

**“The challenge of supporting children with Fetal Alcohol
Spectrum Disorder in Aotearoa New Zealand:
A narrative literature review”**

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Abstract

Objective: *To understand the impact of Fetal Alcohol Spectrum Disorder (FASD) on the individual, their family/whānau, community and society within the Aotearoa New Zealand (ANZ) context. .*

Background: *An alcohol consumption culture has developed over many years in ANZ. This has resulted in emotional and financial costs, not only to the individual, but their family/whānau, communities and to society as a whole. This cost can extend to the unborn child when a woman consumes alcohol while pregnant resulting in permanent damage to their Central Nervous System (CNS). This damage is irreversible and to date there is no successful pharmaceutical intervention.*

Up until 40 years ago, FASD was not recognised, so those affected would either go misdiagnosed or undiagnosed. Interventions were not put in place to support the individual, family/whānau and other societal groups. Subsequently, research and recognition of FASD has developed, but much of this knowledge is not well utilised for the support of those with or caring for those with FASD.

Methods: *To address the research objective a narrative literature review was undertaken. Bronfenbrenner's Ecological Systems Theory provided a framework for synthesis of the literature. Five themes were extracted from the literature and were used to frame the discussion. These themes were: (1) a drinking culture which has developed over time; (2) risk factors for the unborn child; (3) the importance of early diagnosis and intervention for a child with FASD; (4) A multidisciplinary approach to assessment and diagnosis across the life span for those with FASD; and finally (5) ANZ policy implications.*

Discussion: *The child who has FASD symptoms being referred for an assessment and diagnosis, along with an individualised intervention plan being implemented, will provide the best opportunity for the child to flourish. Undiagnosed or wrongly diagnosed young people with FASD symptoms are likely to develop secondary conditions. This will have long term consequences for not only the individual, but their family/whānau, community and ANZ society. This literature review has critiqued the FASD action plan released by the Ministry of*

Health (MoH) in 2016 using international literature resulting in recommendations for future research in the ANZ context.

Summary of Conclusions and Recommendations:

The drinking culture of ANZ has developed since colonisation. Alcohol consumption has cost not only the individual and their families, but communities and ANZ society as a whole although the MoH (2016) has released the FASD Action Plan 2016-2019 with a budget attached to implement the plan, gaps have been identified. These gaps include: the financing of screening, referral, assessment, and diagnosis; along with developing and implementing intervention strategies with all who are affected by FASD. These individualised interventions would help avoid people affected by FASD developing secondary conditions which cost society in the long term. Within the context of ANZ and Treaty obligations, a significant gap identified is the need to consult with Māori in developing policy and programmes that are culturally appropriate for Māori.

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List of Abbreviations

Acronym	Full term
ALAC.....	Alcohol Liquor Advisory Council
ANZ.....	Aotearoa New Zealand
ARBD.....	Alcohol Related Birth Defects
AHW.....	Alcohol Healthwatch
BMI.....	Body Mass Index
CCT.....	Cognitive Control Therapy
CNS.....	Central Nervous System
CYF.....	Child, Youth & Family
FANZ.....	Fetal Alcohol New Zealand
FAS.....	Fetal Alcohol Syndrome
FAST.....	Fetal Alcohol Support Trust
FASD.....	Fetal Alcohol Spectrum Disorder
FAE.....	Fetal Alcohol Effects
FMF.....	Families Moving Forward
HPA.....	Health Promotion Agency
ICD-10.....	International Classification of Diseases – version 10
IQ.....	Intelligence Quotient
LLT.....	Language and Literacy Training
MDT.....	Multidisciplinary Team
MoH.....	Ministry of Health
PAE.....	Prenatal Alcohol Exposure
pFAS.....	Partial Fetal Alcohol Syndrome
QFT.....	Quantity, Frequency, Time
RTLb.....	Resource Teacher: Learning and Behaviour
SES.....	Social Economic Status
UC.....	University of Canterbury
US.....	United States
VABS.....	Vineland Adaptive Behaviour Scale
WHO.....	World Health Organisation

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Chapter One: Setting the scene

Introduction

This chapter outlines the author's journey with respect to her interest in Fetal Alcohol Spectrum Disorder (FASD). It describes Bronfenbrenner's Ecological Model of Human Development which is used as a framework for this literature review. Five key themes pertinent to this dissertation are described:

- a drinking culture that has developed over time
- risk factors for the unborn child
- the importance of early diagnosis and intervention for a child with FASD
- a multi-disciplinary approach to assessment and diagnosis across the lifespan for those with FASD
- policy implications in Aotearoa New Zealand (ANZ)

Chapter Two will present the research question and research method used for this dissertation.

Chapter Three will provide a brief historical overview of a national drinking culture and identify the health impacts resulting from excessive alcohol consumption. Prevalence rates of FASD will be discussed along with policy implications related to alcohol consumption in ANZ.

Chapter Four presents the findings of the literature review using the framework of Bronfenbrenner's (1977) Ecological Systems Theory.

Finally, a summary will be provided of the literature review, limitations of this review will be highlighted and recommendations for future research will be made.

Personal Beginnings

For a number of years I worked for a church-based organisation in five different communities around ANZ, where I was responsible for running a number of programmes for children and families. In 1994, my husband and I were transferred to work in an addiction centre. The following five years were spent by being in the privileged position journeying with a group of young people whose parents were either in treatment or in recovery from substance dependency. Working in the addiction field added a new dimension to my work

with children and families, as the children faced a wide range of issues ranging from behavioural, social and academic though to wider complex family issues. Often I heard these children being referred to as 'bad' or just plain 'defiant'. Some of them were difficult to manage, but I always held a foundational belief that children are often a product of their environment.

In 2004, I was employed at Early Start Project, a Non-Government Organisation where I worked with parents and their infants and young children who were considered to be 'at risk'. One of the 'risk' factors was being born to a mother who had consumed alcohol during their pregnancy. These experiences led me into social work education and in 2005 I completed a Postgraduate Diploma in Health Sciences where I focused on the needs of children and families dealing with mental health issues.

I was raised in a family where consuming alcohol safely on special occasions was a normal part of life, and one where my parents taught us children to drink sensibly. As young people we all experimented with alcohol, however always in the background, was a sense of appropriate alcohol consumption. For a number of years I chose not to consume alcohol but in recent years, I have returned to consuming alcohol on special occasions.

As a social worker I have become increasingly concerned that frontline workers, such as educators, community workers and health workers appear to have a limited knowledge in recognising FASD symptoms in their client group. This dissertation gives me the opportunity to explore this subject in more depth and disseminate information to the relevant workforce.

Statement of the Issue

The definition of Fetal Alcohol Syndrome (FAS) has been subsumed by an umbrella term of Fetal Alcohol Spectrum Disorder (FASD), resulting in varied diagnostic possibilities when considering an individual who was exposed to alcohol consumption prenatally (Warren, Hewitt & Thomas, 2011). However, many frontline professionals in health, education and social service providers have not kept up with this developing knowledge (Green, 2007;

Herrick, Hudson, & Burd, 2011). Therefore, people go undiagnosed and do not receive the appropriate intervention (Dörrie, Föcker, Freunsch, & Hebebrand, 2014).

Framework for the Review

Reid et al., (2015) in their systematic review of FASD interventions across the lifespan conclude that an ecological lens helps explore the multiple issues people with FASD experience. The developmental psychologist, Uri Bronfenbrenner (1917-2005) provides one such ecological lens. He promoted the idea that an individual's development must be considered in the societal and environmental context in which they live, and in his model "the ecological environment is conceived topologically as a nested arrangement of structures, each contained within the next" (Bronfenbrenner, 1977, p. 513). Many different disciplines use this framework to understand and critique systems including: human and family development; culture; education and science. A description of this framework is provided in Chapter Two and will be used to examine and critique the literature.

Overview of key concepts

Risk factors for women consuming alcohol during pregnancy

There are many variables that contribute to the risk factors of an unborn child having FASD. These include a woman having low social-economic-status (SES) and a low body mass index (BMI) and/or having low nutritional intake (May & Gossage, 2011). However, the pregnant woman consuming alcohol is the one definite indicator of a child potentially having FASD. According to the Ministry of Health (MoH, 2015a), consuming seven standard drinks of alcohol, in "a single binge [episode] or more than seven standard drinks in a week is classed as high risk" drinking for any person (p. 4). Research to date has not been able to identify a safe minimum drinking level for a pregnant woman that does not potentially harm the unborn child (Health Promotion Agency [HPA], 2015).

Despite promotion and public awareness campaigns from the government and other relevant agencies, there is research evidence in ANZ which reveals up to "60 per cent of women binge drink prior to pregnancy recognition, 28 per cent continue to drink some alcohol during their pregnancy, and 10 per cent continue to binge drink" (Rogan & Crawford, 2013, p. 174). Although research has not yet identified a safe alcohol consumption level while pregnant for the unborn child, what is clear is that the more alcohol a woman consumes

the increased risk of giving birth to a child with FASD (May & Gossage, 2011, p.24). The encouraging factor is that if a mother ceases consuming alcohol during pregnancy the outcome improves for the unborn baby (Chudley, Conroy, Cook, Loock, Rosales & LeBlanc, 2005).

Fetal Alcohol Spectrum Disorder

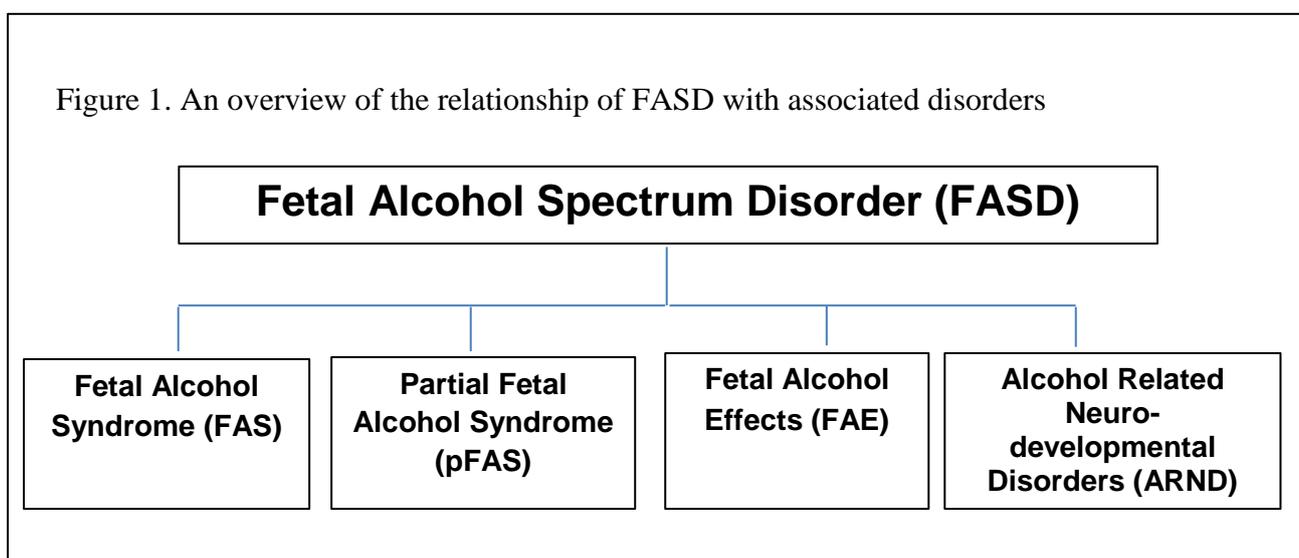
The potential negative effects on the unborn child of alcohol consumption during pregnancy have been a concern in ANZ since 1874 when it was documented in a petition to the House of Representatives (Rogan & Crawford, 2013). Jones and Smith in 1973 (cited May & Gossage, 2011) gave a clearer understanding and formal clinical diagnosis of Fetal Alcohol Syndrome (FAS) was provided when they were able to identify birth defects that resulted directly from a mother consuming alcohol while pregnant. These defects were evident particularly through the babies' presenting facial characteristics, which include a low nasal bridge, thin upper lip and small eye openings (May & Gossage, 2011; Popova et al., 2016). Over the next 40 years, this diagnosis evolved into a spectrum of disorders as clinicians became aware that children who had been exposed to alcohol while in-utero later presented with cognitive and behavioural challenges, but did not have the traditional abnormal facial features (Warren et al., 2011).

Alcohol is a teratogenic substance affecting the normal development of an unborn child due to the creation of a toxic environment for the developing fetus (MoHb, 2015; Olson, Jirikowic, Kartin, & Astley, 2007). The timing, frequency and the amount of alcohol being consumed by the pregnant woman determines the potential damage to the developing fetus (May & Gossage, 2011). Alcohol is not metabolised by the pregnant woman's liver, but travels directly through the placenta to the baby, resulting in the blood alcohol concentration being as high as when the woman consumed the alcohol (Duncan, 2013). Therefore, permanent damage can be caused to vital organs and the brain of the fetus. Damage can impact upon the child's intellectual and physical development extending to all aspects of adulthood (Herrick, Hudson, & Burd, 2011). Alcohol is the only core variable that contributes to a child being diagnosed with FASD (Esper & Furtado, 2014).

The severity of symptoms can lead to a range of diagnoses under the term FASD (Chudley et al., 2005). FASD is an umbrella term to incorporate all areas of the spectrum (Herrick et al., 2011). At one end of the continuum is the diagnosis of Alcohol Related

Neurodevelopmental Disorders (ARDN). Symptoms include neuro-behavioural problems and present in areas including cognitive, social and language deficits. At the more severe end of the spectrum is the diagnosis of Fetal Alcohol Syndrome (FAS). These symptoms include growth deficiencies often to the face and/or small head sizes including lower Intelligence Quotient (IQ), (Olswang, Svensson, & Astley, 2010). In between these two diagnoses is partial Fetal Alcohol Syndrome (pFAS) and Fetal Alcohol Effects (FAE) (Warren et al., 2011).

Figure 1. An overview of the relationship of FASD with associated disorders



Children with FASD present with difficulties in three domains: socialisation; language; and cognition deficits, although they can be individual variance (MoHb, 2015). May and Gossage (2011) suggest that “deficits arise from differences in the extent of alcohol exposure, drinking patterns and other maternal risk factors” (p. 16). These children do not necessarily present with a set of typical symptom, therefore must be considered individually.

To date, there is no pharmaceutical treatment for people with FASD (Dörrie et.al., 2014); however, research in the last decade has highlighted that the ability of a child’s brain affected by Prenatal Alcohol Exposure (PAE) can be moulded and shaped through appropriate early interventions (Thomas, Warren, & Hewitt, 2010). However, when FASD goes undiagnosed at an early age, and no intervention is put in place, these children often

grow into young people and adults who have complex issues: This is referred to as secondary diseases or conditions.

Secondary diseases/conditions/disabilities

The literature uses three different terms to describe the same concept: Secondary disease; secondary conditions; or secondary disabilities. These terms refer to a young person who progresses through adolescence, then adulthood, with undiagnosed or wrongly diagnosed FASD. For the purpose of this discussion, the term secondary condition will be used. According to Herrick, Hudson and Burd (2011), “the consequences of prenatal alcohol exposure are often grave, inhibiting both physical and intellectual development, societal acceptance and adult success” (p.44). For this cohort of young people these consequences can include dropping out of school, being taken advantage of by others, isolation, mental health issues, and conduct disorder leading to criminal behaviour. There is evidence that suggests that as the young person grows into adulthood their adaptive abilities decrease setting them up for adverse experiences (Fagerlund, Autti-Ramo, Kalland, Sanyyila, Hoyme, Marrson & Korkman, 2012). This theme will be referred to later in Chapter Four.

Summary

This chapter has set the scene for this literature review. The author’s personal interest in FASD has been discussed and framework for the review highlighted. Definitions and explanations have been given for three key domains: Risk factors for women consuming alcohol during pregnancy; an explanation of FASD; and a description of secondary condition in this context. The next chapter will detail the methods used for the literature review.

Chapter 2: Methods

Introduction

This chapter will define the research question and describe the theoretical lens used to examine the literature. The terms of reference will be described along with identification of where the literature, and other information, has been sourced.

Research question

What challenges do the Aotearoa New Zealand (ANZ) community face when supporting families who have a child displaying Fetal Alcohol Spectrum Disorder (FASD) symptoms?

Bronfenbrenner's Ecological Theory of Human Development

This narrative literature review examines and critiques literature from 2010-2016 to determine what challenges ANZ society is facing with supporting families with a member who exhibit FASD symptoms. As noted in the previous chapter, Rogan and Crawford (2013) suggested the use of an ecological approach when exploring the topic of FASD so the complexities of the syndrome's variables are considered thoroughly. This literature review uses Bronfenbrenner's holistic and community focused Ecological Systems Theory to provide a framework for the analysis and discussion. It consists of five interconnected systems of influence:

1. The individual who is located at the centre of the microsystem. Areas to consider are all the details of the person including their age, gender, health issues and culture. The microsystem surrounds the individual and includes all the people and systems that directly influence the individual child. These can include the family, friends, daycare, school, church and sports clubs.
2. The mesosystem includes the interactions that happen between the structures of those in the child's micro system. An example of this could be the interaction between the caregiver and the child's teacher (Santrock, 1997).
3. The exosystem represents the larger social system that the child is not directly involved with. An example of this could be the parent's workplace or the School Board of Trustees; the health system where a child is seeing a professional; or the legal system when welfare services are involved with a child's care. These

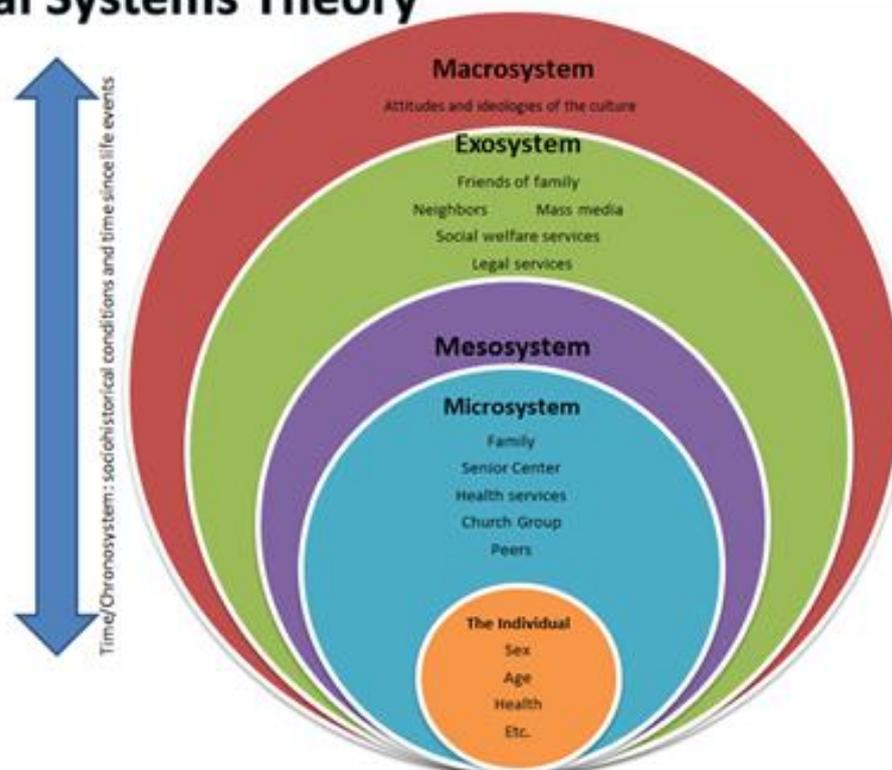
systems have an impact on the child but the child does not have a direct relationship with them.

4. The macrosystem is the outer layer of influences that ripple down and interact within each system the child is influenced by. This system includes cultural attitudes, values and beliefs that are held in the society the child lives. In the case of a child with FASD this includes the drinking culture of the wider society.
5. The chronosystem encompasses all the other systems. This includes defining the time, year and century in which the person is born and the influences that take place as the child grows into an adult. In this case the development of the understanding of FASD symptomology through research over time (Santrock, 1997). The chronosystem can be visualised as interconnecting the other four systems (see Figure One).

This model will provide the framework for the discussion of the historical context of alcohol in Chapter Three, and Chapter Four will discuss the remaining themes identified in the literature.

Figure 2. Bronfenbrenner's Ecological Theory of Human Development. Retrieved from <https://shannondwyer.files.wordpress.com/2014/07/ecological-systems-theory.png>

Ecological Systems Theory



Search method

The literature search was undertaken using CINAHL, Science Direct and Index NZ databases. All databases were searched initially with the term ‘fetal alcohol spectrum disorder’ selecting full text, English language, peer reviewed and dated from 2007 to present day. Science Direct was also filtered by using subscribed journals and open access. This search resulted in a total of 3520 papers. It is possible however, that by only using the American spelling ‘fetal’ and not including the alternative spelling ‘foetal’ that there were articles that could have potentially informed the work, eliminated. Subsequent searches were then narrowed using the words ‘interventions and Fetal Alcohol Spectrum Disorder, MDT and secondary disease and community’. The date was also set at 2010 to present day to access contemporary literature. This narrowed the search to 58 results on CINAHL, 836 results on Science Direct and 13 results on Index NZ. The abstracts were read to select a variety of articles that included a range of research conducted over time and throughout the world in relation to lifespan interventions for people with FASD. Articles that were sourcing the same research were excluded for this literature review. The main articles selected were no older than ten years but several others were selected owing to the significance of the data including the Canadian diagnostic assessment tool (Chudley et al., 2005). As the literature review proceeded, a snowball approach occurred which added other relevant information from websites and personal communication. Table One summarises the information sources.

Table 1: Sources of data for the literature search

Libraries	Database	Website	Personal communication
University of Canterbury	CINAHL	Ministry of Health	General Practitioner
Ara Institute of Canterbury	Science Direct	Health Promotion Agency	Resource Teacher: Learning and Behaviour (RTLB)
	Index NZ	Alcohol Healthwatch (AHW)	Senior Social Worker in Child Youth and Family (CYF)
		The Salvation Army Policy and Parliamentary Unit	

The final literature review considered eight primary sources, twelve secondary sources and six grey sources of information. Primary sources included studies that were quantitative in nature, such as one robust study which highlighted ‘risk’ factors of 756 women (May & Gossage, 2011), to smaller qualitative studies including; for example, Olswang et al. (2010) who observed 12 pairs of school children in a school setting, and a phenomenological study using semi structured interviews with 24 parents along with a focus group of 18 service workers (Petrenko, Tahir, Mahoney, & Chin, 2014). Also, an ANZ qualitative study conducted face-to-face interviews with 24 women who were pregnant or had recently given birth and were asked about their alcohol consumption while pregnant (HPA, 2014a). Focus on ANZ research was particularly important as the literature review aim is to align international research with what the ANZ government have planned in the Action Plan 2016-2019 (MoH, 2016).

Secondary sources used included a meta-analysis of 127 studies of comorbidity issues developing from undiagnosed FASD in global populations (Popova et al., 2016). Along with a systematic review that included 32 studies which were focused on childhood impairments experienced due to PAE (Reid et al., 2015). Non-research literature included topical articles and conversations with practitioners in the field of interest. The literature search was undertaken using a qualitative approach of reviewing for recurring themes. The themes identified were: risk factors in women; importance of early diagnosis and intervention; multi-disciplinary team approach to assessment and secondary conditions resulting from misdiagnosis or wrong diagnosis of FASD.

Summary

This chapter has stated the research question and provided details of the framework used to review the literature. A table was provided to clearly show where information was accessed from. Furthermore, examples of different research methods considered in this literature review were provided and the process of analysing the data was stated.

Chapter Three: The Historical Context

Introduction

This chapter briefly describes the history of alcohol consumption. The health impact of alcohol on the individual, their family, community and society will be discussed. FASD prevalence rates, internationally and nationally, will be described along with the policy response to alcohol consumption in ANZ.

Chronosystem: A drinking culture that has developed over time

There is a long history of alcohol use across many cultures throughout documented history. Its use was common in the British Isles and with colonisation of large parts of the globe by the British, the explorers and immigrants took alcohol on their travels for their personal consumption and for trading purposes (Hutt, 2016). In the late 1700's the British explorers who came to ANZ recorded that the indigenous people were drinking large amounts of water and Māori referred to alcohol as "waipiro" ["stinking water"] or "wai kaha" ["strong water"] (Hutt, 1999, p. 7). Alcohol rarely featured in Māori society during the 1830's but by the time the Treaty of Waitangi was signed in 1840 the traders were beginning to introduce alcohol to the indigenous people throughout ANZ (Hutt, 1999). Harsh and lonely conditions for the early settlers meant alcohol often became a man's companion. In the 1840's the average alcohol consumption of a Pakeha was "45 litres of licit commercial spirits a year and 14 litres of beer" (Hutt, 1999, p. 36). What is interesting is the fact that liquor legislation to contain the use of alcohol was aimed at Māori, as the British wanted to contain the Māori peoples' consumption of alcohol. An example of this was the Ordinance to Prohibit the Sale of Spirits to Natives of 1847.

The late 19th century saw attitudes begin to change towards alcohol consumption both overseas and in ANZ. The Temperance Movement started to advocate for the prohibition of alcohol and sought government protection for the most vulnerable in society, particularly women and children (Coney, 1993). A 1916 petition with 160,000 signatures called for six o'clock closing of public houses, so that men would return home to their families at a reasonable hour. The government saw this legislation would take away the energy from the Temperance Movement petitioning for prohibition, so six o'clock closing was implemented in 1918 (NZ History, 2016, para 1-2). The legislation changed men's drinking culture: many would leave work and go directly to the public house and drink as much as possible until

6pm. Then they staggered home having spent their wages. This became known as the 'six o'clock swill'. Six o'clock closing remained in place until the 1966 License Control Commission introduced the sale of liquor until 10pm. Many believe the six o'clock swill is responsible for the development of the binge drinking culture in ANZ (NZ History, 2016, para 4).

In 2010, The Salvation Army Social Policy and Parliamentary Unit published the document, 'Under the Influence: Reshaping New Zealand's Drinking Culture'. This document highlighted statistics from an Alcohol and Drug Use Survey 2007/08, that 61% of people 16-64 years of age were consuming alcohol on a weekly basis. The report also highlighted that the highest adult rates of alcohol consumption were in ANZ, Australia and Europe (James, 2010). These statistics reflect the drinking culture that has developed in ANZ.

Two surveys were conducted (1995 and 2000) of female alcohol consumption rates in ANZ. The results of the survey showed the heaviest consumption of alcohol was by women 20-24 years of age, but by 2000 this had changed to those aged 18-19 years. This age group also increased their alcohol consumption by 33% in this period. The researchers stated "changes in the drinking behaviour appear to have been accompanied by the development of a more liberal social climate around alcohol consumption" (Habgood, Casswell, & Pledger, 2002, p.16). Contributing to this change was the 1989 Sale of Liquor Act, following which the number of alcohol outlets almost doubled and alcohol was sold in supermarkets (New Zealand Government Parliamentary Council Office, 2016). The NZ Drug Foundation in 2006 released a position paper regarding alcohol and pregnancy. They highlighted that Māori women's drinking patterns and unplanned pregnancy rates contributed to the possibility of them being more likely to have children with FASD (New Zealand Drug Foundation, 2006).

Stuart (2009) also discussed the development of the drinking culture in ANZ with a particular focus on Māori women. She highlighted the earliest record of Māori women consuming alcohol was in the 1860's. She believes Māori turned to alcohol as their culture, health and identity was taken away from them. Early 20th century records showed alcohol consumption was problematic and becoming a social issue for Māori women. This was followed by urbanisation in the 1940's which led to Māori women's roles changing, and many going into paid work. Introduction to sweeter alcoholic drinks such as wine and spirits, along with the later age of childbearing contributed to the development of a drinking culture

for Māori woman (Stuart, 2009). However, Stuart emphasised that it is important to remember that not all Māori women consume alcohol.

The effect of a woman consuming alcohol on a fetus resulting in birth defects has been a concern throughout history (Warren et al., 2011). However, it was not until 1973 that Jones and Smith first described FAS (Popova et al., 2016). Over the last 40 years, research has clarified the potential impact a woman consuming alcohol while pregnant can have on the unborn child's CNS (MoH, 2015)

An ANZ study in 2005 revealed that 552 women who were pregnant or had been pregnant in the past five years showed 53% had consumed alcohol. This study highlighted that 37% of these women stopped consuming alcohol as soon as they knew they were pregnant. A more recent ANZ study (2013) revealed that 34% of 723 woman reported to consuming alcohol prior to their knowledge that they were pregnant, but once they knew they were pregnant 10% of the woman stopped drinking (HPA, 2014a).

The Salvation Army 'State of the Nation Report: Moving Targets' (2016) has some very encouraging news. It reports that overall alcohol consumption for both genders has decreased to a 15 year low, however the volumes of low alcohol content beverages has increased. The authors also reported a decline in unplanned teenage pregnancies in the 15-19 years age group (Johnson, 2016). These statistics show a decline in alcohol consumption which may well lead to a decline in FASD in the future.

The government has released an action plan for 2016-2019 which includes action steps to influence attitude change of pregnant women, partners, family and society on alcohol consumption during pregnancy. Also included in the action steps are developing successful strategies of working with those children, young people and adults with permanent brain damage owing to alcohol consumption while they were in utero. The aim of this action plan is to support people affected by FASD and those who care for them to live a fulfilling life (MoH, 2016).

Health impacts

Popova et al., (2016) discuss the Global Burden of Disease and Injury study in 2010 and note that the cost of alcohol consumption to society was "the fifth leading contributor to

disability and mortality – 3.9% of global disability-adjusted life-years and 5.2% of all global deaths” (p. 1). These estimates are about the individual who is drinking, however, they also acknowledge that alcohol consumption impact upon people closer to the consumer and in this context, an unborn baby. Research estimates that alcohol consumption worldwide is contributing to 200 illnesses that are recognised in the International Classification of Diseases (ICD-10), (Health Promotion Agency [HPA], 2013).

Research conducted between 2004-2007 by the University of Otago investigated the burden of disease, and included the cost of alcohol consumption in ANZ in personal and financial terms. This study stated that alcohol was responsible for the death of 802 New Zealanders aged 80 years or less “43 percent were due to injuries (intentional or unintentional), 30 percent were due to cancer, and 27 percent to other chronic conditions” (HPA, 2013, p. 13). There are twice as many male than female deaths.

The HPA has reported on the health and societal effects of alcohol in ANZ. The author described the complex influences of alcohol in ANZ society, referring to alcohol as a ‘lubricant’ to help people live their daily lives. Effects include the fact that alcohol can be a carcinogen which causes a number of cancers such as throat, bowel, and breast cancers. Dependency can also result from excessive alcohol consumption and an unborn child can have abnormalities as alcohol is a teratogen: a toxin destroying body cells. Furthermore, it contributes to motor vehicle accident fatalities, drownings, domestic violence and assaults. Yet with all that alcohol costs to individuals, families and society, alcohol is still readily available to the consumer and continues to be part of the ANZ culture (HPA, 2013). In 2010 the Law Commission estimated the harm alcohol costs to ANZ society at 5.3 billion ANZ dollars (Rogan & Crawford, 2013).

The World Health Organisation (WHO) reported that the highest alcohol consumption is in the developed world and estimates that people aged 15 and over who consume alcohol are drinking “13.5 grams of pure alcohol a day” (World Health Organisation [WHO], 2014, p. 29). WHO states the highest levels of drinking are in the European region and the United States (US). The intermediate levels of drinking are in the Western Pacific region and the lowest reported levels of alcohol consumption are in the South East Asian and Eastern Mediterranean region (WHO, 2014).

Prevalence Rates of FASD

In 2009 Burd and Christensen (cited Herrick & Hudson, 2011) stated that “approximately 1% of all US newborns are diagnosed with a birth defect or developmental disability related to prenatal alcohol exposure” (p.44) and they believed that 40% of all women who are pregnant in the US expose their unborn children to alcohol. These studies show not only the harm to the individual, but also to the many people around them, including the unborn child.

International research clearly shows a difference in prevalence rates of FASD in Western nations as compared with those that have been colonised, such as South Africa and Brazil. Indigenous people in these colonised countries tend to have higher rates of children being diagnosed with FASD. For example, in South African school children, the prevalence of children at primary school being diagnosed with FASD is “between 2-5% in western countries, but as high as 13.6% -20.9%” in coloured ethnicities of the Cape regions equating to a prevalence rate as high as “40.5-46.4 in 1,000 born children” (Lewis et al., 2015, p. 724). WHO concurs that South Africa’s Western Cape area has the highest rates of FASD in the world (WHO, 2011, section 6). However, other research reports higher rates of FASD in some South African communities estimated “135-207 per 1000 births” (Dörrie et al., 2014, p.865). Esper and Furtado (2014) report Brazil’s prevalence rate of children born with FASD is as high as “38.69 in 1,000 live births” (p.878). Clearly, prevalence rates of FASD differ depending on the country being examined. This is due to a number of factors including screening ability of professionals and resources for diagnostic assessments being available.

Australian research in 2008 reported generally that 80% of Aboriginal mothers whose children were aged between zero and three years did not drink while pregnant and 16% of the mothers reduced their drinking with “only 3.3 per cent drank the same amount or more alcohol during pregnancy” (Duncan, 2013, p.11). In contrast, a further study amongst a remote aboriginal community in 2013 reported a prevalence rate of FAS and pFAS as high as “120 per 1,000” births (Reid et al., 2015, p. 2283). Duncan (2013) states the high rates of FAS reported were linked with other risk factors such as poverty, low social economic status and poor nutrition. Therefore, prevalence rates of FAS will alter depending on which aboriginal community is being studied along with other environmental deficits being experienced by the indigenous people.

Research has also highlighted that the rates of children with FASD symptomology who are placed in foster care settings are alarmingly high. Herrick et al. (2011) found that while “40% of children are prenatally exposed to alcohol in the general populations; nearly 70% of children in the foster care system were prenatally exposed” (p.45). Researchers in Finland also report that a FASD diagnosis in children in care is as high as 50% (Fagerlund et al., 2012, p.4).

In ANZ in 2012 and 2013, up to 19% of all pregnant women were reported to have consumed alcohol at some point, of whom, 28% were less than 25 years of age. Māori women who consume alcohol while pregnant was estimated at 34% compared to 20%, 10% and 4.3% for European, Pacifica and Asian women respectively (MoHa, 2015). The 2015 MoH discussion document highlighted the lack of current data on the number of children in ANZ potentially impacted by FASD. However, they estimated 10% of all pregnant mothers drink alcohol at ‘risk’ levels. The most recent estimated prevalence rate of FASD in ANZ is 3 per 1,000 live births per year. This means each year that 170 newborn children in ANZ may have FASD (MoHb, 2015).

The 2016 Action Plan states that “at least one in two pregnancies are exposed to alcohol: one in ten are exposed at high-risk levels” (MoH, 2016, p.2) and that approximately 50 % of children who are in Child Youth and Family (CYF) care are affected by FASD. Another issue to consider is that approximately two out of five pregnancies are reported as unplanned in ANZ, therefore, woman unknowingly can be consuming alcohol through the early developmental stage of the fetus (MoH, 2016).

Policy Context

The ANZ drinking culture has developed over time and many groups are advocating for changes to ANZ Liquor Laws. The ANZ Law Commission’s report in 2010, ‘Alcohol in Our lives: Curbing the harm’, highlighted target areas for change including: the legal age of consuming alcohol; alcohol being sold in supermarkets; along with liquor stores frequently being located in lower socio economic areas (Palmer, 2010).

Alcohol Action NZ promotes their 5+ Solution to address at risk drinking in this country. They advocate for legislation to “raise alcohol prices, raise the purchase age, reduce alcohol accessibility, reduce marketing and advertising and increase drink-driving counter measures”. The 5+ Solutions have come from the WHO publication called “Alcohol, no

ordinary commodity” (Alcohol Action ANZ, 2016, para.1). The 5+ Solutions are an attempt to change the drinking culture of ANZ and, in the long term, would contribute to reducing the FASD prevalence rates in this country. Another policy initiative linked with individuals and community groups advocating for change is the MoH (2016) development and release of an action plan ‘Taking Action on Fetal Alcohol Spectrum Disorder: 2016-2019’. This action plan is considered further in the next chapter.

Summary

A culture of consuming alcohol in ANZ society has developed over time, commencing with the explorers bringing alcohol into the country for their own pleasure, but also for trading with the indigenous people of ANZ. The health impacts from alcohol consumption have been discussed, specifically, rates for woman consuming alcohol in child bearing years. The international and national prevalence rates of FASD were identified and an introduction to an ANZ policy context was made.

Chapter Four: The Contemporary Context

Introduction

As introduced in the previous chapter, this literature has been viewed through the framework provided by Bronfenbrenner's Ecological Systems Theory. At each level of the system, a theme is highlighted to provide the discussion. These themes are: (1) risk factors for the unborn child; (2) the importance of early diagnosis and intervention for a child with FASD; (3) a multidisciplinary approach to assessment and diagnosis across the life span for those with FASD; and (4) ANZ policy implications.

Theme One: Individual System - Risk factors for the unborn child

The key risk factor for the unborn child is a mother who consumes alcohol while pregnant (May & Gossage, 2011). Historically, it was thought that only women who were 'alcoholics' produced children with FASD (New Zealand Drug Foundation, 2006). However, a number of other risk factors impact upon the mother consuming alcohol have been identified which result in babies being born with permanent brain damage. May and Gossage (2011) reviewed four studies involving 756 mothers from the US, Italy and South Africa whose children had been diagnosed with FASD. The focus of this research was investigating mothers' protective and risk factors (May & Gossage, 2011). They highlighted that risk factors for the fetus with a mother who drinks while pregnant can be classified into three domains: (1) the environment (the context of the mother's life); (2) the agent (alcohol as the substance); and (3) the host (mother who is consuming alcohol). The chance of the unborn child having FASD increases as these three areas intensify in the woman's life. Bignol, Schuster, Fuchs and Iosub (1987) (cited May & Gossage, 2011, p. 21) state that women from a lower social economic group are "15.8 times" more likely to have a child with FAS in comparison with women consuming similar amounts of alcohol from other socio economic groups. They also reviewed Keen, Uriu-Adams, Skalny and Grabeklis's 2010 study of Russian and Ukrainian women. This research discovered that copper and zinc deficits due to poor diet and consuming alcohol increased the risk of children being born with FASD as their unborn child did not receive the nutrients for normal development. May and Gossage (2011) also found that smaller women were over represented in FASD studies and that increased maternal BMI significantly reduces risk of FASD in their children.

Similar findings were found in Esper and Furtado's 2014 systematic review of 15 studies (12 studies in US, two in South Africa and one in Australia), with environmental and

social factors adding to risky alcohol consumption levels for mothers while pregnant. These factors in turn, increased the likelihood of FASD symptoms occurring in the unborn child. The authors stated that:

Although the populations are different, some maternal risk factors were common amongst the studies: older age, lower educational level, having other children with FASD, presence of other family members who abuse alcohol and higher number of children and pregnancies” (Esper & Furtado, 2014, pp. 885-6).

In contrast, research in ANZ conducted with 552 women who were or had been pregnant in the previous five years highlighted that women in the younger age group were more likely to drink or be binge drinkers in early pregnancy. These women were 3.5 times more likely to consume alcohol during pregnancy (Palmer, 2010; Stuart, 2009).

Other contributing factors to damage the developing fetus include the quantity of alcohol the woman is consuming, the frequency and the actual time during the term of the pregnancy the woman consumes alcohol (QFT). For example, binge drinking will result in more harm to the unborn fetus as the blood alcohol concentration will be higher (May & Gossage, 2011). If alcohol is consumed in the early stages of her pregnancy, it may influence the development of the facial features and head size as these develop in first six to nine weeks of gestation. Additionally, consuming alcohol during pregnancy not only increases the risk of a child being born with permanent brain damage but also increases the risk of miscarriage or stillbirth (Dörrie et al., 2014; Stuart, 2009).

Often it is thought that a woman needs to consume alcohol excessively for a fetus to be negatively affected, however, according to the US Surgeon’s General Office:

We do not know what, if any amount of alcohol is safe but we do know the risk of a baby being born with any of the fetal alcohol spectrum disorders increases with the amount of alcohol a pregnant women drinks...when a pregnant women drinks, so does the baby (cited in May and Gossage 2011, p.24).

Predictors of a woman consuming alcohol while pregnant

Research New Zealand discussed in 2014 the psychological predictors of consuming alcohol during pregnancy. These include the number of stressors the woman experiences during her pregnancy including: relationship problems; anxiety over their pregnancy and financial concerns. These factors could lead women to consume alcohol at 'risk' levels. Additionally, an unplanned pregnancy could mean a woman was drinking at heavy levels whilst unaware they were pregnant (HPA, 2014b). Esper and Furtado (2014) include a comprehensive list of maternal risk factors contributing to FAS derived from the 15 studies included in their research (refer to Appendix A). These risk factors include: social demographic features; psychiatric challenges; along with psychological factors and family factors such as alcohol abuse in the family. The individual risk factors for the woman include her history of other substance use, smoking tobacco along with the woman's overall health.

May and Gossage (2014) reported that mothers were not "fully forthcoming and truthful" (p. 864), due to the shame and stigma experienced by the mother in relation to her alcohol consumption while pregnant. Also, a family history can be difficult to obtain as families may be separated for a number of reasons. These factors can contribute to limitations in data collected. Risk factors identified for a woman while pregnant highlights the risk factors to the unborn child having FASD.

Theme Two: Microsystem - The importance of early diagnosis and intervention for a child with FASD

Research shows very clearly that undiagnosed FASD has a detrimental effect for the individual, caregivers/family communities and the wider society. It also identifies that early identification of symptoms will produce the best results for all concerned. However, the wide range of symptomology of FASD differs throughout the development of a child into adulthood therefore, making screening difficult. Some symptoms may cluster at certain age groups but they can also present later for others. “FASD is unique to each person and affected children may display only some of these symptoms ... in varying degrees ranging from mild to severe” (Herrick et al., 2011, p. 46).

As discussed, a woman consuming alcohol at a risk level during her pregnancy is the most significant predictor that their child could have FASD (Olson et al., 2007). Along with considering the symptoms a child is experiencing, other external indicators must be considered in the assessment. Often these children grow up in environments where parents struggle with their own health, money is limited, there may be relationship struggles, or addiction problems (Dörrie et al., 2014). According to Olson et al., (2007) “cumulative risk could be especially harmful for a child made biologically vulnerable by prenatal alcohol exposure” (p. 182). The diagnosis of FASD is complex, therefore early detection of symptoms and referral is essential so the young person can get the best possible intervention to set them up for a fulfilling life.

Children

Herrick et al., (2011) highlight that diagnosis before the age of six is critical. Babies and toddlers with FASD can potentially present with a wide range of issues which include failure to thrive, sleep disturbances, irritability, delays in developmental goals, hearing and visual problems. These issues mean that if not recognised as FASD symptoms, and if interventions are absent, the child is likely to develop more complex issues as they age. These complexities include negative behaviour at home and preschool, an inability to keep up with their peers, difficulty understanding between right and wrong, an inability to read others cues and short term memory problems (Herrick et al., 2011).

FASD symptomology can potentially co-occur with other medical, psychiatric or academic disorders. An experienced team of clinicians can only determine if there are issues

of comorbidity impact upon the individual through a thorough assessment (Olson et al., 2007). This is discussed more fully in the following section. Children who are either moderately or severally exposed to alcohol when they are in utero tend to present with lower IQ, have challenges with memory encoding, storage and retrieval and they may process information much slower (Lewis et al., 2015). Olsen and colleagues (2007) highlighted that this cohort of children would benefit from support workers when starting primary school. They can help by identifying and negotiating any potential hazards that may occur, “Early intervention providers can be proactive and essential gate keepers and guides to the future” (Olson et al., 2007, p.186). This would make the child’s transition to school smoother.

A clinical study of 26 ‘typical’ children aged between five and eight compared with 25 children with FASD was conducted in Washington State by the FAS Diagnostic and Prevention Network. Findings highlighted the importance of early referral so that the children could be diagnosed with FASD and an appropriate specific intervention be put in place for the child and their caregivers. The study also found that a child with FASD was being diagnosed on an average at 9.5 years of age. Experts considered this age did not allow the young person and their caregivers to have access to the best possible interventions that were available as often people have a negative misconception of these undiagnosed children (Olson et al., 2007). Currently in ANZ, the average age of diagnosis is eight years of age (Rogan & Crawford, 2013). Many researchers believe that these age range diagnoses can be made too late to ensure successful implementation of interventions (Paley & O’Connor, 2011).

Dörrie and colleagues (2014) provide a helpful list for caregivers and frontline workers of symptoms which can be experienced by people with PAE across the life span (refer Appendix B). Symptoms being recognised early, a referral made and an early diagnosis given provides an understanding for caregivers and support people that the child/young person has irreversible brain damage and therefore is not intentionally misbehaving and this may mitigate against their being labelled as ‘naughty or bad’. Appropriate support people (family members and/or professionals) can be provided with useful behavioural management strategies rather than being punitive with the child and allows all persons working with the child to be using the same strategies (Petrenko et.al, 2014). Paley and O’Connor (2011) agree with these ideas and state that interventions that target a baby/toddler having poor self-

regulation and heightened response to stress “may help pave the way for more positive developmental trajectories for these children” (Paley & O’Connor, 2011, p. 72).

Paley and O’Connor (2011) discuss ten behavioural intervention strategies that have been tested with this cohort of school aged children. These interventions include: parenting interventions; behavioural and cognitive interventions; language and literacy training (LLT); self-regulation interventions; mathematic training; working memory strategies; adaptive skills training; social skills intervention; and safety skills. Such a large range of interventions is symptomatic of the diverse challenges children and young people with FASD can experience.

Cognitive Control Therapy (CCT) is another intervention Paley and O’Connor reviewed. Initially professionals and school personnel worked together to develop this new intervention. A small trial group of ten children were selected out of 64 students from South Africa’s Western Cape Region, where high rates of FASD are recorded. These ten children were randomly placed into the intervention group or the control group. The control group amalgamated with another school of a similar profile. The intervention group of five children received one hour a week of CCT by a trained staff member. This therapy addressed the five areas of body position, movement and self-awareness, focal attention, processing information strategies even when distracted by stimuli and controlling external information and the ability to categorise information (Paley & O’Connor, 2011).

Results from this intervention were positive for the five students who received CCT. Improvements included positive classroom behaviour, along with an increase in academic and communication skills. Improvements were also noted in student self-efficacy, increased motivation levels, along with an increase in self-confidence and improved emotionality. The control group of children had no changes reported. Paley and O’Connor’s (2011) identified limitations of the study including that the study had a small sample size and was conducted over a short period of time. They concluded there were definitely encouraging results and that further research with a young cohort of children with caregivers’ involvement along with follow up would be beneficial.

Adolescents through to Adulthood

A larger study by Fagerlund and colleagues (2012) in Finland found that 50% of children ‘in care’ were diagnosed with FASD. This research involved 143 children and

adolescents divided into three groups: (1) 73 young people who had been diagnosed with FASD; (2) 30 young people who had a learning disorder but were IQ matched with the FASD group; and (3) 40 young people were matched in age but functioned well. This study focused on adaptive behaviour skills and used the Vineland Adaptive Behaviour Scale (VABS) which measures the three domains of communication, daily living skills, and socialisation. This study was reported as the first of its kind as few children had been screened through the VABS. The results of this study highlighted that children and young people with FASD have fewer adaptive skills than both the children with specific learning disorders and the control group. The study also indicated that these young people with FASD moving into adolescence tended to regress in their adaptive abilities which resulted in declining socialisation skills (Fagerlund et al., 2012).

As noted earlier, lack of diagnosis or wrong diagnosis can lead to a person developing secondary complications (Petrenko et al., 2014). This can result in the child not being able to reach their full potential (Herrick et al., 2011) and undiagnosed babies, children and young people grow into adults who develop secondary conditions (Dörrie et al., 2014; Popova et al., 2016). For example, a more recent systematic review and meta-analysis of 127 studies (Popova et al., 2016) described the comorbidity issues that can result from undiagnosed FASD.

Dörrie and colleagues (2014) conducted a large longitudinal study of 626 same gender twin pairs and their parents. This study highlighted that adulthood can become very problematic if diagnosis and interventions have not been implemented when a person is younger. This study's validity was strengthened by 78% of the original participants being involved in a second study, providing longitudinal affect. Petrenko et al. (2014), suggests that these problematic domains include social problems, unemployment, financial hardship, substance abuse, health issues and parenting problems. Chudley et al., (2005) concur with these problematic domains and add potential head injuries due to the risk taking behaviour of people with FASD. This evidence highlights that supporting young people who have FASD into adulthood is critical as this cohort of people are vulnerable and do not read the cues of others who may not be so supportive (Fagerlund et al., 2012). Training caregivers how to manage and support their young people through this life transition is essential as adults with FASD do not tend to learn from their mistakes. Therefore caregivers working alongside them help them navigate their way forward in life.

A lack of understanding from professionals of FASD symptomology can place these adults into compromising situations and professionals can interpret negatively their reactions and behaviour. Herrick et al. (2011) state, “It is those who work and live with FASD-affected people who must change their interactions to accommodate the cognitive disabilities characteristic of FASD. [They also state] successful management of the multiple disorders in FASD is possible” (p. 48). Therefore, it is essential that when these adolescents/adults with FASD are encouraged to participate in programmes or meetings (voluntary or court appointed), consideration needs to be made for the person’s individual needs due to the FASD symptomology. An example of this may be when a parent with FASD is required to attend a parenting programme. This programme would need to involve a small group of people, and the teaching would need to be quite concrete and presented at a slower pace than normal (Herrick et al., 2011). Potential interventions at this stage of life would need to include developing their problem solving, decision making and behaviour regulation skills (Paley & O’Connor, 2011).

Caregivers

A stable home results in better outcomes for the person with FASD (Thomas et al., 2010). Children with FASD symptoms often experience hyperactivity, inattention and conduct issues. This behaviour can be stressful for the parent/caregiver. Therefore intervention needs to include caregivers developing effective strategies for managing the person with FASD behaviour. When caregivers use these strategies, the relationship between child and caregiver will improve (Paley & O’Connor, 2011). An example of such a programme is operating in the US called Families Moving Forward (FMF). The aim of this programme is to increase the parents’ effectiveness and decrease the child’s negative behaviour. This programme sees the need to change the environment which triggers the child with FASD. The strategies taught also need to be used in the school and community setting. The FMF programme consists of 16 home visits sessions over a nine to eleven month period. By improving the efficacy of parenting strategies, the caregiver becomes more aware of what their family needs, increases their self-care and results in improvements in the child’s behaviour (Paley & O’Connor, 2011). The studies conducted in Finland by Fagerlund and colleagues (2012) concur with Paley and O’Connor (2011) in relation to the need for family intervention. During their studies, they interviewed a small group of caregivers, both biological parents and foster parents. They found the children who remained with their biological parents did much better than those in foster care. However, implementing support

as early as possible is essential, as often the home environment can be stressful and attachment between child and parent can be inhibited (Fagerlund et al., 2012).

Barriers to Intervention

When considering interventions, barriers to accessing these interventions must be discussed. Paley and O'Connor (2011) highlighted that mothers often experience stigma and judgement about consuming alcohol while pregnant. Mothers may also not want to disclose due to fear of having their child uplifted by welfare services. This environment makes it difficult for the practitioners to get an accurate picture of alcohol consumption. Paley and O'Connor (2011) also state that practitioners can also have negative attitudes to FASD diagnoses as they believe diagnosis does not necessarily change anything for the person. This was evident in the ANZ context where conversations with a teaching specialist who worked with staff who had behaviour disordered children in their class rooms (personal communication, January 14, 2016), and a social worker from youth mental health specialities (personal communication, July 22, 2016). Both professionals reflected this attitude by stating that once having a diagnosis for FASD, what do you then do with these children as no specialist service is available. It is important to acknowledge that this attitude is not held by all frontline staff.

Petrenko and colleagues (2014) state that when a “lack of knowledge contribute to multi-system barriers including delayed diagnosis, unavailability of services, and difficulty qualifying for, implementing and maintaining services, FASD is a major health problem” (p.1496). Therefore, educating all professionals especially at the frontline of services is essential so that barriers can be addressed and people who have not been diagnosed or wrongly diagnosed will be supported to go for a full assessment and potential interventions will be put in place (Paley & O'Connor, 2011). Previously in ANZ many frontline professionals were working with children and families with FASD symptoms, but few had the specific training to recognise FASD symptoms (Rogan & Crawford, 2013). As awareness is growing, and frontline workers are becoming educated to be able to identify FASD symptomology, referrals are being made so that the child and caregiver can get the appropriate assessment and diagnosis. Following this a comprehensive plan can be put in place so that the person's particular challenges can be addressed and they can live to their fullest potential (MoH, 2016).

Theme Three: Mesosystem and Exosystem - A multidisciplinary approach to assessment and diagnosis across the lifespan for those with FASD

The international literature identifies the importance of a multidisciplinary team (MDT) approach when providing a diagnosis to a person with FASD symptoms. A young person with potential FASD symptoms can have impairment in many areas of function. These areas can include cognitive, emotional, behavioural, academic and social functioning (Green, 2007); along with other cumulative factors such as parents struggling with their own addictions, domestic violence, poverty issues and unsuitable home environments for the child. Olson et al. (2007) state “cumulative risk could be especially harmful for a child made biologically vulnerable by prenatal alcohol exposure” (p. 182). Chapter Two highlighted that FASD is an umbrella term overarching a specific diagnosis (Chudley et al., 2005) that includes intellectual, behavioural, environmental features of the individual. The strength of a MDT is that each discipline investigates the person’s different areas of functioning including physiological, psychological and environmental factors. A MDT generally consists of a paediatrician who specialises in FASD, psychologist, social worker, speech and language therapist, and occupation therapist (Chudley et al., 2005; Rogan & Crawford, 2013).

A MDT assessing a child who is cared for by their biological mother must consider attachment issues. If the mother’s alcohol consumption was at high levels during her pregnancy, this is likely to impact negatively on the attachment between her and her newborn child resulting in an unstable platform to build future relationships (Fagerlund et al., 2012). Potentially, the child psychologist in the MDT will focus on this issue.

A MDT must give attention to who supports the caregivers. Caring for a child with FASD can be extremely draining due to the child’s cognitive and behavioural challenges (Fagerlund et al., 2012). Herrick, Hudson and Burd (2011) also highlight that interventions include caring for the caregiver too. This can be achieved by supporting them to stay physically and mentally well by attending support groups and having a sound network of family and friends. Also, respite care being put in place will support families to manage long term (Herrick et al., 2011). Often it is the social workers role to consider environmental factors and assess the needs of those who are caring for the primary client (the person with FASD).

As already mentioned caregivers are not always biological parents. Foster care and adoption arrangements can be especially challenging for those caring for a child with FASD. These arrangements can be informally made with extended family, by legal adoption or court appointed. It is not a surprise that children with FASD are over represented in this population. Paley and O'Connor (2011) highlight a study with children who have had PAE experiencing multiple foster care placements. This can be due to children with FASD having extremely challenging behaviour for caregivers to manage which can result in the child being moved as the caregiver cannot, or chooses not to, continue with the placement (Paley & O'Connor, 2011). When a MDT is creating an intervention plan, they need to consider all aspects of the child's life so that extensive supports are placed around not only the person with FASD but the caregivers, teachers and support workers. This is to provide the best environment for the child with FASD to develop positively (Chudley et al., 2005).

Likewise, in the ANZ context, a MDT framework has been developed for working with school-aged children presenting with FASD symptoms. The Ottawa Charter for Health Promotion was utilised as "the framework allows factors underpinning health inequalities to be approached ecologically" (Rogan & Crawford, 2013, p. 174). Therefore, within the assessment teams developed within the District Health Boards (DHB), there are a wide range of professionals involved in the assessment, diagnosis and intervention process. These include a "paediatrician, psychologist, an occupational therapist, a speech and language therapist, and social workers" (Rogan & Crawford 2013, p. 176). Each of these specialists brings their area of expertise in assessment to collect information so as to provide a holistic picture of what is happening for a child and their family. Once the information is gathered and a report of findings is written, this then is shared with people in the child's wider context including parents/caregivers, teachers and other community workers involved with the family. This is in order that the significant people in the child's world have a clear understanding of the child's struggles and gaps of functioning, and so that a plan of intervention can take place and all working with the child with FASD moves forward positively (Rogan & Crawford, 2013).

Theme Four: Macrosystem - Aotearoa New Zealand policy implications

The international research on interventions for people across the lifespan who are affected by FASD sets a sound platform for the way ahead in ANZ. ANZ is not exempt from the rising concern of the potential damage alcohol can have on the unborn child while in utero. Women consuming alcohol while pregnant, knowingly or unknowingly, can result in a child sustaining permanent brain damage which can impact upon them physically, psychologically and socially. As these children grow into adulthood they need to learn new strategies so they can live a fulfilling life and contribute to society.

In the last ten years awareness has grown amongst individuals, community groups and clinicians regarding this cohort of people. Specialised attention and intervention is required to avoid those affected by PAE developing secondary conditions which can lead to devastating effects for themselves, family/whānau, community and the wider society (Herrick et al., 2011).

In 2003 the Alcohol Liquor Advisory Council (ALAC) formed a group called the Aotearoa National Advisory Group on FASD. This group included a wide range of interested parties from parents and caregivers to clinicians and researchers. This group presented a national strategy to the MoH in 2015. Other groups contributing to policy development include Fetal Alcohol New Zealand (FANZ) who were disestablished in 2003, Fetal Alcohol Support Trust (FAST) who was established in 1998 and who continues to work with families with people with FASD by giving support, sharing information and advocating, along with referring people for diagnosis. ALAC also established a national FASD day which is on the 9th September, to raise awareness of FASD in ANZ. In 2010, Alcohol Healthwatch (AHW) made a series of recommendations to government which included creating MDT's, developing FASD diagnostic guidelines, training for clinicians and the community workforce that support individuals with FASD and their family/whanau (Alcohol Healthwatch, 2010).

In early 2016, the government called for submissions from individuals and groups who were concerned that this cohort of people are not understood and do not access the help and support they need. Of the 150 submissions received: 76 were from individuals and 74 were from groups or organisations. A working party analysed these submissions and an Action Plan was submitted to government, approved and released to the public in August 2016.

This action plan, 'Taking Action on Fetal Alcohol Spectrum Disorder: 2016 – 2019', is divided into an overarching goal, eight principles, four priorities and ten action areas. The overarching goal is that "FASD is prevented and people currently living with FASD and their family/whanau live the best possible lives" (MoH, 2016, p. 3), (refer to Appendix C). International research supports this goal, as clearly the literature states FASD is preventable, as discussed in Chapter Two (Lewis et al., 2015; Petrenko et al., 2014; Warren et al., 2011). Intervention is reflected in second half of the Action Plan's overarching goal. The endeavour to identify potential infants, pre-schoolers, school age children, adolescents and adults with FASD symptoms so they can be referred for diagnosis and have the appropriate intervention put in place for that particular person and their support people (May & Gossage, 2011; Paley & O'Connor, 2011).

International literature supports the ten action areas. The first area discusses the need to address the drinking culture of this country, particularly the 'at risk' drinking patterns. Chapter One has discussed the international (Herrick et al., 2011) and national literature (James, 2010) on the drinking culture that has developed over the years. ANZ literature reflects the desire to address this drinking culture, as the cost not only comes in financial terms, but also individual, families, community and the whole of society terms (HPA, 2013). Action area two is raising awareness in the community about the risk factors of consuming alcohol while pregnant. While this literature review was focused on intervention and not prevention, it was still evident in literature gathered that prevention is a top priority and that a public health focus needs to be continually addressed to stop the rising rates of children being born with FASD (Petrenko et al., 2014; Popova et al., 2016; Reid et al., 2015).

Action area three refers to primary care services being equipped with screening and brief intervention tools to be able to recognise FASD symptomology. International literature supports this area of development. Education for the primary care workers is essential so children with FASD symptoms can be identified and sent for assessment as early as possible (Paley & O'Connor, 2011; Reid et al., 2015). The literature review conducted by Research NZ (2014a) reports that 78% of frontline health care providers do discuss alcohol use with women who are pregnant, but they also report to barriers in conducting screening questions. They stated the barriers include: when a practitioner assumes there is not risk; or the relationship between practitioners and client is new; or if there is a drinking issue, the question arises about where do they refer the women to for help (HPA, 2014a). For example,

a first time mother (25 weeks pregnant) stated that she was told by her practice nurse once the pregnancy was confirmed that drinking a couple of drinks each week will not harm the baby (personal communication, November 9, 2016). In a conversation with a nursing educator and ex addictions worker, this professional stated a very strong opinion that research states some drink does not hurt the unborn child (personal communication, November 10, 2016). These two conversations are exemplars of the level of misunderstanding and conflicting viewpoints in relation to FASD and therefore the potential in the need for sound advice is either being misdirected or non-directed.

Specialist women's services have been highlighted in action area four and five. Health services addressing sexual and reproductive health, along with access for women to addiction services, has been considered in the action plan. Both service areas have potential for education and screening of women who are seen in the 'at risk category' of having children with FASD. This focus is also identified clearly in international literature due to the high rate of unplanned pregnancies that occur throughout the world (May & Gossage, 2011). ANZ's unplanned pregnancy rate was reported at 40% by the MoH (2009) following a longitudinal study of a cohort of "6,822 mothers and their children" (HPA, 2014a, p. 25). However, The Salvation Army Social Policy and Parliamentary Unit, State of the Nation Report – Moving Targets, released in February 2016, reports a decline in unplanned pregnancy rates, along with a decline in abortion rates over the last five years. This is attributed to a number of issues, including education programmes along with family and welfare influences (Johnson, 2016).

Action area six and seven discuss the importance of professionals and clinicians responding appropriately to people with FASD and that they are trained to facilitate an appropriate assessment and to diagnosis FASD. Rogan and Crawford (2013) identified DHB's having trained specialists in this area and using the FASD guidelines from Canada. The Health Promotion Advisor at Alcohol Healthwatch has confirmed seven of the 20 DHB's in ANZ have received clinical training and been offered follow up mentoring and workshops by the FASD Centre Aotearoa, a private consultancy who facilitate their clinical training. DHB's involved to date are: Taranaki, Hawkes Bay, Northland, Nelson Marlborough, Bay of Plenty and Waitemata. Currently Auckland, Manukau, Waikato and Canterbury DHB's are interested but not using the Canadian diagnostic tool (personal communication, December 13, 2016). However these DHB's have limited capacity for referrals due to financial constraints.

Noticeably, all except one DHB involved come from the North Island. This raises the question of those children, young people, adolescent and adults who have not yet been diagnosed, along with their family/whanau who need access to these services throughout ANZ. International research readily highlights educating professionals regarding FASD screening, assessment and diagnosis as a priority throughout the world. Often these people go undiagnosed or wrongly diagnosed and then carry with them the stigma associated with negative labels due to their behaviour (Herrick et al., 2011; Petrenko et al., 2014).

A collaborative approach to assessment is essential to gather all the data possible in relation to impairment due to PAE. Agencies working in partnership to provide well thought out pathways for the person with FASD as well as supporting the family/whanau and/or caregiver is reflected in action area eight and nine. International research shows a strong emphasis on the importance of MDT's when assessing and diagnosing people across the lifespan. Also, consideration is not just given to the individual or primary client, but to the whole system that surrounds them including the extended family/whanau, child's teachers or the adult's support workers (Fagerlund et al., 2012; Green, 2007; Reid et al., 2015).

Finally, action area ten highlights the need for further research in relation to prevalence rates of FASD in ANZ, along with developing understanding of neurological damage that takes place due to PAE. All articles considered for this literature review stated the need for further research to be conducted in specific areas relative to the study being discussed. As research continues around the world, a body of evidence based knowledge will continue to inform screening, assessment, diagnosis and intervention for those affected by FASD across the life span.

Two areas of concern have been identified when aligning the FASD action plan with international research. The first concern is funding. In 2013, Rogan and Crawford highlighted a barrier to the diagnosis of FASD in ANZ being that no additional funding was being made available, especially for training of specialist services. However the Honourable Peter Dunne, the Associate Minister of Health, stated in his speech on August 16, 2016 when releasing the action plan:

Specific funding has already been allocated to a number of actions identified in the Plan. \$12 million over four years for intensive alcohol and drug support for pregnant women was allocated in the 2016/2017 Budget. An additional \$1 million was invested

via Criminal Proceeds recovery to develop tools and training for frontline professionals and build New Zealand's evidence base. (New Zealand Government, 2016, para. 5).

However no mention is made regarding financing diagnosis and intervention for those who already have FASD. An article just released from the Dunedin longitudinal study of 1,037 New Zealanders over a 38 year period has highlighted investing in early intervention programmes for children who present with risk factors such as growing up in a “socioeconomically deprived family, exposure to maltreatment, low IQ and poor self-control” is not only positive for the child and their family but is also cost effective in the long term (Caspi et al., 2016, p.1). As the researchers have stated, if a child with risk factors is treated while young this will avoid potentially poor adult outcomes and will benefit ANZ society in the long term.

The second challenge identified was the government response to the indigenous people (Māori) of ANZ. The action plan makes reference to Māori people by weaving the word ‘whanau’ into the document, but does not have a specific focus on Māori people. Statistics in relation to ANZ’s indigenous people often reflect negatively and/or in the context of deprivation in areas including poverty, homelessness, unemployment, teenage pregnancies, domestic violence and alcohol consumptions. Statistics include Māori women consume high levels of alcohol (MoH, 2015a). Therefore in the context of current research of FASD prevalence rates in other indigenous groups it is essential that the ANZ FASD action plan considers Māori women as a significant group to work with to reduce FASD rates in future Māori children.

International research has shown that indigenous people are presenting with high rates of FASD. Some of these rates were discussed in Chapter Two, referring to South African cape, coloured communities (Dörrie et al., 2014), Brazil’s high prevalence rate (Lewis et al., 2015) and aboriginal communities in Australia (Reid et al., 2015). This chapter also highlighted, that in ANZ, Māori women are consuming alcohol while pregnant at rates 15% higher than European and other women (MoH, 2015b). Although statistics are not available on prevalence rates of people with FASD in ANZ, this suggests that Māori women are more at risk due to the higher rates of alcohol consumption. Therefore, more in-depth research is

required to gain understanding of how to work in partnership with Māori to address this area of concern.

Summary

Findings from the literature highlighted five key themes: a drinking culture that has developed over time; risk factors for the unborn child; the importance of early diagnosis and intervention for a child with FASD; a multi-disciplinary approach to assessment and diagnosis across the lifespan for those with FASD; ANZ policy implications. These themes were considered through the framework of Bronfenbrenner's Ecological Systems Theory. Theme one was discussed in Chapter Three under the chronosystem. The second and third themes explored the individual system through to the exosystem with a focus on risk factors, early detection of symptoms, referral, assessment and intervention using a MDT approach. The last two themes explored were from a macrosystem perspective, focusing on policy implications, especially in the light of the recent 'MOH Action Plan on FASD' released in August 2016. A critique of the 'Action Plan' highlighted the gap of funding screening through to intervention and working in partnership with Māori.

Chapter 5: Conclusions and recommendations

Introduction

The aim of this narrative literature review was to answer the research question: What challenges do the Aotearoa New Zealand community face when supporting families who have a child displaying Fetal Alcohol Spectrum Disorder (FASD) symptoms? This chapter provides a summary of the findings from the literature review using the Bronfenbrenner's framework. Implications for the ANZ context will be highlighted throughout this chapter, along with recommendations for future research. Limitations to this paper will be noted and finish with a closing comment from the author.

Chronosystem: A drinking culture that has developed over time

People consuming alcohol has been recorded throughout the centuries, however; there is little evidence that Māori consumed alcohol prior to the colonisation of ANZ. As the explorers and early settlers came to ANZ, so did alcohol (Hutt, 1999). During the 21st century many New Zealanders chose to consume alcohol moderately or not at all, but there are some whose consumption of alcohol has become problematic and costly to society through issues such as road accidents, domestic violence and health (HPA, 2013). These issues not only have an impact on the individual, but also on the family, community and society as a whole. Alcohol being consumed by pregnant women has contributed to PAE, in turn leading to FASD symptoms in newborn children. Although ANZ has no current prevalence rates of FASD it is estimated that 170 children may be born with FAS each year (MoH, 2015b). When these children go undiagnosed without intervention put in place for them, their caregivers and those who work directly with them, they potentially will develop secondary conditions which become a high burden on them, their family and society.

Rogan and Crawford (2013) highlight intervention is essential for those children with FASD and their families and they emphasise the importance of prevention strategies to convince women not to consume alcohol while pregnant. The FASD Action Plan recommends targeting addiction services that are treating women in their childbearing years. However, consideration must be given to implementing a Public Health model to address the drinking culture in ANZ. This would mean a holistic approach to change would occur for Māori and non-Māori, male and female alike (Signal & Ratima, 2015). Therefore future research into applying a Public Health model to FASD in the ANZ context would be beneficial to address the drinking culture in ANZ.

Individual System: Risk factors for the unborn child

Literature has highlighted that there are a number of risk factors for the unborn child having permanent brain damage due to the woman consuming alcohol while pregnant. These risk factors include the woman's environment being: of low social economic status; causing the woman to have a poor nutritional intake; which results in the woman having a low body mass index. These risk factors can lead to a deficit environment for the unborn child to develop in (May & Gossage, 2011). However, alcohol consumption while a woman is pregnant, or planning to become pregnant, is the single indicator of the likelihood of FASD occurrence.

It is encouraging to see the funding attached to the FASD action plan targeting maternity services. However, this does not address the fact that alcohol is often consumed before a woman knows she is pregnant. Therefore, funding is too late for prevention purposes. Consideration must be given to invest in training frontline workers in community services to recognise potential risk factors in the women they meet daily for others reasons. These frontline workers (in all fields) need to be equipped to provide education about the potential of FASD in future children if they choose to consume alcohol when pregnant.

Future research on attachment was also recommended by Fagerlund et al., (2012). Often children with FASD symptomology are born into unstable environments for many reasons. Fagerlund and colleagues (2012), in their Finnish study raise the question of impaired attachment with either the biological mother or caregiver. However, little study to date has been conducted on attachment between a child with FASD and their primary caregiver. It is suggested that research conducted in ANZ regarding attachment between a child with FASD and their caregiver would be valuable to inform intervention programmes for this cohort of people.

Microsystem: The Importance of early diagnosis and intervention for a child with FASD

FASD is an umbrella term which includes four main diagnostic criteria. This diagnosis covers a large range of symptoms including social, behavioural and intellectual deficits resulting from PAE (Warren et al., 2011). The literature has highlighted that the earliest possible diagnosis and intervention for a child with FASD will produce the best outcomes for not only the person, but for those who support them (Paley & O'Connor, 2011). A child with FASD symptomology who remains undiagnosed and has no intervention is at

risk of developing secondary conditions as they grow. This will inhibit them living to the fullest of their potential (Herrick et al., 2011). Therefore it is essential for frontline professionals to be educated in being able to identify FASD symptoms so they can refer their client for assessment.

The current average age of diagnosis in ANZ is eight years of age (Rogan & Crawford, 2013). International programmes indicate earlier diagnosis and intervention is essential for better outcomes, although this research acknowledges there are very few programmes developed for preschool children (Olson et al., 2007). Therefore, future research on current early intervention programmes with at 'risk' families, such as Early Start Project would be valuable. This would provide the opportunity to determine the validity of such a programme with this group of pre-schoolers with FASD and their caregivers/whānau.

Consideration also must also be given to those young people who are slipping through the system, potentially labelled as 'naughty children', due to frontline practitioners being unaware of FASD symptoms. Therefore training for these frontline workers in education, health and social services is essential so they can identify FASD symptomology in children they work with and referrals be made. At present awareness is increasing through the FASD action plan and some frontline workers are becoming better informed, however many still do not recognise FASD symptoms. Therefore a continued drive to promote and provide education will improve the current and future outcomes for the individual, their family/whānau, the community and society as a whole.

Mesosystem and Exosystem: A multidisciplinary approach to assessment and diagnosis across the lifespan for those with FASD

The literature reviewed confirmed that an individual diagnosed with FASD needs to be assessed in the context of their community. A MDT approach to the assessment process provides a comprehensive enquiry to understand what that specific child's needs are, so the best plan can be put in place for all involved in the child's life (Chudley et al., 2005). People, young and old, with FASD symptoms present with deficits in multiple domains of functioning. There are no typical symptoms of FASD as damage to the fetus will be determined by the timing, frequency and amount of alcohol the woman consumed while pregnant (May & Gossage, 2011). Once assessed and diagnosis is confirmed the MDT will provide the individual (if old enough and able to understand), their caregiver and other

professionals involved with an intervention plan. Included in this plan is support for the caregiver as caring for a person (young or old) with FASD can be extremely stressful.

International research provides ANZ with a platform to develop effective strategies for those who have FASD and for their caregivers. Paley & O'Connor (2011) discuss the Family Moving Forward Programme, which helps the caregiver provide a stable living environment for the person with FASD. This programme would be important to consider when developing programmes for the ANZ context. One such programme in ANZ is called 'Fostering Kids' where they provide support and educational opportunities throughout ANZ for families who foster children. Future initiatives could consider in this research, a MDT steering committee developing a programme like this for biological families.

Macrosystem: New Zealand policy implications

Individuals and groups have advocated for a change in policy and funding in response to the challenges faced by families/whānau living with people with FASD. The ANZ Government has responded by releasing 'Taking Action on Fetal Alcohol Spectrum Disorder: 2016-2019', released in August 2016 and has committed a \$12 million budget to implement the action plan. However, as discussed, this funding is provided for addiction support for pregnant women. Therefore, funding also needs to be provided to implement action areas on assessment, diagnoses and planned interventions for those with FASD and their support networks.

When considering ANZ policy implications a significant gap and area of future research is with Māori. Māori women currently consume alcohol at a rate 15% higher than other ANZ ethnic groups (MoH, 2015b) giving a higher forecasted prevalence rate of FASD in their children. Literature has reported on programmes that have been successful with other indigenous groups including the Aboriginal communities in Australia (Reid et al., 2015); Cape Coloured South African children; (Lewis et al., 2015) and Brazil's indigenous people (Esper & Furtado, 2014). More in-depth research of these programmes would be beneficial, as would the application in the ANZ context. Firstly though, consultation with Māori is essential as already a number of health promotion models are well developed which include a Māori worldview, their values, principles and processes to follow (Signal & Ratima, 2015). The 2014 statistics showed ANZ as having a rich mix of ethnic people: "74 per cent

European, 14.9 per cent Māori, 11.8% Asian and 7 per cent Pacific” (Signal & Ratima, 2015, p. 169) with many people relating to more than one culture. This must be considered when developing policy and programmes for those affected by FASD as each culture brings their unique worldview.

Limitations of this study

The limitations of this study include:

- There were many related articles that were not able to be included because the narrow focused area of research limited their inclusion.
- The nature of this small scale dissertation being limited in scope therefore, this work does not provide a holistic review of all contributing factors of FASD. The focus has been on interventions.
- Another limitation includes using the American word ‘fetus’ in the literature search and not including the English spelling of ‘foetus’ may have eliminated useful articles to consider.
- The final limitation to consider is that only a small number of ANZ studies are available which meant it was difficult to provide an ANZ perspective on FASD.

Final Comments:

A two pronged approach to FASD must be considered. Firstly, public health education regarding the potential danger of consuming alcohol while pregnant must be delivered to all parts of society. Secondly, for those people (throughout the life span) who have potential FASD, resources must be made available for screening leading to early referral, diagnosis and effective interventions to be put in place so these people can live the best quality life possible and make a valid contribution the community in which they live. Further consideration must be made at all levels of the ecological system to bring about change for the unborn child, the pregnant woman, those who care for people with FASD, the community in which they live, which will in turn be of benefit to the whole of society.

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Appendix A: Main maternal reported risk factors related with Fetal Alcohol Syndrome

Risk factors

Social demographic

Older age at the birth of the child with FAS (≥ 28 years)
Lower educational level
Marital status: single during pregnancy
Unemployment during pregnancy
Less religious women
Rural residence
Lower income

Psychiatric and neuropsychological factors

Psychiatric morbidity
Cognitive impairments typical in FAS (memory, judgement, learning, abstraction and reasoning)
Suicide attempts
Stress
Physical aggression or sexual abuse

Family

Other children with FAS or with any impairment associated with alcohol abuse during pregnancy
Other family members with alcohol abuse (siblings, maternal father and/or mother)
Partner or father of the child with FAS with alcohol abuse

Substance use and health

Use of tobacco during pregnancy
Use of illegal drugs
Lower weight, height and body mass index

Pregnancy

Less prenatal appointments
Younger age during pregnancy
Late prenatal care
Restriction of uterus growth
Complications during pregnancy and miscarriages
Gravity >3
Parity ≥ 3

Pattern of alcohol consumption

Higher consumption before and during pregnancy
Non-reduction of consumption during pregnancy
Higher current alcohol use
More binge drinking during pregnancy
More weekdays of alcohol consumption
Early age when first drank alcohol and began drinking regularly

Adapted from "Identifying maternal risk factors associated with Fetal Alcohol Spectrum Disorders: a systematic review," by Esper, L., & Furtado, E. 2014., *European Child & Adolescent Psychiatry*, 23, 877-889. doi: 10.1007/s00787-014-0603-2

Appendix B: Developmental aspects of FASD: age-related frequent symptoms

Newborn period and early infancy	Early childhood	Middle childhood	Adolescence	Adulthood
Growth deficits (head circumference, weight, height, BMI)	Growth deficits (head circumference, weight, height, BMI)	Growth deficits (head circumference, weight, height, BMI)	In addition to the symptoms occurring in childhood:	In addition to the symptoms occurring in childhood and adolescence:
Feeding difficulties, irritability	Talkative, intrusive	Inattention, hyperactivity, impulsivity	Poor understanding of abstract concepts	Reducing daily living skills
Sleep disturbances	Friendly, short-tempered	Poor understanding of social interactions	Dropping out of school or training programmes	Impaired peer relationships
Congenital anomalies: Heart defects, limb deficiencies, dys- or hypoplastic kidneys, oral cleft, skin lesions, ocular conditions	Hyperactivity	Impaired functional communication skills: reduced language comprehension	Vulnerability to the influence of others, poor judgment	Susceptibility to victimisation (physically, sexually and emotionally)
	Language development disorder: receptive and expressive deficits	Deficits in executive functioning, poor organisation	Conduct disorder	Unemployment, precarious employment
	Comorbid attachment disorder	Impaired coordination and postural control	Delinquency	Delinquency
Epilepsy or seizures	Poor fine and/or gross motor skills	Memory deficits in learning and recall of place learning, verbal and non verbal information, numbers		Psychiatric disorders: ADHD, mood disorders, panic disorder, substance use disorder including alcohol use disorder

Adapted from “Developmental aspects of FASD: age-related frequent symptoms” by Dörrie, N., Föcker, M., Freunsch, I., & Hebebrand, J. (2014). Fetal alcohol spectrum disorders. *European Child & Adolescent Psychiatry*, 23(10), 863-875. doi: 10.1007/s00787-014-0571-6

Appendix C: Taking Action on Fetal Alcohol Spectrum Disorder: 2016-2019

Goal

FASD is prevented and people with FASD and their Family/ whānau live the best possible lives

Principles

Prioritise prevention	Destigmatisation
Achieve equity of access and outcomes	Collaborate to achieve a collective impact
Focus on supporting families and whānau	Build on strengths
Take a whole-of-government approach	Invest in sustained, systemic change

Priorities

Prevention

Families and whānau understand the risks of drinking during pregnancy and are supported to have healthy, alcohol-free pregnancies.

Women with alcohol and drug issues are consistently receiving proactive, practical and non-judgemental support to improve their health and wellbeing and effectively reduce their risk of having a child with FASD.

Early identification

People with neurodevelopmental impairments are identified early and receive timely and effective assessments from FASD capable teams.

Support

People and their families, whānau and caregivers receive timely, joined up support tailored to their needs, strengths, age and stage.

Evidence

There is an improved New Zealand evidence base so we can make good decisions, effective investments and monitor outcomes and progress.

Action areas

- 1** Increase collaboration and coordination to better support the activities aimed at shifting New Zealand's drinking culture and targeting harmful alcohol consumption.
- 2** Develop and disseminate clear, unambiguous and consistent messages to increase the whole community's awareness of the risks of drinking during pregnancy, including FASD.
- 3** Support primary care to provide high-quality, responsive and equitable maternity care, including screening and brief intervention for alcohol.
- 4** Increase access to equitable and culturally competent sexual and reproductive health care.
- 5** Increase access to support and specialist services for women with alcohol and drug issues.
- 6** Enhance the ability of frontline professionals to recognise and respond effectively and compassionately to people with FASD and other neurodevelopmental impairments.
- 7** Improve the capability of clinicians to diagnose FASD.
- 8** Improve cross-sector collaboration and capacity to provide effective assessments for people showing signs of significant neurodevelopmental impairment.
- 9** Develop a coordinated, consistent, accessible and appropriately resourced pathway for supporting affected people and their families, whānau and caregivers.
- 10** Conduct research into the incidence of FASD and other neurodevelopmental impairments in a New Zealand cohort.

Adapted from "Taking Action on Fetal Alcohol Spectrum Disorder: 2016-2019 An Action Plan." Retrieved December 13, 2016 from <http://www.health.govt.ANZ/publication/taking-action-fetal-alcohol-spectrum-disorder-2016-2019-action-plan>