māori. Māori had a diverse response

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and the higher prevalence of current Māori alcohol and drug issues is likely due to inequities that have occurred as a direct result of colonisation.

### **The Impact of Trauma**

Many Māori, as Indigenous people, experienced trauma through this process of colonisation which constituted loss of land, a suppression of traditional laws and rituals, and subsequent poverty. Reid, Taylor-Moore and Varona (2014) discuss the concept of historical trauma as a response *"to the need for a way of understanding the impact on trauma of colonisation on Indigenous (Aotearoa/New Zealand) peoples that transcends the limitation of current mainstream trauma theory"* (p. 4).

Mainstream trauma theory is based around Post traumatic stress disorder (PTSD). They reason that PTSD places the trauma directly within the individual as a mental disorder and does not account for the 'socio-political context'. In contrast, a historical trauma perspective allows for the *"vicarious traumatisation" through subsequent generations via processes of storytelling and "oral traditions"* (Reid et al., 2014, p. 5).

Historical trauma acknowledges that the trauma is not only transmitted through families but also via the community through 'unresolved grief'. *"Historical unresolved grief is based upon the concept of disenfranchised grief, a state that, according to Brave Heart and DeBryun (1998) occurs if a dominant group delegitimises grief among the other group"* (Reid et al., 2014, p. 5). Tauwiwi (Non-Māori) views of 'we are all one' (New Zealanders) helps to continue the trauma of unresolved grief and grief remains static if grief cannot be acknowledged.

The Waitangi tribunal has endeavoured to acknowledge the injustices that occurred through the process of colonisation and compensated to iwi with financial and cultural settlements. However trauma from colonisation must not be just considered as in the 'long ago past' but instead continues the systems and structures that are established to serve the

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colonisers (Gilmartin & Berg, 2007; Reid et al., 2014). Tuwhai Smith (2012) asserts to move forward we must address the legacy of colonisation, with “*each party recognising and peeling away successive cultural linguistic and psychological layers of colonial power*” (NiaNia et al., 2016, p. 35). Colonisation was and is a deliberate process which results in the destruction of Māori society. Thus we must evaluate our current systems and processes as being part of a colonised structure which may impart further trauma on Māori. These systems and governmental structures need wide ranging and fundamental changes if we are going to be responsive to Māori in the 21<sup>st</sup> century.

### **Impact of Cultural Renaissance and Securing Identity**

There are numerous examples of Māori leadership and success that have made large contributions to the health, education, environmental and political context (Durie, 1994; NiaNia et al., 2016, p. 35; Walker, 2004). Leaders such as Sir Apirana Ngata who served as a politician in the years 1905-1943 worked hard to protect and foster Māori language and culture (Walker, 2004). Mason Durie a Māori psychiatrist has also influenced clinical practice and government health policy (NiaNia et al., 2016, p. 35). There are many more examples of leadership at a local and government level including organisations such as the Māori Women’s Welfare League who continue to challenge the status quo for the benefit of Māori. In 1975 Dame Whina Cooper’s leadership within the league led 5000 people in an hīkoi to protest loss of land and realise economic and social issues that were affecting Māori (Walker, 2004). Together these leaders advocated for protecting Māori identity and interests for the betterment of Māori in years to come.

More recently the emergence of the Māori Party has promoted Māori commitments to: “*Protect Māori language and culture, reinforce the status of the Treaty of Waitangi, promote Māori knowledge, advance Māori educational intuitions, promoting of a just and equitable society without poverty or discrimination, fostering sustainable management and growth of the*

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*economy and providing all New Zealanders with the 'genre de vie' of their aspirations"* (Walker, 2004, p. 405-406). Unfortunately the Māori party were unable to secure a seat in the 2017 Government elections however they have pledged a return to government in 2020 and will continue to fight for their people (Māori Party founder Dame Tariana Turia plans to return to help save the party, 2017).

There has been a resurgence in Fluent Te Reo Māori speakers due to the establishment of Kōhanga Reo (Māori language preschool), full immersion Kura Kaupapa (School operating under Māori custom and language) and increased use of Te Reo Māori in government organisations (Reedy, 2000). Economically, there have also been positive outcomes following treaty settlements where iwi have finally had the capital to invest and expand their interests for the benefit of the iwi or hapū.

This cultural renaissance has been imperative for securing identity not just for Māori today but for future generations. In Te Ao Māori the focus is on the group (collective) rather than the individual (Cargo, 2016) where the collective includes those who have come before and will come after. A secure identity is well recognised as being associated with health and wellbeing (Cherrington, 2009; Durie, 1997; Forrest et al., 2016; NiaNia et al., 2016). At the centre of identity is the concept of connectedness 'Whanaungatanga' and this connectedness may be to other people or to the natural world (Durie, 2001; Lawson-Te Aho & Liu, 2010). For Māori being connected to their culture, whakapapa and land is imperative for ongoing wellbeing.

### **Māori models of health**

Connection to one's culture is advantageous to Indigenous health and has importance not just in New Zealand but also in the international arena (Paradies, 2016). Māori researchers suggest that those Māori who are more connected to their culture and experience

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Manaakitanga, Whānaungatanga, Kaitiakitanga and Rangatiratanga experience better general health and well-being (Durie, 2001; Forster, 2003). Furthermore, western models of health, especially with regard to tertiary service delivery, tend to be driven by diagnosis, whereas, Māori models of health employ a more holistic view of health and wellbeing (Durie, 1994; Pitama et al., 2007).

Durie's (1997) model of health "Te whare tapa whā", which emphasises the importance of four interacting dimensions: taha wairua (spiritual well-being), taha hinengaro (mental/emotional well-being) taha tinana (physical well-being) and taha whānau (family and social well-being)" (p. 23), has been recognised as a sound framework to develop programs and interventions in Aotearoa New Zealand (Cherrington, 2009; NiaNia et al., 2016; Kingi, & Durie, 2000).

In keeping with this model individuals with FASD appear to have significant needs, psychological/emotional (taha hinengaro), family/environmental (taha whānau), spiritual (spiritual health) and physical (taha tinana) which require support irrespective of their IQ level. Children with severe leaning and behavioural needs also require a comprehensive assessment. This assessment must triangulate, through observation and direct report, the neuropsychological results and embed this information within a holistic model of health in order to garner access to meaningful service. Durie's (1997) Te whare tapa whā model may therefore be useful as a basis for not only clinical practice but also to define access to services and supports.

### **Summary**

Māori are inherently a collective society that where identity is based around relationships to each other and the natural environment. The health and wellbeing of Māori has been greatly affected by colonisation and historical trauma through loss of land, loss of

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language and suppression of culture. More recent socio-political changes have also contributed to higher levels of hardship for Māori. Alcohol has become a panacea for this trauma which may explain the overrepresentation of Māori in this current study. However Māori have also shown huge leadership and resilience to create the cultural renaissance that we see today. Systems and structures need fundamental changes if they are to be responsive and address the consequences of current and historical trauma. Māori models of health such as Te whare tapa whā may be useful in not only guiding clinical practice but also providing a framework for service eligibility. Te Tiriti o Waitangi provides a solid platform for Māori and Tauīwi to collaborate and build partnerships in order to achieve this. Chapter Three will detail the research partnership that was established for the current study, however first, Chapter Two will examine the psychological, neuropsychological and developmental literatures with regard to factors that influence adaptive functioning in FASD.

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### **Chapter Two: Review of factors associated with adaptive functioning in FASD**

This chapter will review psychological and social factors that are associated with an FASD diagnosis. Children, adolescents and adults with FASD experience lifelong learning and behavioural impairments that significantly decrease their adaptive functioning (Streissguth et al., 1996; Fagerlund et al., 2012). Chapter Two will first provide an overview of the implications of FASD over the life course. This will be followed by a review of the influence of intelligence quotient (IQ), executive functioning, social cognition and adverse childhood experiences on adaptive functioning in the field of FASD. Developmental and psychological models are examined to establish a framework for measuring these factors for this current study. However, first, the FASD literature will be reviewed to provide an understanding of the life course implications of persons living with a FASD diagnosis.

#### **Life Course Implications of FASD**

People who live with FASD are at risk of developing a number of secondary disabilities especially if their difficulties are not understood and are unsupported early in life (Streissguth et al., 1996). In a US study of clients with a diagnosis of FASD (N = 473) who were 12 years or older; 60% experienced disrupted school experience, 60% experienced trouble with the law, 50% had been confined to either an inpatient mental health centre or incarcerated for a crime, 50% noted inappropriate sexualized behaviour and 30% had alcohol and drug problems (Streissguth et al., 1996). A subset of clients 21 years old (N = 90); were not able to live independently (80%) and had problems with employment (80%) (Streissguth et al., 1996). Due to significant and lifelong learning and behavioural needs, individuals with FASD typically require support and appropriate interventions in order to function to their potential (Paley & O'Connor, 2009; Petrenko & Alto, 2017; Reid et al., 2015).

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Information from a US longitudinal study ( $N = 592$ ) found prenatal alcohol exposure was related to an increased rate of adolescent conduct disorder (Larkby, Goldschmidt, Hanusa, & Day, 2011). In Canada an increased prevalence of FASD has been found for young people in the justice system (Fast, Conry, & Loock, 1999; Rojas & Gretton, 2007). One study, in British Columbia, assessed all youth in a forensic psychiatric inpatient unit over a one year period and found 23.3% ( $N = 287$ ) had an alcohol related diagnosis (Fast et al., 1999). Another study in British Columbia reviewed the files of 230 adolescent males (Indigenous (Canada) = 67 and Non-Indigenous (Canada) = 163) aged 12-18 who had been ordered to attend the Youth Sexual Offense Treatment Program (YSOTP) (Rojas & Gretton, 2007). Rojas and Gretton (2007) found an overall FASD prevalence of 11% with an overrepresentation in Indigenous (Canada) participants. Furthermore, individuals with FASD have an increased risk of not only offending but they are also more likely to become victims of crime (Fraser, 2008) and being taken advantage of (Morrissette, 2001).

In Aotearoa New Zealand, neurodisability is recognised as being an important factor to assess in offenders in the justice system (Lambie, Best, Ioane, Becroft, & Polaschek, 2016; Lynch, 2016). Moreover, the identification of disability, such as FASD, is argued to be crucial for individuals to have meaningful participation in court and justice processes, as well as the development of plans that may decrease re-offending and improve well-being (Lambie et al., 2016).

Individuals with FASD also experience increased prevalence of co-morbid mental health disorders (Weyrauch, Schwartz, Hart, Klug, & Burd, 2017) including increased risk for suicide and addictions (Pei, Denys, Hughes, & Rasmussen, 2011; Thanh & Jonsson, 2016). In a recent meta-analysis of 127 studies, co-morbid conditions such as, conduct disorder, receptive and expressive language disorder and chronic serous otitis media have been identified as having extremely high prevalence in individuals with FASD (Popova et al., 2015). In a Canadian

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cross-sectional study children and youth with FASD (N = 126) completed the Health Utilities Index Mark 3 (HUI3). These children and youth with FASD were found to have significantly lower health-related quality of life when compared to children and youth from the general Canadian population and those with significant disabilities e.g. many who lived with significant physical disability such as blindness, cerebral palsy, deafness, and cognitive impairment or survivors of childhood cancer (Stade, Stevens, Ungar, Beyene, & Koren, 2006). Devastatingly, life expectancy for people with FAS in Alberta Canada has been estimated at 34 years (95% confidence interval 31 to 37 years) (Thanh & Jonsson, 2016) compared with the general Canadian population of 79 years for men and 83 years for women (Statistics Canada., 2012). There is considerable evidence that FASD is a health condition associated with high morbidity and mortality.

Internationally families who raise children with FASD have also reported experiencing significant stress due to challenges parenting a child with brain based differences (Paley, O'Connor, Kogan, & Findlay, 2005; Paley, O'Connor, Frankel, & Marquardt, 2006). In particular, Paley et al. (2006) in a US study of 100 children with prenatal alcohol exposure (6-12 years) found that the level of parenting stress was not associated with a child's IQ but instead was associated with executive functioning and behavioural difficulties that the child experienced.

Children, adolescents and adults with FASD require many more health, education and social services than those people without this diagnosis (Brownell et al., 2012). In the literature, protective factors are identified as living in a stable and nurturing home, diagnosis before 6 years of age, never having experienced violence against oneself, close supervision and eligibility for disability services (Liebschutz et al., 2015; Streissguth et al., 1996; Streissguth et al., 2004). Furthermore, there are economic analyses which predict improving diagnostic and follow up support to people with FASD would reduce the cost of secondary disabilities

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and provide significant benefit to all who are affected by FASD (Thanh, Moffatt, Jacobs, Chuck, & Jonsson, 2012).

In Aotearoa New Zealand a diagnosis of FASD does not broker specific health, disability or education services. Appropriate services can be found in the Disability sector, but access is based on a co-morbid diagnosis of Intellectual Disability (ID). However, many individuals with FASD do not meet diagnostic criteria for ID. In a review of the Developmental Assessment Programme's (DAP) FASD pathway at Hawke's Bay DHB only 50% of children were diagnosed with ID which means half the children diagnosed with FASD are excluded from disability services (Health and Safety Developments, 2015).

Currently the NZ Ministry of Health will accept diagnosis of Intellectual Disability as defined by the Diagnostic and Statistical Manual of Mental Disorders Fourth Edition (DSM-IV-TR), rather than from the updated DSM-V (Ministry of Health, personal communication, , June 17 2014). The DSM-IV-TR defines ID using the term 'mental retardation' which requires both "significantly sub-average intellectual functioning" (IQ below a score of 70, with some adjustment for standard error of measurement) and "significant impairments in at least two domains of adaptive functioning" with impairments occurring before the age of 18 years (American Psychiatric Association, 2000). In comparison to the DSM-IV-TR, the new DSM-V places more emphasis on the importance of adaptive functioning. Although an Intellectual Disability diagnosis under DSM-V requires standardised intelligence testing, there is no requirement for the IQ score to be below a certain threshold (American Psychiatric Association, 2013). This move towards placing more emphasis on adaptive functioning in the DSM V is based on increasing evidence that IQ is not a good measure of everyday life skills (Greenspan, Brown, & Edwards, 2016).

### **Diagnosis and Assessment of FASD**

Despite growing evidence of neuroanatomical effects following prenatal alcohol exposure, most FASD diagnoses are based on discernible physical and cognitive markers rather than hard evidence of structural change within the brain. An FASD diagnosis involves rigorous assessment of many brain domains through neuropsychological assessment, parent/caregiver and teacher report as well as triangulation through clinical observation and judgement (Chudley et al., 2005; Cook et al., 2016).

Currently there is no international diagnostic consensus for FASD. The DSM V does not include a diagnosis of FASD however ‘Neurobehavioural Disorder Associated with Prenatal Alcohol Exposure (ND-PAE)’ appears in the appendix as a diagnosis for further review. Guidelines exist in the form of: Canadian guidelines (Chudley et al., 2005) which were recently revised (Cook et al., 2016), the University of Washington 4-digit code (Astley, 2004) and the Australian Guidelines (Bower & Elliott, 2016) which appear to have largely followed the Revised Canadian guidelines. In Aotearoa New Zealand, there is no formal governmental direction in regard to FASD diagnostic guidelines, although there is clinical consensus to use the revised Canadian guidelines, (McGinn & McLaren, 2015), which in turn broadly aligns with the Australian guidelines.

The present study which began in December 2012 adopted the Canadian guidelines (Chudley et al., 2005) for diagnosis. These guidelines are based on a harmonisation of the Washington 4-digit code which seeks to diagnose the effects of prenatal alcohol exposure based on growth, impairments, dysmorphic facial features, central nervous system (CNS) dysfunction and confirmation of alcohol exposure in pregnancy. A child who meets criteria in all domains (growth, facial features and central nervous system dysfunction) receives a diagnosis of Fetal Alcohol syndrome (FAS). Those children with no (or mild) growth deficiency who have the presence of moderate to severe facial features, meet criteria for CNS dysfunction and have

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confirmed alcohol exposure are diagnosed with Partial Fetal Alcohol Syndrome (pFAS). Those children with no or mild growth deficiency, no or mild facial features, but meet criteria of CNS dysfunction and have confirmation of alcohol exposure are diagnosed with Alcohol Related Neurodevelopmental Disorder (ARND). All of these diagnoses (FAS, pFAS, and ARND) are encompassed under the wider term Fetal Alcohol Spectrum Disorder as per the original Canadian guidelines (Chudley et al., 2005).

Neuropsychological assessment, in all domains, is core to making a FASD diagnosis and providing a profile which is useful for educational and social support planning. Understanding what impairments are influencing a person's ability to function every day (adaptive functioning) is important as this analysis helps plan what supports are required. The following sections will review relevant literature that investigates factors influencing IQ, adaptive functioning, executive functioning, and social cognition alongside psychosocial and environmental complexity in FASD.

### **The Influence of IQ**

Intelligence tests, or measures of IQ, were originally designed for use in the education sector and thus are argued to be highly correlated with academic performance which raises issues of construct validity (Anastasi, 1986). However, IQ becomes increasingly problematic when it is used to determine service eligibility based on diagnostic criteria for Intellectual Disability. Intellectual Disability has been historically defined to include individuals who needed help to function and survive in the world. As Greenspan et al. (2016) eloquently ask *“how appropriate is it to place central reliance on a measure essentially of academic potential as a gateway to receiving developmental services, subsidies and entitlements?”* (p. 242).

There is also potential for IQ test scores to be unreliable due to variation in performance, practice effects or inconsistencies in administration (Greenspan et al., 2016). A longitudinal

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study reviewing cognitive performance in children with an Intellectual Disability found only moderate stability for individual children thus raising the importance of gathering information on life skills and development from a variety of sources (Jenni et al., 2015). A Full Scale IQ score (FSIQ) is made up of multiple test scores from a variety of skills areas. Furthermore when assessing children with neurodevelopmental issues it may be inappropriate to use FSIQ as children may present with a wide range of ability across index and subtest scores (Siegel, Minshew, & Goldstein, 1996).

**IQ and FASD.** Prenatal alcohol exposure has been consistently associated with impaired intellectual functioning, however a wide range of IQ levels are observed in individuals with FASD, with many children performing in the borderline range or higher (Coles et al., 1991; Mattson et al., 1999; Streissguth et al., 1991; Streissguth et al., 1996). Intellectual abilities (IQ) that do not fall in the Extremely Low range (i.e. Greater than 70) may preclude access to disability services that use the Intellectual Disability criterion (such as in Aotearoa New Zealand). In addition, variability in test performance has also been found to be more pronounced in children with FASD (Ali, Kerns, Mulligan, Olson, & Astley, 2017; Kjellmer & Olswang, 2013) and there is evidence that the cognitive impairments in children with FASD may become more pronounced with age (Tamana, Pei, Massey, Massey, & Rasmussen, 2014; Taylor & Enns, 2017), further compounding the problem of using IQ scores alone to determine service eligibility.

The problems of reliability and validity in IQ test scores for children with FASD suggest it may be erroneous to use a Full Scale IQ score as a basis for access to support services. The combination of IQ test variability and potential for decreasing adaptive behaviour in adolescence is worrying when assessing for FASD generally happens at one point in time often around middle childhood. Often repeat assessments in adolescence can be useful but may be rare due to fiscal constraints on health services in Aotearoa New Zealand.

### **The Influence of Adaptive Functioning**

Adaptive functioning, or behaviour, is a diagnostic domain which is often impaired in individuals with FASD (Kodituwakku, 2007; Reid, Shelton, Warner, O'Callaghan, & Dawe, 2017; Streissguth et al., 1996) and is defined as the ability to care for oneself, interact in a social world, and function in the community (Greenspan, 2006; Sparrow, Cicchetti, & Balla, 2006). It includes skills such as communication, self-direction, maintaining health and safety, coping skills and participating in leisure and social activities. Core deficits in adaptive functioning within a FASD diagnosis are often related to ongoing mental health issues, justice issues and being able to maintain adequate health and living arrangements (Clarren, 2009; Fast et al., 1999; National Center on Birth Defects and Developmental Disabilities, 2004; Streissguth et al., 1996).

In typical development adaptive functioning is often aligned with intellectual abilities (Wentzel, 1991). However, children with FASD typically demonstrate lower levels of life /adaptive skills and these adaptive skills may be lower than what would be expected given their level of intellectual functioning (Jirikowic et al., 2008; Reid et al., 2017; Whaley, O'Connor, & Gunderson, 2001). A Canadian study that compared adaptive and behavioural functioning of children (5-9 years) with FASD to typically developing children (FASD N = 25, Comparison N = 23) found children with FASD had significantly more maladaptive behaviour such as hurting self and others, destroying property, and disruptive and uncooperative behaviour (Jirikowic et al., 2008). Similar findings were also found in another Canadian study where children (6-16 years) with FASD (N = 30) showed more difficulties such as a lack of guilt, increased cruelty and acting young for their age compared to typically developing children (N = 30) and children with a diagnosis of ADHD (N = 30) (Nash et al., 2006). A more recent study investigated affective emotional functioning of children aged 8-17 years with FASD (N=31) and typically developing children and adolescents (N = 31) (Kully-Martens et

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al., 2013). Impairments in decision making and risk taking were noted where children and adolescents with FASD completed the Iowa Gambling Task (Bechara et al., 1994) and “*did not appear to learn from negative experiences*” nor did “*performance did not improve with age*”, irrespective of IQ level (Kully-Martens et al., 2013, p. 137).

Individuals with FASD continue to have difficulty managing their independence into adolescence (Crocker, Vaurio, Riley, & Mattson, 2009; Fagerlund et al., 2012). As typically developing children mature into adolescence, adaptive skills usually improve and the children are able to increase their amount of independence and responsibility within their family and school communities. However this trajectory appears to be disrupted with prenatal alcohol exposure with indications that adaptive functioning deficits may become more pronounced in adolescence (Crocker et al., 2009; Panczakiewicz et al., 2016; Thomas, Kelly, Mattson, & Riley, 1998). Children and adolescents with FASD may be more impaired in their adaptive functioning than those who have a specific learning disability (Fagerlund et al., 2012; Thomas et al., 1998), and those who experience psychiatric diagnoses (Boseck, Davis, Cassady, Finch, & Gelder, 2014; Whaley et al., 2001). As a result of the impairments in adaptive functioning found in children, adolescents and adults with FASD, they require many more health, education and social services than those people without this diagnosis (Brownell et al., 2012).

The FASD literature suggests that difficulties in adaptive functioning may be due to impairments in executive functioning skills (e.g. planning, cognitive flexibility, and self-regulation (Davis, Gagnier, Moore, & Todorow, 2013; Schonfeld, Paley, Frankel, & O'Connor, 2006) rather than general intellectual functioning or IQ (Edwards & Greenspan, 2010; Greenspan et al., 2016). Moreover recent findings suggest that children with FASD may also have particular difficulties with social cognition in the areas of emotion understanding and recognition (Greenbaum, Stevens, Nash, Koren, & Rovet, 2009; Kerns, Siklos, Baker, & Müller, 2016; Lindinger et al., 2016; Petrenko, Pandolfino, Quamma, & Olson, 2017;

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Rasmussen, Wyper, & Talwar, 2009; Stevens, Clairman, Nash, & Rovet, 2016) and theory of mind (i.e. understanding another person's perspective) (Lindinger et al., 2016; Rasmussen et al., 2009; Stevens, Dudek, Nash, Koren, & Rovet, 2015). In addition, children with FASD often experience a range of additional adverse psychosocial influences which may further impact their adaptive functioning difficulties (Coggins, Timler, & Olswang, 2007).

**Adaptive functioning and service provision.** The limits of access to service provision determined by an Intellectual Disability (ID) diagnosis is not limited to New Zealand. In North America there have been numerous attempts to develop new ways of ensuring those needing supports have access to them regardless of an Intellectual Disability diagnosis (Greenspan et al., 2016). One of those solutions aims to change disability service criteria to rely on adaptive functioning scores and place less of an emphasis on IQ performance (Greenspan et al., 2016; Harris & Greenspan, 2016). In fact this shift is reflected in the updated DSM V which places more emphasis on adaptive functioning rather than equal emphasis on IQ and adaptive functioning in the DSM IV (American Psychiatric Association & American Psychiatric Association, 2000; American Psychiatric Association, 2013). However, there are issues of content validity and variability in measuring adaptive functioning which suggest that measures of adaptive functioning may also not be a sufficient method to assess need for disability supports.

***Issues of content validity with adaptive functioning.*** Adaptive functioning measures may not be assessing the areas which most impact an individual's ability to function in their community. Measures of adaptive functioning have been criticised due to the lack of emphasis on social judgement and too many items representing low skill level tasks e.g. toileting and dressing (Edwards & Greenspan, 2010; Tassé, 2009). Moreover, it may be more important to also consider issues that are now constructed as maladaptive behaviour such as 'risk vulnerability' and 'gullibility' or 'suggestibility' especially when diagnosing Intellectual

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Disability (Greenspan, 2008; Greenspan et al., 2016) and FASD (Brown, Gudjonsson, & Connor, 2011; Douglas, 2015; Edwards & Greenspan, 2010; Greenspan & Driscoll, 2016).

It is also important that diagnosis and service accessibility is established in criteria that considers an individual's age, culture and own community expectations (Dudley, 2016; Tassé, 2009). Currently, most adaptive functioning scores are based on normative data, often derived from North America which may or may not reflect a person's own community and hence may not be appropriate measure of capabilities (Dudley, 2016).

***Variable reporting in adaptive functioning.*** Adaptive functioning can also result in variable report depending on the reporter and/or the environment. Adaptive functioning information is most often gathered by parent/caregiver and/or teacher report. Thus there also may be a reluctance to provide access to service on adaptive report (questionnaires or interviews) rather than performance (psychological testing) as there have been concerns that reporters or clinicians will provide a biased view in order to garner support accessibility (Greenspan et al., 2016) or even reprieve of criminal penalty (Tassé, 2009). Obtaining corroborating, and culturally relevant, information to support information obtained on the standardised assessment is therefore extremely important (McLachlan, Andrew, Pei, & Rasmussen, 2015; Tassé, 2009). However this is often also based on clinical judgement.

Children with FASD are also very susceptible to environmental influences. Streissguth et al. reviewed the adverse life outcomes of individuals (N = 415, aged 14-51 years) with FASD who took part in a follow-up study of the University of Washington's Fetal Alcohol and Drug Unit (FADU). They found that stability in the home environment was a protective factor to adverse outcomes which was in line with clinical observations. Brown, Wartnik, Connor & Adler (2010) also noted, when proposing their model for forensic FASD assessment, that an individual can often function well in highly structured or familiar environments, such as school,

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but their skills greatly decompensate in highly charged, stressful and unfamiliar situations. Children may therefore function at very different levels both at home and at school depending on their learning and behavioural profile which causes difficulty when trying to derive a singular adaptive functioning profile or score to be used as a proxy for access to service.

In summary, adaptive functioning measures usefully attempt to assess functioning rather than intelligence, however current measures are hindered by a lack of emphasis of social judgement, possibly unreliability of reporting and variability of functioning in different environments and potential problems using North American norms. Instead analysis of what skills are related to successful adaptive functioning, e.g. executive functioning and social cognition, may be more useful to assess strengths, difficulties and areas for intervention.

### **The Influence of Executive Functioning**

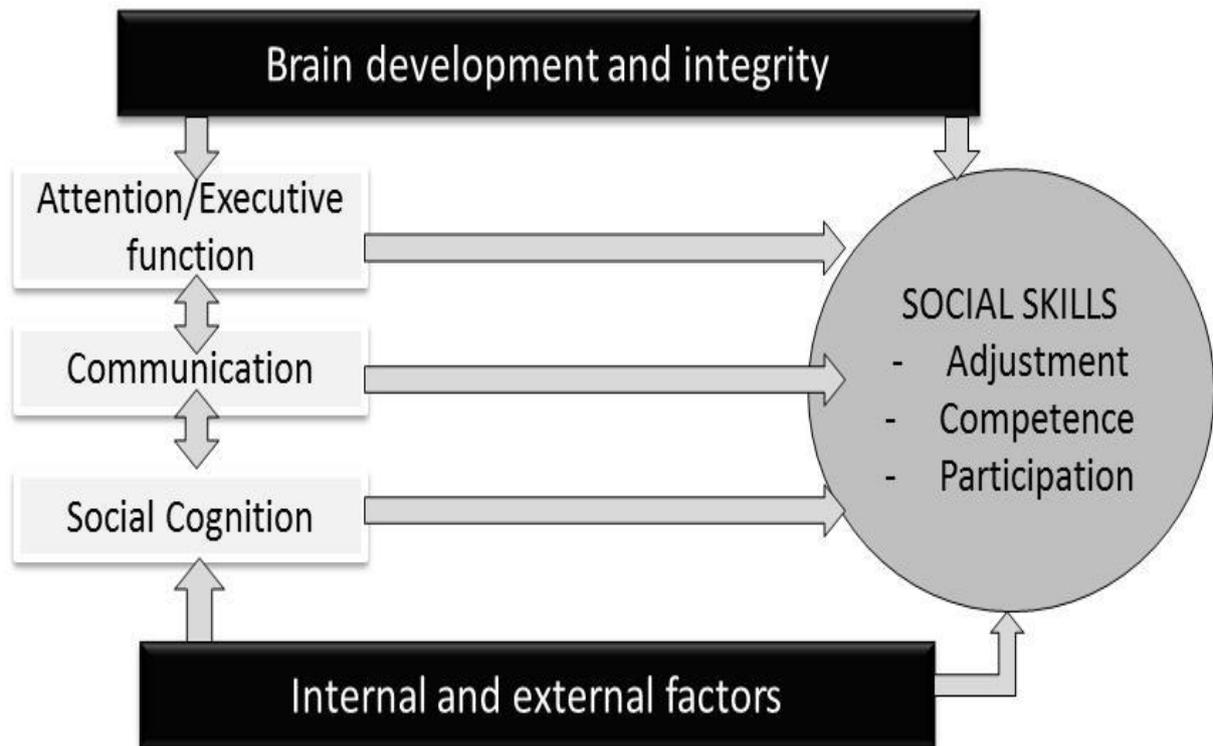
Researchers suggest that executive functioning may play a more important role in successful adaptive functioning, which encapsulates social interaction, communication and independence in daily life (Greenspan et al., 2016; Ware et al., 2012). The construct of executive functioning encapsulates processes of attention, flexible thinking, goal setting, decision making and problem solving (Anderson, 2002; Kodituwakku, 2009). These skills allow the successful negotiation and adaptation to novel and complex situations (Jacobson & Mahone, 2012) and weak executive functioning skills are linked with risky decision making and poor problem solving (Greenspan et al., 2016; Schiebener, García-Arias, García-Villamizar, Cabanyes-Truffino, & Brand, 2015).

Executive functioning skills and processes are imperative for successful adaptive functioning and social interaction. Research suggests executive functioning is related to social and emotional competence in children with FASD (Schonfeld et al., 2006), ADHD (Rinsky &

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Hinshaw, 2011; Tseng & Gau, 2013) autism spectrum disorder (ASD) (Leung, Vogan, Powell, Anagnostou, & Taylor, 2015) and traumatic brain injury (TBI) (Ganesalingam et al., 2011).

Anderson and Beauchamp (2010; 2012b) ‘socio-cognitive integration of abilities model’ (SOCIAL) may be a useful way to conceptualise the contribution executive functioning has on successful adaptive functioning and social interaction (see Figure 1). In particular, this framework highlights the importance of an attention/executive component alongside other factors such as communication skills, social cognition skills, intact brain development, and internal and external contextual factors (discussed later in this chapter) for the development of social skills. The attention/executive function component operationalises abilities such as attentional-control, cognitive flexibility and goal setting. Attentional control is important in social interactions as children need to be able to attend to the right tasks and stop inappropriate automatic responses, while cognitive flexibility is required to generate new solutions negotiate and problem solve. Goal setting requires significant planning skills as a person needs to be able to think into the future, identify a desire/goal and have some understanding of how they will achieve that goal.



*Figure 1.* The socio-cognitive integration of abilities model (SOCIAL). Reprinted from *Developmental social neuroscience and childhood brain insult: Theory and practice.* (p. 6) by V. Anderson, & M. Beauchamp, (Eds.), 2012, New York, US. Copyright Guilford Press. Reprinted with permission.

**FASD and executive functioning.** In terms of FASD diagnosis executive functioning is a core central nervous system domain which appears to be particularly impaired (Khoury, Milligan, & Girard, 2015; Nash et al., 2014). The literature suggests that children and adolescents with prenatal alcohol exposure (or FASD) often have difficulty processing information when the task is complex and requires a great amount of inhibition/self-regulation, flexible thinking, and working memory (Kodituwakku, 2007; Kodituwakku, 2009; Mattson, Crocker, & Nguyen, 2011). The variety of executive functioning impairments (e.g. inhibition, cognitive flexibility, planning, utilising feedback and working memory) which are observed in children with an FASD diagnosis, or prenatal alcohol exposure, have contributed towards the

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current view that these children experience a generalised deficit in their ability to “*adapt to responses based on context, plan for the future and problem solve in novel situations*” (Davis et al., 2013, p. 83). Furthermore although executive functioning impairments are related to the level of cognition they are not fully explained by a child’s general intelligence (IQ) (Khoury et al., 2015; Quattlebaum & O’Connor, 2013; Rai et al., 2016).

Research findings emanating from studies in Canada and the US indicate that children and adolescents with FASD, or confirmed prenatal alcohol exposure, experience significant impairments in all of Anderson and Beauchamp’s (2012b; 2010) attention and executive functioning components; inhibition/attentional control (Enns & Taylor, 2016; Glass et al., 2013; Khoury et al., 2015; Rai et al., 2016; Rasmussen & Bisanz, 2009; Rasmussen et al., 2013), cognitive flexibility or set shifting (Enns & Taylor, 2016; Glass et al., 2013; Khoury et al., 2015; Kingdon, Cardoso, & McGrath, 2015; McGee, Schonfeld, Roebuck-Spencer, Riley, & Mattson, 2008; Rai et al., 2016; Rasmussen & Bisanz, 2009), and planning and utilising feedback (Aragón et al., 2008; Enns & Taylor, 2016; Green et al., 2009; Kingdon et al., 2015; Kodituwakku, Handmaker, Cutler, Weathersby, & Handmaker, 1995; Rai et al., 2016).

***Inhibition/attentional control.*** Several researchers have investigated inhibitory control in children with FASD or significant alcohol exposure using either the California Stroop Test (Mattson, Goodman, Caine, Delis, & Riley, 1999), NEPSY-II Inhibition Test (Rasmussen et al., 2013) or D-KEFS Colour-Word Interference Test (Glass et al., 2013; Rasmussen & Bisanz, 2011). Findings include significant impairments in the inhibition and switching tasks compared to typically developing children and adolescents (Connor, Sampson, Bookstein, Barr, & Streissguth, 2000; Glass et al., 2013; Mattson et al., 1999; Rasmussen & Bisanz, 2011; Rasmussen et al., 2013) which emphasises the difficulty this group of children has with mentally holding information, restraining their automatic response and switching to the desired response.

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A number of international studies (US, Canada and South Africa) have found children and adolescents with prenatal alcohol exposure (aged 4-16 years) show significant impairments in working memory when matched to typically developing children and adolescents (Glass et al., 2013; Green et al., 2009; Kalberg et al., 2013; Norman et al., 2013; Rasmussen et al., 2009; Rasmussen & Bisanz, 2011) and these impairments have been related to brain activation abnormalities in areas known to be implicated in working memory (e.g. right inferior frontal gyrus, right posterior parietal lobe, right dorsolateral prefrontal cortex (DLPFC), and right middle frontal gyrus (Astley et al., 2009a). The ability to hold and mentally manipulate a number of variables at once which working memory tests demand, appears to be particularly impaired in children with FASD even when the influence of IQ is accounted for (Burden, Jacobson, Sokol, & Jacobson, 2005).

**Cognitive flexibility.** Children with prenatal alcohol exposure consistently show marked difficulties with flexible thinking, shifting and concept formation (Kodituwakku, Kalberg, & May, 2001; McGee, Schonfeld et al., 2008; Rasmussen et al., 2013; Vaurio, Riley, & Mattson, 2008). Poor performance has been observed in: 1) generating concepts, 2) perseverative errors, 3) cognitive and 4) poorer ability to shift strategies according to reward response feedback (Kodituwakku et al., 2001; McGee, Schonfeld, et al., 2008). Impairments observed in set shifting and perseverative errors have also been found to contribute towards predicting behavioural difficulties (Kodituwakku et al., 2001). Studies have also found that children's performance in sorting tasks is not necessarily aligned to their IQ level (McGee, Schonfeld, et al., 2008; Vaurio et al., 2008) which again suggests IQ may not be an adequate measure of capacity to adapt to changing environmental demands.

**Planning.** Planning tasks such as the Tower of London (Shallice, 1982), Tower of Hanoi (Anzai & Simon, 1979), Progressive Planning Test (PPT) (Kodituwakku et al., 1995) are often used to assess cognitive planning skills. Studies from the US and Canada have found

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children (8-15 years) with FASD (N=24, Aragón et al., 2008; N = 89, Green et al., 2009) have poorer performance, when compared to typically developing children and adolescents (N= 32, Aragón et al., 2008; N = 92, Green et al., 2009), in Tower type tasks through more rule violations, decreased planning time and needing more moves to complete the task especially as tasks increased in complexity (Aragón et al., 2008; Green et al., 2009).

However, children with FASD nevertheless demonstrate relative strengths in the Tower tasks compared to their performance in other executive functioning tasks, despite overall deficits in planning and problem solving (Glass et al., 2013; Lebel et al., 2008; Rasmussen & Bisanz, 2009). The Tower task is a visuo-spatial planning task where children have to move discs of varying sizes to replicate a specific pattern whilst adhering to a strict set of rules. The task starts easy and becomes more complex therefore enabling children to gain confidence. Children are not required to shift or switch their cognitive focus as required in sorting and inhibition tasks. Furthermore, the task does not require social skills, or adaptation to a changing environment. It may be that the performance in Tower like tasks may be higher than performance in other activities that require a shift of cognitive focus and an understanding of the social context.

### **The Influence of Social Cognition**

Social cognition has been defined as *“those aspects of higher cognitive function which underlie smooth interactions by understanding and processing interpersonal cues and planning appropriate responses”* (Scourfield, Martin, Lewis, & McGuffin, 1999, p. 559). Furthermore, the purpose of social cognition in the context of personal and inter personal goals has also been acknowledged in social cognition definitions such as *“the ability to achieve personal goals in social interaction while simultaneously maintaining positive relationships with others over time and across situations”* (Rubin & Rose-Krasnor, 1992, p. 285).

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Social cognition is important as difficulties in social skills are associated with poorer outcomes in both health and justice arenas (Anderson & Beauchamp, 2012b; Arsenio & Lemerise, 2004; Schonfeld, Mattson, & Riley, 2005). Children and adolescents require adequate social skills to navigate their place in the community and respond to difficult situations in a prosocial way. Impairments in social skills lead to higher risks of delinquency, alcohol and drug misuse, and aggression (Botvin & Kantor, 2000; Boxer, Goldstein, Musher-Eizenman, Dubow, & Heretick, 2005; Fluharty, Heron, & Munaf, 2017; Hawkins, Kosterman, Catalano, Hill, & Abbott, 2005). Children with social difficulties often experience negative feelings (anger, anxiety) and perceptions about themselves (Boxer et al., 2005; Dodge et al., 2002; Trentacosta & Fine, 2010). Often these negative emotions and perceptions precipitate isolation, rejection and disconnection and lead to maladaptive delinquent behaviours.

**Social cognition models.** As shown in the SOCIAL model (see Figure 1) adaptive functioning, especially in the social arena, not only relies on adequate executive functioning (Greenspan et al., 2016) but also requires sufficient social emotional cognition (Anderson & Beauchamp, 2012b; Beauchamp & Anderson, 2010). There are a number of psychological models that seek to explain social and emotional processes. Some models account for developmental changes such as the work by Serena Wieder and Stanley Greenspan that incorporates development from infancy in their Developmental Individual Differences, Relationship-based (DIR®/Floortime™) model (Wieder & Greenspan, 2003). Their model focuses on the importance of social relationships as building blocks to social and cognitive learning especially in relation to children with developmental disorders such as autism.

Selman and Byrne (1974) used Piaget's theory of cognitive development to define social role taking according to developmental stages. Four levels describe social role taking development between the ages of 4 and 10 years: 1) Level 0 – Egocentric role taking, 2) Level 1- Subjective role taking, 3) Level 2 Self-reflective role taking and 4) Level 3 – Mutual role

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taking. These levels recognise the developmental shifts that occur as children progress from being unable to consider different points of view, to being able to being able to consider multiple parties perspectives simultaneously.

Gerris (1981) cited in (Van Manen, Prins, & Emmelkamp, 2001) details eight social cognitive skills, which further define and differentiate Selman and Byne's four levels. The first level starts with simple emotional identification, a skill that emerges in the preschool period, and social skill levels increase in complexity to then account for the ability to understand multiple perspectives and problem solve at around 10 years. See Table 1 for the explanation of the eight cognitive skills and their correlation with Selman's social cognitive levels.

Understanding how social cognitive skills play out in everyday situations is also important. Crick and Dodge (1994) developed their Social Information Processing Model (SIP) which remains a 'gold standard' to understand the management of social information (see Figure 2). The model demonstrates cognitive processes that require a data base of memories, rules, schemas and knowledge to interpret the environment and respond to it in a social way. However, the SIP model focuses more on the information processing aspect of social cognition and does not fully account for other influencing factors such as developmental age, emotional state, temperament and external factors such as social economic status, and culture.

The models outlined by Selman and Byrne (1974), Gerris (1981) and Crick and Dodge (1994) are valuable for their contributions from a developmental or information processing perspective on the influences on social functioning. However, these models are based on typical development and many of the children who present clinically have developmental difficulties associated with brain insults occurring either prenatally or postnatally. With this in mind Yeates et al. (2007; 2012) presented a holistic model which proposes an integration of

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brain function and external factors to conceptualise social competence in children with brain disorder, specifically Traumatic Brain Injury (TBI), recognising this model may also have validity for other neurodevelopmental disorders.

Additional factors are included in another heuristic model of social competence which go beyond the functional and behavioural factors of social skills and adjustment (Yeates et al., 2007; 2012). These factors include insult-related factors (type of insult, severity of insult, regional brain abnormalities) and non-insult related risk and resilience factors (parenting style, family functioning, socioeconomic status) (See Figure 3). The use of an integrative model is important as children learn social rules and etiquette from their environment and culture in their family/whānau and wider community. By recognising the interplay between individual, family and environmental factors within the context of a brain insult Yeates and colleagues have provided a holistic model that represents the biopsychosocial aspects that impact the development of social competence.

The holistic nature of the model of Yeates and colleagues has been important as it has recognised the importance of other internal and external factors that influence a child's ability to be socially successful. However as Beauchamp and Anderson (2012b; 2010) argue, the Yeates model "*does not operationalize the key cognitive and affective components*" (p. 44) and they agree with earlier criticisms that it does not give a developmental theoretical framework for children who are 'at risk' of social problems.

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Table 1

*Developmental perspectives of social cognitive skills*

| Social cognitive level<br>(Selman 1974) | Social Cognitive skills<br>(Gerris, 1981)   | Age            |
|---|---|----------------|
| 1. Ego Centric                          | 1. Identifying – The ability to discern the existence of subjective perspectives of others and oneself and to recognise and label them.<br><br>2. Discriminating – The ability to judge whether two or more observable perspectives are similar or dissimilar without the requirement to verbalise or label the specific.                         | About 4 years  |
| 2. Subjective                           | 3. Differentiating – The awareness or understanding that two or more persons in similar (or dissimilar) situations do not necessarily have similar or identical perspectives.<br><br>4. Comparing – The ability to determine and label discrepancies and similarities between observable perspectives of different persons in the same situation. | About 6 years  |
| 3. Self-reflective                      | 5. Perspective-taking - The ability to infer what perspective another person has. To take the position or role of another person and to infer the perspective of that person.<br><br>6. Relating - The ability to relate at least two perspectives and their causes and vice versa.   | About 8 years  |
| 4. Mutual                               | 7. Coordinating- The ability to take a third person’s position: the awareness that a person’s inference of a perspective of another person can be the object of his own thinking.<br><br>8. Taking into account – The ability to take perspectives of others and oneself into account at the same time.   | About 10 years |

*Note.* Van Manen, T. G., Prins, P. J., & Emmelkamp, P. M. (2001). Assessing social cognitive skills in aggressive children from a developmental perspective: The social cognitive skills test. *Clinical Psychology & Psychotherapy*, 8(5), 341-351. Copyright 2001 by John Wiley and Sons. Reprinted with permission.

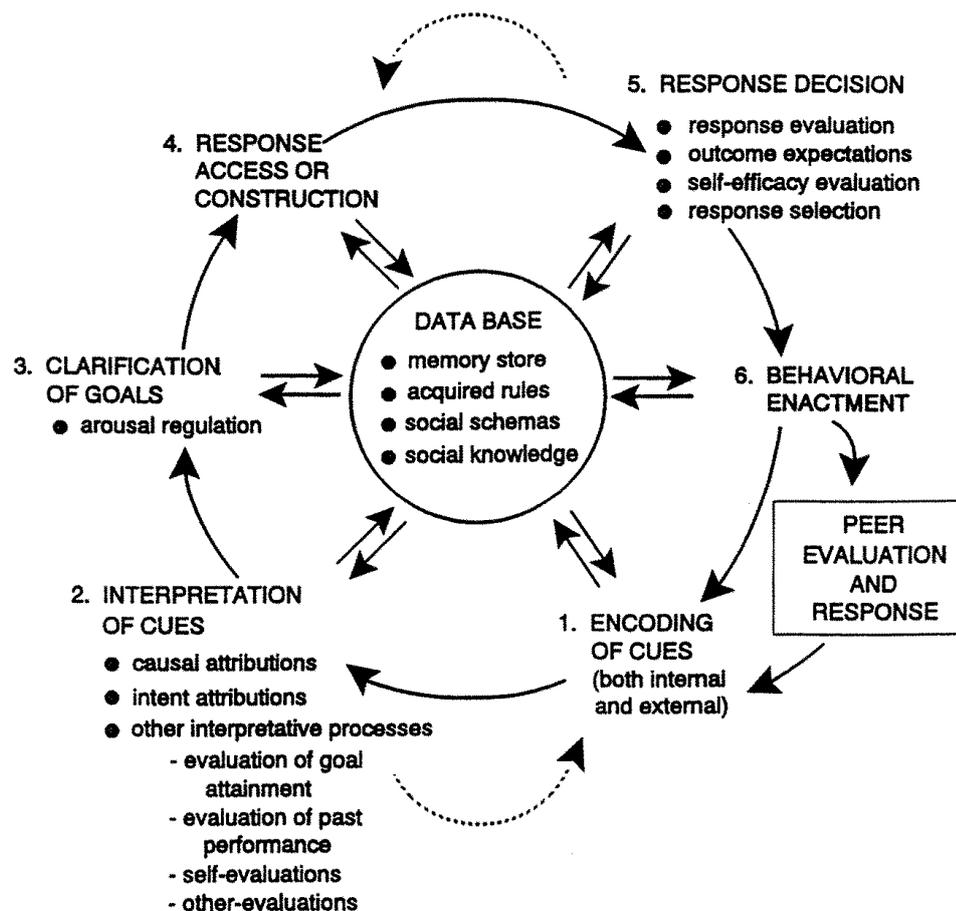
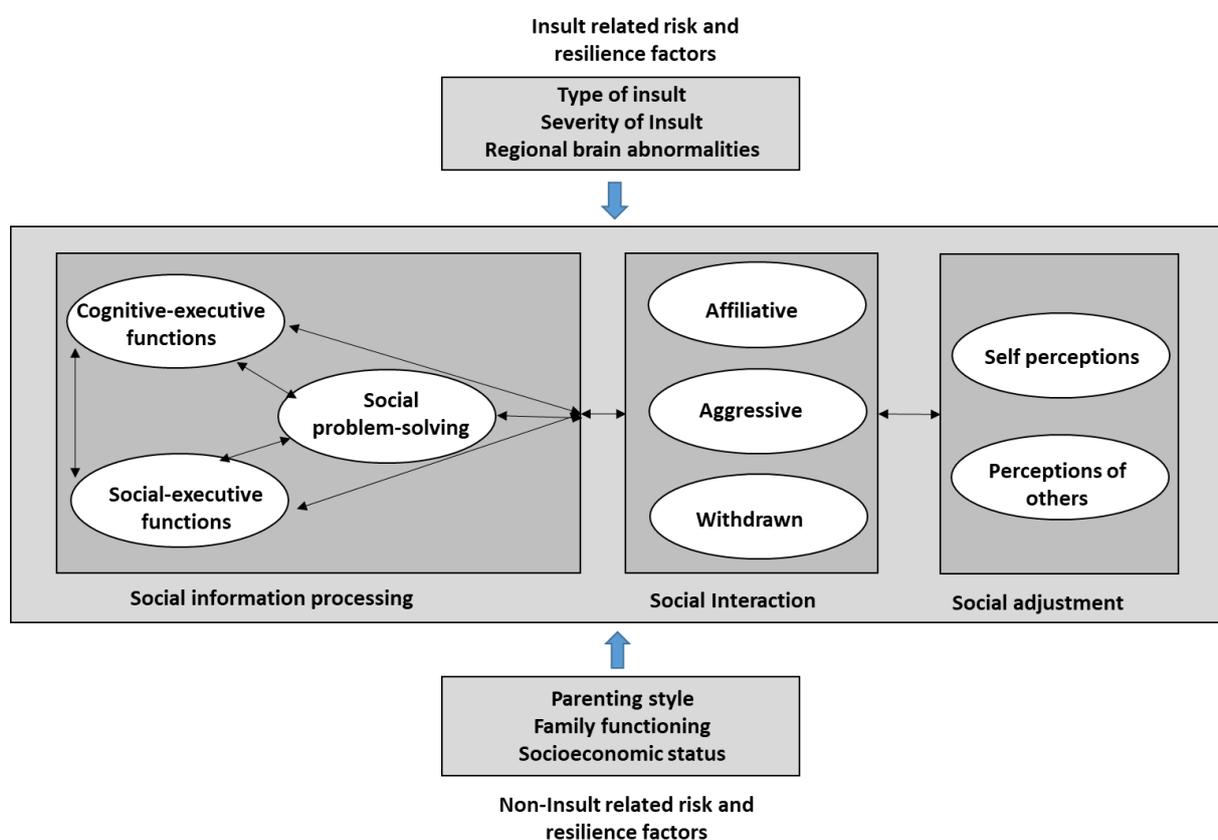


Figure 2. A social information processing model of children’s social adjustment. Reprinted from “A review and reformulations of social-information processing mechanisms of children’s social adjustment,” by N. R. Crick & K. A. Dodge, 1994, *Psychological Bulletin*, 115 (1) p. 76. Copyright 1994 by the American Psychological Association. Reprinted with permission.

Beauchamp and Anderson (2012b; 2010) therefore present their socio-cognitive integration of abilities model (SOCIAL) and extend Yeates’ (2007) model by describing more detailed cognitive and affective skills required for social competence in typically developing children (see Figure 1). The model operationalizes cognitive and affective components and “assumes that the development of intact social skills is dependent on typical maturation of the brain, cognition and behaviour within a supportive context” (Anderson & Beauchamp, 2012b, p. 6).

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Although executive functioning and social cognition are interrelated (for example an individual may inhibit inappropriate responses and plan how they socially interact) there is some evidence to suggest some skills, e.g. social attribution ability, is domain specific (Dodge & Godwin, 2013; Hu, Chan, & McAlonan, 2010). Beauchamp and Anderson's (2012b; 2010) SOCIAL model (see Figure 1) identifies important domain specific cognitive skills and these are outlined in Table 2.



*Figure 3.* An integrative, heuristic model of social competence in children with brain disorder. Reprinted from “Social outcomes in childhood brain disorder: a heuristic integration of social neuroscience and developmental psychology” by K. Yeates, E. Bigler, M. Dennis, C. Gerhardt, K. Rubin, T. Stancin, & K. Vannatta, 2007, *Psychological bulletin*, 133(3), p.538. Copyright 1994 by the American Psychological Association. Reprinted with permission.

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Beauchamp and Anderson's (2012b; 2010) SOCIAL model recognise that social skills require a developmental framework and propose the four sub skills under the social cognition domain face/emotion perception, attribution, theory of mind and moral reasoning are hierarchical nature. For example, children gain skills in face and emotion recognition before they are able to attribute intention or understand another person's perspective. Likewise, children need to be able to understand others perspective to be able to engage in moral and ethical reasoning.

Table 2

*Cognitive sub skills in Beauchamp and Anderson's (2010; 2012b) SOCIAL model*

| Cognitive Domains              | Cognitive Sub skills    | Examples   |
|--------------------------------|-------------------------|--|
| Attention and Executive skills | Attentional control     | Attending to the right information, self-monitoring and inhibiting a response.           |
|                                | Cognitive flexibility   | Adapting to changes in conversation, thinking of different and more effective responses. |
|                                | Goal setting            | Organisation, recognising the goal of the social interaction.                            |
| Communication                  | Expressive language     | Effectively communicating thoughts and feelings.   |
|                                | Receptive language      | Understanding what the other person is saying.   |
| Social Cognition               | Face/emotion perception | Perceiving and identifying emotions on faces.  |
|                                | Attribution             | Assign intent to others behaviour e.g. stereotyping, social judgements.                  |
|                                | Theory of mind          | Understand other people perspectives which may be different to oneself.                  |
|                                | Moral reasoning         | Understanding what is right and wrong from an ethical/moral perspective                  |

**Social cognition and FASD.** FASD has also been associated with significant social difficulties. Children with FASD and/or prenatal alcohol exposure have shown difficulty with emotion understanding and recognition (Greenbaum et al., 2009; Kerns et al., 2016; Lindinger et al., 2016; Petrenko et al., 2017; Rasmussen et al., 2009; Stevens et al., 2016) and theory of

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mind (Lindinger et al., 2016; Rasmussen et al., 2009; Stevens et al., 2015). Research also suggests children and adolescents with FASD experience impairments of social cognition which are higher than what we would expect given their age, general intellectual functioning and executive functioning skills (Lindinger et al., 2016; McGee, Fryer, Bjorkquist, Mattson, & Riley, 2008; Quattlebaum & O'Connor, 2013; Rasmussen et al., 2009; Thomas et al., 1998).

***Emotion recognition.*** Emotion recognition is a core component of social cognition capacity and has been found to be impaired in children with FASD (Greenbaum et al., 2009; Kerns et al., 2016; Lindinger et al., 2016). In a Canadian study comparing social and emotional processing ability of children (6-13 years) with FASD (N = 33), Attention Deficit Hyperactivity Disorder (ADHD) (N = 30) and typically developing children (N = 34), children with FASD were found to demonstrate significantly lower performance in emotional facial processing capacity (Greenbaum et al., 2009). Kerns et al. (2016), in another Canadian study found children (8-14 years) with FASD (N = 22) showed more impairments in emotion recognition when compared to typically developing children (N = 22), although these impairments were related to recognising emotions on adults but not child faces. A study based in South Africa showed children (9-11 years) with FASD (N = 44) showed more impairments in a task that involved recognising both cognitive and affective states from eye expressions when compared with typically developing children (N = 19) (Lindinger et al., 2016).

Way and Rojahn (2012) examined psychosocial skills of children (2-14 years) with FASD (N = 25), typical development (N = 23) and children with Down syndrome (N = 14), matched on gender and developmental age. They found that facial processing ability corresponded to developmental age which suggested emotion recognition impairments may be linked to global developmental issues rather than special impairments in the social and emotional skills domain.

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***Theory of mind.*** Theory of mind has been defined as “*the ability to understand the mental states of others*” (Taber-Thomas & Tranel, 2012, p.77). In the FASD literature differences have been found in theory of mind abilities depending on the age of the child. A Canadian study investigating theory of mind in children with FASD (N = 25) and typically developing children (N = 28) found younger children with FASD (4-6 years) did not show differences when compared to typically developing children, whereas older children (6-8 years) showed significantly poorer performance (Rasmussen et al., 2009). In another Canadian study which included children (8-12 years) with FASD (N = 37) and typically developing children (N = 21) age was significantly related to accurate false belief performance for children with FASD but not typical developing children (Stevens et al., 2015). In other words, typically developing children, as they get older, develop more sophisticated social and emotional abilities, whereas children with FASD appear to not develop these skills as they age.

The age of participants may also affect results where one Canadian study with a wide age range (6-16 years) of participants (FASD = 32, Typically developing children and adolescents = 30) failed to show theory of mind impairments in children with FASD using the NEPSY II Theory of Mind task (Rasmussen et al., 2013). In contrast Stevens et al. (2015) (outlined above) did show that participants in a smaller age range (8-12 years) had significantly impaired theory of mind abilities.

***Social problem solving and moral reasoning.*** Impairments in social problem solving have also been identified. Children (7-11 years) with prenatal alcohol exposure (N = 52) made significantly fewer prosocial goals, more aggressive responses, and showed ineffectual evaluating responses and incorrect understanding of the intent of other children, with difficulties remaining even after controlling for IQ (McGee, Bjorkquist, Price, Mattson, & Riley, 2009). Children and adolescents (10-18 years) with prenatal alcohol exposure (N= 27) have been found to perform at a much lower level of moral maturity than typically developing

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children and adolescents (N = 29), for example, understanding the importance of helping friends and obeying the law (Schonfeld et al., 2005). Stevens et al. (2015) found parents also rated children with FASD lower on measures of empathy (e.g. the feeling a child has towards other people in in different situations) than typically developing children. In addition, a Canadian study also found parent reports of social skills indicated difficulties in perseveration (repeating a behaviour even though there may be no continued use for the behaviour), coping with change, turn taking and responding in conversation in children 8-12 years with FASD (Stevens, Nash, Koren, & Rovet, 2013).

Research that has investigated social skills in children with FASD has generally focused on one aspect of social and emotional cognition, for example emotional recognition or theory of mind. Thus there may be benefit in trying to apply a more holistic model, such as Beauchamp and Anderson's (2012b; 2010) SOCIAL model, that incorporates both internal and external factors as well as other cognitive/executive skills.

### **FASD: Psychosocial and Environmental Complexity**

Prenatal alcohol exposure is not the only factor that impact children's learning and behaviour. Negative environments where children experience trauma through abuse and neglect also impact brain development (Perry, 2002; Shonkoff et al., 2012; Teicher & Samson, 2016). Children with prenatal alcohol exposure may be at increased risk for additional environmental adversity (Coggins et al., 2007; Reid et al., 2017) with an increased prevalence of children with FASD in the care and protection system (Astley et al., 2002; Lange, Shield, Rehm, & Popova, 2013; Smith et al., 2007).

The combination of neurodevelopmental issues and increased psychosocial adversity may also impact on an individual's mental health and well-being. Co-morbid mental health issues are often prevalent in individuals who have a diagnosis of FASD (Pei et al., 2011;

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Streissguth et al., 2004; Weyrauch et al., 2017) and research from North America indicates that many children referred for FASD assessment live with non-biological caregivers and have a higher incidence of mental health disorders (Chasnoff, Wells, & King, 2015; O Connor, McCracken, & Best, 2006).

Therefore, it is important to look at the cumulative effect of both prenatal alcohol exposure and post-natal adversity. There is a suggestion that the increased prevalence of co-morbid mental health issues may be due to a combination of both prenatal alcohol exposure and adverse environmental factors (Pei et al., 2011), such as maternal mental health issues (Astley, Bailey, Talbot, & Clarren, 2000; O'Connor & Kasari, 2000). Children with prenatal alcohol exposure and trauma are also more likely to experience more cognitive and behavioural difficulties than children with trauma but without prenatal alcohol exposure (Henry, Sloane, & Black-Pond, 2007). This cumulative effect has given rise to the Diathesis-stress model which *“holds that some individuals have a dispositional vulnerability of weakness (diathesis) that is only manifested as maladjustment when they experience disadvantageous events (stress)”* (Root, Hastings, & Maxwell, 2012, p. 104).

Support is important not just for children with FASD, but also for the parents/caregivers caring for them. Birth mothers of children with FASD have often been found to have experienced an increased prevalence of; physical and sexual abuse, placement in a youth justice residence and have experienced alcohol abuse from their own parents (Astley et al., 2000). Furthermore, it is also possible that these birth mothers may experience an undiagnosed FASD themselves, and experience neurological impairments that impact their ability to manage everyday life and parent appropriately. Astley et al. (2000) recruited 80 birth mothers to participate in the research through the paediatric diagnostic clinics at the University of Washington and Children’s Hospital and Regional Medical Centre in Seattle, Washington. These birth mothers claimed ‘alcohol helped them cope’ with their life and those women who

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had managed to maintain abstinence reported having a greater level of social support, higher socioeconomic status and were more likely to be connected to a church (Astley et al., 2000).

Equally, higher maternal education and socioeconomic status have been found to be associated with improved neuropsychological functioning in children with FASD (May et al., 2013) and a stable caring environment is recognised as being essential for good outcomes e.g. increased school success, secure attachments and decreased alcohol and drug problems (Kalberg & Buckley, 2007; O'Connor, Kogan, & Findlay, 2002; Olson, Oti, Gelo, & Beck, 2009; Streissguth et al., 2004). Given that supportive environments are typically associated with more positive outcomes for children with FASD, access to services need not just be based on the individual but must include the wider needs of the family if positive outcomes are going to be achieved.

### **Populations in Empirical Studies**

Many research studies investigating FASD are based on clinical data and retrospective review with no comparison group. However, the number of empirical studies involving comparison groups has grown in recent years. Most of this experimental research has been conducted in North America with comparison groups matched on age and gender. Many studies have also matched on socioeconomic status and ethnicity however a number have only matched on age and gender with many comparison groups consisting of higher numbers of Caucasian participants from higher socioeconomic groups. Nonetheless there are notable exceptions and a number of studies matched on age, gender, ethnicity and socioeconomic status (Aragón et al., 2008; Kodituwakku, et al., 2001; Mattson et al., 1999; McGee, Schonfeld et al., 2008; McGee, Bjorkquist, Price et al., 2009; McGee, Bjorkquist, Riley et al., 2009; Panczakiewicz et al., 2016; Quattlebaum & O'Connor, 2013; Schonfeld et al., 2005) (See Table 3).

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Interestingly, most of the studies above that demonstrate well matched comparison groups have examined general, or more cognitive, neuropsychological functioning and many of the studies examining social and emotional cognition in children with FASD have only matched on age and gender (Kerns et al., 2016; Lindinger et al., 2016; Stevens et al., 2015; Stevens et al., 2016). Notable exceptions include studies investigating social and emotional process from San Diego University (McGee, Schonfeld, et al. 2008; Schonfeld et al. 2005; McGee, Bjorkquist, Riley, et al. 2009).

Table 3

*Studies matching on age, gender, ethnicity and socioeconomic status (SES)*

|  | Age | Gender | Ethnicity | SES |
|--|-----|--------|-----------|-----|
| Aragón et al. (2008)                   | ✓   | ✓      | ✓         | ✓   |
| Fuglestad et al. (2015)                | ✓   |        |           | ✓   |
| Glass et al. (2013)                    | ✓   |        | ✓         |     |
| Kerns et al. (2016)                    | ✓   | ✓      |           |     |
| Kodituwakku et al. (2001)              | ✓   | ✓      | ✓         | ✓   |
| Lindinger et al. (2016)                |     | ✓      |           |     |
| Mattson et al. (1999)                  | ✓   | ✓      | ✓         | ✓   |
| McGee, Bjorkquist, Price et al. (2009) | ✓   | ✓      | ✓         | ✓   |
| McGee, Bjorkquist, Riley et al. (2009) | ✓   | ✓      | ✓         | ✓   |
| McGee, Fryer et al. (2008)             | ✓   | ✓      |           |     |
| McGee, Schonfeld et al. (2008)         | ✓   | ✓      | ✓         | ✓   |
| Panczakiewicz et al. (2016)            | ✓   | ✓      | ✓         | ✓   |
| Quattlebaum and O'Connor (2013)        | ✓   | ✓      | ✓         | ✓   |
| Schonfeld et al. (2001)                | ✓   | ✓      | ✓         |     |
| Schonfeld et al. (2005)                | ✓   | ✓      | ✓         | ✓   |
| Stevens et al. (2015)                  | ✓   | ✓      |           |     |
| Stevens et al. (2016)                  | ✓   | ✓      |           |     |
| Vaurio et al. (2011)                   | ✓   |        | ✓         | ✓   |
| Ware et al. (2012)                     | ✓   |        |           |     |
| Wozniak et al. (2016)                  |     | ✓      | ✓         |     |

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### **Aim and Hypothesis**

The literature review suggests that social cognition, executive functioning and adverse childhood experiences are important influences for adaptive functioning in children with FASD. Intelligence Quotient (IQ) has a more variable relationship and is not always a good predictor of adaptive functioning. Consequently, the research in this thesis sought to utilise psychological models to investigate what factors (IQ, social cognition, executive functioning and adverse childhood experiences) are related to everyday adaptive functioning in a sample of children with FASD. This study has also paid particular attention to include a well-matched comparison group (gender, age, ethnicity, maternal education, and socio-economic status).

This research will utilise Beauchamp and Anderson's (2012b; 2010) SOCIAL Model as a way of exploring the role that executive functioning, social cognition and adaptive functioning play in children with FASD. The SOCIAL model (see Figure 1) also best identifies a number of the variables that existing literature suggests will influence social competence and adaptive function in children with FASD. Prenatal alcohol exposure influences brain integrity and external factors such as connection to culture, maternal education and growing up in an environment free of abuse and neglect also influence a child's development. Internal factors such as IQ have some bearing but do not fully explain impairments in social competence and adaptive functioning. Children with FASD have been found to have difficulties in the areas of attention and executive functioning, language and social cognition. Measures for executive functioning and social cognition were therefore chosen to represent the attentional/executive (Inhibition, shifting and goal setting) and social cognition (emotion perception and theory of mind) components in Anderson and Beauchamp's (2012b; 2010) SOCIAL model (see Figure 1). More detailed descriptions of specific assessments are given in Chapter Four.

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It is important that we understand why children with FASD are at such high risk of growing up to experience such adverse outcomes, so that action can be taken to alter this course and ensure they are given the best opportunity to do well in life. In addition there has been no previous research considering these factors in a New Zealand context and taking into account a Māori world view. A cultural perspective is imperative if we are to understand the impact of colonisation on both the individual and the society and identify factors that need to be considered for intervention. The findings will be examined in terms of the implications for essential components of services and supports for children with FASD and their whānau, and how adequately current services support these needs. Intergenerational trauma that continues to impact ongoing development of these children and their whānau will be recognised.

The main hypothesis in this research is that impairments in executive functioning and social cognition, but not IQ, will be associated with impairments in adaptive behaviour in children with FASD. In particular it is hypothesised that:

1. In the comparison group IQ, as well as executive functioning and social cognition, will predict adaptive functioning.
2. In the FASD group executive functioning and social cognition will predict adaptive functioning, rather than IQ.
3. In the FASD group social cognition will predict levels of adaptive functioning independently from executive functioning.
4. Adverse Childhood Experiences (ACEs) data will be related to the level of adaptive functioning for the FASD group.

The next chapter details the partnership process of this study before the methodology is described in Chapter Four.

**Chapter Three: Raranga te Tira - Partnership with Te Wāhanga Hauora Māori**

I am Pākehā.

I have strong personal and professional ties with Māori. But I  
am not Māori.

This chapter will outline the essential elements of Tauwiwi (Non-Māori) and Māori collaboration in research and clinical practice. I will then describe how developed partnerships at a national and local level have provided a platform to build collaboration. Following this, I will outline my collaboration process together with strengths and challenges that arose, which I hope will assist future researchers looking to collaborate and work with Māori in research or clinical settings.

**Essential Elements of Tauwiwi and Māori Collaboration**

First it is important to recognise the importance of the researcher (both Indigenous and non-Indigenous) to place, or ‘locate’ themselves within the community they are researching (Morton Ninomiya & Pollock, 2017; Smith, 2012). Therefore, the following narrative attempts to locate myself within the Māori community and explore my journey of discovering a rich cultural history I initially didn’t know existed.

I grew up in a predominantly Pākehā suburb in Auckland and my early experiences with Māori were mostly formed within the school curriculum and from information that was presented in mainstream media. It would be fair to say that my understanding of the history of Aotearoa New Zealand was poor and I was not aware of the inequities arising from the trauma of colonisation. An early career in accounting and finance did not provide many opportunities to engage further with

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Te Ao Māori, although I did spend time working on District Health Board projects within my role as a management consultant. As Māori are overrepresented in our health system, I am now struck by how little I and my colleagues understood about historical trauma being a determinant of health.

I may have continued on this life path if I had not become very ill while travelling in Africa in 1997. Facing my own mortality in my mid 20s shifted my priorities. Over the next couple of years I explored other vocational options before being accepted into the Clinical Psychology Programme at Victoria University. It was here my awareness of colonisation, trauma and a Māori world view started.

Relationships formed within the Clinical Programme helped to create an understanding of the history of Aotearoa. I was fortunate to have the tutorage of Lisa Cherrington who taught us the importance of understanding cultural needs and thinking about mental health from a Māori perspective. I still remember her lessons and individual supervision sessions as warm, but also perceptive and challenging. For me, the clinical Programme, with the assistance of Lisa Cherrington, Victoria University, and Catherine Love and Charles Waldegrave from the Family Centre, unearthed a history that I was not aware nor proud of. At the same time I was struck by the strength and resilience of Māori and at times yearned to be part of a culture that had so much pride and resourcefulness.

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During this process in the Clinical Psychology Programme I became aware that I was Fourth generation Pākehā and my ancestors who originally settled in Taranaki may have played a part in the trauma that occurred there. I often felt uncomfortable, but early on I resolved to not turn away from that discomfort. Sitting with the uncomfortable reality of Aotearoa New Zealand's history felt the least I could do when so many Māori had experienced far worse in the process of colonisation and assimilation into a Pākehā world. In the end, however, it is not about guilt and blame but acknowledgement and responsibility.

A move to Hawke's Bay, and after my children were born, starting work in the Wāhanga Whakapakari Tamaiti (Child Development Service) was the next step. At first Hawke's Bay struck me as a very stratified community. I had become used to friends from all cultures, religions, and sexuality. Here everyone around me seemed to be like me – Pākehā, middle class, married with children. At work I would visit communities and schools in lower decile areas and discovered how Māori were overrepresented in these areas. My work with FASD spurred a need to connect with my Māori colleagues and the development of my current study established a more formal platform to work from. My journey and understanding had started, but the saying "you don't know what you don't know" resonates loudly with me.

If I am honest this process has been terrifying. This study did not aim to specifically research Māori, however the high numbers of Māori entering our service meant it was imperative to address the cultural context. I wanted to highlight inequities of service that children with

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FASD were not receiving, but my study was not Kaupapa Māori. I was also worried how the high rates of tamariki Māori in our service for FASD assessment would be portrayed once my study's findings were published. However, fear is an important catalyst and fear encouraged me to do my utmost to ensure the information the children and whānau gave me was considered with dignity and understanding of the wider societal context. I could not have done this research without the partnership of Te Wāhanga Hauora Māori and Querida Whatuira-Strickland and Laurie Te Nahu in particular. They have stood by me, gently nudging my learning in the right direction, whilst also challenging me when that needed to happen. Opportunities to take part in Noho Marae, Tu Kaha 2014, 2016, and sessions with Kaumātua have been instrumental in enriching my learning and being.

Outside of the DHB I am also thankful to my friends and mentors for engaging with me in lively discussion around many topics, for example, colonisation, Māori world views, importance of wairua and whānau. Having friendships to explore ideas, ask questions and be vulnerable with is important, when we 'other' people lose the richness and colour. Connections and friendships foster inclusiveness and tolerance. Partnerships need to be formed on mutual trust and respect. I feel extremely privileged to have experienced the warmth and generosity of the Māori community. The many friendships I have made with Māori continue today.

I now cannot fathom living a life that does not understand this country's history from a Māori perspective. I am thankful that academics

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such as Dr Ranginui Walker, Sir Mason Durie, Professor Linda Tuhiwai Smith and Dr Michael King have written passionate and thoughtful accounts of New Zealand and I continually delve into their books for understanding and inspiration. I believe Pākehā have a responsibility to understand how historical trauma is influencing communities today as well as acknowledging the benefits of constructing solutions within a Māori world view. This understanding must change what we say, how we behave, and what we hope for.

I am not Māori. I am Pākehā.

I recognise that I am a product of colonisation and have been educated in Pākehā pedagogy, research and clinical practice. However I also believe Indigenous research is important and therefore must be undertaken with integrity and with collaboration from the Indigenous people. Historically, research with Indigenous peoples has not always been empowering or protective (Morton Ninomiya & Pollock, 2017). *“The term ‘research’ is inextricably linked to European imperialism and colonialism. The word itself is probably one of the dirtiest words in the Indigenous world’s vocabulary”* (Smith, 2012, p. 1). Māori have the view that they have been over-researched and that research has disempowered rather than enhanced Māori communities (Smith, 2012).

While I unquestionably agree that past research injustices cannot be repeated, I sit with others who have recognised the need for quality health research to address inequities many Māori face (Health Research Council of New Zealand, 2010) and emphasise the benefits of Māori inclusion and contribution to this research (King & Turia, 2002). It is my view that expecting Māori to solve health inequities alone also feels unjust and abhorrent. Tauīwi and

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Māori need to work together in partnership to ensure health needs are addressed and health research benefits Māori.

### Developing Partnerships at a National and Local Level

The journey I took in partnering with Māori occurred within the context of already established national and local partnerships and these precedents created the platform to begin the current study's partnership process. Figure 4 below, outlines partnerships at national, local and service levels that have enabled the current study's collaboration. Most importantly, it is Te Tiriti o Waitangi, at the national level, which provides the overall guidance and establishes platforms for local and research partnerships to flourish.

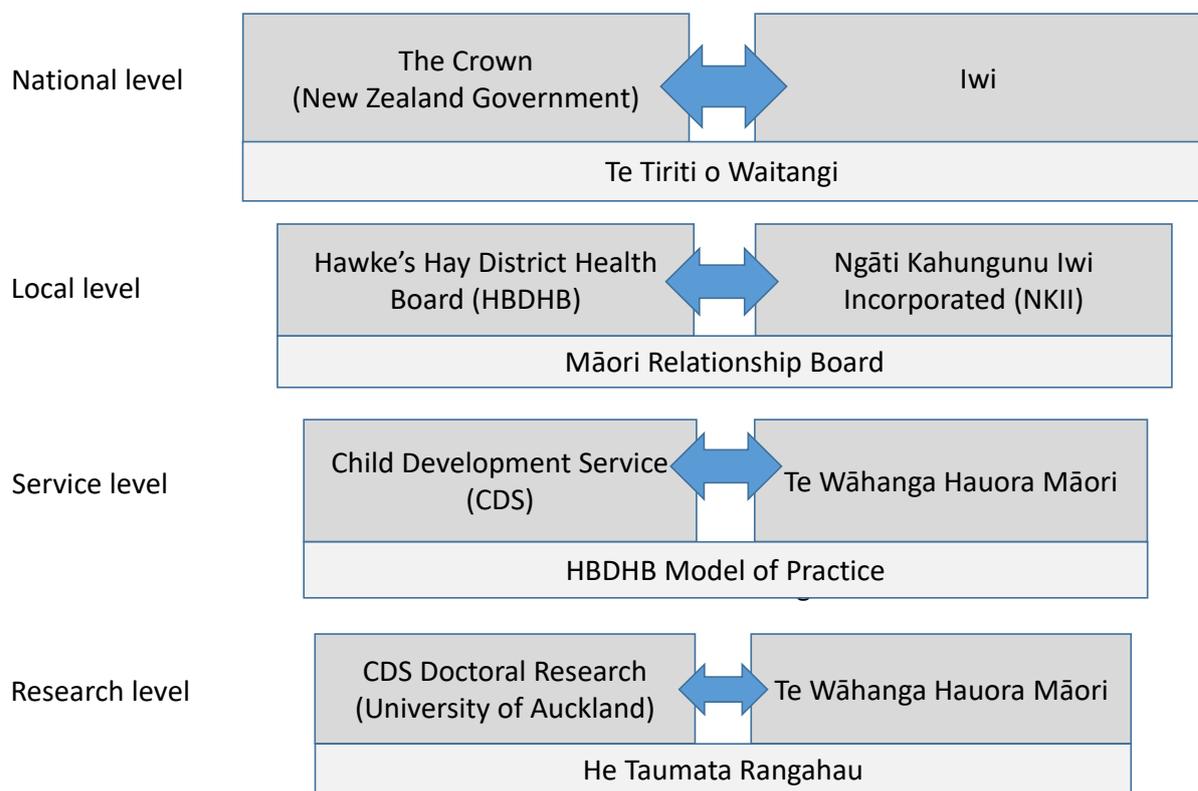


Figure 4. National, local, service and research levels of Māori and Tauīwi partnership.

The following sections will briefly review these national and local partnerships to illustrate their importance in creating research partnerships that are both feasible and honourable.

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**National level partnership - Te Tiriti o Waitangi (Treaty of Waitangi).** In reviewing the implications of Te Tiriti it is first important to consider the history of its formation and influence. Partnerships between the Crown and Iwi began before Te Tiriti with He Wakaputanga o te Rangatiratanga o Nu Tirene (the Declaration of Independence of New Zealand) which was signed in 1835 by 52 Rangatira Māori and the British Crown. The declaration has stated Māori chiefs would retain sovereignty and King William IV would protect New Zealand from others who may threaten independence.

The years following He Wakaputanga o te Rangatiratanga o Nu Tirene saw the British government become increasingly concerned about lawless land transactions. This led in part to the creation of Te Tiriti o Waitangi where the intention of the treaty was to formalise the relationship between the British and Māori, whilst also managing the crime and lawlessness that was occurring with the arrival of settlers. Te Tiriti o Waitangi was written in English and translated into Māori. Most Rangatira (chiefs) that signed Te Tiriti signed the Māori version.

There are fundamental differences between the English and the Māori version of Te Tiriti with the English version clearly stating full ‘sovereignty’ of New Zealand would be given to the British Crown. The Māori version instead used the word *kāwanatanga*, which means governance not ‘sovereignty’, thus Rangatira believed they still had the rights to control and manage their own affairs. This fundamental difference created much disagreement and protest within Aotearoa New Zealand with many Māori asserting their right to *Tino Rangatiratanga*, absolute sovereignty. Furthermore, instead of protecting Māori, the years after 1840 saw many atrocities committed in the spirit of colonisation.

In 1975, under the Treaty of Waitangi Act, the Waitangi tribunal was created to provide a legal process for claims from breach of promises made under the Te Tiriti o Waitangi. The establishment of the Waitangi Tribunal also gave legal direction for interpretation of Te Tiriti.

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Despite the disagreement between English and Māori version of Te Tiriti, the Waitangi Tribunal in (1988) recommended principals of the treaty that would apply in either version. These principles are 1) Principle of partnership, 2) Principle of protection and 3) Principle of participation (Ministry of Māori Development/ Te Puni Kōkiri, 2001). Partnership is particularly important and *“the key to defining the principles of the Treaty is to be found in the idea of partnership and that cooperation is at the heart of the agreed relationship. A principle of protection is nonetheless inherent in that partnership, creating responsibility”*. (Waitangi Tribunal, 1988, p. 185).

It is my opinion that in accordance with New Zealand jurisdiction, the practice of partnership between Māori and Tauwi should therefore be cornerstone in any activity be it industry, government or academic. These precedents, Te Tiriti o Waitangi and the Treaty of Waitangi Act 1975, provide the imperative to partner and also protect Māori. In the current study we sought to adhere to these principles by partnering throughout all of the research stages; planning, data collection, analysis, writing and dissemination of the research findings.

**Local level partnership - Ngāti Kahungunu Iwi Incorporated (NKII) and Hawke’s Bay District Health Board (HBDHB).** Local partnerships also created important precedents for the current study. The partnership between iwi and the crown in the form of Te Tiriti o Waitangi gives a platform to build local partnerships with Hawke’s Bay District Health Board (HBDHB) and Ngāti Kahungunu Iwi Incorporated (NKII) formalising their partnership in the Māori Relationship Board (MRB). In its role in HBDHB, the Māori Relationship Board aims to address health inequities and promote Māori models of health (Hawke's Bay District Health Board, Ngāti Kahungunu Iwi Inc, 2014).

The Māori Relationship Board is an example of how partnership between iwi and local government can be formalised with the intent of working for the benefit of the Māori

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community. The Māori Relationship Board not only provides a communication pathway between NKII and the HBDHB but it has a monitoring and advisory role to ensure planning ensures the needs of Māori are considered and included. This framework establishes a mechanism to ensure the duty of information decision making and principle of mutual benefit are satisfied. These formalised partnerships instil confidence and process for other collaborations, such as the research partnership in the current study, to prosper and provide meaningful solutions.

**Service Level Partnership – Wāhanga Whakapakari Tamaiti (Child Development Service) and Te Wāhanga Hauora Māori.** Partnership not only exists at a corporate level, between HBDHB and NKII, but also at services levels within the HBDHB. The Wāhanga Whakapakari Tamaiti (Child Development Service) has partnered with Te Wāhanga Hauora Māori particularly around the topic of FASD. Prior to the research partnership for the current study CDS and Te Wāhanga Hauora Māori had already started the conversation about how to raise FASD awareness both in health professionals and the community. Together both parties presented to iwi organisations and then at Tu Kaha 2014, which is a Māori Regional Health Conference for the lower North Island of Aotearoa New Zealand, to promote discussion around prenatal alcohol exposure. Examples of partnership through Te Tiriti o Waitangi and Māori Relationship Board provide a platform, precedent and terms of reference that assist in establishing partnerships at many levels of an organisation.

In addition, partnerships do not only occur between services or groups but also between frameworks or models of care that can be used in research and in clinical practice. Both clinical and Māori models of health such as Te Whare Tapa Whā (Durie, 1994) are being used in clinical practice within the Wāhanga Whakapakari Tamaiti (Child Development Service). In research, some Indigenous (Canada) researchers suggest “*research may include qualitative or quantitative methods as long as they are enveloped in Indigenous worldviews*” (Tonmyr &

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Blackstock, 2010, p. 137). In addition, He Awa Whiria (Braided rivers model) in Aotearoa New Zealand is an example where two bodies of knowledge (both Western Science and Kaupapa Māori) are acknowledged and are woven together to create a strong foundation for programmes and interventions (Macfarlane, Blampied, & Macfarlane, 2011). A whakataukī from Sir Āpirana Ngata (Ngata & Ngata, 1993, p. xi) describes the partnership of knowledge systems well:

*‘E tipu e rea mo ngā rā o tō ao;*

*Ko tō ringa ki ngā rākau o te Pākehā, hei oranga mo tō tinana;*

*Ko tō ngākau ki ngā taonga a ō tīpuna Māori,*

*Hei tikitiki mō tō māhunga,*

*Ko tō wairua ki te Atua, Nānā nei i ngā mea katoa’.*

(‘Grow young shoots for the future that is before you. Turn you head to the technology of the Pākehā to ensure your livelihood. Retain the teachings of your ancestors as a legacy for the generations to come. Give your spirit to God, the creator of all’).

Durie describes Ngata’s whakataukī as “*encouraging Māori to seek out knowledge derived from science and technology and to blend it with Māori customary knowledge, retaining the wider spiritual context*” (Durie, 2001, p. 3). My journey has also taught me that Maori and Pākehā epistemology need not to be perceived as mutually exclusive but instead can sit together benefiting from the strengths of both bodies of knowledge.

Te Tiriti o Waitangi, the Māori Relationship Board and service level partnership between CDS and Te Wāhanga Hauora Māori have helped create a space for the current study’s partnership to prosper. This chapter will also outline the partnership process for the current study, but first it is important to also review both the current Indigenous (Aotearoa New Zealand) literature surrounding research practice, and guidelines for research involving Māori that are already established in Aotearoa New Zealand.

### **Essential Elements of Tauwiwi/ Māori research Partnerships**

#### **Wānanga - Understand the history and current context of colonisation.**

It is the responsibility of the researcher to understand the context of Aotearoa New Zealand when analysing and considering the research information. Understanding context assists in creating a space to evaluate how colonisation has led not only to present inequities but also to highlight the strengths and resilience of Māori. Colonisation, both internationally and in New Zealand, has caused inequities in health with Indigenous people shouldering more of the burden than non-Indigenous (Hawke's Bay District Health Board, 2014; Paradies, 2016). Loss of land, a suppression of traditional laws and rituals, loss of life and unlawful imprisonment created historical and intergenerational trauma (Walker, 2004) which continues to affect many Māori today.

Colonisation, therefore, should not be considered just a 'historical' event (Gilmartin & Berg, 2007) and needs to be considered that trauma is transmitted through generations by the establishment of "*fundamental societal level structural and systemic changes brought about by the process of colonisation*" (Reid et al., 2014, p. 13). Non-Indigenous researchers need to be aware that they are embedded in a western or colonial system, and that their own frameworks and political systems may be further contributing to ongoing trauma through silencing the Indigenous voice (Christie, 2007; Ermine, 2007; NiaNia et al., 2016).

The literature has critiqued collaborative research partnerships as sometimes replicating the power imbalance within colonial relationships (Leeuw, Cameron, & Greenwood, 2012). However, this does not mean we should disregard western or Pākehā models or frameworks, but instead be mindful to ensure they are being utilised for the benefit of Māori. More importantly researchers need to position themselves for feedback, reflection and conversation with Māori community.

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For this current study it has been essential to first gain knowledge about the history of Aotearoa and the subsequent inequity that followed. Once knowledge was gained then conversation and reflection could begin within Māori partnerships to ensure the context is recognised, the findings and analysis incorporate a Māori worldview and solutions are responsive.

### **Whakawhanaungatanga - Foster relationships.**

It is important to engage with and involve the community in all stages of research (Pain, 2004). Particular emphasis in community research is given to the establishment of relationships and friendships between the researcher and Indigenous communities (Leeuw et al., 2012). Relationship building takes time. Partnerships are strengthened when parties face dilemma's and are able to find solutions using direct and honest channels of communication. Honesty and directness requires mutual trust so that either party will hear information in a positive way rather than as harsh criticism. These ways of being can only occur when either party has repeated experiences of being heard and respected.

The present study has been strengthened by the mutual trust and friendship of the research partnerships and it has been important that both the researcher and the Māori community have been located in the same geographical location so these relationships could grow in an organic way.

**Memorandum of understanding.** Documentation of responsibilities and commitments are an important part of Indigenous research partnerships (Morton Ninomiya & Pollock, 2017). Agreement of responsibilities are important especially with regard to dissemination of information. This process of consent to disseminate creates sense of trust and assists in ensuring cultural safety for the researcher.

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The present study therefore instituted a memorandum of understanding in the form of He Taumata Rangahau (see Appendix A) before this research began. He Taumata Rangahau defined responsibilities but also allowed for further endorsement and consultation, for example other community endorsement was also sought via presenting to the DHB and local community before presenting at an international conference. Formalising these responsibilities and processes in a written memorandum of understanding is critical for building trust and confidence.

**Mutual benefit.** It is important that research is built on a foundation of trusting relationships and mutual benefits and culturally based solutions (Leeuw et al., 2012; Morton Ninomiya & Pollock, 2017; Tonmyr & Blackstock, 2010). Solution focused research within the context of Māori models of health was a priority for Te Wāhanga Hauora Māori.

In the current study it was therefore important not to only focus on the prevalence of Māori and FASD, but to offer ideas and solutions that would benefit Māori. Indigenous health research requires a collective rather than individual viewpoint and therefore research information needs to be considered within a holistic, whānau model rather than only reporting on individual child characteristics. Within the current study continuous discussion around research findings with Te Wāhanga Hauora Māori ensured the researcher provided interpretations and ideas that were responsive to Māori.

### **Guidelines for Research Involving Māori**

In 2012 the Health Research Council of New Zealand published *Guidelines for Researchers on Health Research involving Māori* in recognition of the need to address matters that are relevant to Māori with a focus on advancing wellbeing for Māori in a way that “*maintains or enhances mana Māori.*” (Health Research Council of New Zealand, 2010, p. 2). The document also included *Te Ara Tika Guidelines for Māori research ethics: A framework for researchers*

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and ethics committee members as an Appendix which outlined examples of minimum standards, good practice and best practice research in accordance to the four tikanga based ethical principles. The Māori ethical framework is outlined in Figure 5 where the inner circle demonstrates best practice, the middle circle is good practice and the outer circle is minimum standard.

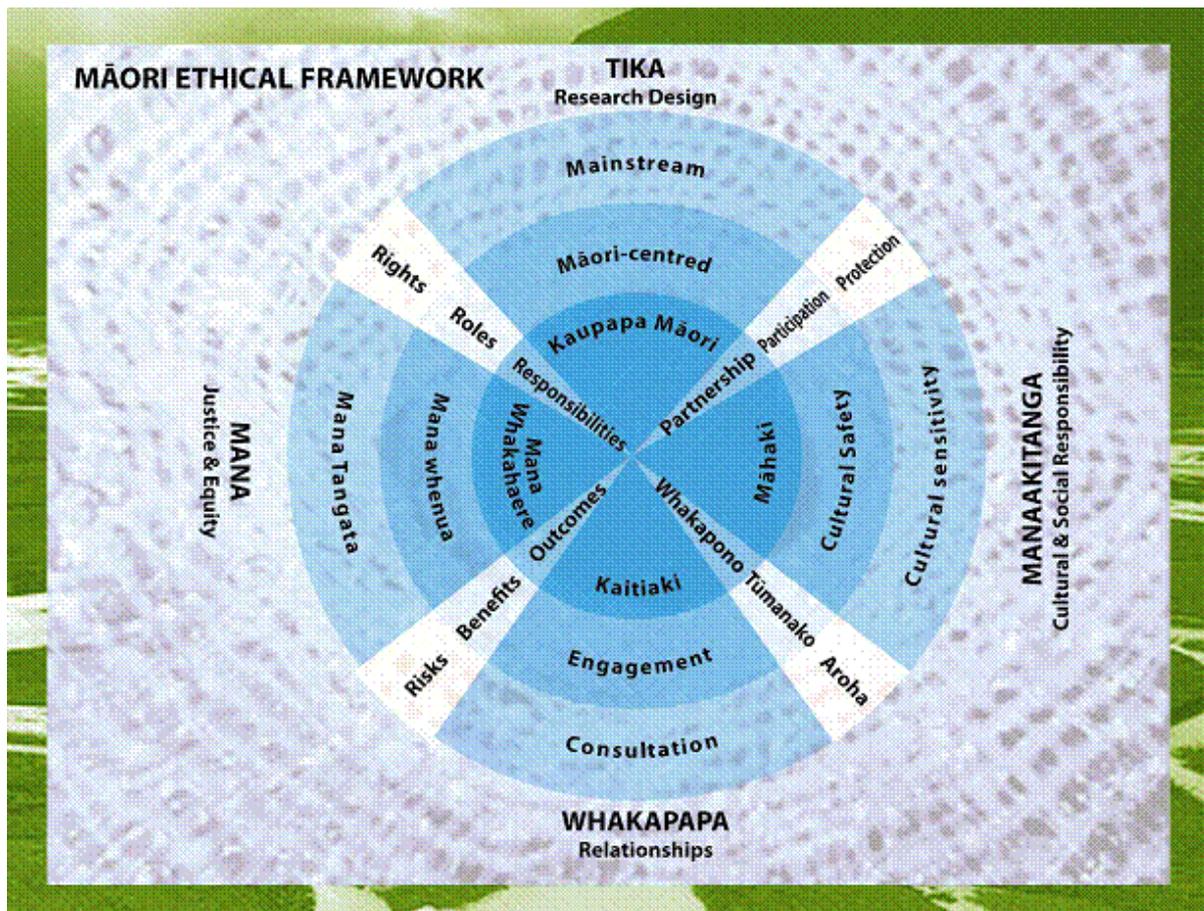


Figure 5. Māori Ethical Framework Health Research Council of New Zealand. Reprinted from “Guidelines for Researchers on Health Research involving Māori” (p. 28) by Health Research Council, 2010, Auckland, NZ. Copyright Health Research Council of New Zealand. Reprinted with permission.

The current study sought to achieve good ethical practice whilst recognising that the research design was not Kaupapa Māori. The levels of ethical practice in the current research

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project in accordance with the Māori Ethical Framework (Health Research Council of New Zealand, 2010) are summarised in Table 4.

Table 4

*Ethical practice in accordance with the Māori Ethical Framework*

| Values/Ethics | Research practice for current study   |
|---------------|---|
| Tika          | Māori Centred – Māori are significant participants and have an active role in mentoring and involvement in the analysis and application of research findings within the context of a Māori world view.  |
| Manaakitanga  | Cultural Safety – Māori partners have participated in ensuring culturally safe implementation. This has included ensuring the consent process satisfied cultural principles as well as guiding the inclusion of Māori concepts to understand research findings.   |
| Whakapapa     | Kaitiaki – Te Wāhanga Hauora Māori are research partners in the present study and have a governance role in the ‘development, execution, and monitoring of the research project’. Te Wāhanga Hauora Māori are also involved in reviewing and endorsing the dissemination of results to ensure findings are directed at enabling benefit to Māori. |
| Mana          | Mana whenua – Partnership was established at the beginning of this research process and He Taumata Rangahau recognise the authority of hapū and iwi.  |

The current study was established within a power sharing model where the coordinating investigator sought assistance to ensure research was culturally safe, ensured informed decision making and also achieved a mutual benefit to both the researcher and the community. Both parties endeavoured to act reasonably, honourably and in good faith. However overtime this partnership became more fluid and moved between Smith’s research

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models. This was evidenced by members of He Taumata Rangahau guiding and mediating the research process (Tiaki Model), the researcher feeling part of Te Wāhanga Hauora Māori (Whangai Model) and striving to create answers to health issues, such as that fit within a Te Ao Māori worldview.

Both the Māori Ethical Framework (Health Research Council of New Zealand, 2010) and Smith's (1990) models identifies mutual respect and specific roles for Māori to ensure Tauwiwi will conduct research that is responsive to Māori. It is my view that, through collaboration and partnership, clinical and Māori models of health can sit alongside each other to provide the best of both worlds for the benefit of whānau. The following section aims to outline the current literature that details essential elements of Māori and Tauwiwi (Non-Māori) research partnerships.

### **The Current Study's Collaboration Process**

The research question for the current study arose from whānau, clinicians and other professionals who were frustrated that a diagnosis of FASD did not meet criteria for disability services despite having significant neurological and adaptive impairments. This research aimed to investigate what cognitive processes were related to a person's ability to be successful in everyday life (adaptive behaviour) and was never conceptualised to be Māori focused research. Whānau expressing frustration were both Tauwiwi and Māori, however, in line with the research literature suggesting that Indigenous (Australia and Canada) people may be overrepresented in FASD (Fitzpatrick et al., 2015; Khan, Robinson, Smith, & Dillard, 2013; Popova et al., 2017), clinical experience within CDS raised an awareness that Māori whānau may also be over represented in the clinical sample of children with FASD.

The research literature has criticised FASD studies in their lack of engagement with Indigenous (Canada) communities (Di Pietro & Illes, 2014). Forming a partnership with Te

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Wāhanga Hauora Māori and ensuring a comparison group was well matched on ethnicity alongside age gender and maternal education were ways this study aimed to remedy issues raised in the literature. A He Taumata Rangahau (Research Advisory Group) was established to ensure our current study was responsive to Māori ambitions and concerns.

**Developing partnerships - He Taumata Rangahau.** At the start of the proposed research project I approached the CDS Kaitakawaenga to discuss how a partnership could be established to ensure cultural safety for both the whānau, myself and other researchers involved. As a result of these discussions Te Wāhanga Hauora Māori agreed to:

*“1) develop terms of reference for the establishment of He Taumata Rangahau [Research Advisory Committee]; 2) act as conduit in the provision of guidance and advice in terms of Māori ethics, values, and cultural imperatives; 3) engage with Tangata Whenua to support consultation processes in accordance with Ngāti Kahungunu protocols; 4) provide first contact and liaison between researcher and Māori communities as required; 5) co-ordinate any required expertise with respect to specialist matters and topics requiring Māori input”.* (Te Nahu, 2013).

The proposal of the present study led to the creation of a more formal partnership in He Taumata Rangahau (HBDHB Research Advisory Group) *“to provide the necessary pathway to ensure HBDHB staff undertaking applications for a research programme within the DHB, comply with HBDHB research policy, and in accordance with Kahungunu best practice, tikanga and kawa.”* (See Appendix A for He Taumata Rangahau Memorandum of understanding).

This present study adhered to the guidelines by consulting, early in the research design, throughout the project and continued in endorsing dissemination of results. This consultation

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has helped shape the analysis of the research findings to ensure they recognised Te Ao Māori concepts within a mainstream scientific investigation.

**Membership.** Membership of the Taumata Rangahau included; Laurie Te Nahu (Programme Administration officer, Health Improvement Directorate), Querida Whatuira-Strickland (Kaitakawaenga), Māori health Operations Team, HBDHB, Kaumātua, Koroua, Kuia and Tāngata Mātauranga from Te Wāhanga Hauora Māori. From the Wāhanga Whakapakari Tamaiti (Child Development Service) myself and Dr Kate Robertshaw were named investigators on this project and formed the other half of this partnership.

**Process.** The partnership between myself and Te Wāhanga Hauora Māori has been fundamental in the planning, implementation, and reflective processes of this study. Particular processes and actions have changed according to the stage of the research activity and are outlined in Table 5 below.

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Table 5

*Process of partnership through He Taumata Rangahau.*

| Research Stage              | Partnership process  |
|-----------------------------|--|
| Planning                    | He Taumata Rangahau reviewed the research plan and offered ideas to ensure cultural safety. There was acceptance from Te Wāhanga Hauora Māori that this was mainstream research but would be conducted and analysed with regard to Te Ao Māori.  |
| Ethics                      | He Taumata Rangahau assisted in investigating, reflecting and solving ethical issues with regard to Māori.   |
| Gathering consent           | Kaitakawaenga also supported the research by visiting whānau with myself to ensure informed consent was being gathered in a culturally safe way.   |
| Data collection             | The data was collected in a way that respected whānau. For example whānau could choose whether their tamariki (children) were assessed in the clinic, at school or at home. Parents of the FASD group were also interviewed rather than given questionnaires about their child's functioning at home.  |
| Analysis and interpretation | Members of He Taumata Rangahau reviewed and gave feedback on data analysis draft writings, papers and this dissertation. Sharing papers and discussion points from a Te Ao Māori perspective helped create a shared vision of discussion points and implications of the study findings. He Taumata Rangahau provided a platform to seek guidance and discussion with Kaumatua.   |
| Dissemination of findings   | When preliminary findings were established members from CDS and Te Wāhanga Hauora Māori collaborated and presented these findings to other HBDHB staff and Māori community in order to gain endorsement and feedback before presenting at conference. He Taumata Rangahau has provided a process for review of this thesis by Te Wāhanga Hauora Māori to ensure the duty of informed decision making continues to be satisfied. Study findings will not be presented or published without endorsement and/or co-authorship from Te Wāhanga Hauora Māori. |

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**Challenges in Tauīwi/ Māori research partnerships.** Indigenous researchers have called for increased focus on the challenges when engaging with non-Indigenous researchers or institutions as “*while conflicts and tensions are inevitable, it is how these uncomfortable moments are addressed that matters.*” (Morton Ninomiya & Pollock, 2017, p. 35). Challenges for the present study included; 1) needing time to build relationships, 2) competing priorities for Māori input, and 3) potential conflict between western/Pākehā and Māori models of health.

***Needing time to build relationships.*** Whanaungatanga is defined as a “*relationship, kinship, sense of family connection - a relationship through shared experiences and working together which provides people with a sense of belonging. It develops as a result of kinship rights and obligations, which also serve to strengthen each member of the kin group. It also extends to others to whom one develops a close familial, friendship or reciprocal relationship*” (Māori dictionary, 2017) and is an essential element of partnerships that requires time to be established. Whakawhanaungatanga was the process of building whanaungatanga (relationships) and occurred when commonality between parties was found. Furthermore, whakawhanaungatanga required time to experience consistent reliable encounters that built trust and connect people.

Difficulties can arise when the researcher is not known to the community when partnerships are requested before whakawhanaungatanga has been established. The importance of co-locality of the researcher and Māori community could not be underestimated as whanaungatanga was strengthened by pre-existing relationships. At times academic deadlines and researcher eagerness was challenged with the need to wait and discuss findings before presenting or disseminating results. Likewise ensuring cultural safety through co-visiting meant a greater level of time and co-ordination. Allowing time to build whanaungatanga and consult and co-ordinate research with Māori is vital for successful partnerships.

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*Competing priorities for Māori input.* Other challenges arose when key staff from Te Wāhanga Hauora Māori were engaged in other important work or projects. Kaitakawaenga provided an acute cultural service at HBDHB therefore when there was a clinical need for cultural support this often overrode previously planned meetings. Likewise reporting lines and managers changed when a key team member moved from the position of Te Pou Arahi to Project Liaison Officer in the Corporate Office. Support for this research project remained ongoing, but priorities and meeting times would sometimes clash and the project required patience and more co-ordination in order to engage in a considerate and yet pragmatic way. These challenges did not mean that the research was unable to continue, instead open communication and trust was required to together establish workable solutions.

*Potential conflict between western/Pākehā and Māori models of health.* There can be challenges when working with both Pākehā and Māori models of health. Western or Pākehā models of health tend to be focused around individual diagnosis which is in contrast to a Māori model of health which adopts a collective holistic model of health. Psychological models focus on formulation and the utilisation of a biopsychosocial model which does consider biological, psychological and social context of health. However our health system generally provides service on the basis of individual diagnosis. Developing collaboration between both Pākehā and Māori models of health also highlighted differences between a diagnostic/reductionistic model of health which was focused on impairment and a holistic model of health which was focused on strength and resilience. Using Māori models of health was sometimes challenging for other health colleagues and using diagnoses was sometimes challenging for those professionals who work more fully in strength and resilience models. However, again these challenges provided opportunities to recognise the merits of both models and in fact impairments and strengths could be conceptualised as being two sides of the same coin depending on the context of which the behaviour is viewed in.

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**Strengths of Tauiwi/ Māori research partnerships.** Tauiwi and Māori research partnerships did result in a number of mutual benefits which included; 1) increasing researcher knowledge of the history of Aotearoa, colonisation and Te Ao Māori 2) raising awareness of health issues and 3) providing precedence for future Tauiwi/Māori research partnerships.

***Increasing researcher knowledge of the history of Aotearoa, colonisation and Te Ao Māori.*** Close partnerships enabled opportunities where the researcher gained more knowledge about Te Ao Māori and the Māori community benefited from shared health knowledge and inclusion in decision making. Increasing researcher knowledge (Wānanga) about the history of Aotearoa, colonisation and Te Ao Māori assisted in providing ideas and solutions that were responsive and holistic. Tamariki with FASD face a number of challenges and their needs must be considered within the environmental context, both current and historical.

***Raising awareness of health issues.*** Other benefits included the researcher and Te Wāhanga Hauora Māori being involved in Hui wider than the specific research topic. Examples of this included discussing the effects of FASD with community, and giving information to Kaumātua and to question how we can raise awareness in local Marae. These discussions built awareness of FASD in the community, suggested avenues for prevention and increased understanding and compassion of those who experience brain differences due to prenatal alcohol exposure.

***Providing precedence for future Tauiwi/Māori research partnerships.*** Successful partnerships can also provide precedence for future researchers and increase confidence of engaging in a process where benefits outweigh challenges. Te Tiriti o Waitangi and national guidelines such as *Guidelines for Researchers on Health Research involving Māori* (Health Research Council of New Zealand, 2010) provide legal and academic instruction about the establishment of partnerships, however much can be learnt from documenting the process and

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practice of these guides in real life research partnerships. Understanding the steps involved in creating this research partnership, alongside recognising challenges and benefits may help to operationalise guidelines for future researchers.

### **Summary**

In the past Indigenous research was grounded in European or colonised frameworks. More recently there has been a recognition that research with Indigenous peoples must involve consultation with the community and ideally be grounded in Indigenous concepts and philosophy (Smith, 2012). For the current study Te Tiriti o Waitangi provided a platform for partnership, participation and protection of Māori. This platform was further enhanced by Māori research guidelines and gave guidance to the collaboration of this Tauīwi and Māori research partnership. Essential elements to this research partnership included; 1) Wānanga - Tauīwi understanding the history and current context of colonisation, 2) Whakawhanaungatanga - fostering relationships, 2) He Taumata Rangahau - agreed memorandum of understanding and 3) A process of mutual benefit. However challenges also arose and included; 1) Needing time to build relationships, 2) Competing priorities for Māori input and 3) Conflict between western Pākehā and Māori models of health. It was important to foster a space for open communication that assisted in solving research issues when they occurred. The bringing together of Māori and Pākehā frameworks was complex and multifaceted, but the advantages of true engagement meant children and whānau in the current study benefited from both bodies of knowledge.

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### Chapter Four: Methodology

The primary aim of this research is to examine the relationships between intellectual functioning, executive functioning, social cognition and adaptive functioning using typical neuropsychological assessments that are currently used in clinical practice with children with FASD. Analysis regarding the psychosocial complexity of children with FASD, including adverse life experiences, will also be conducted.

The main hypothesis in this research is that impairments in executive functioning and social cognition, but not IQ, will be associated with impairments in adaptive behaviour in children with FASD. In particular:

1. In the comparison group IQ, as well as executive functioning and social cognition, will predict adaptive functioning.
2. In the FASD group executive functioning and social cognition will predict adaptive functioning but not IQ.
3. In the FASD group social cognition will predict levels of adaptive functioning independently from executive functioning.
4. Adverse Childhood Experiences will predict the level of adaptive functioning for the FASD group.

This study has followed a scientific inquiry method which collected psychometric data collected from both an FASD group and a matched group of typically developing children without FASD. As noted below, care was also taken to adhering to *Guidelines for Researchers on Health Research involving Māori* (Health Research Council of New Zealand, 2010).

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### **Ethics and Process**

This research received ethical approval from the Central Health and Disability Ethics Committee on the 2<sup>nd</sup> April 2013 (13/CEN/45) and locality approval was given by the Hawkes Bay District Health Board research office. Guidelines such as the Guidelines for Researchers on Health Research involving Māori (Health Research Council of New Zealand, 2010), Ethical Guidelines for Observational Studies (National Ethics Advisory Committee, 2012), Ethical Guidelines for Health Research with Children (Peart & Holdaway, 2000, Updated in 2007 by Nicola Peart) were reviewed alongside consultation with He Taumata Rangahau when establishing the research protocol.

### **Participants**

**FASD Group.** The FASD group included 39 children (30 male / 9 female), between the ages of 8 and 12 years who had been diagnosed with FASD. Recruitment took place between May 2013 and December 2016. Participants in the FASD group were recruited during their assessment for FASD at the Developmental Assessment Programme (DAP), which is part of the Wāhanga Whakapakari Tamaiti Child Development Service (CDS) at Hawke's Bay District Health Board (HBDHB). Confirmed FASD diagnosis was made using the Canadian Guidelines (Chudley et al., 2005), via a multidisciplinary diagnostic team which included Paediatrician, Psychologist, Social Worker and Speech Language Therapist. One participant was recruited through the FASD Centre, Aotearoa which followed clinical protocol for that organisation.

For both organisations the child's Paediatrician provided child and family health information including measures of growth and facial features. Full FASD diagnostic assessment includes additional neuropsychological assessment in areas such as attention, memory, academic achievement as well as school observations and discussion of learning and

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behaviour issues with teachers and relevant professionals working with the child. Language assessments were conducted by the Speech Language Therapist.

Specific diagnoses of FASD under the Canadian Guidelines (Chudley et al., 2005) include Fetal Alcohol Syndrome (FAS), Partial Fetal Alcohol Syndrome (pFAS) and Alcohol Related Neurodevelopmental Disorder (ARND). In the current study three children were diagnosed with Partial Fetal Alcohol Syndrome (pFAS) and 36 children with Alcohol Related Neurodevelopmental Disorder (ARND). No children presented with full Fetal Alcohol Syndrome (FAS).

Children were eligible for inclusion in this study if they were aged between 8-12 years and referred for an FASD assessment as part of the DAP pathway. Forty six children and their whānau consented to be part of the FASD group. One child was excluded due to a history of traumatic brain injury, three did not meet criteria for FASD diagnosis, for two children we were unable to confirm alcohol exposure and one child experienced a severe Intellectual Disability that rendered him unable to complete neuropsychological assessment.

All participants included in the FASD group had confirmed moderate-severe alcohol exposure by retrospective report from birth mothers (49%), birth fathers (18%), extended whānau (26%) or agency documentation (7%). Prenatal alcohol exposure in the first trimester for the clinical group included 24 (62%) consuming 40+ standard drinks per week, 5 (13%) consuming 20-39 drinks per week, and 4 (10%) consuming 7-20 drinks per week. In the second and third trimester alcohol exposure for the clinical group included 15 (39%) consuming 40+ standard drinks per week, 6 (15%) consuming 20-39 drinks per week, 4 (10%) consuming 7-20 drinks per week, one (3%) consumed 2 drinks per week and 7 (18%) did not drink in the second and third trimester. Six participants (15%) had confirmed heavy prenatal exposure in pregnancy but actual quantities could not be ascertained.

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In the FASD group 82% identified as Māori (n= 32), 18% as Tauīwi (Non-Māori) (n=7). Within the clinical group, of those who identified as Māori; 16 identified as Ngāti Kahungunu.

All children in the FASD group reported English to be their main language at home. One child attended Kura Kaupapa and although English was still his main language Te Reo Māori was used where appropriate during the assessment e.g. numbers in digit span. Eleven children were prescribed regular medication and continued to take the medication on assessment days. Medication included methylphenidate for ADHD (9 children), Epilim for seizures (1 child) and Fluticasone for asthma (one child).

**Comparison Group.** The comparison group included 29 children (20 male / 9 female), between the ages of 8 and 12 years. Recruitment took place between May 2014 and December 2016. Participants that formed the comparison group responded to requests from school, community or health professionals. Exclusion criteria for the comparison group included, learning difficulties and previous neurodevelopmental or behavioural diagnosis e.g. Autism, ADHD, children with prenatal alcohol exposure of >1 standard drink per day or > 7 per week. Smoking and other drug use during pregnancy did not constitute exclusion from the comparison group.

Prenatal alcohol exposure report for the comparison group found 26 (90%) participants reported no exposure during trimester 1, 2 or 3. One participant reported drinking <1 drink per week and two participants reported drinking approximately 1 drink per week during the first trimester. In the second and third trimester one participant reported drinking <1 and one participant reported drinking 1 drink per week. As expected there was a significant difference in alcohol exposure between the FASD and comparison group for trimester 1,  $\chi^2(7) = 68.00$   $p < .001$ . and trimester 2 & 3,  $\chi^2(8) = 45.27$ ,  $p < .001$ .

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In the comparison group 72% identified ethnicity as Māori (n= 21), 27% as Tauīwi (Non-Māori) (n=8). Within the comparison group, of those who identified as Māori; 15 identified as Ngāti Kahungunu. A chi-square test of independence was performed to examine ethnicity and no group differences were found  $\chi^2(1) = 0.89, p = .34$ .

All children in the comparison group attended state schools where English is the main language. One child's family spoke Samoan at home however her English language was evaluated and she scored above criterion in the CELF Screener (see below in measures section).

Table 6 summarises key demographic information for both the FASD and the comparison group. As can be seen, the two groups did not differ significantly on age, gender, maternal tertiary education, ethnicity and socioeconomic status. There was however a significant difference in maternal secondary education, unplanned pregnancy, drug use, additional diagnoses and previous contact with other services between the FASD and comparison group.

### Measures

**Demographic and Historical Data.** Demographic and historical information was collected for both FASD and comparison groups. This included age, gender, ethnicity, iwi affiliation, maternal education, deprivation index alcohol exposure, smoking, other substance use, planned pregnancy, home language, connection with Marae, current living arrangements, number of placements, years in current placement, contact with mother and father, previous contact with services, medication, past and current diagnostic information. When maternal education level for the FASD group was unknown they were given a code of no education to treat the data as conservatively as possible when analysing group differences. Deprivation Index was based on the child's home address at the time of assessment and used NZDep2013 index of deprivation scale. The NZDep2013 index uses census data, relating to income, home

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ownership, employment, qualifications, family structure housing access to transport and communications, to provide a deprivation score for geographical areas, normally containing a population of around 60-110 people (Atkinson, Salmond, & Crampton, 2014). Parents and caregivers also rated the child's strengths.

For the FASD group information collected from the Wāhanga Whakapakari Tamaiti (Child Development Service) assessment process was coded under the Adverse Child Experience Survey (ACEs) (Felitti et al., 1998). The Centers for Disease Control and Prevention in the Kaiser Permanente Adverse Childhood Experiences (ACE) Study defined Adverse Child Experiences as: 1) Abuse (Emotional, Physical, Sexual), 2) Household Challenges (Family violence, household substance abuse, household mental illness, parental separation, criminal member in the household), 3) Neglect (Emotional, Physical) to give an indication of an ACEs score (Centers for Disease Control and Prevention, 2016). Scores of >4 have been found to be associated with increased health risks such as alcohol and drug issues, depression, suicide, sexually transmitted diseases and suicide (Dube et al., 2003; Felitti et al., 1998).

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Table 6

*Demographic information for comparison and FASD groups*

| Variable   | FASD<br>N=39 | Comparison<br>N=29 | <i>t-test</i><br><i>t(df)</i> | <i>Chi Square</i><br><i>x<sup>2</sup>(df)</i> | <i>p</i> |
|--|--------------|--------------------|-------------------------------|---|----------|
| Age (years), Mean (SD)                                   | 9.51 (1.12)  | 9.65 (1.12)        | -0.49 (66)                    |   | .77      |
| Gender (% male)  | 30(77%)      | 20(69%)            |                               | 0.54(1)                                       | .46      |
| <b>Maternal Secondary Education</b>                      |              |                    |                               | 8.14(3)                                       | .04      |
| No school qualifications (%)                             | 28 (72)      | 11 (38)            |                               |   |          |
| NCEA level 1 or equivalent (%)                           | 4 (10)       | 8 (28)             |                               |   |          |
| NCEA level 2 or equivalent (%)                           | 5 (13)       | 8 (28)             |                               |   |          |
| NCEA level 3 or equivalent (%)                           | 2 (5)        | 2 (7)              |                               |   |          |
| <b>Maternal Tertiary Education</b>                       |              |                    |                               | 3.12 (3)                                      | .37      |
| No tertiary qualification (%)                            | 31 (80)      | 23 (79)            |                               |   |          |
| Nation Cert level 1-4 (%)                                | 6 (15)       | 3 (10)             |                               |   |          |
| Nation Cert level 5-6/Diploma (%)                        | 2 (5)        | 1 (3)              |                               |   |          |
| Bachelor's Degree (%)                                    | 0            | 2 (7)              |                               |   |          |
| Unplanned pregnancy (%)                                  | 31(80%)      | 18(59%)            |                               | 23.11(2)                                      | <.001    |
| Don't know if pregnancy planned (%)                      | 8(20%)       | 0(0%)              |                               |   |          |
| <b>Other substance use</b>                               |              |                    |                               |   |          |
| Cigarettes (%)   | 36 (92)      | 3 (10)             |                               | 49.09(2)                                      | <.001    |
| Cannabis (%)   | 16 (41)      | 1 (3)              |                               | 13.78(2)                                      | .001     |
| Methamphetamine (incl. 'P') (%)                          | 10 (26)      | 0                  |                               | 9.76(2)                                       | .008     |
| Opiates (%)  | 2 (5)        | 0                  |                               | 2.33(2)                                       | .31      |
| Solvents (%)   | 1 (3)        | 0                  |                               | 1.53(2)                                       | .47      |
| <b>Additional diagnosis after assessment</b>             |              |                    |                               |   |          |
| Intellectual Disability (%)                              | 15 (39)      | 0                  |                               |   |          |
| ADHD (%)   | 24 (62)      | 0                  |                               |   |          |
| Language Disorder (%)                                    | 32 (82)      | 0                  |                               |   |          |
| Anxiety (%)  | 3 (8)        | 0                  |                               |   |          |
| Depression (%)   | 2 (5)        | 0                  |                               |   |          |
| Attachment Difficulties (%)                              | 10 (26)      | 0                  |                               |   |          |
| <b>Previous contact with services</b>                    |              |                    |                               |   |          |
| Resource Teacher of Learning and<br>Behaviour (RTLB) (%) | 35 (90)      | 0                  |                               |   |          |
| Ministry of Education (%)                                | 18 (46)      | 0                  |                               |   |          |
| Seen by Paediatrician (%)                                | 39 (100)     | 17                 |                               |   |          |
| Child Adolescent Mental Health (%)                       | 1 (3)        | 3                  |                               |   |          |
| Oranga Tamariki (CYFs) (%)                               | 21 (54)      | 0                  |                               |   |          |
| Non-government organisations (%)                         | 15 (39)      | 0                  |                               |   |          |

**Prenatal Alcohol Exposure (PAE) Data.** For 19 participants information regarding prenatal alcohol exposure was gathered directly from the birth mothers via retrospective report. For other participants this information was gathered via birth fathers, extended whānau and agency documentation. When report was not from the birth mother we ensured prenatal alcohol report was triangulated from a number of sources (e.g. other whānau members, Child Youth and Family Service (CYFS) documentation, and health records). For the comparison group information came from birth mothers (N = 27) and birth fathers (N = 2). Prenatal alcohol exposure was collected in the same manner that was collected for the Growing up in New Zealand Longitudinal study (GUiNZ), which is a longitudinal study tracking the development of 7,000 New Zealand children from pregnancy into childhood (Morton et al., 2010) to allow for comparison. The question asked in the GUiNZ study was “On average how many drinks of alcohol (Beer, wine or spirits) did you drink 1) before you knew you were pregnant 2) in the first three months of pregnancy and 3) after the first three months of pregnancy”.

**Neuropsychological Data. *General Intellectual Functioning.*** General Intellectual Functioning (IQ) for the FASD group was assessed using the Wechsler Intelligence Scale for Children 4th edition (WISC-IV) (Wechsler, 2003). An abbreviated measure of IQ, Wechsler Abbreviated Scale of Intelligence 2nd edition (WASI-II) (Wechsler & Hsiao-pin, 2011), was used for the comparison group to ensure the time commitment from the children was not onerous.

*WISC-IV.* The WISC-IV core subtests were administered which provided composite scores for; Perceptual Reasoning Index (PRI; Block Design, Picture Concepts, Matrix Reasoning), Verbal Comprehension Index (VCI; Similarities, Vocabulary, Comprehension). Working Memory Index (WMI; Digit Span, Letter Number Sequencing) and Processing Speed

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Index (PSI; Coding, Symbol Search). The WISC-IV has adequate internal consistency for composite indices and FSIQ (0.88-0.97) and adequate test-retest reliability (0.85-0.96) (Wechsler, 2003).

The WISC-IV is readily used for both clinical and research purposes and has been used in adolescents who have experienced early life maltreatment (Vasilevski & Tucker, 2016), children with FASD (Boseck et al., 2014; Enns & Taylor, 2016; Gross, Deling, Wozniak, & Boys, 2014; Lewis et al., 2015; Lindinger et al., 2016; Mattson et al., 2013; Nash et al., 2013), children prenatally exposed to alcohol (Glass et al., 2013; Nguyen et al., 2014) and children with other developmental disorders such as Autism Spectrum Disorder (ASD) (Akbar, Loomis, & Paul, 2013; McDonald et al., 2014), Attention Deficit Hyperactivity Disorder (ADHD) (Kofler et al., 2011; Marton, Wiener, Rogers, Moore, & Tannock, 2009; Tanabe, Whitaker, O'Callaghan, Murray, & Houskamp, 2014; Thaler, Bello, & Etcoff, 2013), Traumatic Brain Injury (TBI) (Levan, Baxter, Kirwan, Black, & Gale, 2015), extreme prematurity (Mangin, Horwood, & Woodward, 2017) and 'giftedness' (Tanabe et al., 2014). The WISC-IV has been used within a New Zealand cohort (16% Māori or Pacific Nation and 84% Pākehā or other ethnicities) to investigate whether iodine supplementation improves cognition (Gordon et al., 2009).

*WASI-II.* In the comparison group, the Wechsler Abbreviated Scale of Intelligence 2nd edition (WASI-II) (Wechsler & Hsiao-pin, 2011) subtests Matrix Reasoning and Vocabulary were used to estimate IQ. The WASI-II was used instead of the WISC-IV to shorten assessment time whilst providing a reliable estimate of IQ. For a child population internal consistency for the WASI-II FSIQ based on two subtests was adequate at 0.93 (Wechsler & Hsiao-pin, 2011). The test-retest reliability was also adequate at 0.89 although sample size was relatively small for test-retest reliability (7-12 participants for each year of the child population) (Wechsler & Hsiao-pin, 2011). The WASI-II has also been used extensively in research to

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estimate general cognitive ability. Populations includes children with posttraumatic stress disorder (MacDonald, Ellis, Pulsifer, & Lyons, 2015; Saltzman, Weems, & Carrion, 2006), ADHD (Bunford et al., 2015; Marton et al., 2009), Autism Spectrum Disorder (ASD) (Hollocks et al., 2014; Semrud-Clikeman, Fine, & Bledsoe, 2014), autism (Ratto et al., 2016), TBI (Schrieff-Elson, Thomas, Rohlwink, & Figaji, 2015) and when examining the relationship between general intelligence and self-control (Meldrum, Petkovsek, Boutwell, & Young, 2017). The WASI has been used in child and adolescent research within New Zealand, but again the participants have been predominantly Pākehā (Harvey et al., 2007; Jack, Leov, & Zajac, 2014; Tan, Healey, Schaugency, Dawes, & Galland, 2014; Willcock, Imuta, & Hayne, 2011).

***Executive Functioning.*** *NEPSY-II: A developmental neuropsychological assessment* (Korkman, Kirk, & Kemp, 2007); *Animal Sorting and Inhibition subtests.* The Animal Sorting task involves the child sorting eight cards into two groups of four cards in using different and novel sorting criteria e.g. big/small animals, sun/rain, animals with stripes/no stripes. This task measures cognitive flexibility, categorisation, and set shifting. Internal consistency for Animal Sorting was adequate in children aged 12 and under (0.70-0.96) although test-retest reliability was slightly lower (0.60-0.75) (Korkman et al., 2007).

The Inhibition subtest involves three tasks (naming, inhibition and switching) over two conditions (shapes and arrows). The naming task requires the child to look at a series of black and white shapes or arrows and name either the shape or direction of the arrow. The inhibition task requires the child to inhibit the automatic response and name the *alternate* shape or direction of the arrow. The switching task involves naming the automatic/correct response when the shape is black and providing an alternate response when the shape is white. Inhibition assesses a child's mental control and ability to stop an automatic response. The inhibition task has been found to show moderate internal consistency (0.48-0.74) and moderate test retest

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reliability (0.35-0.54) although there the sample size for test retest was relatively small (N = 68) (Korkman et al., 2007). The NEPSY II Inhibition was chosen because it did not require reading and therefore would not be influenced by a child's literacy level.

The NEPSY-II has been utilised in research involving children with FASD (Enns & Taylor, 2016; McLachlan et al., 2015; Nash et al., 2014; Rasmussen et al., 2013; Wozniak et al., 2016), prenatal alcohol exposure (Autti-Rämö et al., 2002; Korkman, Kettunen, & Autti-Rämö, 2003; Panczakiewicz et al., 2016), ASD (Akbar et al., 2013; Barron-Linnankoski et al., 2015), TBI (Schrieff-Elson et al., 2015) and extreme prematurity (Logan et al., 2017; Scott et al., 2017). The NEPSY has been used in New Zealand research to investigate childhood TBI (Thickpenny-Davis, Ogden, & Fernando, 2005) but with primarily Pākehā participants. Other research in New Zealand has used the NEPSY-II to investigate ADHD but they have been with pre-school children (Hatch, Healey, & Halperin, 2014; Miyahara, Healey, & Halperin, 2014).

*Delis-Kaplan Executive Functioning System (D-KEFS, Delis, Kaplan, & Kramer, 2001); Tower Test.* The Tower test from the Delis-Kaplan Executive Functioning System requires the child to move five discs to target positions on three pegs in a prescribed number of moves with rules to which the child must adhere. The Tower test measures non-verbal planning, impulsivity and ability to work towards a goal. Internal consistency for children 8-12 years was moderate/high at (.56-.84) with the lower .56 score being at the 8 year age group (Delis et al., 2001). The test-retest reliability was moderate for 8-19 years at .51 (Delis et al., 2001). The D-KEFS Tower test has been used in research with children and adolescents with FASD (Astley et al., 2009b; Enns & Taylor, 2016; Mattson et al., 2013; Rasmussen & Bisanz, 2009), prenatal alcohol exposure (Glass et al., 2013; Mattson et al., 1999; Nguyen et al., 2014), adolescent aggression (Fatima & Sharif, 2016), TBI (Tonks, Williams, Frampton, Yates, & Slater, 2007), adolescents who were preterm (Luu, Ment, Allan, Schneider, & Vohr, 2011), ASD (Akbar et al., 2013; Fitch, Fein, & Eigsti, 2015) and young adults with ASD (Brady et

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al., 2017). No evidence was found for research using the D-KEFS Tower task with New Zealand children or adolescents.

**Communication.** Communication skills in the FASD group were assessed by the CDS Speech Language Therapist using the Clinical Evaluation of Language Fundamentals 4th edition (CELF-4) (Semel, Wiig, & Secord, 2003). The SOCIAL Model (Beauchamp & Anderson, 2012b; 2010) includes receptive and expressive language and this was able to be ascertained using the CELF-4. The comparison group were administered the CELF-Screener (Semel, Wiig, & Secord, 2004) by the psychology researcher to provide a general assessment of language ability and screen for possible language disorders in the comparison group.

*Clinical Evaluation of Language Fundamentals 4th edition (CELF-4).* The CELF-IV assesses core language skills in the following subscales: Receptive Language Scale, Expressive Language Scale, Language Content, Language Structure, Language Working Memory as well as providing a total core language score (Semel et al., 2003). Core language and indices scores demonstrate adequate test re-test reliability (0.77-0.94) with the Core language score being at the 0.90 level and adequate internal consistency (0.85-0.97) for children between the ages of 8 – 12 years (Semel et al., 2003). The CELF-4 has been used in adolescents experiencing mental health issues (Im-Bolter, Cohen, & Farnia, 2013), children with heavy prenatal exposure (McGee, Schonfeld, et al., 2008), children with Autism or Asperger's disorder (Akbar et al., 2013; Koning & Magill-Evans, 2001; McCann, Peppé, Gibbon, O'Hare, & Rutherford, 2007), ADHD (Marton et al., 2009) paediatric traumatic brain injury (Ligeois et al., 2013), and children who were born preterm or with very low birth weight (Reidy et al., 2013).

The CELF-4 has also been used in New Zealand research studies but in some studies participants have been predominantly Pākehā (Kirk & Gillon, 2009) or did not report ethnicity (Moran, Kirk, & Powell, 2012). However, a recent study into hearing, auditory processing and

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language utilised the CELF-4 as an assessment of language impairment (Lount, Purdy, & Hand, 2017) which included 52% (N = 17) Māori youth offenders and 41% (N = 16) comparison participants.

*CELF-Screener.* For children under 13 years the CELF-Screener scores are highly correlated with the CELF-4 Core Language Scores (0.75) and is therefore a good comparison test to use with a FASD group who were administered the full CELF-4 test (Semel et al., 2004). The screening test analyses scores as being above or below a criterion set by age. Normed means and standard deviations are provided in test material and therefore comparison raw scores were able to be converted into z-scores to provide a continuous measure of language skills.

For children under 13 years the CELF-screener shows adequate test-retest reliability for (0.89-0.90) and internal consistency (0.70-0.72) (Semel et al., 2004). The CELF screener has been used to in children with autism (Baum, 2012; Frye et al., 2016), ADHD (Cordier, Munro, Wilkes-Gillan, & Docking, 2013), auditory processing disorder (Kreisman, John, Kreisman, Hall, & Crandell, 2012) but has not yet been used in paediatric FASD or children with prenatal alcohol exposure research. In New Zealand the CELF-screener has been used to investigate the relationship between socio-economic status and school age language (Van Dulm & Southwood, 2016) and appears to be a good screen for severe speech-language impairments in school age children (Musgrave, 2007).

*Social Cognition.* *The Test of Problem Solving-3 Elementary (TOPS-3, Bowers, Huisinigh, & LoGiudice, 2005).* The Test of Problem Solving-3 Elementary encompasses a number of cognitive processes such as executive functioning, language and social-emotional thinking. For the purposes of this study however the TOPS-3 will be considered under the heading social-emotional cognition as it requires a child to analyse everyday social situations.

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The Test of Problem Solving 3rd edition (TOPS-III) requires children to look at a photo depicting a social situation and then answer a series of questions about each photo. There are 18 photos in total. Questions are scored (0,1,2) and skills are analysed according to the subscales: Making Inferences, Sequencing, Negative Questions, Problem Solving, Predicting, and Determining Causes and a score for the Total test performance. Test-retest reliability was adequate at the total test score level (0.84) with moderate internal consistency at the subtest score level (0.56-0.69) (Bowers et al., 2005). The TOPS-3 was also strongly correlated with a Social Processing Interview based on a measure established by Dodge et al. (2002) (McGee, Bjorkist, Riley, et al., 2009). The TOPS-3 is used clinically in assessing children with FASD (Rasmussen et al., 2010), in research with children who have prenatal alcohol exposure (McGee, Bjorkist, Price et al., 2009) as well as children with ASD (Demopoulos, Hopkins, & Davis, 2013; Stichter, O'Connor, Herzog, Lierheimer, & McGhee, 2012).

*Social Cognitive Skills Test (SCST, Van Manen, Prins, & Emmelkamp, 2009).* The Social Cognitive Skills Test (SCST) assesses social reasoning skills. The SCST was purchased in Dutch from Bohn Stafleu van Loghum, however this test has been used in English for research purposes (Coleman, Hare, Farrell, & Van Manen, 2008) and Bohn Stafleu van Loghum provided the English translation for the current study. The SCST consists of seven social stories that are presented both visually (cartoon) and verbally (via a story). The child is then asked eight questions about the story which align with social development skills that develop between 4-12 years. The SCST was chosen because it was able to assess social skills from younger developmental age. In addition, many other social reasoning assessment tools for children in middle childhood and adolescents rely on verbal vignettes. In the current study the children in the FASD group had low language skills alongside significant developmental difficulties therefore the visual supports and young developmental baseline age (4-5 years) of the SCST best suited this research population.

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The tool uses Selman and Byrne (1974) four developmental stages of social and emotional development (see Table 1) which corresponds to eight developmental levels defined by Gerris (1981). In the test there is one question for each of these developmental levels per story. Validity and reliability evidence was calculated using a sample of reasonable size ( $N = 2264$ ) and internal consistency was shown to be adequate at the total score level (0.95) and (0.78-0.91) at the four developmental levels set by Selman and Byrne (1974; Van Manen et al., 2009) with a Dutch population. Test–retest reliability was also adequate at the total score level (0.82) and (0.71-0.79) at the four developmental levels (Van Manen et al., 2009). There appears to be some evidence of construct validity with aggressive children scoring poorer on the SCST than non-aggressive children (Van Manen et al., 2001). The SCST has been used in research with childhood aggression and oppositional behaviour (Muris, Meesters, Vincken, & Eijkelenboom, 2005; Van Manen et al., 2001) and children with autism spectrum disorders (Coleman et al., 2008).

*Diagnostic Analysis of Nonverbal Accuracy (DANVA-2, Nowicki & Duke, 1994).* The SCST has an emotional recognition stage however the stimuli are cartoons and do not have the range of subtle facial emotional expressions seen in people. The Diagnostic Analysis of Nonverbal Accuracy (DANVA-2) - Facial recognition scale (Nowicki & Duke, 199) has been used widely in research and provides an assessment of emotion recognition and labelling using photos of children and adults. The DANVA – facial recognition test has two subsets, an adult subset and a child subset. Each subset has 24 stimuli and requires participants to identify the facial emotion as being; happy, sad, angry, or fearful (scared). There are six of each facial emotions in each subset. Half of the emotions are rated as high intensity and half as low intensity. The DANVA -2 has been used with a variety of individuals differing in age, race/nationality, gender, psychological disorders and levels of intelligence (Nowicki, 2010). The DANVA-2 Facial Recognition Scales have also shown evidence of adequate internal

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consistency (0.71-0.90) although slightly lower consistency for children below third grade (Nowicki, 2010). The DANVA-2 Facial Recognition has also demonstrated adequate test-retest reliability (0.74-0.90), although lower test-retest scores were found for preschool children (Nowicki, 2010). These scales also showed adequate convergent and discriminant validity with the DANVA-2 Facial recognition found to be unrelated to intelligence scores (Crowe, Beauchamp, Catroppa, & Anderson, 2011; Nowicki, 2010). The DANVA-2 has been used in children with FASD (Kerns et al., 2016), ASD (Berard, 2014; Demopoulos et al., 2013), learning disabilities (Petti, Voelker, Shore, & Hayman-Abello, 2003), chromosomal disorders (Shashi et al., 2012), and TBI (Bonner et al., 2008; Tlustos et al., 2011) and childhood psychopathology (Guyer et al., 2007).

None of these social cognition tests have been used within New Zealand child and adolescent research populations.

***Adaptive functioning data.*** *Vineland II Adaptive Behaviour Scales* (Sparrow, Cicchetti, & Balla, 2005). The parents/caregivers in the FASD group were administered the Vineland II via structured interview, whereas the comparison group completed the parent/caregiver questionnaire. Use of structured interview to assess adaptive behaviour for clinical purposes has been endorsed due to the increased depth, breadth and reliability of information gathered in this manner (Tassé, 2009). This assessment (structured interview and questionnaire) examines the child's skills required for everyday living at home. There are three domains: Communication (Receptive, Expressive, and Written), Daily Living skills (Personal, Domestic, and Community) and Socialisation (Interpersonal relationships, Play and Leisure, Coping) with an overall Adaptive Behaviour Composite score. Scores for the three main domains and the composite scores are converted to standard scores with a mean of 100 and standard deviation of 15. The parent/caregiver versions also include a scale of behaviour which is comprised of internalising behaviour (e.g. anxiety, avoidant, sad) externalising behaviour (impulsive,

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aggressive, loses control) and a total maladaptive behaviour score. The Vineland II – Parent Version (combined interview and questionnaire forms) has good internal consistency (0.83-0.97) at the total composite and domain level scoring level for children in the 8-12 year age range. The Vineland II – Parent Version also has good evidence for test-retest reliability (8-12 years) for the Adaptive Behaviour Composite (0.93) and for the three main domains (0.82-0.91).

Adaptive functioning information for the FASD group was also gathered via school. Their teachers completed a Teacher Version of the Vineland II questionnaire which included different questions but the same three domains of Communication, Daily Living Skills and Socialisation. However Daily Living Skills subdomains are adjusted to Personal, Academic and School Community. The Vineland II – Teacher Version has good internal consistency (0.93-0.98) at the total composite and domain level scoring level for the 8-12 year age range. The Vineland II has been shown to have good evidence for test-retest reliability (8-12 years) for the Adaptive Behaviour Composite (0.93) and for the three main domains (0.78-0.88).

The Vineland-II has been used in research examining children with FASD (Boseck et al., 2014; Fagerlund et al., 2012; Goh et al., 2016; Kerns et al., 2016; McLachlan et al., 2015; O'Connor et al., 2006), prenatal alcohol exposure (Brusati, 2015; Crocker et al., 2009; Panczakiewicz et al., 2016; Quattlebaum & O'Connor, 2013; Whaley et al., 2001), ADHD (Balboni, Incognito, Belacchi, Bonichini, & Cubelli, 2017; Boseck et al., 2014; Charman, Carroll, & Sturge, 2001), autism (McDonald et al., 2015; Ratto et al., 2016), childhood stroke (Greenham et al., 2017), preterm and very low birthweight (Fjørtoft et al., 2015) and externalising behaviour problems (C. Clark, Prior, & Kinsella, 2002; Farmer et al., 2015).

The Vineland II has not been used widely in New Zealand research however it was included to review the outcomes of an intervention programme in a small cohort of adults with

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forensic history and Intellectual Disability (Sakdalan, Shaw, & Collier, 2010) and small cohort of New Zealand children with autism to examine the effects of adaptive communication methods (Achmadi et al., 2014).

### **Procedure**

**Data collection process.** The research protocol was established with consultation from He Taumata Rangahau as part of the research partnership with Te Wāhanga Hauora Māori (HBDHB). A standardised approach was taken in the administration of the assessments. However, for all tamariki and whānau, especially in the FASD group, time was taken to build a relationship and establish connections prior to the assessment process. An information sheet and consent form were given to participants (parents/guardians) to ensure they knew of the study protocol and their accompanying rights. The information sheet was often read aloud to the parents/guardians and children to ensure their understanding of the research and their rights. Informed consent was gained from the parents/guardians and assent was given by the children. Whānau were encouraged to take time to think about participation and discuss with other whānau members. Information was given in English as all of the study participants stated English as their first language. Initially the Kaitakawaenga from Te Wāhanga Hauora Māori (HBDHB), as part of He Taumata Rangahau, visited Māori whānau with the researcher to ensure cultural safety for both participants and the researcher. When the Kaitakawaenga was satisfied of cultural safety and that research processes respected whānau, she no longer visited with the researcher.

**FASD Group.** Demographic and historical information, including ACEs data, was collected using a combination of interview and file/documentation review (see Appendix D for templates). Neuropsychological assessments were generally conducted over 2-3 sessions at school or in the clinic depending on the preference of the whānau. Assessment sessions were approximately 2 hours duration with breaks. Children were monitored for fatigue and the child

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was offered breaks or the session was stopped when it was not in the best interests of the child to continue. Effort was made to ensure the neuropsychological measures for this research occurred at approximately the same position in the assessment session. Adaptive functioning data was collected via structured interview and whānau in the FASD group could choose whether they were interviewed at home or in the clinic. The parent-rated adaptive functioning interview was usually between 1-2 hours in duration and most interviews were completed within one appointment. Teacher-rated adaptive functioning was collected via questionnaire.

***Comparison Group.*** Assessment of comparison participants required only one session either at home or in the clinic depending on the preference of whānau. Demographic and historical information was collected via interview. Neuropsychological assessment was conducted within 2-2 ½ hours with breaks offered. Parents of comparison group children were given the Vineland II Parent questionnaire to complete. Comparison group parents completed this questionnaire whilst their child was participating in the assessment or they took the questionnaire home and returned it via mail. The comparison group children were given a \$20 book voucher and their whānau was given a \$20 supermarket voucher as koha in order to thank them for their time and participation.

**Data analysis.** All analyses were conducted in SPSS version 24.0 for IBM. Frequencies and descriptive statistics were performed to examine demographic information, IQ, executive functioning, social cognition, ACEs and adaptive functioning (composite and domain scores). Descriptive statistics for psychosocial factors such as socioeconomic status, living arrangements, resilience and adverse childhood experiences were conducted to investigate psychosocial complexity.

Social cognition tasks (TOPS-3, SCST, and DANVA) and executive functioning tasks (Animal Sorting, Inhibition and Tower test) were analysed separately and also as a composite

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executive functioning (EF-COG) and social cognition (SC-COG) score. The z score for each measure was calculated and the summation of the z scores for each variable (executive functioning and social cognition) formed the composite score. The DANVA- Facial Recognition Task provided two z scores for both the child and adult recognition tasks.

Assumptions of skewness and kurtosis was violated for teacher-rated Adaptive Behaviour (Skewness of 2.02 ( $SE = 0.39$ ) and Kurtosis 9.06 ( $SE = 0.77$ )); teacher Daily Living Skills, (Skewness of 2.315 ( $SE = 0.39$ ) and Kurtosis 10.12 ( $SE = 0.77$ )); and teacher Socialisation (Kurtosis 3.90 ( $SE = 0.77$ )). Winsorization was conducted to address an extreme score thus correcting the kurtosis and skewness of these variables and therefore allowing for the use of parametric tests.

T-tests were then employed for continuous data to examine between group (FASD and Comparison) differences for all variables. If Levene's Test was statistically significant at  $p < 0.05$  then appropriate adjustments were made to degrees of freedom. Effect size for t-Tests are reported using Cohen's  $d$  (small = 0.2 medium = 0.5 and large = 0.8) (Cohen, 1992). Chi Square was used for between group analyses of categorical data.

Within group Pearson product moment correlations  $r$  (small = 0.1, moderate = 0.30, large = 0.50) (Cohen, 1992) were performed to investigate relationships between IQ, parent/caregiver and teacher adaptive functioning and ACES information. Relationships at the composite level directed further detailed analysis. Once the assumptions for multiple linear regression were satisfied, (Field, 2013) a multiple linear regression was conducted to investigate predictors of Adaptive functioning.

Field (2013) outlines sample size guidelines, utilising Cohen's (1988) benchmark of 0.8 power, which posits a sample size of 36 should give 80% power to detect a large effect size when three predictors are entered into a multiple linear regression model. The current research

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sample size of 39 for the FASD group should give adequate power to detect a large effect size in a multiple linear regression model with three predictors for the FASD group.

Three children in the FASD group did not have parent/caregiver-rated adaptive behaviour data and a different set of three children in the FASD group did not have teacher-rated adaptive behaviour data. Therefore, analysis related to adaptive functioning was conducted on 36 children with FASD and 29 comparison group children.

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## Chapter Five: Results

### Key psychosocial factors linked to adaptive functioning

The distribution of children in the FASD and comparison groups on a number of psychosocial factors that may be linked to adaptive functioning for each group are summarised in Table 7.

**Socio-economic status.** Many children in the FASD and comparison groups live in high deprivation areas with 76% of comparison group children and 72% of children with FASD, living in areas with a decile rating of 8 or higher (10 = highest level of deprivation and 1 = least deprivation). The Deprivation index was negatively skewed for both groups; skewness of; -1.24 (SE = 0.38) and kurtosis of 0.65 (SE = 0.74) for the FASD group, and skewness of; -1.14 (SE = 0.44) and kurtosis of 0.91 (SE = 0.85) for the comparison group. To examine whether the FASD children lived in higher deprivation areas than the comparison group children, a chi-square test was conducted. In order to conduct a valid Chi-square test, deciles were collapsed into low deprivation (Deciles 1-5) and high deprivation (Deciles 6-10). There was no significant difference in the frequency of children living in high deprivation areas between the two groups ( $\chi^2_{(1)} = 0.37, p = .54$ ). There were no significant associations between deprivation index level and IQ or adaptive functioning measures in either the comparison or FASD group (all p-values > .12). This may, however, have been due to the limited spread in deprivation index scores.

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Table 7

*Distribution of FASD and comparison group children on psychosocial factors linked to adaptive functioning.*

| Variable                                    | FASD<br>N=39 | Comparison<br>N=29 | <i>t</i> -test<br><i>t</i> | <i>Chi</i><br><i>Square</i> | <i>p</i> |
|---|--------------|--------------------|----------------------------|-----------------------------|----------|
| <b>Deprivation Index</b>                    |              |                    |                            |                             |          |
| Deciles 1-4 (%)                             | 4 (10)       | 3 (10)             |                            | 0.37                        | .54      |
| Deciles 5-6 (%)                             | 6 (15)       | 2 (7)              |                            |                             |          |
| Deciles 7-8(%)                              | 6 (15)       | 12 (41)            |                            |                             |          |
| Deciles 9-10 (%)                            | 23 (59)      | 12 (41)            |                            |                             |          |
| Unplanned pregnancy (%)                     | 31 (80)      | 17 (59)            |                            | 23.11                       | <.001    |
| Don't know if pregnancy planned (%)         | 8 (20)       | 0                  |                            |                             |          |
| Contact with mother (%)                     | 26 (67)      | 27 (93)            |                            | 6.76                        | .009     |
| Contact with father (%)                     | 26 (67)      | 28 (96)            |                            | 9.09(1)                     | .003     |
| <b>Current Living arrangements</b>          |              |                    |                            |                             |          |
| Both birth parents (%)                      | 6 (16)       | 16 (55)            |                            |                             |          |
| Live with mother (%)                        | 9 (23)       | 11 (38)            |                            |                             |          |
| Live with father (%)                        | 4 (10)       | 2 (7)              |                            |                             |          |
| Whānau (%)                                  | 13 (33)      | 0                  |                            |                             |          |
| Adopted (%)                                 | 1 (3)        | 0                  |                            |                             |          |
| Caregiver (%)                               | 4 (10)       | 0                  |                            |                             |          |
| Youth Residence (%)                         | 2 (5)        | 0                  |                            |                             |          |
| Number of Placements – Mean (SD)            | 2.28 (1.38)  | 1.03 (0.18)        | -5.60 <sup>a</sup>         |                             | <.001    |
| Years in current placement - Mean (SD)      | 6.5 (3.70)   | 9.6 (1.12)         | 4.94 <sup>a</sup>          |                             | <.001    |
| <b>Adverse Childhood Experiences (ACEs)</b> |              |                    |                            |                             |          |
| ACEs score 0 (%)                            | 1 (3%)       | -                  |                            |                             |          |
| ACEs score 1 (%)                            | 9 (23%)      | -                  |                            |                             |          |
| ACEs score 2-3 (%)                          | 8 (20%)      | -                  |                            |                             |          |
| ACEs score 4-5 (%)                          | 11 (28%)     | -                  |                            |                             |          |
| ACEs score 6-8 (%)                          | 10 (26%)     | -                  |                            |                             |          |

Note: <sup>a</sup> Adjusted for degrees of freedom due to unequal variances.

**Current and historical living arrangements.** A total of 82% of children with FASD were living with whānau, including 33% with one birth parent and 15% with both birth parents. In the FASD group 67% of children had contact with their birth mother and similarly 67% had contact with birth father. Of these children 82% had contact with either their birth mother or

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birth father. In addition, 64% of the children in the FASD group had experienced more than one placement (31% 2 placements, 28% 3-4 placements, and 5% 6 placements). However, children in the FASD group had experienced greater level of stability in the later years with most children residing in their current placement for at least three years ( $M = 6.54$ ,  $SD = 3.70$ ). It was reported that 26% of the birth mothers and 31% of the birth fathers had experienced some degree of learning problems at school. However, many whānau caregivers did not know about learning needs of the birth parents, therefore it is possible that these results are an underestimation.

The comparison group showed much more stability in many measures. All comparison group resided with at least one birth parent (Both parents = 55%, Mother = 38%, Father = 7 %) and 97 % had lived in only one placement.

**Resilience.** Of those who identified as Māori, 71% of the comparison group and 75% of the FASD group reported that they were connected to their Marae. In the FASD group 64% of the parents/caregivers and 90% in the comparison group reported at least one strength in their child. Strengths in the FASD group included; 33% sport, 18% arts, 13% practical tasks whereas in the comparison group strengths were described as 21% maths, 17% language, 3 % science, 38% sport, 7% arts, and 3% practical tasks.

**Adverse Childhood Experiences (ACEs) FASD group only.** Adverse Childhood Experiences information was gathered for the FASD group via Child Development Service clinical pathway. As the comparison group were not involved in a clinical pathway, ACEs data was not gathered for them. In summary, children with FASD had experienced a great deal of adversity with 54% of the group having a score greater than 4, and 26% of children in this group exposed to 6 or more adverse experiences ( $M = 3.82$ ,  $SD = 2.35$ ).

### Between-group analysis for IQ, executive functioning, social cognition, and adaptive functioning

Between-group comparisons on the neuropsychological variables were conducted, with the p-value adjusted for multiple comparisons using a Bonferroni correction ( $p = .05/\text{number of comparisons}$ ). The significance level was set at  $p < .003$ .

Table 8

*Mean performance on IQ, executive functioning, social cognition and adaptive functioning of FASD and comparison groups*

| Variable                             | FASD Group<br>(N= 39)<br>Mean (SD) | Comparison Group<br>(N = 29)<br>Mean (SD) | <i>t</i> -test<br><i>t</i> ( <i>d</i> ) | <i>p</i> |
|--------------------------------------|------------------------------------|---|---|----------|
| IQ (WISC-IV & WASI)                  | 68.18 (9.82)                       | 97.86 (14.12)                             | 9.42 (2.44) <sup>a</sup>                | <0.001   |
| <b>WISC-IV</b>                       |                                    |   |   |          |
| Verbal Comprehension index           | 69.72 (9.79)                       | -   | -                                       | -        |
| Perceptual Reasoning Index           | 78.69 (12.19)                      | -   | -                                       | -        |
| Working Memory Index                 | 71.74 (11.15)                      | 97.10 (9.17)                              | -9.98 (2.48)                            | <.001    |
| Processing Speed Index               | 77.15 (11.60)                      | -   | -                                       | -        |
| <b>Language</b>                      |                                    |   |   |          |
| CELF ( z score)                      | -2.23 (0.88)                       | 0.36 (0.78)                               | -12.46 (3.11)                           | <.001    |
| <b>Executive Functions</b>           |                                    |   |   |          |
| Tower (SS)                           | 8.92 (2.92)                        | 11.35 (1.23)                              | 4.65 (1.08) <sup>a</sup>                | <.001    |
| Animal Sorting (SS)                  | 4.69 (3.22)                        | 10.48 (2.59)                              | 7.96 (1.98)                             | <.001    |
| Inhibition Total Errors (SS)         | 3.26 (3.41)                        | 9.79 (2.66)                               | 8.56 (2.14)                             | <.001    |
| EF-composite                         | -4.38 (2.23)                       | 0.54 (1.33)                               | 11.32 (2.68) <sup>a</sup>               | <.001    |
| <b>Social Cognition</b>              |                                    |   |   |          |
| TOPS-3 (Scaled Score)                | 71.33(10.36)                       | 97.17 (8.41)                              | 11.00 (2.74)                            | <.001    |
| SCST (z score)                       | -1.34 (0.79)                       | 0.15 (0.76)                               | 7.86 (1.92)                             | <.001    |
| DANVA Adult errors (Inverse z score) | -0.71 (1.00)                       | 0.03 (1.04)                               | 2.94 (0.73)                             | <.001    |
| DANVA Child errors (Inverse z score) | -0.89 (1.25)                       | -0.25 (0.98)                              | 2.28 (0.57)                             | <.001    |
| SC-composite                         | -4.14 (2.00)                       | -0.16 (1.78)                              | 8.49 (2.10)                             | <.001    |

*Note.* <sup>a</sup> Adjusted for degrees of freedom due to unequal variances.

IQ = Intelligence quotient; WISC-IV = Wechsler Intelligence Scale for Children 4th edition, WASI-II = Wechsler Abbreviated Scale of Intelligence 2nd edition, CELF = Clinical Evaluation of Language Fundamentals, EF-composite = Executive functioning composite score, TOPS-3 = Test of Problem Solving-3 Elementary, SCST = Social Cognitive Skills Test, DANVA = Diagnostic Analysis of Nonverbal Accuracy, SC-composite = Social cognition composite score.

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The comparison group scored significantly higher than the FASD group on all measures of general intellectual functioning, executive functioning and, social cognition with all p-values < .001 (see Table 8).

In addition, the comparison group scored at a significantly better level than the FASD group on parent/caregiver-rated adaptive behaviour (Bonferroni-adjusted level of  $p < .007$ ), with all p-values < .001 (see Table 9). Note higher scores indicate more ability except in total maladaptive, internalising and externalising behaviour where higher scores signify more behaviour problems.

Table 9

*Mean parent and teacher ratings of adaptive functioning of FASD and comparison groups*

|                                     | FASD<br>Group<br>(N= 36)<br>Mean (SD) | Comparison<br>Group<br>(N = 29)<br>Mean (SD) | <i>t</i> -test<br><i>t</i> ( <i>df</i> ) | <i>p</i> |
|-------------------------------------|---------------------------------------|--|--|----------|
| <b>Vineland-II Parent/Caregiver</b> |                                       |  |  |          |
| Adaptive Composite                  | 72.61 (5.42)                          | 106.07 (16.92)                               | 9.71 (2.67) <sup>a</sup>                 | <.001    |
| Communication                       | 70.22 (5.20)                          | 98.76 (14.52)                                | 10.01(2.61) <sup>a</sup>                 | <.001    |
| Daily Living Skills                 | 77.83 (8.30)                          | 112.66 (16.87)                               | 10.12 (2.62) <sup>a</sup>                | <.001    |
| Socialisation                       | 74.42(9.17)                           | 104.76 (16.78)                               | 8.74 (2.24) <sup>a</sup>                 | <.001    |
| Total maladaptive behaviour c       | 19.28 (2.02)                          | 15.37 (1.82)                                 | 8.07 (2.01)                              | <.001    |
| Internalising behaviour c           | 18.00 (1.96)                          | 15.45 (2.01)                                 | 5.16 (1.28)                              | <.001    |
| Externalising behaviour c           | 19.28 (2.50)                          | 14.97 (2.04)                                 | 7.48 (1.89)                              | <.001    |
| <b>Vineland-II Teacher</b>          |                                       |  |  |          |
| Adaptive Composite                  | 70.33 (7.86) <sup>b</sup>             | -  | -  | -        |
| Communication                       | 72.58 (10.03)                         | -  | -  | -        |
| Daily Living Skills                 | 67.94 (7.98) <sup>b</sup>             | -  | -  | -        |
| Socialisation                       | 75.92 (11.24) <sup>b</sup>            | -  | -  | -        |

Note. <sup>a</sup> Adjusted for degrees of freedom due to unequal variances. <sup>b</sup> Data has been winsorized for these variables. - Denotes missing data not collected for comparison group.

**Relation between components of neuropsychological functioning, adverse childhood experiences and adaptive functioning**

To investigate our hypotheses and understand which variables were related to adaptive functioning, first, correlations were conducted, followed by multiple linear regression analyses. This enabled us to determine whether scores on measures of adaptive functioning were directly influenced by significantly associated key variables (e.g., IQ, executive functioning and social cognition, and adverse childhood experiences). The FASD and comparison groups were analysed separately due to the magnitude of the between-group differences in neuropsychological performance and ratings of adaptive functioning.

**Correlational analysis.** First Pearson correlations were calculated within the groups of cognitive measures used to assess the FASD and Comparison groups (see Appendix B). The majority of correlations were as expected with broader measures (e.g. FSIQ), significantly correlated with their index/domain scores (e.g., Verbal Comprehension Index, Perceptual Reasoning Index, Working Memory Index, Processing Speed Index) .

Correlations within the subscores of adaptive functioning were also calculated (see Appendix B). As 5 of the 6 correlations between the domains scores and composite scores for Parent/Caregiver ratings of adaptive functioning for both groups were above .76 (exception was Communication and Composite,  $r = .66$  ,  $p \leq .01$ , for FASD group), the adaptive functioning composite score, rather than domain scores, was used as an overall measure of functioning. Similarly, the composite score was used as an overall measure of adaptive functioning for Teacher ratings, with correlations between the domain and composite score all greater than .79. There was no significant correlation between parent/caregiver and teacher adaptive behaviour composite scores within the FASD group  $r(33) = 0.19$ ,  $p = .30$ . Therefore parent and teacher adaptive-rated functioning were analysed separately.

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Following these preliminary correlations, the correlations between the variables of interest and adaptive functioning were calculated (details shown in Appendix B).

***IQ and adaptive functioning.*** First we investigated the hypothesis that IQ would be related to adaptive functioning in the comparison group but not in the FASD group. In both the FASD group and the comparison group correlations between Full Scale IQ and parent/caregiver-rated Adaptive Behaviour Composite score only approached significance (Comparison group:  $r(29) = 0.34, p = .07$ ; FASD group:  $r(36) = 0.32, p = .06$ ). However, there was a significant relationship between FSIQ and *teacher*-rated Adaptive Behaviour Composite Score for the FASD group ( $r(36) = 0.46, p = .005$ ).

For the FASD group, when the individual indices making up the FSIQ on the WISC-IV were examined, it was clear that only the Verbal Comprehension Index (VCI),  $r(36) = 0.46, p = .005$  and Working Memory Index (WMI),  $r(36) = 0.34, p = .04$  were correlated with the teacher-rated adaptive behaviour composite score, not the Perceptual Reasoning Index (PRI) or Processing Speed Index (PSI).

***Executive functioning and adaptive functioning.*** The second hypothesis was that executive functioning would be significantly related to adaptive functioning in both the FASD and comparison groups. Within the FASD group the correlation between the EF-comp and parent/caregiver adaptive functioning composite score was marginally significant  $r(36) = 0.33, p = .05$ . When individual executive functioning tasks were examined there was a significant correlation between Animal Sorting and the parent/caregiver adaptive behaviour composite score for the FASD group,  $r(36) = .35, p = .04$ , but no significant correlations with other executive functioning tasks (Inhibition and Tower tests).

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Within the comparison group there was no significant correlation between the parent/caregiver adaptive behaviour composite score and the executive functioning composite score (EF-comp), nor any of the individual executive functioning tasks (all p-values > .62).

There were slightly different findings in the FASD group for teacher-rated adaptive functioning. The correlation between EF-comp and teacher rated adaptive functioning composite score was significant,  $r(36) = 0.34, p = .04$  but there were no significant correlations at the level of individual executive functioning tasks (Tower, Sorting and Inhibition tests).

***Social cognition and adaptive functioning.*** Social cognition was also hypothesised to be related to adaptive functioning in both the FASD and comparison group. In both groups there was no significant association between the social cognition composite score (SC-comp) and parent/caregiver adaptive functioning composite scores. In the FASD group no individual social cognition tests (TOPS-3, SCST or DANVA) were significantly correlated with parent-rated adaptive functioning. In the comparison group only the Test of Problem Solving, TOPS-3, showed a significant association with the parent/caregiver adaptive functioning composite score  $r(29) = 0.38, p = .04$ .

Conversely, there were many significant associations between teacher-rated adaptive functioning and social cognition for the FASD group (see Table 10). A strong correlation was found between SC-comp and teacher adaptive behaviour composite score,  $r(36) = 0.62, p < .001$ . Further analyses showed significant correlations with all of the individual social cognition tasks and teacher-rated adaptive functioning (all p-values < .02) with the exception of DANVA child emotional recognition.

Table 10

*Correlations between social cognition tasks and teacher-rated adaptive functioning*

|               | Teacher<br>Communication | Teacher<br>Daily Living<br>Skills | Teacher<br>Socialisation | Teacher<br>ABC |
|---------------|--------------------------|-----------------------------------|--------------------------|----------------|
|               | <i>r</i>                 | <i>r</i>                          | <i>r</i>                 | <i>r</i>       |
| TOPS-3        | 0.36*                    | 0.35*                             | 0.15                     | 0.38*          |
| SCST          | 0.44**                   | 0.44**                            | 0.37*                    | 0.42**         |
| DANVA - adult | 0.43**                   | 0.44**                            | .45**                    | 0.54**         |
| DANVA - child | 0.43**                   | 0.26                              | 0.31                     | 0.41*          |
| SC-comp       | 0.62***                  | 0.54**                            | 0.43**                   | .62***         |

Note: TOPS-3 = Test of Problem Solving-3 Elementary, SCST = Social Cognitive Skills Test, DANVA = Diagnostic Analysis of Nonverbal Accuracy, SC-composite = Social cognition composite score. ABC Adaptive behaviour Composite. \*  $p \leq .05$  level, \*\*  $p \leq .01$ , \*\*\*  $p \leq .001$ .

**Adverse Childhood Experiences (ACEs) and adaptive functioning.** ACEs information was only collected for the FASD group as part of their clinical assessment through the Wāhanga Whakapakari Tamaiti (Child Development Service). We hypothesised that ACEs would be significantly associated with adaptive functioning in the FASD group. As predicted, there was a significant correlation between ACEs scores and teacher-rated Adaptive Behaviour Composite scores,  $r(36) = -0.37, p = .03$ . The correlation between ACEs and parent-rated adaptive functioning approached significance  $r(36) = -0.30, p = .08$ .

**Regression analyses.** The second component of the analyses involved multiple linear regression models, performed to investigate which predictors (IQ, Executive functioning, Social Cognition, Verbal Comprehension, and Adverse Childhood Experiences) directly influence scores on ratings of adaptive functioning. A maximum of three predictor variables per regression model were used. Correlations between predictor variables revealed significant correlations between the three cognitive predictors, ranging from .53 to .61,  $p$ -values  $< .01$ .

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Firstly, we examined predictors of parent/caregiver-rated adaptive functioning and then teacher-rated adaptive functioning, separately for the FASD group and comparison groups.

### ***IQ, executive functioning and social cognition as predictors of adaptive functioning.***

Separate multiple linear regression analyses were calculated to investigate whether IQ, executive functioning and social cognition directly influenced parent/caregiver-rated adaptive functioning for the FASD and comparison group. The results of the regression found the model was not significant for the FASD group,  $R^2 = 0.14$  ( $F(3,32) = 1.71, p = .19$ ) or comparison group,  $R^2 = 0.15$  ( $F(3,25) = 1.45, p = .25$ ).

The same model as above was used to investigate whether these variables directly influenced teacher-rated adaptive functioning for the FASD group. A significant regression model was found  $R^2 = 0.43$  ( $F(3,32) = 7.89, p < .001$ ). The social cognition composite score (SC-comp) was the only significant independent predictor, Beta (standardised) = 0.55,  $p = .002$  (see Table 11).

Table 11

*Regression analysis for variables (IQ, EF-comp, SC-comp) predicting teacher-rated adaptive functioning in the FASD group*

| Predictor variables | b     | SE    | Standardised $\beta$ | <i>t</i> | <i>p</i> |
|---------------------|-------|-------|----------------------|----------|----------|
| (constant)          | 63.54 | 12.85 |                      | 4.95     | .000     |
| IQ                  | 0.22  | 0.16  | 0.25                 | 1.42     | .17      |
| EF-comp             | -0.33 | 0.61  | -0.10                | -0.54    | .59      |
| SC-comp             | 2.25  | 0.66  | 0.55                 | 3.42     | .002**   |

*Note.* IQ = General intellectual functioning, EF-comp = Executive functioning composite score, SC-comp = Social cognition composite score.

\*  $p \leq .05$  level, \*\*  $p \leq .01$ , \*\*\*  $p \leq .001$ .

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Further analysis of what aspects of social cognition predicted teacher-rated adaptive functioning was conducted. A multiple linear regression analysis was performed to investigate the contribution of the three social cognition measures (TOPS-3, SCST, DANVA–adult) that were significantly correlated with teacher-rated adaptive functioning. The analysis found the regression model was significant  $R^2 = 0.38$ , ( $F(3,32) = 6.49$ ,  $p = .001$ ), with the only significant independent predictor the DANVA adult facial recognition, Beta (standardised) = 0.42,  $p = .008$  (see Table 12).

Table 12

*Regression analysis for variables (TOPS-3, SCST, and DANVA-adult faces) predicting teacher-rated adaptive functioning in the FASD group*

| Predictor variables | b     | SE    | Standardised $\beta$ | <i>t</i> | <i>p</i> |
|---------------------|-------|-------|----------------------|----------|----------|
| (constant)          | 66.20 | 10.00 |                      |          |          |
| TOPS-3              | 0.136 | 0.12  | 0.18                 | 1.12     | .27      |
| SCST                | 2.12  | 1.68  | 0.20                 | 1.26     | .22      |
| DANVA-adult faces   | 3.35  | 1.18  | 0.42                 | 2.84     | .008**   |

*Note.* TOPS-3 = Test of Problem Solving-3 Elementary, SCST = Social Cognitive Skills Test, DANVA = Diagnostic Analysis of Nonverbal Accuracy.

\*  $p \leq .05$  level, \*\*  $p \leq .01$ , \*\*\*  $p \leq .001$ .

***Verbal Comprehension and Working Memory Indices as predictors of teacher-rated adaptive functioning.*** In the previous regression model that used the composite cognitive scores as predictors (see Table 12), IQ was not a significant predictor of teacher-rated adaptive functioning. However, only two of the four WISC-IV indices contributing to the Full Scale IQ, Verbal Comprehension (VCI) and Working Memory (WMI), were significantly correlated with teacher-rated adaptive functioning of children with FASD. Thus individual index scores may be better predictors of adaptive functioning than Full Scale IQ, which also includes the two Index scores (Perceptual Reasoning Index and Processing Speed Index) that have no

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association with ratings of adaptive functioning. Therefore a further model was tested in which both VCI and WMI were included as individual predictors of teacher-rated adaptive behaviour, as well as the social cognition composite score. The results of the regression found the model was significant,  $R^2 = 0.37$ , ( $F(2,33) = 7.76$ ,  $p = .000$ ), however only social cognition was a significant independent predictor ( $\beta = 0.50$ ,  $p = .005$ ) (see Table 13).

Table 13

*Regression analysis for variables (Verbal Comprehension Index, Working Memory Index and Social Cognition-comp) predicting teacher-rated adaptive functioning in the FASD group*

| Predictor variables | b     | SE    | Standardised $\beta$ | t    | p      |
|---------------------|-------|-------|----------------------|------|--------|
| (constant)          | 63.89 | 13.44 |                      |      |        |
| WMI                 | 0.10  | 0.11  | 0.14                 | 0.97 | .34    |
| VCI                 | 0.11  | 0.14  | 0.14                 | 0.83 | .41    |
| SC-comp             | 2.05  | 0.68  | 0.50                 | 3.00 | .005** |

*Note.* VCI = Verbal Comprehension Index, WMI = Working Memory Index, SC-comp = Social cognition composite score

\*  $p \leq .05$  level, \*\*  $p \leq .01$ , \*\*\*  $p \leq .001$ .

### *ACEs and social cognition as predictors of teacher-rated adaptive functioning.*

Finally a multiple linear regression was conducted to investigate whether Adverse Childhood Experiences Score (ACES) (which was significantly correlated with teacher-rated adaptive functioning) was a significant independent predictor of teacher-rated adaptive functioning, when included in a model along with the social cognition composite. The model was significant,  $R^2 = 0.44$  ( $F(3,32) = 12.69$ ,  $p < .001$ ). However, once again the social cognition composite score (SC-comp) was the only significant predictor when all three variables were entered into the model (see Table 14).

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Table 14

*Regression analysis for variables (ACEs and SC-comp) predicting teacher-rated adaptive functioning in the FASD group*

| Predictor variables | b     | SE   | Standardised $\beta$ | <i>t</i> | <i>p</i> |
|---------------------|-------|------|----------------------|----------|----------|
| (constant)          | 83.13 | 2.76 |                      |          |          |
| ACEs                | -0.75 | 0.46 | -0.22                | -1.64    | .11      |
| SC-comp             | 2.30  | 0.56 | 0.56                 | 4.15     | <.001*** |

*Note.* VCI = Verbal Comprehension Index, ACEs = Adverse Childhood Experiences, SC-comp = Social Cognition composite score.

\*  $p \leq .05$  level, \*\*  $p \leq .01$ , \*\*\*  $p \leq .001$ .

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## **Chapter Six: Discussion**

The following three chapters will discuss the research findings with regard to the psychological literature (Chapter Six), a Te Ao Māori perspective (Chapter Seven) and implications for service delivery and interventions (Chapter Eight).

### **Main research findings**

The children with an FASD diagnosis who participated in this study have severe impairments in the area of IQ, executive functioning, social cognition and adaptive functioning compared to typically developing children matched on age, gender, ethnicity, maternal tertiary education and socio-economic status. These results confirm that FASD is a severe and pervasive neurodisability, which is likely to affect a child's ability to succeed at school (Glass et al., 2017; Reid, Shelton, Warner, O'Callaghan, & Dawe, 2017), negotiate successful social relationships (McGee, Bjorkquist, Price, et al., 2009; Stevens, Nash, Koren, & Rovet, 2013) and build independence skills they require for adolescence and adulthood (Freunscht & Feldmann, 2011; Lynch, Kable, & Coles, 2015).

In this study we examined whether IQ, executive functioning, social cognition and adverse childhood experiences directly influence adaptive functioning as rated by parents/caregivers for the FASD group and the comparison group, and as rated by teachers for the FASD group. None of the selected variables directly influenced parent/caregiver ratings of their child's adaptive functioning. This was not in line with our hypothesis and possible explanations for this will be discussed below.

In our FASD group, however, our findings showed that adaptive functioning as rated by teachers, was directly influenced by some factors. The key finding was that social cognition, especially the ability to recognise emotions, was an important independent predictor of teacher-rated adaptive functioning. This provides partial support for our hypothesis that social

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cognition plays an important part in everyday functioning in children. It was surprising that this finding was not also present in parent/caregiver-rated adaptive functioning, and possible explanations will be discussed below. Unfortunately, we were not able to examine teacher-rated adaptive functioning in the comparison group as we only collected parent/caregiver-rated adaptive functioning.

Importantly, although IQ and executive functioning (i.e. the ability to plan, think flexibly and inhibit responses) were correlated with teacher-rated adaptive functioning in the FASD group, they did not predict teacher-rated adaptive functioning when the model included social cognition. In fact, social cognition was the only independent predictor of teacher-rated adaptive functioning. This suggests that social and emotional skills are cornerstone for successful adaptive functioning for children with FASD in school environments and as reported by the teachers.

### **Factors influencing adaptive functioning in children with FASD**

The present study demonstrates that children with FASD have significant impairments in adaptive functioning when rated by parents/ caregivers and teachers. These findings support previous research which has also highlighted significant deficiencies in adaptive functioning in people with FASD when compared to typically developing children and adolescents (Crocker et al., 2009; Fagerlund et al., 2012; Jirikowic et al., 2008), children who were matched on IQ (Fagerlund et al., 2012) and older children experiencing mental health issues (Whaley et al., 2001). However, these studies only included parent/caregiver-rated adaptive functioning, although all used the same scale as the present study, Vineland Adaptive Behaviour Scales; Structured interview, (Sparrow et al., 2005) with the exception of Jirikowic et al. (2008).

In spite of this, there has been limited examination of the factors which predict these poorer everyday life skills. The following sections will discuss the findings of this study

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regarding the relation between IQ, executive functioning and social cognition and adaptive functioning. We found more relations with teacher rather than parent/caregiver-rated adaptive functioning in the FASD group, which may be due to the limited variance in parent/caregiver adaptive functioning scores (discussed further below), as well as possible ecological validity issues in the measures used. The results will then be considered within the context of the psychosocial complexity that exists for children with FASD in this study, including the implications of these findings for the requirements of services that meet their needs.

**IQ and adaptive functioning.** As noted above no independent predictors of parent-reported adaptive functioning were identified. Although IQ was moderately correlated with parent/caregiver-rated adaptive functioning in both FASD *and* comparison groups, these only approached significance, suggesting the relationship between IQ and parent-reported adaptive functioning is not robust. There has been much commentary in the FASD literature regarding lower parent-reported adaptive functioning than what we would expect given their IQ level, which may be at a much higher level (Edwards & Greenspan, 2010; Paley & Auerbach, 2010). The current finding also shows a variable relationship between IQ and adaptive functioning, which provides support for research that suggest deficits in adaptive functioning in children with FASD are not fully explained by lower IQ (Jirikowic et al., 2008; Kully-Martens et al., 2013; Quattlebaum & O'Connor, 2013; Whaley et al., 2001).

One possibility that must be considered is that the lack of a relationship between IQ and parent reported-adaptive functioning may partially reflect the age of the children (8-11 years) in the current study, as deficits in adaptive functioning may become more pronounced in older children and adolescents even when intellectual ability can remain relatively stable (Crocker et al., 2009; Fagerlund et al., 2012; Thomas, Kelly, Mattson, & Riley, 1998; Whaley et al., 2001). Furthermore different parents may have different expectations of their child's behaviour and this may affect how they report their child's functioning. In contrast different teachers

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may report more similarly as they are trained in education and developmental expectations. It is also possible that our small sample size influenced these results as the correlations between parent/caregiver adaptive functioning and IQ were approaching statistical significance. Finally, parents/caregivers assigned only a small range of possible ratings of adaptive behaviour in the FASD group (range 60 - 81), which reduced the distribution of scores and thus reduced the possibility of finding a relationship between IQ and the child's ability to functioning at home. In contrast, the teacher ratings of adaptive functioning were more varied.

Conversely there was a significant moderate to strong relationship between IQ and teacher-rated adaptive functioning for the FASD group. This may partially reflect the content of the questions on the teacher adaptive functioning questionnaire, which are more heavily loaded with academic tasks that are more likely to have a stronger IQ component than the questions on the parent version. For example, the Daily Living Skills domain rated by teachers, included a subdomain dedicated to academic tasks (which the parent adaptive functioning measure does not have) such as reading, writing and mathematics. Intelligence tests have been constructed from the education curricula (Harris & Greenspan, 2016) and subsequently IQ scores have been found to be correlated with academic performance (Anastasi, 1986; Glass et al., 2017; Greenspan et al., 2016). In summary the teacher-rated adaptive functioning questions may therefore be measuring constructs that are more related to IQ than parent/caregiver-rated adaptive functioning questions, which don't contain academic task information.

Interestingly, the comparison group information also did not demonstrate a strong relationship between IQ and parent/caregiver-rated adaptive functioning despite having a much wider spread of adaptive functioning scores (79-148). However, the adaptive functioning scores in the comparison group were *significantly* higher than in the FASD group. It is therefore possible that IQ and adaptive functioning are not strongly related when children function at a higher level.

**Executive functioning and adaptive functioning.** Executive functioning is a complex construct consisting of many contributing cognitive processes that are required to manage and function in today's world. The current study measured a child's ability to stop a response (NEPSY-II: Inhibition), think flexibly (NEPSY II: Animal Sorting) and plan a sequence in order to achieve a goal (D-KEFS: Tower test). All of these cognitive processes contribute to the general rubric of executive functioning.

Overall the findings of the present study are consistent with the research literature that has found children with FASD experience significant impairments in executive functioning compared to typically developing children and adolescents (Khoury et al., 2015; Kodituwakku, 2009; Mattson et al., 2011; Vaurio et al., 2008; Ware et al., 2012). We hypothesised that executive functioning would be related to adaptive functioning in the comparison and FASD group due to the need for planning, cognitive flexibility and self-regulation in everyday functioning and independence (Davis et al., 2013; Schonfeld et al., 2006). However, in contrast to our hypothesis executive functioning was not related to parent caregiver-rated adaptive functioning in either the comparison or FASD groups.

No individual measure of executive functioning was associated with parent/caregiver-rated adaptive functioning in the comparison group, and only one individual measure (animal sorting) was marginally related in the FASD group. In the FASD group overall executive functioning was moderately associated with teacher-rated adaptive functioning. However, executive functioning was not an independent predictor of either parent/caregiver or teacher rated adaptive functioning executive functioning once it was considered alongside social cognition.

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*Why did executive functioning not predict adaptive functioning?* Existing psychological theories are relatively consistent with regard to the idea that adequate executive functioning is important for successful independence and adaptive skills (Greenspan et al., 2016; Lezak, 2012). However, research also suggests executive functioning skills are related to the level of social and emotional competence in children with FASD (Schonfeld et al., 2006), ADHD (Rinsky & Hinshaw, 2011; Tseng & Gau, 2013) autism spectrum disorder (ASD) (Leung, Vogan, Powell, Anagnostou, & Taylor, 2015) and traumatic brain injury (TBI) (Ganesalingam et al., 2011). It may be, therefore, that the executive functioning skills such as planning, thinking flexibly and stopping an automatic impulse may also be required in some types of social cognition abilities which may explain why executive functioning was not a significant predictor in models that included social cognition. Indeed, the two composite scores for executive functioning and social cognition were significantly associated ( $r = .50$ ). Nevertheless, our results indicate that the executive functioning measures in this study did not independently influence ratings of adaptive functioning,

As noted above, teacher-rated adaptive functioning was significantly associated with the executive functioning composite score in the FASD group. Had this study not included social cognition measures we would have come to the same conclusion as many previous studies that suggest that executive functioning skills contribute to the ability of a child with FASD to function adaptively at school (Clark, Prior, & Kinsella, 2002; Fuhs, Nesbitt, Farran, & Dong, 2014; Samuels, Tournaki, Blackman, & Zilinski, 2016; Schonfeld et al., 2006) and to the propensity to engage in risky behaviours (Ursache & Raver, 2015). But instead, our findings suggest social and emotional competence may play a more critical role in adaptive functioning at school. However, it is worth noting that interventions that aim to improve executive functioning in children with FASD have produced behavioural improvements in at least one study (Nash et al., 2014). In accordance with Beauchamp and Anderson's SOCIAL model

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(2010; 2012b), it may be that executive functioning facilitates the development of social skills and it is these social skills that affect behaviour and adaptive functioning.

The failure of executive functioning to predict adaptive functioning for the FASD group may also be due to the method and content of assessment tools. The ecological validity of executive functioning assessment tests has long been a subject of discussion for researchers, where it is recognised that tests that do not contain practical or social elements may be less able to reflect skills required for everyday life (Anderson, 2002). Furthermore clinical based assessments are also not able to replicate the richness of real world situations (Anderson, 2002; Chaytor & Schmitter-Edgecombe, 2003). Although the social and emotional assessment methods used in the current study were also based in the clinic they employed assessment methods which were based on real life scenarios which may be more likely to reflect actual functioning at home and school.

The ages of the children in the current study may have also affected the failure to find a relationship between executive functioning and adaptive functioning. Ware et al. (2012) found executive functioning predicted adaptive behaviour in alcohol-exposed children and adolescents. However, the ages for the alcohol-exposed participants' ranged from 8-18 year with a mean age of approximately 12 years whereas our study's mean age was approximately 9 ½ years for both groups. Executive functioning skills develop greatly during the period of middle childhood and into adolescence (Anderson, 2002; Anderson, Anderson, Northam, Jacobs, & Catroppa, 2001). This increase in skills may be due to the brain development in white matter that facilitates executive functioning during childhood and adolescence (Barnea-Goraly, et al., 2005). In adolescence, increased executive functioning skills may lead to stronger associations between executive functioning and parent/caregiver and teacher-rated adaptive functioning (Anderson et al., 2001; Ware et al., 2012).

*Differences in executive functioning and adaptive functioning between comparison and FASD group.* In the comparison group, no statistically significant relationships were found between executive functioning and parent/caregiver-rated adaptive functioning. These results are similar to previous research which also found no associations in the typically developing children and adolescents but did find significant relationships between executive functioning and adaptive behaviour in the FASD group (Ware et al., 2012). It is possible that our results may be due to the difference in cognitive ability between both groups as there is some evidence to suggest that there may be more individual variability in adaptive functioning in individuals with higher IQ's (Kane & Oakland, 2015; Kane, Oakland, & Brand, 2006). For example, children with higher overall cognitive abilities may show much higher verbal or visual skills but these do not necessarily correlate to the same degree of increased functioning in day-to-day life, which may be more related to the expectations and demands of different parents.

Another factor that may have influenced this result in the comparison group are discrepancies between performance-based measures and reports via questionnaires. Some researchers suggest that the correlations between parent report and performance-based measures are weak (Gross et al., 2014; Nguyen et al., 2014; Silver, 2014). However others have found parents were able to estimate their child's intellectual abilities, but had much better prediction at lower levels of ability, (Chandler, Howlin, Simonoff, Kennedy, & Baird, 2016). It is possible that parents are more likely to accurately identify impairments and this may apply, not only to estimating intellectual ability, but also to reporting adaptive functioning. If parents and are more able to accurately describe functioning in children with lower abilities then this may also partly explain why relationships between executive functioning and adaptive behaviour were found in the FASD group but not in the comparison group as the FASD group presented with significant impairments across all domains.

*Performance on individual executive functioning tasks in the FASD group.* Although the FASD group performed significantly below that of the comparison group they did show relative strengths in non-verbal tasks e.g. Perceptual Reasoning Index (WISC-IV) and the Tower Test (D-Kefs), one of the executive function measures that is a non-verbal measure of planning and organisation. Our finding that these tasks were a relative strength of children with FASD is consistent with other studies examining these skills in this population (Glass et al., 2013; Lebel et al., 2008; Rasmussen & Bisanz, 2009). The Tower task is a non-verbal measure of planning and organisation which also starts off relatively easy and slowly gains complexity allowing the child to learn a strategy. Our results, along with existing literature, suggest that children with FASD may show relative strengths in activities that do not rely on verbal instructions or responses and contain ample opportunities to practice a strategy.

Other researchers have also reported that children and adolescents with FASD have higher Perceptual Reasoning Index scores than Verbal Comprehension Index scores (Enns & Taylor, 2016). The children in the Enns & Taylor study (2016) demonstrated Full Scale IQs (FSIQ) in the mid 70's, similar to the children in the current study who demonstrated a mean FSIQ of 68. In contrast other research in which children with FASD had FSIQ scores in the mid 80's, found similar levels of verbal and perceptual scores (Nash et al., 2013). Together this suggests that there may be relative non-verbal strengths in children with lower overall cognitive abilities.

Of the three individual executive function tasks, only animal sorting, which involves higher level executive functioning abilities of cognitive flexibility and categorisation, showed a significant association with parent-rated adaptive functioning in the FASD group. Only one previous study has investigated what executive functioning abilities predicted adaptive behaviour in children with heavy prenatal alcohol exposure (9-14 years) (Ware et al., 2012). They found Design Fluency-Switching and Trail Making Test-Switching (D-Kefs) predicted

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poorer adaptive functioning in the alcohol exposed group, with no relationship between an inhibition task (Colour Word Interference: D-Kefs). These results, alongside the finding of the present study, suggest that it may be a child's ability to think flexibly and switch between concepts and ideas that is more connected with their ability to adapt in everyday life.

**Social cognition and adaptive functioning.** The findings of this study are consistent with the recent literature that has found significant impairments of social cognition in children with FASD (Kerns, Siklos, Baker, & Müller, 2016; Lindinger et al., 2016; Stevens, Dudek, Nash, Koren, & Rovet, 2015). In addition, consistent with our hypothesis we found a very strong relationship between measures of social cognition and teacher-rated adaptive functioning, with the social cognition composite the *only* significant unique predictor of teacher-rated adaptive functioning for the FASD group. In fact, all measures of social cognition were significantly associated with the teacher adaptive functioning composite score. In addition, neither IQ, executive functioning nor Adverse Childhood Experiences (ACEs) were significant predictors of teacher-rated adaptive functioning of the FASD group when the social cognition composite score was part of the model.

The present study's finding that social cognition was the only significant predictor of teacher adaptive functioning supports consensus in the general literature that social and emotional skills are imperative for teacher perceived school success (Dodge et al., 2002; Durlak, Weissberg, Dymnicki, Taylor, & Schellinger, 2011; Macfarlane, Macfarlane, Graham, & Clarke, 2017; Zins, Bloodworth, Weissberg, & Walberg, 2004). It is vital that teachers are aware that the child with FASD will react inappropriately in part because of their inability to interpret adult emotions and facial expressions. This suggests a focus on social and emotional skills during clinical assessment is important as it may provide guidance for intervention especially in the school environment.

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However, there has been limited research investigating predictors of adaptive functioning in the school environment for children with FASD. This is despite an increased prevalence of school disruption, school dropout and lack of formal education qualifications in individuals with FASD (Freunsch & Feldmann, 2011; Streissguth et al., 2004). Success at school is important as it is seen as preventative for adverse outcomes such as juvenile offending (Farrington, Loeber, & Ttofi, 2012; Katsiyannis, Ryan, Zhang, & Spann, 2008), mental health issues (Bond et al., 2007; Shochet, Dadds, Ham, & Montague, 2006) and later unemployment (Woodward & Fergusson, 2000). Prenatal alcohol exposure has also been found to be related to school success and children with prenatal alcohol exposure have shown to have marked impairments in their academic abilities (Glass et al., 2017; Johnson et al., 2017; Rasmussen & Bisanz, 2011; Reid, Shelton, Warner, O'Callaghan, & Dawe, 2017; Sayal et al., 2014) and demonstrate more externalising behaviour problems at school (Quattlebaum & O'Connor, 2013).

In contrast, the social cognition composite did not significantly predict parent/caregiver-reported adaptive functioning for either the FASD or comparison groups. Consistent with the explanation given above, this may be because of the limited variance in the adaptive functioning ratings provided by parent/caregivers of the FASD children. It is also possible that these social and emotion tasks (DANVA, SCST, and TOPS-3) better reflect the types of activities required to function successfully at school rather than at home. For example, children are required to communicate and socialise with a much greater number and variety of children and adults compared to what they need to manage at home.

There is also a great deal of complexity in establishing psychometrically sound tools that accurately reflect a child's real life social skills in all situations (Anderson, 2002; Anderson et al., 2017; Hayward & Homer, 2017). There was only one significant association between individual social cognition measures and parent/caregiver-rated adaptive functioning, namely

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the TOPS-3 with parent-rated adaptive functioning for the comparison group. The Test of Problem Solving is a task that involves analysing a series of photos about real life events and giving verbal answers to questions about those photos. The use of real photos and everyday situations in the TOPS-3 may better reflect the skills measured in parent-rated adaptive functioning for the comparison group.

While there is a small amount of research in the FASD field that investigates the relationship between parent-rated adaptive functioning and behavioural concerns with specific components of social and emotional cognition, our findings suggest that recognising emotions, especially on adult faces, is strongly linked to teacher-rated adaptive functioning at school. Errors in facial emotional processing have previously been linked to poorer parent-rated adaptive functioning on the Vineland II (Kerns et al., 2016). In terms of maladaptive behaviour, poorer facial emotional processing has been found to be related to parent-reported aggressive behaviour (Kerns et al., 2016). Social skills as reported by parents and teachers, and behavioural issues reported by teachers have been found to be significantly related to a child's ability to understand another person's perspective and choose an appropriate response for a character in a story (Greenbaum, Stevens, Nash, Koren, & Rovet, 2009). In contrast, Kerns et al (2016) did find a relationship between parent-reported CBCL aggressive behaviour and social problems but this was only facial processing. This may indicate that facial emotional recognition may be the most important influence.

One of the measures in the present study, the Social Cognitive Skills Test (SCST) has a strong theory of mind component. Being able to understand other people's situations, intentions and beliefs is extremely important in developing social and life skills. Previous FASD research has found marked impairments in theory of mind skills (Lindinger et al., 2016; Rasmussen et al., 2009; Stevens et al., 2016). The present study found children with FASD

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have significantly lower theory of mind skills as measured by the SCST, which also supports the premise that theory of mind skills are challenged in children with FASD.

**Adverse Childhood Experiences (ACEs) and adaptive functioning.** Other variables such as Adverse Childhood Events that initially appeared to be significant predictors' of teacher-rated adaptive functioning ceased to be significant when social cognition was taken into account. In contrast to our hypothesis ACEs was not related to teacher-rated adaptive functioning when social cognition was included in the model.

Child maltreatment has been linked with difficulties in emotional understanding and theory of mind in a number of studies (Cicchetti, Rogosch, Maughan, Toth, & Bruce, 2003; O'Reilly & Peterson, 2014; Pears & Fisher, 2005a). It is possible Adverse Childhood Experiences (ACEs) have influenced a child with FASD adaptive functioning, however the relationship may be facilitated by the impact Adverse Childhood Experiences have on a child's social skills. In the present study there was a high prevalence of Adverse Childhood Experiences in the FASD group. However, for many of these children these experiences occurred at an early age and they had then been in a stable placement for a number of years. Stable placements may build social skills through the development of secure relationships or attachments. Therefore it is possible that for the children in this study, social skills may have been learnt within supportive relationships from stable placements despite early adversity.

**The importance of emotion recognition (adult faces) for adaptive functioning at school.** Emotion recognition was an important predictor for teacher-rated adaptive functioning in adult but not child faces. Recent literature has also reported that children with FASD show impairments in emotion recognition and understanding (Kerns et al., 2016; Lindinger et al., 2016; Petrenko, Pandolfino, Quamma, & Olson, 2017; Stevens et al., 2016). Our findings specifically support studies that also report more impairment in recognising emotions in adult

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rather than child faces (Kerns et al., 2016). Normative data on the DANVA-II facial recognition measures found that for children, child faces may be easier to interpret than adult faces (Nowicki, 2010). Emotions on adult's faces may also be more difficult for children to recognise, which may cause misunderstanding between the child and the teacher in the classroom.

The DANVA facial recognition test was constructed in North America and includes people from Caucasian, African American and Asian ethnicities. It is possible that the children in the current study may have performed better if the faces reflected their own culture. However again the comparison children, who had comparable ethnicity and deprivation indices scored in accordance with the US norms, indicating the difficulties children with FASD had with this task is not due to test characteristics alone.

Most research investigating emotional processing in children with FASD has tended to match on chronological age rather than mental age (Greenbaum et al., 2009; Kerns et al., 2016). However, some researchers suggest that social and emotional process skills must be considered with respect to the child's mental rather than chronological age. In a comparison with children with Down syndrome and typically developing children, children with prenatal alcohol exposure showed significant social problems (Way & Rojahn, 2012). However, Way and Rojahn (2012) found no differences in facial processing between children with FASD and typically developing children who were matched on mental age and argued facial processing was attributable to the mental age of the child. In the present study social and emotional scores, except for recognising emotions on child faces, were significantly related to IQ. However, IQ ceased to be an important predictor for teacher adaptive functioning when social and emotional cognition was included in the model. This suggests that a child's social and emotional abilities, especially facial emotion processing, provide a unique contribution to the variance of adaptive functioning at school.

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The importance of recognising emotions is well recognised in the literature, as interpreting emotions is typically viewed as the first stage of social information processing (Crick & Dodge, 1994; Lemerise & Arsenio, 2003) and is critical to socio-emotional competence (Halberstadt, Denham, & Dunsmore, 2001). Crick and Dodge's (1994) Social Information Processing model (SIP) requires an individual to encode and interpret cues in social interactions before they are able to decide how to clarify goals, decide on a response and then implement/enact that response. If a child has difficulty at the initial stages of encoding and interpreting emotional cues (emotion recognition) then they are going to have much more difficulty making the right social choice and acting appropriately.

If children are not able to correctly read the emotional cues of the adults around them they may also be less able to connect with their teachers. Positive relationships between teachers and children facilitate both academic and adaptive learning. Furthermore, impairments in reading the emotional state of their teacher may result in misunderstanding and frustration especially if the child also has difficulty with impulse control issues. Misunderstandings and frustrations may threaten positive relationships between the teacher and the child thus resulting in a less effective learning environment. Another reason for the significant relationship between recognising emotions on adult's faces and teacher-rated adaptive functioning is that teachers may be more likely to rate children higher if they like and are connected to them.

It is possible that those children who have an increased need for support may be less likely to receive support because they are less connected. Furthermore, children learn and connect with others when they are calm and regulated. Many children with FASD have difficulties in self-regulation (Kodituwakku et al., 1995; Nash et al., 2014) and are therefore susceptible to environmental influences. These children often require the adults around them to support and manage their regulation issues. Cumulative risk factors such as difficulty recognising emotions, social interpretation bias and behaviour problems may be detrimental

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when building relationships with the adults in the child's life (Schofield, Biggart, Ward, & Larsson, 2015).

Difficulties in emotion processing and understanding have been found to be prevalent in children who have experienced maltreatment (Cicchetti, 2016; Pears & Fisher, 2005), and neuroimaging studies have shown atypical activation in emotional discrimination tasks in children who have experienced abuse (Hart & Rubia, 2012). Children who have experienced abuse and neglect are also more likely to have insecure attachment styles (Howe, Brandon, Hinnings, & Schofield, 1999; Perry, 2002) which may also interfere with their ability to relate and connect with their teacher. The relationship between maltreatment and emotion processing impairments appears to be consistent in younger children (Pears & Fisher, 2005; Pollak, Cicchetti, Hornung, & Reed, 2000), whereas older children have demonstrated more accuracy (Pollak & Sinha, 2002; Pollak, 2005) suggesting children may adapt and normalise in their emotion-processing skills as they age. The present study found children with FASD in middle childhood continue to demonstrate significant impairments in their ability to recognise facial emotions which may indicate persistent neurological damage from alcohol exposure.

### **Differences between parent and teacher report for the FASD group.**

Analysis showed there were different findings depending on whether adaptive functioning was rated by the teacher or parent/caregivers of the children in the FASD group. In general more significant relationships were found for teacher rated, rather than parent/caregiver-rated adaptive functioning and there was no significant correlation between parent/caregiver-rated and teacher rated adaptive functioning. As previously mentioned, this suggests that the Vineland parent and teacher questionnaires may measure slightly different constructs, with teacher-rated skills more heavily loaded on academic tasks and parent/caregiver-rated skills including domestic duties such as helping with cleaning and

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cooking. Furthermore, parents/caregivers and teachers may also have different expectations of behaviour and success (Dirks et al., 2012; Silver, 2014).

A child may also perform differently in different environments, situations and contexts, for example, home, school and clinic room (De Los Reyes & Kazdin, 2005; Dirks, De Los Reyes, Briggs-Gowan, Cella, & Wakschlag, 2012; Silver, 2014). Teachers have a classroom to manage, therefore behaviour that may be tolerated at home may not be tolerated at school (Dirks et al., 2012). On the other hand, school may provide increased structure and routine which enables better adaptation in that environment (Drabick, Gadow, & Loney, 2007) and teachers may have better understanding of typical development. In addition, whilst parents report's on problematic behaviour may be affected by their own level of stress, their report may also be biased because of their attachment to their child (Milan, Wortel, Ramirez, & Oshin, 2017). Other researchers who have examined social cognition with parent and teacher reports of aggressive behaviour have also found stronger relationships with teacher rather than parent report (Dodge et al., 2002). The school setting may require higher levels of social and emotional understanding due to the number and variability of the peers and teachers a child is required to interact with.

The lack of relationships between parent and teacher reports may also be influenced by biases due to parental mental health or stress (De Los Reyes & Kazdin, 2005; Youngstrom, Loeber, & Stouthamer-Loeber, 2000). Many of the parents in the FASD group rated high levels of maladaptive behaviour, which previous research has associated with elevating parental stress (Paley et al., 2005; Paley et al., 2006). It is likely then that parents and caregivers of the FASD group may be experiencing high levels of stress which may bias their interpretations of their child's day-to-day level of functioning.

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In the end however it is important to recognise the usefulness of understanding variability in a child's profile and look for why their behaviour changes in different contexts or why a parent or teacher may be biased to report a certain way. These factors influencing variability are often markers for intervention as they highlight strengths and areas of resiliency as well as detailing challenges that these children face.

### **Application of SOCIAL Model**

Beauchamp's and Anderson's SOCIAL model (2012b; Beauchamp & Anderson, 2010) details social skills in a typically developing population (see Figure 1). This model attempts to provide a holistic understanding (including internal/external factors, cognitive, communication and social and emotional abilities) for the development of social skills and adjustment in children. The present study gives some support to this model for children who have experienced prenatal alcohol exposure and have a diagnosis of FASD. Specifically, the FASD group performed significantly below a matched comparison group who had limited or no prenatal alcohol exposure, giving evidence that external factors, such as prenatal alcohol exposure, can affect brain integrity.

In keeping with the model there initially appeared to be some support for significant relationships between factors such as IQ, executive functioning, Adverse Childhood Experiences (ACEs) and verbal skills with adaptive functioning as rated by the teacher. However these relationships ceased to play an important role independent of social cognition which was the most important factor influencing adaptive functioning in this sample of children with FASD, especially in the school context. This finding supports the idea that assessing social cognition and providing an intervention that builds and supports social and emotional competence is paramount (Anderson & Beauchamp, 2012a; Durlak et al., 2011; Macfarlane et al., 2017).

### **Complexity in children with FASD**

A child's potential is not just affected by their neurological functioning but also from environmental influences. The current study measures environmental factors such as adverse childhood experiences (ACEs), parental learning difficulties, and deprivation and living arrangements. However, it is important to note environmental factors do not operate independently and it is the cumulative effects of multiple influences that most often have the biggest impact.

**Adverse Childhood Experiences (ACEs).** In the current study many children in the FASD group experienced a number of adverse life events. In the FASD group 54% of children had experienced more than 4 adverse events in childhood as measured by the ACEs framework (Centers for Disease Control and Prevention, 2016; Felitti et al., 1998), which includes events such as abuse, neglect, family violence, household substance abuse, parental mental health issues and household criminal behaviour. Moreover, ACEs scores were significantly associated with behaviour issues at home. These results are in line with previous research that found almost half of the children referred for FASD evaluation in a clinic in Alberta, Canada, had ACEs scores of 4 or more (McLachlan et al., 2015).

Adverse Childhood Events may not only influence the current presentation but have also been found to impact long term health and wellbeing not just in childhood but into adulthood, and more adverse events have been associated with increased risk of negative outcomes (Anda et al., 2006; Dong et al., 2004; Felitti et al., 1998). Researchers suggest adverse outcomes for children are driven by the negative environments and household chaos caused by factors such as parental psychopathology and substance issues rather than direct parental behaviour (Anda et al., 2002; Briant, Holmes, Deater-Deckard, King-Casas, & Kim-Spoon, 2017). There also appears to be high prevalence of adversity for children with prenatal alcohol exposure which puts them at risk of 'double jeopardy' (Coggins et al., 2007; Henry et

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al., 2007; Smith et al., 2007; Yumoto, Jacobson, & Jacobson, 2008). More positive outcomes have been associated with lower exposure to violence in early childhood (Liebschutz et al., 2015), and higher financial resources (Meppelder, Hodes, Kef, & Schuengel, 2015; Raver, Blair, & Willoughby, 2013; Rochette & Bernier, 2014). It is imperative that interventions consider the impact of these adverse life events and attempt to ensure children's environments are free from trauma in the future.

**Socio-economic factors.** Other environmental factors such as poverty and socioeconomic status can also impact children's behaviour and development (Arán-Filippetti & Richaud De Minzi, M C, 2012; Raver et al., 2013; Ursache & Noble, 2016). In the current study there was also a high level of reported learning difficulties in either the birth mother or father in the FASD group and many of the participants resided in a high deprivation areas. Children with FASD are experiencing a number of environmental issues which have the potential to cumulatively increase their risk for poor outcomes. Children with significant neurological damage, as evidenced in those that meet criteria for FASD, who also experience adversity, poverty and school difficulties often have an increased need for access to services in both health and education. Thus service criteria and supports need to be based not only on a diagnosis of FASD, but also around multiple indicators of disadvantage and risk that frequently accompany children with this diagnosis.

**The impact of stress in the home environment.** An absence of childhood adversity such as abuse, neglect, poverty and violence does not necessarily mean a home environment is free of stress. Research suggests parents caring for children with intellectual disabilities (ID) experience high level of parenting stress due to challenging behaviours observed in children with Intellectual Disability (Meppelder et al., 2015). Prenatal alcohol exposure is also associated with child behaviour problems, and this challenging behaviour is then linked to parental stress (Paley et al., 2005; Paley et al., 2006). In the present study 72% of children with FASD were demonstrating maladaptive behaviour, e.g. school refusal, aggression, defiance, in the elevated or clinically significant range. It is likely then that parents and caregivers may be experiencing high levels of stress due to the child's behaviour issues alone.

Supportive home and community environments with high levels of monitoring are associated with more resilience in both the FASD literature (Liebschutz et al., 2015; Olson et al., 2009; Streissguth et al., 2004) and the wider developmental literature (Goldstein, Faulkner, & Wekerle, 2013; Mistry, McCarthy, Yancey, Lu, & Patel, 2009; Tiet, Huizinga, & Byrnes, 2010). Caregivers under stress may find it more difficult to provide the supportive highly supervised environment that is associated with resilience and more positive outcomes and therefore need appropriate support according to whānau not individual need (Cherrington, 2009).

**Living arrangements.** In the current study a third of the children with FASD were cared for by whānau who were not their mother or father. The literature suggests kinship/whānau carers may experience fewer supports and higher levels of stress than non-kinship carers (Bass, Shields, & Behrman, 2004; Harnett, Dawe, & Russell, 2012). Within a Māori worldview the whole whānau has the responsibility of ensuring children are properly raised and supervised (Ministry of Justice, 2001), however an urban society may not provide the same support structures and whānau can easily be stretched beyond their ability and

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resources. Furthermore, grandparents caring for their grandchildren may experience another layer of grief and trauma due to the breakdown of their own child's parenting ability that led to the grandchild needing to be cared for by themselves (Harnett et al., 2012). Whānau carers may therefore require more support than non-whānau carers in order to provide the type of environment that will allow the child to develop to their full potential.

The current study findings suggest that children with FASD experience significant complexity in the form of increased experience of adverse childhood experiences, poverty, stress and separation from their parents. These factors need to be included and recognised when eligibility for service is being considered. The next section will review service eligibility with regard to the children with FASD in the current study.

**FASD, language and school services.** Most of the children with FASD (82%) in the current study were assessed as having a Speech and Language Disorder, and children with FASD had verbal skills well below that of a matched comparison group. However only 46% of children with FASD had previous Ministry of Education input. We found a number of children in the FASD group with language disorders who have not, and will not, receive input from the Ministry of Education (including Speech Language Therapy) despite having significant language needs which appear to be affecting their ability to function at school.

The way health and education services are currently contracted and delivered is therefore creating service gaps and children with complex needs are not getting the early intervention and support they need. The school curriculum relies heavily on language and many of the measures of success are based around literacy. However language skills are not only important for academic success but are also the basis for communication. Poor language skills can lead to communication breakdowns which can then have a detrimental impact on behaviour. Moreover, children and adolescents with FASD often experience school failure and

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exclusion (Streissguth et al., 2004), therefore it is important to assess and offer support to ensure success.

**FASD and Mental Health Services.** Mental Health services may have appropriate therapists with the skills to be able to support children and their whānau to manage behavioural needs. Additionally, the literature suggests there may be a high prevalence of co-morbid mental health disorders in individuals with FASD (Pei et al., 2011; Popova et al., 2015; Weyrauch et al., 2017). In Aotearoa/ New Zealand referral to a Child and Adolescent Mental Health Service (CAMHS) requires a moderate/severe mental health issue defined by the Diagnostic and Statistical Manual of Mental Disorders (American Psychiatric Association, 2013).

In the present study few of the children with FASD had associated depressive or anxiety symptoms, although there was a high prevalence of children with a co-morbid ADHD diagnosis in the FASD group. A diagnosis of ADHD on its own does not necessarily broker access to Child and Adolescent Mental Health Service especially if already medicated. It is likely that the prevalence of mental health difficulties increases later in adolescence and adulthood. However, it is concerning that these children, despite presenting with significant learning and behavioural difficulties, may not qualify for tertiary child and adolescent mental health services in their younger years, which is where many skilled professionals reside. There is limited scope for preventative work despite data suggesting very high risk of mental health problems across the life course.

**FASD and Disability Services.** These findings of the present study are in line with previous research that shows children with FASD are performing significantly below their typically developing peers in measures of IQ, executive functioning, social cognition and adaptive functioning. (Glass, Ware, & Mattson, 2014; Kodituwakku, 2009; Mattson et al.,

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2011; Riley & McGee, 2005). These children are also at risk due to the influence of adverse childhood experiences, poverty and stress in the home environment. Although children with a diagnosis of FASD experience severe neurological impairments they only meet criteria for disability support services if they have a co-morbid diagnosis of Intellectual Disability. In the current study, all 39 participants in the FASD group demonstrated severe neurological impairment which is required for a FASD diagnosis, however only 39% of these children received an additional co-morbid diagnosis of Intellectual Disability, which enabled a referral to disability services.

*What about service entry based on adaptive functioning?* Adaptive functioning is an integral part of an Intellectual Disability diagnosis, therefore normative data also needs to be considered in relation to an individual's age, culture and own community expectations (Dudley, 2016; Tassé, 2009). The current study measured adaptive functioning in a comparison group that was matched on age, gender ethnicity, and socioeconomic status. Maternal education was also matched at the tertiary level, although at the secondary level the comparison group demonstrated higher levels of education. Thus it was interesting to find that, in the comparison group the parent-rated adaptive scores, especially in the daily living skills domain, were higher than the US norms developed for the Vineland II.

Other international research has also found higher adaptive functioning scores than adaptive behaviour norms however, in previous research the mean IQ has been significantly higher than test norms (Jirikowic et al., 2008). Although there may have been a selection bias where parents of higher functioning children may be more likely to engage in this research project, it is interesting to note that the IQ scores of the present study's comparison group correspond to the Australian and NZ norms. Our children in Aotearoa New Zealand may be functioning in everyday life at a much higher level than expected if we compare them to the North America norms. If this is the case then the adaptive functioning thresholds that are

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required for a DSM-IV-TR Intellectual Disability diagnosis may also be set too low and we should be concerned about those individuals who score above the current threshold of 70.

In NZ access to disability services is based on a diagnosis of Intellectual Disability using DSM-IV-TR criteria which relies on severe impairment of adaptive functioning plus a Full Scale IQ score below 70 (+ or – standard error). We may suppose then, that the Intellectual Disability criteria assumes co-linearity of IQ and adaptive functioning. However, in the current study we only found a significant relationship between IQ and teacher-rated adaptive functioning, with only a limited relationship in parent-rated adaptive functioning. Moreover there was no correlation between teacher and parent/caregiver-rated adaptive functioning for the FASD group. This lack of a consistent relationship between IQ and adaptive functioning, alongside variability in adaptive functioning ratings and issues of using North American norms, suggest that service provision based on a diagnosis of Intellectual Disability is problematic.

The current study demonstrates that children with FASD experience significant learning and behavioural needs often in the context of substantial psychosocial adversity. Given this complexity support services may be better organised using holistic models of health that examine the collective rather than individual strengths and challenges.

### **Limitations**

**Influence of culture.** Although neuropsychological impairments are consistently associated with FASD it is important to once again review contextual environmental factors that may impact performance. There is much discussion about the validity of neuropsychological assessment for Indigenous populations especially as assessments are based on western expectations of intelligence. There is also a scarcity of Indigenous normative data and tests are almost always constructed using the English language (Dingwall & Cairney, 2010). Research conducted in Aotearoa New Zealand suggests Māori may perform lower than

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American and Pākehā participants in language-based tasks which are constructed in North America (Barker-Collo, 2001; Barnfield & Leathem, 1998). However in one study this result may have been confounded with the presence of more Traumatic Brain Injury (TBI) and substance use in participants who were Māori (Barnfield & Leathem, 1998) and in the Barker-Collo (2001) study only a small sample of Māori ( $N = 15$ ) were included. Furthermore both these studies involved adult and not child participants. In other research no statistically significant differences were found in verbal learning when comparing Māori and Pākehā, although both groups performed better on the New Zealand version (Barker-Collo, Clarkson, Cribb, & Grogan, 2002). Participants may therefore perform better in tests which are constructed in their own cultural context (Dudley, 2016).

With regard to FASD, there has been limited research investigating differences in neuropsychological performance based on ethnicity. However one study did find Indigenous (Canada) children with FASD performed lower than Caucasian children in measures of verbal IQ (Rasmussen, Horne, & Witol, 2006), although they did not specify whether English was the first language for the Indigenous (Canada) participants. A similar result was found in Aotearoa New Zealand where Māori men compared well in tests that relied on attention and memory, less well on tests that were more aligned to formal education, and better on a visuo-spatial test (Ogden & McFarlane-Nathan, 1997). In general, the research suggests there may be a trend for Indigenous participants to score lower on verbal tests which are constructed in Western psychological and language frameworks.

While it is possible that the verbal tests may disadvantage Māori, our finding that there was statistically significant relationship between Verbal comprehension (as assessed by the WISC-IV) and teacher-rated adapted functioning is concerning. The education system has also been constructed from a western pedagogy and therefore may be disadvantaging Māori who have strengths in other areas. Including pedagogy that is more aligned with a Te Ao Māori

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perspective in the mainstream school system may improve overall functioning and allow these children to reach their full potential.

**Influence of Gender.** The current study selected children between the ages of 8-12 who received a FASD diagnosis through the Wāhanga Whakapakari Tamaiti (Child Development Service) FASD pathway. A gender imbalance occurred in the current study (77% male) as the majority of children referred for a FASD assessment in the Developmental Assessment Program (DAP) are boys. Recent research found boys and girls with FASD are similarly affected by prenatal alcohol exposure although slight differences have been found in neuropsychological profiles with girls demonstrating poorer non-verbal IQ (May, Tabachnick et al., 2017) and boys exhibiting stronger skills in their ability to define words. (Panczakiewicz et al., 2016).

Although girls and boys are similarly affected by exposure to alcohol there may be differences in the way they present clinically. Research suggests that boys, especially those that experience developmental issues such as ADHD and FASD, exhibit more externalising behaviour than girls (Abikoff et al., 2002; Diamantopoulou, Rydell, Thorell, & Bohlin, 2007; Stevens et al., 2015). Sixty-two percent of children in the study also had a co-morbid diagnosis of ADHD, therefore it is possible that boys are referred to the service because they are more difficult to manage than girls, not because girls are not affected by prenatal alcohol exposure.

Research suggests that girls in general may have an advantage in facial emotion processing (McClure, 2000; Thompson & Voyer, 2014), perspective taking and empathy (Van der Graaff et al., 2014). These gender differences in social and emotional cognition are supported in the FASD literature where girls have shown better recognition of emotional expression, theory of mind and empathy (Lindinger et al., 2016; Stevens et al., 2015), although in one study boys performed significantly better in the NEPSY contextual theory of mind task

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(Lindinger et al., 2016). Girls diagnosed with FASD have been rated as having fewer social skills than boys (Rasmussen, Becker, McLennan, Urichuk, & Andrew, 2011; Schonfeld et al., 2006), however it was suggested that this may be due to girls needing more behavioural problems if they are to be identified as needing intervention. Nevertheless, it is possible that the high proportion of boys in the current study has skewed the social and emotional results. Future research should endeavour to investigate possible gender differences when analysing the relationship between social and emotional skills and everyday life functioning.

**Gathering alcohol exposure information.** Another limitation was the way alcohol information was collected. Alcohol exposure was collected using the same structure as the longitudinal Growing Up in New Zealand (GUiNZ) study, therefore the present study recorded frequency (number of standard drinks per week) rather than pattern of alcohol consumption. There is general consensus that a 'binge' pattern of pre-natal alcohol exposure is more harmful to the developing fetus (May et al., 2013). Despite only quantifying frequency rather than pattern all children in the current study satisfied criteria for alcohol exposure according to the Canadian Guidelines (Chudley et al., 2005). In fact this study represents a highly exposed population with 62% of children exposed to 40+ standard drinks per week in the first trimester and 39% exposed to 40+ standard drinks per week in the second and third trimester. In the future information regarding pattern of alcohol exposure may provide more accurate information about risk of subsequent developmental issues.

In addition, there were children in the study that were also exposed to prenatal drug (e.g. cannabis and methamphetamine). Unfortunately, our sample size was not large enough to analyse the additional effects of drug exposure. In the future large scale studies that are able to differentiate between different prenatal alcohol and drug exposure level may be useful to identify those children most at risk of neurodevelopmental problems.

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Research suggests a potential trend of underreporting prenatal alcohol exposure (Alvik, Haldorsen, Groholt, & Lindemann, 2006; Ceccanti et al., 2014; Lange, Shield, Koren, Rehm, & Popova, 2014) with retrospective reporting possibly producing more accurate information than collecting information whilst a woman is pregnant (Alvik, Haldorsen, Groholt, & Lindemann, 2006). In Aotearoa New Zealand, Mallard, Connor, and Houghton (2013) discuss the possibility that social desirability bias may have underestimated the prevalence and amount of high risk drinking in their questioning of post-partum women. In the current study heavy amounts of alcohol use was reported with almost half (49%) from birth mothers themselves. It may be possible that when women want to understand the developmental issues in their own child, they may be more likely to share the extent of their drinking patterns when a non-judgemental environment is provided by health professionals.



### **Chapter Seven: Consideration of findings within a Te Ao Māori perspective.**

The present study found that children with FASD have much poorer adaptive functioning, social and emotional competence (taking another person's perspective, recognising emotions), executive functioning (thinking flexibly, planning and inhibiting a response) and general intellectual functioning than a well-matched comparison group of their typically developing peers. Importantly the study found social cognition is the most important and only predictor associated with adaptive functioning (life skills) at school for children with FASD. Other factors such as IQ, executive functioning, verbal skills and adverse childhood experiences are no longer independent predictors of adaptive functioning at school when considered simultaneously with social cognition. In particular it seems that recognising emotions on adult's faces was the most important social-cognitive factor influencing adaptive functioning at school of children with FASD.

If we are to use our findings to try and inform the development of positive solutions for these children and their whānau the next step is to interpret and examine these findings and the context in which they occur within a Te Ao Māori perspective. This next section will outline key concepts and values of Māori society and discuss why social and emotional competence is so important within a Te Ao Māori world view and the context in which these children are growing up.

#### **Structure of traditional Māori society**

Māori society and structure was organised in terms of whakapapa with people living in kin groups; iwi (tribe), hapū (sub tribe), whānau (family) (Walker, 2004). Although there may have been one primary allegiance, ties could be established with other kin groups through participating in common activities, whether it be work or leisure (Ministry of Justice, 2001). This structure relied on social connectedness, and the strength of the whānau, hapū and iwi was

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determined by ascertaining whanaungatanga especially with regard to defence in times of war (Ministry of Justice, 2001).

Social connectedness was not just important for societal structure but also in the passing down of values and beliefs. Oral traditions such as the sharing of pūrākau (myths and tribal narratives) and whakataukī (proverbs) were used to establish the principles and laws of the people (Rameka, 2016). Decisions were made by consensus rather than authoritarian approaches. Thus learnings were imparted through social dialogue and extensions or adjustments to principles and laws occurred through discussion and agreement.

The structure and values within Māori society requires and demonstrates a highly developed level of social and emotional competence. Especially in a traditional society, Māori needed to be able to understand the emotions, intents and beliefs of others, reflect on others position, compare with their own and then find solutions that made sense to all. Metaphors were often used and orators need to be *“flowing and entertaining but have order and structure to ensure remarks are not misinterpreted”* (Durie, 2001, p. 88). Difficulties such as those observed in the current study; e.g. executive functioning impairments (planning thinking flexibly and stopping an automatic impulse), language difficulties, learning problems, would have greatly impacted a person’s ability to function at this level. However, this is where living as a collective demonstrated great benefits as people were able to have a specific role in the community whilst being supported by others.

Solving problems in accordance with tikanga also required a high level of social and emotional competence. The Ministry of Justice (2001) commissioned a report He Hīnātore ki Te Ao Māori which aimed to provide a Māori perspective’ on justice issues and processes. In this report they gave examples of how justice issues would be solved in accordance with tikanga. A key concept in providing solutions within a Te Ao Māori perspective was stated as

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being *“It is important for different members of the collective to recognise and observe their own position and the relationship with the wider group by respecting social and cultural boundaries they should operate in”* (Ministry of Justice, 2001, p. 97). Challenges in social and emotional skills such as emotion recognition, theory of mind, understanding another person’s perceptive, intentions and beliefs are therefore cornerstone to identifying and solving issues in accordance to tikanga.

The concept of Whakawhanaungatanga, finding connection and building relationships, is fundamental in Māori society and is essential to a creating a secure identity and establishing an effective system of support, which in turn facilitates overall wellbeing (Cherrington, 2009; Durie, 2016; Forrest et al., 2016; Ministry of Justice, 2001). Whakawhanaungatanga also plays an important role in the patient and health professional relationship to as engagement is key to effective health interventions for Māori (Levack et al., 2016; Pitama, Huria, & Lacey, 2014; Walker et al., 2017). Social and emotional competence therefore not only facilitates a secure identity but also contributes to how that individual may or may not broker the health services that they need. Being unable to recognise emotions on faces may incur misunderstanding and hinder the establishment of positive relations. The children in this study exhibited poor social and emotional skills and have an increased need for support and supervision, however due to their difficulties they may be less likely to be able to form the relationships and connections that will help garner the assistance they require.

Values of Manaakitanga (kindness and sharing) and Aroha (love, compassion and respect) are central to Te Ao Māori pedagogy (Durie, 2001; Macfarlane et al., 2017). However in order to demonstrate kindness you must first realise that someone is in need of care. In the present study the children with FASD demonstrated significant impairment in reading emotions on adult’s faces and this was an important predictor for successful adaptive functioning at school. Children who find it difficult to interpret others emotions may be less

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likely to show kindness and caring, not because they are ‘mean’ or ‘unfriendly’ but because they haven’t recognised another person is sad, angry or scared. Teachers can support students in these processes by showing Manaakitanga and Aroha to students with FASD, however this first requires Whakawhanaungatanga between the student and teacher. The findings of the present study support research that has identified significant impairments in the social and emotional competence of children with FASD. If the teacher is not aware of these difficulties or does not focus on supporting social and emotional learning then the process of Whakawhanaungatanga is likely to be very difficult.

Today Māori also require a higher level of social and emotional competence for day-to-day functioning within both Māori and Pākehā worlds. As illustrated above social and emotional skills are essential to the tikanga and Māori concepts of Whakawhanaungatanga, Manaakitanga, and Aroha. Before colonisation occurred, members of the whānau and hapū lived together collectively. If someone had difficulty managing their social connectedness then others would be there to support. The impacts of colonisation and urbanisation have meant that people are often living independently from their whānau and at a distance from their ancestral land. Therefore support structures may not be available, and children despite significant challenges in the area of social and emotional competence, are required to independently manage themselves both at home and at school. Moreover many of the children and whānau in this study experienced psychosocial complexities such as trauma and poverty which often require higher levels of emotional competence to manage and recover from.

A triple jeopardy exists where children with FASD have significant difficulties managing social situations, parents may have less emotional availability due to managing stressors of trauma and poverty, and support is no longer able to be garnered to the same extent as would have happened when living collectively. The health and education systems try to offer support, but as detailed in Chapter Six this is fragmented and often these children and

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their whānau fall through the cracks. The health system is based on diagnosis and therefore creates barriers to those who need support where their individual diagnosis does not broker access to services. Systems need to recognise holistic need and ensure whānau who need support have access to services. The solutions need to not only focus on building social and emotional competence in the child, but also to focus on building competence and well-being within the whānau. Interventions and supports need to be based on holistic Māori models which address also build upon values such as Whakawhanaungatanga, Manaakitanga, and Aroha.

### **Alternative solutions – Māori models of health**

The present study evaluated the association of IQ and adaptive behaviour and found that IQ did not have a strong relationship with adaptive functioning (home or school) for the comparison or FASD group. This raises an important question as to whether service delivery based on diagnosis of individual problems e.g. Intellectual Disability, is valid. These children with FASD experienced multiple impairments across many domains which must also be considered in a holistic context. Furthermore children in the FASD group experienced multiple risk factors in psycho-social and environmental complexity. Service eligibility based around a diagnosis that is focused on IQ as a key determinant of adaptive functioning is therefore limited and will not necessarily target the most vulnerable.

In terms of the study findings it may seem feasible and useful to use measures of adaptive functioning for service eligibility rather than a diagnosis of Intellectual Disability which still relies on an IQ score under DSM-IV-TR (American Psychiatric Association, 2000). However, relying on adaptive functioning scores, as they are currently measured, is problematic not only in terms of construct reliability and validity issues (Edwards & Greenspan, 2010; Greenspan et al., 2016; Tassé, 2009), but also because it again focuses on

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the individual and does not consider the whole person and their wider psychosocial environment.

It is also important to not only examine the challenges but also the positive aspects within the whānau and community; for example, three quarters of the whānau in this study were connected to their Marae and the majority could identify strengths in their child. Positive outcomes are driven by warm and supportive environments therefore criteria to access support services must include whānau and school needs.

Māori Models of health provide a holistic basis to review need within a culturally safe and appropriate context. Within Te Whare Tapa Whā we can see that current services are separately brokered around one of the four components. Difficulties in taha hinengaro may broker service to the individual child in health (Disability, Mental Health) or education services. However as outlined above many of the children with FASD in this study did not meet the criterion thresholds required to access these services. When services are brokered on separate components we can lose the cumulative effect when a number of risks/issues are present. Many children with FASD also experience the complexities of poor physical health, housing issues, (Taha tinana), whānau separation or issues such as family violence (taha whānau), and loss of connection to their land and where they belong (taha wairua). Moreover children who experience prenatal substance exposure may be more vulnerable to the impact of environmental adversity (Yumoto et al., 2008). If eligibility for service is based on each issue considered separately then the system (such as the current New Zealand system) will inevitably fall well short of supporting these children and their whānau in a culturally appropriate way.

### **Impact of Colonisation**

Before examining this concept of holistic service criteria, we must acknowledge that social disadvantage is connected to historical and current trauma. Māori, as Indigenous people

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experienced trauma through this process of colonisation which constituted loss of land, a suppression of traditional laws and rituals, and subsequent poverty (Rangihau, 1988; Saggars & Gray, 1998; Walker, 2004) and it is clear that historical trauma has contributed to the current inequities that Māori are facing today (Durie, 2001; Lawson-Te Aho & Liu, 2010; Walker, 2004). However, Reid, Taylor-Moore and Varona (2014) go further and suggest that trauma is transmitted through generations by the establishment of “fundamental societal level structural and systemic changes brought about by the process of colonisation” (p. 526). The findings of the current study found that only 39% gained access to disability services. Furthermore none of the children would be eligible for speech and language services due to being over the age of 8 and few present with mental health issues that fit a child and adolescent family service. These children have severe neurological impairments, with many having experienced a number of Adverse Childhood experiences, within the context of a colonised society and Pākehā systems. Our current health and education systems disadvantage Māori by not providing access to appropriate support to our most vulnerable whānau. This is called institutional racism.

### **Institutional Racism**

A description on ‘institutional racism’ can be found in Puao-te-ata-tu (daybreak) ministerial report for the Department of Social Welfare which says “It is a bias in our social and administrative institutions that automatically benefits the dominant race or culture, whilst penalising minority and subordinate groups” (Rangihau, 1988, p. 78). The report discusses how Māori are disadvantaged from a monocultural bias that may be invisible to those inside the systems as it is perceived as the norm. Institutional racism does not assume that those people working in the system are racist. Instead the institutional bias does not serve nor address the needs of the minority group and in fact further disadvantages them.

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Puao-te-ata-tu was written in 1988 and although there have been improvements in training, communication and practice with regard to Māori, evidence still exists for institutional racism and marginalisation (Came, Doole, McKenna, & McCreanor, 2017; Came, 2014; Walker et al., 2017; Wepa, 2016). Institutions and service criteria that are established within a Pākehā culture do not always recognise the need for Māori issues to be considered within Māori models of health and wellbeing. Government strategy and policy aims to base itself on best practice, however best practice is often founded on international research which may not always be applicable to the Aotearoa New Zealand context (Came, 2014).

The present study has found a large proportion of the children referred for an FASD assessment are Māori and the way services are contracted for these children are fragmented with many children denied access to tertiary health service despite presenting with significant need. This gives an example of how western/Pākehā models of health, especially when they are formed around diagnoses, do not acknowledge and support the level of need that is present. It is true that these Pākehā, or western, models of health may not also satisfy the needs of either Pākehā or any other cultural group who experience FASD. However in general Pākehā are not experiencing the corresponding, historical trauma, level of inequality and social disadvantage that is present within Māori communities (Hawke's Bay District Health Board, 2014; Ministry of Health, 2015). Māori have specific cultural needs that must be viewed in a holistic way to in order to address the increasing risk factors that threaten a positive life experience for a child with FASD.

### **Kaupapa Māori and mainstream services**

The evidence suggests Kaupapa Māori interventions may be the most effective for Māori (Durie, 2001; Rankine, Gregory, Tonks, & Thompson-Evans, 2013). Examples such as PATU™ (Forrest et al., 2016) which focuses on whanaungatanga (relationships and connectedness) to reduce obesity, and Aukati Kaipapa (Dowden & Taite, 2001) (Māori

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smoking cessation programme) show how positive changes can occur when it is based within a Māori worldview. However not all Māori have the benefit of Kaupapa Māori Health providers especially when the need is for specialist services. Therefore mainstream services need to provide service in a way that supports the culture of the client. Clinicians are taught to conceptualise a person in a holistic way and holistic frameworks are not foreign concepts to psychologists, medical professionals and other therapists who generally work within a biopsychosocial model (Engel, 1980). Clinicians, with appropriate support and training, should be able to incorporate Māori Models of health into their practice (Durie, 2016). What is still missing, is the holistic view when brokering services. Service provided on the basis of IQ, or, presence of a mental health issue in an individual, provides a fragmented way of understanding health and well-being. It is the systems and structures, alongside the professionals, that need to change to align with Māori models of health.

### **Summary**

The present study found children with FASD perform poorly on multiple measures including their ability to function in everyday life both at home and at school. Social and emotional competence is the most important predictor of adaptive functioning in children with FASD and social and emotional skills form the foundation of a Māori world view and values such as whanaungatanga, Manaakitanga and Aroha. These children also experience many risk factors (low socio-economic status, multiple placements and history of adverse childhood experiences). They need specific services that understand all of these elements to ensure children and whānau receive appropriate support. In order to develop social and emotional skills in children and facilitate change from a Te Ao Maori perspective we need to utilise Māori models which recognise historical trauma and empower cultural identity. Institutional racism can be reduced by providing system/service criteria which is based on the holistic need of the child and whānau.

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### **Chapter Eight: Implications and solutions for service delivery and interventions**

The present study found that in a sample of 8-11 year old New Zealand children social and emotional cognition, especially emotion recognition, is the most important predictor of adaptive functioning at school for children with FASD. Most of the children and whānau in the present study identified as being of Māori descent and over 70% of Māori children from both comparison and FASD groups had some connection with their Marae. Solutions therefore must be considered and developed within a Māori worldview.

It is important to recognise that Māori society is founded on collective philosophies where highly developed social and emotional skills are required for many practices such as whakawhanaungatanga (building relationships), manaakitanga (caring for others) and wānanga (traditional knowledge and learning). It seems then that Kaupapa Māori interventions may best fit the needs of Māori with FASD (Durie, 2001; Rankine et al., 2013). However, such interventions are not currently readily available suggesting that solutions need to be found that encapsulate both Māori and western psychological approaches to maximise the potential to meet the needs of children with FASD and their whānau living in contemporary NZ society.

He Awa Whiria (Braided rivers model) acknowledges two bodies of knowledge (both Western Science and Kaupapa Māori) as being important when developing programmes and interventions (Macfarlane, Blampied, & Macfarlane, 2011). In this model both Western Science and Kaupapa Māori methodologies have a bidirectional role and both are able to inform programmes developed in each domain. Programmes are also evaluated from both perspectives and are deemed effective when both Western Science and Kaupapa Māori evaluations reach consensus for effectiveness. This type of model would be appropriate for children with FASD in the present study as clinical practice and research would be useful if developed alongside a Kaupapa Māori knowledge base and framework.

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Services and programmes need to encapsulate a holistic view of support needs due to the high levels of psychosocial complexity experienced by children in the FASD group. Māori models of health such as Te Whare Tapa whā provide a basis to identify whānau strength and resilience as well as areas that need support and intervention. However, colonisation and urbanisation have meant people are required to be more independent so there is also a need to build skills in the individual child (social skills training) as well as whānau and community. The next few sections will discuss the research findings to identify ways to potentially improve services for children with FASD and their whānau from both a western clinical and Kaupapa Māori services perspective.

### **Building skills in the child**

In the present study children with FASD demonstrated significant difficulties in their ability to recognise emotions on people's faces, take another person's perspective and use social and emotional knowledge to solve a problem. Furthermore these skills were the strongest predictor of adaptive functioning at school. It is important to note that the majority of children in both the FASD and comparison groups were Māori and, although tools were developed in western cultures, it was evident that children with FASD performed much lower than the comparison children who performed in accordance to the measures normative data.

In light of the present findings it makes sense that assessments for FASD include examination of a child's social and emotional abilities. Performance based information around social skills is important but it is also important to triangulate information with observations and report from parents and teachers. The findings from the present study showed that parent and teacher report on adaptive functioning can differ. Understanding social and emotional skills in different contexts is important to guide interventions. Overall, we may speculate that interventions that aim to improve social and emotional skills will improve the child with FASD's ability to function in everyday life.

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Self-regulation is an important conduit to social and emotional competence. If children are unable to calm and regulate themselves then they are more likely to engage in hostility, aggression and misattribution (Lengua, Sandler, West, Wolchik, & Curran, 1999; Nash et al., 2014; Shields, Cicchetti, & Ryan, 1994). In the current study a high proportion of the children with FASD demonstrated maladaptive behaviour in the clinical range that included aggression, meltdowns, impulsivity and inattention and 62% also met criteria for a diagnosis of Attention Deficit Hyperactivity Disorder. Correspondingly scores on the Inhibition task were extremely low for children with FASD. The profile of these children from both performance and report measures indicates self-regulation is a key point for intervention.

The prevalence of difficulties such as impulsivity, inattention and disinhibition in children with FASD have led some researchers to become interested in the ALERT program for self-regulation®. The ALERT program focuses on self-regulation and building skills in children to recognise their own arousal and emotional states. This program has been associated with improvements in executive functioning skills, social cognition and emotional problem solving (Nash et al., 2014; Soh et al., 2015; Wells et al., 2012) although there has been limited evaluation whether these improvements have been sustained over time and generalised to the classroom environment.

In addition the Child Friendship Training (CFT) (Frankel & Myatt, 2003) was adapted for children with FASD (Laugeson et al., 2007) and has been successful at reducing hostile attributions, improving social skills and reducing behaviour problems (Keil et al., 2010; O'Connor et al., 2006; O'Connor et al., 2012). However these improvements were found via parent ratings and clinic performance-based measures and when teachers were asked to rate social skills and behaviour problems, no improvements were noted at school (O'Connor et al., 2006).

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In the Child Friendship Training programme both children and their parents, but not teachers, take part in the training. The increased understanding in parents may have thus provided a more supportive environment at home where the child was more able to demonstrate appropriate social behaviour. Without teachers having that integral FASD knowledge, and ability to provide individual support, children were not able to demonstrate aforementioned improvements in the school environment, adding weight to the argument that interventions need to somehow involve the whole whānau system which includes teachers at school.

Furthermore, when reviewing the Child Friendship Training programme it seemed the focus was on peer interaction e.g. joining play, being a good sport, how to handle teasing rather than building specific skills around recognising and interpreting emotions. The present study found recognising emotions on adults faces was a key predictor of adaptive functioning at school and therefore inclusion of interventions aimed at improving these skills may help build social and emotional competence, which may improve overall adaptive functioning at school.

### **Building support in the whānau.**

Whilst it is important to focus on building skills in the child, interventions must recognise the importance of adult (parents/caregivers, teachers) support and guidance. However support from parents and caregivers may be difficult to give when they themselves are experiencing many other stressors e.g. financial stress, trauma, mental health difficulties and substance issues. As discussed in Chapter Six, many of the children in this study have experienced high levels of Adverse Childhood Experiences such as abuse, neglect, exposure to family violence, household substance use, household mental illness, and parental separation. In addition, many live in households with low socioeconomic status and do not live with their birth parents. This psychosocial complexity highlights the need for wrap around support not just for the child but also the whānau.

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The children in the present study also demonstrated significant difficulties in their ability to communicate, organise themselves, think flexibly, and stop automatic impulses. They require *much* more supervision than a typically developing child of the same age. The whānau looking after these children have an increased need for support due to the challenges of caring for a child with FASD and coping with other stressors both social and financial.

Interventions must focus on supporting whānau as well as improving the social and emotional skills in the child. In terms of the previously mentioned programmes (CFT and ALERT program) both have a strong parent/caregiver component than builds understanding, compassion and response strategies to support their children (O'Connor et al., 2012; Wells et al., 2012). In the wider literature interventions that focus on improving attachment and creating security for the child have been shown to decrease problem behaviours and increasing parental sensitivity (Alto & Petrenko, 2017). In the FASD literature parental education and training have also been found to be a key component of a variety of interventions (Bertrand, 2009, Study 4; Coles, Kable, & Taddeo, 2009; Kable, Coles, Strickland, & Taddeo, 2012). Specific intervention programmes such as 'Families Moving Forward' (Bertrand, 2009, Study 5; Petrenko, Pandolfino, & Robinson, 2017) have aimed at increasing skills and capacity of the child's immediate family. Whilst these programmes are not specifically aimed at social and emotional learning they have been found to, increase parental knowledge, reduce parental distress and improve problem behaviours (Bertrand, 2009, Study 5; Coles et al., 2009; Kable et al., 2012; Petrenko et al., 2017). Supporting the whānau to understand the child appears to be a consistent part of successful interventions with children experiencing FASD.

In Te Ao Māori the concept of whānau should not be limited to blood relatives but include other individuals who have a close relationship with the child e.g. teachers and family friends (Cherrington, 2009). Furthermore, a supportive school environment is important for

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academic and social success and thus teachers play an important role in a child with FASD's support network (Clark et al., 2014; J. H. Green, 2007).

School professionals have also called for the need to consider the holistic needs of the child and recognise that capabilities must be built across the whole school environment (Pei, Job, Poth, & Atkinson, 2013; Poth, Pei, Job, & Wyper, 2014). However, as outlined above with the Child Friendship Training and ALERT Program, there has been limited intervention research in the area of social and emotional learning for children with FASD in the school environment.

In the wider educational literature, a meta-analysis involving 213 school-based Social and Emotional Learning (SEL) programmes, involving typically developing children from kindergarten to high school, found SEL was associated with improved social and emotional capability, more positive behaviour and academic achievement (Durlak et al., 2011). Goals for SEL as proposed by the Collaborative for Academic, Social and Emotional Learning (CASEL) include improved self-awareness, self-management, social awareness, relationship skills, and responsible decision making (Greenberg, Domitrovich, Weissberg, & Durlak, 2017). However, any social and emotional learning programmes targeted at the general population would need adjustment to accommodate individual cognitive and adaptive profiles of children with FASD. The current study found social cognition, especially recognising emotions on adult's faces was a strong predictor of adaptive functioning at school, suggesting these areas may be a key focus for intervention.

Children with FASD have a need for increased support by their parents/caregivers, teachers and wider whānau. In general children with FASD have difficulty adapting knowledge to new situations (Davis et al., 2013) therefore adults around them need to increase their understanding, respond to the individual profile of the child and often provide higher

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levels of supervision and guidance. If this can't be accessed through natural supports then the whānau need to have access to health and education services regardless of whether the child has an Intellectual Disability. Whānau-based interventions have support in the international FASD literature (Bertrand, 2009; Reid et al., 2015) and are also cornerstone in culturally-responsive interventions for Māori (Durie, 2001). The following section will review important cultural considerations in interventions that support social and emotional learning both at home and in the classroom.

### **Developing solutions that are culturally responsive.**

Recommendations and proposed interventions for children with FASD must be entrenched within a culturally responsive framework and programmes need to address the cultural needs and “collaborate with local stakeholders” (Petrenko & Alto, 2017, p. 88). In the present study many of the children and their whānau identified as being Māori and therefore solutions must be responsive under a Te Ao Māori framework.

However, this does not mean that solutions developed with reference to both Western Clinical and Kaupapa Māori service approaches will not also be useful to children of other ethnicities. Findings that point to the need for greater acknowledgement and interventions in the area of social and emotional cognition are found in the international literature, suggesting these focus points are important across a range of cultures. For Māori, however, relationships and connectedness form the basis of their whole society and epistemological infrastructure and are therefore argued to be particularly critical.

Durie (2004) was in agreement with developmental and educational psychologists (Bruner, 1996; Vygotsky, 1978) when he stated that relationships are fundamental in a learning environment and “*Learning is more likely to occur where there is positive relationship between teacher and learner; where aspirations overlap; and where teachers can engage with learners*

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*at a personal level*” p. 128. In the present study, the strong relationship between adaptive functioning at school and social and emotional competence in children with FASD, especially recognising emotions on adult’s faces, provides evidence that children who have difficulty with social and emotional skills also find it hard to function independently and academically at school.

Children with FASD experience so many more learning challenges, that it is logical that they require *more* connection, support and positive relationships in order to achieve success and independence at school. However, these children’s social and emotional difficulties mean that their ability to form connections may be the most fundamental of their problems. Whānau and teachers need to understand this and support these children to initiate and maintain relationships and connections if they are to succeed at school.

School success is extremely important not just in childhood but for the whole lifespan. *“Next to whānau, schools are foundational to the process of enabling young people to become active participants in, and contributors to society.”* (Macfarlane, 2016, p. 226). The findings of the present study show that children with FASD experience significant learning difficulties, behaviour problems and have often been exposed to high levels of environmental stressors such as abuse, neglect, poverty and household substance and mental health issues. The present study also found no relationship between parent/caregivers and teachers rating of adaptive functioning. This suggests that children may function differently in different environments and/or may be perceived differently by different raters. It is therefore important that both home and school are involved in planning and support programmes so that the whole child is understood.

In order to establish holistic and coordinated support, positive relationships need to be built between whānau and school (Macfarlane, 2016). Professionals working with whānau

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may have access to holistic Māori frameworks such as; Te whare tapa whā (Durie, 1994), Te Wheke (Pere, 1991), Te Whāriki (Early Childhood Curriculum) (Ministry of Education, 2017), Te Pae Māhutonga (Durie, 1999) that can be useful in identifying strengths and areas of difficulty across many areas. As outlined in Chapter Seven children with FASD often have needs in all of the four pillars of Te whare tapa whā: Taha hinengaro (mental and emotional health), taha tinana (physical health), taha whānau (family health), and taha wairua (spiritual health). Māori models of health therefore provide a solid framework for assessment and intervention guidance.

Furthermore, it is imperative that any interventions that are proposed are both whānau based (Cherrington, 2009; Cram, 2012; McLachlan, Levy, McClintock, & Tauroa, 2015) and school based. As discussed earlier FASD interventions failed to show improvements in the classroom when only the child and parents were involved (O'Connor et al., 2006). It is counterproductive to build capacity in the child without building skills in their environment. Whānau need to be empowered and feel connected. Clinicians need to focus on whanaungatanga and ensure they are addressing factors that empower Māori.

Health and education professionals need to increase their understanding about the context of Aotearoa and why Māori are experiencing a great deal of inequity. Participating in decolonisation workshops will increase understanding about Pākehā privilege and how this has affected Māori both historically and in current society. Government policies must also address the effects of colonisation and focus on child and whānau poverty and trauma. Institutional racism will only diminish when governments and professionals increase their understanding of colonisation, and subsequently design systems and services that address the holistic needs of Māori.

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Being culturally responsive means we also need to consider not only a holistic approach to supporting children with FASD but also how any proposed programmes are delivered in a culturally competent way. Durie (2001; 2016) introduces the Marae model as a way of understanding different patterns of thinking that need to be considered if programmes are to be culturally responsive (see Table 15). Future interventions and programmes aimed at supporting children and their whānau with FASD, need to understand the differences in patterns of thinking and behaviour between Māori and Tauīwi (Non-Māori). Moreover, to be culturally responsive, western clinical interventions will need to be adjusted in order to incorporate a more culturally competent framework that better reflects the children and whānau involved.

Table 15.

### *Marae and non-Marae Patterns of Thinking and Behaving*

|                                       | Marae   | Non-Marae  |
|---------------------------------------|---|--|
| Direction of psychological energy     | Outwards, away from smaller and towards larger levels.<br>Relationships are end points                        | Inwards, towards smaller units.<br>Individuation is an end point.  |
| Progression of thoughts and behaviour | Bounded and ordered.<br>Sequence shaped by nature of relationships.   | Time is a limiting factor.<br>Activity accommodates time available.  |
| Communication styles                  | Abstract and inferential.<br>Meaning comes from context.<br>Integration of cognition, emotion.                | Economic use of words.<br>Meaning comes from preciseness and detail.<br>Separation of thoughts and feelings. |
| Identity formation                    | Composite identity, grounded in land. Identity embraces self, others, environment.<br>Portability is limited. | Identity reflects capacity for individuation. Identity is portable.  |

*Note.* Reprinted From *Mauri Ora: The Dynamics of Māori Health* (p. 90) by M. Durie, 2001, Melbourne, Australia. Copyright (2001) Oxford University Press. Reprinted with permission

An example of the differences between Marae and Non Marae can be found with Western psychology which tends to sit in the non Marae space. Even though relationships are

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recognised as important, they are considered within a formulation of the individual. For Maori relationships are the end point and not a mechanism for individual wellness. It is therefore important that interventions not only aim to build skills in the child with FASD, but they also have a fundamental aim to strengthen relationships for the child, whānau, and their community.

Identity is another important focus for intervention as for Māori a secure identity is often associated with sustainable well-being (Cherrington, 2009; Durie, 2016; Forrest et al., 2016; Ministry of Justice, 2001). In addition, identity is founded through connections whether that be with the land or human relationships (Durie, 2001; Lawson-Te Aho & Liu, 2010). The findings of the present study found children with FASD have significant challenges in their social and emotional skills, which in turn affects their ability to make connections. Interventions that address the social and emotional needs of children with FASD need to be embedded within support programmes and interventions if children with FASD are to develop a secure identity and connection with their culture.

Connection with Marae (as noted above and in Chapter Seven) is arguably one obvious way to try and build identity and stronger relationships (people and environment), but due to the transience of contemporary society many Māori do not have regular physical contact with their Marae. However the Marae atea (space) that Durie (2001) describes can be used as a metaphor to guide how interventions can be delivered with regard to negotiation, space, time and ways of thinking. All interventions whether they are aiming at building skills in the child, whānau (parents/caregivers and teachers) or wider environment can sit in the Marae space.

International studies that show promise in developing social emotional skills (Keil et al., 2010; Nash et al., 2014; O'Connor et al., 2006; Wells et al., 2012) also need to be adapted to ensure the content fits with a Te Ao Māori perspective. The use of holistic Māori models such as Te whare tapa whā (Durie, 1994), Te Wheke (Pere, 1991), Te Whāriki (Early

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Childhood Curriculum) (Ministry of Education, 2017), Te Pae Māhutonga (Durie, 1999) provide a foundation for assessment and direction for intervention that could be used to sit alongside the international interventions to see if synergy can be obtained. The Marae model must not be confined to the physical Marae. Instead we need to incorporate Māori knowledge and frameworks into institutional (health and education) processes to increase access and participation in services for children and their whānau experiencing FASD.

### **Future Research**

This study has shown that IQ has a limited relationship to everyday adaptive functioning and IQ in this sample of children with FASD. Furthermore their significant impairments in social and emotional skills appear to be strongly related to adaptive functioning, especially at school. In particular recognising emotions on adults faces appear to be strongly related to children's adaptive functioning at school.

These findings may have important implications in the quality of life and individuals with FASD experience. Children, adolescents and adults with FASD experience life-long adversity and many are excluded from school, victimised and exploited (Fraser, 2008; Morrisette, 2001; Streissguth et al., 1996). Maintaining positive relationships with not only their peers but also with the adults that support them is likely to be a protective factor. However their own social and emotional abilities may mean they respond inappropriately and need others to understand their difficulties as they are unable to form positive relationships by themselves. It is possible that the inability to form relationships is key to why children and adolescents are excluded, however, more research is required in this area to further understand the drivers of school exclusions for children and adolescents with FASD. Intervention research which examines the outcomes of social skills training alongside a whānau support model would be useful to know whether this is an effective treatment option. Outcomes need to not just be evaluative from a clinical perspective but also encompass Māori values and frameworks.

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### Summary

Children with FASD experience significant learning and behaviour difficulties, often in the context of psychosocial complexity. Furthermore, impairments in social and emotional cognition appear to be the most important influence on adaptive functioning especially at school. These children may have challenges, in all of the pillars of Te Whare Tapa Whā: psychological/emotional (taha hinengaro), family/environmental (taha whānau), spiritual (taha wairua) and physical (taha tinana) health. Support needs to be accessed on the wider needs of the individual *and* whānau rather than individual diagnostic label.

The current western or Pākehā models of care can be considered an example of institutional racism as they dramatically fall short of providing access and support to Māori with FASD. In the long-term Aotearoa/ New Zealand needs a system that provides accessibility and interventions need to consider a collective approach and holistic models of care if we are going to truly address inequity and complexity of all children and whānau who live with FASD.



## References

- Abikoff, H. B., Jensen, P. S., Arnold, L. E., Hoza, B., Hechtman, L., Pollack, S., . . . Hinshaw, S. (2002). Observed classroom behavior of children with ADHD: Relationship to gender and comorbidity. *Journal of Abnormal Child Psychology*, *30*(4), 349-359. <https://doi.org/10.1023/A:1015713807297>
- Achmadi, D., Sigafos, J., van der Meer, L., Sutherland, D., Lancioni, G. E., O'Reilly, M. F., . . . Marschik, P. B. (2014). Acquisition, preference, and follow-up data on the use of three AAC options by four boys with developmental disability/delay. *Journal of Developmental and Physical Disabilities*, *26*(5), 565-583. <https://doi.org/10.1007/s10882-014-9379-z>
- Ajwani, S., Blakely, T., Robson, B., Tobias, M., & Bonne, M. (2003). *Decades of disparity: Ethnic mortality trends in New Zealand 1980-1999*. Wellington: Ministry of Health and University of Otago. Retrieved from <http://www.otago.ac.nz/wellington/otago024494.pdf>
- Akbar, M., Loomis, R., & Paul, R. (2013). The interplay of language on executive functions in children with ASD. *Research in Autism Spectrum Disorders*, *7*(3), 494-501. <https://doi.org/10.1016/j.rasd.2012.09.001>
- Ali, S., Kerns, K. A., Mulligan, B. P., Olson, H. C., & Astley, S. J. (2017). An investigation of intra-individual variability in children with fetal alcohol spectrum disorder (FASD). *Child Neuropsychology*, *1-21*. <https://doi.org/10.1080/09297049.2017.1302579>
- Alto, M. E., & Petrenko, C. L. (2017). Fostering secure attachment in low-and middle-income countries: Suggestions for evidence-based interventions. *Evaluation and Program Planning*, *60*, 151-165. <https://doi.org/10.1016/j.evalprogplan.2016.11.003>
- Alvik, A., Haldorsen, T., Groholt, B., & Lindemann, R. (2006). Alcohol consumption before and during pregnancy comparing concurrent and retrospective reports. *Alcoholism: Clinical and Experimental Research*, *30*(3), 510-515. <https://doi.org/10.1111/j.1530-0277.2006.00055.x>
- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders: (DSM-5®)*. Arlington, VA: American Psychiatric Publication.
- American Psychiatric Association, (2000). *Diagnostic and statistical manual of mental disorders. Fourth Edition, Text Revision*. Washington, DC: American Psychiatric Association.
- Anastasi, A. (1986). Evolving concepts of test validation. *Annual Review of Psychology*, *37*(1), 1-16. <https://doi.org/10.1146/annurev.ps.37.020186.000245>
- Anda, R. F., Felitti, V. J., Bremner, J. D., Walker, J. D., Whitfield, C. H., Perry, B. D., . . . Giles, W. H. (2006). The enduring effects of abuse and related adverse experiences in childhood. *European Archives of Psychiatry and Clinical Neuroscience*, *256*(3), 174-186. <https://doi.org/10.1007/s00406-005-0624-4>
- Anda, R. F., Whitfield, C. L., Felitti, V. J., Chapman, D., Edwards, V. J., Dube, S. R., & Williamson, D. F. (2002). Adverse childhood experiences, alcoholic parents, and later

- risk of alcoholism and depression. *Psychiatric Services*, 53(8), 1001-1009. <https://doi.org/10.1176/appi.ps.53.8.1001>
- Anderson, P. (2002). Assessment and development of executive function (EF) during childhood. *Child Neuropsychology*, 8(2), 71-82. <https://doi.org/10.1076/chin.8.2.71.8724>
- Anderson, V., Anderson, P., Northam, E., Jacobs, R., & Catroppa, C. (2001). Development of executive functions through late childhood and adolescence in an Australian sample. *Developmental Neuropsychology*, 20(1), 385-406. [https://doi.org/10.1207/S15326942DN2001\\_5](https://doi.org/10.1207/S15326942DN2001_5)
- Anderson, V., & Beauchamp, M. (2012a). *Developmental social neuroscience and childhood brain insult: Theory and practice*. New York: The Guilford Press.
- Anderson, V., & Beauchamp, M. (2012b). SOCIAL: A theoretical model of developmental social neuroscience. In V. Anderson, & M. Beauchamp (Eds.), *Developmental social neuroscience and childhood brain insult: Theory and practice* (1st ed., pp. 3). New York: The Guildford Press.
- Anderson, V., Beauchamp, M. H., Yeates, K. O., Crossley, L., Ryan, N., Hearps, S. J., & Catroppa, C. (2017). Social competence at two years after child traumatic brain injury. *Journal of Neurotrauma*, 34(14), 2261-2271. <https://doi.org/10.1089/neu.2016.4692>
- Anzai, Y., & Simon, H. A. (1979). The theory of learning by doing. *Psychological Review*, 86(2), 124-140. <https://doi.org/10.1037/0033-295X.86.2.124>
- Aragón, A. S., Kalberg, W. O., Buckley, D., Barela-Scott, L. M., Tabachnick, B. G., & May, P. A. (2008). Neuropsychological study of FASD in a sample of American Indian children: Processing simple versus complex information. *Alcoholism: Clinical and Experimental Research*, 32(12), 2136-2148. <https://doi.org/10.1111/j.1530-0277.2008.00802.x>
- Arán-Filippetti, V., & Richaud De Minzi, M C. (2012). A structural analysis of executive functions and socioeconomic status in school-age children: Cognitive factors as effect mediators. *Journal of Genetic Psychology*, 173(4), 393-416. <https://doi.org/10.1080/00221325.2011.602374>
- Arsenio, W. F., & Lemerise, E. A. (2004). Aggression and moral development: Integrating social information processing and moral domain models. *Child Development*, 75(4), 987-1002. <https://doi.org/10.1111/j.1467-8624.2004.00720.x>
- Astley, S. J., Aylward, E. H., Olson, H. C., Kerns, K., Brooks, A., Coggins, T. E., . . . Richards, T. (2009a). Functional magnetic resonance imaging outcomes from a comprehensive magnetic resonance study of children with fetal alcohol spectrum disorders. *Journal of Neurodevelopmental Disorders*, 1(1), 61-80. <https://doi.org/10.1007/s11689-009-9004-0>
- Astley, S. J., Aylward, E. H., Olson, H. C., Kerns, K., Brooks, A., Coggins, T. E., . . . Richards, T. (2009b). Magnetic resonance imaging outcomes from a comprehensive magnetic resonance study of children with fetal alcohol spectrum disorders. *Alcoholism: Clinical and Experimental Research*, 33(10), 1671-1689. <https://doi.org/10.1111/j.1530-0277.2009.01004.x>

- Astley, S. J. (2004). *Diagnostic guide for fetal alcohol spectrum disorders: The 4-digit diagnostic code*. 3rd ed. Seattle, WA: University of Washington Publication Services. Retrieved from <https://depts.washington.edu/fasd/pn/htmls/4-digit-code.htm>
- Astley, S. J., Bailey, D., Talbot, C., & Clarren, S. K. (2000). Fetal alcohol syndrome (FAS) primary prevention through FAS diagnosis: II. A comprehensive profile of 80 birth mothers of children with FAS. *Alcohol and Alcoholism*, *35*(5), 509-519. <https://doi.org/10.1093/alcalc/35.5.509>
- Astley, S. J., Olson, H. C., Kerns, K., Brooks, A., Aylward, E. H., Coggins, T. E., . . . Jirikowic, T. (2009c). Neuropsychological and behavioral outcomes from a comprehensive magnetic resonance study of children with fetal alcohol spectrum disorders. *The Canadian Journal of Clinical Pharmacology*, *16*(1), 178-201. Retrieved from <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4188550/>
- Astley, S. J., Stachowiak, J., Clarren, S. K., & Clausen, C. (2002). Application of the fetal alcohol syndrome facial photographic screening tool in a foster care population. *The Journal of Pediatrics*, *141*(5), 712-717. <https://doi.org/10.1067/mpd.2002.129030>
- Atkinson, J., Salmond, C., & Crampton, P. (2014). *NZDep2013 index of deprivation*. New Zealand, Ministry of Health. Retrieved from <http://www.health.govt.nz/publication/nzdep2013-index-deprivation>
- Autti-Rämö, I., Autti, T., Korkman, M., Kettunen, S., Salonen, O., & Valanne, L. (2002). MRI findings in children with school problems who had been exposed prenatally to alcohol. *Developmental Medicine and Child Neurology*, *44*(2), 98-106. <https://doi.org/10.1017/S0012162201001748>
- Baer, J. S., Sampson, P. D., Barr, H. M., Connor, P. D., & Streissguth, A. P. (2003). A 21-year longitudinal analysis of the effects of prenatal alcohol exposure on young adult drinking. *Archives of General Psychiatry*, *60*(4), 377-385. <https://doi.org/10.1001/archpsyc.60.4.377>
- Balboni, G., Incognito, O., Belacchi, C., Bonichini, S., & Cubelli, R. (2017). Vineland-II adaptive behavior profile of children with attention-deficit/hyperactivity disorder or specific learning disorders. *Research in Developmental Disabilities*, *61*, 55-65. <https://doi.org/10.1016/j.ridd.2016.12.003>
- Barker-Collo, S. L. (2001). The 60-item Boston naming test: Cultural bias and possible adaptations for New Zealand. *Aphasiology*, *15*(1), 85-92. <https://doi.org/10.1080/02687040042000124>
- Barker-Collo, S., Clarkson, A., Cribb, A., & Grogan, M. (2002). The impact of American content on California verbal learning test performance: A New Zealand illustration. *Clinical Neuropsychologist*, *16*(3), 290-299. <https://doi.org/10.1076/clin.16.3.290.13856>
- Barnea-Goraly, N., Menon, V., Eckert, M., Tamm, L., Bammer, R., Karchemskiy, A., ... & Reiss, A. L. (2005). White matter development during childhood and adolescence: a cross-sectional diffusion tensor imaging study. *Cerebral cortex*, *15*(12), 1848-1854. <https://doi.org/10.1093/cercor/bhi062>
- Barnfield, T. V., & Leathem, J. M. (1998). Neuropsychological outcomes of traumatic brain injury and substance abuse in a New Zealand prison population. *Brain Injury*, *12*(11), 951-962. <https://doi.org/10.1080/026990598122007>

- Barron-Linnankoski, S., Reinvall, O., Lahervuori, A., Voutilainen, A., Lahti-Nuuttila, P., & Korkman, M. (2015). Neurocognitive performance of children with higher functioning autism spectrum disorders on the NEPSY-II. *Child Neuropsychology*, *21*(1), 55-77. <https://doi.org/10.1080/09297049.2013.873781>
- Bass, S., Shields, M. K., & Behrman, R. E. (2004). Children, families, and foster care: Analysis and recommendations. *The Future of Children*, *14*(1), 5-29. <https://doi.org/10.2307/1602752>
- Baum, K. T. (2012). *Measurement of intelligence in children and adolescents with autism spectrum disorder: Factors affecting Performance* (Order No. 3554289). Available from Health Research Premium Collection; ProQuest Central; ProQuest Dissertations & Theses Global. (1316919120). Retrieved from <https://search-proquest-com/docview/1316919120?accountid=8424>
- Beauchamp, M. H., & Anderson, V. (2010). SOCIAL: An integrative framework for the development of social skills. *Psychological Bulletin*, *136*(1), 39. <https://doi.org/10.1037/a0017768>
- Bechara, A., Damasio, A., Damasio, H., & Anderson, S. (1994). Insensitivity to future consequences following damage to human prefrontal cortex., *50*, 7-15. [https://doi.org/10.1016/0010-0277\(94\)90018-3](https://doi.org/10.1016/0010-0277(94)90018-3)
- Berard, N. C. M. (2014). *Executive function, social emotional learning, and social competence in autism spectrum disorder* (Doctoral dissertation, University of Regina, Regina, Canada). Retrieved from <http://hdl.handle.net/10294/5735>
- Bertrand, J. (2009). Interventions for children with fetal alcohol spectrum disorders (FASDs): Overview of findings for five innovative research projects. *Research in Developmental Disabilities*, *30*(5), 986-1006. <https://doi.org/10.1016/j.ridd.2009.02.003>
- Bond, L., Butler, H., Thomas, L., Carlin, J., Glover, S., Bowes, G., & Patton, G. (2007). Social and school connectedness in early secondary school as predictors of late teenage substance use, mental health, and academic outcomes. *Journal of Adolescent Health*, *40*(4), 357.e9-e18. <https://doi.org/10.1016/j.jadohealth.2006.10.013>
- Bonner, M. J., Hardy, K. K., Willard, V. W., Anthony, K. K., Hood, M., & Gururangan, S. (2008). Social functioning and facial expression recognition in survivors of pediatric brain tumors. *Journal of Pediatric Psychology*, *33*(10), 1142-1152. <https://doi.org/10.1093/jpepsy/jsn035>
- Boseck, J. J., Davis, A. S., Cassady, J. C., Finch, W. H., & Gelder, B. C. (2014). Cognitive and adaptive skill profile differences in children with attention-deficit hyperactivity disorder with and without comorbid fetal alcohol spectrum disorder. *Applied Neuropsychology: Child*, *4*(4), 230-236. <https://doi.org/10.1080/21622965.2013.877392>
- Botvin, G. J., & Kantor, L. W. (2000). Preventing alcohol and tobacco use through life skills training. *Alcohol Research and Health*, *24*(4), 250-257. <https://doi.org/10.1002/yd.20086>
- Bower, C., & Elliott, E. (2016). Report to the Australian government department of health: "Australian guide to the diagnosis of fetal alcohol spectrum disorder (FASD)". Retrieved from <https://alcoholpregnancy.telethonkids.org.au/contentassets/>

6bfc4e8cd1c9488b998d50ea4bff9180/australian-guide-to-diagnosis-of-fasd\_all-  
appendices.pdf

- Bowers, L., Huisingh, R., & LoGiudice, C. (2005). *TOPS 3, elementary: A test of reasoning in context: Skill area: Problem solving and reasoning, developmental ages: 6-0 through 12-11 years*. East Moline, IL: LinguiSystem.
- Boxer, P., Goldstein, S. E., Musher-Eizenman, D., Dubow, E. F., & Heretick, D. (2005). Developmental issues in school-based aggression prevention from a social-cognitive perspective. *Journal of Primary Prevention, 26*(5), 383-400.  
<https://doi.org/10.1007/s10935-005-0005-9>
- Brady, D. I., Saklofske, D. H., Schwean, V. L., Montgomery, J. M., Thorne, K. J., & McCrimmon, A. W. (2017). Executive functions in young adults with autism spectrum disorder. *Focus on Autism and Other Developmental Disabilities, 32*(1), 31-43.  
<https://doi.org/10.1177/1088357615609306>
- Brave Heart, Maria Yellow Horse, & DeBruyn, L. M. (1998). The American Indian holocaust: Healing historical unresolved grief. *American Indian and Alaska Native Mental Health Research, 8*(2), 56. Retrieved from <https://search-proquest-com.ezproxy.auckland.ac.nz/docview/236003962?accountid=8424>
- Brieant, A., Holmes, C. J., Deater-Deckard, K., King-Casas, B., & Kim-Spoon, J. (2017). Household chaos as a context for intergenerational transmission of executive functioning. *Journal of Adolescence, 58*, 40-48.  
<https://doi.org/10.1016/j.adolescence.2017.05.001>
- Brown, N. N., Gudjonsson, G., & Connor, P. (2011). Suggestibility and fetal alcohol spectrum disorders: I'll tell you anything you want to hear. *The Journal of Psychiatry & Law, 39*(1), 39-71. <https://doi.org/10.1177/009318531103900103>
- Brown, N. N., Wartnik, A. P., Connor, P. D., & Adler, R. S. (2010). A proposed model standard for forensic assessment of fetal alcohol spectrum disorders. *The Journal of Psychiatry & Law, 38*(4), 383-418. <https://doi.org/10.1177/009318531003800403>
- Bruner, J. S. (1996). *The culture of education*. Cambridge, MA: Harvard University Press.
- Brusati, G. M. (2015). *A method of explaining memory deficits in children with prenatal alcohol exposure* (Master's thesis, San Diego State University) Retrieved from <https://search-proquest-com/docview/1679285104?pq-origsite=gscholar>
- Bunford, N., Brandt, N. E., Golden, C., Dykstra, J. B., Suhr, J. A., & Owens, J. S. (2015). Attention-deficit/hyperactivity disorder symptoms mediate the association between deficits in executive functioning and social impairment in children. *Journal of Abnormal Child Psychology, 43*(1), 133-147. <https://doi.org/10.1007/s10802-014-9902-9>
- Burden, M. J., Jacobson, S. W., Sokol, R. J., & Jacobson, J. L. (2005). Effects of prenatal alcohol exposure on attention and working memory at 7.5 years of age. *Alcoholism: Clinical and Experimental Research, 29*(3), 443-452.  
<https://doi.org/10.1097/01.ALC.0000156125.50577.EC>
- Came, H., Doole, C., McKenna, B., & McCreanor, T. (in press). Institutional racism in public health contracting: Findings of a nationwide survey from New Zealand. *Social Science & Medicine*. <https://doi.org/10.1016/j.socscimed.2017.06.002>

- Came, H. (2014). Sites of institutional racism in public health policy making in New Zealand. *Social Science & Medicine*, *106*, 214-220.  
<https://doi.org/10.1016/j.socscimed.2014.01.055>
- Cargo, T. (2016). Kaihau waitū: Attributes gained through a mother's milk. In W. Waitoki, & M. Levy (Eds.), *Te manu kai I te mātauranga: Indigenous psychology in aotearoa/ new zeland* (pp. 242-269). Wellington, New Zealand: The New Zealand Psychological Society.
- Centers for Disease Control and Prevention. (2016). CDC-kaiser ACE study. Retrieved from <https://www.cdc.gov/violenceprevention/acestudy/about.html>
- Chandler, S., Howlin, P., Simonoff, E., Kennedy, J., & Baird, G. (2016). Comparison of parental estimate of developmental age with measured IQ in children with neurodevelopmental disorders. *Child: Care, Health and Development*, *42*(4), 486-493  
<https://doi.org/10.1111/cch.12346>
- Charman, T., Carroll, F., & Sturge, C. (2001). Theory of mind, executive function and social competence in boys with ADHD. *Emotional and Behavioural Difficulties*, *6*(1), 31-49.  
<https://doi.org/10.1080/13632750100507654>
- Chasnoff, I. J., Wells, A. M., & King, L. (2015). Misdiagnosis and missed diagnoses in foster and adopted children with prenatal alcohol exposure. *Pediatrics*, *135*(2), 264-270.  
<https://doi.org/10.1080/13632750100507654>
- Chaytor, N., & Schmitter-Edgecombe, M. (2003). The ecological validity of neuropsychological tests: A review of the literature on everyday cognitive skills. *Neuropsychology Review*, *13*(4), 181-197.  
<https://doi.org/10.1023/B:NERV.0000009483.91468.fb>
- Cherrington, L. (2009). *Te hohounga mai i te tirohanga māori: The process of reconciliation: towards a Māori view. The delivery of conduct problem services to Māori*. Wellington, New Zealand: Ministry of Social Development. Retrieved from <https://www.msd.govt.nz/about-msd-and-our-work/publications-resources/research/conduct-problems-best-practice/te-hohounga-mai-i-te-tirohanga-maori.html>
- Cheung, J., Timmins, J., & Wright, C. (2015). *Patterns of alcohol consumption during pregnancy in a recent cohort of expectant mothers*. Wellington, New Zealand: Superu. Retrieved from <http://www.superu.govt.nz/sites/default/files/Alcohol%20and%20Pregnancy%20Research%20Report.pdf>
- Christie, G. (2007). Culture, self-determination and colonialism: Issues around the revitalization of Indigenous legal traditions. *Indigenous Law Journal*, *6*, 13-29. Retrieved from <https://ssrn.com/abstract=1626416>
- Chudley, A. E., Conry, J., Cook, J. L., Looock, C., Rosales, T., & LeBlanc, N. (2005). Fetal alcohol spectrum disorder: Canadian guidelines for diagnosis. *Canadian Medical Association Journal*, *172*(5), S1-S21. <https://doi.org/10.1503/cmaj.1040302>
- Cicchetti, D. (2016). Socioemotional, personality, and biological development: Illustrations from a multilevel developmental psychopathology perspective on child maltreatment. *Annual Review of Psychology*, *67*, 187-211. <https://doi.org/10.1146/annurev-psych-122414-033259>

- Cicchetti, D., Rogosch, F. A., Maughan, A., Toth, S. L., & Bruce, J. (2003). False belief understanding in maltreated children. *Development and Psychopathology*, *15*(4), 1067-1091. <https://doi.org/10.1017/S0954579403000440>
- Clark, C., Prior, M., & Kinsella, G. (2002). The relationship between executive function abilities, adaptive behaviour, and academic achievement in children with externalising behaviour problems. *Journal of Child Psychology and Psychiatry*, *43*(6), 785-796. <https://doi.org/10.1111/1469-7610.00084>
- Clark, E., George, M. A., Hardy, C., Hall, W. A., MacMillan, P. D., Wakabayashi, S., & Hughes, K. (2014). Exploratory study of the effectiveness of a professional development program on the academic achievement and classroom behavior of students with fetal alcohol spectrum disorder in British Columbia, Canada. *The International Journal of Alcohol and Drug Research*, *3*(1), 25-34. <https://doi.org/10.7895/ijadr.v3i1.119>
- Coggins, T. E., Timler, G. R., & Olswang, L. B. (2007). 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. *Language, Speech, and Hearing Services in Schools*, *38*(2), 117. <https://doi.org/10.1044/0161-1461>
- Cohen, J. (1988). *Statistical power analysis for the behavioural sciences*. Hillsdale, USA: Lawrence Erlbaum Associates,
- Cohen, J. (1992). A power primer. *Psychological Bulletin*, *112*(1), 155. <https://doi.org/10.1037/0033-2909.112.1.155>
- Coleman, N., Hare, D. J., Farrell, P., & Van Manen, T. (2008). The use of the social cognitive skills test with children with autistic spectrum disorders. *Journal of Intellectual Disabilities*, *12*(1), 49-57. <https://doi.org/10.1177/1744629507086608>
- Coles, C. D., Brown, R. T., Smith, I. E., Platzman, K. A., Erickson, S., & Falek, A. (1991). Effects of prenatal alcohol exposure at school age. I. physical and cognitive development. *Neurotoxicology and Teratology*, *13*(4), 357-367. [https://doi.org/10.1016/0892-0362\(91\)90084-A](https://doi.org/10.1016/0892-0362(91)90084-A)
- Coles, C. D., Kable, J. A., & Taddeo, E. (2009). Math performance and behavior problems in children affected by prenatal alcohol exposure: Intervention and follow-up. *Journal of Developmental & Behavioral Pediatrics*, *30*(1), 7-15. <https://doi.org/10.1097/DBP.0b013e3181966780>
- Connor, P. D., Sampson, P. D., Bookstein, F. L., Barr, H. M., & Streissguth, A. P. (2000). Direct and indirect effects of prenatal alcohol damage on executive function. *Developmental Neuropsychology*, *18*(3), 331-354. <https://doi.org/10.1207/S1532694204Connor>
- Cook, J. L., Green, C. R., Lilley, C. M., Anderson, S. M., Baldwin, M. E., Chudley, A. E., . . . Rosales, T. (2016). Fetal alcohol spectrum disorder: A guideline for diagnosis across the lifespan. *Canadian Medical Association Journal*, *188*(3), 191-197. <https://doi.org/10.1503/cmaj.151425>
- Cordier, R., Munro, N., Wilkes-Gillan, S., & Docking, K. (2013). The pragmatic language abilities of children with ADHD following a play-based intervention involving peer-to-peer interactions. *International Journal of Speech-Language Pathology*, *15*(4), 416-428. <https://doi.org/10.3109/17549507.2012.713395>

- Cram, F. (2012). *Safety of subsequent children: Māori children and whānau: A review of selected literature*. Wellington, New Zealand: Families Commission. Retrieved from <http://www.superu.govt.nz/sites/default/files/SoSC-Maori-and-Whanau.pdf>
- Crick, N. R., & Dodge, K. A. (1994). A review and reformulation of social information-processing mechanisms in children's social adjustment. *Psychological Bulletin*, *115*(1), 74. <https://doi.org/10.1037/0033-2909.115.1.74>
- Crocker, N., Vaurio, L., Riley, E. P., & Mattson, S. N. (2009). Comparison of adaptive behavior in children with heavy prenatal alcohol exposure or attention-deficit/hyperactivity disorder. *Alcoholism: Clinical and Experimental Research*, *33*(11), 2015-2023. <https://doi.org/10.1111/j.1530-0277.2009.01040.x>
- Crowe, L. M., Beauchamp, M. H., Catroppa, C., & Anderson, V. (2011). Social function assessment tools for children and adolescents: A systematic review from 1988 to 2010. *Clinical Psychology Review*, *31*(5), 767-785. <https://doi.org/10.1016/j.cpr.2011.03.008>
- Cullen, H. (1984). *Alcohol and the Māori people: A history*. In D. Awatere, S. Casswell, H. Cullen, L. Gilmore, & D. Kupenga (Eds.), *Alcohol and the Māori people* (pp. 1–22). Auckland, New Zealand: Alcohol Research Unit, University of Auckland.
- Davis, K. M., Gagnier, K. R., Moore, T. E., & Todorow, M. (2013). Cognitive aspects of fetal alcohol spectrum disorder. *Wiley Interdisciplinary Reviews: Cognitive Science*, *4*(1), 81-92. <https://doi.org/10.1002/wcs.1202>
- De Los Reyes, A., & Kazdin, A. E. (2005). Informant discrepancies in the assessment of childhood psychopathology: A critical review, theoretical framework, and recommendations for further study. *Psychological Bulletin*, *131*(4), 483. <https://doi.org/10.1037/0033-2909.131.4.483>
- Delis, D. C., Kaplan, E., & Kramer, J. H. (2001). *Delis-Kaplan executive function system (D-KEFS)*. San Antonio, TX: The Psychological Corporation.
- Demopoulos, C., Hopkins, J., & Davis, A. (2013). A comparison of social cognitive profiles in children with autism spectrum disorders and attention-deficit/hyperactivity disorder: A matter of quantitative but not qualitative difference? *Journal of Autism and Developmental Disorders*, *43*(5), 1157-1170. <https://doi.org/10.1007/s10803-012-1657-y>
- Di Pietro, N. C., & Illes, J. (2014). Disparities in Canadian Indigenous health research on neurodevelopmental disorders. *Journal of Developmental and Behavioral Pediatrics*, *35*(1), 74-81. <https://doi.org/10.1097/DBP.0000000000000002>
- Diamantopoulou, S., Rydell, A., Thorell, L. B., & Bohlin, G. (2007). Impact of executive functioning and symptoms of attention deficit hyperactivity disorder on children's peer relations and school performance. *Developmental Neuropsychology*, *32*(1), 521-542. <https://doi.org/10.1080/87565640701360981>
- Dingwall, K. M., & Cairney, S. (2010). Psychological and cognitive assessment of Indigenous Australians. *Australian and New Zealand Journal of Psychiatry*, *44*(1), 20-30. <https://doi.org/10.3109/00048670903393670>
- Dirks, M. A., De Los Reyes, A., Briggs-Gowan, M., Cella, D., & Wakschlag, L. S. (2012). Annual research review: Embracing not erasing contextual variability in children's behavior - theory and utility in the selection and use of methods and informants in

- developmental psychopathology. *Journal of Child Psychology and Psychiatry and Allied Disciplines*, 53(5), 558-574. <https://doi.org/10.1111/j.1469-7610.2012.02537.x>
- Dodge, K. A., Laird, R., Lochman, J. E., Zelli, A., Bierman, K. L., Coie, J. D., . . . Pinderhughes, E. E. (2002). Multidimensional latent-construct analysis of children's social information processing patterns: Correlations with aggressive behavior problems. *Psychological Assessment*, 14(1), 60-73. <https://doi.org/10.1037/1040-3590.14.1.60>
- Dodge, K. A., & Godwin, J. (2013). Social-information-processing patterns mediate the impact of preventive intervention on adolescent antisocial behavior. *Psychological Science*, 24(4), 456-465. <https://doi.org/10.1177/0956797612457394>
- Dong, M., Giles, W. H., Felitti, V. J., Dube, S. R., Williams, J. E., Chapman, D. P., & Anda, R. F. (2004). *Insights into causal pathways for ischemic heart disease*. *Circulation*, 110(13), 1761-1766. <https://doi.org/10.1161/01.CIR.0000143074.54995.7F>
- Douglas, H. (2015). Foetal alcohol spectrum disorders: A consideration of sentencing and unreliable confessions. *Journal of Law and Medicine*, 23(2), 427-442. Retrieved from [https://www.researchgate.net/publication/296484845\\_Foetal\\_Alcohol\\_Spectrum\\_Disorders\\_A\\_consideration\\_of\\_sentencing\\_and\\_unreliable\\_confessions](https://www.researchgate.net/publication/296484845_Foetal_Alcohol_Spectrum_Disorders_A_consideration_of_sentencing_and_unreliable_confessions)
- Dowden, A., & Taite, S. (2001). *Aukati kaipapa 2000 evaluation report*. Wellington, New Zealand: Ministry of Health. Retrieved from [http://www.moh.govt.nz/notebook/nbbooks.nsf/0/F04C49F6662328CCCC25755E007A4E7C/\\$file/Aukati%20Kai%20Paipa%202000.pdf](http://www.moh.govt.nz/notebook/nbbooks.nsf/0/F04C49F6662328CCCC25755E007A4E7C/$file/Aukati%20Kai%20Paipa%202000.pdf)
- Drabick, D. A., Gadow, K. D., & Loney, J. (2007). Source-specific oppositional defiant disorder: Comorbidity and risk factors in referred elementary schoolboys. *Journal of the American Academy of Child & Adolescent Psychiatry*, 46(1), 92-101. <https://doi.org/10.1097/01.chi.0000242245.00174.90>
- Dube, S. R., Felitti, V. J., Dong, M., Chapman, D. P., Giles, W. H., & Anda, R. F. (2003). Childhood abuse, neglect, and household dysfunction and the risk of illicit drug use: The adverse childhood experiences study. *Pediatrics*, 111(3), 564-572. Retrieved from <http://pediatrics.aappublications.org.ezproxy.auckland.ac.nz/content/pediatrics/111/3/564.full.pdf>
- Dudley, M. (2016). Māori and neuropsychological assessment. In W. Waitoki, & M. Levy (Eds.), *Te manu kai i te mātauranga: Indigenous psychology in Aotearoa/ New Zealand* (pp. 187-206). Wellington: The New Zealand Psychological Society.
- Durie, M. (1994). *Whaiora: Māori health development*. Auckland, New Zealand: Oxford University Press.
- Durie, M. (2001). *Mauri ora: The dynamics of Māori health*. Melbourne, Australia: Oxford University Press.
- Durie, M. (2016, May) *Māori in the 21st century*. Workshop presented for Compass Seminar, Gisborne, New Zealand.
- Durie, M. H. (1997). Māori cultural identity and its implications for mental health services. *International Journal of Mental Health*, 26(3), 23-25. <https://doi.org/10.1080/00207411.1997.11449407>

- Durie, Mason (1999), 'Te Pae Mahutonga: a model for Māori health promotion', Health Promotion Forum of New Zealand Newsletter 49, 2-5 December 1999. Retrieved from <http://hauora.co.nz/resources/tepaemahutongatxtvers.pdf>
- Durie, M. (2004). Māori achievement: Anticipating the learning environment. In M. Durie (Ed.), *Ngā tini whetū: Navigating Māori futures* (pp. 125-138). Wellington: Huia Publishers.
- Durlak, J. A., Weissberg, R. P., Dymnicki, A. B., Taylor, R. D., & Schellinger, K. B. (2011). The impact of enhancing students' social and emotional learning: A meta-analysis of school-based universal interventions. *Child Development*, 82(1), 405-432. <https://doi.org/10.1111/j.1467-8624.2010.01564.x>
- Ebbett, E., & Clarke, D. (2010). Māori identification, alcohol behaviour and mental health: A review. *International Journal of Mental Health and Addiction*, 8(2), 214-231. <https://doi.org/10.1007/s11469-009-9200-x>
- Edwards, W. J., & Greenspan, S. (2010). Adaptive behavior and fetal alcohol spectrum disorders. *J. Psychiatry & L.*, 38, 419. <https://doi.org/10.1177/009318531003800404>
- Engel, G. L. (1980). The clinical application of the biopsychosocial model. *Am J Psychiatry*, 137(5), 535-544. <https://doi.org/10.1176/ajp.137.5.535>
- Enns, L. N., & Taylor, N. M. (2016). Factors predictive of a fetal alcohol spectrum disorder: Neuropsychological assessment. *Child Neuropsychology*, 1-23. <https://doi.org/10.1080/09297049.2016.1251894>
- Ermine, W. (2007). The ethical space of engagement. *Indigenous LJ*, 6, 193-203. Retrieved from [http://heinonline.org.ezproxy.auckland.ac.nz/HOL/Page?handle=hein.journals/ilj6&div=12&g\\_sent=1&casa\\_token=&collection=journals](http://heinonline.org.ezproxy.auckland.ac.nz/HOL/Page?handle=hein.journals/ilj6&div=12&g_sent=1&casa_token=&collection=journals)
- Fagerlund, Å, Autti-Rämö, I., Kalland, M., Santtila, P., Hoyme H, E., Mattson N, S., & Korkman, M. (2012). Adaptive behaviour in children and adolescents with foetal alcohol spectrum disorders: A comparison with specific learning disability and typical development. *European Child & Adolescent Psychiatry*, 21(4), 221-231. <https://doi.org/10.1007/s00787-012-0256-y>
- Farmer, C., Butter, E., Mazurek, M. O., Cowan, C., Lainhart, J., Cook, E. H., . . . Aman, M. (2015). Aggression in children with autism spectrum disorders and a clinic-referred comparison group. *Autism*, 19(3), 281-291. <https://doi.org/10.1177/1362361313518995>
- Farrington, D. P., Loeber, R., & Ttofi, M. M. (2012). Risk and protective factors for offending. In B. Welsh & D. Farrington (Eds.), *The Oxford Handbook of Crime Prevention*, (pp. 46-69). New York: Oxford University Press.
- Fast, D. K., Conry, J., & Loock, C. A. (1999). Identifying fetal alcohol syndrome among youth in the criminal justice system. *Journal of Developmental and Behavioral Pediatrics*, 20(5), 370-372. Retrieved from [http://www.asantecentre.org/\\_Library/docs/IdentifyingFASYouth.pdf](http://www.asantecentre.org/_Library/docs/IdentifyingFASYouth.pdf)
- Fatima, S., & Sharif, I. (2016). Executive functions, parental punishment, and aggression: Direct and moderated relations. *Social Neuroscience*, 12(6), 717-729. <https://doi.org/10.1080/17470919.2016.1240710>

- Felitti, V. J., Anda, R. F., Nordenberg, D., Williamson, D. F., Spitz, A. M., Edwards, V., . . . Marks, J. S. (1998). Relationship of childhood abuse and household dysfunction to many of the leading causes of death in adults: The adverse childhood experiences (ACE) study. *American Journal of Preventive Medicine, 14*(4), 245-258. [https://doi.org/10.1016/S0749-3797\(98\)00017-8](https://doi.org/10.1016/S0749-3797(98)00017-8)
- Field, A. (2013). *Discovering statistics using IBM SPSS statistics*. London, UK: Sage Publications Ltd.
- Fitch, A., Fein, D. A., & Eigsti, I. (2015). Detail and gestalt focus in individuals with optimal outcomes from autism spectrum disorders. *Journal of Autism and Developmental Disorders, 45*(6), 1887-1896. <https://doi.org/10.1007/s10803-014-2347-8>
- Fitzpatrick, J. P., Latimer, J., Carter, M., Oscar, J., Ferreira, M. L., Carmichael Olson, H., . . . Try, J. (2015). Prevalence of fetal alcohol syndrome in a population-based sample of children living in remote Australia: The Lililwan project. *Journal of Paediatrics and Child Health, 51*(4), 450-457. <https://doi.org/10.1111/jpc.12814>
- Fitzpatrick, J. P., Latimer, J., Olson, H. C., Carter, M., Oscar, J., Lucas, B. R., . . . Hawkes, G. (2017). Prevalence and profile of neurodevelopment and fetal alcohol spectrum disorder (FASD) amongst Australian aboriginal children living in remote communities. *Research in Developmental Disabilities, 65*, 114-126. <https://doi.org/10.1016/j.ridd.2017.04.001>
- Fjørtoft, T., Grunewaldt, K. H., Løhaugen, G. C. C., Mørkved, S., Skranes, J., & Evensen, K. A. I. (2015). Adaptive behavior in 10-11 year old children born preterm with a very low birth weight (VLBW). *European Journal of Paediatric Neurology, 19*(2), 162-169. <https://doi.org/10.1016/j.ejpn.2014.11.006>
- Fluharty, M. E., Heron, J., & Munaf, M. R. (2017). Longitudinal associations of social cognition and substance use in childhood and early adolescence: Findings from the avon longitudinal study of parents and children. *European Child & Adolescent Psychiatry, 1*-14. <https://doi.org/10.1007/s00787-017-1068-x>
- Forrest, R., Taylor, L., Roberts, J., Pearson, M., Foxall, D., & Scott-Chapman, S. (2016). PATU™: Fighting fit, fighting fat! The hinu wero approach. *AlterNative: An International Journal of Indigenous Peoples, 12*(3), 282. <https://doi.org/10.20507/AlterNative.2016.12.3.6>
- Forster, M. (2003). Te hoe nuku roa: A journey towards Māori centered research. *Ethnobotany Research and Applications, 1*, 047-054. Retrieved from <http://lib-ojs3.lib.sfu.ca:8114/era/index.php/era/article/viewFile/28/17>
- Frankel, F. H., & Myatt, R. (2003). *Children's friendship training*. New York: Brunner-Routledge.
- Fraser, C. (2008). Victims and fetal alcohol spectrum disorder (FASD): A review of the issues. *Victims of Crime Research Digest, 1*, 24-28. Retrieved from [http://www.examenequitesalariale.gc.ca/eng/rp-pr/cj-jp/victim/rr07\\_vic4/rr07\\_vic4.pdf#page=24](http://www.examenequitesalariale.gc.ca/eng/rp-pr/cj-jp/victim/rr07_vic4/rr07_vic4.pdf#page=24)
- Freunscht, I., & Feldmann, R. (2011). Young adults with fetal alcohol syndrome (FAS): Social, emotional and occupational development. *Klinische Pädiatrie, 223*(01), 33-37. <https://doi.org/10.1055/s-0030-1261927>

- Frye, R. E., Slattery, J., Delhey, L., Furgerson, B., Strickland, T., Tippet, M., . . . Melnyk, S. (2016). Folic acid improves verbal communication in children with autism and language impairment: A randomized double-blind placebo-controlled trial. *Molecular Psychiatry*, 00, 1-10. <https://doi.org/10.1038/mp.2016.168>
- Fuglestad, A. J., Whitley, M. L., Carlson, S. M., Boys, C. J., Eckerle, J. K., Fink, B. A., & Wozniak, J. R. (2015). Executive functioning deficits in preschool children with fetal alcohol spectrum disorders. *Child Neuropsychology*, 21(6), 716-731. <https://doi.org/10.1080/09297049.2014.933792>
- Fuhs, M. W., Nesbitt, K. T., Farran, D. C., & Dong, N. (2014). Longitudinal associations between executive functioning and academic skills across content areas. *Developmental Psychology*, 50(6), 1698-1709. <https://doi.org/10.1037/a0036633>
- Ganesalingam, K., Yeates, K. O., Taylor, H. G., Walz, N. C., Stancin, T., & Wade, S. (2011). Executive functions and social competence in young children 6 months following traumatic brain injury. *Neuropsychology*, 25(4), 466-476. <https://doi.org/10.1037/a0022768>
- Gerris, J. (1981). *Onderwijs en sociale ontwhikkeling (education and social development)*. Lisse: Swets & Zeitlinger.
- Gilmartin, M., & Berg, L. D. (2007). Locating postcolonialism. *Area*, 39(1), 120-124. <https://doi.org/10.1111/j.1475-4762.2007.00724.x>
- Glass, L., Moore, E. M., Akshoomoff, N., Jones, K. L., Riley, E. P., & Mattson, S. N. (2017). Academic difficulties in children with prenatal alcohol exposure: Presence, profile, and neural correlates. *Alcoholism: Clinical and Experimental Research*, 41(5), 1024-1034. <https://doi.org/10.1111/acer.13366>
- Glass, L., Ware, A. L., Crocker, N., Dewese, B. N., Coles, C. D., Kable, J. A., . . . Mattson, S. N. (2013). Neuropsychological deficits associated with heavy prenatal alcohol exposure are not exacerbated by ADHD. *Neuropsychology*, 27(6), 713-724. <https://doi.org/10.1037/a0033994>
- Glass, L., Ware, A. L., & Mattson, S. N. (2014). Neurobehavioral, neurologic, and neuroimaging characteristics of fetal alcohol spectrum disorders. *Handbook of Clinical Neurology*, 125(3), 435-462. <https://doi.org/10.1016/B978-0-444-62619-6.00025-2>
- Goh, P. K., Doyle, L. R., Glass, L., Jones, K. L., Riley, E. P., Coles, C. D., . . . Kalberg, W. O. (2016). A decision tree to identify children affected by prenatal alcohol exposure. *The Journal of Pediatrics*, 177, 121-127. <https://doi.org/10.1016/j.jpeds.2016.06.047>
- Goldstein, A. L., Faulkner, B., & Wekerle, C. (2013). The relationship among internal resilience, smoking, alcohol use, and depression symptoms in emerging adults transitioning out of child welfare. *Child Abuse & Neglect*, 37(1), 22-32. <https://doi.org/10.1016/j.chiabu.2012.08.007>
- Gordon, R. C., Rose, M. C., Skeaff, S. A., Gray, A. R., Morgan, K. M., & Ruffman, T. (2009). Iodine supplementation improves cognition in mildly iodine-deficient children. *The American Journal of Clinical Nutrition*, 90(5), 1264-1271. <https://doi.org/10.3945/ajcn.2009.28145>
- Green, C. R., Mihic, A. M., Nikkel, S. M., Stade, B. C., Rasmussen, C., Munoz, D. P., & Reynolds, J. N. (2009). Executive function deficits in children with fetal alcohol

- spectrum disorders (FASD) measured using the Cambridge neuropsychological tests automated battery (CANTAB). *Journal of Child Psychology and Psychiatry*, 50(6), 688-697. <https://doi.org/10.1111/j.1469-7610.2008.01990.x>
- Green, J. H. (2007). Fetal alcohol spectrum disorders: Understanding the effects of prenatal alcohol exposure and supporting students. *Journal of School Health*, 77(3), 103-108. <https://doi.org/10.1111/j.1746-1561.2007.00178.x>
- Greenbaum, R. L., Stevens, S. A., Nash, K., Koren, G., & Rovet, J. (2009). Social cognitive and emotion processing abilities of children with fetal alcohol spectrum disorders: A comparison with attention deficit hyperactivity disorder. *Alcoholism: Clinical and Experimental Research*, 33(10), 1656-1670. <https://doi.org/10.1111/j.1530-0277.2009.01003.x>
- Greenberg, M. T., Domitrovich, C. E., Weissberg, R. P., & Durlak, J. A. (2017). Social and emotional learning as a public health approach to education. *The Future of Children*, 21(1), 13-32. Retrieved from <http://www.jstor.org/stable/44219019>
- Greenham, M., Anderson, V., Hearps, S., Ditchfield, M., Coleman, L., Mackay, M. T., . . . Gordon, A. L. (2017). Psychosocial function in the first year after childhood stroke. *Developmental Medicine & Child Neurology*, 59(10), 1027-1033. <https://doi.org/10.1111/dmcn.13387>
- Greenspan, S. (2008). Foolish action in adults with intellectual disabilities: The forgotten problem of Risk-Unawareness. *International Review of Research in Mental Retardation*, 36, 147-194. [https://doi.org/10.1016/S0074-7750\(08\)00005-0](https://doi.org/10.1016/S0074-7750(08)00005-0)
- Greenspan, S., Brown, N. N., & Edwards, W. (2016). FASD and the concept of “intellectual disability equivalence”. In M. Nelson & M. Trussler (Eds.), *Fetal alcohol spectrum disorders in adults: Ethical and legal perspectives* (pp. 241-266). Switzerland: Springer.
- Greenspan, S., & Driscoll, J. H. (2016). Why people with FASD fall for manipulative ploys: Ethical limits of interrogators’ use of lies. In M. Nelson & M. Trussler (Eds.), *Fetal alcohol spectrum disorders in adults: Ethical and legal perspectives* (pp. 23-38) Switzerland: Springer.
- Gross, A. C., Deling, L. A., Wozniak, J. R., & Boys, C. J. (2014). Objective measures of executive functioning are highly discrepant with parent-report in fetal alcohol spectrum disorders. *Child Neuropsychology*, 21(4), 531-538. <https://doi.org/10.1080/09297049.2014.911271>
- Guyer, A. E., McClure, E. B., Adler, A. D., Brotman, M. A., Rich, B. A., Kimes, A. S., . . . Leibenluft, E. (2007). Specificity of facial expression labeling deficits in childhood psychopathology. *Journal of Child Psychology and Psychiatry*, 48(9), 863-871. <https://doi.org/10.1111/j.1469-7610.2007.01758.x>
- Halberstadt, A. G., Denham, S. A., & Dunsmore, J. C. (2001). Affective social competence. *Social Development*, 10(1), 79-119. <https://doi.org/10.1111/1467-9507.00150>
- Harnett, P. H., Dawe, S., & Russell, M. (2012). An investigation of the needs of grandparents who are raising grandchildren. *Child & Family Social Work*, 19(4), 411-420. <https://doi.org/10.1111/cfs.12036>

- Harris, J. C., & Greenspan, S. (2016). Definition and nature of intellectual disability. In N. Singh (Ed.), *Handbook of evidence-based practices in intellectual and developmental disabilities* (pp. 11-39). Georgia, USA: Springer. [https://doi.org/10.1007/978-3-319-26583-4\\_2](https://doi.org/10.1007/978-3-319-26583-4_2)
- Hart, H., & Rubia, K. (2012). Neuroimaging of child abuse: A critical review. *Frontiers in Human Neuroscience*, 6, 1-24. <https://doi.org/10.3389/fnhum.2012.00052>
- Harvey, M. A., Harvey, M. A., Sellman, J. D., Harvey, M. A., Sellman, J. D., Porter, R. J., . . . Frampton, C. M. (2007). The relationship between non-acute adolescent cannabis use and cognition. *Drug and Alcohol Review*, 26(3), 309-319. <https://doi.org/10.1080/09595230701247772>
- Hatch, B., Healey, D. M., & Halperin, J. M. (2014). Associations between birth weight and attention-deficit/hyperactivity disorder symptom severity: Indirect effects via primary neuropsychological functions. *Journal of Child Psychology and Psychiatry*, 55(4), 384-392. <https://doi.org/10.1111/jcpp.12168>
- Hawke's Bay District Health Board. (2014). *Health equity in Hawke's Bay technical report*. Hawke's Bay, New Zealand: Hawke's Bay District Health Board. Retrieved from [http://www.hawkesbay.health.nz/page/pageid/2145884299/Health\\_inEquity\\_in\\_Hawkes\\_Bay](http://www.hawkesbay.health.nz/page/pageid/2145884299/Health_inEquity_in_Hawkes_Bay)
- Hawke's bay District Health Board & Ngāti Kahungunu Iwi Inc. (2014). *Terms of reference: Hawke's Bay District Health Board and Māori relationship board*. Hawke's Bay, New Zealand: Hawke's Bay District Health Board. Retrieved from <file:///C:/Users/HP450G4/Downloads/MRB-TOR.pdf>
- Hawkins, J. D., Kosterman, R., Catalano, R. F., Hill, K. G., & Abbott, R. D. (2005). Promoting positive adult functioning through social development intervention in childhood: Long-term effects from the Seattle social development project. *Archives of Pediatrics & Adolescent Medicine*, 159(1), 25-31. <https://doi.org/10.1001/archpedi.159.1.25>
- Hayward, E. O., & Homer, B. D. (2017). Reliability and validity of advanced theory-of-mind measures in middle childhood and adolescence. *British Journal of Developmental Psychology*, 35(3), 454-462. <https://doi.org/10.1111/bjdp.12186>
- Health and Safety Developments. (2015). *Hawke's bay district health board developmental assessment programme FASD assessment pathway: Process evaluation*. Wellington: Health Promotion Agency. Retrieved from <https://www.hpa.org.nz/research-library/research-publications/hawke%E2%80%99s-bay-district-health-board-developmental-assessment-programme-fasd-assessment-pathway-process>
- Health Research Council of New Zealand. (2010). *Guidelines for researchers on health research involving Māori 2010*. Auckland, New Zealand: Health Research Council of New Zealand. Retrieved from [https://gateway.hrc.govt.nz/funding/downloads/Guidelines\\_for\\_researchers\\_on\\_health\\_research\\_involving\\_M%C4%81ori.pdf](https://gateway.hrc.govt.nz/funding/downloads/Guidelines_for_researchers_on_health_research_involving_M%C4%81ori.pdf)
- Henry, J., Sloane, M., & Black-Pond, C. (2007). Neurobiology and neurodevelopmental impact of childhood traumatic stress and prenatal alcohol exposure. *Language, Speech, and Hearing Services in Schools*, 38(2), 99-108. [https://doi.org/10.1044/0161-1461\(2007/010\)](https://doi.org/10.1044/0161-1461(2007/010))

- Heuer, B. (1972). *Māori women*. Wellington: A. H. & A. W. Reed.
- Ho, R., & Jacquemard, R. (2009). Maternal alcohol use before and during pregnancy among women in Taranaki, New Zealand. *Journal of the New Zealand Medical Association*, *122*(1306), 20-32. Retrieved from <https://search-proquest-com/docview/1034255510?accountid=8424>
- Hollocks, M. J., Jones, C. R., Pickles, A., Baird, G., Happé, F., Charman, T., & Simonoff, E. (2014). The association between social cognition and executive functioning and symptoms of anxiety and depression in adolescents with autism spectrum disorders. *Autism Research*, *7*(2), 216-2228. <https://doi.org/10.1002/aur.1361>
- Horwood, L. J., & Fergusson, D. M. (1998). *Psychiatric disorder and treatment seeking in a birth cohort of young adults*. Wellington: The Ministry Health. <https://doi.org/10.1.1.582.817>
- Howe, D., Brandon, M., Hinnings, D., & Schofield, G. (1999). *Attachment theory, child maltreatment and family support*. Basingstoke, UK: Macmillan.
- Hu, Z., Chan, R. C. K., & McAlonan, G. M. (2010). Maturation of social attribution skills in typically developing children: An investigation using the social attribution task. *Behavioral and Brain Functions*, *6*(10), 1-8. <https://doi.org/10.1186/1744-9081-6-10>
- Huckle, T., You, R. Q., & Casswell, S. (2010). Socio-economic status predicts drinking patterns but not alcohol-related consequences independently. *Addiction*, *105*(7), 1192-1202. <https://doi.org/10.1111/j.1360-0443.2010.02931.x>
- Hunting, G., & Browne, A. J. (2012). Decolonizing policy discourse: Reframing the 'problem' of fetal alcohol spectrum disorder. *Women's Health and Urban Life*, *11*(1), 35-53. Retrieved from <http://hdl.handle.net/1807/32417>.
- Hutt, M. (1999). *Māori and alcohol: A history*. Wellington, New Zealand: Health Services Research Centre.
- Im-Bolter, N., Cohen, N. J., & Farnia, F. (2013). I thought we were good: Social cognition, figurative language, and adolescent psychopathology. *Journal of Child Psychology and Psychiatry*, *54*(7), 724-732. <https://doi.org/10.1111/jcpp.12067>
- Jack, F., Leov, J., & Zajac, R. (2014). Age-related differences in the free-recall accounts of child, adolescent, and adult witnesses. *Applied Cognitive Psychology*, *28*(1), 30-38. <https://doi.org/10.1002/acp.2951>
- Jacobson, L. A., & Mahone, E. M. (2012). Educational implications of executive dysfunction. In S. Hunter & E. Sparrow (Eds.), *Executive Function and Dysfunction*, (pp. 232-246). Cambridge, UK: Cambridge University Press.
- Jenni, O. G., Fintelmann, S., Caflisch, J., Latal, B., Rousson, V., & Chaouch, A. (2015). Stability of cognitive performance in children with mild intellectual disability. *Developmental Medicine and Child Neurology*, *57*(5), 463-469. <https://doi.org/10.1111/dmcn.12620>
- Jirikowic, T., Kartin, D., & Olson, H. C. (2008). Children with fetal alcohol spectrum disorders: A descriptive profile of adaptive function. *Canadian Journal of Occupational Therapy*, *75*(4), 238-248. <https://doi.org/10.1177/000841740807500411>

- Johnson, S. E., O'Leary, C., Bower, C., Lawrence, D., Cunningham, N., Semmens, J., & Zubrick, S. R. (2017). Maternal alcohol disorders and school achievement: A population cohort record linkage study in Western Australia. *BMJ Open*, 7(5), e014599. <https://doi.org/10.1136/bmjopen-2016-014599>
- Jones, K., Smith, D., Ulleland, C., & Streissguth, A. (1973). Pattern of malformation in offspring of chronic alcoholic mothers. *The Lancet*, 301(7815), 1267-1271. [https://doi.org/10.1016/S0140-6736\(73\)91291-9](https://doi.org/10.1016/S0140-6736(73)91291-9)
- Kable, J. A., Coles, C. D., Strickland, D., & Taddeo, E. (2012). Comparing the effectiveness of on-line versus in-person caregiver education and training for behavioral regulation in families of children with FASD. *International Journal of Mental Health and Addiction*, 10(6), 791-803. <https://doi.org/10.1007/s11469-012-9376-3>
- Kalberg, W. O., May, P. A., Blankenship, J., Buckley, D., Gossage, J. P., & Adnams, C. M. (2013). A practical testing battery to measure neurobehavioral ability among children with fetal alcohol spectrum disorder. *The International Journal of Alcohol and Drug Research*, 2(3), 51-60. <https://doi.org/10.7895/ijadr.v2i3.83>
- Kalberg, W. O., & Buckley, D. (2007). FASD: What types of intervention and rehabilitation are useful? *Neuroscience & Biobehavioral Reviews*, 31(2), 278-285. <https://doi.org/10.1016/j.neubiorev.2006.06.014>
- Kane, H., & Oakland, T. D. (2015). The differentiation of adaptive behaviours: Evidence from high and low performers. *Educational Psychology*, 35(6), 675-688. <https://doi.org/10.1080/01443410.2014.893558>
- Kane, H. D., Oakland, T. D., & Brand, C. R. (2006). Differentiation at higher levels of cognitive ability: Evidence from the United States. *The Journal of Genetic Psychology*, 167(3), 327-341. <https://doi.org/10.3200/GNTP.167.3.327-341>
- Katsiyannis, A., Ryan, J. B., Zhang, D., & Spann, A. (2008). Juvenile delinquency and recidivism: The impact of academic achievement. *Reading & Writing Quarterly*, 24(2), 177-196. <https://doi.org/10.1080/10573560701808460>
- Keefe, V., Reid, P., Ormsby, C., Robson, B., Purdie, G., Baxter, J., & Ngati Kahungunu Iwi Incorporated. (2002). Serious health events following involuntary job loss in New Zealand meat processing workers. *International Journal of Epidemiology*, 31(6), 1155-1161. <https://doi.org/10.1093/ije/31.6.1155>
- Keefe-Ormsby, V. (2005). *Tihei mauri ora*. Wellington, New Zealand: Wellington School of Medicine and Health Sciences. Retrieved from <http://www.otago.ac.nz/wellington/otago019561.pdf>
- Keil, V., Paley, B., Frankel, F., & O'Connor, M. J. (2010). Impact of a social skills intervention on the hostile attributions of children with prenatal alcohol exposure. *Alcoholism: Clinical and Experimental Research*, 34(2), 231-241. <https://doi.org/10.1111/j.1530-0277.2009.01086.x>
- Kerns, K. A., Siklos, S., Baker, L., & Müller, U. (2016). Emotion recognition in children with fetal alcohol spectrum disorders. *Child Neuropsychology*, 22(3), 255-275. <https://doi.org/10.1080/09297049.2014.993310>

- Khan, B. A., Robinson, R. F., Smith, J. J., & Dillard, D. A. (2013). Prenatal alcohol exposure among Alaska Native/American Indian infants. *International Journal of Circumpolar Health, 72*(1), 20973. <https://doi.org/10.3402/ijch.v72i0.20973>
- Khoury, J. E., Milligan, K., & Girard, T. A. (2015). Executive functioning in children and adolescents prenatally exposed to alcohol: A meta-analytic review. *Neuropsychology Review, 25*(2), 149-170. <https://doi.org/10.1007/s11065-015-9289-6>
- Kingdon, D., Cardoso, C., & McGrath, J. J. (2015). Research review: Executive function deficits in fetal alcohol spectrum disorders and attention-deficit/hyperactivity disorder - a meta-analysis. *Journal of Child Psychology and Psychiatry and Allied Disciplines, 57*(2), 116-131. <https://doi.org/10.1111/jcpp.12451>
- Kingi, T. K. & Durie, M. (2000). "*Hua oranga*" A Māori measure of mental health outcome. Palmerston North, New Zealand: Massey University. Retrieved from <http://citeseerx.ist.psu.edu/viewdoc/summary?doi=10.1.1.583.3912>
- Kirk, C., & Gillon, G. T. (2009). Integrated morphological awareness intervention as a tool for improving literacy. *Language, Speech, and Hearing Services in Schools, 40*(3), 341-351. [https://doi.org/10.1044/0161-1461\(2008/08-0009\)](https://doi.org/10.1044/0161-1461(2008/08-0009))
- Kjellmer, L., & Olswang, L. B. (2013). Variability in classroom social communication: Performance of children with fetal alcohol spectrum disorders and typically developing peers. *Journal of Speech, Language, and Hearing Research, 56*(3), 982-993. [https://doi.org/10.1044/1092-4388\(2012/11-0345\)](https://doi.org/10.1044/1092-4388(2012/11-0345))
- Kodituwakku, P. W. (2007). Defining the behavioral phenotype in children with fetal alcohol spectrum disorders: A review. *Neuroscience and Biobehavioral Reviews, 31*(2), 192-201. <https://doi.org/10.1016/j.neubiorev.2006.06.020>
- Kodituwakku, P. W. (2009). Neurocognitive profile in children with fetal alcohol spectrum disorders. *Developmental Disabilities Research Reviews, 15*(3), 218-224. <https://doi.org/10.1002/ddrr.73>
- Kodituwakku, P. W., Handmaker, N. S., Cutler, S. K., Weathersby, E. K., & Handmaker, S. D. (1995). Specific impairments in Self-Regulation in children exposed to alcohol prenatally. *Alcoholism: Clinical and Experimental Research, 19*(6), 1558-1564. <https://doi.org/10.1111/j.1530-0277.1995.tb01024.x>
- Kodituwakku, P. W., Kalberg, W., & May, P. A. (2001). The effects of prenatal alcohol exposure on executive functioning. *Alcohol Research and Health, 25*(3), 192-198. Retrieved from <http://web.a.ebscohost.com/ehost/pdfviewer/pdfviewer?vid=1&sid=2b9bc1ed-a8a4-479f-aaf8-9367ce4b10d3%40sessionmgr4008>
- Kodituwakku, P. W., May, P. A., Clericuzio, C. L., & Weers, D. (2001). Emotion-related learning in individuals prenatally exposed to alcohol: An investigation of the relation between set shifting, extinction of responses, and behavior. *Neuropsychologia, 39*(7), 699-708. [https://doi.org/10.1016/S0028-3932\(01\)00002-1](https://doi.org/10.1016/S0028-3932(01)00002-1)
- Kofler, M. J., Rapport, M. D., Bolden, J., Sarver, D. E., Raiker, J. S., & Alderson, R. M. (2011). Working memory deficits and social problems in children with ADHD. *Journal of Abnormal Child Psychology, 39*(6), 805-817. <https://doi.org/10.1007/s10802-011-9492-8>

- Koning, C., & Magill-Evans, J. (2001). Social and language skills in adolescent boys with Asperger syndrome. *Autism, 5*(1), 23-36.  
<https://doi.org/10.1177/1362361301005001003>
- Korkman, M., Kettunen, S., & Autti-Rämö, I. (2003). Neurocognitive impairment in early adolescence following prenatal alcohol exposure of varying duration. *Child Neuropsychology, 9*(2), 117-128. <https://doi.org/10.1076/chin.9.2.117.14503>
- Korkman, M., Kirk, U., & Kemp, S. L. (2007). *NEPSY –Second edition (NEPSY-II)*. San Antonio, TX: Psychological Corporation.
- Kreisman, N. V., John, A. B., Kreisman, B. M., Hall, J. W., & Crandell, C. C. (2012). Psychosocial status of children with auditory processing disorder. *Journal of the American Academy of Audiology, 23*(3), 222-233. <https://doi.org/10.3766/jaaa.23.3.8>
- Kully-Martens, K., Treit, S., Pei, J., & Rasmussen, C. (2013). Affective decision-making on the Iowa gambling task in children and adolescents with fetal alcohol spectrum disorders. *Journal of the International Neuropsychological Society, 19*, 137-144.  
<https://doi.org/10.1017/S1355617712001026>
- Lambie, I., Best, C., Ioane, J., Becroft, A., & Polaschek, C. (2016). What every judge and lawyer needs to know about s. 333 psychiatric/psychological court reports. *New Zealand Law Journal, 1*, 24-37. Retrieved from  
[http://www.lexisnexis.com/nz/legal/results/enhPubTreeViewDoc.do?nodeId=TAACAALAAK&backKey=20\\_T26848843406&refPt=&pubTreeWidth=376](http://www.lexisnexis.com/nz/legal/results/enhPubTreeViewDoc.do?nodeId=TAACAALAAK&backKey=20_T26848843406&refPt=&pubTreeWidth=376)
- Lange, S., Probst, C., Gmel, G., Rehm, J., Burd, L., & Popova, S. (2017). Global prevalence of fetal alcohol spectrum disorder among children and youth: A systematic review and meta-analysis. *JAMA Pediatrics, 171*(10), 948-956.  
<https://doi.org/10.1001/jamapediatrics.2017.1919>
- Lange, S., Shield, K., Rehm, J., & Popova, S. (2013). Prevalence of fetal alcohol spectrum disorders in child care settings: A meta-analysis. *Pediatrics, 132*(4), 980-995.  
<https://doi.org/10.1542/peds.2013-0066>
- Larkby, C. A., Goldschmidt, L., Hanusa, B. H., & Day, N. L. (2011). Prenatal alcohol exposure is associated with conduct disorder in adolescence: Findings from a birth cohort. *Journal of the American Academy of Child and Adolescent Psychiatry, 50*(3), 262-271. <https://doi.org/10.1016/j.jaac.2010.12.004>
- Laugeson, E. A., Paley, B., Schonfeld, A. M., Carpenter, E. M., Frankel, F., & O'Connor, M. J. (2007). Adaptation of the children's friendship training program for children with fetal alcohol spectrum disorders. *Child & Family Behavior Therapy, 29*(3), 57-69.  
[https://doi.org/10.1300/J019v29n03\\_04](https://doi.org/10.1300/J019v29n03_04)
- Law Commission. (2009). *Alcohol in our lives: An issues paper on the reform of New Zealand's liquor laws*. Wellington, New Zealand: Law Commission. Retrieved from  
<http://www.lawcom.govt.nz/sites/default/files/projectAvailableFormats/NZLC%20IP15.pdf>
- Lawson-Te Aho, K., & Liu, J. H. (2010). Indigenous suicide and colonization: The legacy of violence and the necessity of self-determination. *International Journal of Conflict and Violence (IJCV), 4*(1), 124-133. <https://doi.org/10.4119/UNIBI/ijcv.65>

- Lebel, C., Rasmussen, C., Wyper, K., Walker, L., Andrew, G., Yager, J., & Beaulieu, C. (2008). Brain diffusion abnormalities in children with fetal alcohol spectrum disorder. *Alcoholism: Clinical and Experimental Research*, 32(10), 1732-1740. <https://doi.org/10.1111/j.1530-0277.2008.00750.x>
- Leeuw, S. d., Cameron, E. S., & Greenwood, M. L. (2012). Participatory and community-based research, Indigenous geographies, and the spaces of friendship: A critical engagement. *The Canadian Geographer/Le Géographe Canadien*, 56(2), 180-194. <https://doi.org/10.1111/j.1541-0064.2012.00434>
- Lemerise, E. A., & Arsenio, W. F. (2003). An integrated model of emotion processes and cognition in social information processing. *Child Development*, 71(1), 107-118. <https://doi.org/10.1111/1467-8624.00124>
- Lengua, L. J., Sandler, I. N., West, S. G., Wolchik, S. A., & Curran, P. J. (1999). Emotionality and self-regulation, threat appraisal, and coping in children of divorce. *Development and Psychopathology*, 11(1), 15-37. Retrieved from [https://www-cambridge-org./core/journals/development-and-psychopathology/article/emotionality-and-self-regulation-threat-appraisal-and-coping-in-children-of-divorce/2058D8313D8DF35842EC22FE752D6525](https://www.cambridge-org./core/journals/development-and-psychopathology/article/emotionality-and-self-regulation-threat-appraisal-and-coping-in-children-of-divorce/2058D8313D8DF35842EC22FE752D6525)
- Leung, R. C., Vogan, V. M., Powell, T. L., Anagnostou, E., & Taylor, M. J. (2015). The role of executive functions in social impairment in autism spectrum disorder. *Child Neuropsychology*, 22(3), 336-344. <https://doi.org/10.1080/09297049.2015.1005066>
- Levack, W. M., Jones, B., Grainger, R., Boland, P., Brown, M., & Ingham, T. R. (2016). Whakawhanaungatanga: The importance of culturally meaningful connections to improve uptake of pulmonary rehabilitation by Māori with COPD—a qualitative study. *International Journal of Chronic Obstructive Pulmonary Disease*, 11, 489-501. <https://doi.org/10.2147/COPD.S97665>
- Levan, A., Baxter, L., Kirwan, C. B., Black, G., & Gale, S. D. (2015). Right frontal pole cortical thickness and social competence in children with chronic traumatic brain injury: Cognitive proficiency as a mediator. *The Journal of Head Trauma Rehabilitation*, 30(2), E24-E31. <https://doi.org/10.1097/HTR.0000000000000040>
- Lewis, C. E., Thomas, K. G. F., Dodge, N. C., Molteno, C. D., Meintjes, E. M., Jacobson, J. L., & Jacobson, S. W. (2015). Verbal learning and memory impairment in children with fetal alcohol spectrum disorders. *Alcoholism: Clinical and Experimental Research*, 39(4), 724-732. <https://doi.org/10.1111/acer.12671>
- Lezak, M. D. (2012). *Neuropsychological assessment* (5th Ed.). New York, USA: Oxford University Press.
- Liebschutz, J. M., Crooks, D., Rose-Jacobs, R., Cabral, H. J., Heeren, T. C., Gerteis, J., . . . Frank, D. A. (2015). Prenatal substance exposure: What predicts behavioral resilience by early adolescence? *Psychology of Addictive Behaviors*, 29(2), 329- 337. <https://doi.org/10.1037/adb0000082>
- Ligeois, F. J., Mahony, K., Connelly, A., Pigdon, L., Tournier, J., & Morgan, A. T. (2013). Pediatric traumatic brain injury: Language outcomes and their relationship to the arcuate fasciculus. *Brain and Language*, 127(3), 388-398. <https://doi.org/10.1111/acer.12961>

- Lindinger, N. M., Malcolm-Smith, S., Dodge, N. C., Molteno, C. D., Thomas, K. G. F., Meintjes, E. M., . . . Jacobson, S. W. (2016). Theory of mind in children with fetal alcohol spectrum disorders. *Alcoholism: Clinical and Experimental Research, 40*(2), 367-376. <https://doi.org/10.1111/acer.12961>
- Logan, J. W., Dammann, O., Allred, E. N., Dammann, C., Beam, K., Joseph, R. M., . . . Kuban, K. (2017). Early postnatal illness severity scores predict neurodevelopmental impairments at 10 years of age in children born extremely preterm. *Journal of Perinatology, 5*(1), 606-614. <https://doi.org/10.1038/jp.2016.242>
- Lount, S. A., Purdy, S. C., & Hand, L. (2017). Hearing, auditory processing, and language skills of male youth offenders and remandees in youth justice residences in New Zealand. *Journal of Speech, Language, and Hearing Research, 60*(1), 121-135. [https://doi.org/10.1044/2016\\_JSLHR-L-15-0131](https://doi.org/10.1044/2016_JSLHR-L-15-0131)
- Luu, T. M., Ment, L., Allan, W., Schneider, K., & Vohr, B. R. (2011). Executive and memory function in adolescents born very preterm. *Pediatrics, 127*(3), e639-e646. <https://doi.org/10.1542/peds.2010-1421>
- Lynch, N. (2016). *Neurodisability in the youth justice system in New Zealand: How vulnerability intersects with justice*. Retrieved from <http://neurodisabilitiesforum.org.nz/wp-content/uploads/2016/05/Neurodisabilities-Forum-2016-Report-1.pdf>
- MacDonald, H. Z., Ellis, B. H., Pulsifer, M. B., & Lyons, M. (2015). Executive functioning in children with posttraumatic stress disorder symptoms. *Journal of Child and Adolescent Trauma, 8*(1), 1-11. <https://doi.org/10.1007/s40653-015-0037-0>
- Macfarlane, A., Blampied, N., & Macfarlane, S. (2011). Blending the clinical and the cultural: A framework for conducting formal psychological assessment in bicultural settings. *New Zealand Journal of Psychology, 40*(2), 5-15. Retrieved from <http://www.psychology.org.nz/wp-content/uploads/NZJP-Macfarlane.pdf>
- Macfarlane, A. H., Macfarlane, S., Graham, J., & Clarke, T. H. (2017). Social and emotional learning and Indigenous ideologies in Aotearoa New Zealand: A biaxial blend. In: E. Frydenberg, A. Martin, R. Collie. (Eds.). *Social and emotional learning in Australia and the Asia-Pacific*. Springer, Singapore (pp. 273-289) Singapore: Springer. [https://doi.org/10.1007/978-981-10-3394-0\\_15](https://doi.org/10.1007/978-981-10-3394-0_15)
- Macfarlane, S. (2016). A partnered approach to psychological assessment: He ritenga whaimōhio. In W. Waitoki, & M. Levy (Eds.), *Te manu kai I te mātauranga: Indigenous psychology in Aotearoa/ New Zealand* (pp. 225-241). Wellington: The New Zealand Psychological Society.
- Mallard, S. R., Connor, J. L., & Houghton, L. A. (2013). Maternal factors associated with heavy periconceptional alcohol intake and drinking following pregnancy recognition: A post-partum survey of New Zealand women. *Drug and Alcohol Review, 32*(4), 389-397. <https://doi.org/10.1111/dar.12024>
- Mallard, S. R., Gray, A. R., & Houghton, L. A. (2012). Delaying mandatory folic acid fortification policy perpetuates health inequalities: Results from a retrospective study of postpartum New Zealand women. *Human Reproduction (Oxford, England), 27*(1), 273-282. <https://doi.org/10.1093/humrep/der387>

- Mancall, P. C., Robertson, P., & Huriwai, T. (2000). Māori and alcohol: A reconsidered history. *Australian and New Zealand Journal of Psychiatry*, *34*(1), 129-134. <https://doi.org/10.1046/j.1440-1614.2000.00693.x>
- Mangin, K. S., Horwood, L. J., & Woodward, L. J. (2017). Cognitive development trajectories of very preterm and typically developing children. *Child Development*, *88*(1), 282-298. <https://doi.org/10.1111/cdev.12585>
- Māori dictionary. (2017). Retrieved from <https://maoridictionary.co.nz/search?idiom=&phrase=&proverb=&loan=&histLoanWords=&keywords=whanaungatanga>
- Marriott, L., & Sim, D. (2015). Indicators of inequality for Māori and Pacific people. *The Journal of New Zealand Studies*, *20*, 24-50. Retrieved from <https://ojs.victoria.ac.nz/jnzs/article/view/3876>
- Marton, I., Wiener, J., Rogers, M., Moore, C., & Tannock, R. (2009). Empathy and social perspective taking in children with attention-deficit/hyperactivity disorder. *Journal of Abnormal Child Psychology*, *37*(1), 107-118. <https://doi.org/10.1007/s10802-008-9262-4>
- Mattson, S. N., Crocker, N., & Nguyen, T. T. (2011). Fetal alcohol spectrum disorders: Neuropsychological and behavioral features. *Neuropsychology Review*, *21*(2), 81-101. <https://doi.org/10.1007/s11065-011-9167-9>
- Mattson, S. N., Goodman, A. M., Caine, C., Delis, D. C., & Riley, E. P. (1999). Executive functioning in children with heavy prenatal alcohol exposure. *Alcoholism: Clinical and Experimental Research*, *23*(11), 1808-1815. <https://doi.org/10.1111/j.1530-0277.1999.tb04077.x>
- Mattson, S. N., Roesch, S. C., Glass, L., Deweese, B. N., Coles, C. D., Kable, J. A., . . . Adnams, C. M. (2013). Further development of a neurobehavioral profile of fetal alcohol spectrum disorders. *Alcoholism: Clinical and Experimental Research*, *37*(3), 517-527. <https://doi.org/10.1111/j.1530-0277.2012.01952.x>
- Mattson, S. N., Riley, E. P., Gramling, L., Delis, D. C., Jones, K. L., & of Dysmorphology, T. D. (1997). Heavy prenatal alcohol exposure with or without physical features of fetal alcohol syndrome leads to IQ deficits. *The Journal of Pediatrics*, *131*(5), 718-721. [https://doi.org/10.1016/S0022-3476\(97\)70099-4](https://doi.org/10.1016/S0022-3476(97)70099-4)
- May, P. A., Baete, A., Russo, J., Elliott, A. J., Blankenship, J., Kalberg, W. O., . . . Hoyme, H. E. (2014). Prevalence and characteristics of fetal alcohol spectrum disorders. *Pediatrics*, *134*(5), 855-866. <https://doi.org/10.1542/peds.2013-3319>
- May, P. A., Fiorentino, D., Coriale, G., Kalberg, W. O., Eugene Hoyme, H., Aragón, A. S., . . . Ceccanti, M. (2011). Prevalence of children with severe fetal alcohol spectrum disorders in communities near Rome, Italy: New estimated rates are higher than previous estimates. *International Journal of Environmental Research and Public Health*, *8*(6), 2331-2351. <https://doi.org/10.3390/ijerph8062331>
- May, P. A., Blankenship, J., Marais, A., Gossage, J. P., Kalberg, W. O., Joubert, B., . . . Hasken, J. (2013). Maternal alcohol consumption producing fetal alcohol spectrum disorders (FASD): Quantity, frequency, and timing of drinking. *Drug and Alcohol Dependence*, *133*(2), 502-512. <https://doi.org/10.1016/j.drugalcdep.2013.07.013>

- May, P. A., De Vries, M. M., Marais, A., Kalberg, W. O., Buckley, D., Adnams, C. M., . . . Manning, M. A. (2017). Replication of high fetal alcohol spectrum disorders prevalence rates, child characteristics, and maternal risk factors in a second sample of rural communities in South Africa. *International Journal of Environmental Research and Public Health*, *14*(5), 522. <https://doi.org/10.3390/ijerph14050522>
- May, P. A., Gossage, J. P., Marais, A., Hendricks, L. S., Snell, C. L., Tabachnick, B. G., . . . Viljoen, D. L. (2008). Maternal risk factors for fetal alcohol syndrome and partial fetal alcohol syndrome in South Africa: A third study. *Alcoholism: Clinical and Experimental Research*, *32*(5), 738-753. <https://doi.org/10.1111/j.1530-0277.2008.00634.x>
- May, P. A., Tabachnick, B. G., Gossage, J. P., Kalberg, W. O., Marais, A., Robinson, L. K., . . . Hoyme, H. E. (2013). Maternal factors predicting cognitive and behavioral characteristics of children with fetal alcohol spectrum disorders. *Journal of Developmental & Behavioral Pediatrics*, *34*(5), 314-325. <https://doi.org/10.1097/DBP.0b013e3182905587>
- May, P. A., Tabachnick, B., Hasken, J. M., Marais, A., de Vries, M. M., Barnard, R., . . . Kalberg, W. O. (2017). Who is most affected by prenatal alcohol exposure: Boys or girls? *Drug & Alcohol Dependence*, *177*, 258-267. <https://doi.org/10.1016/j.drugalcdep.2017.04.010>
- McCann, J., Peppé, S., Gibbon, F. E., O'Hare, A., & Rutherford, M. (2007). Prosody and its relationship to language in school-aged children with high-functioning autism. *International Journal of Language and Communication Disorders*, *42*(6), 682-702. <https://doi.org/10.1080/13682820601170102>
- McClure, E. B. (2000). A meta-analytic review of sex differences in facial expression processing and their development in infants, children, and adolescents. *Psychological Bulletin*, *126*(3), 424-453. <http://doi.org/10.1037/0033-2909.126.3.424>
- McDonald, C. A., Thomeer, M. L., Lopata, C., Fox, J. D., Donnelly, J. P., Tang, V., & Rodgers, J. D. (2014). VABS-II ratings and predictors of adaptive behavior in children with HFASD. *Journal of Developmental and Physical Disabilities*, <http://doi.org/10.1007/s10882-014-9411-3>
- McDonald, C. A., Thomeer, M. L., Lopata, C., Fox, J. D., Donnelly, J. P., Tang, V., & Rodgers, J. D. (2015). VABS-II ratings and predictors of adaptive behavior in children with HFASD. *Journal of Developmental and Physical Disabilities*, *27*(2), 235-247. <http://doi.org/10.1007/s10882-014-9411-3>
- McGee, C. L., Bjorkquist, O. A., Price, J. M., Mattson, S. N., & Riley, E. P. (2009). Social information processing skills in children with histories of heavy prenatal alcohol exposure. *Journal of Abnormal Child Psychology*, *37*(6), 817-830. <https://doi.org/10.1007/s10802-009-9313-5>
- McGee, C. L., Bjorkquist, O. A., Riley, E. P., & Mattson, S. N. (2009). Impaired language performance in young children with heavy prenatal alcohol exposure. *Neurotoxicology and Teratology*, *31*(2), 71-75. <https://doi.org/10.1016/j.ntt.2008.09.004>
- McGee, C. L., Fryer, S. L., Bjorkquist, O. A., Mattson, S. N., & Riley, E. P. (2008). Deficits in social problem solving in adolescents with prenatal exposure to alcohol. *American*

- Journal of Drug and Alcohol Abuse*, 34(4), 423-431.  
<https://doi.org/10.1080/00952990802122630>
- McGee, C. L., Schonfeld, A. M., Roebuck-Spencer, T. M., Riley, E. P., & Mattson, S. N. (2008). Children with heavy prenatal alcohol exposure demonstrate deficits on multiple measures of concept formation. *Alcoholism: Clinical and Experimental Research*, 32(8), 1388-1397. <https://doi.org/10.1111/j.1530-0277.2008.00707.x>
- McGinn, V., & McLaren, Z. (2015, November). *The FASD clinical update on the revised Canadian guidelines*. Workshop presented at the New Zealand FASD clinicians meeting in association with Alcohol Healthwatch, Auckland, New Zealand.
- McLachlan, A., Levy, M., McClintock, K., & Tauroa, R. (2015). A literature review: Addressing Indigenous parental substance use and child welfare in Aotearoa: A whānau ora framework. *Journal of Ethnicity in Substance Abuse*, 14(1), 96-109.  
<https://doi.org/10.1080/15332640.2014.947460>
- McLachlan, K., Andrew, G., Pei, J., & Rasmussen, C. (2015). Assessing FASD in young children: Exploring clinical complexities and diagnostic challenges. *Journal of Population Therapeutics and Clinical Pharmacology*, 22(1), e108-e124. Retrieved from <http://www.jptcp.com/articles/assessing-fasd-in-young-children-exploring-clinical-complexities-and-diagnostic-challenges.pdf>
- Meldrum, R. C., Petkovsek, M. A., Boutwell, B. B., & Young, J. T. N. (2017). Reassessing the relationship between general intelligence and self-control in childhood. *Intelligence*, 60, 1-9. <https://doi.org/10.1016/j.intell.2016.10.005>
- Meppelder, M., Hodes, M., Kef, S., & Schuengel, C. (2015). Parenting stress and child behaviour problems among parents with intellectual disabilities: The buffering role of resources. *Journal of Intellectual Disability Research*, 59(7), 664-677.  
<https://doi.org/10.1111/jir.12170>
- Meurk, C., Lucke, J., & Hall, W. (2014). A bio-social and ethical framework for understanding fetal alcohol spectrum disorders. *Neuroethics*, 7(3), 337-344.  
<https://doi.org/10.1007/s12152-014-9207-2>
- Milan, S., Wortel, S., Ramirez, J., & Oshin, L. (2017). Depressive symptoms in mothers and daughters: Attachment style moderates reporter agreement. *Journal of Abnormal Child Psychology*, 45(1), 171-182. <https://doi.org/10.1007/s10802-016-0156-6>
- Ministry of Education, New Zealand. (2017). Te whariki: He whāriki mātauranga mō ngā mokopuna o Aotearoa (Early Childhood Curriculum). Wellington, New Zealand: *Ministry of Education*. Retrieved from <https://www.education.govt.nz/assets/Documents/Early-Childhood/Te-Whariki-Early-Childhood-Curriculum-ENG-Web.pdf>
- King, A. & Turia, T. (2002). *He korowai oranga*. Wellington, New Zealand: Ministry of Health. Retrieved from [http://www.moh.govt.nz/notebook/nbbooks.nsf/ea5ef2c0e4ab8ac485256caa0065e3eb/af7785c39a64d0c6cc256a4c006ec22d/\\$FILE/maorihealthstratdisc.pdf](http://www.moh.govt.nz/notebook/nbbooks.nsf/ea5ef2c0e4ab8ac485256caa0065e3eb/af7785c39a64d0c6cc256a4c006ec22d/$FILE/maorihealthstratdisc.pdf)
- Ministry of Health. (2013). *2011/12 New Zealand health survey*. Wellington, New Zealand: Ministry of Health. Retrieved from <https://www.health.govt.nz/nz-health-statistics/national-collections-and-surveys/surveys/current-recent-surveys/new-zealand-health-survey>

- Ministry of Health. (2015). *Tatau kaukura: Māori health chart book 2015 (3rd edition)*. (No. 978-0-478-44863-4). Wellington, New Zealand: Ministry of Health. Retrieved from <https://www.health.govt.nz/system/files/documents/publications/tatau-kahukura-maori-health-chart-book-3rd-edition-oct15.pdf>
- Ministry of Justice. (2001). *He hīnātore ki te ao Māori: A glimpse into the Māori world*. Wellington, New Zealand: Ministry of Justice. Retrieved from [file:///C:/Users/HP450G4/Downloads/HeHinatoreKiTeAoMaori%20\(1\).pdf](file:///C:/Users/HP450G4/Downloads/HeHinatoreKiTeAoMaori%20(1).pdf)
- Ministry of Māori Development/ Te Puni Kōkiri. (2001). *He tirohanga o kawa ki te Tiriti o Waitangi*. Wellington, New Zealand: Te Puni Kōkiri. Retrieved from <https://www.tpk.govt.nz/en/a-matou-mohiotanga/crownmaori-relations/he-tirohanga-o-kawa-ki-te-tiriti-o-waitangi>
- Mistry, R., McCarthy, W. J., Yancey, A. K., Lu, Y., & Patel, M. (2009). Resilience and patterns of health risk behaviors in California adolescents. *Preventive Medicine, 48*(3), 291-297. <https://doi.org/10.1016/j.ypmed.2008.12.013>
- Miyahara, M., Healey, D. M., & Halperin, J. M. (2014). One-week temporal stability of hyperactivity in preschoolers with ADHD during psychometric assessment. *Psychiatry and Clinical Neurosciences, 68*(2), 120-126. <https://doi.org/10.1111/pcn.12096>
- Moran, C., Kirk, C., & Powell, E. (2012). Spoken persuasive discourse abilities of adolescents with acquired brain injury. *Language, Speech, and Hearing Services in Schools, 43*(3), 264-275. <https://doi.org/10.1044/0161-1461>
- Morrisette, P. J. (2001). Fetal alcohol syndrome: Parental experiences and the role of family counselors. *The Qualitative Report, 6*(2), 1-20. Retrieved from <http://nsuworks.nova.edu/tqr/vol6/iss2/1>
- Morton Ninomiya, M. E., & Pollock, N. J. (2017). Reconciling community-based Indigenous research and academic practices: Knowing principles is not always enough. *Social Science and Medicine, 172*, 28-36. <https://doi.org/10.1016/j.socscimed.2016.11.007>
- Morton, S., Atatoa Carr, P. E., Bandara, D. K., Grant, C. C., Ivory, V. C., Kingi, T. R., . . . Pryor, J. E. (2010). *Growing up in New Zealand: A longitudinal study of New Zealand children and their families. Report 1: Before we are born*. Auckland: New Zealand: Growing Up in New Zealand. Retrieved from <http://www.growingup.co.nz/en/research-findings-impact/study-reports.html>
- Muris, P., Meesters, C., Vincken, M., & Eijkelenboom, A. (2005). Reducing children's aggressive and oppositional behaviors in the schools: Preliminary results on the effectiveness of a social-cognitive group intervention program. *Child & Family Behavior Therapy, 27*(1), 17-32. [https://doi.org/10.1300/J019v27n01\\_02](https://doi.org/10.1300/J019v27n01_02)
- Musgrave, J. A. (2007). *The effectiveness of the Otago screening protocol in identifying school-aged students with severe speech-language impairments*. (Unpublished master's dissertation). University of Canterbury, Christchurch, New Zealand.
- Nash, K., Rovet, J., Greenbaum, R., Fantus, E., Nulman, I., & Koren, G. (2006). Identifying the behavioural phenotype in fetal alcohol spectrum disorder: Sensitivity, specificity and screening potential. *Archives of Women's Mental Health, 9*(4), 181-186. <https://doi.org/10.1007/s00737-006-0130-3>

- Nash, K., Stevens, S., Greenbaum, R., Weiner, J., Koren, G., & Rovet, J. (2014). Improving executive functioning in children with fetal alcohol spectrum disorders. *Child Neuropsychology*, *21*(2), 191-209. <https://doi.org/10.1080/09297049.2014.889110>
- Nash, K., Stevens, S., Rovet, J., Fantus, E., Nulman, I., Sorbara, D., & Koren, G. (2013). Towards identifying a characteristic neuropsychological profile for fetal alcohol spectrum disorders 1. Analysis of the motherisk FASD clinic. *Journal of Population Therapeutics and Clinical Pharmacology*, *20*(1), e44-e52. Retrieved from <http://www.jptcp.com/articles/towards-identifying-a-characteristic-neuropsychological-profile-for-fetal-alcohol-spectrum-disorder-analysis-of-the-motherisk-fasd.pdf>
- National Ethics Advisory Committee. (2012). *Ethical guidelines for observational studies: Observational research, audits and related activities. Revised Edition*. Wellington, New Zealand: Ministry of Health. Retrieved from <https://neac.health.govt.nz/system/files/documents/publications/ethical-guidelines-for-observational-studies-2012.pdf>
- Ngata, H. M., & Ngata, W. (1993). *English-Māori dictionary*. Wellington, New Zealand: Learning Media Ltd.
- Nguyen, T. T., Glass, L., Coles, C. D., Kable, J. A., May, P. A., Kalberg, W. O., . . . Mattson, S. N. (2014). The clinical utility and specificity of parent report of executive function among children with prenatal alcohol exposure. *Journal of the International Neuropsychological Society*, <https://doi.org/10.1017/S1355617714000599>
- NiaNia, W., Bush, A., & Epston, D. (2016). *Collaborative and Indigenous mental health therapy: Tātaihono-stories of Māori healing and psychiatry*. New York, USA: Taylor & Francis.
- Norman, A. L., O'Brien, J. W., Spadoni, A. D., Tapert, S. F., Jones, K. L., Riley, E. P., & Mattson, S. N. (2013). A functional magnetic resonance imaging study of spatial working memory in children with prenatal alcohol exposure: Contribution of familial history of alcohol use disorders. *Alcoholism: Clinical and Experimental Research*, *37*(1), 132-140. <https://doi.org/10.1111/j.1530-0277.2012.01880.x>
- Nowicki, S. (2010). *A manual and reference list for the diagnostic analysis of nonverbal accuracy*: Unpublished manuscript, Atlanta, Georgia: Emory University.
- Nowicki, S., & Duke, M. P. (1994). Individual differences in the nonverbal communication of affect: The diagnostic analysis of nonverbal accuracy scale. *Journal of Nonverbal Behavior*, *18*(1), 9-35. <https://doi.org/10.1007/BF02169077>
- O Connor, M. J., McCracken, J. T., & Best, A. (2006). Under recognition of prenatal alcohol exposure in a child inpatient psychiatric setting. *Mental Health Aspects of Developmental Disabilities*, *9*(4), 105-108. Retrieved from <https://pdfs.semanticscholar.org/66e6/09482f7ebb9c6157c8338d7e06c0c5d40b5a.pdf>
- O'Reilly, J., & Peterson, C. C. (2014). Maltreatment and advanced theory of mind development in school-aged children. *Journal of Family Violence*, *30*(1), 93-102. <https://doi.org/10.1007/s10896-014-9647-9>
- O'Connor, M. J., Frankel, F., Paley, B., Schonfeld, A. M., Carpenter, E., Laugeson, E. A., & Marquardt, R. (2006). A controlled social skills training for children with fetal alcohol spectrum disorders. *Journal of Consulting and Clinical Psychology*, *74*(4), 639-648. <https://doi.org/10.1037/0022-006X.74.4.639>

- O'Connor, M. J., Kogan, N., & Findlay, R. (2002). Prenatal alcohol exposure and attachment behavior in children. *Alcoholism: Clinical and Experimental Research*, 26(10), 1592-1602. <https://doi.org/10.1111/j.1530-0277.2002.tb02460.x>
- O'Connor, M. J., Laugeson, E. A., Mogil, C., Lowe, E., Welch-Torres, K., Keil, V., & Paley, B. (2012). Translation of an evidence-based social skills intervention for children with prenatal alcohol exposure in a community mental health setting. *Alcoholism: Clinical and Experimental Research*, 36(1), 141-152. <https://doi.org/10.1111/j.1530-0277.2011.01591.x>
- O'Connor, M. J., & Kasari, C. (2000). Prenatal alcohol exposure and depressive features in children. *Alcoholism: Clinical and Experimental Research*, 24(7), 1084-1092. <https://doi.org/10.1111/j.1530-0277.2000.tb04654.x>
- Office of the Children's Commissioner. (2015). *State of care 2015: What we learnt from monitoring child youth and family*. Wellington, New Zealand: Office of the Children's Commissioner. Retrieved from <http://www.occ.org.nz/assets/Publications/OCC-State-of-Care-2016.pdf>
- Ogden, J. A., & McFarlane-Nathan, G. (1997). Cultural bias in the neuropsychological assessment of young Māori men. *New Zealand Journal of Psychology*, 26(2), 2-12. Retrieved from <http://www.psychology.org.nz/wp-content/uploads/NZJP-Vol262-1997-1-Ogden.pdf>
- O'Leary, C., Leonard, H., Bourke, J., D'Antoine, H., Bartu, A., & Bower, C. (2012). Intellectual disability: Population-based estimates of the proportion attributable to maternal alcohol use disorder during pregnancy. *Developmental Medicine and Child Neurology*, 55(3), 271-277. <https://doi.org/10.1111/dmcn.12029>
- Olson, H. C., Oti, R., Gelo, J., & Beck, S. (2009). "Family matters:" Fetal alcohol spectrum disorders and the family. *Developmental Disabilities Research Reviews*, 15(3), 235-249. <https://doi.org/10.1002/ddrr.65>
- Ontario Federation of Indian Friendship Centres. (2013). *Fetal alcohol spectrum disorder: A position paper*. Toronto, Canada: OFIFC. Retrieved from <http://www.ofifc.org/publication/fetal-alcohol-spectrum-disorder-position-paper>
- Pacey, M. (2008). *Fetal alcohol syndrome and fetal alcohol spectrum disorder among aboriginal peoples*. Prince George, BC: National Collaborating Centre for Aboriginal Healing. Retrieved from <https://www.cnsa-nccah.ca/docs/health/RPT-FASDAboriginalReviewPrevalence-Pacey-EN.pdf>
- Pain, R. (2004). Social geography: Participatory research. *Progress in Human Geography*, 28(5), 652-663. <https://doi.org/10.1191/0309132504ph511pr>
- Paley, B., & O'Connor, M. J. (2009). Intervention for individuals with fetal alcohol spectrum disorders: Treatment approaches and case management. *Developmental Disabilities Research Reviews*, 15(3), 258-267. <https://doi.org/10.1002/ddrr.67>
- Paley, B., & Auerbach, B. E. (2010). Children with fetal alcohol spectrum disorders in the dependency court system: Challenges and recommendations. *The Journal of Psychiatry & Law*, 38(4), 507-558. <https://doi.org/10.1177/009318531003800407>
- Paley, B., O'Connor, M. J., Frankel, F., & Marquardt, R. (2006). Predictors of stress in parents of children with fetal alcohol spectrum disorders. *Journal of Developmental &*

- Behavioral Pediatrics*, 27(5), 396-404. <https://doi.org/10.1097/00004703-200610000-00005>
- Paley, B., O'Connor, M. J., Kogan, N., & Findlay, R. (2005). Prenatal alcohol exposure, child externalizing behavior, and maternal stress. *Parenting: Science and Practice*, 5(1), 29-56. [https://doi.org/10.1207/s15327922par0501\\_2](https://doi.org/10.1207/s15327922par0501_2)
- Panczakiewicz, A. L., Glass, L., Coles, C. D., Kable, J. A., Sowell, E. R., Wozniak, J. R., . . . Mattson, S. N. (2016). Neurobehavioral deficits consistent across age and sex in youth with prenatal alcohol exposure. *Alcoholism: Clinical and Experimental Research*, 40(9), 1971-1981. <https://doi.org/10.1111/acer.13153>
- Paradies, Y. (2016). Colonisation, racism and Indigenous health. *Journal of Population Research*, 33, 83-96. <https://doi.org/10.1007/s12546-016-9159-y>
- Pears, K. C., & Fisher, P. A. (2005). Emotion understanding and theory of mind among maltreated children in foster care: Evidence of deficits. *Development and Psychopathology*, 17(1), 47-65. <https://doi.org/10.1017/S0954579405050030>
- Peart, N., & Holdaway, D. (2000). Guidelines for health research with children. *New Zealand Bioethics Journal*, 1(2), 3-9. Updated in 2007 by Nicola Peart. Retrieved from <http://www.hrc.govt.nz/sites/default/files/HRC%20Guidelines%20for%20Health%20Research%20with%20Children.pdf>
- Pei, J., Denys, K., Hughes, J., & Rasmussen, C. (2011). Mental health issues in fetal alcohol spectrum disorder. *Journal of Mental Health*, 20(5), 473-483. <https://doi.org/10.3109/09638237.2011.577113>
- Pei, J., Job, J. M., Poth, C., & Atkinson, E. (2013). Assessment for intervention of children with fetal alcohol spectrum disorders: Perspectives of classroom teachers, administrators, caregivers, and allied professionals. *Psychology*, 4(03), 325-334. <https://doi.org/10.4236/psych.2013.43A047>
- Pere, R. R. (1991). *Te wheke: A celebration of ultimate wisdom*. Gisborne, New Zealand: Ao Ako.
- Perry, B. D. (2002). Childhood experience and the expression of genetic potential: What childhood neglect tells us about nature and nurture? *Brain and Mind*, 3(1), 79-100. <https://doi.org/10.1023/A:1016557824657>
- Petrenko, C. L. M., & Alto, M. E. (2017). Interventions in fetal alcohol spectrum disorders: An international perspective. *European Journal of Medical Genetics*, 60(1), 79-91. <https://doi.org/10.1016/j.ejmg.2016.10.005>
- Petrenko, C. L., Pandolfino, M. E., & Robinson, L. K. (2017). Findings from the families on track intervention pilot trial for children with fetal alcohol spectrum disorders and their families. *Alcoholism: Clinical and Experimental Research*, 41(7), 1340-1351. <https://doi.org/10.1111/acer.13408>
- Petrenko, C. L. M., Pandolfino, M. E., Quamma, J., & Olson, H. C. (2017). Emotional understanding and social problem-solving in school-aged children with fetal alcohol spectrum disorders: Promising targets for intervention. *Journal of Population Therapeutics and Clinical Pharmacology*, 24(2), 21-31. <https://doi.org/10.22374/1710-6222.24.2.5>

- Petti, V. L., Voelker, S. L., Shore, D. L., & Hayman-Abello, S. E. (2003). Perception of nonverbal emotion cues by children with nonverbal learning disabilities. *Journal of Developmental and Physical Disabilities, 15*(1), 23-36. <https://doi.org/10.1023/A:1021400203453>
- Pitama, S., Huria, T., & Lacey, C. (2014). Improving Māori health through clinical assessment: Waikare o te waka o meihana. *The New Zealand Medical Journal (Online), 127*(1393), 107-119. Retrieved from <http://journal.nzma.org.nz/journal/127-1393/6108/>
- Pitama, S., Robertson, P., Cram, F., Gillies, M., Huria, T., & Dallas-Katoa, W. (2007). Meihana model: A clinical assessment framework. *New Zealand Journal of Psychology, 36*(3), 118-125. Retrieved from <http://web.b.ebscohost.com.ezproxy.auckland.ac.nz/ehost/pdfviewer/pdfviewer?vid=0&sid=60118f3e-9d20-4815-a28d-a108d7ef4f23%40sessionmgr103>
- Pollak, S. D. (2005). Early adversity and mechanisms of plasticity: Integrating affective neuroscience with developmental approaches to psychopathology. *Development and Psychopathology, 17*(3), 735-752. <https://doi.org/10.1017/S0954579405050352>
- Pollak, S. D., Cicchetti, D., Hornung, K., & Reed, A. (2000). Recognizing emotion in faces: Developmental effects of child abuse and neglect. *Developmental Psychology, 36*(5), 679-688. <https://doi.org/10.1037/0012-1649.36.5.679>
- Pollak, S. D., & Sinha, P. (2002). Effects of early experience on children's recognition of facial displays of emotion. *Developmental Psychology, 38*(5), 784-791. <http://doi.org/10.1037/0012-1649.38.5.784>
- Popova, S., Lange, S., Probst, C., Parunashvili, N., & Rehm, J. (2017). Prevalence of alcohol consumption during pregnancy and fetal alcohol spectrum disorders among the general and aboriginal populations in Canada and the United States. *European Journal of Medical Genetics, 60*(1), 32-48. <http://doi.org/10.1016/j.ejmg.2016.09.010>
- Popova, S., Lange, S., Shield, K., Mihic, A., Chudley, A. E., Mukherjee, R. A. S., . . . Rehm, J. (2015). Comorbidity of fetal alcohol spectrum disorder: A systematic review and meta-analysis. *The Lancet, 387*(10022), 978-987. [http://doi.org/10.1016/S0140-6736\(15\)01345-8](http://doi.org/10.1016/S0140-6736(15)01345-8)
- Poth, C., Pei, J., Job, J. M., & Wyper, K. (2014). Toward intentional, reflective, and assimilative classroom practices with students with FASD. *The Teacher Educator, 49*(4), 247-264. <http://doi.org/10.1080/08878730.2014.933642>
- Quattlebaum, J. L., & O'Connor, M. J. (2013). Higher functioning children with prenatal alcohol exposure: Is there a specific neurocognitive profile? *Child Neuropsychology, 19*(6), 561-578. [10.1080/09297049.2012.713466](http://doi.org/10.1080/09297049.2012.713466)
- Rai, J. K., Abecassis, M., Casey, J. E., Flaro, L., Erdodi, L. A., & Roth, R. M. (2016). Parent rating of executive function in fetal alcohol spectrum disorder: A review of the literature and new data on aboriginal Canadian children. *Child Neuropsychology, 19*(6), 561-578. <http://doi.org/10.1080/09297049.2016.1191628>
- Rameka, L. (2016). Kia whakatōmuri te haere whakamua: 'I walk backwards into the future with my eyes fixed on my past'. *Contemporary Issues in Early Childhood, 17*(4), 387-398. <https://doi.org/10.1177/1463949116677923>

- Rangihau, J. (1988). *PUAO-TE-ATA-TU (day break). The report of the ministerial advisory committee on a Māori perspective for the Department of Social Welfare*. Wellington, New Zealand: The New Zealand Government. Retrieved from <https://www.msd.govt.nz/documents/about-msd-and-our-work/publications-resources/archive/1988-puaoteatatu.pdf>
- Rankine, J., Nairn, R., Barnes, A. M., Gregory, A., Kaiwai, H., Borell, B., ... McCreanor, T. (2008). *Media and te Tiriti o Waitangi 2007*. Auckland, New Zealand Kupu Tea: Media & te Tiriti Project. Retrieved from <http://www.trc.org.nz/media-and-te-tiritio-waitangi-2007>
- Rankine, J., Gregory, A., Tonks, A., & Thompson-Evans, T. (2013). *Women and alcohol in Aotearoa/New Zealand: Te waipiro me ngā wāhine i Aotearoa* Wellington, New Zealand: Alcohol Healthwatch and Women's Health Action. Retrieved from [http://www.ahw.org.nz/Portals/5/Resources/Briefing%20papers/2013/WomenAlcoholReport%20\(jenny%20rankin\)%202013.pdf](http://www.ahw.org.nz/Portals/5/Resources/Briefing%20papers/2013/WomenAlcoholReport%20(jenny%20rankin)%202013.pdf)
- Rasmussen, C., Becker, M., McLennan, J., Urichuk, L., & Andrew, G. (2011). An evaluation of social skills in children with and without prenatal alcohol exposure. *Child: Care, Health and Development*, 37(5), 711-718. <https://doi.org/10.1111/j.1365-2214.2010.01152.x>
- Rasmussen, C., Benz, J., Pei, J., Andrew, G., Schuller, G., Abele-Webster, L., . . . Lord, L. (2010). The impact of an ADHD co-morbidity on the diagnosis of FASD. *Journal of Population Therapeutics and Clinical Pharmacology*, 17(1), e176-e176. Retrieved from <http://www.jptcp.com/articles/the-impact-of-an-adhd-comorbidity-on-the-diagnosis-of-fasd.pdf>
- Rasmussen, C., & Bisanz, J. (2009). Executive functioning in children with fetal alcohol spectrum disorders: Profiles and age-related differences. *Child Neuropsychology*, 15(3), 201-215. <https://doi.org/10.1080/09297040802385400>
- Rasmussen, C., & Bisanz, J. (2011). The relation between mathematics and working memory in young children with fetal alcohol spectrum disorders. *The Journal of Special Education*, 45(3), 184-191. <https://doi.org/10.1177/0022466909356110>
- Rasmussen, C., Horne, K., & Witol, A. (2006). Neurobehavioral functioning in children with fetal alcohol spectrum disorder. *Child Neuropsychology*, 12(6), 453-468. <https://doi.org/10.1080/09297040600646854>
- Rasmussen, C., Tamana, S., Baugh, L., Andrew, G., Tough, S., & Zwaigenbaum, L. (2013). Neuropsychological impairments on the NEPSY-II among children with FASD. *Child Neuropsychology*, 19(4), 337-349. <https://doi.org/10.1080/09297049.2012.658768>
- Rasmussen, C., Wyper, K., & Talwar, V. (2009). The relation between theory of mind and executive functions in children with fetal alcohol spectrum disorders. *The Canadian Journal of Clinical Pharmacology (Journal Canadien De Pharmacologie Clinique)*, 16(2), e380-e380. Retrieved from <http://www.jptcp.com/articles/the-relation-between-theory-of-mind-and-executive-functions-in-children-with-fetal-alcohol-spectrum-disorders.pdf>
- Ratto, A. B., Anthony, B. J., Kenworthy, L., Armour, A. C., Dudley, K., & Anthony, L. G. (2016). Are non-intellectually disabled black youth with ASD less impaired on parent

- report than their white peers? *Journal of Autism and Developmental Disorders*, 46(3), 773-781. <https://doi.org/10.1007/s10803-015-2614-3>
- Raver, C. C., Blair, C., & Willoughby, M. (2013). Poverty as a predictor of 4-year-olds' executive function: New perspectives on models of differential susceptibility. *Developmental Psychology*, 49(2), 292-304. <https://doi.org/10.1037/a0028343>
- Reedy, T. (2000). Te Reo Māori: The past 20 years and looking forward. *Oceanic Linguistics*, 39(1), 157-168. <https://doi.org/10.1353/ol.2000.0009>
- Reid, J., Taylor-Moore, K., & Varona, G. (2014). Towards a social-structural model for understanding current disparities in Māori health and well-being. *Journal of Loss and Trauma*, 19(6), 514-536. <https://doi.org/10.1080/15325024.2013.809295>
- Reid, N., Dawe, S., Shelton, D., Harnett, P., Warner, J., Armstrong, E., . . . O'Callaghan, F. (2015). Systematic review of fetal alcohol spectrum disorder interventions across the life span. *Alcoholism: Clinical and Experimental Research*, 39(12), 2283-2295. <https://doi.org/10.1111/acer.12903>
- Reid, N., Shelton, D., Warner, J., O'Callaghan, F., & Dawe, S. (2017). Profile of children diagnosed with a fetal alcohol spectrum disorder: A retrospective chart review. *Drug and Alcohol Review*, 36(5), 677-681. <https://doi.org/10.1111/dar.12519>
- Reidy, N., Morgan, A., Thompson, D. K., Inder, T. E., Doyle, L. W., & Anderson, P. J. (2013). Impaired language abilities and white matter abnormalities in children born very preterm and/or very low birth weight. *The Journal of Pediatrics*, 162(4), 719-724. <https://doi.org/10.1016/j.jpeds.2012.10.017>
- Riley, E. P., Infante, M. A., & Warren, K. R. (2011). Fetal alcohol spectrum disorders: An overview. *Neuropsychology Review*, 21(2), 73-80. <https://doi.org/10.1007/s11065-011-9166-x>
- Riley, E. P., & McGee, C. L. (2005). Fetal alcohol spectrum disorders: An overview with emphasis on changes in brain and behavior. *Experimental Biology and Medicine*, 230(6), 357-365. <https://doi.org/10.1177/15353702-0323006-03>
- Rinsky, J. R., & Hinshaw, S. P. (2011). Linkages between childhood executive functioning and adolescent social functioning and psychopathology in girls with ADHD. *Child Neuropsychology*, 17(4), 368-390. <https://doi.org/10.1080/09297049.2010.544649>
- Robertson, P., Huriwai, T., Potiki, T., Friend, R., Durie, M. (2002). Working with Māori who have alcohol and drug-related problems. In G. Hulse, J. White, G. Cape (Eds.), *Management of Alcohol and Drug Problems*, (pp. 328-344). Victoria, Australia: Oxford University Press.
- Rochette, É, & Bernier, A. (2014). Parenting, family socioeconomic status, and child executive functioning: A longitudinal study. *Merrill-Palmer Quarterly*, 60(4), 431-460. <https://doi.org/10.1353/mpq.2014.0024>
- Rojas, E. Y., & Gretton, H. M. (2007). Background, offence characteristics, and criminal outcomes of aboriginal youth who sexually offend: A closer look at aboriginal youth intervention needs. *Sexual Abuse: A Journal of Research and Treatment*, 19(3), 257-283. <https://doi.org/10.1007/s11194-007-9048-1>
- Root, A., Hastings, P., & Maxwell, K. (2012). Environmental contributions to the development of social competence. In Anderson, V. & M. Beauchamp, M. (Eds.),

*Developmental social neuroscience and childhood brain insult: Theory and practice* (pp. 91-115). New York: The Guilford Press.

- Roozen, S., Peters, G. -. Y., Kok, G., Townend, D., Nijhuis, J., & Curfs, L. (2016). Worldwide prevalence of fetal alcohol spectrum disorders: A systematic literature review including meta-analysis. *Alcoholism: Clinical and Experimental Research*, *40*(1), 18-32. <https://doi.org/10.1111/acer.12939>
- Saggers, S., & Gray, D. (1998). *Dealing with alcohol: Indigenous usage in Australia, New Zealand and Canada*. New York: Cambridge University Press.
- Sakdalan, J. A., Shaw, J., & Collier, V. (2010). Staying in the here-and-now: A pilot study on the use of dialectical behaviour therapy group skills training for forensic clients with intellectual disability. *Journal of Intellectual Disability Research*, *54*(6), 568-572. <https://doi.org/10.1111/j.1365-2788.2010.01274.x>
- Saltzman, K. M., Weems, C. F., & Carrion, V. G. (2006). IQ and posttraumatic stress symptoms in children exposed to interpersonal violence. *Child Psychiatry and Human Development*, *36*(3), 261-272. <https://doi.org/10.1007/s10578-005-0002-5>
- Samuels, W. E., Tournaki, N., Blackman, S., & Zilinski, C. (2016). Executive functioning predicts academic achievement in middle school: A four-year longitudinal study. *The Journal of Educational Research* *109*(5), 479-490. <https://doi.org/10.1007/10.1080/00220671.2014.979913>
- Sayal, K., Heron, J., Draper, E., Alati, R., Lewis, S. J., Fraser, R., . . . Gray, R. (2014). Prenatal exposure to binge pattern of alcohol consumption: Mental health and learning outcomes at age 11. *European Child and Adolescent Psychiatry*, *23*(10), 891-899. <https://doi.org/10.1007/s00787-014-0599-7>
- Schiebener, J., García-Arias, M., García-Villamisar, D., Cabanyes-Truffino, J., & Brand, M. (2015). Developmental changes in decision making under risk: The role of executive functions and reasoning abilities in 8- to 19-year-old decision makers. *Child Neuropsychology*, *21*(6), 759-778. <https://doi.org/10.1080/09297049.2014.934216>
- Schofield, G., Biggart, L., Ward, E., & Larsson, B. (2015). Looked after children and offending: An exploration of risk, resilience and the role of social cognition. *Children and Youth Services Review*, *51*, 125-133. <https://doi.org/10.1016/j.childyouth.2015.01.024>
- Schonfeld, A. M., Mattson, S. N., Lang, A. R., Delis, D. C., & Riley, E. P. (2001). Verbal and nonverbal fluency in children with heavy prenatal alcohol exposure. *Journal of Studies on Alcohol and Drugs*, *62*(2), 239-246. <https://doi.org/10.15288/jsa.2001.62.239>
- Schonfeld, A. M., Mattson, S. N., & Riley, E. P. (2005). Moral maturity and delinquency after prenatal alcohol exposure. *Journal of Studies on Alcohol and Drugs*, *66*(4), 545-554. <https://doi.org/10.15288/jsa.2005.66.545>
- Schonfeld, A. M., Paley, B., Frankel, F., & O'Connor, M. J. (2006). Executive functioning predicts social skills following prenatal alcohol exposure. *Child Neuropsychology*, *12*(6), 439-452. <https://doi.org/10.1080/09297040600611338>
- Schrieff-Elson, L. E., Thomas, K., Rohlwick, U. K., & Figaji, A. A. (2015). Low brain oxygenation and differences in neuropsychological outcomes following severe pediatric

- TBI. *Child's Nervous System*, 31(12), 2257-2268. <https://doi.org/10.1007/s00381-015-2892-2>
- Scott, M. N., Hunter, S. J., Joseph, R. M., O'Shea, T. M., Hooper, S. R., Allred, E. N., . . . Kuban, K. (2017). Neurocognitive correlates of attention-deficit hyperactivity disorder symptoms in children born at extremely low gestational age. *Journal of Developmental & Behavioral Pediatrics*, 38(4), 249-259. <https://doi.org/10.1097/DBP.0000000000000436>
- Scourfield, J., Martin, N., Lewis, G., & McGuffin, P. (1999). Heritability of social cognitive skills in children and adolescents. *British Journal of Psychiatry*, 175(6), 559-564. <https://doi.org/10.1192/bjp.175.6.559>
- Selman, R. L., & Byrne, D. F. (1974). A structural developmental analysis of levels of role taking in middle childhood. *Child Development*, 45(3), 803-806. <https://doi.org/10.2307/1127850>
- Semel, E., Wiig, E. H., & Secord, W. A. (2003). *Clinical evaluation of language fundamentals (CELF-4)*. San Antonio, TX: The Psychological Corporation.
- Semel, E., Wiig, E., & Secord, W. (2004). *Clinical evaluation of language fundamentals-screening test Australian & New Zealand language adapted edition (CELF-4 screener)*. Sydney, Australia: NCS Pearson.
- Semrud-Clikeman, M., Fine, J. G., & Bledsoe, J. (2014). Comparison among children with children with autism spectrum disorder, nonverbal learning disorder and typically developing children on measures of executive functioning. *Journal of Autism and Developmental Disorders*, 44(2), 331-342. <https://doi.org/10.1007/s10803-013-1871-2>
- Shallice, T. (1982). Specific impairments of planning. *Philosophical Transactions of the Royal Society of London. Series B, Biological Sciences*, 298, 199-209. Retrieved from <http://rstb.royalsocietypublishing.org/content/royptb/298/1089/199.full.pdf>
- Shashi, V., Veerapandiyam, A., Schoch, K., Kwapil, T., Keshavan, M., Ip, E., & Hooper, S. (2012). Social skills and associated psychopathology in children with chromosome 22q11.2 deletion syndrome: Implications for interventions. *Journal of Intellectual Disability Research*, 56(9), 865-878. <https://doi.org/10.1111/j.1365-2788.2011.01477.x>
- Shields, A. M., Cicchetti, D., & Ryan, R. M. (1994). The development of emotional and behavioral self-regulation and social competence among maltreated school-age children. *Development and Psychopathology*, 6(1), 57-75. <https://doi.org/10.1017/S0954579400005885>
- Shochet, I. M., Dadds, M. R., Ham, D., & Montague, R. (2006). School connectedness is an underemphasized parameter in adolescent mental health: Results of a community prediction study. *Journal of Clinical Child & Adolescent Psychology*, 35(2), 170-179. [https://doi.org/10.1207/s15374424jccp3502\\_1](https://doi.org/10.1207/s15374424jccp3502_1)
- Shonkoff, J. P., Garner, A. S., Siegel, B. S., Dobbins, M. I., Earls, M. F., McGuinn, L., . . . Wegner, L. M. (2012). The lifelong effects of early childhood adversity and toxic stress. *Pediatrics*, 129(1), e232-e246. <https://doi.org/10.1542/peds.2011-2663>
- Siegel, D. J., Minshew, N. J., & Goldstein, G. (1996). Wechsler IQ profiles in diagnosis of high-functioning autism. *Journal of autism and developmental disorders*, 26(4), 389-406. <https://doi.org/10.1007/BF02172825>

- Silver, C. H. (2014). Sources of data about children's executive functioning: Review and commentary. *Child Neuropsychology*, 20(1), 1-13. <https://doi.org/10.1080/09297049.2012.727793>
- Singal, D., Brownell, M., Chateau, D., Hanlon-Dearman, A., Longstaffe, S., & Roos, L. L. (2017). The psychiatric morbidity of women who give birth to children with fetal alcohol spectrum disorder (FASD): Results of the Manitoba mothers and FASD study. *Canadian Journal of Psychiatry*, 62(8), 531-542. <https://doi.org/10.1177/0706743717703646>
- Smith, L. T. (2012). *Decolonizing methodologies: Research and Indigenous peoples* (Second ed.). Dunedin, New Zealand: Otago University Press.
- Soh, D. W., Skocic, J., Nash, K., Stevens, S., Turner, G. R., & Rovet, J. (2015). Self-regulation therapy increases frontal gray matter in children with fetal alcohol spectrum disorder: Evaluation by voxel-based morphometry. *Frontiers in Human Neuroscience*, 9, 108-112. <https://doi.org/10.3389/fnhum.2015.00108>
- Sorenson, M. P. K. (1956). Land purchase methods and their effect on Māori population, 1865-1901. *The Journal of the Polynesian Society*, 65(3), 183-199. Retrieved from <http://www.jstor.org/stable/20703557>
- Sparrow, S. S., Cicchetti, D. V., & Balla, D. A. (2005). *Vineland adaptive behavior scales: (Vineland II)*. Livonia, MN: Pearson Assessments.
- Stade, B. C., Stevens, B., Ungar, W. J., Beyene, J., & Koren, G. (2006). Health-related quality of life of Canadian children and youth prenatally exposed to alcohol. *Health and Quality of Life Outcomes*, 4(1), 81-91. <https://doi.org/10.1186/1477-7525-4-81>
- Stanley, E. (2017). From care to custody: Trajectories of children in post-war New Zealand. *Youth Justice*, 17(1), 57-72. <https://doi.org/10.1177/1473225416669145>
- Statistics Canada. (2012). Life expectancy at birth, by sex, by province. Retrieved from <http://www.statcan.gc.ca/tables-tableaux/sum-som/101/cst01/health26-eng.htm>
- Stevens, S. A., Dudek, J., Nash, K., Koren, G., & Rovet, J. (2015). Social perspective taking and empathy in children with fetal alcohol spectrum disorders. *Journal of the International Neuropsychological Society*, 21(1), 74-84. <https://doi.org/10.1017/S1355617714001088>
- Stevens, S. A., Clairman, H., Nash, K., & Rovet, J. (2016). Social perception in children with fetal alcohol spectrum disorder. *Child Neuropsychology*, 23(8), 980-993. <https://doi.org/10.1080/09297049.2016.1246657>
- Stichter, J. P., O'Connor, K. V., Herzog, M. J., Lierheimer, K., & McGhee, S. D. (2012). Social competence intervention for elementary students with Asperger's syndrome and high functioning autism. *Journal of Autism and Developmental Disorders*, 42(3), 354-366. <https://doi.org/10.1007/s10803-011-1249-2>
- Streissguth, A. P., Aase, J. M., Clarren, S. K., Randels, S. P., LaDue, R. A., & Smith, D. F. (1991). Fetal alcohol syndrome in adolescents and adults. *JAMA: The Journal of the American Medical Association*, 265(15), 1961-1967. <https://doi.org/10.1001/jama.1991.03460150065025>
- Streissguth, A. P., Barr, H. M., Kogan, J., & Bookstein, F. (1996). *Understanding the occurrence of secondary disabilities in clients with fetal alcohol syndrome (FAS) and*

*fetal alcohol effects (FAE)*. Washington, Seattle: University of Washington School of Medicine, Department of Psychiatry and Behavioural Sciences.

- Streissguth, A. P., Bookstein, F. L., Barr, H. M., Sampson, P. D., O'Malley, K., & Young, J. K. (2004). Risk factors for adverse life outcomes in fetal alcohol syndrome and fetal alcohol effects. *Journal of Developmental & Behavioral Pediatrics*, 25(4), 228-238. <https://doi.org/10.1097/00004703-200408000-00002>
- Stuart, K. (2009). Trading off: A grounded theory on how Māori women negotiate drinking alcohol during pregnancy. (Unpublished master's thesis). Massey University, Wellington, New Zealand.
- Taber-Thomas, B. C., & Tranel, D. (2012). Social and moral functioning: A cognitive neuroscience perspective. In V. Anderson, & M. Beauchamp (Eds.), *Developmental social neuroscience and child hood brain insult: Theory and Practice* (pp. 65-90). New York: The Guilford Press.
- Tait, C. L. (2003). *Fetal alcohol syndrome among aboriginal people in Canada: Review and analysis of the intergenerational links to residential schools*. Ottawa, Canada: Aboriginal Healing Foundation. Retrieved from <http://www.ahf.ca/downloads/fetal-alcohol-syndrome.pdf>
- Tamana, S., Pei, J., Massey, D., Massey, V., & Rasmussen, C. (2014). Neuropsychological impairments and age-related differences in children and adolescents with fetal alcohol spectrum disorders. *Journal of Population Therapeutics and Clinical Pharmacology*, 21(2), e167-e180. Retrieved from <http://www.jptcp.com/volume-issue.php?volume=21&issue=2&year=2014&journal=jptcp>
- Tan, E., Healey, D., Schaughency, E., Dawes, P., & Galland, B. (2014). Neurobehavioural correlates in older children and adolescents with obesity and obstructive sleep apnoea. *Journal of Paediatrics and Child Health*, 50(1), 16-23. <https://doi.org/10.1111/jpc.12390>
- Tanabe, M. K., Whitaker, A. M., O'Callaghan, E. T., Murray, J., & Houskamp, B. M. (2014). Intellectual ability as a predictor of performance on the Wisconsin card-sorting test. *Applied Neuropsychology: Child*, 3(4), 275-283. <https://doi.org/10.1080/21622965.2012.757700>
- Taonui, R. (2010). Mana tamariki: Cultural alienation: Māori child homicide and abuse. *AlterNative: An International Journal of Indigenous Peoples*, 6(3), 187-202. <https://doi.org/10.1177/117718011000600301>
- Māori Party founder Dame Tariana Turia plans to return to help save the party, 2017. Retrieved from <https://www.stuff.co.nz/national/politics/97243900/mori-party-founder-dame-tariana-turia-plans-return-to-help-save-the-party>.
- Tassé, M. J. (2009). Adaptive behavior assessment and the diagnosis of mental retardation in capital cases. *Applied Neuropsychology*, 16(2), 114-123. <https://doi.org/10.1080/09084280902864451>
- Taylor, N., & Enns, L. (2017). Age-related differences in neuropsychological assessment of fetal alcohol spectrum disorder: A cross-sectional study. *Biochemistry and Cell Biology*. Advance online publication. <https://doi.org/10.1139/bcb-2017-0081>

- Te Nahu, L. (2013). *Research terms of reference for proposed development of taumata rangahau*. Hastings. New Zealand: Hawke's Bay District Health Board.
- Teicher, M. H., & Samson, J. A. (2016). Annual research review: Enduring neurobiological effects of childhood abuse and neglect. *Journal of Child Psychology and Psychiatry*, 57(3), 241-266. <https://doi.org/10.1111/jcpp.12507>
- Thaler, N. S., Bello, D. T., & Etcoff, L. M. (2013). WISC-IV profiles are associated with differences in symptomatology and outcome in children with ADHD. *Journal of Attention Disorders*, 17(4), 291-301. <https://doi.org/10.1177/1087054711428806>
- Thanh, N. X., & Jonsson, E. (2016). Life expectancy of people with fetal alcohol syndrome. *Journal of Population Therapeutics and Clinical Pharmacology*, 23(1), e53-e59. Retrieved from <http://www.jptcp.com/articles/life-expectancy-of-people-with-fetal-alcohol-syndrome.pdf>
- The Waitangi Tribunal. (2004). *The mohaka ki ahuriri report*. Wellington, New Zealand: Legislation Direct. Retrieved from <https://www.waitangitribunal.govt.nz>
- Thickpenney-Davis, K. L., Ogden, J. A., & Fernando, K. (2005). The starship post-traumatic amnesia scale: Does it predict outcome after mild to moderate traumatic brain injury in children aged 3 to 7 years? *Brain Impairment*, 6(02), 101-108. <https://doi.org/10.1375/brim.2005.6.2.101>
- Thomas, S. E., Kelly, S. J., Mattson, S. N., & Riley, E. P. (1998). Comparison of social abilities of children with fetal alcohol syndrome to those of children with similar IQ scores and normal controls. *Alcoholism: Clinical and Experimental Research*, 22(2), 528-533. <https://doi.org/10.1111/j.1530-0277.1998.tb03684.x>
- Thompson, A. E., & Voyer, D. (2014). Sex differences in the ability to recognise non-verbal displays of emotion: A meta-analysis. *Cognition and Emotion*, 28(7), 1164-1195. <https://doi.org/10.1080/02699931.2013.875889>
- Tiet, Q. Q., Huizinga, D., & Byrnes, H. F. (2010). Predictors of resilience among inner city youths. *Journal of Child and Family Studies*, 19(3), 360-378. <https://doi.org/10.1007/s10826-009-9307-5>
- Tlustos, S. J., Chiu, C. P., Walz, N. C., Taylor, H. G., Yeates, K. O., & Wade, S. L. (2011). Emotion labeling and socio-emotional outcomes 18 months after early childhood traumatic brain injury. *Journal of the International Neuropsychological Society*, 17(06), 1132-1142. <https://doi.org/10.1017/S1355617711001202>
- Tonks, J., Williams, W. H., Frampton, I., Yates, P., & Slater, A. (2007). Reading emotions after child brain injury: A comparison between children with brain injury and non-injured controls. *Brain Injury*, 21(7), 731-739. <https://doi.org/10.1080/02699050701426899>
- Tonmyr, L., & Blackstock, C. (2010). Commentary: Indigenous health special issue. *International Journal of Mental Health and Addiction*, 8(2), 135-144. <https://doi.org/10.1007/s11469-010-9272-7>
- Trentacosta, C. J., & Fine, S. E. (2010). Emotion knowledge, social competence, and behavior problems in childhood and adolescence: A meta-analytic review. *Social Development*, 19(1), 1-29. <https://doi.org/10.1111/j.1467-9507.2009.00543.x>

- Tseng, W. L., & Gau, S. S. F. (2013). Executive function as a mediator in the link between attention-deficit/ hyperactivity disorder and social problems. *Journal of Child Psychology and Psychiatry and Allied Disciplines*, *54*(9), 996-1004. <https://doi.org/10.1111/jcpp.12072>
- Ursache, A., & Noble, K. G. (2016). Neurocognitive development in socioeconomic context: Multiple mechanisms and implications for measuring socioeconomic status. *Psychophysiology*, *53*(1), 71-82. <https://doi.org/10.1111/psyp.12547>
- Ursache, A., & Raver, C. C. (2015). Iowa gambling task performance and executive function predict low-income urban preadolescents' risky behaviors. *Personality and Individual Differences*, *79*, 1-6. <https://doi.org/10.1016/j.paid.2015.01.010>
- Van der Graaff, J., Branje, S., De Wied, M., Hawk, S., Van Lier, P., & Meeus, W. (2014). Perspective taking and empathic concern in adolescence: Gender differences in developmental changes. *Developmental Psychology*, *50*(3), 881. <https://doi.org/10.1037/a0034325>
- Van Dulm, O., & Southwood, F. (2016). Does socioeconomic level have an effect on school-age language skills in a developed country? *Stellenbosch Papers in Linguistics Plus*, *49*, 59-84. <https://doi.org/10.5842/49-0-667>
- Van Manen, T. G., Prins, P. J. M., & Emmelkamp, P. M. G. (2001). Assessing social cognitive skills in aggressive children from a developmental perspective: The social cognitive skills test. *Clinical Psychology & Psychotherapy*, *8*(5), 341-351. <https://doi.org/10.1002/cpp.319>
- Van Manen, T. G., Prins, P. J. M., & Emmelkamp, P. M. G. (2009). *Sociaal-cognitieve vaardigheden test (SCVT): Handleiding*. Houten, Netherlands: Bohn Stafleu van Loghum.
- Vasilevski, V., & Tucker, A. (2016). Wide-ranging cognitive deficits in adolescents following early life maltreatment. *Neuropsychology*, *30*(2), 239-246. <https://doi.org/10.1037/neu0000215>
- Vaurio, L., Riley, E. P., & Mattson, S. N. (2008). Differences in executive functioning in children with heavy prenatal alcohol exposure or attention-deficit/hyperactivity disorder. *Journal of the International Neuropsychological Society*, *14*(1), 119-129. <https://doi.org/10.1017/S1355617708080144>
- Vaurio, L., Riley, E. P., & Mattson, S. N. (2011). Neuropsychological comparison of children with heavy prenatal alcohol exposure and an IQ-matched comparison group. *Journal of the International Neuropsychological Society*, *17*(3), 463. <https://doi.org/10.1017/S1355617711000063>
- Vygotsky, L. S. (1978). *Mind in society: The development of higher mental process*. Cambridge, MA: Harvard University Press.
- Waitangi Tribunal. (1988). *Report of the Waitangi Tribunal on the Muriwhenua fishing claim*. Wellington, New Zealand: Waitangi Tribunal. Retrieved from [https://forms.justice.govt.nz/search/Documents/WT/wt\\_DOC\\_68478237/Muriwhenua%20Fishing.pdf](https://forms.justice.govt.nz/search/Documents/WT/wt_DOC_68478237/Muriwhenua%20Fishing.pdf)
- Walker, R. C., Walker, S., Morton, R. L., Tong, A., Howard, K., & Palmer, S. C. (2017). Māori patients' experiences and perspectives of chronic kidney disease: A New Zealand

- qualitative interview study. *BMJ Open*, 7(1), e013829.  
<https://doi.org/10.1136/bmjopen-2016-013829>
- Walker, R. (2004). *Ka whawhai tonu mātou: Struggle without end* (Rev. ed.). Auckland, New Zealand: Penguin Group (NZ).
- Ware, A. L., Crocker, N., O'Brien, J. W., Deweese, B. N., Roesch, S. C., Coles, C. D., . . . Mattson, S. N. (2012). Executive function predicts adaptive behavior in children with histories of heavy prenatal alcohol exposure and attention-deficit/hyperactivity disorder. *Alcoholism: Clinical and Experimental Research*, 36(8), 1431-1441.  
<https://doi.org/10.1111/j.1530-0277.2011.01718.x>
- Watt, M. H., Eaton, L. A., Choi, K. W., Velloza, J., Kalichman, S. C., Skinner, D., & Sikkema, K. J. (2014). "It's better for me to drink, at least the stress is going away": Perspectives on alcohol use during pregnancy among South African women attending drinking establishments. *Social Science and Medicine*, 116, 119-125.  
<https://doi.org/10.1016/j.socscimed.2014.06.048>
- Way, E. L., & Rojahn, J. (2012). Psycho-social characteristics of children with prenatal alcohol exposure, compared to children with Down syndrome and typical children. *Journal of Developmental and Physical Disabilities*, 24(3), 247-268.  
<https://doi.org/10.1007/s10882-012-9269-1>
- Wechsler, D. (2003). *Wechsler intelligence scale for children—Fourth edition (WISC-IV)*. San Antonio, TX: The Psychological Corporation.
- Wechsler, D., & Hsiao-pin, C. (2011). *WASI-II: Wechsler abbreviated scale of intelligence (Second ed.)*. San Antonio, TX: The Psychological Corporation.
- Wells, A. M., Chasnoff, I. J., Schmidt, C. A., Telford, E., & Schwartz, L. D. (2012). Neurocognitive habilitation therapy for children with fetal alcohol spectrum disorders: An adaptation of the alert program ®. *American Journal of Occupational Therapy*, 66(1), 24-34. <https://doi.org/10.5014/ajot.2012.002691>
- Wentzel, K. R. (1991). Relations between social competence and academic achievement in early adolescence. *Child development*, 62(5), 1066-1078.  
<https://doi.org/10.1111/j.1467-8624.1991.tb01589.x>
- Wepa, D. (2016). *Struggling to be involved: A grounded theory of Māori whānau engagement with healthcare* (Unpublished Doctoral dissertation), Auckland University of Technology, Auckland New Zealand.
- Weyrauch, D., Schwartz, M., Hart, B., Klug, M. G., & Burd, L. (2017). Comorbid mental disorders in fetal alcohol spectrum disorders: A systematic review. *Journal of Developmental and Behavioral Pediatrics*, 38(4), 283-291.  
<https://doi.org/10.1097/DBP.0000000000000440>
- Whaley, S. E., O'Connor, M. J., & Gunderson, B. (2001). Comparison of the adaptive functioning of children prenatally exposed to alcohol to a nonexposed clinical sample. *Alcoholism: Clinical and Experimental Research*, 25(7), 1018-1024.  
<https://doi.org/10.1111/j.1530-0277.2001.tb02311.x>
- Wieder, S., & Greenspan, S. I. (2003). Climbing the symbolic ladder in the DIR model through floor time/interactive play. *Autism*, 7(4), 425-435.  
<https://doi.org/10.1177/1362361303007004008>

- Willcock, E., Imuta, K., & Hayne, H. (2011). Children's human figure drawings do not measure intellectual ability. *Journal of Experimental Child Psychology, 110*(3), 444-452. <https://doi.org/10.1016/j.jecp.2011.04.013>
- Woodward, L. J., & Fergusson, D. M. (2000). Childhood peer relationship problems and later risks of educational under-achievement and unemployment. *The Journal of Child Psychology and Psychiatry and Allied Disciplines, 41*(2), 191-201. <https://doi.org/10.1017/S002196309900520X>
- Wozniak, J. R., Mueller, B. A., Mattson, S. N., Coles, C. D., Kable, J. A., Jones, K. L., . . . Sowell, E. R. (2016). Functional connectivity abnormalities and associated cognitive deficits in fetal alcohol spectrum disorders (FASD). *Brain Imaging and Behavior, 11*, 1432-1445. <https://doi.org/10.1007/s11682-016-9624-4>
- Yeates, K. O., Bigler, E. D., Dennis, M., Gerhardt, C. A., Rubin, K. H., Stancin, T., . . . Vannatta, K. (2007). Social outcomes in childhood brain disorder: A heuristic integration of social neuroscience and developmental psychology. *Psychological Bulletin, 133*(3), 535. <http://doi.org/10.1037/0033-2909.133.3.535>
- Yeates, K. O., Bigler, E. D., Gerhardt, C. A., Rubin, K. H., Stancin, T., Taylor, H. G., & Vannatta, K. (2012). Theoretical approaches to understanding social function in childhood brain insults. In V. Anderson, & M. Beauchamp (Eds.), *Developmental social neuroscience and childhood brain insult. Theory and Practice* (pp. 207-230). New York: The Guilford Press.
- Youngstrom, E., Loeber, R., & Stouthamer-Loeber, M. (2000). Patterns and correlates of agreement between parent, teacher, and male adolescent ratings of externalizing and internalizing problems. *Journal of Consulting and Clinical Psychology, 68*(6), 1038. <http://doi.org/10.1037/0022-006X.68.6.1038>
- Yumoto, C., Jacobson, S. W., & Jacobson, J. L. (2008). Fetal substance exposure and cumulative environmental risk in an African American cohort. *Child Development, 79*(6), 1761-1776. <http://doi.org/10.1111/j.1467-8624.2008.01224.x>
- Zins, J. E., Bloodworth, M. R., Weissberg, R. P., & Walberg, H. J. (2004). The scientific base linking social and emotional learning to school success. *Journal of Educational and Psychological Consultation, 17*(2-3), 191-210. <http://doi.org/10.1080/10474410701413145>
- Zuccolo, L., Lewis, S. J., Smith, G. D., Saya, K., Draper, E. S., Fraser, R., . . . Gray, R. (2013). Prenatal alcohol exposure and offspring cognition and school performance. A mendelian randomization natural experiment. *International Journal of Epidemiology, 42*(5), 1358-1370. <http://doi.org/10.1093/ije/dyt172>

## Appendix A - Taumata Rangahau

### TAUMATA RANGAHAU RESEARCH TERMS OF REFERENCE<sup>3</sup>

#### BACKGROUND

There is an expectation a researcher working with a Māori community, a Kaupapa Māori Research approach will be used. A Kaupapa Māori approach to research anticipates that the researcher has competency in Māori cultural practices and that both the researcher and the research participants will be comfortable with and conversant in, customary Māori practice.

Kaupapa Māori Research (KMR) methodologies are premised on traditional Māori cultural beliefs, values and social practices. The key principles of KMR approach are tikanga Māori, te reo (Māori language), whānau (family) and whakapapa (genealogy).

Tikanga refers to customary practices of social interaction. It is about doing what is right, interpreting accurately what is observed and acknowledging Māori etiquette. As the subtleties of culture are embedded in language, the researcher must have, at least, a basic level of proficiency in te reo.

Within this framework the whānau is seen as the mainframe of the individual. Each person has a responsibility and an obligation to that structure grounded in the common connections through whakapapa. These terms of reference therefore suggests that in order to guide research proposals within the HBDHB meta-questions about research that involve whānau may include;

1. Who has helped define the research problem?
2. For whom is the study worthy and relevant?
3. Who says so?
4. Which cultural group will be the one to gain new knowledge from this study?
5. To whom is the researcher accountable?
6. Who will gain most from this study?

These questions are similar to those asked by granting bodies such as the Health Research Council in their assessment of Māori research proposals. It means that we no longer have to rely on the internal ethics of a research. We have granting bodies and ethics committees who screen researchers for us. Graham Smith (1990) proposed four models whereby non-Māori have been able to carry out culturally appropriate research:

1. **Tiaki Model** – (Mentor Model) where the research process is guided and mediated by authoritative Māori people (e.g. Jim Ritchie and Bob Mahuta).
2. **Whangai Model** – (Adoption Model) the researcher becomes one of the whānau who just happens to be doing research (e.g. Anne Salmond).

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<sup>3</sup> Te Nahu, L, 2017, Programme Administration Officer, Māori Health Improvement Team, Health Improvement Directorate, HBDHB

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3. **Power Sharing Model** where community assistance is sought by the researcher so that a research enterprise can be developed in a meaningful way.
4. **Empowering Outcomes Model** – where the research supplies answers and information that Māori want to know.

### INTRODUCTION

Over recent years appropriate ways to conduct research with Māori and within Māori communities have been developed. Approaches such as involving Māori, employing Māori, research for and by Māori are some examples that build on the pioneering work of others as a valid research methodology.

To this end, many Māori are now much more aware of the effects of research and its potential to both empower and disempower different groups. Researchers generally are now more aware of culturally appropriate practices for meeting and interacting in ways that are uniquely Māori.

As Māori researchers redefine best practice and thus construct difference positively for the benefit of Māori. As fields of enquiry have grown there has been increased involvement at various levels in research with a resultant flowering of information knowledge that is sensitive to Māori needs.

The intent therefore for the establishment of a Taumata Rangahau (HBDHB Research Advisory Group] is to provide the necessary pathway to ensure HBDHB staff undertaking applications for a research programme within the DHB, comply with HBDHB research policy, and in accordance with Ngāti Kahungunu best practice, tikanga and kawa.

The terms of reference which follows acts a guide to ensure the success of the research programme:

### TERMS OF REFERENCE

Title of the Advisory Group – Taumata Rangahau HBDHB. Membership includes;

- Laurie Te Nahu – Programme Administration Officer, Health Improvement Directorate, HBDHB.
- Querida Strickland Whatuira – Kaitakawaenga, Māori Health Operations Team, HBDHB.
- Koroua, Kuia, Kaumātua.
- Tāngata Mātauranga.

### Policy & Guidelines

#### **Policy Ref: Reducing Inequalities Best Practice Guidelines Whānau Ora**

(Operational Policy Manual, HBDHB/OPM/067, Date reviewed, December 2013, Executive Leadership Team).

#### **Policy Ref: 8.5: The Public Health and Disability Act 2000.**

(Section 4 and Part 3 impose requirements on DHB's to involve Māori in decision making)

Consultation with Māori will involve Iwi stakeholders and be undertaken in an appropriate manner i.e. at times and places where Māori can attend. Failure to adequately consult was a major issue in the Wai 692 claim.

Māori participation within HBDHB occurs at a governance level through a Memorandum of Understanding (MoU) between Ngāti Kahungunu Iwi Incorporated (**NKII**) and **HBDHB** on behalf of

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Māori. NKII have Iwi representatives on the **HBDHB Advisory Committee's**, and are involved with the appointment of Māori Board members who provide advice to both Māori service providers and Health services. The representative body within the HBDHB for NKII is the Māori Relationships Board (**MRB**).

### **Policy Reference 8.7 - Best Practice Policy and Guidelines**

Te Tiriti o Waitangi (the Treaty principles) of partnership, participation and protection will be actively addressed and undertaken in good faith. This will occur from the outset of the project .i.e. from the negotiating and formulation of the research to the final outcome. Māori Relationship Board (MRB) is the representative body for the tangata whenua of the Hawkes Bay district need to be included in the consultation process.

1. Courtesy letters regarding research for postgraduate papers or pilot studies will be conveyed to Te Wahanga Hauora Māori who will acknowledge receipt and request to be kept informed.
2. More indepth correspondence asking for advice and full consultation on aspects of research may generate a longer wait time.
3. A time line of two weeks allows for a letter of acknowledgement to be received. If time has passed and no acknowledgement has been received then researcher contact Māori Health.

### **Policy 8.7.1 – Rāranga Tohutohu (Guidelines)**

1. Researchers are invited to address how the research will benefit Māori, including how information will be shared with Māori.
2. Before research is initiated, consent may be required for iwi groups, particularly if the research may potentially breach tikanga or involve sensitive issues. This is over and above individual consent.
3. Some issues may also require consent from the iwi and/or hapū especially where ownership may belong to collective stakeholders.
4. Informed consent (written and verbal) may be sought from Māori participants and/or whānau involved in the research. This includes requests for body parts/tissue and/or substances (including genetic material) to be collected for research purposes.
5. Return, retention or disposal procedures will be discussed and agreed to by participants.
6. A specified time will be allowed for consultation and decisions to be reached.
7. Confidentiality will be maintained, particularly where individuals may be identified.
8. An email, copy of the proposal, letter to be sent to the Management of Māori Health Service and MRB.
9. The Māori Health Service will forward letter/email/copy of proposal to Māori providers, groups e.g. Māori Women's Welfare League and any other relevant groups.
10. These groups will individually feedback to researcher if they wish to be further involved in the consultation process.

### **Mauri ora!**



## Appendix B - Correlational Analysis

Table B1.

*Correlational analyses between domain and composite scores for parent/caregiver-rated adaptive functioning for the FASD group.*

| Adaptive functioning<br>(domain/composite) | 1       | 2       | 3       | 4 |
|--|---------|---------|---------|---|
| 1. Communication                           | -       |         |         |   |
| 2. Daily Living Skills                     | 0.32    | -       |         |   |
| 3. Socialisation                           | 0.39*   | 0.36*   | -       |   |
| 4. Composite score                         | 0.66*** | 0.76*** | 0.82*** | - |

*Note:* \*  $p \leq 0.05$ , \*\*  $p \leq 0.01$ , \*\*\*  $p \leq 0.001$

APPENDIX B

Table B2.

*Correlational analyses between domain and composite scores for teacher-rated adaptive functioning for the FASD group.*

| Adaptive functioning<br>(domain/composite) | 1                   | 2                   | 3                   | 4 |
|--|---------------------|---------------------|---------------------|---|
| 5. Communication                           | -                   |                     |                     |   |
| 6. Daily Living Skills                     | 0.70 <sup>***</sup> | -                   |                     |   |
| 7. Socialisation                           | 0.48 <sup>**</sup>  | 0.67 <sup>***</sup> | -                   |   |
| 8. Composite score                         | 0.79 <sup>***</sup> | 0.85 <sup>***</sup> | 0.86 <sup>***</sup> | - |

*Note:* \*  $p \leq 0.05$ , \*\*  $p \leq 0.01$ , \*\*\*  $p \leq 0.001$

APPENDIX B

Table B3.

*Correlational analyses between domain and composite scores for parent/caregiver adaptive functioning for the comparison group.*

| Adaptive functioning<br>(domain/composite) | 1                   | 2                   | 3                   | 4 |
|--|---------------------|---------------------|---------------------|---|
| 1. Communication                           | -                   |                     |                     |   |
| 2. Daily Living Skills                     | 0.57 <sup>***</sup> | -                   |                     |   |
| 3. Socialisation                           | 0.48 <sup>**</sup>  | 0.68 <sup>**</sup>  | -                   |   |
| 4. Composite score                         | 0.79 <sup>***</sup> | 0.89 <sup>***</sup> | 0.85 <sup>***</sup> | - |

*Note:* \*  $p \leq 0.05$ , \*\*  $p \leq 0.01$ , \*\*\*  $p \leq 0.001$

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Table B4.

*Correlational analysis between all variables (IQ, executive functioning, social cognition, ACEs and adaptive functioning) for the FASD group.*

|                      | 1       | 2       | 3       | 4       | 5       | 6       | 7       | 8       | 9       | 10      | 11      | 12      | 13      | 14      | 15     | 16   | 17 |
|----------------------|---------|---------|---------|---------|---------|---------|---------|---------|---------|---------|---------|---------|---------|---------|--------|------|----|
| 1. VCI               | -       |         |         |         |         |         |         |         |         |         |         |         |         |         |        |      |    |
| 2. PRI               | 0.42**  | -       |         |         |         |         |         |         |         |         |         |         |         |         |        |      |    |
| 3. WMI               | 0.37*   | 0.40*   | -       |         |         |         |         |         |         |         |         |         |         |         |        |      |    |
| 4. PSI               | 0.24    | 0.47**  | 0.46**  | -       |         |         |         |         |         |         |         |         |         |         |        |      |    |
| 5. FSIQ              | 0.69*** | 0.82*** | 0.71*** | 0.71*** | -       |         |         |         |         |         |         |         |         |         |        |      |    |
| 6. Tower             | 0.26    | 0.45**  | 0.28    | 0.23    | 0.43**  | -       |         |         |         |         |         |         |         |         |        |      |    |
| 7. AS                | 0.54*** | 0.22    | 0.22    | 0.07    | 0.37*   | 0.08    | -       |         |         |         |         |         |         |         |        |      |    |
| 8. Inhibition        | 0.30    | 0.46**  | 0.44**  | 0.22    | 0.48**  | 0.52**  | 0.11    | -       |         |         |         |         |         |         |        |      |    |
| 9. EF-comp           | 0.53*** | 0.54*** | 0.45**  | 0.25    | 0.61*** | 0.74*** | 0.57*** | 0.79*** | -       |         |         |         |         |         |        |      |    |
| 10. TOPS-3           | 0.71*** | 0.35*   | 0.27    | 0.09    | 0.50*** | 0.20    | 0.49**  | 0.40*   | 0.52*** | -       |         |         |         |         |        |      |    |
| 11. SCST             | 0.57*** | 0.50*** | 0.28    | 0.24    | 0.58*** | 0.20    | 0.33*   | 0.36*   | 0.43**  | 0.49*** | -       |         |         |         |        |      |    |
| 12. DANVA<br>- adult | 0.40*   | 0.22    | 0.39*   | 0.01    | 0.35*   | 0.36*   | 0.18    | 0.41**  | 0.45**  | 0.29    | 0.40*   | -       |         |         |        |      |    |
| 13. DANVA -<br>Child | 0.04    | 0.22    | 0.31    | -0.05   | 0.17    | 0.13    | -0.21   | 0.29    | 0.10    | 0.12    | 0.23    | 0.64*** | -       |         |        |      |    |
| 14. SC-comp          | 0.63*** | 0.46**  | 0.43**  | 0.12    | 0.58*** | 0.31    | 0.30    | 0.50*** | 0.53**  | 0.71*** | 0.76*** | 0.74*** | 0.64*** | -       |        |      |    |
| 15. ACEs             | -0.20   | -0.23   | -0.11   | 0.16    | -0.15   | -0.05   | -0.12   | -0.22   | -0.19   | -0.09   | -0.10   | -0.34*  | -0.37*  | -0.27   | -      |      |    |
| 16. Parent<br>ABC    | 0.20    | 0.22    | 0.23    | 0.27    | 0.32    | 0.17    | 0.35*   | 0.15    | 0.33    | 0.14    | 0.20    | 0.15    | 0.04    | 0.19    | -0.30  | -    |    |
| 17. Teacher<br>ABC   | 0.46*** | 0.24    | 0.34    | 0.20    | 0.46**  | 0.20    | 0.24    | 0.30    | 0.34*   | 0.38*   | 0.42*   | 0.54*** | 0.41*   | 0.62*** | -0.37* | 0.19 | -  |

*Note:* IQ assessed using the WISC-IV (FASD group) and WASI-II (comparison group). WISC-IV = Wechsler Intelligence Scale for Children 4th edition, WASI-II = Wechsler Abbreviated Scale of Intelligence 2nd edition, VCI = Verbal Comprehension Index, PRI = Perceptual Reasoning Index, WMI = Working Memory Index, PSI = Processing Speed Index, FSIQ = Full Scale IQ, AS = Animal Sorting, EF-comp = Executive functioning composite score, TOPS-3 = Test of Problem Solving-3 Elementary, SCST = Social Cognitive Skills Test, DANVA = Diagnostic Analysis of Nonverbal Accuracy, SC-comp = Social cognition composite score, ABC = Adaptive Behaviour Composite.

\*  $p \leq 0.05$ , \*\*  $p \leq 0.01$ , \*\*\*  $p \leq 0.001$ .

APPENDIX B

Table B5.

*Correlational analysis between all variables (IQ, executive functioning, social cognition, ACEs and adaptive functioning) for the comparison group.*

|                      | 1     | 2       | 3      | 4       | 5      | 6    | 7       | 8       | 9       | 10      | 11   | 12 |
|----------------------|-------|---------|--------|---------|--------|------|---------|---------|---------|---------|------|----|
| 1. WMI               | -     |         |        |         |        |      |         |         |         |         |      |    |
| 2. FSIQ              | 0.39* | -       |        |         |        |      |         |         |         |         |      |    |
| 3. Tower             | -0.04 | -0.50** | -      |         |        |      |         |         |         |         |      |    |
| 4. AS                | 0.15  | 0.38*   | -0.25  | -       |        |      |         |         |         |         |      |    |
| 5. Inhibition        | 0.07  | 0.13    | -0.38* | 0.34    | -      |      |         |         |         |         |      |    |
| 6. EF-comp           | 0.13  | 0.17    | -0.10  | 0.80*** | 0.77** | -    |         |         |         |         |      |    |
| 7. TOPS-3            | 0.33  | 0.59*** | -0.26  | 0.28    | 0.30   | 0.30 | -       |         |         |         |      |    |
| 8. SCST              | 0.09  | 0.52**  | -0.43* | 0.31    | 0.06   | 0.11 | 0.65*** | -       |         |         |      |    |
| 9. DANVA<br>- adult  | -0.02 | 0.23    | -0.17  | 0.19    | 0.18   | 0.19 | 0.48**  | 0.44*   | -       |         |      |    |
| 10. DANVA -<br>Child | -0.27 | -0.15   | -0.16  | 0.20    | 0.35   | 0.31 | 0.22    | 0.26    | 0.55**  | -       |      |    |
| 11. SC-comp          | 0.06  | 0.44*   | -0.36  | 0.34    | 0.27   | 0.29 | 0.79*** | 0.83*** | 0.78*** | 0.62*** | -    |    |
| 12. Parent<br>ABC    | 0.21  | 0.34    | -0.08  | 0.02    | 0.10   | 0.05 | 0.38*   | 0.32    | 0.24    | -0.10   | 0.30 | -  |

*Note:* IQ assessed using the WISC-IV (FASD group) and WASI-II (comparison group). WISC-IV = Wechsler Intelligence Scale for Children 4th edition, WASI-II = Wechsler Abbreviated Scale of Intelligence 2nd edition, VCI = Verbal Comprehension Index, PRI = Perceptual Reasoning Index, WMI = Working Memory Index, PSI = Processing Speed Index, FSIQ = Full Scale IQ, EF-comp = Executive functioning composite score, TOPS-3 = Test of Problem Solving-3 Elementary, SCST = Social Cognitive Skills Test, DANVA = Diagnostic Analysis of Nonverbal Accuracy, SC-comp = Social cognition composite score, ABC = Adaptive Behaviour Composite.

\*  $p \leq 0.05$ , \*\*  $p \leq 0.01$ , \*\*\*  $p \leq 0.001$



## Appendix C - Information Sheets and Consent Forms



# Information Sheet – Child Development Service Group

Study title: *The effects of drinking alcohol whilst pregnant.*

Locality: **Hawke's Bay**

Ethics committee ref.: *13/CEN/45*

Lead investigator: **Andi Crawford**

Contact phone number: **878 8109 (Extn 5815)**

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My name is Andi Crawford, I am a Clinical Psychologist at the Child Development Service (CDS) at Hawke's Bay DHB. I am conducting research as part of my PhD at the University of Auckland.

I would like to invite you and your child to take part in a study on the potential effects of drinking alcohol while pregnant on your child. It is your choice to take part in this study. If you don't want to take part, you don't have to give a reason, and it won't affect the care you or your child receive. If you do want to take part now, but change your mind later, you can pull out of the study up until December 2016.

This Information Sheet will help you decide if you would like your child to take part. It sets out why we are doing the study, what you and your child's participation would involve, what the benefits and risks to you and your child might be, and what would happen after the study ends. If you are interested in taking part, we will go through this information with you and answer any questions you may have. We expect this will take about 15 minutes. You may also want to talk about the study with other people, such as family, whānau, friends, or healthcare providers. Feel free to do this.

If you agree for your child to take part in this study, you will be asked to sign and you will be given a copy of both the Information Sheet and the Consent Form to keep.

This document is 4 pages long. Please make sure you have all the pages.

### Why are we doing the study?

## APPENDIX C

This study aims to find out about what long term effects drinking alcohol while pregnant has on the child. We know that alcohol affects the child's thinking ability. This study aims to understand more about the specific nature of the areas of thinking that are affected. By understanding these thinking abilities better we are more able to tailor interventions to help those children who may have been affected by alcohol.

### **What would your participation involve?**

Your child's participation will involve completing some pen/ paper and computer tasks.

As your child is part of a Developmental Assessment Program (DAP) assessment he/she will be completing the study tasks as part of his or her usual DAP assessment process. This will involve visiting the clinic a number of times to complete assessments by the Paediatrician, Speech Language Therapist, Occupational Therapist and Psychologist. The number of times you will be required to visit will depend on your child's level of comfort and fatigue. On average you may have to visit the clinic 4-5 times for an assessment. It is possible that some of these assessments may be conducted at home or at school to reduce the burden of visiting the clinic.

Your child's involvement will only be required in this current assessment only. However it will take some time to assess all the children required for this study and therefore this study is not due to be completed until 2019.

### **What are the benefits of participating?**

There are no direct benefits to you or your child for your participation. Participants in this study will benefit indirectly from helping to create a community that understands the difficulties that can arise from drinking alcohol while pregnant. It will also help understand the difficulties these children face and enable us to tailor support and interventions for children and their families.

### **What are the rights of participants in the study?**

You and your child's participation in this study is voluntary and you are free to decline to take part or to withdraw from the research up until December 2016. Whether you and your child decide to participate or not, or whether you later decide to withdraw this will in no way disadvantage care or advice you or your child will receive.

You will receive feedback about your child's performance through the usual DAP process which involves a written report and face to face explanation of what it means.

### **What will happen after the study ends, or if you pull out?**

Data will be destroyed after 10 years, or earlier if you pull out. However the information will be kept in their medical file as per usual clinical practice.

## APPENDIX C

All participant data will be given a secure code that only the investigators in this study will have access to. This code will ensure data is not identifiable to the general public and study results will be reported by group and not individually. Every effort will be made to ensure information remains secure. For example the key code will be kept separately and securely from the raw data. Electronic data will be stored on a computer which is secured with password and fingerprint access and only accessible by the research team named below. Hard copies of assessment material will also be kept securely within the Child Development Service. Your child's data may also be used in future research by the research team.

A summary of the study findings will be available in the PhD thesis held at the University of Auckland. A copy of the research study once completed and written up in article format can sent out if you select this option in the consent form. Participants are also welcome to contact Andi Crawford to hear about study progress and findings at any time.

### **Risks and safety**

There are no expected side effects involved with this study as we are only observing your child's performance in pen and paper task and administering an interview about your child's functioning. However in the unlikely event your child was injured in this study, they would be eligible for compensation from ACC just as they would be if they were injured in an accident at sport or at home. If you have private health or life insurance, you may wish to check with your insurer that taking part in this study won't affect your cover.

### **Where can you go for more information about the study, or to raise concerns or complaints?**

If you have any questions, concerns or complaints about the study at any stage, you can contact any member of the research team.

If you want to talk to someone who isn't involved with the study, you can contact an independent health and disability advocate on:

Phone: 0800 555 050  
Fax: 0800 2 SUPPORT (0800 2787 7678)  
Email: [advocacy@hdc.org.nz](mailto:advocacy@hdc.org.nz)

You can also contact the health and disability ethics committee (HDEC) that approved this study on:

Phone: 0800 4 ETHICS  
Email: [hdecs@moh.govt.nz](mailto:hdecs@moh.govt.nz)

Funding has been granted from the Hawke's Bay Medical Research Association to support this research. Andi is available to answer any questions you may have about this study on 878 8109 Extn 5815.

## APPENDIX C

### **The research teams contact details:**

Andi Crawford (Clinical Psychologist)  
Coordinating Investigator: 06 878 8109 extn 5815  
Email: [Andi.Crawford@hbdhb.govt.nz](mailto:Andi.Crawford@hbdhb.govt.nz)

Dr Lynette Tippett (PhD, Associate Professor)  
Supervisor: 09 373 7599 extn 8851  
Email: [l.tippett@auckland.ac.nz](mailto:l.tippett@auckland.ac.nz)

Dr. Elizabeth Peterson (PhD, Senior Lecturer) – Supervisor: 09 373 7599 extn 89693  
Email: [e.peterson@auckland.ac.nz](mailto:e.peterson@auckland.ac.nz)

Dr Kate Robertshaw (Neurodevelopmental Paediatrician)  
Expert Advisor: 06 878 8109 extn  
Email: [Kate.Robertshaw@hbdhb.govt.nz](mailto:Kate.Robertshaw@hbdhb.govt.nz)

Dr Valerie McGinn (PhD, Child & Adolescent Neuropsychologist)  
Expert Advisor  
Email [vcmcginn@ihug.co.nz](mailto:vcmcginn@ihug.co.nz)

### **Health and Disability Advocate**

North Island – Auckland and North: 0800555 050  
Lower North Island: 0800 423 638  
Free Fax (NZ wide): 0800 2787 7678  
Email (NZ wide): [advocacy@hdc.org.nz](mailto:advocacy@hdc.org.nz)

### **Fetal Alcohol Network NZ**

<http://www.fan.org.nz>

### **Maori Research Advisory Committee**

Laurie Te Nahu (Pou Ārahi Taiohi)  
Phone : 06 878 8109 extn:  
Email : [Laurie.TeNahu@hbdhb.govt.nz](mailto:Laurie.TeNahu@hbdhb.govt.nz)

Querida Strickland (Kaitakawaenga)  
Phone: 06 878 8109 extn:  
Email: [Querida.Strickland@hbdhb.govt.nz](mailto:Querida.Strickland@hbdhb.govt.nz)

If you have any questions about ACC, contact your nearest ACC office or the investigator.  
Email: [www.acc.co.nz](http://www.acc.co.nz)

General Enquires ACC:  
Phone: (04)918 7700  
Fax: (04) 918 7701  
Email: [information@acc.co.nz](mailto:information@acc.co.nz)

In the unlikely event of a physical injury as a result of your participation in this study, you may be covered by ACC under the Injury Prevention, Rehabilitation and Compensation Act. ACC cover is not automatic and your case will need to be assessed by ACC according to the provisions of the 2002 Injury Prevention Rehabilitation and Compensation Act. If your claim is accepted by ACC, you still might not get any compensation. This depends on a number of factors such as whether you are an earner or non-earner. ACC usually provides only partial reimbursement of costs and expenses and there may be no lump sum compensation payable. There is no cover for mental injury unless it is a result of physical injury. If you have ACC cover, generally this will affect your right to sue the investigators.



## Consent Form - Child Development Service Group

*Your letterhead*

### Declaration by participant:

I have read, or have had read to me in my first language, and I understand the Information Sheet for this study which is investigating the effects of alcohol use in pregnancy. I have had the opportunity to ask questions and I am satisfied with the answers I have received for my child's participation. I have been given a copy of the Participant Information Sheet and Consent Form to keep.

I have had the opportunity to use whānau (family) support or a friend to help me ask questions and understand the study.

I have had time to consider whether my child will take part and I know who to contact if I have any concerns or questions about the study.

I understand that my child's participation in this study is voluntary (my choice) and that they/I may withdraw from the study at any time and this will in no way affect my child's future health care.

I understand that my participation in this study is confidential and that no material which could identify my child will be used in any reports on this study.

I understand my child's data will be stored for 10 years then destroyed.

I understand my child's data may be used in future research.

I would like a copy of the research study once completed and written up in article format. (Please note: there will be a significant delay between data collection and publishing of the results as this study is not due to be completed until December 2019).

Yes  No

The best address to send this to is:

Email: \_\_\_\_\_

Home: \_\_\_\_\_

I consent to being contacted about future research in which my child and I can take part if I so chose.  Yes  No

I freely agree for my child to participate in this study.

Participant's name: \_\_\_\_\_

Signature: \_\_\_\_\_ Date: \_\_\_\_\_

## APPENDIX C

### Declaration by member of research team:

I have given a verbal explanation of the research project to the participant, and have answered the participant's questions about it.

I believe that the participant understands the study and has given informed consent to participate.

Researcher's name: \_\_\_\_\_

Signature: \_\_\_\_\_

Date: \_\_\_\_\_

**Research Title:** Executive Functioning, social cognition and adaptive functioning in children with Foetal Alcohol Spectrum Disorder.  
**Contact:** andi.crawford@hbdhb.govt.nz

Andi Crawford



## Information Sheet – Control Group

|                    |   |                        |                             |
|--------------------|---|------------------------|-----------------------------|
| Study title:       | <i>The effects of drinking alcohol whilst pregnant.</i> |                        |                             |
| Locality:          | <b>Hawke's Bay</b>                                      | Ethics committee ref.: | <b>13/CEN/45</b>            |
| Lead investigator: | <b>Andi Crawford</b>                                    | Contact phone number:  | <b>878 8109 (Extn 5815)</b> |

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My name is Andi Crawford , I am a Clinical Psychologist at the Child Development Service (CDS) at Hawke's Bay DHB. I am conducting research as part of my PhD at the University of Auckland.

I would like to invite you and your child to take part in a study looking at the potential effects of drinking alcohol while pregnant on the child. You and your child are being invited to take part in this research as part of the control group, because your child has only had low risk (or no) exposure to alcohol whilst you were pregnant, and your child can be matched to other children who have been exposed to significant alcohol, on age, gender, ethnicity and maternal education. Having a matched control group of children of low-risk alcohol exposure will help ensure that any differences we find are due to alcohol and not some other factor.

It is you and your child's choice to take part in this study. If you, or they, don't want to take part, you don't have to give a reason, and it won't affect the care you receive. If you or your child do want to take part now, but change your mind later, you can pull out of the study up until December 2016.

This Information Sheet will help you decide if you would like your child to take part. It sets out why we are doing the study, what your participation would involve, what the benefits and risks to you might be, and what would happen after the study ends. If you and your child are interested in taking part, we will go through this information with you and answer any questions you may have. We expect this will take about 15 minutes. You may also want to talk about the study with other people, such as family, whānau, friends, or healthcare providers. Feel free to do this.

If you agree to take part in this study, you will be asked to sign a Consent Form and you will be given a copy of both the Information Sheet and the Consent Form to keep. This document is 4 pages long. Please make sure you have all the pages.

### **Why are we doing the study?**

This study aims to find out about what long term effects drinking alcohol while pregnant has on the child. We know that alcohol affects the child's thinking abilities. This study aims to understand more about the specific nature of the areas of thinking that are affected. By understanding children's thinking better, we will be more able to tailor interventions, both at home and in school, to help those children who may have been affected by alcohol.

### **What would your participation involve?**

Your child's participation will involve completing some pen/ paper and computer tasks. Children and parents/guardians in the control group will be required for a 2 hour block either at home or in the clinic. During this time parents/guardians will be asked to complete a questionnaire and children will be asked to answer pen/paper and computer tasks by Andi Crawford. Children will be offered a break and will be asked how they are feeling throughout the session. If the tasks are unable to be completed in the time then families/whānau may be asked for their consent to return to the clinic to complete the tasks at another time that suits the family/whānau.

Your child's involvement will only be required for this assessment. However it will take some time to assess all the children required for this study and therefore this study is not due to be completed until 2019.

### **What are the benefits of participating?**

This study will help improve knowledge about how heavy consumption of alcohol whilst pregnant affects children's development. Some children are so affected that they meet criteria for a Fetal Alcohol Spectrum Disorder (FASD). FASD is a lifelong disability that can affect a child's physical growth, thinking ability, behaviour, and emotional development. Participants in this study will benefit from helping to create a community that understands the difficulties that can arise from drinking alcohol while pregnant. It will also help understand the difficulties these children face and enable us to tailor support and interventions for children and their families. Children will receive a book voucher and parents/guardians a supermarket voucher for their time and effort in this research project.

For control group participants there is a risk that this assessment identifies a previously unknown cognitive (thinking) difficulty in your child. If this occurs then I will discuss this with you and offer a referral to the Paediatrician at the Child Development Service.

### **What are the rights of participants in the study?**

You and your child's participation in this study is voluntary and you and your child are free to decline to take part or to withdraw from the research up until December 2016. Whether you decide to participate or not, or whether you later decide to withdraw this will in no way disadvantage care or advice you or your child will receive.

## APPENDIX C

You also have the right to access information about you as collected as part of this study and parents/guardians will receive a summary feedback from your child's participation.

### **What will happen after the study ends, or if you pull out?**

All participant data will be given a secure code that only the investigators in this study will have access to. This code will ensure data is not identifiable to the general public and study results will be reported by group and not individually. Every effort will be made to ensure information remains secure. For example the key code will be kept separately and securely from the raw data. Electronic data will be stored on a computer which is secured with password and fingerprint access and only accessible by the research team named below. Hard copies of assessment material will also be kept securely within the Child Development Service. Your data may also be used in future research by the research team.

Control group data will be destroyed after 10 years, or earlier if you pull out. Raw data will be destroyed via the secure and confidential system in CDS.

A summary of the study findings will be available in the PhD thesis held at the University of Auckland. A copy of the research study once completed and written up in article format can sent out if you select this option in the consent form. Participants are also welcome to contact Andi Crawford to hear about study progress and findings at any time.

### **Risks and safety**

There are no expected side effects involved with this study as we are only observing your child's performance in pen and paper task and administering an questionnaire about your child's functioning. However in the unlikely event your child was injured in this study, they would be eligible for compensation from ACC just as they would be if you were injured in an accident at sport or at home. If you have private health or life insurance, you may wish to check with your insurer that taking part in this study won't affect your cover.

### **Where can you go for more information about the study, or to raise concerns or complaints?**

If you have any questions, concerns or complaints about the study at any stage, you can contact any member of the research team.

If you want to talk to someone who isn't involved with the study, you can contact an independent health and disability advocate on:

Phone: 0800 555 050  
Fax: 0800 2 SUPPORT (0800 2787 7678)  
Email: [advocacy@hdc.org.nz](mailto:advocacy@hdc.org.nz)

You can also contact the health and disability ethics committee (HDEC) that approved this study on:

Phone: 0800 4 ETHICS  
Email: [hdecs@moh.govt.nz](mailto:hdecs@moh.govt.nz)

## APPENDIX C

Funding has been granted from the Hawke's Bay Medical Research Association to support this research. Andi is available to answer any questions you may have about this study on 878 8109 Extn 5815.

### **The research teams contact details:**

Andi Crawford (Clinical Psychologist)  
Coordinating Investigator: 06 878 8109 extn 5815  
Email: [Andi.Crawford@hbdhb.govt.nz](mailto:Andi.Crawford@hbdhb.govt.nz)

Dr Lynette Tippett (PhD, Associate Professor)  
Supervisor: 09 373 7599 extn 88551  
Email: [l.tippett@auckland.ac.nz](mailto:l.tippett@auckland.ac.nz)

Dr. Elizabeth Peterson (PhD, Senior Lecturer) – Supervisor: 09 373 7599 extn 89693  
Email: [e.peterson@auckland.ac.nz](mailto:e.peterson@auckland.ac.nz)

Dr Kate Robertshaw (Neurodevelopmental Paediatrician)  
Expert Advisor: 06 878 8109 extn  
Email: [Kate.Robertshaw@hbdhb.govt.nz](mailto:Kate.Robertshaw@hbdhb.govt.nz)

Dr Valerie McGinn (PhD, Child & Adolescent Neuropsychologist)  
Expert Advisor  
Email [vcmcginn@ihug.co.nz](mailto:vcmcginn@ihug.co.nz)

### **Health and Disability Advocate**

North Island – Auckland and North: 0800555 050  
Lower North Island: 0800 423 638  
Free Fax (NZ wide): 0800 2787 7678  
Email (NZ wide): [advocacy@hdc.org.nz](mailto:advocacy@hdc.org.nz)

### **Fetal Alcohol Network NZ**

<http://www.fan.org.nz>

### **Maori Research Advisory Committee**

Laurie Te Nahu (Pou Ārahi Taiohi)  
Phone : 06 878 8109 extn:  
Email : [Laurie.TeNahu@hbdhb.govt.nz](mailto:Laurie.TeNahu@hbdhb.govt.nz)

Querida Strickland (Kaitakawaenga)  
Phone: 06 878 8109 extn:  
Email: [Querida.Strickland@hbdhb.govt.nz](mailto:Querida.Strickland@hbdhb.govt.nz)

If you have any questions about ACC, contact your nearest ACC office or the investigator.  
Email: [www.acc.co.nz](http://www.acc.co.nz)

General Enquires ACC:  
Phone: (04)918 7700  
Fax: (04) 918 7701  
Email: [information@acc.co.nz](mailto:information@acc.co.nz)

In the unlikely event of a physical injury as a result of your participation in this study, you may be covered by ACC under the Injury Prevention, Rehabilitation and Compensation Act. ACC cover is not automatic and your case will need to be assessed by ACC according to the provisions of the 2002 Injury Prevention Rehabilitation and Compensation Act. If your claim is accepted by ACC, you still might not get any compensation. This depends on a number of factors such as whether you are an earner or non-earner. ACC usually provides only partial reimbursement of costs and expenses and there may be no lump sum compensation payable. There is no cover for mental injury unless it is a result of physical injury. If you have ACC cover, generally this will affect your right to sue the investigators.



## Consent Form - Controls

### Declaration by participant:

I have read, or have had read to me in my first language, and I understand the Information Sheet for this study which is investigating the effects of alcohol use in pregnancy. I have had the opportunity to ask questions and I am satisfied with the answers I have received for my child's participation. I have been given a copy of the Participant Information Sheet and Consent Form to keep.

I have had the opportunity to use whānau (family) support or a friend to help me ask questions and understand the study.

I have had time to consider whether my child will take part and I know who to contact if I have any concerns or questions about the study.

I understand that my child's participation in this study is voluntary (my choice) and that they/ I may withdraw from the study at any time and this will in no way affect my child's future health care.

I understand that my child's participation in this study is confidential and that no material which could identify them will be used in any reports on this study.

I understand my child's data may be used in future research.

I understand my child's data will be stored for 10 years then destroyed.

I would like a copy of the research study once completed and written up in article format. (Please note: there will a significant delay between data collection and publishing of the results).

Yes  No

The best address to send this to is:

Email: \_\_\_\_\_

Home: \_\_\_\_\_

I consent to being contacted about future research in which my child and I can take part if I so chose.  Yes  No

I freely agree for my child to participate in this study.

Participant's name: \_\_\_\_\_

Signature: \_\_\_\_\_ Date: \_\_\_\_\_

## APPENDIX C

### Declaration by member of research team:

I have given a verbal explanation of the research project to the participant, and have answered the participant's questions about it.

I believe that the participant understands the study and has given informed consent to participate.

Researcher's name: \_\_\_\_\_

Signature: \_\_\_\_\_

Date: \_\_\_\_\_

**Research Title:** Executive Functioning, social cognition and adaptive functioning in children with Foetal Alcohol Spectrum Disorder.  
**Contact:** andi.crawford@hbdhb.govt.nz

Andi Crawford



## Child Information Sheet

Study title: *The effects of drinking alcohol whilst pregnant. 13/CEN/45*

Lead investigator: **Andi Crawford**

Contact phone number:

**878 8109 (Extn 5815)**

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This study aims to find out more about what happens when women drink alcohol in pregnancy. We know that alcohol in pregnancy affects children's thinking skills but we don't know much detail.

By understanding how children think we are more able to help those children who have been affected by alcohol.

You will be asked to complete a few activities that look at how you think about things. Your parents will be asked to give some information about how well you can do things at home and at school.

This information will be kept safe by Andi Crawford and not given to anyone who is not part of this study.

You can choose whether to take part in this study or not. You are free to ask any questions at anytime about anything!

Please write your name here if you are happy to take part in this study.

Name: \_\_\_\_\_

Date: \_\_\_\_\_

Investigator name: \_\_\_\_\_

Date: \_\_\_\_\_



**Appendix D - Case templates**  
**Child Development Service group - Case Information**

Code: \_\_\_\_\_

| Reporter  |  |
|---|--|
| Who was the reporter  | Birth Mother = 0<br>Birth father = 1<br>Whānau / Family = 2<br>Friend = 3<br>Health professional = 4<br>Care & Protection = 5<br>Other _____ = 6 |
| Alcohol whilst pregnant   |  |
| 1. How many standard units of alcohol were consumed per week before you were pregnant | No. of stand units per week before pregnant _____  |
| 2. Was the pregnancy planned?   | No = 1<br>Yes = 0  |
| 3. How many weeks were you when you found out you were pregnant?                      | _____ weeks  |
| 4. How many standard units were consumed during pregnancy per week                    | No. of stand units per week during pregnancy _____   |

| 5. On average how many drinks of Alcohol - beer, wine, spirits – |  |   |  |
|--|--|---|--|
|  | a. Did you drink per week <u>before becoming pregnant or before you were aware you were pregnant</u> | b. Did you drink per week <u>in the first 3 months of pregnancy</u> | c. Did you drink per week <u>after the first 3 months of pregnancy</u> |
| I did not drink alcohol  | 0  | 0   | 0  |
| Less than 1 drink per week                                       | 1  | 1   | 1  |
| 1 drink per week   | 2  | 2   | 2  |
| 2 drinks per week  | 3  | 3   | 3  |

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|                               |    |    |    |
|-------------------------------|----|----|----|
| 3 drinks per week             | 4  | 4  | 4  |
| 4-6 drinks                    | 5  | 5  | 5  |
| 7 –9 drinks                   | 6  | 6  | 6  |
| 10-14 drinks                  | 7  | 7  | 7  |
| 15 – 19 drinks                | 8  | 8  | 8  |
| 20 to 39 drinks               | 9  | 9  | 9  |
| 40 or more drinks             | 10 | 10 | 10 |
| <b>DO NOT READ OUT</b> DK/Ref | 99 | 99 | 99 |

| <b>Other substance use</b>   |  |
|--|--|
| 6. Did you consume any other substances whilst pregnant                              | <p>Cigarettes = 0<br/> Cannabis = 1<br/> Methamphetamines = 2<br/> Opiates = 3<br/> Solvents = 4<br/> Other Please specify _____ = 5</p>   |
| <b>Child strengths and difficulties</b>  |  |
| 7. Has your child ever diagnosed by a health professional with any of the following? | <p>Intellectual Disability = 1<br/> Autism Spectrum Disorder = 2<br/> Attention Deficit Hyperactivity Disorder = 3<br/> Anxiety Disorder = 4<br/> Depression = 5<br/> Attachment Disorder = 6<br/> Conduct Disorder = 7<br/> Language Disorder = 8<br/> Other _____ = 9<br/> None = 10</p> |
| 8. Is your child on any medication?  | <p>Yes = 1<br/> No = 0<br/> If Yes, Please Specify _____</p>   |
| 9. Has your child had previous referrals made to                                     | <p>None = 0<br/> RTL B = 1<br/> Special Ed = 2<br/> Paediatrician = 3<br/> CAFS = 4<br/> Application for ORS = 5<br/> NGO programmes = 6<br/> Other _____ = 7</p>  |

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|  |   |
|--|---|
| <p>10. Have other people ever singled your child out for being better than MOST others their own age for any of the following?</p> | <p>Ability in mathematics = 0<br/>                 Ability in science or social sciences e.g., computer science, chemistry, sociology = 1<br/>                 Ability in English, Maori or other languages = 2<br/>                 Ability in communication skills e.g., public speaking, debating = 3<br/>                 Ability in sport (including coaching), skateboarding etc = 4<br/>                 Ability in the written arts e.g., creative writing or formal writing = 5<br/>                 Ability in the creative arts e.g., visual, drawing, painting music, handicraft or dramatic = 6<br/>                 Ability in technical, mechanical or practical skills e.g., computers, electronics, video games wood or metal working, cooking, gardening = 7<br/>                 None of these = 8<br/>                 DK/Ref = 9</p> |
|--|---|

**Check with the investigator whether you qualify for this study**

**Demographic Information**

|  |   |
|--|---|
|  |   |
| <p>11. Gender</p>  | <p>Male = 1<br/>                 Female = 0</p>   |
| <p>12. Ethnicity (Please select which ones apply to you)</p> | <p>Pākeha = 0<br/>                 Maori = 1<br/>                 Pacific Nation = 2<br/>                 Asian = 3<br/>                 Other (Please Specify _____) = 4</p> <p>Which is your main ethnicity _____<br/>                 Iwi _____</p> <p>Involvement with Marae: Yes = 1<br/>                 No = 0</p> |
| <p>13. Languages your child speaks at home</p>               | <p>English = 0<br/>                 Maori = 1<br/>                 Samoan = 2<br/>                 Tongan = 3<br/>                 Other (Please Specify _____) = 4</p> <p>Which is their main language spoken to converse about everyday things _____</p>  |

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| <b>Current Arrangements</b>   |   |
|---|---|
| 14. Who does the child live with.   | <p style="text-align: right;">Both Birth Parents = 0<br/>           Mother = 1<br/>           Father = 2<br/>           Step parent = 3<br/>           Extended Family = 4<br/>           Adoptive Family = 5<br/>           Caregiver = 6<br/>           CYF / Residence = 7<br/>           Youth Justice Residence = 8<br/>           Other _____ = 9</p> |
| 15. Has the child ever been in CYFS care  | <p style="text-align: right;">Yes = 1<br/>           No = 0</p>   |
| 16. Multiple placements   | <p style="text-align: right;">Yes = 1<br/>           No = 0</p> <p style="text-align: center;">Number of placements _____</p>   |
| 17. Does the child have contact with the mother   | <p style="text-align: right;">Yes = 1<br/>           No = 0</p>   |
| 18. Does the child have contact with the father   | <p style="text-align: right;">Yes = 1<br/>           No = 0</p>   |
| <b>Maternal Education</b>   |   |
| 19. What is the birth mothers highest completed secondary school qualification?   |   |
| <p style="text-align: right;">No secondary school qualifications = 0<br/>           NZ School Cert or National Certificate/NCEA level 1 = 1<br/>           NZ 6th Form Cert or National Certificate/NCEA level 2 or NZ UE before 1986 = 2<br/>           NZ Higher School Certificate or NZ University Entrance from NZ Bursary or National Certificate/NCEA level 3 = 3<br/>           NCEA level 4 = 4<br/>           Other NZ secondary school qualification - please specify _____ = 5<br/>           overseas secondary school qualification = 6<br/>           DK/Ref = 7</p> |   |
| 20. What is the birth mothers highest completed qualification?  |   |
| <p style="text-align: right;">Trade Certificate or National Certificate levels 1-4 = 0<br/>           Diploma below bachelors level (e.g., teachers or nursing diploma) or National Certificate levels 5 or 6 = 1<br/>           Bachelor's degree = 2<br/>           Bachelor's degree with honours, or postgraduate diploma = 3<br/>           Master's Degree = 4<br/>           PhD = 5<br/>           other - please specify ..... = 6<br/>           DK/Ref = 7<br/>           None of the above = 8</p>  |   |

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| Pre-natal Risk factors                     |   |
|--|---|
| 21. Learning difficulties – Mother         | No = 0<br>Yes = 1<br>Suspected = 2<br>Unknown = 3 |
| 22. Mental Health Problems – Mother        | No = 0<br>Yes = 1<br>Suspected = 2<br>Unknown = 3 |
| 23. Reported problem with alcohol – Mother | No = 0<br>Yes = 1<br>Suspected = 2<br>Unknown = 3 |
| 24. Treated for alcohol addiction - Mother | No = 0<br>Yes = 1<br>Suspected = 2<br>Unknown = 3 |
| 25. Reported problem with drugs – Mother   | No = 0<br>Yes = 1<br>Suspected = 2<br>Unknown = 3 |
| 26. Learning Difficulties – Father         | No = 0<br>Yes = 1<br>Suspected = 2<br>Unknown = 3 |
| 27. Mental Health Problems – Father        | No = 0<br>Yes = 1<br>Suspected = 2<br>Unknown = 3 |
| 28. Reported problem with alcohol - Father | No = 0<br>Yes = 1<br>Suspected = 2<br>Unknown = 3 |
| 29. Treated for alcohol addiction - Father | No = 0<br>Yes = 1<br>Suspected = 2<br>Unknown = 3 |

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|  |   |   |
|--|---|---|
| 30. Reported problem with drugs – Father                       | No = 0<br>Yes = 1<br>Suspected = 2<br>Unknown = 3 |   |
| 31. Child experienced a head injury leading to unconsciousness | No = 0<br>Yes = 1<br>Suspected = 2<br>Unknown = 3 |   |
| 32. Other Contributing medical Condition (e.g. heart defect)   | If Yes Please specify _____<br>Yes = 1<br>No = 0  |   |
| <b>Post-natal Risk factor – Issues of Nurture</b>              |   |   |
|  | Past  | Current   |
| 33. Has the child experienced physical abuse                   | No = 0<br>Yes = 1<br>Suspected = 2<br>Unknown = 3 | No = 0<br>Yes = 1<br>Suspected = 2<br>Unknown = 3 |
| 34. Has the child experienced sexual abuse                     | No = 0<br>Yes = 1<br>Suspected = 2<br>Unknown = 3 | No = 0<br>Yes = 1<br>Suspected = 2<br>Unknown = 3 |
| 35. Has the child experienced neglect                          | No = 0<br>Yes = 1<br>Suspected = 2<br>Unknown = 3 | No = 0<br>Yes = 1<br>Suspected = 2<br>Unknown = 3 |
| 36. Has the child witnessed Domestic Violence                  | No = 0<br>Yes = 1<br>Suspected = 2<br>Unknown = 3 | No = 0<br>Yes = 1<br>Suspected = 2<br>Unknown = 3 |
| <b>Post Assessment Information</b>                             |   |   |
| FASD 4 digit Code  |   |   |
| FASD Diagnosis   | FAS = 1<br>pFAS = 2<br>ARND = 3<br>No diag.= 4    |   |

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|                 |  |
|-----------------|--|
| Other Diagnosis | Intellectual Disability = 1<br>Autism Spectrum Disorder = 2<br>Attention Deficit Hyperactivity Disorder = 3<br>Anxiety Disorder = 4<br>Depression = 5<br>Attachment Disorder = 6<br>Conduct Disorder = 7<br>Language Disorder = 8<br>Other _____ = 9 |
|-----------------|--|

## Control – Case Information

Code: \_\_\_\_\_

| Reporter   |  |
|--|--|
| Who was the reporter   | <div style="text-align: right;">           Birth Mother = 0<br/>           Birth father = 1<br/>           Whānau / Family = 2<br/>           Friend = 3<br/>           Health professional = 4<br/>           Care &amp; Protection = 5<br/>           Other _____ = 6         </div> |
| Alcohol whilst pregnant  |  |
| 37. How many standard units of alcohol were consumed per week before you were pregnant | No. of stand units per week before pregnant _____  |
| 38. Was the pregnancy planned?   | No = 1<br>Yes = 0  |
| 39. How many weeks were you when you found out you were pregnant?                      | _____ weeks  |
| 40. How many standard units were consumed during pregnancy per week                    | No. of stand units per week during pregnancy _____   |

| 41. On average how many drinks of Alcohol - beer, wine, spirits – |  |   |  |
|---|--|---|--|
|   | a. Did you drink per week <u>before becoming pregnant or before you were aware you were pregnant</u> | b. Did you drink per week <u>in the first 3 months of pregnancy</u> | c. Did you drink per week <u>after the first 3 months of pregnancy</u> |
| I did not drink alcohol   | 0  | 0   | 0  |
| Less than 1 drink per week  | 1  | 1   | 1  |
| 1 drink per week  | 2  | 2   | 2  |
| 2 drinks per week   | 3  | 3   | 3  |
| 3 drinks per week   | 4  | 4   | 4  |
| 4-6 drinks  | 5  | 5   | 5  |

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|                               |    |    |    |
|-------------------------------|----|----|----|
| 7 –9 drinks                   | 6  | 6  | 6  |
| 10-14 drinks                  | 7  | 7  | 7  |
| 15 – 19 drinks                | 8  | 8  | 8  |
| 20 to 39 drinks               | 9  | 9  | 9  |
| 40 or more drinks             | 10 | 10 | 10 |
| <b>DO NOT READ OUT</b> DK/Ref | 99 | 99 | 99 |

| <b>Other substance use</b>  |   |
|---|---|
| 42. Did you consume any other substances whilst pregnant                              | Cigarettes = 0<br>Cannabis = 1<br>Methamphetamines = 2<br>Opiates = 3<br>Solvents = 4<br>Other Pleas specify _____ = 5  |
| <b>Child strengths and difficulties</b>   |   |
| 43. Has your child ever diagnosed by a health professional with any of the following? | Intellectual Disability = 1<br>Autism Spectrum Disorder = 2<br>Attention Deficit Hyperactivity Disorder = 3<br>Anxiety Disorder = 4<br>Depression = 5<br>Attachment Disorder = 6<br>Conduct Disorder = 7<br>Language Disorder = 8<br>Other _____ = 9<br>None = 10 |
| 44. Is your child on any medication?  | Yes = 1<br>No = 0<br>If Yes, Please Specify _____   |
| 45. Has your child had previous referrals made to                                     | None = 0<br>RTLB = 1<br>Special Ed = 2<br>Paediatrician = 3<br>CAFS = 4<br>Application for ORS = 5<br>NGO programmes = 6<br>Other _____ = 7   |
| 46. Have other people ever singled your child out for being better than MOST          | Ability in mathematics = 0<br>Ability in science or social sciences e.g., computer science, chemistry, sociology = 1<br>Ability in English, Maori or other languages = 2  |

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|   |   |
|---|---|
| <p>others their own age for any of the following?</p> | <p>Ability in communication skills e.g., public speaking, debating = 3</p> <p>Ability in sport (including coaching), skateboarding etc = 4</p> <p>Ability in the written arts e.g., creative writing or formal writing = 5</p> <p>Ability in the creative arts e.g., visual, drawing, painting music, handicraft or dramatic = 6</p> <p>Ability in technical, mechanical or practical skills e.g., computers, electronics, video games wood or metal working, cooking, gardening = 7</p> <p>None of these = 8</p> <p>DK/Ref = 9</p> |
|---|---|

| <b>Maternal Education</b>  |  |
|--|--|
| <b>47. What is the birth mothers highest completed secondary school qualification?</b> |  |
|  | <p>No secondary school qualifications = 0</p> <p>NZ School Cert or National Certificate/NCEA level 1 = 1</p> <p>NZ 6th Form Cert or National Certificate/NCEA level 2 or NZ UE before 1986 = 2</p> <p>NZ Higher School Certificate or NZ University Entrance from NZ Bursary or National Certificate/NCEA level 3 = 3</p> <p>NCEA level 4 = 4</p> <p>Other NZ secondary school qualification - please specify _____ = 5</p> <p>overseas secondary school qualification = 6</p> <p>DK/Ref = 7</p> |
| <b>48. What is the birth mothers highest completed qualification?</b>                  |  |
|  | <p>Trade Certificate or National Certificate levels 1-4 = 0</p> <p>Diploma below bachelors level (e.g., teachers or nursing diploma) or National Certificate levels 5 or 6 = 1</p> <p>Bachelor's degree = 2</p> <p>Bachelor's degree with honours, or postgraduate diploma = 3</p> <p>Master's Degree = 4</p> <p>PhD = 5</p> <p>other - please specify ..... = 6</p> <p>DK/Ref = 7</p> <p>None of the above = 8</p>  |

**Check with the investigator whether you qualify for this study**

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**Demographic Information**

|   |   |
|---|---|
| <b>Demographic Information</b>                        |   |
| 49. Gender  | Male = 1<br>Female = 0  |
| 50. Ethnicity (Please select which ones apply to you) | Pākehā = 0<br>Maori = 1<br>Pacific Nation = 2<br>Asian = 3<br>Other (Please Specify _____) = 4<br>Which is your main ethnicity _____<br>Iwi _____<br>Involvement with Marae: Yes = 1<br>No = 0                |
| 51. Languages your child speaks at home               | English = 0<br>Maori = 1<br>Samoa = 2<br>Tongan = 3<br>Other (Please Specify _____) = 4<br>Which is their main language spoken to converse about everyday things _____  |
| <b>Current Arrangements</b>                           |   |
| 52. Who does the child live with.                     | Both Birth Parents = 0<br>Mother = 1<br>Father = 2<br>Step parent = 3<br>Extended Family = 4<br>Adoptive Family = 5<br>Caregiver = 6<br>CYF / Residence = 7<br>Youth Justice Residence = 8<br>Other _____ = 9 |
| 53. Has the child ever been in CYFS care              | Yes = 1<br>No = 0   |
| 54. Multiple placements                               | Yes = 1<br>No = 0<br>Number of placements _____   |
| 55. Does the child have contact with the mother       | Yes = 1<br>No = 0   |
| 56. Does the child have contact with the father       | Yes = 1<br>No = 0   |

