

Faculty of Health Sciences

**Understanding Fetal Alcohol Spectrum Disorder (FASD) through
the Stories of Nyoongar Families and how can this Inform Policy
and Service Delivery**

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**This thesis is presented for the Degree of
Doctor of Philosophy
of
Curtin University**

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Declaration

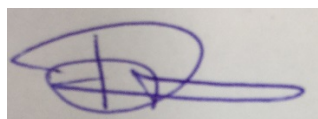
To the best of my knowledge and belief this thesis contains no material previously published by any other person except where due acknowledgement has been made.

This thesis contains no material that has been accepted for the award of any other degree or diploma in any university.

The research presented and reported in this thesis was conducted in accordance with the National Health and Medical Research Council National Statement on Ethical Conduct in Human Research (2007) – updated March 2014.

The proposed research study received human research ethics approval from the Curtin University Human Research Ethics Committee Approval Number (EC00262).

Signature:

A handwritten signature in blue ink, consisting of several overlapping loops and a long horizontal stroke extending to the right.

Date: 30.05.2018

DEDICATION

In loving memory of our sister
Lynette Gail Heir (nee Williams)

14.5.68 – 8.11.16

You inspired us all and was everything strong and loving that is family
Forever our communicator

and for our brother

Marja Man

27.11.60 – 22.7.14

You lived your life with undiagnosed FASD, and adversity walked with you every day, and still you taught us how to love, laugh and care for family

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ABSTRACT

Fetal Alcohol Spectrum Disorder (FASD) is a serious mainstream global health problem and is the leading cause of preventable intellectual disability in the world. Furthermore, FASD is an irreversible disability caused by prenatal alcohol consumption, with a range of serious effects including, but not limited to; neurodevelopmental abnormalities including cognitive and executive functioning, central nervous system, and organ damage. Whilst, significant research on FASD has been undertaken over the past 40 years, there remains gaps in expertise relating to FASD prevalence and interventions. Furthermore, Australia remains well behind countries such as Canada in terms of diagnostic capacity and service delivery. Without FASD diagnosis and intervention there is a clear consensus of the negative life trajectory for individuals with FASD, including high prevalence of mental health (risk of suicide), ongoing recidivism and remaining one of the most vulnerable groups in society throughout the world.

This thesis applied a mixed methods approach, including qualitative and quantitative and was underpinned by Indigenous Standpoint theory and an established Critical Reference Group consisting of Aboriginal and non-Aboriginal people. The aims of this research were two-fold: to record the experiences of families caring for Aboriginal children with FASD in the south west of Western Australia; and to explore the level of awareness of FASD amongst the Aboriginal community. The sites of data collection included Perth and the country towns of Northam, Albany, Bunbury, Tambellup and Katanning. A total of 180 Aboriginal men and women aged from 16 years upwards participated in the survey developed for this project. In the qualitative aspect, six families including 3 relative carers and 3 foster carers were interviewed on their experiences in raising Aboriginal children with FASD. In total the six families cared for 9 Aboriginal children with FASD, and three of the families cared for siblings with FASD.

The findings of this study support the baseline of international evidence of children with FASD coming into care earlier and staying longer than any other children in OOHC; and families cared for the children with none or little respite and support, and

had received no training in FASD. Further, the social and financial impact on families raising children with FASD in this study was profound and none of the families were able to remain a two income family. There is also clear consensus of the significant economic cost of FASD to society, and exorbitant funds and resources to be saved by investing in diagnosis and services whilst children are young. In terms of children it is critical to be aware of FASD to avoid misdiagnosis and incorrect treatment plans that may exacerbate the disability. In terms of adults, it is critical to adapt all aspects of services applicable such as parenting programmes, alcohol and drug treatment, mental health, primary health approaches, employment programmes and supporting adults with FASD to parent their children and to have the potential to break the cycle of what is now being recognised as generational FASD, and multiple cases of FASD within the one family.

Whilst, FASD is a mainstream concern, for Indigenous people, FASD exists against the backdrop of colonisation, stolen generations, and systemic racism. Literature identifies it is critical that interventions on FASD for Indigenous people are decolonised and led by Indigenous people and agencies. Much attention is given to the fact that FASD is completely preventable, whilst theoretically correct, more attention and resources would be better focussed on the reasons for risky consumption of alcohol by women, and the insurmountable barriers preventing women from seeking help. The findings of the literature review and this study highlight the need for the urgent adaptation of services in consideration of undiagnosed FASD amongst children and adults.

Stigma, social discourse and lack of FASD awareness contributes to the barriers in urgent reforms necessary in policy and service delivery for the population with FASD throughout the world. In this context, FASD training, awareness, adequate policies and resources are critical across jurisdictions such as health, criminal justice and education. The key findings of this study identified culturally secure health service delivery on FASD for Aboriginal people and the preferred delivery was in community forums or small groups, and one on one. This is imperative as FASD is a sensitive topic and identified culturally secure approaches will ameliorate feelings of stigma; and promote a “no shame and no blame” approach within the community.

CONFERENCE PRESENTATIONS

International Conference Presentations:

- Our Gurlonngas, Our Future; Fetal Alcohol Spectrum Disorder (FASD): How relevant is a trauma informed approach in Perth, Western Australia?” Presented at Winnipeg, Manitoba: Living Well FASD and Mental Health Conference; and the International Network of Indigenous Health Knowledge and Development Conference: Canada (2014).
- International Indigenous Health Knowledge and Development Conference (Winnipeg, Manitoba). University of Calgary (Post Graduate Students)

Key note presentations:

- Understanding Fetal Alcohol Spectrum Disorder (FASD) and how may this inform policy and practice. Secretariat of National Aboriginal and Islander Child Care (SNAICC); Annual General Meeting, November 2016. Victoria
- Shifting Expectations ~ Understanding FASD and the ways forward: WA Aboriginal Alcohol and other Drug Worker Forum: April 2016

National Presentations:

- Foetal Alcohol Spectrum Disorder, Juveniles and the Criminal Justice System. Presented at the National Judicial College of Australia: Sentencing: New Challenges. 2018. Australian National University. Canberra.
- National Indigenous Incarceration Conference, Brisbane. FASD in an Aboriginal community. 2018
- Opening Pandora’s Box: Fetal Alcohol Spectrum Disorder (FASD) and Out of Home Care. (2017). Secretariat of National Aboriginal and Islander Child

Care. SNAICC National Conference, Canberra.

- Fetal Alcohol Spectrum Disorder (FASD) in Nyoongar Country ~ What do we need to know in terms of family, awareness and advocacy? Secretariat of National Aboriginal and Islander Child Care (SNAICC) National Conference, September 2015

Presentations:

- Understanding the impact of FASD on Nyoongar families: Advancing FASD Research Together Research Symposium, Telethon Institute for Kids. October 2016
- Our families living with FASD
Fetal Alcohol Spectrum Disorder Sharing Solutions Institute of Advanced Studies; University of Western Australia, August 2015.
- Fetal Alcohol Spectrum Disorder ~ Tools to work with clients
Social and emotional wellbeing workforce support unit combined regional and statewide forum, May 2015.

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LIST OF ABBREVIATIONS

ADHD	Attention Deficity Hyperactivity Disorder
ARBD	Alcohol Related Birth Defects
ARND	Alcohol Related Neurodevelopmental Disorder
CRG	Critical Reference Group
DCP	Department of Child Protection
DYHS	Derbarl Yerrigan Health Service
FAE	Fetal Alcohol Affects
FAS	Fetal Alcohol Spectrum
FASD	Fetal Alcohol Spectrum Disorder
NGOs	Non Government Organisations
ODD	Oppositional Defiant disorder
OOHC	Out of Home Care
PAE	Prenatal alcohol exposure
PCAP	Parent Child Assistance Program
WA	Western Australia

DEFINITIONS

Gurlongas	Nyoongar word for babies and young children
Maarja	Yamatji word meaning ‘boss’
Nyoongar	Aboriginal people from the south west region of Western Australia
Yamatji	Aboriginal people from the Gascoyne region of Western Australia
Winyarn	Nyoongar word meaning dependant on context, either feeling sick or depressed or having no money

Prologue

A Call for Champions

When I found this out, it was devastating to know, because I didn't want to give up on them, and I didn't want them to give up on life, I didn't want life to keep throwing these curveballs at them, I wanted to give them some hope, and I wanted some hope myself, because it seemed so hopeless. (Relative Carer, 2015)

The silent story of FASD within all our families has been there for many years, waiting to be recognised, and understood by society. FASD was and continues to be misdiagnosed as other disabilities, mental health or remains undiagnosed. Family narratives of FASD must be told to bring forward hope, reforms and a new era of awareness to replace what is too often described as “despair and hopelessness” by families caring for children and adolescents with FASD in Australia.

Imagine the daily adversity that walks with the many who struggle every day with undiagnosed FASD and irreversible brain damage. From a six year old child struggling at school to self-regulate their behaviour, and realising they are “different” to the adult who cannot understand why it is they cannot remember important dates, that have serious consequences such as breaching parole. Imagine, what it is like to feel failure at school every day as a six year old child, and wonder why you cannot control your impulses and behaviour. The six year old begins to feel alone and has trouble keeping friends, and this has an early impact on their self-worth and self-esteem. The adult with FASD lives his or her life always feeling judged and wonders if they will ever be able to overcome the feelings of depression, and why it is they repeat the same mistakes over and over.

In Australia today, the same six year old will still remain at high risk of not being diagnosed as this is dependent on the awareness of those around him/her, and *who will take on the system and advocate for this child?* A diagnosis of FASD, is the catalyst for change and quality of life, whilst the adult will most likely *never* be diagnosed unless they are incarcerated, and someone recognises the pattern of circumstances that point to FASD. Without support and diagnosis, the tragic end for many will be premature death as infants, and young adults.

Every day, those with undiagnosed FASD are failed systematically, and it is their families/carers who will face this adversity with them and struggle to care for them and to keep them safe in the hope they will have some quality of life. Further, due to the lack of awareness of FASD, children will remain at risk of being misdiagnosed and carers will be wrongly informed to complete parenting programmes that do not cater for parenting children with FASD. Their families and carers will struggle against all odds, and the social and financial impact and sacrifices on the family will be profound. Stability of placements of children with FASD will continue to remain at risk of breaking down without respite, and support services.

On many levels, there is a critical amount of urgent work ahead for my own community, and for the mainstream community, at the policy and service delivery level. This in itself *calls for Champions* at every level, to protect those who are the most vulnerable in our community. The intersection of Aboriginality and FASD is even more disturbing, considering systemic racism and lack of services for Aboriginal people. Fetal Alcohol Spectrum Disorder (FASD) is there in our families and communities and with courage, and knowledge we will never not see it again.

Get on to every single service that you can, that's Aboriginal and non-Aboriginal, especially the ones that claim to help people with disabilities, because this is a real disability, no matter what anybody says, no matter whatever box you try and put it into. You have a child that has a mental disability, they have inability to cope or function that normal children do, from a young age it's obvious, that cause and effect stuff is not there with cognitive, they don't understand right or wrong, that they're actually doing wrong, that's why half of the prisons are filled with them, because they don't know what they've done. (Relative Carer, 2015)

I would be saying jump up and down as loud as you can for the child.... stay strong in your instincts, trust yourself, and ask for help, and especially with medical professionals, if at first you don't have success try a different doctor; don't stay with a doctor if you are not happy. Find someone who is actually going to help you and your child (Foster Carer, 2015)

CHAPTER 1

Introduction

Introduction of the researcher

It is an important part of Nyoongar and global Indigenous protocol to firstly introduce myself and my family line (Kickett, 2011; Ardill, 2013, Wilson, 2008). My name is Robyn Williams and I am a Nyoongar woman, and a descendant of Nyoongar and Yamatji people from Western Australia. The boundaries for Nyoongar country includes the South West region of Western Australia and just below the town of Geraldton and the furthest point east before the towns of Coolgardie and Esperance. Nyoongar country consists of fourteen clans and includes Nganda, Amangu, Yuat, Balardong; Whadjuk, Pindjarup, Wardandi, Biblelmen; Minang, Kaneang, Wilman, Nadji Nadji, Wudjari and Njunga. These clans co-existed for many thousands of years and were governed by their own lores and protocols.

Dreamtime account of Nyoongar origins claim that the creator Rainbow Serpent gave life and sustenance to the people who, in return, became caretakers of the land (Van den Berg, 2002, p.26).

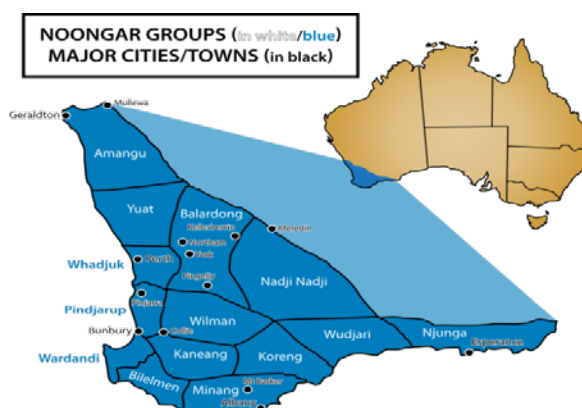


Figure 1: Map of Nyoongar Country

Rationale for the Study

A family's call in 2008

In 2008, I was employed as a Research Officer with the Aboriginal Alcohol and Drug Service (AADS) in Perth, Western Australia. We were privileged to have a visiting international speaker Carolyn Hartness, a Native American from the US, and well

known FASD expert and advocate. Hartness provided a thorough overview of FASD, and myself and several others experienced the light bulb moment, and the sinking feeling of the gravity of what lay ahead of us, and where were we to start and how much was there to learn? It became clear the majority of the workforce and community were in relatively the same position as myself in terms of lack of awareness of FASD. In general terms, the range of FASD awareness ranged from zero knowledge to having heard of FASD previously, but nothing that was understood at any kind of depth. For myself as the researcher, this was to present as one of the most significant challenges in approaching this research project.

What is Fetal Alcohol Spectrum Disorder (FASD)

Fetal Alcohol Spectrum Disorder (FASD) is the umbrella term used to describe the range of serious effects on an infant that may occur following exposure to alcohol during pregnancy and was first published in 2004 (Plevitz, Smith, Gould, 2008). The FASD spectrum includes the following; Fetal Alcohol Spectrum (FAS); Partial Fetal Alcohol Syndrome (PFAS); Alcohol Related Neurodevelopmental Disorder (ARND) and Alcohol Related Birth Defects (ARBD). Partial FAS (PFAS) is based on infants born without the facial characteristics of FAS, and knowledge of mothers' alcohol consumption during pregnancy. These effects may include physical, mental, behavioral and learning disabilities and have lifelong implications (Chudley, Conroy, Cook, Look, Rosales, LeBlanc. 2005). According to Millar (et al, 2017, p.4)

FASD is a permanent neurodevelopmental disorder caused by prenatal exposure to alcohol...FASD results in physical, emotional and intellectual disabilities that are unique to each child and where the effects may exist on a continuum from clinically indistinguishable to very severe (Streissguth & O'Malley, 200).

Diagnosis of FASD is also imperative in educating the mother of the risks of consuming alcohol and preventing another child in the same family being born with FASD (Streissguth, et al 2004). Women who have had a child with FASD are at high risk of having more children affected with FASD (Nguyen, Coppens, & Riley, 2011). It is important to note that all areas of the spectrum of FASD are the result of brain damage that is irreversible. Hellermans, Sliwowska, Verma & Weinberg, (2010, p.1206) states:

All alcohol-affected individuals have permanent brain damage that may have serious implications for academic and vocational success, social inclusion and emotional well-being.

Experts agree that while FASD is irreversible the quality of life may be increased through early diagnosis, intervention and ongoing support (Streissguth, Bookstein, Barr, Sampson, O'Malley & Kogan, 2004). O'Malley, notes (2007, p.12):

Finally, it is equally critical to remember that prenatal alcohol cause effects on organ and system development in the body so co-morbid medical problems are relatively common.....and include structural abnormalities in the eye, ear, heart, kidney, liver and skeletal system.

In some cases literature refers to FAS and PFAS as being the “severe” parts of the spectrum, implying that the remaining parts of the spectrum; FAE (Fetal Alcohol Affects) and Alcohol Related Birth Defects (ARBD) are the “mild” sections of FASD. According to Stanley, (2015), the semantics used such as the terms “severe” and “mild” in describing FASD create misconceptions and confusion about an already complex disability. In a recent criminal justice case an expert witness advised the appellant was not severely affected as his did not have the physical features of FASD (Stanley, 2015). O'Malley (2014, p.242) states:

Alcohol is a teratogenic prenatal neurotoxin that not only differentially affects the structure of the developing brain (eg. The developing hippocampus, cerebellum and corpus callosum) throughout pregnancy, but also critically changes the balance of the developing neurotransmitters.

The elephant in the room/family: FASD

In 2008, I commenced working with a Nyoongar family in a support role, and the family were caring for their two young nephews who were suspected, and later diagnosed to have FASD. After several years of caring for the young nephews under great duress and no support, the carers asked if I would document their story which I found humbling and courageous due to the sensitivity of FASD in the Aboriginal and wider mainstream community. I agreed to this request and felt it was critical for research to commence advocating for urgently needed recognition and changes for carers and children with FASD.

However, with my then limited knowledge of FASD, mixed with a degree of personal denial, I still did not realise the full extent of FASD within my own family. In agreeing to document this family's story on FASD, I had no idea of my own family's story with FASD and that I was about to embark upon a personal journey of shock, denial, loss and grief, healing, learning, acceptance and understanding of FASD within my own

family. The impact of awareness within families is profound and critical to nurturing and protecting children with FASD. Prior to 2008, I had never heard of the term FASD, Fetal Alcohol Spectrum, or Fetal Alcohol Spectrum Disorder (FASD). My first job straight from University in 1997 was at the Office of Aboriginal Health where I was employed as a Research Officer in the Aboriginal health policy unit. From my own experience, the term FASD was not on the radar within this office or anywhere in the wider health arena. I now reflect on the following prior to my new understanding and knowledge of FASD:

1. I had often observed undiagnosed FASD in my own extended family, without knowing what this was, and thought at the time that I was observing sick babies/children and adults with possible mental health disorders that was not related to any particular disability and therefore nothing to further explore and question.
2. I have become aware of FASD and the impact on the individual and family at a late age in my own life. In relation to those family members struggling with undiagnosed FASD, I feel a sense of guilt for not understanding and I could have better supported, rather than disregarding their now obvious patterns of behaviour as just bad behaviour, mental health; childish, and stubbornness.
3. I can now identify the suspected generational FASD within my own family. As a young child, I can recall an older cousin display characteristics/behaviour common to FASD, and then have his own child born with Fetal Alcohol Spectrum (FAS) in the early 1990s. This young child from birth, struggled with severe health problems and at the age of three went into a coma and after a short period on life support passed away. The cause of my nephew's death was never fully explained and for cultural reasons the parents would not allow an autopsy. His passing was a painful and traumatic experience for the parents and our extended family, and at no time was there ever any mention of Fetal Alcohol Spectrum (FAS) or FASD. Consequently, there appeared to be nothing to learn from this tragic passing of a young life, in terms of what damage was possible from prenatal alcohol exposure (PAE).

Significance of the research:

Oh you don't get services, sorry you're too dumb for that job or you can't do that job just leave, it's not finding anything I mean and then there's...the bullying part, whether it's in the community or in the jail or in their home (Pei, Leung,

Jampolsky, & Alsbury, 2016, p.66)

FASD is a serious global mainstream health issue, and not solely an Indigenous problem, and this will be further discussed in chapter two. Regardless of race, the issue of FASD is contentious, surrounded by stigma and not consistently acknowledged, and addressed is the potential harm to the individual, family and community (Gelb & Rutman, 2011; Bell, Andrew, Di Pietro, Chudley, Reynolds & Rancine 2015). Furthermore, the issue of undiagnosed FASD in adults rarely receives attention, until adults end up incarcerated in the criminal justice system (Dej, 2011, Douglas, 2015). Douglas (2015) notes a recent Western Australian case where all the red flags of FASD were identified in a young Aboriginal woman incarcerated, however, final identification of FASD came only after the young woman was hospitalised for seizures, and an electroencephalogram (EEG) displayed abnormal brain structure.

Therefore, those with undiagnosed FASD are amongst the most vulnerable in society, and at risk of ongoing adverse life events (Olson, Oti, Gelo & Beck, 2009). The number of individuals with undiagnosed FASD throughout the world is considered to be significant (May, Baete, Russo, Elliot, Blankenship, Kalberg & Home 2014; Olson, et al, 2009). Compounding this further is the fact FASD is often generational and with multiple siblings within the same family (O'Malley, 2014; Duncan, 2013; Lange, Shield, Rehm & Popova, 2013).

FASD must be comprehensively understood and addressed in Australian policy and across the broad social sector, particularly service delivery. Literature highlights there is limited qualitative studies on the experiences of families and FASD. Therefore, Australian qualitative research on the carer/family experiences with FASD, has enormous benefits for the wider Australian public, in terms of engaging with the community on the sensitive topic of FASD, and informing policy and service delivery.

Critical Gaps and a lack of awareness of FASD and Aboriginal history within Australia:

Literature review identifies that that the majority of literature on FASD is from Canada and North America, with a growing body of literature now emerging in Australia. However, Australia is noted as being fifteen years behind these countries (McLean

& McDougall, 2014). Commencing this PhD in FASD was challenging due to several reasons; there remains a general lack of awareness of FASD within Australian society, and this includes health professionals; and there are still significant gaps in research, policy and service delivery (Mutch, Watkins, Jones, & Bower, 2013). Further, there was no services dedicated to deal with FASD for both the child or adult with FASD, or their parents and carers. The only agency at the time of this PhD was the national agency 'NO FASD', and this is a non-government agency established by carers of children with FASD in Australia. Further, it is important to note there were no services available in 2014 to deal with FASD that is a lifelong disability.

One of the underlying principles of this research includes the sharing of family narratives in facilitating agency and to inform and decolonise evidence base and service delivery for Aboriginal people. Anecdotally, the teaching of Aboriginal Australian history is often not included in the core curriculum of Australian universities, particularly in the social sciences. To the knowledge of the researcher, the only university with a compulsory core unit on Aboriginal studies in health sciences is Curtin University in Western Australia. Within tertiary studies, developing knowledge on Aboriginal history and families often remains an elective unit, and not compulsory, in the human service curriculum. The issue of learning about Australia history and developing cultural competence is critical in challenging ethnocentrism and systemic racism prevalent within systems (Ranzijin, McConnochie, & Nolan, 2009).

Study Objectives:

The objectives for this research project were:

- 1. To apply a case study approach to document the experiences of parents/carers caring for Aboriginal children with FASD.**

This is the first study to document the experiences of carers of Aboriginal children with FASD within Western Australia. International literature identifies there is a paucity of qualitative research on the experiences of carers and families raising children with FASD, and this is critical to informing interventions and service delivery.

2. To explore the impact of FASD on the health and economic status of families caring for children with FASD.

Literature identifies the majority of children with FASD will not be raised by their biological parents; hence it was critical to capture the experiences of carers, in terms of the impact on the health and economic status of the family. Particularly, as many carers have generally none to limited awareness of FASD at the time of placement (Bobbit, Baugh, Andrew, Cook, Green, Pei, Rasmussen, 2016).

3. To capture the range of understandings and knowledge of FASD on Aboriginal people in the south west region

Generally, awareness of FASD within mainstream society and the general community was relatively low at the time of designing this research project (Bower & Elliot, 2016). The level of awareness of health professionals in Western Australia was found to be as low as 12 per cent by Payne (et al, 2005). Therefore, it was critical to explore the level of awareness of FASD amongst the Aboriginal community in the south west region. Further, this was the first study on FASD to be undertaken in Australia, which allowed for engagement of the Aboriginal community across multiple sites in the South west region of Western Australia.

Brief overview of methods

The methodology for this research has included a mixed methods (Walters, 2006) approach utilizing the following; a developed survey instrument, and case studies. A critical case study approach is based on the premise that the ability of people to change their circumstances is constricted by political, economic and social settings (Shanks & Bekmamedova, 2013). Utilising case studies allowed the researcher to capture the narratives of participants and explore the phenomena of FASD in Aboriginal families.

A critical reference group (CRG) was established to guide the research and provided expertise in terms of cultural security and FASD. The CRG mainly consisted of Aboriginal people with expertise in the areas of clinical practices; medical and psychology; community development and policy; Aboriginal health; parents with experience with caring for children with FASD, both Aboriginal and non-Aboriginal.

The CRG played a key role as experts and in the development of the survey tool and qualitative questions for families.

An Indigenous methodological approach was applied throughout this research project to ensure cultural security and engagement from the Aboriginal community. Further discussion on the importance of applying Indigenous methodologies will be discussed in chapter 4, Research Design. Data collection for the developed survey was undertaken in the South west region of Western Australia, and the towns included Northam, Bunbury, Albany, Katanning, Tambellup and Perth. Qualitative family interviews were held with families both Aboriginal and non-Aboriginal caring for Aboriginal children with FASD and also included foster and relative carers. These families resided in both rural and urban areas.

Researcher Family Cultural Background:

It is necessary for me to provide you with my background details and to explain how my role as storyteller has been enhanced. My upbringing taught me to treasure differences between cultures, though in meeting Indigenous people in Canada, United States and Australia, I have noticed that we share similar beliefs and a common spirituality (Wilson, 2008 p.33). In the beginning of this chapter, I introduced myself and my family. Here, I will further expand on my family background as it captures, the experiences of the ongoing adversity which confronted Aboriginal families in Western Australia, as a result of colonisation. I was born in 1966, and on reflection of historical facts, realise that I was fortunate to have not been removed from my family, as the removal of children was still occurring, well after I was born until the 1970s (Ranzijin et al, 2009).

I recognize my own privilege and remain emphatic to all Aboriginal people who were removed from their families. I know Aboriginal people younger than myself who were removed from their family during the stolen generations, and it has impacted on them and subsequent generations. The profound psychological impact of removal has now been well documented and the devastating impact on Aboriginal families (Taylor & Guerin, 2014).

The trauma of removal from ones family and culture is truly felt from one generation

to the next. Later in this thesis, the topic of trauma and transgenerational trauma relating to Fetal Alcohol Spectrum Disorder will be discussed. My father Bruce Williams was a Nyoongar man born into a large family in the south west town of Gnowangerup in 1940. My mother May Williams (Foley) is a Yamatji woman born in the Gascoyne area. The impact of colonization and historical policies has had a profound impact on previous generations within my family, resulting in two generations of children being removed in my mother's family. My siblings and myself are the first generation that have not been removed in our family. Despite the extreme adversity of the past, my family and culture has indeed survived.



Figure 2: Family Photo:

Left to right: Grandmother Tilly Foley (nee Anderson); children Coral, Harold and May (my mother); photo taken approximately 1950s, Carnarvon, Western Australia (Note: not long after this photo Coral, Harold and May were removed from Grandmother Tilly and placed in Institutions under the 1905 Act. Grandmother Tilly's children were placed in Institutions including Sister Kate's, Carnarvon and Roelands mission.)

My maternal grandparents, Bill Foley and Tilly Anderson were removed as young children under the historical 1905 Act from their mothers, families and the Kimberley region of Western Australia in the early 1900s. Grandfather Bill, and Grandmother Tilly were then placed at the Moore River Settlement and were not permitted to leave until they were young adults. As adults, my grandparents were given permission to marry by the Chief Protector AO Neville, and they settled down in the town of Carnarvon, and had their children Violet, Brian, May, Harold and Coral.

My grandparents were never given any information on their family or where they came from and the country they were removed from as young children. Consequently, in their lifetime they were never reunited with their families and country before they died. This simple fact has haunted my mother and her siblings throughout life and caused them immeasurable heart ache and grief and is part of the intergenerational trauma within our family.

Tragically, history repeated itself, and my mother and all her siblings were removed from my grandparents in the late 1940s under the same historical policy the 1905 Act. My mother and her siblings were then separated and detained in different institutions in Western Australia including; Sister Kate's; Carnarvon and Roelands mission until they were all 16 years of age. My oldest uncle Tony was removed by the Government many years before and placed at the Sister Kate's institution. My grandparents strongly challenged the removal of their children and sought Citizenship rights in the hope their children would be returned. Grandfather Bill approached a lawyer in Carnarvon, but despite all their best efforts with limited resources and support, they were unable to have any of their children returned to their custody.

The years at these institutions were devastating for my mother and her siblings, and were marked by constant confusion, homesickness, trauma, loneliness, physical and sexual abuse, malnutrition, culminating in a deep sadness. I recall my mother telling me how distressed she was many times for the babies and young children she had to care for as she was fearful they would not find their parents again as they were so young on entering the mission. My mother and her siblings were not reunited with their parents until they were young adults and were fortunate in the sense that both their parents were still alive when they returned home from the institutions of Sister Kate's, Roelands and Carnarvon mission. However, my oldest Uncle Tony was not as fortunate and his mother had passed away in 1967, before he had the chance to meet his mother Tilly.



Figure 3: Family Photo

Grandparents paternal side: Grandmother Kathleen Williams (nee Colbung) and Grandfather Bert “Womber” Williams, Tambellup, Western Australia.

My paternal grandparents were Kathleen Williams (nee Colbung) and Bert “Womber” Williams. My grandparents were Nyoongar people coming from the south west region and they had a large family. My father’s siblings included Phyllis, Raphael, Max, Barry, Merlene, Edward, Lang, Bertram, Dinny, Steven, Walley and Cleve. My grandparents and their family lived at the Gnowangerup reserve, as Nyoongar people were not permitted to live in country towns, and reserves were established on the outskirts of town. Later the family moved to nearby town of Tambellup. On my father’s side most of my father’s siblings were not removed, however, as told to me by father’s brother (Uncle) as young children, they still lived with the constant threat of removal and would often run and hide in the bush if any strangers/non-Aboriginal people appeared (Personal communication, 2004).

My parents were both born in Western Australia in 1940 and their births coincided with another significant turning point with historical government policies coming into their most powerful time of control and oppression over Aboriginal people in this state. The parent Act of 1905 was replaced by the 1936 Act which extended powers of the Protector AO Neville and addressed the few weaknesses of the 1905 Act (Haebich, 1988a). The 1936 Act was implemented and well established four years prior to my parents’ birth.

Arguably, the most significant change was the increased control of the state over Aboriginal children. The government was now in control of nearly all Aboriginal children regardless of whether their parents were married or not and the age was

extended from 16 until 21 (Haebich, 1988a). The historical policies were not repealed under 1963, however the removal of Aboriginal children did not cease until the 1970s (Haebich, 1988a; Ranzijn, McConnochie, & Nolan, 2009a). Consequently, the power of these policies did not simply end in 1963.

For the next 35 years, these generations of Aboriginal families lived during some of the worst decades with colonization at its height of extreme oppression and colonial power (Eckermann, Dowd, Chong, Nixon, Gray & Johnson, 2010). This story of both my parents was common for many Aboriginal families. The removal of Aboriginal children occurred throughout Australia and finally received acknowledgement and was and is referred to as the “Stolen Generations” (Ivec, Braithwaite, & Harris, 2012).

The term intergenerational trauma was at this time not known or articulated and families had no support in dealing with their trauma of living under the oppressive government policies and extreme poverty (Ranzijn et al., 2009a). According to Libesman (2016, p.47)

There is barely an Indigenous family in Australia who has not been impacted by Australian Government policies to remove children from their families and assimilate them into non-Indigenous Australian society. The impacts are psychological and physical. They are pervasive.

Aboriginal families were well aware the removal of a child, could result in two things, either not seeing the child until many years later, or never seeing that child return to their family for a host of reasons, such as not having the information provided as to how they could later reconnect with their family. I recall my mother often telling my sisters and myself stories of the mission and how lucky we were to have the life we had safe with our parents. During my childhood, I was privileged to have loving parents who were both strong in their love of family, community and culture.

My siblings and myself were also privileged to grow up in the safety of a large extended Aboriginal family. We lived firsthand with the diversity of Aboriginal culture, as we had a parent from two different regions in the state, and with different experiences of colonisation. We were taught to respect and know our family and extended family with many relatives. We saw this love and generous support from our large extended family when our father passed away suddenly at the age of 41, when

myself and my sisters were then still young children. This also included non-blood relations, who through life had at some point been supportive to our parents and vice versa. This was our introduction as young children to what reciprocity meant within our culture.



Figure 4: Carrolup Native Settlement, Marribank in the Great Southern, Western Australia

A Therapeutic model: Marribank Aboriginal Family Centre 1952 – 1988

In the early 1980s, Aboriginal people still had limited if any avenues of external social support or advocacy and were recovering from widespread displacement and the stolen generations over many decades. The removal of Aboriginal children occurred until the 1970s and it would be many years before mainstream Australia had even heard of the term, “Stolen Generations” (Ranzijn, McConnochie, & Nolan, 2009b).

In 1983, my first job after leaving school was at the (former) Carrolup Native Settlement, and later renamed the Marribank Farm Training School in 1951 and became known as the Marribank Family Centre in 1952, until its closure in 1989. Carrolup Native Settlement was established by the Government in 1915 and was closed in 1922 and reopened in 1939. Aboriginal children removed under historical government policies were placed at Carrolup until they were approximately 16 years of age. Marribank Family Centre is located in the South west region and is approximately 30 kilometres from Katanning.

It was here as a young 17 year old adult in the early 1980s, that I witnessed some of the last group of Nyoongar children removed under historical government policies and

saw the impact of removal on children first hand. It was certainly one thing to grow up hearing the stories of the stolen generations from my mother, and then to personally see the impact on young Aboriginal children and this was a full circle moment in my life. Naturally, my experiences at Murrumbidgee had a deep and profound impact on my life, and I again realized the privilege of growing up with my family, and never having to question where you come from, or have to make the connections with family and culture.

The criteria for staying at Murrumbidgee community at that time, was for Aboriginal families who were either homeless or had been evicted from their accommodation. Murrumbidgee was an alcohol free community and was funded at this time by the Baptist Church, however, most of the services were provided by the community on extremely low wages or on volunteer basis. My own wages that I received during these years as a support person were in fact very low and were half the award rate wage at that time.

Anecdotal evidence from the Aboriginal community members over the years consistently supports that the Murrumbidgee community was successful in supporting many Aboriginal families to remain intact and provided social and therapeutic programmes for youth and adults. To my knowledge, Murrumbidgee Family Centre was never evaluated in terms of supporting Aboriginal families in crisis, and the effects of grief, loss and transgenerational trauma. On reflection of the undocumented success stories coming from the Murrumbidgee community, it is a poignant reminder that the expertise for dealing with social issues that are intense or otherwise, has always been within the Aboriginal community.

The achievements of Murrumbidgee Aboriginal community both in the short and long term was no small feat in consideration of the attempted cultural genocide by historical government policies on Aboriginal culture and families. Furthermore, in the evidence-based world that intervention programmes and policy are developed, it is the achievements and the success of places such as Murrumbidgee that were never documented or considered in informing policy and service delivery for Aboriginal people.

In the face of constant adversity confronting Aboriginal people such as poverty, grief and loss, intergenerational trauma, racism, many children from these families went on

and continue to achieve highly successful lives, such as; raising stable families and still supporting others in the community; instilling cultural pride in both family and the community, attending and completing University degrees; becoming accomplished renowned artists; and are today, strong respected advocates in the community.

One Nyoongar artist, Peter Farmer went on to hold many art exhibitions and recently worked with the world-renowned designer Professor Jimmy Choo. Importantly, Farmer also developed and delivers art therapy projects for the Aboriginal community. Farmer incorporates Nyoongar traditional dreamtime stories that have been passed down from his father, who was raised by his grandmother. Culture and stories remain critical to identity, and contributes to resilience, and improving social and emotional well-being (Kickett, 2011). These art therapy programmes have been well received by all ages of the community and remain a critical therapeutic tool that is culturally appropriate for Aboriginal people. Further, art therapy is also evidence based as an important tool, for working with children and adults living with FASD and trauma (Gerteisen & Anchorage, 2008). Farmer generously donated his artworks for the cover of the survey tool developed for this FASD research project.

In the early 1980s, Aboriginal people were not well represented in the tertiary sector, and it was at Marribank that myself along with others were for the first time encouraged and supported to consider attending University. After several more years working and as a mature age student, I completed a University Aboriginal bridging course to gain University entrance and then completed my undergraduate degree in Sociology/Anthropology, and later a Master of Arts degree.

In 2013, the fact that I was accepted and have undertaken a PhD, is also a credit to the generous mentoring and support from my community and living and working at the Marribank Aboriginal community. My time working and living at Marribank community for several years gave me the opportunity to begin the healing process from the sudden death of my father in 1981. My achievements in academia and research are also part of the undocumented success stories coming from those of us who were at the Marribank Family Centre. I have since had the privilege of working in Aboriginal affairs for over 20 years in areas such as Aboriginal education, health policy and training/community development; academia and research in Aboriginal

community based agencies. It was whilst working in the field of Aboriginal affairs that I was first introduced to the topic of FASD.

Later in this thesis, I will provide a more historical account of the Western Australian historical government policies and alcohol. I have provided a brief overview of my family and cultural background for two reasons, firstly as an Aboriginal person undertaking Aboriginal research it is protocol to provide an introduction of my family and myself (Wilson, 2008). Secondly, what is outlined in this brief overview of my family background provides a glimpse into the impact of colonization on Aboriginal people and families in Australia.

Terminology

Within this thesis, the terms Aboriginal and Indigenous will be used interchangeably. The term Aboriginal in this study is also inclusive of Torres Strait Islander people. The style of writing in this thesis has attempted to lean towards a storytelling style for several reasons; firstly out of respect of Aboriginal ways and preferred communication style; and secondly for this research to be accessible to an audience outside of academia.

Overview of the Thesis

Chapter One provides an introduction of the researcher as an Aboriginal person, and a glimpse of the impact of colonisation, particularly the stolen generations on Aboriginal culture and families and the for this study on FASD in Nyoongar country.

Chapter Two provides a brief overview of International literature on FASD, and some of the historical background on FASD. This chapter explores the importance of understanding FASD as an invisible disability, and the FASD spectrum and provides an insight into some of the complexities to understanding FASD. The chapter also highlights the gaps in expertise in FASD that exist globally.

Chapter Three provides an overview of Australian literature and recent policy developments on FASD in Australia. This chapter provides a brief summary of key research that includes the lack of awareness of health professionals. A brief historical overview of Western Australia and Aboriginal people is provided highlighting

historical policies and intergenerational trauma.

Chapter Four provides an overview of Indigenous research methods that were applied in this study. Discussion on the importance of decolonisation in research methodology, particularly relating to FASD is provided.

Chapter Five provides the results for the developed survey tool for this project, titled “Our Gurlonggas, Our Future”. This tool was developed to explore the level of FASD awareness within the Aboriginal community. In total 180 Aboriginal people participated in this survey across five sites including Perth, Albany, Tambellup, Katanning, Bunbury. The chapter includes the analysis of results using SPSS statistical software based on age, gender and other variables as provided.

Chapter Six provides the qualitative data results for the interviews held with families who have cared and in most cases are still caring for Aboriginal children/adults living with FASD. These case studies highlight the common themes of caring for their child, and in some instances from childhood to early adulthood. Case studies are presented to identify the impact of raising children with FASD on families and carers.

Chapter Seven provides a summary of the case studies with each family, as highlighted in chapter six. In total there were six case studies, and this included both relative and foster carers. Additionally, a reflective interpretive commentary and reflection on secondary disabilities for each family is provided.

Chapter Eight provides a conclusion to the thesis, highlighting the key themes that have emerged from both the data collected (surveys and family interviews) aligning it with the literature review and responds to the research questions. This chapter includes recommendations to inform policy and service delivery practice for FASD within Australia, and particularly for the Aboriginal community in Nyoongar country.

CHAPTER 2

Literature Review: Part 1 Global overview of FASD

As an adoptive parent of (a child with FASD). I am finding that the world is divided in two: those who can see and recognize these children...and those to whom this situation remains an invisible epidemic. (Olsen, 2009, p.235)

Introduction:

FASD has become a serious global health problem and affects all ethnic and socio-economic groups, and is now more common than Cerebral Palsy or Downs Syndrome (Fagerlund, Autti-Ramo, Hoyme, Mattson & Korkman, 2011). Further, FASD is an irreversible lifelong disability, and is the leading cause of a preventable intellectual disability in the world (Clarren, Salmon, & Jonsson, 2011; Thomas, Warren & Hewitt, 2010). Despite this, FASD is not officially accepted as a disability in the world or Australia. Whilst, considerable research has been undertaken on FASD, there remains considerable gaps of knowledge in the expertise, including transition to adulthood and the impact on family.

Globally, stigma contributes to barriers in raising awareness of FASD, and for women to access appropriate services, in seeking interventions and support (Bell et al, 2015; Grant, Brown, Dubovsky, Sparrow & Ries, 2013). Therefore, the issue of social discourse and stigma will be discussed further in this chapter. This chapter will briefly look at different countries globally in terms of progress in FASD awareness and service delivery and provides a brief overview of international based literature on FASD. The impact of FASD on the child and family will be discussed at length in this chapter.

Historical background of FASD

In 1968, a small research project examining the impact of alcohol and pregnancy was conducted by Lemoine, Harousseau, Borteyru, Menoet, (1968) in France (Hayes, D'Antoine, & Carter, 2014). This research later became the impetus for the study by Jones in the US in 1973, who then applied the term Fetal Alcohol Spectrum (FAS). The term FAS was used to describe the acute symptoms of the disorder and in recent years the term Fetal Alcohol Spectrum Disorder (FASD) has been adopted by North

America, and Australia to describe the wide range of the disorder (Pyett, 2007).

In 1978, two of the first FAS programmes were funded in the US, and Canada and the US worked collaboratively in attempts to address FASD (Grant & Clarren, 2014). Despite the increasing amount of research undertaken there still remain significant gaps in expertise on FASD. FASD prevalence is generally unknown throughout the world, and contributing factors will be discussed later in this chapter. Further, there is not a great deal of qualitative literature on evidence based therapies, and the impact of FASD on the family and carers (Mukherjee & Wray, 2013).

Since 1973, the number of articles published on fetal alcohol exposure (FAE) amounts to approximately 3,900, with 40 per cent being published after 2000. Despite gained momentum, there also continues to be a global lack of awareness on FASD that is compounded by associated stigma (Bell, Andrew, Di Pietro, Chudley, Reynolds & Racine, 2015). For individuals and families living with FASD at the coalface, research has not kept pace with the constant adversity and complex issues that confront families. Particularly, when children transition to adulthood, and remain vulnerable in a society with service delivery that is largely ad hoc or non-existent (Mukherjee & Wray, 2013). Further, Wilson (2013) notes the majority of research on FASD has focused on medical and scientific spheres, and not the social needs of FASD for individuals and families.

The Invisible Disability: FASD

FASD is often referred to as the Invisible Disability, and the majority of children born with FASD will not have the physical characteristics of the disability. According to Andrew (2011) the identifying facial dysmorphology of Fetal Alcohol Spectrum (FAS) occurs from alcohol consumption during days 19 to 21 of gestation. Only a minority, approximately 10%, will be born with facial dysmorphology that is the characteristics identifiable as Fetal Alcohol Spectrum (FAS) (Andrew, 2011). However, as the child grows up, the facial characteristics have also been known to disappear. As FASD is largely an invisible disability it is difficult to recognise, and subsequently diagnose. Consequently, many people will go undiagnosed, or will be misdiagnosed with other conditions such as ADHD. Those on the FASD spectrum that do not display facial dysmorphology are even more vulnerable to not being correctly assessed or diagnosed by health professionals. Further, many with FASD

will have an average IQ level at the lower end and are usually not classified as having an intellectual disability. Consequently, many with FASD find it difficult to access services and support (Sparrow, Grant, Connor & Whitney, 2013).

Diagnosis of FASD: children and adults

According to McFarlane (2011, p.1)

Access to diagnostic and assessment services for fetal alcohol spectrum disorder in adults is relatively rare in the world. Since 2002, the Lakeland Centre for Fetal Alcohol Spectrum Disorder (LCFASD) in northeastern Alberta has been providing community based mobile diagnostic and assessment services for adults prenatally exposed to alcohol.

Further, diagnosis of Fetal Alcohol Spectrum becomes more difficult to diagnose as a child with FASD grows and develops due to the original facial characteristics of FAS beginning to disappear. Further, not all children are born with visible FAS characteristics, and neurological and cognitive impairment is often not evident until later in childhood (Pyett, 2007). According to Temple, Ives & Lindsay, 2015, internationally there are few diagnostic options for adults living with FASD.

Diagnosing adults is a new field and critical to providing appropriate services and support for this vulnerable population. Further, it was noted that in an adult clinic in Toronto, 40 per cent of the adults who had been diagnosed were now parents themselves, and at risk of having children with FASD (Temple, et al, 2015). In a study conducted by Streissguth (1997), 40 per cent of women living with FASD were drinking alcohol during their pregnancy, and 17 per cent of their children had been diagnosed with FASD (Chudley, Kilgour, Cranston, & Edwards, 2007).

Badry & Bradshaw (2011) provide a comprehensive review of the international literature on the assessment and diagnosis of FASD for adults. This review highlighted that whilst it still remains difficult for a child to receive a correct diagnosis of FASD, it becomes more complex for an adult to access a FASD diagnosis. Complicating factors include: adults may no longer have identifiable features; adults may have experienced some form of physical head trauma and whether medical records of prenatal alcohol exposure can be ascertained. Lack of diagnosis for adults contributes to extreme lifelong adversity, and many adults will not have the cognitive ability to self-advocate. More discussion on adults with FASD is provided later in this chapter.

Further, FASD continues to be misdiagnosed as Attention Deficit Hyperactivity Disorder (ADHD); Cognitive Impairment and other mental health disorders (Andrew, 2011). However, in some areas of the world where there is good access to diagnostic services, prevalence rates for FASD are provided. In North America, prevalence rates range from nine per 1000 births (Andrew, 2011). Globally the prevalence rates for FASD are estimated at 3 to 5 per 1000 births (Thanh, Jonsson, Salmon, & Sebastianski, 2014). According to Burd (2016, p.923)

FASD is highly recurrent within siblings and across generations...Few, if any countries have the capacity to use multidisciplinary diagnostic clinics to manage the new cases of FASD born each year. The development of enough multidisciplinary teams with the capacity to assess hundreds of thousands of affected but undiagnosed people is unlikely.

Methods of studying FASD Prevalence Studies

The three main methods of studying the prevalence of FASD include; passive systems, clinic based studies and active case ascertainment methods (Burns, Breen, Bower, O'Leary, & Elliot, 2013). These records include information that is collected from birth registries or disability clinics. The second method is clinic based studies that are undertaken in prenatal or antenatal clinics. Third, is the active case ascertainment systems that are used in specialty referral clinics in outreach populations or in schools. Caution must be applied when active case ascertainment methods are used with high risk populations as the findings cannot be applied directly to the general population (Riley, Clarren & Jonsson, 2011). According to Burns (et al, 2013) there are several advantages to using the active case methods, including more likelihood of diagnosing a larger number of children with FASD.

Secondary Disabilities

A significant turning point in global FASD research and expertise was the longitudinal research conducted by Streissguth et al (2004) identifying the secondary disabilities that arise from the lack of early diagnosis and intervention with FASD. The majority of the participants involved in this study were white (60 per cent) and this study was conducted in the US. The research involved 415 participants and was the first study to identify the secondary disabilities that arise from FASD. Secondary disabilities identified and subsequently confirmed in other studies include:

- Problems with education/schooling

- Alcohol and drug misuse
- Mental health
- Involvement with the criminal justice system

Secondary disabilities also include failure to complete schooling; and repeated incarceration. From the findings, 65 per cent had received remedial assistance in their schooling, however 53 per cent had been suspended from school and 29 per cent had been expelled, 58 per cent had difficulty relating to their peers at school and 55 per cent were repeatedly disruptive. Sixty seven per cent had experienced sexual abuse and or domestic violence. Results also found the majority 90 per cent, will develop mental health issues, such as depression, posttraumatic stress disorder (PTSD); anxiety and bipolar. Further, mental illness as a secondary disability, is not the result of the initial organic damage to the brain, but is the accumulating factors of the lack of early intervention; failure of having good supports; and further trauma from multiple care placements and neglect and abuse (Andrew, 2011). Individuals with FASD were also at high risk of suicide and attempting suicide (Pei, Denys, Hughes, & Rasmussen, 2011). According to Petrenko, Tahir, Mahoney & Chin, 2014, p.1497)

The factors considered most protective against the development of secondary conditions in this population include living in a stable and nurturing home, not having frequent changes of household, early diagnosis, provision of developmental disabilities services and not being a victim of violence.

Another reason it is critical to diagnose FASD is to guide the best therapeutic modality. For most individuals with FASD cognitive therapeutic approaches will not be effective. Youth with FASD often do not respond well to cognitive therapy due to their multiple disabilities (Brown, 2012). Further, there is a paucity of research on interventions that have been developed to cater for individuals with FASD. Caregivers who have expertise in caring for family members with FASD are often not consulted on appropriate treatments, or sought for feedback (Grant, Novick, Graham & Ernst, 2014).

Mental Health and Suicide

The over representation of high incidence of mental health amongst individuals with FASD is well documented (Pei, Denys, Hughes & Rasmussen, 2011; O'Malley, 2014). Further, review of literature identifies mental health co-morbidity with FASD

(Weyrauch, Schwartz, Hart, Klug & Burd, 2017). Weyrauch, (et al, 2017) asserts FASD still remains largely undiagnosed within society, and notably this has serious implications for individuals with FASD, with mental comorbidity, and according to Weyrauch (et al, p.283),

FASD is commonly underdiagnosed in clinical settings...People with FASD have been reported to experience more internalizing disorders, such as depression and anxiety, and more externalizing disorders such as attention-deficit/hyperactivity disorder (ADHD), than the general population.

In the earlier study conducted by Streissguth, Bookstein, Barr, Sampson, O'Malley & Kogan (2004), more than half the adults in this study had depression, and the risk of suicide was reportedly high, with 43 per cent contemplating suicide and 23 per cent had made previous attempts. Further, according to Streissguth, Barr, & Kogan (1996), 90 per cent of the adults were found to have mental health problems and 23 per cent of adults with FASD had attempted suicide, and some more than once. This rate of attempted suicide was five times higher than the national average. According to Moore & Riley (2015), most adults with FASD without support will develop mental health disorders. Research highlights the secondary disability of mental health is high for many adults with FASD and of particular concern is standard mental health approaches will not be effective for this population (Weyrauch, et al, 2017; O'Malley, 2014; Lutke, & Antrobus, 2004)

According to expert O'Malley (2014), until very recently, the classification systems of the International Classification of Diseases (ICD) and the Diagnostic and Statistical Manual of Mental Disorders (DSM) did not consider ARND and FASD. Further, this created a barrier in effective management and treatment plans for individuals affected by PAE. However, according to Weyrauch (et al, 2017), the latest version of the DSM includes a diagnostic category associated with PAE in the fifth revision.

Burd (2016) advises the recent inclusion into the DSM is clinically useful and this allows the diagnosis of FASD by Paediatricians, psychiatrists, and neurologists. Children with FASD are often misdiagnosed early with ADHD, ODD or bipolar disorder (O'Malley, 2014). Further O'Malley (2014, p.240) argues early diagnosis for children is critical to avoid misdiagnosis such as attachment disorder, and states:

In making such a diagnosis, professionals invalidate the valuable objective

observations of foster or adoptive parents and immobilize many, thus through misdiagnosis denying the child effective parenting.

Famy, Streissguth & Unis, (1998) conducted the first research on FASD and mental health, and found the incidence of depression was extremely high amongst both male and female adults with FASD, and the majority had elevated alcohol and drug misuse. According to Huggins, Grant, O'Malley, & Streissguth, (2008), limited research has been undertaken on suicide rates amongst those living with FASD. The majority who attempted suicide in this research study did not have an intellectual disability and were reported as having an IQ level of 85. Pei (et al 2011, p.446) asserts the following:

There is already clear research demonstrating the detriments of PAE; however, there is limited research on interventions designed especially for those of the FASD population who have attempted suicide and who experience substance abuse, mental disorders and criminal activities...given the multiple systems of support often required to meet the needs of this complex population, further research into cost effective and feasible approaches to integrated service delivery are warranted.

Research undertaken by Huggins (et al, 2008) also found a high rate of suicide attempts amongst adults with FASD. According to Huggins (et al, 2008), standard suicidal interventions and protocols apply for adults with FASD, however, communication of interventions must consider neuropsychological deficits. Huggins (et al, 2008) asserts that approaches must also consider neuropsychological deficits in memory and adults with FASD may find it difficult to recall past events or medications. Further, impulsivity common to adults with FASD, makes adults vulnerable to suicide attempts, and families have to be advised to minimize risks by removing easy access to items such as firearms.

FASD and the Criminal Justice System

Studies over the last two decades have shown that people with fetal alcohol spectrum disorders (FASD) have the kind of brain damage that increases risk of criminal behavior. Thus.....FASD is likely to affect a sizable minority of individuals involved in the justice system. Most of these defendants have never been diagnosed because they lack the facial abnormalities and severe intellectual deficiency that would have improved identification and diagnosis in childhood. (Brown, Burd, Grant, Edwards, Adler & Streissguth, 2015, p.1)

As identified in the longitudinal study by Streissguth et al (2004), one of the secondary disabilities of FASD is involvement in the criminal justice system. The majority of

youth and adolescents who encounter residential treatment or incarceration will do so without a FASD diagnosis (Brown, 2012). Whilst, there is a lack of empirical data of prevalence rates of adults and youth, it is likely that the prevalence rates within correctional systems is likely to be high (Popova et al, 2011). According to Kelly (2011) 60 per cent of individuals with FASD will come into contact with the criminal justice system. Individuals with FASD are particularly vulnerable in dealing with the law, and this is compounded by a general lack awareness by the system and staff. Memory deficits caused by FASD contributes to missed appointments with probation officers with adverse consequences for not attending and ongoing recidivism.

According to literature (Pei et al, 2016; Popova, Lange, Bekmuradov, Mihic & Rehm 2011) few studies have been conducted to estimate the prevalence of FASD in the criminal justice system other than in Canada and the USA. Based on Canadian studies it is estimated that youth with FASD are 19 times more likely to be incarcerated. The prevalence for adults incarcerated in Canada was estimated at 3,686 adults in the Canadian correctional system in 2008/2009 (Popova et al, 2011). However, in a more recent study by Popova, Lange, Burd & Rehm, (2015), the prevalence rate of FASD in the correctional system had an increased estimate at 3870 in Canada. Estimating prevalence within the criminal justice system is challenging due to the lack of standard screening and diagnostic tools, and also the difficulty in diagnosing adults. Popova et al (2015) estimated the costs in Canada for incarceration of adults with FASD was \$356.2 million annually in 2011/2012. These costs do not include any further expenses that may be incurred, such as mental health services. Popova et al (2015, p.80) states

A portion of these costs may be avoided if standardized screening and diagnostic tools to identify individuals with FASD were standard practice within the criminal justice system. Unfortunately, nearly all offenders with FASD in the correctional system in Canada are currently undiagnosed.

Consequently, early detection and intervention may influence alternative sentencing programmes and begin to improve recidivism for adults with FASD. Involvement within the Criminal justice system for adults with FASD who are parents may also make them vulnerable to having their parental rights terminated. The justice system has statutes that may terminate parental rights if there is the perceived opinion of neglect of the children. Further, for juveniles social programmes aimed at preventing recidivism will not work for children with FASD. Tragically, a theme amongst

individuals with FASD is also making false confessions to crimes they did not commit and with no comprehension of the serious consequences. In a recent case in New Zealand, a young man falsely confessed to a crime of murder, and his plea was accepted and he spent 22 years in prison. He was recently diagnosed with FASD, and it was legally proven that he had made a false confession to the crime. The high court in New Zealand overturned his conviction (Gibbs & Sherwood, 2017).

Economic cost of FASD

The economic costs of FASD to society, are well documented in FASD research and literature (Thanh, et al, 2011; Popova, Lange, Probst, Parunashvili, & Rehm, 2017). In 2009, the annual cost of FASD in Canada was estimated conservatively at 6.2 billion dollars. According to Eguiagaray Scholz & Giogi, (2016) the costs estimated for FASD are likely to be substantially underestimated, as most cost analysis only considers FAS, and not the remainder of the spectrum. Further, the cost analysis does not include the burden on family and costs resulting from poor quality of life (Eguiagaray et al, 2016).

In a recent study conducted by Popova, Lange, Burd & Rehm, (2013), it was estimated the annual economic costs for children with FASD within Canada welfare system are significant and ranges from 57.9 to 198 million. A further finding from this research highlighted that the age group 11 – 15 years of age required the most expenditure from annual costs (Popova, et al, 2013). The authors suggest most foster carers are not fully prepared for raising children with FASD leading to multiple placements, and increased further costs on the welfare system (Popova, et al, 2013).

Further, the lifelong disability of FASD often contributes to a poverty trap that is compounded by factors such as families coming from a low socio economic background, and serious health and social problems common to FASD. The economic burden on the individual and the family is profound, particularly when secondary disabilities occur such as mental health or involvement with the criminal justice system (Brown & Rodger, 2009; Thahn, Jonsson, Moffatt, & Dennett, 2013). The social and economic impact of FASD on the individual and the family is immeasurable.

Comorbidity with FASD

Recent research on FASD has importantly identified the high prevalence of

comorbidity of FASD with other health conditions. In this respect, comorbidity with FASD is the rule rather than the exception for individuals living with FASD (Hayes, 2014). Popova, Lange, Shield, Mihic, Chudley, Mukherjee & Rhee (2016) recently conducted a systematic review of studies examining comorbidity with FASD and found 428 comorbid conditions. This was the first study of its kind to examine comorbidity amongst FASD populations and was found to be hundred times higher than mainstream in the US. Popova (et al, 2016, p.8) states

Understandably, the number of comorbid disorders found to co-occur in individuals with FASD can also account for the lower than expected prevalence estimates for FASD (ie. underdiagnosis), probably because of the shadowing that might occur by the other disease conditions.

In an earlier study undertaken by Leenaars, Denys, Henneveld, & Rasmussen, (2012), on children with FASD, as high as 89% of the children were found to have at least one comorbid condition. The identification of comorbidity informs what adaptations are critical in the treatment approaches when disorders co-exist with FASD. Other disorders that are commonly identified include: ADHD, Oppositional Defiant Disorder, Depression and Bipolar. Popova (et al, 2016) recommended better routine investigation of individuals that presented with comorbid conditions.

Increased alcohol consumption of females

In the last two decades the consumption of alcohol by women throughout the world has increased dramatically, and generally it is widespread that approximately 20 per cent of women still consume alcohol during pregnancy. Compounding this is the lack of confidence that health specialists have in diagnosing FASD, and in some countries such as Italy, as high as 50 per cent of doctors continue to advise their patients that there is no harm in consuming alcohol during pregnancy. In the past few decades and with the rise of feminism and equality, the consumption of alcohol by women has generally increased throughout the world. This is important to note, and experts agree this has contributed to increased FASD prevalence rates throughout the world. Moreover, according to Popova et al (2015, p.76)

The prevalence of drinking alcohol during pregnancy among the general population has been reported to be: 14% in Canada; 30% in the United States, 33% in the United Kingdom, 83% in Russia and 89% in Ireland.

Further, literature highlights that the increased drinking occurs more amongst women

of child bearing age. According to Vagnarelli, Palmi, Garcia-Algar, Falcon, Memo, & Pichini, (2011) in Europe, the increase in the alcohol and tobacco consumption of women also reflects the changing roles of women. In Europe, women are reportedly drinking at higher rates in the UK than women in France and Spain (Plant, 2014). Additionally, many young women do not realise for several weeks that they are pregnant, due to irregular menstrual cycles. Further despite improved contraception availability in affluent countries such as the US and Australia, the rate of unplanned pregnancies continues to remain high. In the US each year, approximately half the pregnancies of four million women are unplanned, and of this amount 500,000 women continued to use alcohol during pregnancy, and of this amount 2 per cent reported drinking at harmful levels (Brown, et al 2015).

Reasons women drink

Research highlights the common theme of early traumatic life events as the major factor to the consumption of alcohol and substances at risky levels by women (Pei, et al, 2016; Singal, Brownell, Hanlong-Dearman, Chateau, Longstaffe & Roos, 2016, Clarren, Salmon, & Jonsson, 2011; Streissguth et al, 2004; Grant, Huggins, Connor, & Streissguth, 2005; Poole & Greaves, 2012; Grant, et al 2014). Early trauma histories include; sexual abuse, exposure to violence, separation from parents, multiple placements, early mortality of primary caregivers, and physical abuse. Furthermore, as adults, women often experience incarceration, family violence, sexual violence, poverty, and poor health including co-morbidity of mental health disorders (Grant et al, 2011; Grant, 2005). Further, Grant et al (2005, p.91) argues:

Specific risk factors for women's depression have been identified in the literature; many of these also predict co-occurring substance abuse. Poverty is perhaps the strongest of these, especially in mothers with young children...Adult risk factors for women include victimization and sexual violence, homelessness, acute and chronic illness and a critical unsupportive partner.

In terms of prevention of FASD, little is known about adult women living with FASD, and the incidence of alcohol and substance use (Grant et al, 2014). However, earlier landmark research by Streissguth (et al 1996), highlights that the incidence of substance and alcohol use is likely to be high. Clarren (2009) argues that a child born with FASD is biomarker for a mother who also possibly has FASD. Gelb and Rutman (2011) completed a study and literature review on women with FASD with alcohol and substance misuse problems. The literature highlights that women with FASD are

extremely vulnerable to being abused and ongoing abuse as children and as adults. Consequently, many women with FASD have more than one significant traumatic event in their life. Gelb and Rutman (2011, p.19) states

In Sherry's case, she experienced many of the life-history traumas associated with women's substance use: In addition to the physical abuse in this foster home, Sherry was raped at age 9 by a 16 year old foster brother and then subjected to ongoing sexual abuse until she was removed from this home at age 11....Sherry's marriage was extremely troubled and characterized by violence, abuse, and alcohol and drug use.

According to Grant (et al, 2014), women who have suspected FASD, but were never diagnosed are unlikely to comply with treatment programmes due to cognitive impairment, and lack of executive functioning (Grant et al, 2013). Grant, (et al, 2013) argues that many of these women without support, lose custody of their children, due to alcohol abuse and are likely to have another child who is exposed to PAE. Furthermore, research by Grant (et al, 2014) found women who were not successful in regaining custody were not likely to remain abstinent from alcohol and substances and were at risk of having a subsequent pregnancy exposed to PAE. Grant (et al, 2104, p.11) makes the following statement:

While substance abuse treatment is generally an essential component of child welfare family plans, a relatively low proportion of substance abusing mothers involved in the child welfare system complete treatment, which typically results in placement of their children in substitute care and the beginning of a new generation of adaptive problems.

Further, there is no empirical evidence on the completion rates for adults with FASD within treatment settings, and is likely that programmes will not work for adults with FASD. Heddrick (et al, 2011) explains that group activities require adults to retain information within treatment programmes and do not cater for adults who have FASD, as the majority experience memory deficits. Grant et al (2013), asserts treatment programmes for adults with FASD must also cater for mental illness such as the Assertive Community Treatment (ACT). This treatment involves a multidisciplinary team of specialists, such as social work; nursing, psychiatry and treatment extends well beyond problems of substance abuse to include case management and other services. Popova (et al, 2013.p.8) asserts the following:

Many if not most individuals with FASD entering substance abuse treatment will not be recognized as having FASD...very few substance abuse treatment programs have the needed adaptations for clients with FASD. This gap in

services may increase their risk of treatment failure and/or relapse. Treatment strategies of women with FASD should be different from those of men.

Society still holds biological mothers as responsible for children born with FASD. In turn, biological mothers are often reluctant to seek help, in fear of judgement and discrimination. The barriers for women seeking treatment are well documented, and include stigma, fear of child apprehension; transport; childcare; locally available services (Gelb & Rutman, 2011). Services also generally lack the capacity and knowledge to cater for comorbidity of mental health and addictions. Women experience feelings of guilt and shame, and the lack of understanding of FASD. Australian research also highlights that services in Australia, for women must be improved in terms of being more accessible and effective. Stigma and shame are critical factors that prevents women from accessing services for problematic substance abuse and risky drinking.

The relationship women have with their partner may also influence their alcohol consumption and their attitude to seeking help for problematic drinking. Further, similar to international reports, Australian women also hold legitimate fears of having their children removed by child welfare services and this becomes another factor in preventing them from seeking intervention (McLean & McDougall, 2014). Later in this thesis, the impact of colonisation on Aboriginal people and women will be discussed in more depth. Colonisation and relating intergenerational trauma continues to impact on Aboriginal women and contribute to alcohol consumption at risky levels and binge drinking. In terms of Indigenous women, cultural safety must be paramount in the design and delivery of treatment services. This is compounded by lack of self-determination, racism, and lack of appropriate services to work with Aboriginal families (Cuneen, 2016).

Another key area identified in supporting women with FASD, is that support must also address the real life urgency such as social issues. Major ideological shifts needed were identified in service delivery and include from medical model to harm reduction; child welfare to supporting families and shifting blame from failure of the mother to failure of the system (Gelb & Rutman, 2011). It is also critical to apply a disability lens for intervention treatments with FASD. Comprehensive training and education on FASD

should be mandatory for all staff in the alcohol and drug field. It is critical that all staff have good awareness of FASD, in terms of behavioural and cognitive components of FASD. Staff need to also work through issues of stigma that confront adults living with FASD. Literature also identifies that intensive case management and mentoring is another best practice in working with adult clients with FASD. Case management also includes advocating for clients with other service providers, in areas such as helping clients' secure stable housing.

Australian studies indicate the reasons women drink varies, and women who have drunk in previous pregnancies generally continue to consume alcohol in subsequent pregnancies. Women with a high income are more likely to consume alcohol before and during pregnancy (Elliot, 2015). Consumption of alcohol during pregnancy was also related to drinking with partners. McBride & JohnAson (2016), found that 75 per cent of women consumed alcohol during pregnancy did so with their partner. Furthermore, 40 per cent of the drinking was initiated by the male partner. The active role of male partners indicates the responsibility of alcohol consumption during pregnancy should not be placed on the female alone, and should target the wider community (McBride & Johnson, 2016).

Trauma informed approach with FASD

An emerging field in supporting trauma is working from a trauma informed approach and practice. The aim of this approach is the enhancement and understanding of complex trauma and to therefore eradicate any potential of re-traumatising the client (Poole & Greaves, 2012). Importantly, for Indigenous clients this approach includes considering and understanding trauma from a historical perspective. The acknowledgement of intergenerational trauma in a trauma informed approach allows for better informed healing approaches and strategies (Menzies, 2012). Harber (2012) describes how a trauma informed approach has been successful in working with youth affected by FASD. Children and adolescents with FASD who have experienced trauma have a wider range of problems including, dysmaturity, memory problems; behavioural and social.

This project involves the use of creative drama and role plays, and allows young people with FASD the opportunity to have an externalized form of expression. Creative drama

allows young people to role play real life stories, with the safety of playing back. This also teaches social skills for the transition to adulthood. Further, drama therapy facilitates kinaesthetic learning, that is a more appropriate learning style for individuals with FASD. Review of literature also highlights the memory deficits of children with FASD and research undertaken by Loomes et al (2008) found in their study that rehearsal training to be another compatible strategy to improving memory deficits in children with FASD.

Stigma and Social discourse on FASD

Beliefs that anticipated negative life trajectories are unavoidable lets the community, social and health systems of the hook regardless of systematic “structural social inequality” that exists for individuals with FASD and their future children....Moreover, these beliefs may be reinforced because of the multigenerational effects of FASD and the fact that women with FASD are generally at high risk to have a baby with FASD. (Bell, Andrew, Di Pietro, Chudley, Reynolds & Racine, 2015, p.5)

According to Bell (et al, 2015) the development of social discourse on FASD has played a key role in the stigma associated with FASD. Social discourse emerged in the early stages of FASD awareness in Canada and continues to have an impact on the representation of FASD within society. Much of this has been extremely negative and continues to influence the stigma associated with FASD and contributes to barriers in adequate public awareness campaigns and service delivery (Bell, et al, 2015). Sociologist Dej (2011) argues the discourse on FASD implies there is a level of deviance associated with the condition and a continuum that sees an infant born with FASD as a victim, until adolescence where they often become enmeshed in the criminal justice system and are then seen as criminal or a perpetrator. Discourse on FASD was also influenced by the fear that children who were damaged had the potential to become adults who could be dangerous in society.

Shankar (2015) notes social discourses has influenced the following discourses; hurt and damaged child with FASD; birth mothers are responsible and to blame for this condition in their children; FASD is a preventable condition; FASD is the domain of children, and FASD is largely an Aboriginal problem. The other message that became accepted was that FASD was a preventable disorder, but also one that was incurable (Shankar, 2015). Whilst, FASD is not incurable, it is contestable that FASD is

completely preventable, as many women are unaware of early pregnancy, further, many women continue to consume alcohol during pregnancy, after they are aware of pregnancy.

Ethical Implications of Stigma against Fetal Alcohol Spectrum Disorder

In the model provided by Bell (et al, 2015, p.3), describes the different loads of stigma associated with FASD, including the child with FASD, birth mothers and carers, and often this is based on negative beliefs. Further, Bell (et al, 2015) argues it is important to recognise how stigma plays out across the lifespan. Social discourse on FASD have become dominant over time, and continues to stigmatise FASD within the community, particularly for birth mothers and Aboriginal women. Further, it is now well documented that the issue of adults with FASD still remains an area that is largely neglected (Shankar 2015).

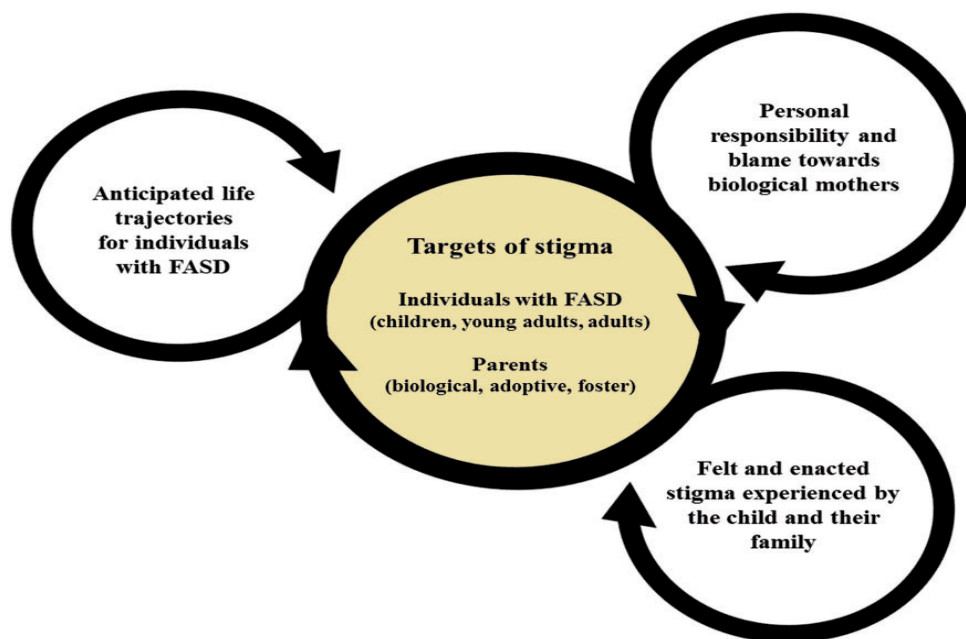


Figure 4: Loads of stigma experienced by those affected by fetal alcohol spectrum disorder (FASD)

Hunting & Browne (2012) argue health policies overlook the complexities of the social position of women and lean towards a discourse that blames and stigmatizes women (Hunting & Brown, 2012). According to Hunting & Fraser (2012) Canadian health policy and research has generally failed to examine the social factors that contribute to women drinking during pregnancy. In this context, the societal risk factors of trauma

such as domestic violence; sexual and physical abuse that often contribute to risky drinking patterns are minimised. Race privilege has also played an instrumental role in FASD policy and discourse. A previous study in America found that women of colour were ten times more likely to be reported to authorities if an infant was exposed to prenatal alcohol or drug use than non-Aboriginal women. Further, the same study found that non-Aboriginal women were in larger numbers using illicit drugs and alcohol during pregnancy (Paltrow, 1998).

Research of FASD prevalence has indeed not kept up with the mainstream population, but generally the first point of call is to conduct prevalence studies in places such as child welfare or juvenile detention centres. Whilst, such prevalence studies are indeed warranted, this is an important point to consider when noting these institutions are also globally overrepresented by Indigenous children due the historical legacy of colonisation and intergenerational trauma. It then becomes resoundingly a fait accompli and by default, Indigenous people will ultimately outnumber mainstream in what is considered the prevalence rates of FASD throughout the world. It is well documented that the mainstream studies of prevalence of FASD are still to gather momentum (May et al, 2014).

Aboriginal Dysfunction and FASD

Authors such as Cunneen (2016); Libesman (2016), and Garond (2014) argue the portrayal of Aboriginal dysfunction and rise of neoliberalism plays an integral role in the prevention of agency of Aboriginal people and self-determination. Of particular concern is the dominant view of Aboriginal dysfunction with the decrease of service funding to Aboriginal agencies. Further, lack of appropriate resources and services correlates with the rise of Aboriginal youth in detention and the increasing numbers of Aboriginal children in OOHC (Cunneen, 2016). Negative and socially racist representation and discourse on Aboriginal people in Australia is nothing new and will be discussed at length in chapter three. Australian Indigenous academic Hammill (2003) describes how Aboriginal children with learning disabilities are labelled and portrayed as bad children. Cunneen (2016) cites the evidence of three states including Western Australia, where Indigenous youth at police contact in comparison with non-Indigenous youth were more likely to be charged and arrested, than receive cautionary notice. Therefore, highlighting systemic and racist differences in the system and

policing.

There continues to be striking similarities in the social indicators of Indigenous groups throughout the world. It is critical to approach the prevalence of FASD of Indigenous people with extreme caution. Further, writers, globally warn FASD is not an Indigenous problem. Rather, the dominant discourse on FASD is still influenced by the misconception that FASD is predominately a problem of Indigenous people. Salmon (2013) argues that the social discourse on FASD must be decolonised and the intersection of racism and history be duly noted and addressed. Furthermore, academia has also influenced misconceptions in the discourse on FASD, contributing to some bias in FASD diagnosis, and particularly for Indigenous communities. Consequently, FASD discourse must also be decolonised, as it further stigmatises those communities who have already been disadvantaged historically, and continue to be affected socially by stigma and racism.

Colonisation has contributed to the contemporary position of Indigenous people globally being over represented in; OOHC; incarceration, domestic violence; suicide; and appalling mortality rates (Libesman, 2004; Cuneen, 2016). Further, racism also plays a fundamental role in the social determinants for Indigenous people in terms of advocating their own agency. This has led to the discourse contributing to the misconception that FASD is predominately an Indigenous problem. Indigenous communities both in Canada and Australia have identified FASD and taken on the challenge of beginning to address FASD within their own communities (Fitzpatrick et al, 2015; Tait, 2003).

Impact of FASD across the lifespan

Fetal alcohol syndrome is not just a childhood disorder; there is a predictable long-term progression of the disorder into adulthood, in which maladaptive behaviors present the greatest challenge to management. Ann Streissguth, JAMA. (Chudley, Kilgour, Cranston, & Edward, 2007, p.261)

Review of literature indicates that service delivery in the FASD area has focused far more resources on children than adults. There is a paucity in the literature on the transition from childhood to adulthood for individuals living with FASD (Rangmar, 2014). Diagnosing adults presents another complex range of problems, such as

educating professionals on being able to recognize the possibility of FASD in an adult; and problems accessing reliable prenatal alcohol history, particularly if the birth mother is not available or in some cases may be deceased. Studies indicate that most adults with FASD will not be raised by biological parents, and there is a high mortality rate of mothers who give birth to children with FASD (Brown et al, 2015). Both children and adults with FASD often have dysmaturity which is emotional development that is well below their chronological age. Compounding this is the stigma attached to FASD and the public opinion that a negative life trajectory is inevitable.

Prevalence of FASD amongst adults is generally unknown (Chudley et al 2007). Whilst there are no known mortality rates of FASD for adults in Canada, the estimated mortality rate for children with FASD is 6 per cent. However, the mortality rate of FASD is arguably high given the lack of diagnosis, intervention, and serious social problems relating to secondary disabilities. Under the current diagnostic capacity for adults, it is only possible to diagnose one end of the spectrum and that is FAS. For adults with cognitive and behavioural difficulties, a FASD related diagnosis cannot be made without maternal history of prenatal alcohol exposure (Chudley, et al 2007). It is likely that adults with FASD will not be able to live a completely independent life and will need the support of services and family for the remainder of their life. Adversity for adults escalates particularly in the context of lack of care and case management; making them vulnerable to homelessness; abuse and domestic violence (Brown, 2012). Review of literature indicates trauma across the lifespan also plays a role in escalating the deficits of FASD.

Review of literature highlights that diagnosis of FASD for adults becomes a significant turning point personally, socially and economically. Diagnosis is critical for implementing strategies that will address the deficits of the disability, and avoid the mis match of inappropriate treatment strategies, such as cognitive behaviour therapy, and being able to access disability benefits (Grant et al 2013). In terms of treatment for FASD clients with alcohol and substance abuse problems very little is known. However, Grant et al, (2013) points out that approximately 2.6 million people in the US enter treatment for alcohol and substance abuse, with only around half this amount successfully completing. Grant et al (2013) argue that one of the likely reasons for this

high failure rate is that many of this population may be undiagnosed adults with FASD.

Future vocational and employment opportunities for adults with FASD is bleak without support from carers, and understanding of potential employers (Duquette & Orders, 2013). Adults with FASD in the workplace also expressed being discriminated against by their colleagues, upon understanding they have a disability (Duquette & Orders 2013). A common sentiment expressed by adults who were able to receive their diagnosis with FASD, is that the diagnosis gave them important answers as to why they had struggled throughout their lives and could not function the same as their peers. This was a critical revelation that is often denied to adults with FASD, due to lack of diagnostic opportunity as children. With this new found knowledge, they were able to reassess their own life with support and make adjustments that accommodated their disability.

Steven Neafcy writes: I was not diagnosed with FASD until I was 43 yrs old and not knowing the reasons for my actions was very frustrating. I was really a person who wanted to do good!! I could not understand what drove me to disappoint those I wanted to be proud of me. I was so lost! With this information I could pick up from that point and not keep bashing my head against the wall trying to be normal and function like those who don't have brain damage. This is impossible! (Chudley, et al, 2007, p.12).

The intensity of social support will vary from each adult to the next with FASD, in terms of independent living, for instance, one adult may require 24 hour supervision and another may require a daily check in by a carer/support worker. Access to case management, or a mentor has also proven to increase the quality of life for the adult with FASD in terms of receiving more services and an increase in income (Chudley, et al 2007). In a study undertaken by Grant (2005 et al) the findings were consistent with a similar study undertaken by Streissguth (et al 2004) and found that young women with FASD have a poor quality of life and high levels of psychiatric distress and behavioral problems.

Most of the female participants in this study were non-Indigenous and young, unmarried poorly educated, and the majority of the women were already mothers. Almost half of the participants had unstable housing. As young children, the participants all had mothers who abused alcohol and 46 per cent had abused illegal drugs. The majority of the participants had been sexually or physically abused, and

only 27 per cent had been raised by their biological families. Four per cent of participants as young women were already experiencing serious health problems such as kidney failure.

In Sweden a study by Rangmar, Hjern, Vinnerljung, Stromland, Aronson & Fahlke, (2015) was conducted on 79 adults with a FAS diagnosis, and the mean age of the participants was 32. The results found that the majority of the participants had received special education, half were unemployed and on a disability pension; had high rates of admission for alcohol abuse and their rates of psychiatric disorders was high at 33 per cent and they were more likely to use prescribed psychotropic drugs. Every second person in this study was employed, in low paying jobs and was reported as sheltered employment provided under the Swedish Public Employment Service.

Adult Undiagnosed FASD: Research Case study

The literature highlights that FASD prevalence rates throughout the world are generally underestimated and influenced by lack of awareness of health professionals and access to diagnostic services. This implies there is significant population that has never received the opportunity to be diagnosed, and the following case study illustrates this point. A case study undertaken by Sparrow (2013, et al) highlights the important issues of the lack of diagnosis in adults and the devastating impact on their quality of life in terms of the negative life trajectory without FASD diagnosis and support. As previously stated, the adult with undiagnosed FASD remains vulnerable to extreme diversity and at risk of continuing unstable and dysfunctional cycles, particularly when they become parents without diagnosis and support.

In this case study, Nina (not her real name) had never been diagnosed as a child; and she presented as young adult in her early 20s. Nina had just lost custody of her two young children as a result from substance abuse and she was living in temporary housing. Nina advised she had experienced significant problems with learning at school and for this reason dropped out early. Throughout her life, Nina had experienced traumatic events that included being physically and emotional abused as a child by caregivers and adults. Nina completed neuropsychological testing that included five domains of cognitive and behavioural functioning that is affected by parental alcohol exposure.

The neuropsychological evaluation revealed significant deficits consistent with FASD, and her IQ level fell within the range of mental retardation. The assessment also identified her strengths and the best way of learning for Nina. The results were shared with Nina's case manager, child welfare, housing service providers, and mental health. These services were advised of Nina's deficits, highlighting that Nina had a reading ability of fourth grade and therefore did not respond well to written child custody orders. Collectively, the services then responded and catered for both Nina's deficits in her abilities and her strengths. As a result, and intensive ongoing support from agencies; Nina regained custody of her children and remain sober. Nina's children were also enrolled in a therapeutic childcare facility for their development and educational needs.

Importantly, Nina also became confident and with support was able to self-advocate for herself. The writers argue that there were many important lessons to be learned from this case study, and sadly the Neuropsychologist was the first person to explain to Nina how FASD had affected her in all areas of her life. Without this testing, intervention and recognition of ongoing support, it is highly unlikely that Nina would have regained custody of her two children and the support structures put in place in order for her and her children to have family reunification. To date another 20 women have been assisted with Neuropsychological testing as adults, and similar service plans implemented.

Parents with FASD

Limited research has yet been undertaken on the experiences of parents with FASD raising their children (Rutman & Bibber, 2009). Moreover, it is documented that as many as 50 per cent of individuals with FASD will have children. However, little attention is given to FASD that may be generational in the family (Lange, et al 2013; Choate, 2013). The literature highlights there is a common risk of children from parents with FASD going into the care system. O'Malley (2014) argues that approaches to FASD must be from a transgenerational perspective, to break cycles of generational FASD. It is important to recognize with intervention and ongoing support, adults living with FASD as with any disability may have a life that is stable, productive and raise families (Malbin, 2002).

Choate (2013), notes that no attention in Canada has been given on how to assess the capacity of parents with FASD to parent their children, and cautions the label of FASD does not mean a parent cannot adequately parent their child. In terms of parents' capacity, there are other important questions around appropriate supports that parents with FASD may require. To date, there has been the presumption that parents with FASD will not be able to parent adequately. Further, research by Booth & Booth (1989) found that this presumption did not hold up to scrutiny. Choate (2013) identifies a number of factors for parent capacity including; whether the child also has FASD; has the parent been properly supported by well trained professionals in the past; parent's developmental history including trauma; is the parent committed to include support strategies.

Importantly, Choate (2013) and Herrick, Hudson, & Burd, (2011) recommend child welfare agencies adopt a strength based approach as coming from a deficit approach overwhelms the parent with FASD, and ultimately set them up to fail. Herrick (et al, 2011) asserts that adults with FASD can parent successfully, based on the premise they are supported by services that understand FASD. The author further explains when adults develop secondary disabilities due to lack of diagnosis, and early intervention, this places them at significant risk of having their children removed. Furthermore, they are also at risk of having a child exposed to PAE. Herrick (et al 2011) also point out that is imperative that any parenting education programs are adapted for parents with FASD.

As indicated, the number of parents with FASD who are parents and raising their children is likely to be significant (Grant, Huggins, Connor, Pedersen, Whitney & Streissguth, (2004). A qualitative study conducted in Canada, interviewed 15 parents who had suspected FASD and were caring for their children. The concerns from the parents with FASD included; breaking the cycle and achieving better life for their children and this included trying to abstain from alcohol and substance abuse. Many parents also indicated that they did not have positive parenting role models themselves; and felt judged by social workers who did not have good understanding of FASD, and therefore any parenting mistakes were seen as being neglectful on the parent. In turn, this caused undue stress on the parent and also increased the chances of the children being placed in care by social workers who lacked awareness of FASD.

Parents expressed their fear of seeking help with issues such as substance abuse as they were conscious of being on the radar of the care system, and were fearful of having their children removed (Grant et al, 2004). The programmes that these parents reported were the most useful in supporting them as parents were outreach oriented FASD programmes that were non-judgmental, and taught homemaker programs and basic life skills. It is important to note that memory problems occur with many adults living with FASD, and memory deficits may start as young as childhood.

In another study conducted by Denys, Rasmussen & Henneveld (2011), fifty per cent of the clients were diagnosed with FASD and the remainder were suspected of having FASD. The programme design “Step by Step” was adapted from the PCAP model, and clients were matched with a mentor to work with them for a 3 year period. The role of the mentor was to assist the clients in accessing supports such as housing, addiction treatment, resources, and parent support. Similar to other studies, the majority of participants had experienced traumatic events and had a high rate of mental health disorders and depression. The majority of participants indicated they were satisfied with the mentor programme in assisting clients to access critical social services, and this was measured by the level of reduction of crisis needs.

My definition of success for John who has FAS, is to avoid imprisonment, addiction, homelessness, parenthood, and accidental death. (Kellerman, 2003, p.1)

Impact of FASD on the family

Whilst, the economic costs of FASD to society have been well documented, the social and emotional costs to the individual with FASD and family are immeasurable (Piyadasa, 2010). The literature highlights that the majority of children with FASD will not be raised by their biological parents, and children with FASD are overrepresented in the care system throughout the world. Parenting and caring of children with FASD is vastly different from caring for children who do not have special needs such as FASD. Further, many will also need support for the rest of their lives. Raising children with FASD generally requires different parenting strategies as often traditional parenting styles may not be successful with children affected by FASD. Behavioural issues and adaptive skills become more challenging when children with FASD have been subjected to unstable home or multiple placements (Fagerlund,

Autti-Ramo, Kalland, Santtila, Hoyme, Mattson & Korkman, 2012). Furthermore, the literature identifies that frequently there is more than one child/individual in the family with FASD. Popova, Lange, Burd, Urbanoski & Rehm, 2013, p.8) argues:

First, all individuals with FASD have an affected family member and many will have multiple affected family members. Second, nearly all individuals with FASD have neurocognitive impairments that will affect their response to substance abuse treatment.

Carers often find children with FASD do not have the emotional development as per their chronological age, and this creates many social problems for the child. Stable homes and routines also play a critical role in preventing the onset of secondary disabilities. In a study undertaken on children in the US care system who had all experienced trauma. Children who had a FASD diagnosis were compared to children without FASD who had all experienced similar maltreatment in care settings. Results were disturbing in that children who had FASD were found to cope more poorly across all areas such as neurodevelopmental measures (attention, memory); behavioural problems; social problems related to attention deficit hyperactivity disorder (ADHD) (Olsen et al 2009).

Carers of children with FASD also experience difficulties in receiving respite care. This is a common theme for carers, and respite care is critical in preventing burn out of carers. In research undertaken by Goodman (2009) it was also identified that respite carers need to be well trained in FASD, as often children cannot cope with the change of routines. This in turn, creates more stress for the primary carer, and makes respite too difficult to manage when the child returns home. Carers are often unsupported and unprepared for the complex needs of a child with FASD. Whilst there remains lack of support for such carers, it is likely that many carers will be unable to care for children with FASD on a long term basis. Carers also express their frustration with the lack of awareness that still exists within society. Further one of the important protective factors in preventing the onset of secondary disabilities is stable placement of care. A study undertaken recently by Mukherjee & Wray (2013) examined the impact of raising a child with FASD upon the carers in the United Kingdom (UK). The prevalence rates of FASD are unknown in the UK, however, it was reported that possibly a third of children in care were suspected of having FASD. Prior to this

research project, no research of this kind has been undertaken in the UK.

The themes identified were;

- carers believed their difficulties with caring for a child with FASD were belittled
- lack of knowledge of professionals, and having to educate professional people
- having to “fight” for things
- feeling isolated and unsupported
- feeling blamed and misunderstood
- family stress
- concern for the future.

Furthermore, these themes identified from carers in the UK are similar to other studies undertaken in Canada and Australia.

The Challenges of FASD Prevalence in an International context

There are challenges in obtaining accurate FASD prevalence rates throughout the world. Without FASD prevalence rates, it remains difficult in gaining sufficient ongoing funding to have FASD diagnostic clinics; interventions and to promote awareness. Further, awareness of FASD as a disability requires what International expert Malbin describes as a “Paradigm shift” in understanding the full complexity of FASD (Malbin, 2002). The challenges in obtaining consistent prevalence rates of FASD are:

- FASD is an Invisible Disability
- Diagnostic criteria that varies from country to country and within a country
- Complexity of FASD, and the masquerading of other disorders and misdiagnosis
- Lack of awareness and stigma of FASD from health professionals
- Methodological differences in prevalence studies, ranging from clinic based data to passive surveillance data and active case findings
- Lack of diagnostic clinics for children and adults

O'Malley, (2014) argues also that the diagnosis and prevalence rates of FASD in individuals has also been significantly impacted by the lack of appropriate neuropsychiatric diagnostic formulation. The International Classification of Diseases (ICD) and the Diagnostic and Statistical Manual of Mental Disorder (DSM) do not

include disorders resulting from prenatal alcohol exposure (PAE). This is critical to note as the only FASD longitudinal study undertaken by Streissguth (et al, 2004) found that over 90 per cent of individuals with FASD had developed mental health or psychiatric problems.

Individuals living with FASD have become one of the most vulnerable groups in the world, both as children and adults and with many facing extreme adversity for the remainder of their lives. They remain vulnerable due to the complexity of the disorder; lack of awareness, and children with FASD, become adults with FASD. Badry (2011) argues that individuals with FASD remain vulnerable across their lifespan to drug and alcohol abuse; psychiatric disorders and abuse and neglect, and this is referred to as cascading vulnerabilities and exacerbates stress and trauma. Further, this is also compounded by lack of diagnosis of FASD or access to diagnosis and dedicated services for children and adults living with FASD. Fergulund (et al 2012, p.222) argues:

Thus within the population of individuals with FASD there exist a large group of undiagnosed children who are subject to structural and functional disabilities due to both prenatal damage from a teratogen and the long-term consequences of a social disadvantage.

Consequently, many individuals with FASD have and continue to miss the opportunity for diagnosis during their childhood. Writers such as Ferguland, (et al, 2012) argue that there is potentially a large undiagnosed population throughout the world living with FASD. Moreover, in many cases specialists such as Paediatricians have not provided a diagnosis as they are reluctant to stigmatise the individual and the family. Stigma and FASD will be further discussed later in this chapter. Therefore, accurate prevalence rates of FASD are generally unknown and difficult to ascribe across populations and are often conservative figures. However, access to diagnosis is improving and some prevalence rates have been provided now in areas such as Canada; North America, Italy; South Africa and Australia.

Most of the expertise on FASD is concerned with children and there is a paucity of literature on the transition to adulthood with FASD. Many adults with FASD also become parents themselves and without support and intervention become part of a

cycle that has not been adequately recognised and FASD has also become transgenerational in many families. With more than one generation of FASD within the family. Further, the travesty is the adversity confronting those with FASD is rarely acknowledged or understood by the western world. Leading expert O'Malley (2014) argues that any services and interventions need to also consider FASD from a transgenerational perspective. The literature also highlights that in as many as 50 per cent of children with FASD, it is likely they have a sibling with FASD and a parent with FASD.

Global FASD prevalence

According to literature FASD prevalence rates, are generally unknown throughout the world. As previously stated countries vary widely in terms of their diagnostic capacity and general awareness of FASD within the community. Some provinces of Canada are better resourced in terms of FASD diagnostic centres and services than other parts of the country. According to Thanh, Jonsson, Moffatt, Dennett, Chuck & Birchard, (2015), estimates of FASD prevalence are improving with better access to diagnostic services. In North America the estimated prevalence rates are 9.1 per 1000 births. In Alberta, the prevalence rate in 2012 was estimated at 10 per 1000 births, resulting in 46,000 people living with FASD in Alberta and 500 new cases of FASD a year.

Overall, it is estimated that there are currently 260,000 adolescents and adults living in Canada with FASD (Rutman & Van Bibber, 2009). However, Salmon & Clarren later estimated the overall population in Canada with FASD in 2011 as being 340,000 people. As stated these figures are estimates, and as there are parts of Canada that have less access to diagnostic services, these figures would be an under estimation of the accurate prevalent rate. Whilst, there is considerable experience and expertise in countries such as Canada, large sections of the overall population still have little or no awareness of FASD (George & Hardy, 2014).

May (et al, 2014) undertook a recent prevalence study amongst first grade children in the US and the findings challenge previous estimates provided for this country. This was an important study undertaken in a Midwestern US city where the majority of the population were white and predominately middle class, with only 11 per cent living below the poverty line. The report findings were that the prevalence rates for FASD

ranged from 6 to 9 per 1000. The prevalence rates are higher than those identified in any previous studies in Canada, Europe or the US. According to Grant et al (2013), the prevalence rate for FASD in the US is estimated to be 5 per cent of the population.

According to May, Keaster, Bozeman, Goodover, Blankenship, & Hoyme (2015), prior to 2014 only three prevalence studies were undertaken in the US that applied an active case ascertainment method, and these methods were pioneered previously in South Africa and Italy. May et al (2015, p.119) states

Many undiagnosed cases of FAS and other FASD exist in the US population, and active case ascertainment studies are designed to find them and to estimate the true prevalence.

In another study undertaken by May et al (2015) in the US prevalence rates again were higher than previously estimated. This was a large prevalence study that applied the same diagnostic methods and the prevalence rates for FASD were estimated at 10.9 – 25.2 per 1,000 or 1.1 – 2.5 per cent of the population. The number of children involved in this study was 1278, and mothers of children found to have FAS or PFAS were significantly lower in their own educational attainment. Roozen, Peters, Kok, Townend, Nijhuis, & Curfs (2016) undertook a systematic literature review to ascertain worldwide FASD prevalence rates, the findings also supported that worldwide prevalence rates were higher than previously estimated. High prevalence rates were found for PFAS in the countries of South Africa; Croatia, and Italy. The highest recorded prevalence rates for ARBD was found in Australia (Roozen, et al, 2016).

Canada and USA

The child welfare system has moved far afield from the original mandate of providing help to vulnerable children and instead has moved to a system of programs designed to increase the involvement of professionals while reducing the legal liability that agencies face when working with 'high need' children (Jones, 2004, p.13)

In the 1980s, led by carers and parents in both Canada and the USA, peer support groups were active in increasing awareness of FASD within the community. By the early 1990s this had grown to formalised FASD networks in both countries. These networks worked tirelessly and have been instrumental in consistently raising

awareness, advocacy and lobbying for the establishment of FASD diagnostic services. These support networks led by the community have played a critical role in the support of families and individuals living with FASD. Other important initiatives have included information and referral, personal advocacy, summer camp, respite care and training in FASD (Olsen et al 2009). However, whilst Canada and the USA are the leading countries in FASD diagnosis and service delivery, there still remain gaps in knowledge and diagnostic services and awareness within these countries. Literature from Canada and the USA has flagged the following areas as the continuing gaps in FASD knowledge and expertise, and requiring further research and attention:

- Over representation of children with FASD within the care system
- The transition of adulthood
- The impact of FASD on families
- Misconception that FASD is an Indigenous problem
- Intervention strategies and case management approach challenging traditional child welfare practices

Alberta, Canada: Advocacy and FASD in OOHC

In the late 1980s in Alberta, FASD became recognized as a serious health and social problem. It was estimated that there were 23,000 Albertans living with FASD and despite the dedicated FASD resources and services, approximately 360 new FASD births born annually. To this end considerable funding has been allocated in this province towards FASD, amounting to 37 million in recent years. Alberta has established itself as a world leader in this field with the adoption of a FASD strategy and significant funding allocated to FASD. However, Shankar (2015) writes that the political and social context towards FASD has shifted dramatically from its early premise.

In the early 1990s Alberta experienced an economic recession due to falling gas and oil prices. In turn severe government cuts were made in areas of social services, particularly child welfare. The government was criticized for reducing funds of welfare payments to families in need, and amongst this FASD was raised as the reason the rates of children in care was increasing. Initially, the government gave acknowledgement of FASD as a concern, however, only limited funds were committed to programmes and services. It was only after significant advocacy by caregivers and

social workers that substantial funding was obtained by the Alberta government.

Initially this change was led by a Canadian social worker who after many years working in the care system began to notice the same developmental issues in children, and the common denominator was prenatal alcohol exposure. This led to meetings and support from Government and training curriculum on FASD was developed in 1992 for social workers and child protection workers. Subsequently, many children in the care system were assessed and diagnosed with FASD. Prior to this time, it was noted that many foster and adoptive parents looked after children with FASD, with no training or awareness, overwhelmed with exhaustion many foster care placements broke down.

However, whilst there are key areas of Alberta that have FASD programmes, there are also many areas as well where no programmes exist, as FASD developed out of a child welfare concern (Shankar, 2015). In some provinces, compulsory units on FASD are included in the curriculum for Social Work students, providing them with a strong foundation for working with clients and families struggling with FASD. Pelech, Badry, & Daoust, (2013, p121) argue the following important point relating to case work practice in OOHC:

In Alberta, Canada, there has been a growing recognition that traditional models of casework for children in care do not work for children with FASD, due to concerns regarding behavioural challenges, requirements for supervision and structure, and the need for placement stability and permanency. This recognition has paralleled recognition of the need for a model of practice that specifically addresses the placement needs of children with FASD in care.

Lessons from Canada

Poole, Schmidt, Green & Hemsing (2016) provide a comprehensive review of service gaps and what interventions have worked in Canada in the past 10 years, including health promotions, and interventions for vulnerable families. Health promotions messages of warning labels on alcohol bottles, has had a limited impact in raising awareness and changing beliefs of risks associated with FASD. According to Poole (et al, 2016) the most successful evidence based intervention is the long established PCAP programme, that provides support for families over a three year period. This

programme allows the case manager to build relationships with the client, and have had successful outcomes in women abstaining and reducing alcohol and drug intake; completing treatment programmes and achieving housing stability. More discussion on PCAP is provided later in this chapter. Further, Poole (et al, 2016) argues the barriers for accessing treatment services, remain due to the fears women have in having their children apprehended by the welfare system.

Prevalence of FASD in OOHC

It is well documented that the majority of children with FASD will not be raised by their biological parents and will be raised in care. Children with FASD are over represented in the care system; and come into care at a younger age and stay longer than other children (Millar, Thompson, Schwab, Hanlon-Dearman, Goodman, Koren & Masotti, 2017). Fuchs (2010, p238) states:

Finally both the legal and placement histories confirm that permanent wards with FASD were spending, on average, approximately three quarters of their lives in the care of an agency, about 15% more than any other children who are permanent wards.

Further, the study by Fuchs (2010) found an over representation of Aboriginal children with FASD in Manitoba. According to research by Fuchs (2010), approximately 17% of children in care in Canada have FASD, however this figure is reportedly conservative. The position of children over represented with FASD in Canada is not unique to Canada. In Chile, the prevalence of FAS in child welfare was reported as 62 per 1,000; USA 10 – 15 per 1,000; Russia prevalence was estimated at 150 per 1,000. In orphanages in Brazil the rate was estimated at 277 per 1,000. Elliot, Payne, Morris, Haan & Bower (2008) survey of Paediatricians found that 49 per cent of children in care in Australia had been assessed with FASD. Further Paediatricians were confident of another 12 per cent had FASD, but felt a diagnosis would stigmatise the child.

In Alberta, Canada there has been growing concern that models of care for children are not appropriate for children with FASD. In a Canadian study by Greenbaum, Stevens, Nash, Koren & Rovet (2009) on 33 children with FASD in care found that 97 per cent had experienced multiple home placements since birth with 27 per cent having experienced more than four placements. That was in comparison to another cohort of

children who had only experienced one placement. Bertrand (2009, p.21) provides the following statements on children with FASD in the care system:

Unfortunately, the very factors that protect children with FASDs from developing secondary disabilities are the ones that children in the child welfare system frequently lack, such as being raised in a stable, nurturing home; being diagnosed before 6 years of age; having no sexual or physical abuse history; not changing households every few years...Thus children with FASDs and their families need interventions tailored to their foster care experiences, and which can provide skills that mitigate negative experiences as well as counteract any lack of protective factors.

Fagerlund et al (2012) completed the first study in Helsinki that compared the adaptive behaviour skills of children and adolescents with FASD to the same age group of children with similar IQ levels and specific learning disorders (SLD). The study also identified that children remain undiagnosed of FASD at high levels, and the majority of children with FASD had also been in the care system. Adaptive behaviour was considered under the categories of three domains; communication, daily living skills and socialization. According to Fagerlund et al (2012, p.221)

Without adequate intervention, adolescents and young adults with FASD run a great risk of marginalization and social maladjustment, costly not only to society but also to the lives of the many young people with FASD.

The study findings found that the group with FASD in comparison with the group with SLD performed consistently lower in adaptive behaviour skills (Fagerlund et al, 2012). Further, the impairments in social skills become more apparent with age. However, it was also noted that children with FASD who had not been removed from their birth families demonstrated better ability in their adaptive skills.

Missed FASD diagnosis and misdiagnosis in OOHC

In keeping with the adage that it takes a village to raise a child, one could add for children affected by FASD, that it takes a dedicated team to promote placement stability and better life trajectories (Pelech, et al, 2013, p.120)

Chasnoff, Wells & King (2015) recently undertook the first study in the US that assessed the number of children and adolescents amongst the care system and adopted children who had been missed for diagnosis for FASD and secondly who had received a misdiagnosis. The number of participants in this study was 156 children and adolescents. The results identified that the number of young people who had been previously missed for a diagnosis of FASD was 86.5 per cent. The number of children

who had been misdiagnosed was 6.4 per cent. The most common reason for referral was behavioural problems (Chasnoff et al, 2015).

Further, the majority of the children recently diagnosed with FASD were also found to have a co-occurring mental health diagnosis, 66.7 per cent had two or more mental health diagnoses combined with FASD. Importantly, the diagnoses enabled an urgent review of their current medication and treatments; 17.3 per cent required dental work and 69.9 per cent required specialized educational services. Upon correct diagnosis of FASD, ten children no longer required medications for ADHD. The findings of this important study highlight the profound impact that delayed and incorrect diagnosis has on children in terms of lack of correct treatment modalities and medication in the prevention of secondary disabilities.

Transitioning from Child welfare with FASD to adulthood

As previously stated, in the early 1980s awareness of FASD was raised as it was clearly recognized as being overrepresented in child welfare in Alberta. The issue of children in care with FASD, also raises critical issues for supporting children making the transition to adulthood. Transition to adulthood needs to incorporate firstly having care extended and secondly ensuring that a long transitional phase is put in place. Burnside and Fuchs (2013) conducted a qualitative study of young people with FASD who had been in the care system in Manitoba, to explore their experiences of transitioning out of care. This study involved 20 young people aged between 16 – 21 years, with equal representation of gender. Whilst the sample was small, the participants came from all four Child and Family Service authorities in Manitoba. Fourteen of the participants were still in care at the time of the study and four youth had left care with an extension of services prior to leaving the child welfare system. Most of the youth involved in the study had experienced multiple placements that ranged between two and twenty changes of placement. Nine had left school without completing high school.

The participants understanding of FASD was generally very little, and those who had been diagnosed expressed their shame with the disability, believing that others would judge them differently. The common theme in the research was the longing for family connections, and participants expressed their own unresolved grief and loss at not

having close biological family ties. In turn, this also affected the self-worth of participants, as they blamed themselves for not having their families. A disturbing finding was that most of the youth did not have conversations with their social workers and foster care families about transitioning out of care. Whilst, social workers did offer most of the young people an extension of care past the age of eighteen, other important basic skills were not taught, such as cooking, budgeting, and keeping a job. Further, six of the ten females, had already had their first child and two were pregnant with their second. Burnside and Fuchs (2013) research also identified that an extension of care past the age of eighteen was critical in preparing young people to transition to adulthood with FASD.

Early intervention with FASD

Experts agree that it is critical for any child born with FASD to have early diagnosis, and early intervention to prevent the onset of secondary disabilities. According to (Streissguth et al., 2004) without intervention and support, as high as ninety percent of individuals with FASD will develop mental health problems. Further, experts agree that although FASD is irreversible the quality of life may be increased through early intervention and ongoing support (Streissguth et al., 2004). With diagnosis, the individual has the potential to avoid the negative life trajectory that is common for those individuals who do not have diagnosis. International expert Dr Kieran O'Malley argues that it is important to look at FASD from a generational perspective, recognising that often there is more than one generation of FASD within a family. Further O'Malley cautions that until we approach FASD from this perspective, it will be difficult to completely address FASD. According to Leenaars, Denys, Henneveld & Rasmussen, (2012, p431)

Streissguth et al. identified five protective factors including living in a good quality, stable home environment, infrequent changes in living environment, not being exposed to violence, receiving services for developmental disabilities, and being diagnosed before the age of 6.

Streissguth (et al, 2004) concluded that without early intervention, provision of good services and family support, children are at high risk of social and behavioural problems for the remainder of their lives. Further, the secondary effects of FASD, with the disability have been known to intensify during the lifetime of the individual with FASD. Diagnosis of FASD also increases agency and self-advocacy for the individual

living with FASD. Further, individuals living with FASD with the appropriate support and intervention have been able to succeed in life. It is imperative to note that people with FASD have unique strengths and with appropriate support and intervention have been able to avoid the negative life trajectory and have stable and successful lives. According to Malbin, adults with FASD have held been able to attend University or college training, and have had a range of positions including, a teacher; a drug and alcohol counsellor; and have been able to be successful at parenting themselves.

Interventions for children and families living with FASD

Internationally, Fetal Alcohol Spectrum Disorder (FASD) has emerged as having a significant impact on communities and systems...such as health (eg. primary care, acute care and specialty care), education, justice and social services. FASD is a complex neurodevelopmental disorder that results in permanent disabilities. The cognitive and behavioural disability-related profiles and subsequent service needs of affected individuals change across their lifespans (Masotti, Longstaffe, Gammon, Isbister, Maxwell & Hanlon-Dearman, 2015, p.1)

Review of literature identifies that there is a paucity of literature on appropriate interventions for children diagnosed with FASD. Reid, Dawe, Shelton, Harnett, Warner, Armstrong & O'Callaghan (2015), asserts that this is an urgent concern, as it is well documented that early interventions are critical to minimizing and preventing the onset of secondary disabilities. A long standing complaint reported from parents and carers is that clinicians are reluctant to diagnose as there are no known effective treatments for children with FASD. Piyadas (et al, 2011) argues that whilst a great deal of research has been undertaken on FASD, cross fertilization from clinical to practice and interventions has rarely occurred. Until recently interventions and strategies for FASD had been adapted from the disabilities field, combined with trial and error and consultation with clinicians; parents and carers. Interventions within this field have also been largely developed and implemented without being evaluated systematically or scientifically.

Bertrand (2009) undertook a review of five specific FASD intervention programmes that were implemented in five diverse locations in the US. According to Bertrand (2009) no other systematic reviews of intervention programmes had been undertaken, prior to this study. The findings were that all five programmes were successful in

producing results that demonstrated targeted behaviours and skills. The participants were children aged between 6 to 11 years of age, who had a confirmed history of prenatal alcohol exposure. In one research study 78 children participated and the majority of the children were in foster care, and a small number had been adopted. In particular, most of the programmes also achieved statistical significance in their results.

Moreover, these FASD intervention programmes also highlighted important lessons that emerged and possibly explained their high success rates, and this included the provision of more training for carers/parents. Another intervention programme was aimed at providing children with tools in being able to socially interact better. Many children with FASD have trouble sustaining friendships, due to neurocognitive damage and misreading social cues. Learning social skills is critical to improve social relations with peers. This intervention also addressed an important part of social living for children with FASD, and these new skills would hopefully prevent them from feeling further alienated and alone with their disability.

Programmes were also implemented that addressed behaviours and support for children to be able to learn self-regulation with their behaviour. This is another critical intervention and also included training for parents and carers. Interventions that address behaviour training for children and which offer carers and parents' tools are critical to reduce some of the carer and parent stress. It is well documented that Carers and parents experience severe stress in caring for children and as previously stated often without respite.

Parent Child Assistance Programme (PCAP)

The PCAP Model was first developed in the USA in 1991 and has since been widely replicated in Canada since 1998, with the first sites in Manitoba. PCAP is an intensive three year case management programme and its main objective is the prevention of further births within the family that are exposed to alcohol and other drugs. PCAP case managers are highly trained para professionals and work with clients in establishing personal goals. Supervision of case managers is provided by experienced clinicians in either mental health, social work or the alcohol and drug field. Case managers meet with clients twice a month, and have a case load of 16 families. The model has proven

successful with women entering treatment and achieving sobriety. There are now currently 30 programmes based on this model in Western Canada.

Parent-Child Assistance Program (PCAP) Intervention for women with FASD

A study completed in the US by Grant et al (2004), focused on the needs of 19 young women who were identified or suspected of having FASD. These women were enrolled in an existing PCAP programme for a 12 month period. The existing PCAP programme was adapted for the cognitive deficits of the young women. To this end, PCAP staff received further training in FASD. Grant et al (2004, p.503) states

Clients; poor short-term memory often resulted in information or instructions being quickly forgotten. Although their long-term memory could be fine, their information storage was often disorganized so information was difficult to retrieve.

Most of the female participants were non-Aboriginal, unmarried, and poorly educated, almost all the women had been physically or sexually abused as children and only 47 per cent were in stable housing. Most of the women were mothers, however only half of the children were living with their biological mothers. Forty seven percent had already experienced chronic health issues such as kidney failure, and 68 per cent had been incarcerated. Seventy one per cent had been diagnosed with a psychiatric disorder. At baseline of the project only 16 per cent of the clients medical and mental health needs were being adequately met. At the conclusion of the programme, 84 per cent had secured stable housing. Another outcome was the majority of women were abstaining from alcohol and drug use. The findings also included that working with FASD clients under this framework was successful, however, required more intensive advocacy and case management by PCAP staff.

Education and children with FASD

The United States Department of Health and Human Services reported a Washington study which estimated that 35% of individuals with FASD has been in jail or prison and that more than 50% had been in trouble with the law. Given this, there is a societal advantage to adapting the education system to meet the needs of individuals with FASD in order to support completion of education and occupational strategies (Millar, et al, 2017. P7).

According to Glass, Moore, Akshoomoff, Jones, Riley & Mattson (2017), for the past three decades there has been awareness of the significant challenges and the secondary

disability of problems with education. Further, Glass (et al, 2017), argued despite this awareness there remains gaps in knowledge in school based interventions for children with FASD. Throughout the world, teachers are generally not prepared or trained for the special needs of students with FASD (Carpenter, 2014). The prevalence of FASD in schools in Croatia, Italy, South Africa, Sweden and the USA is estimated to be between 2 to 6 per cent (Millar et al, 2017). Without remedial supports, and importantly understanding and training by teachers in FASD, students are basically set up to fail in the mainstream school system. Literature identifies that children with FASD have a range of complex learning needs, and combined with not being able to self-regulate their behaviour, this is often seen as behavioural problems within the school system (Millar, et al, 2017; Carpenter, 2014). As a consequence, many children with FASD disengage with the school system and often drop out of school early.

Canada has been active in formulating FASD policy and a range of services to cater for children with FASD. Whilst there still remains considerable gaps in service delivery for children and adults living with FASD, some support programmes have been established in the form of specialized schools in Winnipeg, Manitoba in 1995 (Millar, et al, 2017). Millar (et al, 2017) advises the Winnipeg School Division (WSD) developed their first school in 1995 and has since grown to now include junior high school. The teachers are trained in FASD, and the classrooms are small with 8 children in each class, 1 teacher and two educational aids. These specialised schools for students with FASD cater for their developmental age, and not their chronological age. Further, the school programme includes meeting the social, educational and emotional needs of the student. Millar (et al, 2017) asserts schools are ideally placed to address feelings of shame, loneliness and stigma often experienced by students with FASD. Further, this is critical noting the high incidence of mental health in children with FASD.

Advocacy for educational needs for students with FASD

Duquette, (et al, 2012) identified that it is critical for carers to continue to advocate for their children in the education system. Some parents found that even with the diagnosis of FASD this sometimes did little in persuading the teacher of adapting teaching programmes for their children. Further, in this study by Duquette (et al, 2012) carers reported they had to consistently advocate within the school system, and on occasions,

carers were left with no other option but to home school their child.

Another study by Hellerman, Sliwowska, Verma & Weinberg (2010) recorded the experiences of adoptive parents of adolescents and young adults with FASD. Participants included 36 parents, 10 from the USA and 26 from Canada, 20 of the parents still had adolescents in school and 16 had young adults who had either left school without graduation or had manage to graduate from high school. The majority of participants had adopted their children before the age of 5 years. Parents who had adopted their children at birth were aware the child had FASD. Other parents, however, were given no indication that the child had been prenatally exposed to alcohol or had suspected FASD. Most of the parents in this study were a traditional two parent family structure. The findings were that their children struggled within the school system, and for most of the children, these problems escalated throughout their schooling years, leading to disengagement, dropping out and early drinking of alcohol. For some parents their children had also been incorrectly diagnosed with ADHD.

Parents of older children sought further assistance upon the secondary disabilities, and finally received a diagnosis of FASD. Some parents chose to home school their children when the problems became too difficult in the school system. Generally, parents spent considerable time, and energy in advocating for the special needs of their children with FASD, some parents enlisted the support of other advocates and lawyers in presenting the case for their child's needs to be accommodated within the school system. The parents involved in this study stressed that advocating for their children was extremely hard work in educating the system, and teachers, on an ongoing basis.

Parents also stressed that there was a need to monitor schools in meeting the needs of their children. To this end, parents advised that their children experienced loss of self-esteem; depression and falling grades and often fell into a negative spiral. Parents advised the constant advocacy required was stressful personally, particularly when schools were resistant to the needs of students with FASD, and subsequently caused burn out for some, and stress on some marriages. Hellerman (et al, 2010) concluded that special needs legislation does not automatically facilitate that schools meet the educational needs of children with FASD.

In a later study conducted by Poth (et al, 2014) participants in this study included; 31 teachers; 7 administrators, 16 allied professionals and 6 caregivers, the aim of this research was to explore multiple perspectives on the experiences of students with FASD in the educational system. Allied professionals highlighted that much of the recorded information on students with FASD was negative and deficit based, and here they pointed out that it was important to look past this kind of documented information and get to know the student on an individual basis, and not be influenced. This point was captured in the following statement:

I don't want to look at (cumulative files) because so much of it is...negative (with) a lot of kids I have worked with, we would not have had nearly so much success... had (I) read the (cumulative file) first. (Poth et al, 2014, p.254)

The findings included that smaller classrooms were a better alternative, and for curriculum to focus more on basic literacy; vocational and life skills for better preparation for adult life. Teachers felt that an individualized teaching approach was more effective for students with FASD. According to Millians (2015) carers of children with FASD need to receive training on the educational needs of their children. This would provide carers with more confidence to advocate for the children at school. Further, Millians (2015) argued that school based interventions were critical in supporting children with FASD cope with the academic, behaviour and social demands of the schooling system.

Global awareness of FASD

In the review of literature, it is disturbing to note the different commencement dates globally for countries in addressing and recognising FASD within their own country. The timeframes range from 15 – 30 years apart, with some countries beginning to address FASD only within the last decade. According to Olsen (et al, 2009) countries around the globe have been complacent in implementing national guidelines that raise awareness of the risks of drinking alcohol during pregnancy. Arguably, this has also had an impact on the lack of global prevalence rates of FASD, as different countries offered no diagnostic services until recently. Australia's prevalence rates of FASD remain largely unknown as the diagnostic tool was only accepted within the last two years. Further, the World Health Organisation (WHO) has only included prenatal alcohol exposure as a concern with the adoption of the first global strategy aimed at reducing harmful drinking of alcohol in 2010. Consequently, the timeframe of having

the capacity in providing FASD diagnosis and monitoring prevalence rates has been considerably different and in terms of resources for each country.

Clearly, Canada and the USA have been the International leaders in FASD research with service delivery dating back to 1978. Globally, other countries have lagged behind Canada and North America in beginning to address FASD around the world. For instance, Ireland only published their first study on FASD as recent as 2010, despite having one of the highest underage and binge drinking patterns in the world. However, France was active in their research on FASD and is the only country in Europe to have warning labels on the dangers of alcohol beverages for pregnant women.

Germany

Germany has had an interesting early history of FASD research whereby case study research was undertaken by Paediatricians Majewski in 1978 and by Spohr and Steinhausen in the early 1980s. Despite this relatively early start in research no FASD prevalence studies have been undertaken in Germany. However, the German Drug Commission estimates that around 10,000 births occur each year of infants who have been damaged by alcohol, with 4,000 estimated as having full FAS. Additionally, drinking alcohol during pregnancy is reportedly widespread.

Despite having no FASD prevalence rates, Germany has implemented critical FASD services that include specialized assisted living for adults with FASD. This caters for individuals who require more intensive support and supervision during the day. Other supportive accommodation is provided for those adults who do not require as much intensive support. Germany also has one of the oldest European FAS support organisations, FASworld Deutschland which also provides online support and has 17 regional support groups for parents, as well as raising awareness. There are two specialist FASD diagnosis clinics in Munster and Berlin.

Italy

According to Vagnerelli (et al, 2011) there are no national clinical protocols for FAS/FASD in Italy and Spain. Further, it was noted that women in both Italy and Spain were now increasing their levels of drinking and binge drinking patterns in the

child bearing age group. Earlier research was conducted in Italy in 1990, and in 2003, research in collaboration with an American group began the first active ascertainment study of FASD in the region around Rome. The study conducted on FASD prevalence in communities around Italy and Rome found that rates were considerably higher than previously estimated. Research was conducted with school age children aged 6, and the results found rates for FASD ranged from 4.0 to 12.0 per 1,000; Partial FAS ranged from 18.1 to 46.3 per 1,000 and FASD ranged between 23.1 and 62.6 per 1,000 or 2.3% to 6.3% of the children. The methods applied in the study were well established active case ascertainment by a highly specialised team.

The authors (May et al, 2011) argued that these high FASD rates raised questions as to overall FASD prevalence rates in Western Europe. Prior to this study there has not been many active case ascertainment studies undertaken in the USA or Europe. The authors argued that whilst the results of FASD prevalence were high, they were confident in the methods applied throughout the study. The majority of the participants in this study were middle class. Insight was also provided by this study population as to being generally well nourished and well educated, in comparison to the poorly nourished, low SES and binge drinking population and still produced a high prevalence of FASD.

In another survey study conducted in Italy on FASD awareness and drinking patterns produced findings that 18% of women continued to use alcohol during pregnancy and 50% of Italian doctors continued to advise their pregnant patients that it was fine to drink occasionally. Similar to other countries, Neonatologists and paediatricians advised of their low confidence in being able to diagnose FAS. Further, these specialists felt that their training was not adequate enough in assisting them with making FASD diagnosis. In regards to families there are currently no agencies that provide support to families or individuals that live with FASD.

Netherlands

FASD awareness in the Netherlands has really only gained momentum in the past decade, prior to that acknowledgement of FASD was sporadic and not consistent. However, in this relatively short period of time there are now two dedicated FASD diagnostic centres in the Netherlands, and importantly, these clinics also caters for

adults as well as children, generally FASD diagnostic clinics do not diagnose adults. Similar to other countries, alcohol consumption was estimated in 2005 as being between 35 to 50 per cent of women continuing to drink alcohol whilst pregnant. A recent study in Rotterdam identified that 37 per cent of pregnant women continued to consume alcohol during pregnancy. These women largely came from a middle class background and were well educated.

Research was recently undertaken by Knuiman, Rijk, Hoksbergen, van Baar (2014) in adopted children from central and Eastern Europe by Dutch parents. According to these authors, there is a paucity of research undertaken on FASD prevalence on children who have been adopted. Recently research has identified that children adopted from Eastern Europe are at high risk of having FASD. Reportedly, one third of women in Russia of bearing age drank alcohol on a regular basis. Between 2003 and 2012, 3462 Polish children were placed for International adoption, and prenatal alcohol exposure was considered to be a risk factor amongst these children. The FASD prevalence rate for these children adopted from Poland was high, and further it was likely that some children had not been diagnosed.

South Africa

South Africa has been active since 1997 with the establishment of the Foundation for Alcohol Related Research (FARR) a non-government agency to address the challenges of substance abuse and the impact of alcohol in South Africa. FARR has been instrumental in raising awareness of FASD within South Africa, with over 50 reports and importantly that has led to prevention models. Further, 10 non-government organisations (NGOs) have been established to address FASD awareness, prevention and education. The South African Minister for Health has now included FAS as one of the four major birth defects in South Africa.

FARR conducted FASD research in several communities in Johannesburg, Gauteng Province and two communities from the Northern Cape Province. The first prevalence study was undertaken in 1996 and 1997. For ethical reasons and to maximise the potential for interventions and further prevention of FASD, young school aged children were selected for the first and subsequent prevalence studies. However, prevalence studies conducted in discrete communities should not transfer to the wider

population, due to the composition of that region. The findings from prevalence studies conducted identified the following risk factors; women who were found to have one child with FASD were at high risk of having another or more children with FASD; education and religion was seen as a protective factor, as women who were religious were less unlikely to drink alcohol (Vilene, 2014).

In a recent comprehensive active case ascertainment study undertaken in South Africa, the findings included some of the highest prevalence rates of FASD found in a study population. The prevalence rates of FASD were reported as between 135.1 and 207.5 per 1,000 (May, 2013 et al). The study was conducted in the Western Cape Province (WCP) of South Africa and has a population of 5.3 million people, and 40% of the population reside in small towns and rural areas. Recreational drinking patterns were reported as weekend binge drinking consumption by both men and women. Further, it was reported that one-quarter of the women continued drinking alcohol throughout the pregnancy. The methods used in this study were more comprehensive than previous prevalence studies conducted in South Africa, allowing the inclusion of the full spectrum of FASD, resulting in a higher and more accurate FASD prevalence rates.

New Zealand

The burden of alcohol harm to society costs the New Zealand government 5.3 billion per annum. Despite, general public awareness within New Zealand, the incidence of female drinking remains high, with 60 per cent of women consuming alcohol at risky levels and 28 per cent continuing to drink alcohol during pregnancy. The prevalence of fetal alcohol syndrome in New Zealand was first identified back in 1996 by Leversha & Marks using the passive methodology the prevalence rate identified was 0.11 per 1,000.

The passive methodology only reports the most severe cases of the FASD spectrum, and does not capture the full spectrum of FASD. Further this rate was seen as being an underestimate of the true prevalence of FASD in the country. To date, no further prevalence studies have been conducted in New Zealand. However, a good understanding and awareness of FASD has prevailed in this country and whilst no comprehensive prevalence studies have been undertaken the agency Alcohol

Healthwatch has been active in providing regional and national health services to reduce alcohol-related harm.

Further, Alcohol Healthwatch have been successful in increasing education and awareness of FASD amongst the juvenile justice system within New Zealand. This has led to a successful collaboration with the youth justice area and resulted in clinicians being trained and enlisted to provide diagnosis for young people highly suspected of having FASD appearing before the youth court system. Funding was secured to provide specialist clinicians who were trained by FASD experts from Canada and the USA. The Canadian FASD diagnostic guidelines have worked well in New Zealand and has been evaluated identifying that the diagnostic pathways was both feasible and urgently justified. Alcohol Healthwatch have actively continued to build capacity within the New Zealand workforce sector, and began delivering training in FASD in 2010 to agencies such as police, correction services; school and non-government agencies.

Conclusion

This chapter has provided a review of global FASD literature that identifies the key elements of the complexities of this disability in terms of lack of awareness in the community; lack of diagnostic services and stigma. FASD is the leading cause of an intellectual disability throughout the world. Global FASD prevalence is unknown, however, there is enough evidence to suggest that FASD is prevalent throughout the world, and with increased alcohol consumption in the past two decades is likely to be increasing. To this end, FASD diagnostic clinics and methods are also improving; however, it will continue to take a concerted effort of each country to raise awareness to address prevention of FASD particularly amongst the medical profession.

This chapter has also highlighted some of the challenges of countries beginning to address the complexity of FASD and the gaps in knowledge and expertise such as transition to adulthood. Interestingly, some countries such as New Zealand have not allowed the lack of prevalence data to deter them from implementing FASD diagnostic and support services.

The next chapter and part two of this literature review, will focus on Australia and

research on FASD. In this context, attention will also focus on the colonization experiences of Aboriginal people and the forming discourse of FASD and Aboriginal people. It is well documented that any approaches to FASD and Indigenous people must be seen in view of the historical and social impact of colonisation.

CHAPTER 3

Part 2: Australia Literature Review

We were also told that in WA children are being born who are 2nd or 3rd generation children with FASD. This means children born with FASD may have parents and grandparents who have FASD....Given that FASD is diagnosed in other countries it is unacceptable that West Australians, and Australians, are still waiting for the government to sign off on an agreed diagnostic tool for FASD. (Education and Health Standing Committee, 2012, p.6)

Introduction to the Chapter

This chapter will provide a brief overview of Australian research and literature relating to FASD. The current FASD prevalence studies in Australia has concentrated more on Fetal Alcohol Spectrum (FAS) than the wider spectrum of FASD, creating a significant gap in Australian knowledge of FASD (House of Representatives, 2012). Currently, in Western Australia there is limited capacity in providing FASD diagnostic services, and lack of awareness amongst health professionals. Whilst, there is a lack of awareness of FASD within Australia, there has been an increasing momentum from the overall community for FASD to be addressed.

This chapter will also focus on the representation of Aboriginal people and FASD in Australia, and provides a brief historical overview and comparison with the position of Indigenous people of Canada. It is well documented that colonisation has contributed significantly to the similar contemporary social indicators, such as the high rates of Indigenous children in OOHC for both countries. This highlights the instrumental role that colonization and systemic racism continues to play in the contemporary position of Indigenous people of these countries, and this is further compounded by the social discourse on FASD and Indigenous people.

Early Advocacy Australia and NOFASD

Prior to Australian research gaining momentum, early advocacy and lobbying remained active at the community and grass roots level. Similar to Canada, early advocacy was led and continues by carers and birth mothers such as Sue Miers, Lorian Hayes, and Anne Russell. In 1999, Miers founded the National Organisation for Fetal Alcohol Syndrome and Related Disorders, and the name was later changed to

NOFASD. NOFASD largely operates on a volunteer basis with a group of dedicated volunteers. NOFASD is the only dedicated Australian FASD agency and provides support and advocacy for families and individuals living with FASD.

Background to Australian Research on FASD

The first Australian publication by Collins & Turner, 1978 on Fetal Alcohol Spectrum Disorder was published in 1980. This publication described six children who were born to alcoholic mothers, in an attempt to increase the awareness of FAS in Australia (Elliot, 2014). Another Australian study was later conducted by Walpole and Hockey (1980) and this failed to demonstrate the link between low to moderate alcohol consumption and the connection to FASD or neurological damage. Consequently, this contributed to the belief that it was generally safe for Australian women to consume low to moderate alcohol consumption during pregnancy (Elliot, 2014).

According to the World Health Organisation (WHO), Australia has one of the largest alcohol consumption rates in the world (Elliot, 2014). Prior to ten years ago the level of awareness, and research on FASD within Australia was generally sporadic, with the next stage of Australian research undertaken by authors such as O’Leary (2002); Hammill (2003); Harris & Bucens (2003); and Elliot & Bower (2004). In 1992, a survey of South Australian GPs found that only 42 per cent could identify the harmful daily level of alcohol intake for women. In comparison to recent surveys of health specialists by Payne et al (2005) the awareness of health professionals was even lower at 12 per cent. Similar to the rest of the world, the diagnosis of FAS/FASD does not meet the criteria for a disability within Australia. There are no dedicated services with resources in Australia to support families with children with FASD or adolescents/adults with FASD. The recent Western Australian Inquiry into FASD made reference to FASD as the “Invisible disability” (Western Australian Legislative Assembly, 2012:6). In Australia, parents/carers of children with FASD, care for these children with little recognition and no support, and some families care for more than one child with FASD.

Australian FASD Government Reports and FASD Diagnosis

Within the last decade there has been an increasing number of government reports, both at a state and national level undertaken on FASD (Closing the Gap Clearinghouse,

2014). These include a federal parliamentary inquiry in 2011, and revision of guidelines for alcohol use during pregnancy in 2009 (Elliot, 2015). In 2010, the first framework model of care on Fetal Alcohol Spectrum was launched in Perth, Western Australia. This report identified a number of key areas that needed to be addressed including; lack of access to diagnosis; children in care and juvenile centres. The main focus of this report was on prevention and promoting awareness of FASD across sectors. The report highlighted that Australian FASD prevalence rates was unknown due to lack of screening and diagnostic capacity. Moreover 50 per cent of pregnancies in Australia, continue to be unplanned. Across work sectors, the report advocated for interagency partnerships and that training for health professionals be established with some urgency. Currently, there continues to be significant gaps to screen, diagnose and treat FASD in Western Australia. This limitation of this report was it did not identify the urgent need for FASD interventions, particularly across the lifespan.

In 2012, the Western Australian government released its comprehensive report titled: Foetal Alcohol Spectrum Disorder: the invisible disability. The report also highlighted that there was now likely to be two or three generations of FASD within the one family. The inquiry was critical of the following issues relating to FASD in Australia:

- In 2012, there was still no accepted diagnostic tool in Australia, and that less than 50 per cent of health professionals in WA routinely asked about alcohol use during pregnancy.
- The high likelihood that FASD was probably being misdiagnosed for ADHD and mild autism.
- Physicians lacked the expertise and awareness of appropriate intervention programmes for children with FASD.
- The critical impact of FASD not being recognized as a disability, and therefore families not receiving funding, and support for their special needs across the lifespan. However, in terms of the economic costs of FASD, it was estimated that over a 40 year period one person with FASD would cost the community \$1,000,000.
- The significant disadvantage of juveniles and adults with FASD in the Western Australian criminal justice system.

McLean & McDougall (2014) undertook an Australia review of the current issues and policy directions required for addressing FASD in Australia. In summary, the authors note that Australia was well behind countries such as the US and Canada, and the development of programmes and policies to address FASD has been on an ad hoc basis across various Australian jurisdictions. Prevalence rates were unknown due to the lack of diagnostic screening, and knowledge of professionals. Further, the perceived stigma and lack of services was also believed to contribute to the unknown prevalence of FASD in Australia. Whilst a few studies have been undertaken to explore the level of understanding of FASD amongst health professionals, no studies to date have examined the level of knowledge and understanding of Aboriginal people in urban areas within Australia. In the past decade considerable research and national inquiries on FASD has been undertaken within Australia. However, this action whilst urgently needed has not yet translated into dedicated service delivery for children living with FASD in Australia.

Alcohol consumption and Australian women

In a study conducted by Colvin, Payne, Parsons, Kurinczuk & Bower (2007) a random sample of non-Indigenous women in Western Australia was surveyed 12 weeks after the delivery of their babies. The results found 46.7 per cent of women had not planned their pregnancy, and most women 79.8 per cent reported drinking alcohol during the first 3 months before pregnancy and 58.7 per cent continued drinking alcohol one trimester into their pregnancy. Whilst women generally reduced their alcohol consumption as their pregnancy progressed, 10-14 per cent continued drinking outside the guidelines for pregnancy. Further, between 1995 and 2006 it was reported that the rate of risky drinking in women in Australia had more than doubled to 12 per cent. The report noted that age was a significant factor in women stopping alcohol during pregnancy, and women under the age of 25 years, were more likely to stop drinking than women aged 36 years or older.

Alcohol consumption by Indigenous Australian people is lower than the mainstream population, and 25 per cent of Aboriginal people do not consume alcohol compared to 19 per cent of non-Aboriginal people. However, risky consumption of alcohol is higher for Aboriginal people who do consume alcohol in comparison to non-Aboriginal people (McClellan & McDougall, 2015). Australian studies have also found

that alcohol consumption in relation to low and high socio economic status (SES) to be similar in contrast, to high alcohol consumption being more commonly associated to low SES (FARE, 2012).

Further, women who were more highly educated were found to be more likely to continue drinking while pregnancy. This pattern of older women continuing to consume alcohol during pregnancy is also similar to studies of consumption by women during pregnancy in Europe (Fare, 2012). However, female consumption of alcohol also needs to be viewed in context with the social reasons that often contribute to women consuming alcohol at harmful levels. Public health programmes that further stigmatise or blame women will not encourage women to seek assistance for reducing or abstaining alcohol use.

Another recent study of 142 pregnant women conducted by McBride, Carruthers & Hutchinson (2012) in Perth, Western Australia, found that women who ceased alcohol during pregnancy had less formal education and were engaged in home duties full time. Half of the women in this group who were more highly educated reported to continuing alcohol consumption at low levels during pregnancy. This study found that women who continued drinking during pregnancy were more likely to consume alcohol at home or at the home of a friend (McBride, et al, 2012).

FASD prevalence Australia

Studies in Australia have predominately been based on passive surveillance systems, which have a number of limitations, particularly, under-ascertainment. This likely reflects under-diagnosis and under-reporting of cases and lack of screening of children at risk from alcohol exposure (Burns, Breen, Bower, O'Leary & Elliot, 2013, p.465).

The prevalence of FASD in Australia is unknown, due to the lack of a national diagnostic tool (Department of Health, 2010), and lack of awareness of health professionals. As highlighted above, the Australian national FASD diagnostic guidelines was implemented recently in 2016. According to Burns (et al 2013), initially prevalence of FAS was monitored through the birth defects registers in four states within Australia. However, this method only recorded FAS and not the full spectrum in Australia. Further with linkage to the rural Paediatric database saw an

increase of 38 per cent in FAS prevalence rates (Burns, et al, 2013). In a recent Australian report by McLean & McDougall (2014), it was suggested that two per cent of Australian children are born with FASD. It is evident from literature that consuming alcohol during pregnancy is common, and in another survey of Australian women, 31.6 per cent stated they would consume alcohol in future pregnancies. Elliot (2015, p.2) states.

In one Australian study, more than half the children diagnosed by paediatricians with fetal alcohol syndrome already had an affected sibling, indicating missed opportunities for prevention. Education can change health professionals' knowledge and practice and influence the advice they give about drinking in pregnancy.

Moreover, fifty per cent of women identified that their preferred source of information on alcohol use during pregnancy was from general practitioners. In an Australian survey of paediatricians; the majority surveyed agreed that a diagnosis would stigmatize the family and the child. Twelve per cent of paediatricians were convinced of FAS, but did not record a diagnosis of FAS due to the associated stigma (Bell et al., 2015). Bell (et al, 2015) argues that it is imperative that a model of Stigma be incorporated in approaching FASD policy and service delivery.

General practitioners remain unconfident in their awareness of FASD, and were reluctant to be seen as stigmatizing women. Only 45 per cent of doctors routinely screen for alcohol use during pregnancy. Previously, the prevalence for FAS was obtained from the Western Australian Births Defects registry and the Rural Paediatric Service data base (O'Leary 2004; Department of Health 2010). Some of the obstacles contributing to non-diagnosis include; lack of routine screening of infants and children known to be at harm, due to alcohol misuse; the absence of screening for alcohol use during pregnancy, lack of knowledge of FASD by carers and health professionals, and the perceived stigma that is attached to a FASD diagnosis by many health professionals (Payne, et al, 2005).

In the recent development of Australian government policies on FASD (Commonwealth of Australia, 2012), there remains a strong focus on prevention and raising awareness of FASD in the community. Currently, there are basic gaps in service delivery for an individual with FASD from birth to adulthood. It remains

difficult to obtain a diagnosis for infants and young children who are theoretically in the best category to diagnose if there are indicators of low birth weight and visible FAS facial characteristics.

It is critical to note, that there has only been one FASD prevalence study conducted in Australia and that is the Liliwan study in the Fitzroy Crossing region in Western Australia. This study resulted in the highest rates recorded for ARBD in the world. However, there are currently no comparison prevalence studies with other populations within Australia. Further, internationally, prevalence studies have mainly focused on populations and regions where there is sampling bias towards what is perceived to be a high consumption of alcohol (McClellan & McDougal, 2014).

Liliwan [Fitzroy Crossing]

Liliwan - is the Kimberley Kriol term for “all the little ones” and was the title of the first population based prevalence study to be conducted in Australia (Fitzpatrick, et al 2013). This study was an initiative of the Aboriginal community in Fitzroy Crossing, which is located in the Kimberley region of Western Australia. Diagnosis guidelines were adapted from Canadian guidelines and involved a multidisciplinary team including members of the community. The study involved 127 women and 95% were Indigenous. The prevalence rates for FAS/pFas was 120 per 1000 children. Training on FASD was also provided to education and health staff. The community were also proactive in implementing alcohol restrictions within the community and this had an immediate social positive impact. Study limitations were the small sample size and that it was conducted in a remote community.

Awareness of FASD and Australian research

Whilst a significant amount of research has now been undertaken in Australia, and policy development, this has not yet translated into dedicated services for children and individuals living with FASD within Australia. Australia continues to lack clear and consistent messages on the risks of consuming alcohol during pregnancy, resulting in varied perceptions of the risks. This is important to note given the number of Australian women reported at 26% who continue to consume alcohol, on awareness of pregnancy (Eguiagaray, et al, 2016).

Eguiagaray (et al, 2016), undertook a comprehensive analytical review of Australian media portrayals of FASD within Australia. The findings identified there continues to be a lack of understanding of FASD in Australia, and this lends to extreme negative misconceptions of shame, confusion and lack of empathy for individuals with FASD. The writers further explain media portrayals of FASD in Australia includes the frames of sympathy and shame (Eguiagaray, et al, 2016). Under the frame of sympathy, children with FASD are posited as victims of deviant mothers, and deserving of sympathy (Eguiagaray, et al, 2016). Discourse that hold birth mothers as responsible is destructive and shaming lends to controversial public opinion on FASD calling for women to legally responsible; and to be sterilised (Eguiagaray, et al, 2016). Further, Aboriginal women were also identified as a special group requiring urgent government intervention. Eguiagaray, (et al, 2016, p52) states

The government was also constructed as neglecting to take responsibility for punishment of women who consume alcohol during pregnancy. Such articles suggest that the government's hands-off approach was a problem, claiming that the government should make alcohol consumption during pregnancy "an offence punishable by law".

In terms of research exploring awareness of FASD within Australia, there has been to date three surveys undertaken in Western Australia exploring the level of awareness amongst Paediatricians, health professionals, and early childhood staff. Two surveys were conducted by Payne, (et al, 2005) and Elliot (et al, 2006) in Western Australia, to measure the knowledge, practices and opinions of health professionals in Western Australia relating to FASD. Health professionals surveyed included; paediatricians; general practitioners; obstetricians, community nurses, Aboriginal health workers, and allied health professionals (Payne et al, 2005).

The study by Elliot (et al, 2006) focused on the FASD knowledge of paediatricians in Western Australia in 2004. The results were disturbing; as only 43 per cent believed women should abstain from alcohol during pregnancy. The majority 69 per cent felt diagnosis would be stigmatising for the child, and only 4.5 per cent were confident to deal with a patient with FAS, and only 23 per cent routinely screened for alcohol during pregnancy. In the study undertaken by Payne (et al, 2005) confirmed that only 12 per cent of health professionals in Western Australia knew the four diagnostic features of FASD, despite many recently receiving training on the topic. Even though

health professionals expressed a reluctance to diagnose FASD, as they believed it would stigmatise the child, they were aware of the importance of early intervention for a child with FASD, and the need to prevent the occurrence in further subsequent pregnancies in the same family (Elliot et al, 2006; Payne et al, 2005).

According to Frances (2014), much of the Australian research agenda has focused more on the awareness of FASD amongst sectors such as health professionals and criminal justice system, whilst international research is focusing more now on effective interventions and strategies for this population. A research project was conducted in Western Australia in 2011 and 2012 to assess the level of knowledge in early care settings in Western Australia. Survey sample size was 236 and the majority of participants had worked in the early childhood sector. Findings included that the majority of participants felt they did not have the appropriate skills or training to work confidently with students with FASD. Seventy two staff suspected they had worked with students with FASD, however, only 26 staff felt confident in assisting the family to make a referral for diagnosis. Feedback also included that staff generally did not understand suspected FASD, and children's behaviour was often labelled as naughty (Frances, 2014).

Development of Australian FASD Diagnostic guidelines and progress

Change is going to occur only when it is possible to prove how prevalent FASDs are (Rogan & Crawford, 2014 p.181)

As discussed in the previous chapter, access to FASD diagnosis is critical for children living with FASD and to initiate early intervention to prevent the onset of secondary disabilities. Diagnosis is also critical to select the correct treatments and to prevent unnecessary medications or misdiagnosis for ADHD. Elliot, (2014, p.299) states:

For children with ADHD, there is limited evidence of benefit from stimulant medication for hyperactivity and impulsivity but not attention, but a risk of adverse effects including decreased appetite, headache and insomnia.

According to Watkins (et al 2014), there remains no international consensus on guidelines for FASD diagnosis and there still remains a paucity of empirical evidence on the guidance of strategies. At the recent 5th International FASD conference, experts agreed that identification of FASD globally would improve with a single set of

guidelines (Astley, 2014). Earlier research by Payne (et al 2005) also highlighted the need for further information and resources to improve the identification of FASD within Australia. The lack of national guidelines has also impacted on the lack of diagnosis of FASD within Australia (Watkins, et al 2014).

To this end, research and consultation was recently undertaken by Watkins (et al, 2014) on the development on guidelines for FASD assessment in Australia. The methodology included surveying health professionals throughout Australia and a two day workshop that included FASD experts, carers, and birth mothers of children with FASD. The consensus was that international guidelines should be adapted to Australia to assist in the diagnosis and referral for FASD. However, Astley (2014) argued that Australia should have used existing FASD guidelines and expressed concern on the development of another set of FASD referral guidelines. In response, Watkins (et al 2014) responded that Australia has adapted guidelines as existing diagnostic guidelines lacked consensus on all aspects of diagnosis.

In 2016, the Australian government endorsed and accepted an Australian national FASD diagnostic tool based on Canadian guidelines (Bower & Elliot, 2016). Under these new guidelines, FASD is no longer an umbrella term and has now become a diagnostic label. FASD diagnosis involves a multidisciplinary team including but not restricted to; paediatrician, psychologist, social worker, speech and language pathologist and an occupational therapist. The guidelines highlight the importance of documented records of PAE, particularly when not available from the birth mother, and other trusted sources include; relative, partner, community member who had direct observation of PAE.

Documentation from sources such as child protection, medical, legal or other records, including alcohol related injury are important to assessing FASD (Bower & Elliot, 2016). The test also involves identifying strengths and weakness in the child to assist in appropriate recommendations for interventions. The guidelines also highlight that clinicians should have cultural awareness training as this may impact on their engagement with Aboriginal families, and on the diagnostic assessment. Special considerations for assessment apply to children under the age of 6 as the developing brain has the capacity for change.

Australia FASD Prevalence in OOHC

In South Australia, parental substance misuse was responsible for 70 per cent of children entering OOHC (Parkinson & McLean, 2013). Whilst, there is limited research in Australia on children in care with FASD, current research reflects the same international pattern of over representation of children with FASD in OOHC. According to McLean & McDougal, (2014, p.10):

Estimates of the percentage of children with FASD raised by people other than their biological parents range from 60% to 80% across Australia, Canada and North America.

In earlier research by Elliot & Bower (2004), it was found that the majority of children who were diagnosed with FAS in Australia were not living with their biological parents and were living in foster care. Further, the mothers were also found to have more than one child with FAS. Later, research by Elliot (et al, 2014) surveying Paediatricians in Australia found that 49 per cent of children in care had been assessed for FASD. Another 12 per cent were strongly suspected by specialists of having FASD, however, Paediatricians believed that a diagnosis would stigmatise the child. Whilst, Australian government reports and research conclude that children in care with FASD are overrepresented, there appears to be no or minimal strategic planning in addressing the issue of children in care with FASD (McLean & McDougal, 2014). The National FASD report noted serious issues of FASD relating to the care system including; the lack of trained carers; and carers may not be experienced in identifying developmental delays in children. The following quote was taken from a carer (National FASD report, 2012 p.122):

One of the unexpected difficulties that I came across is that, even though I have a nearly three-year old who has quite a clear diagnosis of FAS, they are unable to actually access (NSW Family and Community Services) funded services because there is no global developmental delay or a delay in at least two areas....When you are looking at a very uncertain future of what to expect in terms of her needs much later in life, the carers will have to look at funding speech therapy, occupational therapy and other different therapy services because they cannot access them through the public system.

Further, it is critical that children in care that are suspected of having been prenatally exposed to alcohol are screened and have access to diagnosis, particularly before they age out of the system (Duncan, 2013). This becomes more urgent in consideration of the lack of diagnostic centres for adults with FASD in Australia.

Family and FASD

It is important to note that there has been limited attention given to generational FASD within the same family in both global and Australian literature on FASD. Duncan, (2013, p13) states:

There are now children being born who have parents and grandparents with FASD. FASD will continue to have an impact on future generations until the community and government place great importance on the safety of the unborn child.

Most of the current literature on carers and parenting of children with FASD has been undertaken internationally, with some recent research undertaken in Australia. As previously stated in chapter two, there have been limited studies on the impact of raising children with FASD on families. Two research projects on FASD and the family in Australia were carried out by Breen & Burns (2012) and the Telethon Institute on Child Health Research (TICHR) (Wilkins, et al, 2013). Breen & Burns (2012) conducted a national study which explored FASD in families and Wilkins (et al, 2013) looked at carers who cared for both Aboriginal and non-Aboriginal children with FASD in Perth, Western Australia. Both projects concluded that carers often felt their concerns were not validated or listened and identified the following themes from parents/carers in their research:

- Frustration and stress at the lack of diagnosis. Long waiting times for diagnosis
- Lack of resources
- The issue of FASD not meeting the Australian criteria for a Disability
- Lack of acknowledgement and validation of caring for children with FASD
- Lack of knowledge and awareness of health professionals (frustration at having to often educate health professionals on FASD)
- The urgent need for supportive services for children/individuals with FASD
- High levels of stress and anxiety for the child with FASD and the family

Breen & Burns (2012) interviewed a total of 29 carers/parents from around Australia. Although the authors did not include any limitations in the research project, the failure to identify the ethnicity of the participants is I believe one such limitation, as it does not provide a demographic of who the participants were and if any were Aboriginal. The methodology consisted of both quantitative and qualitative, with the research tools

being adapted from international studies undertaken on FASD. Breen & Burns (2012) identified that some of the carers who were related to the children in their care were now looking after them as young adults with FASD. Carers also expressed their frustration in often knowing more about FASD, than the health professionals they sought help from, and this included having to educate health professionals. A literature search failed to identify any dedicated research undertaken in Australia that specifically explores the experiences of carers/parents that cared for Aboriginal children in Australia.

The literature highlights that many children with FASD are placed in the foster care system (Koponen, et al, 2009). There are several reasons for this; parents are often unable to care for the children and those that drink continue to consume alcohol at risky levels. In some cases, it has been suggested that the parents of children with FASD also have FASD (Douglas, 2010). This suggests that in some families both internationally and in Australia there is now more than one generation of FASD, and the cycle has unwittingly been repeated. There are also individuals who are affected by FASD and have never had the opportunity to be diagnosed or recognized as having FASD. Often a predictable pathway begins to emerge for the child with FASD, resulting in numerous foster care placements and the onset of secondary disabilities (Koponen, et al. 2009).

In Aboriginal families, it is often the grandparents, siblings/extended family who will be the nominated carer for children with undiagnosed FASD in the family. The grandparents/extended family are often mature age, and likely to have chronic illnesses and limited resources to care for their grandchildren with FASD. This was supported by Australian research undertaken by Douglas & Walsh (2013, p. 72) who state:

Grandparents really burn-out and a lot of them are taking on that responsibility of the grandchildren when they should be enjoying life...I have a lot of respect, actually for grandparents who become kinship carers because I've seen over and over again they're really amazing people – and I've had many of them as clients – in terms of doing it all over again and going through such trauma with their own children and then bringing up grandchildren.

FASD and Criminal Justice System:

Recent research undertaken at the Banksia Hill detention centre in WA, found results of the highest prevalence rate of FASD in the world (Bower, Watkins, Mutch, Marriott,

Freeman, Kippin, Safe, et al, 2018). Within this population cohort, the majority of the young people incarcerated were males and were Indigenous. The results found that 89% of the youth incarcerated had at least one domain of severe neurodevelopmental impairment. The majority of the youth diagnosed had no physical facial characteristics of FASD. Therefore, staff at this detention centre would not have been able to identify FASD based on any physical appearances.

Other recent Western Australian research findings based on data linkages evidence by Hafekost (et al, 2017) found children from mothers with maternal alcohol use were at increased risk of being involved in the criminal justice system. This study, compared data from 1983 to 2007, based on mothers who had an alcohol related diagnosis (Hafekost, et al, 2017). Data linkage sources included justice contact, academic outcomes and child protection. The findings included that children from OOHC were twice as likely to have contact with the criminal justice system and an over representation of Indigenous mothers and children. Whilst, the writers accurately highlight the need for holistic interventions and integrated services. What was lacking from this analysis was the inclusion of systemic racism, and the lack of appropriate services for Aboriginal families (Cuneen, 2016).

According to Douglas (2010), very limited research has been undertaken on individuals with FASD and the criminal justice system in Australia. Further, Douglas (2010) argues that FASD has received scarce attention from criminal courts in Australia. Individuals with FASD often receive a range of diagnoses and misdiagnoses such as ADHD; and Oppositional Defiance Disorder (ODD). A recent case in Western Australia involved a 21 year old Aboriginal woman, who had a brief history of offending. The early history of this young woman had the indicators of undiagnosed FASD; raised by grandparents due to mothers problematic drinking; and the young girl had a low IQ range. After breaching court orders, the woman was sentenced to prison and shortly after became distressed and began to have seizures. Medical results demonstrated abnormality in the brain structure, and was evidence of FASD. Douglas (2010, p.432) states:

The two year sentence of imprisonment was ultimately appealed...Tragically by the time the matter was returned for resentencing in August 2014, AH was acutely psychotic and in the prison hospital...The Court of Appeal observed that neither the protection of the community nor the aim of deterrence justified a prison

sentence and found the incarceration had contributed to the deterioration of AH's mental health.

The Western Australian report (Department of Health, 2010) suggests there are a significant number of adolescents in juvenile detention centres in Western Australia with undiagnosed FAS/FASD. Further, there is limited opportunity for the identification of FASD whilst juveniles are incarcerated and states (Department of Health, 2010, p.16).

It is likely that there are significant numbers of incarcerated juveniles in WA with undiagnosed FASD/FASD. Currently the only opportunities for identification are if a magistrate or defence lawyer refers an individual to have their fitness to plea assessed by a psychiatrist or when a juvenile justice officer refers for an assessment.

Individuals with FASD in the criminal justice system have diminished capacity and do not understand the severity of their circumstances. Without diagnosis and advocacy, an adult with FASD appears to be non-conforming within the process of rehabilitation. However, it is the lack of intellectual capacity and cognitive ability that prevents conforming in rehabilitation. The risk of appearing non-conforming in the criminal justice system and without support increases the likelihood of reoffending and longer sentences.

Despite the landmark research and recommendations of the national Royal Commission into Aboriginal Deaths in custody almost two decades ago, Aboriginal people continue to be incarcerated at far higher levels and Aboriginal women are now the fastest growing prison population (Marchetti, 2005). Programs in prisons and therapies that are based on cognitive therapy generally do not cater for adults with FASD who have memory difficulties resulting in trouble with planning and developing strategies to manage their behaviours (Douglas, et al, 2012). This is a critical fact in planning interventions and or modifying and changing services to cater for adults with FASD. Important research recently undertaken by Badry, (et al, 2015) examined the overrepresentation of Aboriginal people with mental health and cognitive disabilities in the criminal justice system. The methodology included a qualitative approach of case study narratives of Aboriginal women and men, including key parts of their life stories and pathways into prison. Badry et al (2015, p.156) states

There are enormous costs to government of the current approach of managing

Indigenous people with mental and cognitive disability via the criminal justice system, and the toll on Indigenous people is catastrophic.

Amongst the findings in the qualitative data for this project was that FASD is highly likely to be affecting a significant number of Aboriginal people in the criminal justice system in Australia. However, the Mental Health Disorders and Cognitive Disability (MHDCD) data set makes limited reference to FASD. The report findings also highlighted the urgency of screening for FASD in the criminal justice system and for support and education of FASD to human service agencies.

The Telethon Institute on Child Health Research (TICHR) recently conducted research with the criminal justice system in Western Australia in 2013 (Mutch, et al, 2013). The research identified staff in this sector have frequently observed adults and adolescents displaying behaviour common to FASD. Including; repeat offending; low IQ levels and short term attention span. Staff surveyed on their knowledge of FASD in the criminal justice system included police, lawyers, judicial officers and Department of correction staff. Results confirmed the majority thought that FASD was a real problem. Currently, TICHR has recently commenced a study of prevalence within the Banksia Hill detention Centre in Perth Western Australia. This is the first study of its kind within Australia and recent literature highlights that the prevalence is likely to be high.

Western Australian research by Blagg, Tulich & Bush (2015) recently explored diversionary pathways for Indigenous Youth with FASD in the criminal justice system. This research was conducted primarily in the Kimberley region of Western Australia, and highlighted the significant over-representation of Indigenous youth in the criminal justice system. In Western Australia, the diagnosis of FASD under the Criminal Law (Mentally Impaired Accused) Act 1996 (WA) has the serious potential of carrying an indefinite sentence. Further, this has been the case for Rosie Fulton who was born with FASD and was imprisoned for 21 months, after it was deemed that she was not fit to stand for trial. Fulton was not provided with any support or treatment (Blagg, et al 2015).

Blagg (et al, 2015) recommended the urgent need for reform of the Criminal Law (Mentally Impaired) Act. Further, multi-disciplinary approaches are urgently required for addressing the complex needs of Indigenous children with FASD, particularly when coming into contact with the criminal justice system. Other approaches that were suggested included a New Zealand model that supports the family of the young person being involved and engaged in the decision making process of the criminal justice system, wherever possible. This approach facilitates respect and empowers the family, and is an important community based alternative to the criminal justice system.

Colonisation and Indigenous People of Canada, North America and New Zealand

The next section of this chapter, provides a brief overview of colonisation and Indigenous people, with a particular emphasis on the Canadian and Australian experience. Saggars, Walter & Gray (2011) asserts the historical and social context of colonisation on Indigenous people, has contributed to the contemporary position of Indigenous people. Saggars, et al (2011, p.4) argues:

History is a powerful determinant of a people's health. This is dramatically illustrated when the health of indigenous people in Australia, Canada and New Zealand is compared to that of the settler populations that colonised their lands

The period of colonisation for the Indigenous people of Canada, America and Australia was a period of rapid social change (Westby & Inglebret, 2012). Collectively the experiences of colonisation were profoundly devastating for the Indigenous peoples of New Zealand; Canada, and North America, and continue to impact on the mortality and morbidity rates for these groups in contemporary times. Australian Indigenous people continue to have the worst morbidity and mortality rates. One of the reasons suggested for these worst mortality rates is that Australia was the only country to not provide a treaty to their Indigenous people (Taylor, 2014). The removal of Indigenous children from families and culture was practiced for many decades in Australia, Canada and North America. Consequently, there are similarities with intergenerational trauma and its impact on subsequent generations in these countries.

Western Australian Colonisation and Aboriginal people

Prior to European colonisation in Western Australia in 1829, Nyoongar people enjoyed an affluent lifestyle rich in a culture that had survived for many thousands of years. Nyoongar people cared for the land and the environment, and there are many

creation/dreaming stories of special significance. Nyoongar people occupied some of the best lands in Western Australia, consequently European colonisers were keen to dispossess Nyoongar people of these lands as swiftly as possible. At the time of colonisation there was approximately 7 – 10,000 Nyoongar people living in the south west region (Green, 1984). Colonisation for Aboriginal people was a devastatingly long process that affected many generations of Aboriginal people. Racism and ethnocentrism played an instrumental role in the longstanding segregation of Aboriginal people from mainstream community. There were no agencies that supported Aboriginal people at this point of history.

Western Australian Historical Government Policies 1886, 1905, 1936 Acts

In the early 1800s, European people throughout Australia initially believed the Aboriginal race would eventually die out. However, when it became evident that Aboriginal people had indeed survived the initial onslaught of colonisation, government policies aimed at segregating and controlling Aboriginal people were implemented throughout Australia. The Western Australian Government developed its first policy in 1886, that was followed by the 1905 and 1936 Act, which collectively had devastating implications for Nyoongar people and their families. In Western Australia, numerous reserves were established in places such as Moore River Settlement, Carrolup and Sister Kates. Reserves were also established on the outskirts of many towns, and Aboriginal peoples movements were strictly controlled by government policies.

In 1915, a new Administrator AO Neville was employed as the Protector in Western Australia. As an administrator, Neville was active in exposing the weaknesses of the 1905 Act to the government. At this time, Neville was frustrated as not all Aboriginal people throughout Western Australia came under his control. Consequently, these weaknesses were addressed and the Act was amended and became the 1936 Act. The 1936 Act, represented one of the most oppressive legislations enforced upon Aboriginal people in the history of Western Australia. The Act addressed the weaknesses of its parent Act of 1905, and served to be even more controlling and oppressive than the 1905 Act. The Act also occurred after the bleakest period of Australia's history, which was the depression of 1929.

Circumstances for Aboriginal people at this time were severe, with many suffering from malnutrition, high unemployment, and poor health. Nyoongar people were not eligible for the same rights afforded to non-Aboriginal people, as in access to unemployment benefits, health services, education and unions. Further, the 1936 Act further strengthened the power and control of the state of Aboriginal people in the following four areas (Haebich, 1988b):

- Definition of a “Native” was extended to include nearly all Aboriginal people who now came under the control of the State
- Guardianship of “Native” children was extended to the Protector, regardless of whether parents were married or not, and the age was increased from 16yrs to 21yrs.
- Employment: Permits had to be obtained by non-Aboriginal people to employ Aboriginal people, making it more difficult for Aboriginal people to gain employment
- Marriage: The protector was given the power to withhold permission for marriage to Aboriginal people. In short, this was to “breed” out the colour of Aboriginal people.

Western Australia 1944 Citizenship Act and access to alcohol

The government of Western Australia created and implemented the 1944 Citizenship Act for Aboriginal people as an opportunity to apply for an exemption from the control of the historical policies. Aboriginal people had to apply to the “Protector of Natives” and were granted exemption on the proviso that they did not associate with other “Natives”, or use their language. There were several motivating factors for “why” Aboriginal people applied for exemption, firstly, it offered freedom from the oppressive control of the government; and Aboriginal people were also for the first time able to purchase and consume alcohol, however again on the proviso that they did not share this alcohol with other Aboriginal people. In a similar timeframe in Canada until 1951, it was also illegal to sell or provide alcohol to an Indian (Salmon, 2013).

Aboriginal families who had had their children removed, such as my grandparents also applied for their Citizenship rights thinking that these new found rights would overturn the states removal of their children, and they would automatically be returned to their

families. Tragically, this was not the case for my grandparents and other Aboriginal families, who saw this act as a last opportunity to have their children returned to their families (personal communication).

Impact and consequences of historical government policies:

Historical government policies were not repealed until 1963, however as stated in chapter 1, the removal of Aboriginal children occurred well until the 1970s, highlighting that the most destructive part of colonisation did not end simply end in 1963. The consequences of historical policies to Nyoongar people were devastating; and included the loss of parts of Nyoongar dialects; the right to develop an economic basis on the same basis of non-Aboriginal people resulting in widespread poverty. Poor and inadequate housing throughout Western Australia, had a devastating impact on the health and mortality rates of Nyoongar people. It is well documented, that Aboriginal children received a substandard education at institutions, and were educated for the purpose of becoming domestics and labourers.

For decades, Aboriginal people did not have access to basic human rights; quality education, housing, and the right to participate in the economy. Another reason Aboriginal people had so few supporters was due to the racism that permeated Australian society. It was also in the interests of powerful groups such as Government, unions and many industries, to continue to “pay” unequal or no wages to Aboriginal men and women. Sargent (1988) argues that Australian capitalism benefited significantly from cheap Aboriginal labour for many decades.

Historical Alcohol consumption under policies

Legislation in Western Australia was passed in 1843 that prohibited the supply or sale of alcohol to Aboriginal people. Prior, to the 1944 Act, Aboriginal people were not permitted to purchase or consume alcohol. A consequence of having to seek permission to purchase and consume alcohol under these circumstances was the start of binge drinking by Aboriginal people. For many Aboriginal people, this type of harmful drinking practice has continued to the present day. Likewise, Canadian Indigenous peoples drinking patters under such historical control also includes binge drinking patterns. Further to this Act, Aboriginal people in Western Australia were not permitted to purchase and consume alcohol until 1963.

Historical policies relating to alcohol were not repealed until 1973 (Brady, 1991), with the only exception of being granted “citizenship rights” under the 1944 Citizenship Act. However, as previously explained these Citizenship rights were difficult to maintain on the criteria for no further association with other “Natives” and to cease using Aboriginal languages and practices. Further, for many Aboriginal people alcohol became a symbol of equality, after decades of prohibition. Saggars & Gray (1998, p.86) in reference to colonisation and alcohol consumption by Indigenous people make the following statement:

It is unlikely that it (patterns of drinking among Indigenous people) has arisen from unique circumstances within Indigenous societies. In our view, explanation of this phenomenon requires consideration of what is common to them all. That is, the experience of colonialism, the destruction of traditional economies, exploitation and marginalization, the loss of power entailed in these processes, and the responses of Indigenous people to them. A model of indigenous drinking must take this as the starting point, and other factors need to be considered in the context of these political and economic relationships.

In contemporary times, it is critical to note that whilst many Indigenous people consume alcohol at risky levels; a large number in both countries also do not consume alcohol. Both Indigenous populations in each country make up only a small percentage of the population.

Survival and resurgence of Nyoongar people and culture

Despite the attempted genocide of Aboriginal culture and the oppressive government policies, Nyoongar people and culture survived. There are a number of factors contributing to Nyoongar culture surviving and this includes the ability of Aboriginal people to adapt and Aboriginal culture often went underground in places such as Moore River Settlement in Western Australia. Maushart (1993) in “Sort of place like home, remembering Moore River Settlement” describes some of the ways Aboriginal kinship adapted and for instance, Aboriginal people often “adopted” young Aboriginal children who did not have blood relatives at the settlement. My mother May, also recalls with fondness the strong relationships that were formed with some of the other children who were also placed at the mission in Carnarvon (personal communication, 1996). According to Haebich (1988), some of the historical government policies also backfired as the government had consistently shown great reluctance to fund the resources necessary to carry out policies and states (p.356).

It is ironic that the official policy of enforced assimilation through the native settlement scheme and efforts of the white community to sweep the Aboriginal “problem” under the carpet by isolating Aborigines on town reserves should have played an important role in forging this identity.

Contemporary position of Australian Indigenous people

High rates of morbidity and mortality mean that most Aboriginal and Torres Strait Islanders experience their own and others illness and premature death on a painfully regular basis (Saggers et al, 2011, p. 5)

Historical government policies have contributed significantly to the poor social indicators amongst the Aboriginal population across Australia. Aboriginal people continue to be over represented in the justice system, child welfare and have the highest suicide rates in the world. Whilst, it is well documented that Aboriginal people have the worst mortality rates in Australia, there is a paucity of research that investigates the health outcomes of Aboriginal children residing in metropolitan areas Eades, Read, Stanley, Eades, McCaullay & Williamson (2008). In contemporary times, the overall Australian Indigenous population is approximately three percent of the Australian population, and due to the early mortality rate, the Indigenous population is a young population, with the majority under the age of 25 years. In WA the median age for the Aboriginal population is 22 years of age (Williams, Lawrence, Wilkes, Shipp, Eades, Mathers, Kaldor, Gray, 2014).

However, despite the significant adversity of the past, Aboriginal people throughout Australia, have advocated and fought for basic human rights; and self- determination, including the establishment of Aboriginal community controlled agencies in the 1970s. These agencies include; Aboriginal medical services and Legal Services throughout Australia. Another initiative that was driven by the Aboriginal community was the establishment of the Community Development Employment Programme (CDEP) in the 1970s.

Community Development Employment Programme (CDEP)

The Federal Government CDEP was implemented in the 1970s in remote areas of Australia, and was basically a “working for the dole” programme. Over time, CDEP expanded and was requested in Aboriginal communities throughout Australia. In brief, CDEP was successful, however, parts of CDEP were perceived as flawed as

many Aboriginal people remained on CDEP for many years without the employment benefits of superannuation, and normal work entitlements. However, this purview did not consider adults living with disabilities or undiagnosed disabilities such as FASD. Eckermann, Dowd, Chong, Nixon, Gray & Johnson (2010, p.57) reminds us of the following critical point:

CDEP provided the unemployed with a measure of dignity, that is they were contributing to their communities, and sheltered them from having to deal with what they often perceived as hostile, domineering and uncaring mainstream employment services which made unreasonable demands.

In retrospect, CDEP at its height of operation offered those with undiagnosed FASD in the Aboriginal population the opportunity to work in a strongly supported work environment. CDEP generally included work such as gardening and environmental cleaning services, and was repetitive, which is an ideal work environment for adults living with FASD (Russell, 2008). Importantly, this programme would have also facilitated improved social and emotional well-being and provided purpose for individuals, who would generally not have been employed within mainstream society. Unfortunately, not enough was known about FASD in Australia at the time CDEP was the largest employer of Aboriginal people, and the unrecognised social and economic benefits and outcomes for adults living with FASD.

The CDEP was discontinued in 2009 for non-remote communities in Australia. Finally, CDEP also provided income protection within the Centrelink system for those with FASD, as they were not subject to Centrelink reporting requirements, whilst employed under CDEP. In hindsight, the benefits of the CDEP was never evaluated for providing a critical programme for adults living with disabilities, such as FASD.

([http://www.abs.gov.au/ausstats/abs@.nsf/Products/6287.0~2011~Chapter~Community%20Development%20Employment%20Projects%20\(CDEP\)](http://www.abs.gov.au/ausstats/abs@.nsf/Products/6287.0~2011~Chapter~Community%20Development%20Employment%20Projects%20(CDEP))

Global Removal of Indigenous children

It's like our story that we had as natives. My whole family's been in the system, like seriously, my whole family, my brothers, cousins, aunts, all that...and my parents were in the residential schools. The same story that gets passed down from each generation...It's really, really sad because you kinda think, it makes you think like...why us? (Dylan First Nations youth in care) (de finney, 2011, p.362)

Whilst the removal of many thousands of Indigenous children occurred in the countries of Canada, US and Australia, there is limited literature that compares the profound effects of this experience collectively. The systematic removal and abuse of Indigenous children for many decades will stand forever as a gross violation of human rights and breach of international law (Ranzijn et al., 2009b). In Canada between the years of 1840 and 1983 it was estimated that 100,000 Indigenous children were removed and placed in residential schools (Menzies, 2012). Disturbingly, the number of Aboriginal children removed from families in Australia was approximately 100,000 children. However, not one Aboriginal family was not affected by the experience of removal as Aboriginal families, are based on the extended family structure.

The majority of the children removed in Australia were under the age of 8 years of age. Further, children were frequently used as a tool to manipulate adults for their ongoing “free” or cheap labour. Many families were also left intact with their children for the primary reason of the need of the free labour that was provided by Aboriginal adults. Indeed, often police were only alerted to the presence of Aboriginal families, when non-Aboriginal people did not want Aboriginal families living in their area; or did not have an economic need for their labour (Haebich, 1988b).

Aboriginal children in Australia were removed from their families as infants and young children under the pretext of protection and education, when in fact they were given sub-standard education and grossly inadequate diets, and often the living conditions were often more inferior than their homes they were removed from. In my mother’s case, her family were living in a tent and the Government removed my mother and her siblings and placed them in Carnarvon mission. This mission was also a tent and was home to my mother and her siblings for the remainder of her childhood (personal communication 2014).

Furthermore, many Indigenous children were psychologically and sexually abused in these institutions (Ranzijn et al, 2009). They were forbidden to use their traditional languages, and customs, and were not permitted to associate with their siblings. A further travesty was that upon leaving these institutions many found it extremely difficult to reconnect back to their families and culture (Haebich, 2000). As adults Aboriginal people who had been removed experience; post-traumatic stress disorder

(PTSD); homelessness, incarceration, substance abuse, suicide, depression, early onset of chronic illness and low self-worth and self-esteem.

Contemporary overrepresentation of Indigenous children in OOHC

In an era of interventionist and punitive approaches to child welfare, child protection systems appear to prefer to operate without basic safeguards for the rights of parents...At the same time, institutional processes reproduce a pathological view of Indigenous culture and parenting. In some respects this is not new, however, dysfunction has been reinterpreted and reinforced through the imperatives of risk and managerialism. At the same time there is a failure of support systems for parents in need of assistance and a failure to adequately fund public legal assistance for Indigenous parents (Cuneen, 2016, p.39)

Whilst Indigenous populations of Canada and Australia make up only approximately three percent of the overall population, Indigenous children continue to be significantly over represented in OOHC (Libesman, 2004). Given the history of removal for both countries, the escalating rates of children in care should be seen as national priority. In the context of addressing FASD and disadvantage in Indigenous communities, the cycle and overrepresentation of Indigenous children must be properly acknowledged and addressed.

Douglas & Walsh (2013,p.62) in reference to Australian over representation of Indigenous children provide the following statement from their research:

Lawyers in our study stated: 'it's still Stolen Generation all over again but just covertly' and: They're just being hung out to dry. That's reality. And its no – the practices are no better today than in the 1940s and 50s, where the government took all the Aboriginal people and put them in Trust areas. The only difference is this is more legalized. The government has written the legislation to make it nice and legal, and for the perceived benefit of the community as a whole....lawyers are now often acting for parents whose children are the fifth generation of children in their family removed into state care.

Canadian First Nations academic Blackstock (2007) argues the number of Indigenous children from Canada in care today now outnumbers the total number of children removed and placed in residential schools. Further, the main reasons provided for the removal of Indigenous children in both Canada and Australia from their families is the perceived neglect of the children. The “neglect” category is intrinsically linked with the legacy of poverty that has stemmed from colonisation and intergenerational trauma. Both Indigenous populations live in poverty, that at times is comparable to

third world conditions. Further racism plays a role in the hyper surveillance and ongoing monitoring of Indigenous families and children, leading often to removal of children from their families (Sinclair, 2015). In both countries, the rates of physical and sexual abuse are not higher in Indigenous communities in comparison to mainstream communities (Trocme, Knock & Blackstock, 2004). Similarly, Australian writers Douglas & Walsh (2013,p. 59), argue the following:

Indigenous Australian children are significantly over-represented in out of home care. Figures evidencing this over-representation continue to increase at a startling rate. Similar experiences have been identified among native peoples in Canada, the United States and New Zealand...historical factors, discriminatory approaches and legal structures and processes contribute to the high rates of removal and, we argue to the perpetuation of the stolen generations.

Definney (et al, 2011) asserts a critique of neoliberalism; neo-colonialism and social justice should be applied in analysing the contemporary overrepresentation of Indigenous children in the care system. Neoliberalism ideologies has sustained the status quo of ongoing poverty within Indigenous communities, and facilitates the misconception that everyone has equal opportunities (De finney et al 2011). In contemporary times neoliberalism and privatisation has created another level of serious inequities confronting Indigenous people of both countries.

In Western Australia, the number of Aboriginal children in care is now the second highest in the country with Aboriginal children approximately 54 per cent of children in OOHC. In the Australian system, there remains limited avenues of recourse for challenging the department once children have been removed under legislation. This harks back to the previous era of my grandparents, where historically, there was no avenues for recourse for my grandparents in having their children returned to their custody.

The trauma of removal of children in contemporary times continues to affect not only the parents, but the extended family as well, continually adding to the accumulated trauma for Indigenous people. The devastating outcomes for Indigenous families in both Canada and Australia are often fatal, as both groups experience the highest suicide rates amongst their Indigenous people. In Western Australia, the highest suicide rates in the world have been recorded amongst the Indigenous population. Further, as confirmed by research undertaken by Elliot (2014) many children in the care system

have special needs and there is a high prevalence of FASD within the care system.

Intergenerational trauma of Indigenous people (Australia and Canada)

In the past decade, intergenerational trauma and the removal of Indigenous children has been finally acknowledged at a national level in both Canada and Australia. Intergenerational trauma is the ongoing result from living under the control of historical government policies and the removal of children from their families. This trauma became transgenerational and moves from one generation down to the next. Based on the extended networks for each Indigenous population, the trauma is also shared communally and is not isolated to one person, or to one generation (Tait, 2003).

Further, Ranzijn (et al, 2009) describes cascading trauma as the spillover effect, such as the impact of incarceration of a parent and its impact on the children and extended family. To cope with trauma, many Indigenous people finally free from the oppression and control of historical polices self-medicated their trauma with alcohol. Generations of Indigenous people were not given a chance with resources to recover from removal and trauma and for many years in Australia, no dedicated services were established to provide support for intergenerational trauma (Ranzijn et al, 2009). Menzies (2012) asserts that it is only in the past two decades that intergenerational trauma as a broader framework has been available in understanding the impact of historical policies and the residential school systems on Indigenous people of Canada. Indicators on the impact of intergenerational trauma in Canada includes the following:

- **individual indicators:** such as lack of belonging;
- **family indicators:** chronic or episodes of family violence;
- **community indicators:** increased alcohol and drug use and low levels of cultural values such as reciprocity; and
- **national indicators:** such as lack of support for holistic programmes.

Further, professionals have often used posttraumatic stress disorder (PTSD) in understanding addiction and mental health issues of First Nations peoples, however this approach ignores the issue of intergenerational trauma. Menzies (2012, p.180) states:

The cumulative impact of trauma experienced by both children and their parents as a result of Canada's residential school policy continues to have consequences

for subsequent generations of children.

Systemic racism and Indigenous people

Further trauma is exacerbated by the power imbalance and systemic racism by non-Indigenous people and other social factors such as early mortality of Aboriginal people. Ranzijn et al (2009, p.124) argues

Breaking the cycle of trauma is made much harder by the racism which many Indigenous Australians experience on a daily basis.....racism is “oxygen” which keeps the pain of transgenerational trauma alive and prevents the wounds from healing. Healing transgenerational trauma is a two-fold practice, involving the development of contemporary Indigenous healing practices and a deliberate and sustained effort on the part of non-indigenous Australians to challenge racism to prevent it being perpetuated through succeeding generations.

In the above quote, Ranzijn et al (2009) highlights the pervasive role that racism plays in society, particularly institutional racism and the portrayal that all people have equal access socially and economically, however, systems and institutions remain entrenched with western worldviews and ideologies. A considerable amount of work has been undertaken in Australia on intergenerational trauma for Australian Aboriginal people, particularly by Atkinson (2014). Douglas & Walsh (2013, p.65), also provide the following observation from their research with Australian lawyers in Australia:

I have noticed an absolute bias against indigenous parents. It’s almost like the department can’t believe that if you are indigenous you are not necessarily violent or an alcoholic.

Atkinson (2014) argues that a sociological and historical lens is imperative to understand the impact of trauma for colonised populations. Huria, Cuddy, Lacey & Pitama, (2014), in a study undertaken on Maori nurses in New Zealand highlights the manner that racism continues to impact on Maori professionals and the Maori community within the health system. In this study the authors argue that institutionalised racism continues to be prevalent, and consequently creates an increased workload for Maori nurses to navigate the health service system on behalf of Maori patients. Further, the cultural skills, and knowledge of Maori nurses is generally not recognised or valued within health systems.

Decolonising FASD approaches for Indigenous people:

Understanding constructs such as dislocation and colonization are critical in

treatment...Today there is greater understanding of the dynamics of violence and trauma and the connection to coping...There is also a better appreciation of the strengths within Aboriginal communities and traditional knowledge and practice (Badry & Wight Felske, 2013, 135).

Increasingly, Canadian researchers Tait (2003); Salmon (2011); Badry & Wight Felske (2013) argue that interventions on FASD must be decolonised for Indigenous people in view of the historical and social context. Further, Salmon points out FASD interventions within Canada have been designed for the dominant population and serve to only further oppress First nations people of Canada. Indigenous Canadian academic Tait (2003) argues the historical context of residential schools and intergenerational trauma for Indigenous people has contributed to risky drinking patterns as Indigenous people medicated their trauma with alcohol.

Tait (2003) highlights that not enough prevalence studies have been conducted within mainstream populations to support the notion FASD is largely an Indigenous problem. Rather, for Indigenous populations, FASD is different in terms of the historical transgenerational trauma and the likelihood of diagnostic bias that has racist undertones. This is further exacerbated by racism and poverty that confronts many Indigenous people throughout the world. Similarly, Badry & Felske (2013) agree with this sentiment and add that interventions for Indigenous people must be culturally responsive and respond directly to the complex social issues including trauma, and substance abuse. Badry & Felske describe the magnitude of pain caused by colonisation and intergenerational trauma, contributing often to feelings of powerlessness and frustration for Indigenous people. Badry & Felske (2013, p.133) provide the following model in explaining the interconnection between trauma, alcohol abuse and child welfare.

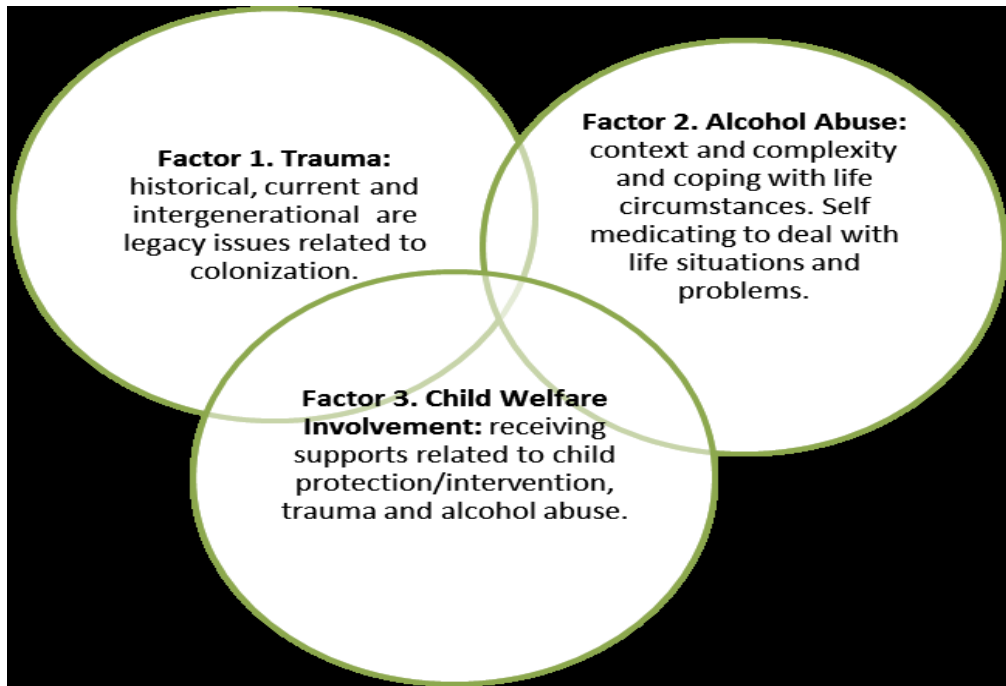


Figure 5: Model in explaining the interconnection between trauma, alcohol abuse and child welfare.

Salmon (2010) also provides a valuable critique on FASD prevention campaigns that are both provocative and problematic for advancing movements of social justice. In Canada, 11-15 per cent of women reportedly consumed alcohol during their last pregnancy. Salmon argues that any prevention strategies aimed at First Nations women must consider the political and social context of colonization and racism. One of the significant barriers that prevents FASD diagnosis is stigma within society that is associated with the disability. Further diagnostic bias has also been documented with minority groups, such as Indigenous people of Canada (Bell et al., 2015). Whilst it is well documented that FASD is not an “Indigenous problem”, policy and social discourse has created the misconception and attitude that FASD is an Indigenous issue (Hunting & Browne, 2012). Rutman (2013, p.118), asserts approaches for Indigenous people must include a holistic approach and provides the following model:

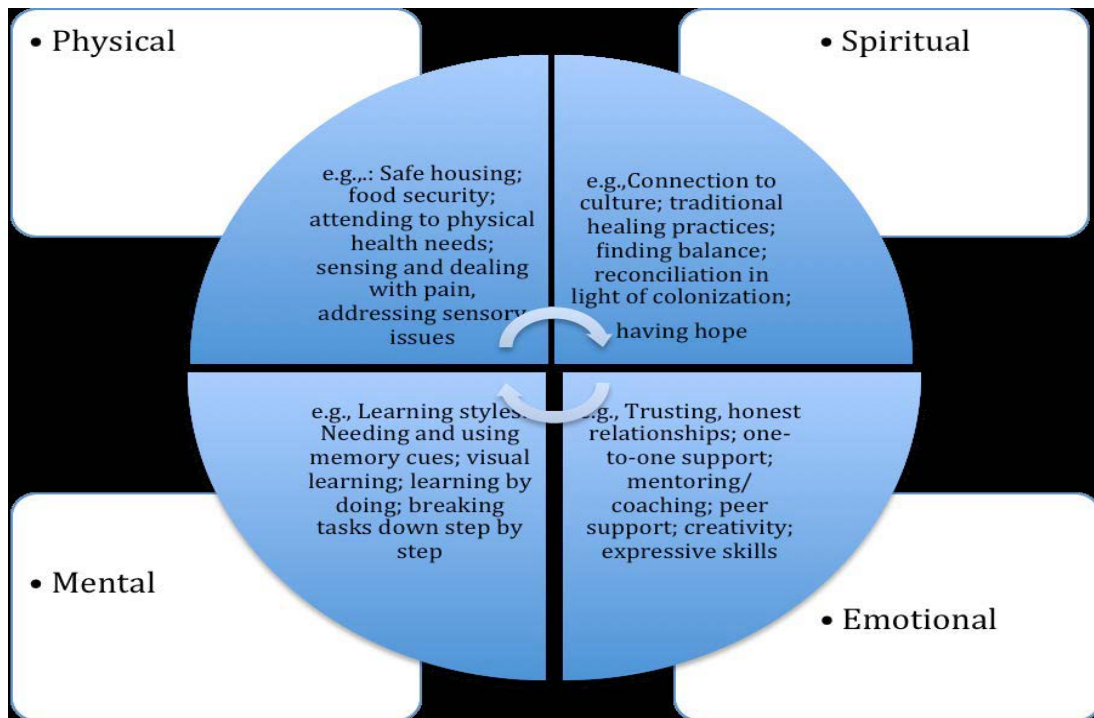


Figure 6: FASD-Effects and FASD-informed approaches considered holistically

Conclusion

This chapter has provided a brief overview of Australian FASD research and reports. In summary, within the last decade a significant amount FASD research has been undertaken in Australia, including surveying the knowledge of health professionals. However, collectively this research has not yet translated to dedicated FASD services for individuals and families living with FASD. Disturbingly the number of mainstream Australian women who continue to drink alcohol during pregnancy is similar to other parts of the world, and also during pregnancy. Compounding this is the lack of confidence and awareness of doctors and other health professionals in Australia. This chapter has highlighted the prevalence rates of FASD within Australia is unknown similar to other parts of the world. Obtaining accurate prevalence rates of FASD is reliant on having adequate screening and access to FASD diagnostic tools, and health and allied health professionals having good awareness of FASD, and further addressing the negative stigma associated with FASD. In Australia, only two studies have been undertaken that look at the impact of caring for children with FASD.

This chapter has also focussed on Aboriginal people and provided a brief history of Western Australian historical acts, and intergenerational trauma that was common to not only Indigenous people in Australia, but in Canada and the US. FASD is not an

Indigenous problem but has been misrepresented as such, and the social discourse on FASD has continued to contribute to this misconception. This highlights that research and western paradigms continue to misrepresent Aboriginal issues, to the detriment of not only Aboriginal people but the mainstream community as well. In the next chapter, an overview of Aboriginal methodologies will be provided and why this approach was chosen as the most appropriate framework in guiding this research project within the Aboriginal community.

CHAPTER 4

Research Design and Methods

Decolonization is a process where Indigenous peoples, whose communities were severely affected by colonial expansion, genocide, and cultural assimilation recover their power. Furthermore, decolonization has been described as a healing journey that may involve grief, anger, rage, growth, empowerment....In this process, there is a commitment to Indigenous people and their right to self-determination, not only from an economic or political view-point but also with respect to research (Marsh Cote-Meek, Toulouse, Najavits & Young, 2015, p.3).

Introduction to the Chapter

This chapter will provide an overview of approaching research from an Aboriginal/Nyoongar worldview, and working within the Aboriginal community on sensitive topics such as FASD. The previous chapter has briefly outlined the catastrophic impact that colonisation has had on Aboriginal people. Moreover, social discourses based on racist and ethnocentric views continue to stigmatise and misrepresent FASD as predominately an Aboriginal problem. This is critical to note as it adds another layer to the stigma already associated with FASD. Ultimately, this is a serious public health concern, as international evidence clearly indicates that FASD, is not an Aboriginal problem. Further, it is well known that in the context of western research, that research on Indigenous people has been largely deficit based and has therefore failed to recognise and acknowledge the strengths of Aboriginal families and cultures.

Research aims and Objectives

The overall aim of this research project was twofold; firstly to explore the understanding of FASD amongst the Aboriginal community in the South West region of Western Australia; secondly to record the stories of parents/carers that have cared for Aboriginal children with FASD. A mixed methods approach was chosen for this study as a qualitative approach alone would not have provided enough comprehensive data to inform policy and service delivery, particularly on information on FASD (Richards & Morse, 2007).

Methods of Data Collection

Methods of data collection included an in-depth review of global and international literature and policies on FASD. A mixed methods approach including qualitative and quantitative approaches was applied in this research project. An international study tour of Canada and the US was undertaken in the second year of this study. The tour included training with leading international FASD experts Diane Malbin, and Dr Dorothy Badry in Canada. The tour also included attending and presenting at International FASD conferences in Canada in 2014. The study tour was an invaluable experience due to the lack of specialized FASD training and service delivery in Australia at the time of this research project. The learning exchange with Canada was also critical given the similar histories of colonisation and oppression of Indigenous people of Australia and Canada.

Australian consultation

The consultation process within this project was consistent through the involvement of the established CRG and the Centre for Research Excellence in Aboriginal Health and Wellbeing (CRE). The national CRG had extensive expertise in FASD, research and Aboriginal health; and included Lorain Hayes; Dr Jan Hammill, Dr Paula Edgill; Karen Ugle, Ken Kelly, Vicki Russell and Anne Russell. As members of the CRG were based both locally and nationally, meetings were held by teleconference, and during the course of this project, the researcher met with each member of the CRG. The researcher also stayed in touch with the CRG via regular phone and email contact.

Contact with the CRG also facilitated important peer debriefing throughout the project, and CRG members were generous with their time for debriefing sessions with the researcher. During this research project, progress and presentations of this project were made twice yearly to the CRE from 2013 to 2015. The CRE included Aboriginal and non-Aboriginal Clinicians and researchers such as Professor Fiona Stanley with national and international expertise in research; clinical practices, and Aboriginal health. These presentations included each stage of the planning and design of this project, and allowed for feedback from the CRE.

Australian historical research and misrepresentation of Australian Indigenous people

Historically, research has continued to take intellectual property from Indigenous people globally, and a poignant sentiment expressed by Aboriginal elders, is that if you want something dead, just have it researched (Kovach, 2009). This sentiment reflects the intensity of the lasting mistrust Indigenous people have of research. Moreover, this has also been raised by pioneering Indigenous researchers in this field, such as Smith (1999) and Rigney (2001). Kovach (2009) reminds us of the power of research as it ultimately informs policies, which in turns influences the framework design of service delivery. There remains insurmountable evidence of the ongoing need to include Indigenous input at all levels of policy and service delivery, however, this rarely translates into practice. To this end, the importance of applying an Indigenous methodological approach will be discussed in terms of research design, and engaging within the local Aboriginal community in the south west region of Western Australia. Indeed, as mentioned in chapter 2, Canadian researcher Salmon (2011) cautions that research on FASD must be decolonised (Salmon, 2011).

Whilst, historical policies have long been repealed, social and political contexts continue to dominate and impact on Aboriginal people and their ability to facilitate their own structure and agency for ongoing change. This is imperative to note given that FASD is a relatively new area in Australia in comparison to other countries. However, as noted in the international literature, FASD interventions still remains an emerging field.

Historically, research was an intrinsic part of the colonisation process and served powerful stakeholders such as Government; academia, anthropologists; land owners; capitalism and the wider community in colonizing Aboriginal people in Australia. It is well documented that Indigenous people are the most researched people in the world and continue to distrust the practice of research (Rigney, 2001; Smith, 1999). The historical research agenda in Australia was not emphatic or interested in the widespread dispossession and displacement of Aboriginal people upon Australian colonization. Nor, was it concerned with the impact of rapid social change of colonization on Aboriginal culture and the relating trauma over many generations. Indeed, even during early colonization, academia had relevant theories to apply to the

process of colonization, such as the theory of anomie, in describing the impact of rapid social change.

In Australia, research contributed to the misrepresentation of Indigenous people; culture, spirituality; and gender relations within Australian Aboriginal societies. In 1915, Durkheim, in the *Elementary forms of Religion* was quick to label Australian Indigenous people as the most primitive in the world (Durkheim, 1915). Such statements served to further influence academics and theorists for many decades and reinforced racist ideologies of western superiority. Research and academia has maintained a significant power imbalance that has continued to subjugate Indigenous voices and culture. This was a powerful process throughout colonization and served to further enhance colonial power and oppression for Aboriginal people.

For Indigenous peoples, research did not offer any liberation from colonization, but rather acted to maintain the status quo. Indeed, research exacerbated the trauma and oppression that was already well entrenched throughout colonization. Generally, each academic discipline remained silent on Indigenous people such as historians or were dominant in their approach such as Anthropologists. In each respect, both disciplines were devastating in their silence and their misrepresentation of Aboriginal people. In Australia, a challenge eventually came from anthropologist William Stanner who wrote his thought provoking book *The Great Australian Silence* in the 1960s (Ranzijn et al 2009).

Conceptual framework: Indigenous Standpoint Theory

Indigenous communities raise concerns that they are overresearched and tired of research always asking the same questions and reproducing the same answers, thus pressuring researchers to open the discourse on mixed methods research so as to enable new debates and approaches to emerge (Chilisa & Tscheko, 2014, p.222).

In the past two decades, western research has increasingly come under scrutiny by Indigenous academics and community, consequently, Indigenous researchers have developed an Indigenous research paradigm (Martin, 2003). Many unanswered questions remain as to why the underlying issues of Aboriginal poverty; morbidity and mortality continues particularly in the affluent countries, of Canada and Australia.

Indigenous academics Walters & Anderson (2013) assert that choosing the correct methodology is critical in guiding the research process in obtaining true social phenomena. Indigenous methodology continues to be an emerging field and Smith's (1999) groundbreaking work on decolonizing methodologies highlights the flaws in western research approaches, and argues that methodologies must be decolonised. Guba and Lincoln (2005) also identified that western frameworks did not privilege the voices of Indigenous people. Collectively; Indigenous academics Simonds & Christopher (2013) Porsanger (2004); Huggins (1991); Rigney (1997); Smith (1999) and Moreton-Robinson (2000) argue western research methodologies needed to be decolonized in order to represent the truth of Aboriginal people and be able to embrace an Indigenous philosophy. Chilisa (2012) provides a comprehensive critique on western approaches to research and their role in oppressing Indigenous people throughout the world. Further, Chilisa (2012) notes the emerging body of Indigenous methodology as critical in challenging western science, and facilitating positive service delivery outcomes that is urgently required for Indigenous communities.

This research project applied an Indigenous Standpoint approach in this study, as it describes how all elements of an Aboriginal philosophy and worldview are interrelated. Standpoint theory originated from feminist scholars, however, the term and concept of standpoint is conceptualized differently in Indigenous Standpoint theory (Walters & Anderson, 2013). Standpoint theory has been used by marginalized groups who have been largely excluded within the research process (Walters & Anderson, 2013).

Aboriginal Philosophy

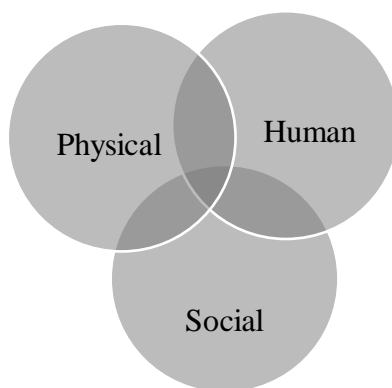


Figure 8: Indigenous standpoint

An Indigenous standpoint encompasses the interconnectedness of the human, social and physical world as it relates to Aboriginal culture, and was further developed by West (1998). The Indigenous ontology outlines the interconnection between the realms of the human, social and physical reality for Aboriginal people. This conceptual framework was the best approach to conduct this research, as it underpins Aboriginal ways of doing, and knowing within the community, and importantly, this approach gives privilege to Aboriginal voices in the project. Further, western frameworks have marginalised Aboriginal people as the “other”, rather than being inclusive. According to Foley (2003), the Indigenous standpoint approach is critical in challenging the existing power imbalance that has been created by western frameworks. According to Nakata (2007, p.215) in discussing Indigenous standpoint states

For Indigenous students, academics and researchers, standpoint theory in my mind is a method of inquiry, a process for making more intelligible “the corpus of objectified knowledge about us” as it emerges and organizes understanding of our lived realities – not to produce the “truth” of the Indigenous position to but to better reveal the workings of knowledge and how understanding of Indigenous people is caught up and implicated in its work.

Whilst, Indigenous people are not a homogenous group, there are certain commonalities and one is that all elements of Indigenous life are interconnected and related (Walters and Anderson, 2003). Canadian Indigenous Academic Wilson (2008) refers to this as relatedness. An Aboriginal approach of conducting research includes knowing what obligations and protocols exist, and the privilege that is extended to myself as an Aboriginal researcher. This privilege cannot be underestimated or taken for granted by myself as a researcher.

In this context, this allowed myself, as the Aboriginal researcher to also wear the hat of Aboriginal community member with concerns for improving health and social issues in our community. However, this dual role was in balance with Aboriginal protocols and the ethics of working as a researcher. The interconnection of Aboriginal researcher and community member is a balancing act that takes maturity, and sound understanding of Aboriginal protocols and ways of doing things within an Aboriginal worldview. In turn, the Aboriginal community expect that Aboriginal researchers will operate according to Aboriginal protocols at each stage of the research and engagement with the community.

Aboriginal Philosophy and Ontology: Aboriginal worldview

It is well documented that Australian Aboriginal people's existence dates approximately 50,000 years well before western civilization (Ranzijn et al 2009). Aboriginal worldviews existed and guided a lifestyle that had lived in relative harmony within the group; physical world of the environment, neighbours and religion (spiritual world). All spheres of Aboriginal life were interrelated and were the basis of the Aboriginal philosophy and worldview. Therefore, the epistemology of this framework is influenced by understanding the nature and structure of the Aboriginal worldview.

The Aboriginal worldview remains in an opposing contrast to a western worldview. The concept of power operated in a different form, and was gained by age and respect and adherence to social and religious obligations. Consequences for not observing social and religious obligations were generally immediate and swift, and accepted as part of Aboriginal Lore. Aboriginal social structures were based on one that is largely egalitarian. This minimised the individual need and countered the desire for power. Observance to religious and spiritual beliefs also played its role in countering the quest for power. Boundaries between neighbouring groups were well observed and taking another's land held no real attraction, as neighbouring land held no religious significance. In contemporary times, the land your family originates from still holds special significance whether the individual or family continues to live in that "country region" or not. For Aboriginal people, the term "country" refers to the regional boundaries as understood by Aboriginal people, and where your family originates from (Bennett, et al 2011). The country region such as Nyoongar country is the basis of my identity. Aboriginal people from other regions of Australia can identify which part of the country my family originates from based on the name of the language group. This immediately, informs discussion and establishes rapport, as each party usually begin to identify which families they have met or are familiar with from that country region (Bennett et al, 2011).

Indigenous methodology and mixed methods

A mixed methods approach that uses an indigenous research paradigm seeks to integrate multiple ways of knowing and seeing the world, multiple standpoints, and multiple values...both quantitative and qualitative approaches are indigenized (Chilisa & Tsheko, 2014, p223).

Whilst, Indigenous methodology continues to be an emerging field, there is a paucity of literature on applying a mixed methods approach in Indigenous research (Chilisa & Tsheko, 2014). In essence, observance to Indigenous protocols, epistemology, and Indigenous ways of knowing, does not change based on the chosen method selected to work within the community. Indigenous researchers Walter & Anderson (2014) also provide a compelling argument for Indigenous methods to be applied in quantitative research with Aboriginal people. These authors argue that often a deficit lens is applied in quantitative research within the Aboriginal community. In turn, this influences negative outcomes from the research.

Within this project, an Indigenous lens was applied to the design of the survey tool for this research project and was culturally relevant to the targeted audience by the following;

- chosen format (paper based), language;
- gender sensitive and informed questions (in consultation with Aboriginal males and females);
- historically and socially applicable to the contemporary reality of Aboriginal people in Western Australia.

For instance, the question relating to the stolen generations, yielded the response that the majority of participants 56 per cent were either themselves or an immediate family member part of the stolen generations. In informing service delivery, this response provides further evidence of the importance for a trauma and culturally informed approach for working with Nyoongar people in the south west, WA. Further, results yielded from this survey supported the appropriate cultural design of the survey tool, and results confirmed Aboriginal people's preferred manner for learning on FASD was in person, small groups, and community forums. Similar to the manner in which the survey was facilitated by the researcher and in person. An online survey approach would generally not work with Indigenous people, as it requires access to wifi, and computer. Further, an online survey does not facilitate engagement, yarning or being able to share information.

Indigenous methodology and Intergenerational trauma

In a landmark study undertaken on Indigenous methodological approaches and

intergenerational trauma, Marsh (et al, 2015), argue that Indigenous based approaches are critical for both research with Indigenous people and for the design of service delivery for Indigenous people. In particular, the authors provide a compelling argument highlighting Indigenous methods and culturally safe practices as essential in adequately addressing intergenerational trauma for Indigenous people. Gelb & Rutman (2011) agree and assert that understanding and knowledge of cultural values and needs must be paramount in the delivery of services for Indigenous people. Stewart (2008) also argues that western treatment models and the discipline of psychology has failed to address intergenerational trauma experienced by Indigenous people. Further, intergenerational trauma is compounded by the political and social contexts impacting on Indigenous people. Indeed, the lack of understanding of cultural values, has contributed to the high disengagement levels of Indigenous people in western treatment and programmes for substance abuse and mental health.

As an Indigenous researcher, this study has been enhanced by applying Indigenous methodology in all data collection including qualitative and quantitative. Indigenous methodology enhances and facilitates agency for Indigenous people, whilst promoting their voices during consultation. According to Finney, Green & Brown (2009), Indigenous research must inform evidence base that may be translated immediately into service delivery. In turn, the survey results from this study inform approaching FASD in a culturally secure manner, whilst also building workforce and community capacity through FASD training. This approach was imperative in approaching the sensitive topic of FASD within the Aboriginal community.

Aboriginal/Nyoongar ways of knowing Axiology: The role of values and Local Nyoongar Protocols

The term axiology refers to understanding the role of values in research (Walters & Anderson 2013). A core part of the value system in Aboriginal culture is understanding and therefore adhering to Aboriginal protocols. Not observing this value system potentially places the research project at risk of poor engagement and results, and undermines the credibility of the researcher.

The methods applied in the data collection included a strict adherence to Nyoongar protocols throughout the project. Understanding protocols was critical for ensuring

cultural safety and security in dealing with a sensitive topic as FASD within the Nyoongar community. According to Marsh (et al, 2015) in conducting research with Indigenous communities, the researcher should begin the research firstly, from Indigenous protocols, rather than a theoretical position. Indigenous researchers and professional people working within their communities are expected to observe and adhere to protocols (Bennett, Zubrzycki & Bacon, 2011). Further, the researcher being Nyoongar, and conducting research in Nyoongar country, does not exclude the researcher from not observing Indigenous protocols. Rather, the community expect nothing less than such protocols to be observed. The next paragraph provides further discussion on following Indigenous protocols.

Whilst, the Nyoongar researcher had ethics clearance, it would be disrespectful to not also seek permission from elders. Indigenous protocols generally commence with seeking permission to begin research in a town from a respected elder. Seeking permission before commencing research also facilitates cultural safety for the community. Several years earlier, the researcher on seeking permission for another research project, was advised that the time was not good for the community. The community had experienced several suicides of young men in that particular town, and the time was not appropriate to take part in research that had any risk of triggering any undue stress or emotional harm. The following further expands on Indigenous protocols in the discussion on relatedness; reciprocity and understanding relationships.

Introductions and respecting relationships

Relationships are also at the core of Aboriginal life, as they serve to guide conversations and are the means of connecting with other Aboriginal people who you meet for the first time. Introductions observe protocols in identifying previous generations and this contributes to establishing an instant rapport (Wilson, 2008). Introductions will be made by identifying parents, and grandparents, and the regional area that your family and yourself originate from (Martin, 2003). This informs the conversation immediately, and connections are then made to the immediate and extended family. Elders will share stories of family members that have now passed on, as I have often had the privilege of hearing during my travels, research and data collection for prior work and the current study. This process of identifying oneself and family also creates transparency that is critical in building rapport and trust within

Indigenous communities.

Generally short stories of family members will be exchanged and shared in an introduction making these meetings often profound experiences. Indeed, these cultural introductions are in a manner therapeutic, as many Aboriginal people have missing information on their families due to colonization and removal of Aboriginal children. Personal information relating to families may take decades to find, and many times not within the lifetime of that particular family member, as was the case of my grandparents on my mother's side of the family. In 2017, my mother May aged 77 was reunited for the first time with her father Bill Foley's family in Fitzroy Crossing. However, this search began many decades before with my grandfather Bill, therefore the search for answers had extended beyond his life and was a process that took close to hundred years within this family.

Relatedness: Grandmother Tilly's story

A few years ago, I recall the privilege of meeting an elder for the first time in the town where my mother was born. Introductions of ourselves, and grandparents were made as per normal Aboriginal protocols (Bennett et al, 2011). Upon hearing the name of my Grandmother Tilly Foley, the elder was immediately pleased and began to tell me an important story about my grandmother who had been a respected Aboriginal midwife in that region. The elder proudly shared her story about how my grandmother had successfully delivered many Aboriginal babies in the town, herself included. I had never heard this amazing story about Grandmother Tilly, who passed away in 1967, aged 63. The timeframe of when my grandmother was a midwife was likely to have been the late 1940s, and 50s in rural Western Australia. During this era, the social climate of racist ideologies were powerful and Aboriginal people had no access to health services. Further, this included segregated health service delivery for many decades, whereby it was common practice for Aboriginal people to receive medical treatment in the hospital yard or verandah until the 1960s. Generally, Aboriginal women gave birth under these same conditions (Saggers & Gray, 1991).

Therefore, in knowing the historical timeframe of this story, it provides a better appreciation of how important this role was by my Grandmother, and other Aboriginal midwives, and why it was so highly regarded by the local Aboriginal community and

remembered in this way. In true Aboriginal reciprocal manner, the elder gave myself and my family the gift of this precious story to be shared again amongst the younger generations of our family.

Whilst, Aboriginal people are gifted storytellers, many stories have not been told as many of our families have been in survival mode for decades with the devastating impact and trauma of colonization and child removal (Maushart, 1993). Poetically, it is almost as if many of our precious family stories have been asleep, and are waiting for the chance to be woken up, and shared again and celebrated amongst family and friends. Oral stories remain an integral part of Indigenous culture and identity, particularly when history has denied many families access to family genealogy and stories.

Strengths of Aboriginal families kinship system

The strengths of Aboriginal families are numerous and includes the structure of the extended kinship system that is a common feature of Indigenous families throughout the world. A further example of the strength of Aboriginal families is the ability to look after family members, and this often extends to non-blood relatives. Family are often the first point of call for Aboriginal people in distress and crisis. The survey results of this study also support this fact, and highlight in times of crisis it is the family, that Aboriginal people turn to rather than outside services. As previously discussed in the literature review, there are a host of reasons for poor engagement of service delivery of the Aboriginal community, and in brief is due to the legacy of colonisation and system institutional racism.

Another strength of Aboriginal families within their worldview is to see the person as being only temporarily in a vulnerable state. The Nyoongar term “Winyarn” is a versatile word, that may mean; you are feeling sick/distressed, or you have no money, or you feel depressed. In the Aboriginal worldview it is state of being that is temporary and the key point being here is that it is generally free from judgement and stigma, as everybody experiences their times of feeling “winyarn”. It is a way of communicating to others that today I need some extra support either emotional or financial. The other important point here is that families in Australia, have not been given access to knowledge, tools and awareness to deal with the disability of FASD.

Families who may be caring for children under kinship care, with an undiagnosed FASD disability may never break the cycle of poverty. Poverty in this respect, is the poverty that leaves families reliant on public housing, which is often an added stress, as overcrowding continues to be an issue for Aboriginal families.

Relatedness and adapting

Relationships that are based on a shared history of supporting each other, trust, respect and cultural obligation will generally last for life, and indeed future generations. Many strong relationships of Aboriginal people were formed during the years of the stolen generations, whereby many Aboriginal people of different groups were forced to live together at institutions and missions (Maushart, 1993; personal communication, 2004). The kinship system adapted and adopted those who were not blood relatives into family (Maushart, 1993). Within Nyoongar families maintaining relationships includes observing protocols in general family life; at times reciprocity; visiting your country, attending funerals or having your family represented at a funeral; keeping contact at important times with extended family, such as when family members are critically ill. In this regard, Aboriginal families are flexible and understanding of the social and economic pressures that impact on all families. However, they are less forgiving if it appears you have made little effort in maintaining your relationships with family and country over an extended period of time. In this respect, relationships also provide the connection between Aboriginal people whether you are related closely or not. First Nations academic Shawn Wilson, makes the following comment regarding the importance of relationships (Wilson, 2008, p80)

Its collective, it's a group, it's a community. And I think that's the basis for relationality. That is, it's built upon the interconnections, the interrelationships, and that binds the group...but it's more than human relationships. And maybe the basis of that relationship among Indigenous people is the land. It's our relationship to the land. There's a spiritual connection to the land. So it's all of those things.

Maintaining and respecting relationships within the Aboriginal community was of course taught to my siblings and myself by my parents and extended family. In turn, we have taught our children the next generation, the importance of knowing family and relationships within the extended family. Based on knowing and respecting relationships, the community response and engagement to the survey was strong in each site. This was evident based on the overall number of participants engaging in

this project, and the good representation of both Aboriginal males and females.

Yarning with the Nyoongar community about FASD (Interview Style and Questions)

Australian Aboriginal researcher Bessarab & Ng'andu (2010) asserts that yarning is a legitimate research method, and culturally secure approach for working within the Aboriginal community. Yarning also minimizes the risk of further trauma in dealing with sensitive issues. This approach becomes even more important, as there are no dedicated services to support families with FASD. The topic of FASD is a sensitive one in any community, as blame can be easily attributed to the mother. This in itself, could place Aboriginal women at undue risk.

Yarning begins at the surface of social yarning and then deepens to serious concerns, an example was yarning with relative carers, who had young family members in their care and suspected that a child had FASD (Bessarab & Ng'andu, 2010). Whilst, the pathways to a diagnosis with FASD is long, it does not prevent what family members are already aware of in terms of the child's patterns of behaviour and the fact, families observed prenatal alcohol consumption during the child's pregnancy. In using a collaborate yarning approach, the researcher was able to flag the importance and urgency of awareness and advocacy in yarning with the Aboriginal community about FASD (Bessarab & Ng'andu, 2010).

The survey tool, Our Gurlonngas, Our future, was designed and intended to be an icebreaker that would provide some initial information on FASD and would facilitate yarning about FASD within our community in a culturally safe way. Under the right circumstances, Aboriginal people are happy to yarn, talk and raise concerns. The right circumstances include working in a culturally secure manner, and in this case it was advantageous that the researcher was Nyoongar and mature age. However, just being Nyoongar, is not always enough and the community will not engage with you completely if you have not maintained some form of relationships with extended family. Having maintained relationships within your family, also plays a role in how much the community will engage with you as a Nyoongar researcher.

The survey tool acted as an icebreaker, and on completing the survey, the researcher

asked each participant if they had any questions or feedback on the survey, and this initiated social yarning with participants who were willing to engage further. This included general enquiries about FASD; to more serious concerns, relating to the suspicion that young and older family members had undiagnosed FASD. Through the process of yarning, the suspicion of possible undiagnosed FASD was based on family members observing PAE, and now observing behavioural problems within children, both at home and at school.

Older participants frequently made the statement that they believed they had witnessed children with FASD in their community, and referred to behaviour problems as the common indicator. Other community members expressed their concerns about observing women consume alcohol during pregnancy. In some cases, email contacts of the researcher were exchanged and details of diagnostic clinics in Western Australia were provided at each site, when requested. Collaborative yarning also led to the frequent requests from each site for FASD training in the community.

Reciprocity

In contemporary times, reciprocity remains an important cultural obligation within Aboriginal culture (Kickett, 2011). Further, reciprocity is based on mutual respect and the extended family (Eckerman, et al, 2006). Aboriginal culture is based on oral traditions and stories, therefore, Aboriginal people have great memories of recalling stories, events and important times (Kickett, 2011). Reciprocity is providing support when it is urgently needed to family and extended family members and this will be returned to you later in some form of support either monetary or social. As Kickett (2011) describes good deeds are remembered for life, and also benefits the next generation of your family. This in turn will also influence how well Aboriginal people will engage with you as an Aboriginal researcher. The elderly lady who had known my grandmother made an instant connection to myself, and this established an immediate good rapport, and she was happy to speak to me for a longer period of time, even though she was a busy community person with many demands on her time.

Reciprocity became an important part of survival for Aboriginal people during oppressive times, as the only support Aboriginal people had, was other Aboriginal people. In this respect this is also included Aboriginal people outside of extended

family who were not blood related. During the long years at institutions such as Roelands, Carrolup, Moore River Settlement, close bonds were formed between Aboriginal people who were not related (Maushart, 1993). Whilst engaging with the community during data collection, the researcher was conscious of the obligation of reciprocity, and was asked by the community in each site visited to return at a later date and provide training on FASD. The request for training was responded to by the researcher and training was delivered at three of the six sites before the conclusion of this project.

At several of the sites in the country, the researcher was also invited to attend meetings at government and non-government agencies. These agencies were health focused and requested information on FASD. This took extra time, however, it was important to attend as the community were concerned in their towns of the lack of awareness of FASD. Researchers need to be conscious of reciprocity and be sincere in responding to any requests that arise from engaging with the community. This request also demonstrated that the communities are strongly concerned about FASD within their families and communities. See further discussion in this chapter relating to meetings attended by the researcher, at the request from the community and FASD training that was designed and delivered to the Aboriginal community prior to the end of this project.

Ethical Issues

The researcher actively worked to ensure no harm was subjected to the participants and to this end, included Aboriginal community members, key Aboriginal and non-Aboriginal agencies, academics and the CRG in all levels of consultation. In developing this project consultation was also held with Ms Lorian Hayes, an Aboriginal elder/academic with extensive personal and professional expertise in FASD. The process and conduct of the researcher was undertaken in a manner that was respectful and non-discriminative, and sensitive to the Aboriginal and non-Aboriginal community. This study was guided by the National Health and Medical Research Council's Values and Ethics Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health (NHMRC, 2003).

Ethical approval was received from the Western Australian Aboriginal Health Ethics Committee (WAAHEC) and Curtin University. Ethical consent was also sought and approved by the Department for Child Protection in Western Australia, as the researcher anticipated the high probability of interviewing a family with children on care orders with the department. Participants also received a gift voucher of \$20 for their time. Participants for the family case studies received a voucher of \$50 for their time, as this involved more time than the surveys. Aboriginal participants who completed the family interviews were not asked to complete a survey, as the researcher felt this would have overloaded the participant.

Further in observing cultural protocols, permission to commence the survey in each country towns was sought by approaching a respected local elder. This occurred regardless that the study had both WAAHEC and Curtin University ethics approval. This allowed the community to have the power in approving the survey and the research, and gave respect to elders in each site. In seeking approval, the researcher outlined to each Elder what the survey and project was about and gave elders the opportunity to view the survey, particularly pointing out the most sensitive areas of the survey. This gave Elders the opportunity to make an informed decision. In all towns approval was sought by an elder and research commenced upon their approval in each town. Australian Aboriginal researcher Hornung (2013) terms this process as seeking cultural approval, and is a critical part of the research process that is often missed in working within the Aboriginal community.

In a previous research study conducted by the researcher, the same approach was applied and on one occasion, approval by the local community was not forthcoming and the research did not proceed in that town. The reason provided was that there had been several suicides by young Aboriginal men in the town over a short period of time, and therefore each family in that town had been impacted and were still dealing with grief and loss.

Selection of Participants for case studies

The criteria for case studies included either a parent/carer who has/had cared for an Aboriginal child in the South West region with confirmed or suspected FASD. The inclusion of “suspected” FASD was included in the criteria as the FASD diagnostic

tool is still in the planning and implementing stages in Australia. In each case of suspected FASD, a specialist had advised the family that they believed the child/ren had FASD. In most cases, these families also kept in contact with these specialists who were informed in recognizing FASD in children. Further, as mentioned in international FASD studies, to have excluded a family because they lacked a formalized FASD diagnosis would have further marginalized those families based on the systematic failure of access to FASD diagnosis (Rutman & Bibber, 2000).

Recruitment of participants for family interviews was undertaken by purposeful sampling and snowballing, and also included the family who had in the first instance asked that their experiences be recorded. In another case, two other families were keen to have their experiences recorded in caring for Aboriginal children with FASD. In this study none of the children were raised by their biological parents and all the children were or had been in the OOHC. This included both Aboriginal and non-Aboriginal carers. Two of the carers were based in a rural town and three carers were based in Perth.

Carers interviewed included both Aboriginal and non-Aboriginal carers. Given the increasing rate of overrepresentation of Aboriginal children in care in Australia, many Aboriginal children are also placed in care both short and long term with non-Aboriginal carers. This research project was deliberately mindful of inclusion of both Aboriginal and non-Aboriginal carers and not excluding one over the other. As stated it was critical to be inclusive of the experiences of carers, and what issues faced carers and if there were any differences between Aboriginal and non-Aboriginal carers. The number of carers interviewed were: three Aboriginal relative carers and three non-Aboriginal foster carers.

Case Studies: Length of Family Interviews

The interview questions were semi structured and were conducted in a yarning style to achieve good rapport with participants during the interview. With permission from participants, the interviews were recorded. Participants were also advised that they would be all de-identified, and that the participants could stop the interview at any time if they chose. Generally, the interviews went for 1.5 hours with carers. Due to the intense workload involved of a mixed methods approach, transcripts of the

interviews were completed by a research assistant who had extensive experience with Aboriginal families and had a good understanding of Nyoongar language. However, transcripts were checked by the researcher against the recordings, and were transcribed verbatim. As part of reciprocity the researcher asked each participant if there was any further information on FASD that they required. Most of the families and also members of the community with surveys were keen to have good information on tools for families with FASD.

Phase 1: Critical Reference Group (CRG)

A Critical Reference Group was established at the commencement of the PhD research Project. The CRG membership included largely Indigenous and non-Indigenous people with expertise of FASD. Local Noongar people with expertise in health, mental health/psychology, welfare and community development also participated on the CRG. The CRG was formed to guide the researcher in the development of the survey, case study questions and the International Study Tour. The guidance of the CRG also ensured that the tools and research approach was undertaken in a culturally secure manner. There was significant advantages to forming the CRG, it was necessary to have membership on a national level as at the time of this study, this amount of expertise was not available in Western Australia. The only disadvantage to have a national CRG was that time differences between the states made it more difficult to convene meetings of this group.

Phase 2: Design of the Survey Tool

The design and development of the survey tool was undertaken after a literature search did not identify any appropriate survey tools for the study population. The CRG also played a key role in advice on the development of the survey tool. Further consultation was made with other key agencies, such as the National Drug Research Unit (Professor Dennis Gray, and Professor Ted Wilkes); Telethon Institute for Kids; and Aboriginal supervisors. Aboriginal artwork was generously donated by well-known local Nyoongar artist Peter Farmer. The artwork on the cover of the survey depicts the symbol of the “birthing tree” that is significant in Nyoongar culture. The suggestion for the inclusion of the birthing tree came from Ken Kelly, who was a CRG member and played a key role in giving advice in this research project. In traditional times, the birthing tree was the place where childbirth occurred, under the protection and

supervision of Aboriginal women who were well experienced in the traditional ways of childbirth.



**Figure 10: Our Gurlonngas, Our Future
With Permission of Artist: Peter Farmer 2014**

The survey was titled “Our Gurlonngas, Our Future”. The word “Gurlonngas” is the Nyoongar word for babies and young children. On review of literature by (Badry & Wight Felske, 2013) and their work on FASD with Native American women in Canada, it was a conscious decision to not use the terms “FASD” or “Fetal Alcohol Spectrum Disorder” in the title of the survey. The inclusion of Nyoongar language in the title, makes the survey firstly accessible and interesting in terms of what does the community need to be aware of to protect the health of our young children and our next generation. The inclusion of Nyoongar language also pays respect to local Nyoongar culture and people, and the survey looks culturally appropriate.

Content of the survey

The survey included five sections within the survey, and had an overall total of 50 questions. A total of seven qualitative questions were also included allowing the participants to make comments in relation to FASD. The titles of each section included:

- Section 1: Demographics
- Section 2: Understanding FASD
- Section 3: Alcohol

Section 4: History and family

Section 5: Information on FASD

The survey included a preamble introduction, as for many people in both the Aboriginal and non-Aboriginal community, the topic of FASD is a new topic. Therefore, it was critical to inform participants of this fact, and the preamble was worded as follows:

*Your participation today is important. The topic of Fetal Alcohol Spectrum Disorder (FASD) is something that we are **all** still learning about in every community. This survey will help us find out what our community knows and what information is missing. Your answers will stay confidential and no-one will be able to identify you. In this survey Fetal Alcohol Spectrum Disorder is also referred to as Fetal Alcohol Spectrum.*

Phase 3: Administration of survey

The survey was a paper based survey and was filled out by participants. A paper based survey gave the participant the opportunity to raise any questions they had in regards to the topic of FASD. The researcher was present as participants completed the survey, and only on two occasions did participants ask the researcher to assist and read out the questions in the survey. An online survey tool would not have facilitated the opportunity for yarning about FASD. This also required that Aboriginal people have access to a computer, internet and basic skills in computers, which is generally an issue for elderly people.

Pilot Survey

The survey tool was piloted amongst Aboriginal people both males and females in Perth, Western Australia. A total of 10 participants ranging from the ages of 18 to 70 years of age participated. The survey pilot was conducted prior to commencing data collection. The feedback from the participants was the following: language used in the survey was easy to understand; participants did not find any of the questions invasive or offensive; participants were receptive to the flow of the design of the survey and participants were also generally interested in asking further questions on FASD.

Selection of Participants for Survey

The criteria for the survey was Aboriginal people aged from 16 years and upwards

including both males and females living in the South West region of Western Australia. The researcher was also guided by trusted local Aboriginal people for participants in the survey. In this context, local people informed on important issues such as “sorry business”, as in which family member, may have recently had a loss and or funeral in their family. This strategy was to avoid potential undue risk or harm to community people, and it would have been inappropriate professionally and culturally to approach any individuals who had recently had a loss in the family.

Research Survey Sites

Sites	Place	Male	Female
Site 1	Northam	2	9
Site 2	Albany	6	11
Site 3	Katanning	13	17
Site 4	Tambellup	11	23
Site 5	Bunbury	6	15
Site 6	Perth	32	35
	Total	70	110

The sites where the survey was undertaken included; Northam, Perth, Katanning, Tambellup, and Bunbury. From the beginning of this study, the researcher was advised by the CRG to include Aboriginal men. As the researcher was a Nyoongar woman of mature age, this may have encouraged the level of engagement from both Aboriginal men and women, in terms of being able to ask questions of a sensitive nature around FASD. This is not suggesting young people Aboriginal and non-Aboriginal are not capable of undertaking research in Aboriginal communities, however, Aboriginal people respect age and lived experiences, and feel more comfortable discussing sensitive topics with an older person. An example of sensitive discussions was the question posed by an Aboriginal father at a country site, who was concerned that his previous long term heavy drinking may have had a detrimental impact on his children during pregnancy.

Qualitative Data (Reliability)

Patton (2002) asserts that credibility of research is demonstrated by the credibility of the researcher, and the researcher having a personal commitment to naturalistic

inquiry. Guba and Lincoln (1985), outline fundamental principles for establishing credibility in research, such as prolonged engagement; triangulation, peer debriefing, persistent observation and member checking. The researcher spent considerable time and prolonged engagement at each of the five sites in country areas, and went back to two sites for a second visit to ensure good engagement with the community both Aboriginal and non-Aboriginal. Generally, the Indigenous community hold Indigenous researchers to a higher level of accountability, and they expect an Indigenous researcher already comes with knowledge and adherence to Indigenous protocols. The researcher throughout this process consistently engaged with peer debriefing; and engagement was on a one to one basis with the Aboriginal community in both the survey and family interviews. This provided a rich source of observation and discussion in this project.

Patton (2002) claims reliability of research is based on the selection or design of appropriate tools and the approach of the researcher to the topic. Appropriate tools are then able to engage and capture the true phenomena from the community. The researcher worked with the CRG with expertise in FASD, and Aboriginal community development in the design of all tools. The process of designing the survey was rigorous including literature review; consultation with the CRG and was also peer reviewed by senior researchers from the National Drug Research Institute, and Telethon Institute for Kids.

Patton (2002), asserts the instrument must then be administered in a standardized manner during data collection. All surveys were administered by the researcher at each site, due to the sensitive nature of FASD, and this ensured the researcher was immersed in the research from the design of the tool, data collection and engagement with the Aboriginal community; input and analysis of data into SPSS. Further, the researcher also administered all the interviews with the six families, and analysed the themes of the family interviews. The transcripts of the interviews with each family member were transcribed verbatim. The researcher checked the final transcripts of the interviews against the recordings. Transcripts were then coded for thematic analysis within the Indigenous framework. Due to the sensitive nature of the FASD within families, the researcher debriefed regularly with members of the CRG.

Patton (2002) claims successful qualitative research hinges on the credibility and expertise of the researcher. As previously outlined, this research had community credibility, as the research was initiated from a Nyoongar family and this was based on mutual trust, respect and relationships. Credibility, also encompasses the researcher being Indigenous, however, this alone is also not enough, and the researcher has been working within Perth and the south west region in Aboriginal affairs for the past 20 years. Further, the researcher has maintained cultural obligations within the Aboriginal community. The researcher approached this study to build the capacity of the Aboriginal community, and the flow on effects has included workforce development for key Aboriginal non-Aboriginal agencies in Perth and the south west region. The strong engagement of 180 Aboriginal participants is a reflection of credibility of the research approach, and the request for FASD training.

Insider research as an Indigenous researcher and Reflexivity

Aboriginal elders teach that even though a cultural insider may have an easier time connecting with Aboriginal communities, the responsibility of the cultural insider is much greater because he or she is familiar with the culture and required protocols (Marsh, et al, 2015, p.4)

As relating to Indigenous protocols, the Indigenous researcher should seek permission from the local communities before commencing research within the community, and permission was sought from Elders prior to commencing at each site. Working as a Nyoongar researcher in Nyoongar country affords you the benefit of insider knowledge of community/family dynamics, and politics. Importantly, it also gives you the understanding of communication through body language, and understanding nuances of communication within the Aboriginal community. For instance, understanding and respecting times of silence, and allowing the community to reflect, and consider information. However, if there are any negative impacts resulting from the research, it is the Aboriginal researcher who will have to live with those consequences not only professionally but on a personal level. (Smith, 1999). This is important particularly when dealing with sensitive topics such as FASD.

Smith (1999) outlines some of the fundamental principles that Indigenous researchers conducting inside research must include such as; reflexivity; involvement of elders, and the researcher should conduct themselves with humility. Further, Smith (1999)

asserts reflexivity is an important process that the Indigenous researcher must remain conscious of throughout the research project. This sentiment is also supported by Indigenous academic Martin (2003, p.25) who states:

Reflexivity in research design affords the “space” to decolonize western methodologies, then harmonise and articulate Indigenist research. Reflexivity challenges us to claim our shortcomings, misunderstandings, oversights and mistakes to re-claim our lives and make strong changes to our current realities.

Reflexivity involves the researcher thinking critically about the research process due to the community relationships of the researcher to the community. This also involves playing a diplomatic role, and being able to decline invitations that may cause undue stress to participants. For instance, during this research, the researcher declined an invitation to survey women at a women’s refuge, as the women were likely to be in a vulnerable state from escaping domestic violence. Being constantly reflexive guided the researcher to always question what was potentially harmful and to place the welfare of the community first and foremost before the outcomes of the research. In terms of humility, the researcher should also be conscious at all times of the power imbalances, between themselves and the community.

Reflexivity was used in planning and timing research visits and knowing when to be flexible around such important times as funerals, and community meetings. This approach and knowledge also protects the community, as the researcher should not approach the community at times of escalated stress, or times of grief (sorry business). However, the Aboriginal community also expects an Aboriginal researcher to know this information first hand, and not operating with such principles will quickly lose respect and credibility for the Aboriginal researcher within the community.

Guba and Lincoln (2005) describe reflexivity as researchers reflecting critically on themselves during research, and interrogating individual ways of thinking in conducting research. The process of reflexivity forces the researcher to challenge their own values and knowledge and what they bring to the research process (Guba & Lincoln, 2005). This includes being conscious of personal bias that the researcher may unconsciously carry. In this research project, the researcher was conscious of personal bias, and worked hard as an Aboriginal researcher work in the same approach with non-Aboriginal participants. In this respect, the researcher actively worked in having

the same empathy towards all participants caring for Aboriginal children with FASD, regardless of race.

Power imbalances

Smith (1999), articulates that Indigenous researchers must be conscious of power imbalances in conducting research within their own community. As a Nyoongar woman having lived in Perth, and having worked in Aboriginal affairs my whole career, being conscious of any power imbalances was foremost in my approach throughout this project. In this context, Aboriginal researchers not only place their professional credibility but also their community and cultural credibility at stake in not employing correct practices and cultural protocols in research.

In undertaking this project, the researcher utilised local cultural knowledge in terms of Aboriginal language; body language; vernacular; nuances and knowing when it was appropriate to use Aboriginal language with other Aboriginal people whom I was meeting for the first time. Aboriginal people are generally not comfortable with people who display overfamiliar behaviour until some rapport or family/cultural connection has been established. Further, this research provided an important opportunity to demonstrate to my local Aboriginal community how research undertaken appropriately and with trust, may be an important tool in advocacy for change in addressing serious concerns such as FASD.

This project also demonstrated that research has practical benefits in starting the conversation on FASD within the community, and feedback received from the community supported this in each site. The researcher endeavoured to ensure power imbalances were addressed and minimized by the following strategies in this project; adherence at all times to Aboriginal protocols and not commencing in sites until consultation and approval was given by a respected Elder. This also included the introduction of myself (family cultural group) to other Aboriginal people whom I met for the first time. In this respect, relatedness assisted in knowing if there were any further expected cultural obligations.

The researcher ensured for suitable timing for surveys and interviews to be undertaken at times suitable for the community. For instance, showing respect for funerals and

waiting the correct amount of time before re-engaging with the community. All participants were advised they did not have to take part in the survey, and could also stop at any time, after commencing. Further, the researcher reminded the Aboriginal community of the limited knowledge of FASD by the mainstream community, as it remains a misconception to think FASD is a well understood topic in Australia. Further, the researcher also advised the community that FASD is a global, mainstream health problem, and was not solely, an “Aboriginal problem”. All participants for the family interviews chose themselves the venue where interviews took place.

Rigour

Richards & Morse (2007) remind us that good research is dependent on the skill level of the researcher and highlight the researcher must be maximally prepared for the project. To this end, the researcher did not commence any engagement and data collection within the community, until the researcher had completed an extensive self-orientation including undertaking a FASD literature review and completed international training in FASD in both the US and Canada in 2014. In total, the researcher undertook, two FASD training sessions; the first with renowned FASD trainer Diane Malbin for three days in Oregon, and the second session on FASD case management in child protection with experienced FASD trainer Donna Debolt in Calgary. The researcher attended three FASD conferences, the first Australian FASD conference in 2013, and two FASD conferences in Alberta, Canada in 2014. The conferences included the latest interventions and research on FASD; and also provided the researcher with in depth knowledge of FASD across the lifespan.

The researcher found it was imperative to have in depth knowledge and training on FASD to enhance informed meaningful discussions within the community, particularly as there was a lack of FASD awareness by all sectors. Consequently, the researcher was confident in discussing FASD within the community. Kovach (2009) outlines fundamental principles that demonstrate rigour in the research, and this includes triangulation, including data gained from multiple sources. Rigour in this thesis was robust during this project, as FASD is generally unknown in the mainstream and Aboriginal community and the researcher’s initial knowledge of FASD was limited before commencing this project. Collectively, this approach provided the researcher with expertise to engage within the wider community with an in-depth

understanding of FASD. To this end, the researcher engaged with the community both Aboriginal and non-Aboriginal in presenting training on FASD.

Rigour in this study was also enhanced by the applied mixed methods methodology and consequently produced a rich source of data in the survey and the qualitative studies. The themes identified in the survey results were consistent across sites in this project. The researcher also conducted extensive peer debriefing with FASD specialists in Australia, Canada and the US. Rigour was further demonstrated by being able to access six different sites in the region, including good representation from both Aboriginal men and women.

Quantitative data

As previously highlighted, the researcher collected all surveys completed and was then responsible for the input of all surveys and the analysis of the data. Quantitative data from the survey was entered into SPSS, and the data was then coded and cleaned of any errors by the researcher. Descriptive frequency tables were run for all questions, to assist in identifying any emerging themes in the data. This stage was also useful in then undertaking cross tabulations of more than one question for comparisons in the data.

Table 1: Description of Independent variables:

Variable	Description
Age	The age of participants in this survey was aged 16 years and upwards.
Gender	Participants were asked to identify their gender and categorized as: male and female
Identity	Identity included four Western Australian Aboriginal language groups such as: Wongi, Yamatji, and Nyoongar.
Aboriginal	The selection criteria inclusion for this survey was Aboriginality. All of the participants identified themselves belonging to Aboriginal community. Furthermore, the Aboriginal groups identified by participants were; Nyoongar, Wongi, Yamatji and Nyoongar/Yamatiji; Nyoongar/Wongi. The questions also allowed participants to identify other Aboriginal language groups outside of these groups.
Employment	Employment category included; full time, part time, casual employment and not employed looking for work, and not looking for work.
Parenting	This question asked participants to indicate whether they had children.
Education	Levels of education is important in contributing to an increased awareness of FASD within society. Participants were asked to select their highest level of educational attainment.
Trauma	Trauma included questions of negative life experiences that participants had either witnessed or experienced.
Stolen Generations	This question asked participants if themselves or any member of their immediate and extended family had been removed under the Australian historical policies of the Stolen Generations

Table 2: Description of dependent variables

Variable	Description
Alcohol use	Alcohol use includes the amount of times alcohol is used in week, and this question comes from the screening tool Audit C. The categories included; frequency of alcohol consumption; how many standard drinks on occasion; and consuming alcohol with a partner.
Level of awareness of FASD	Participants were asked to self-rate their level of awareness of FASD in one of three categories; a lot; little; and None. Review of Australian literature (McLean & McDougall, 2014; Payne et al, 2005) argues that the level of awareness of FASD in both the wider Australian society and community level continues to be unreasonably low. Consequently, this question explored the level of knowledge, and asked participants to self-rate their own knowledge of FASD.
Signs and symptoms of FASD among children	Signs and symptoms of FASD in children included ten different categories, identified based on extensive review of literature; Streissguth et al, 1996, Brown, 2015; Carpenter, et al 2014; May, et al, 2014.
Signs and symptoms of FASD among adults	Signs and symptoms of FASD in adults included eleven different categories, identified based on extensive review of literature; Streissguth et al 1996; Carpenter, et al 2014; Rutman & Bibber, 2009.

Duty of Care

The researcher was at all times conscious of duty of care to participants and the community, as FASD is a sensitive topic. The researcher worked in this project with a strong understanding of the responsibility of facilitating research within the Aboriginal community, particularly research that has a sensitive nature such as FASD. This also includes engaging and working at a pace that responds to the social and emotional needs of the Aboriginal community. The researcher was flexible when engaging with the community at all times throughout this research. The involvement

of elders in each town and local community members also guided the researcher in seeking participants to minimize any risk of triggering trauma for participants. For instance, to reduce risk to any families who may have recently experienced traumatic or may have recently had a death in the family.

The CRG membership also included Karen Ugle, who is an Nyoongar psychologist, and Karen was active in providing feedback to the researcher and the development of the questionnaires in the project. Karen Ugle has many years' experience in counselling, and programme development in the Nyoongar community. All members of the CRG were instrumental in providing their expert advice to minimize any potential harm to the community. Ken Kelly as the only male representative and a Nyoongar male, provided an important Aboriginal male perspective to the design of this research, survey tool and undertaking of the project in the Aboriginal community.

Practical benefits of the research to the community

An Indigenous standpoint framework demands that research has the principles of having a practical benefit to the Indigenous community. As stated in chapter one, this research commenced with a request from a Nyoongar family to record their story and challenges of raising children with FASD. In the next section, the practical benefits of this research project are outlined as research should include the potential to have an immediate and practical benefit to the community. Further expansion on the practical benefits to the community are outlined in chapter eight.

FASD Introduction Sessions

Capacity building of Aboriginal and non-Aboriginal Agencies and carer groups in Western Australia

As previously highlighted in Chapter 3, Australia remains well behind countries such as Canada in service delivery and training in FASD, and this has a serious ongoing impact on individuals and families living with FASD. Prior to commencing this project, the researcher consulted with the Derbarl Yerrigan Health Service (DYHS) in Perth, Western Australia. The DYHS is a key Aboriginal agency and is the largest Aboriginal Medical Service in Western Australia. DYHS supported this project and has been in partnership throughout the research project, and this has involved meeting with the CEO, staff of DYHS, presenting to the board, and sending progress reports of the project. Further in 2015, the DYHS also requested the researcher to deliver training on FASD to staff of the DYHS.

Whilst conducting the research project in sites both in the country and metropolitan area, the request and demand for training and information sessions has been high. The researcher was requested to provide training on FASD on a later date to suit the community at all sites involved in the project. As there are no dedicated services in Western Australia to cater to individuals and families with FASD, it was critical to engage and build capacity of key agencies. Here it is critical to note that at the time of this research project, there was no FASD training available in providing tools for families or workforce in Western Australia. To this end, prior to commencing data collection within the Aboriginal community, the researcher met with key Aboriginal agencies such as the Yorgum Aboriginal Counselling service and presented FASD introductory training sessions on two occasions to Yorgum staff in September 2013, and May 2014. This was the first time this agency had received introductory training on FASD.

In this respect, the researcher was also able to promote the services of Yorgum Aboriginal Counselling Service if participants felt they needed to debrief or seek counselling on this topic. Consequently, the research project had a flow on practical benefit of building capacity within the Aboriginal community. Indeed, it was common to hear families frustrated at the lack of understanding of FASD by the general workforce, including health professionals. Further this is also backed up by

international literature on the lack of support and services for carers, leading to high levels of frustration and increased anxiety. The researcher also delivered a training and information FASD session to the only support group of carers for families caring for children with FASD in this state in August 2015. Further during 2015 presentations were made at the following agencies:

- Aboriginal Alcohol Drug Service (AADS) and this involved ongoing engagement and arranging a training session for the staff of this agency
- Banksia Hill detention centre
- South West Aboriginal Medical Service in Bunbury
- Katanning health service (government)
- Department of Child Protection, Rockingham
- Yorgum Aboriginal Counselling Service
- Palmerston Rehabilitation Service in Albany.
- Northam Aboriginal women's group

International Consultation

International feedback to survey tool and Study tour: Canada and North America

An international study tour on FASD was undertaken to North America and Canada in November and October in 2014. This study tour to visit world leading FASD experts and services was successful and critical in informing and guiding this PhD research project. Engagement with the International community on FASD was also a critical part of this project, and engagement in Canada and the US included the following people/agencies;

- Carers in both Canada and US, multiple sites
- FASD trainers with over 20 years' experience
- International FASD experts such as Dr Badry, and Dr Fuchs
- Director of Manitoba FASD Diagnostic Centre
- Staff working in PCAP programmes in Canada

There was a great deal of interest expressed in the survey tool that was developed for this project, and on numerous occasions and forums, I was given the opportunity to discuss and present the survey. This included: Fetal Alcohol and other Neurobehavioural conditions (FASCETS) training in Oregon; Native American

community workers; FASD experts such as Dr Don Fuchs and Dr Dorothy Badry in Canada. The feedback received was a great deal of interest in the tool, and that it was the first tool of its kind developed (Dr Fuchs). I was also asked for copies of the tool from carers and trainers working in FASD. Based on this research project, I had papers accepted at the following international conferences:

1. International Network of Indigenous Health Knowledge and Development Conference 2014 (Winnipeg)
2. Living Well FASD and mental health Conference 2014 (Winnipeg)
3. Bow Valley College, Calgary (College Students, Addictions studies)
4. University of Calgary (Post Graduate Students)
5. Grand Prairie Learning Circles (Social Work students)

The researcher received positive feedback from several FASD experts including Dr Fuchs, and Dr Badry to the survey tool in terms of being applicable to other communities, Aboriginal and non-Aboriginal. Further, I also received similar feedback from the Canadian Native American community. The education and raising of awareness of FASD within Australia continues to be an urgent issue, and this study trip has provided me with the increased knowledge, tools and networks that are critical to working competently in this PhD research project on FASD and in the wider community. The FASD training I received was easily adaptable for both families and workforce in Australia, and currently families/workforce generally have received none or little training in FASD. FASD training is also imperative and urgently needed for Social workers, teachers, Occupational therapists, and case managers working with children or adults with FASD. This also extends to the wider sector such as the Education Department, Alcohol and drugs and the Criminal justice area. FASD training will also raise awareness of the disability and would assist in the prevention of FASD.

Limitations of the study

The limitations in the research were influenced by time and budget constraints, as the researcher travelled to multiple sites in the South West region. Budget constraints meant that the researcher was not able to get to any other towns in the Wheatbelt area, past Northam, and other major towns in the South west region. The number of completed surveys was not large enough to be considered as a representative sample

of the Aboriginal community, however, it does provide a snapshot of the level of awareness of FASD within the Aboriginal community in the south west region of WA. For further discussion of the limitations of this study, see concluding chapter eight.

Conclusion

This chapter has provided an outline of Indigenous standpoint theory, and highlights that research in the past has marginalized and subjugated the voices of Indigenous people. This is well documented throughout the world and has contributed to the intense mistrust that the Indigenous community have of the research process. Indigenous academics such as Smith (1999); West (1998); Rigney (2001), and Martin (2003) argue historically research has been an integral part of the colonisation process, therefore research paradigms must be decolonized. The Indigenous standpoint theory provides a framework for guiding research with Aboriginal people that importantly privileges their voices in a manner, where other research paradigms have failed. Further, it demands that research be conducted in consultation with the community and there are practical immediate benefits for the community.

The Indigenous researcher must also be reflexive in this process and my role as an Indigenous researcher, does not mean I automatically know everything Nyoongar. Rather, my cultural knowledge provides me with knowledge as to where is the best place to start and what framework better honours the experiences and voices of Aboriginal people (Nakata, 2007). The next chapter five, provides the findings and analysis of the survey undertaken at multiple sites in the south west region. This survey explores the knowledge and awareness of what Aboriginal peoples understand about FASD, and how this knowledge may inform policy and service delivery.

CHAPTER 5

“Our Gurlonngas, Our Future” Survey results

“Everyone in the community needs to know about this problem and to know the effects that it has on the fetus whilst in utero” (female participant, WA 2015)

Introduction

This chapter includes the quantitative results of the survey “Our Gurlonngas, Our Future”. The term Gurlonngas is the Nyoongar word for babies and young children. Description of the development of this survey tool was provided in the previous Chapter 4, Research and Methods. To date consistent health promotions on FASD has been sparse within Australia, and in Western Australia. As previously highlighted Payne et al (2005) identified that only twelve per cent of health professionals in Western Australia were confident of their awareness of FASD. Consequently, it was also critical to survey the Aboriginal community in the south west to explore the knowledge and awareness of FASD within the south west region. Results from this survey provide useful data to informing the development of appropriate health promotional materials for FASD within the Aboriginal community, and possibly the wider community.

Characteristics of Participants

Table 3 below present *Characteristics of Participants* details of participants who participated in the survey and included 180 Aboriginal people; aged from 16 years and upwards. This included 109 females (60.6 per cent) and 71 males (39.4 per cent). The age range of participants was 16 - 67 years of age; and the median age was 44 and the standard deviation was 14 years. The sites where participants took part in the survey included Perth; and the country towns of Northam; Bunbury, Albany, Katanning and Tambellup. The majority of participants 79 per cent identified as being Nyoongar; 12 per cent identified as Yamatji from the Gascoyne area; and 7 per cent identified as Wongi from the Goldfields region; 6 per cent identified as both Nyoongar and Yamatji heritage. Seven per cent identified as Aboriginal people not descended from these language groups but were living in the south west region of Western Australia. The majority of participants in this study 84 per cent were cared for by their mother and 46

per cent were cared for by their father. Seventeen per cent were cared for by a Grandmother and 12 per cent were cared for by a grandfather. For the majority of participants the primary carer giver did not change during childhood, and 17 per cent did experience a change of primary care giver. Please see table 3 below.

Table 3: Characteristics of participants 2015 (n=180)

Characteristics	Frequency	Percentage
Age	Median: 44; SD	
Age range: 16 – 67 years	14.61 years	
Gender		
Female	109	60.6
Male	71	39.4
	180	100.0
Aboriginal Country		
Perth	57	31.7
South West	114	63.3
Other	9	5.0
Birth mother		
Perth	6	3.3
South West	133	73.9
Other	41	22.8
Birth father		
Perth	5	2.8
South West	126	70.0
Other	49	22.8
Identity		
Nyoongar	143	79.4
Yamatji	23	12.8
Wongi	14	7.8
Nyoongar/Yamatji	11	6.1
Other	13	7.2
Who mainly raised you as a child		
Mum	152	84.4
Dad	84	46.7
Sister	11	6.1
Brother	12	6.7
Nan	32	17.8
Pop	23	12.8
Aunty	21	11.7
Uncle	19	10.6
Cousin	4	2.2
Foster family/Foster carers	7	3.9
Other	11	6.1

Primary care status (did this change)		
Yes	32	17.8
No	148	82.2

Personal Characteristics

The majority of participants were either married 26 per cent or living in a defacto relationship 29 per cent, and 40 per cent reported single status. The majority of participants had children at 78 per cent, and 30 per cent had either 4 or 5 children. In response to the age participants were at the age of their first child, the majority of participants were aged between the age range of 17 to 21 years; 7 per cent were aged 17; 8 per cent were aged 18, 9 per cent were aged 19 and the highest number 13 per cent was at age 20 and the next highest 11 per cent for age 22. Please see Table 4 below

Table 4: Personal Characteristics (n=180)

Characteristics	Frequency	Percentage
Status		
Single	73	40.6
Married	47	26.1
Defacto	53	29.4
Divorced/widowed	7	3.9
Do you have any children		
Yes	143	78.9
No	37	20
Age of respondents at first childbirth		
15-19	60	33.3
20-24	83	46.1
No child	37	20.6
How many children		
1 child	25	13.9
2 children	22	12.2
3 children	24	13.3
4 children	31	17.2
5 children or more	23	12.8
Not sure	20	11.1
Not applicable	35	19.4

Education attainment

The majority of participants had completed year 10 at thirty per cent and another thirty per cent reported to have completed year 11, and twelve per cent had completed year 12. Seventeen per cent had completed a degree or diploma. Five per cent were currently attending high school, and 5 per cent were attending TAFE and 3 per cent were attending university. The majority of participants were not currently studying, and this reflects that 44 per cent were employed, as illustrated in the table Income and employment. Table 5 presents details of the educational level of the participants.

Table 5: Education attainment (n=180)

Highest level of education:	Frequency	Percentage
Completed primary school	7	3.9
Year 9	31	17.2
Year 10	54	30.0
Year 11	25	30.0
Year 12	23	12.8
Apprenticeship	2	1.1
Bridging program	4	2.2
Degree or diploma	31	17.2
Post graduate, masters, or PhD	3	1.7

Income

Twenty Seven per cent reported to be in receipt of Newstart; and seventeen per cent were receiving the Pension. Twenty eight per cent were in full time employment, and twenty eight per cent reported to be looking for employment. It should be noted some participants indicated that they were full time carers, and this question did not cater for those participants unable to work due to their role as carers. The majority of participants were renting their homes, and twenty one per cent reported they were boarding. Fourteen per cent were buying their homes. Please see table 6 below.

Table 6: Income and Employment (n=180)

Characteristics	Frequency	Percentage
Receiving Centrelink Support		
Pension	31	17.2
Newstart	50	27.8
Disability	12	6.7
Abstudy	7	3.9
Carers pension	14	7.8
None of the above	66	36.7
Employment		
Full time	52	28.9
Part time	20	11.1
Casual	8	4.4
Looking for work	51	28.3
Not looking	49	27.2

Accommodation (n=180)

The majority of participants 54 per cent were in rental accommodation; the next highest group 21 per cent were currently boarding; and 14 per cent were purchasing their own homes. Three per cent were homeless at the time of this study and 6 per cent listed their accommodation as other than these categories. Please see table 7 below.

Table 7: Accommodation (n=180)

Accommodation	Frequency	Percentage
Buying	26	14.4
Renting	98	54.4
Boarding	39	21.7
Homeless	6	3.3
Other	11	6.1

Awareness of Fetal Alcohol Spectrum Disorder (FASD)

The majority of participants 61 per cent had heard of the term Fetal Alcohol Spectrum Disorder (FASD), and 38 per cent had never heard of FASD. The majority 75 per cent had been aware of FASD for longer than 2 years and twenty four per cent had only been familiar with the term in the past 12 months – 2 years. However, only 10 per cent felt they had a strong awareness of FASD, and the majority 55 per cent felt they only had limited knowledge of FASD and 34 per cent had no knowledge of FASD.

In response to where they obtained their knowledge on FASD; 22 per cent identified health professionals, 21 per cent identified their family; 14 per cent stated health promotions, and 12 per cent identified Aboriginal organisations. An overwhelming 91

per cent felt that it was important to know about FASD. In terms of whether participants family had received any information on FASD; 42 per cent stated no; 37 per cent were unsure and 20 per cent identified yes. In response to the question, do you think anyone in your family extended or immediate may have FASD; the majority 47 per cent were unsure; 37 per cent identified yes and fourteen per cent identified no. Please see table 8 below.

Table 8: Awareness of Fetal Alcohol Spectrum Disorder (FASD) (n=180)

Awareness of FASD	Frequency	Percentage
Yes	110	61.1
No	70	38.9
Length aware of FASD		
Recently within the last 12 months	26	14.4
Between 1-2 years ago	18	10.0
Longer than 2 years ago	136	75.6
Source of Information		
Family member	38	21.1
Health professional (Nurse, GP, Health worker)	40	22.2
Health promotions	26	14.4
School teacher	3	1.7
Social worker	5	2.8
Police	3	1.7
Media	10	5.6
Aboriginal organization	22	12.2
Other	10	5.6
Level of FASD Awareness		
A lot	18	10.0
A little	100	55.6
None	62	34.4
Important to know about FASD		
Yes	165	91.7
No	7	3.9
Unsure	8	4.4
Family received information on FASD		
Yes	36	20.0
No	76	42.2
Unsure	68	37.8
Anyone in your family possibly have FASD		
Yes	68	37.8
No	26	14.4
Unsure	86	47.8

Willingness to receive information on FASD

In response to the question would you like any information on FASD; 67 per cent reported 'yes'; and 25 per cent reported 'no'. The kind of information that participants reported they would like to receive; 93 per cent indicated basic information, 44 per cent reported referral for diagnosis, 45 per cent reported referral for help with other services; 47 per cent reported supporting a family member with FASD; 47 per cent reported prevention and 42 per cent reported all of the above. In response to how would you like information on FASD delivered; the majority 45 per cent reported small groups, fifty five per cent reported community forums; and 18 per cent reported one on one. Please see Table 9 below:

Table 9: Willingness to receive information on FASD (n=121)

Willingness to receive information on FASD (n=180)	Frequency	Percentage
Yes	121	67.2
No	46	25.6
Unsure	13	7.2

Preferred types of Health Promotion (n=121)	Frequency	Percentage
Basic information	113	93.4
Referral for diagnosis	54	44.6
Referral for help with other services	55	45.5
Supporting a family member with FASD	57	47.1
Prevention	58	47.9
All of the above	51	42.1
Other	26	21.6

Preferred ways to receive FASD health promotions (n=121)		
Small groups	55	45.5
One on one	22	18.2
Community forums	67	55.4
Online	18	14.9
Not sure	17	14.0

Information on Alcohol (n=180)

In responding to questions on alcohol, fifty eight per cent reported they had seen a lot of consumption of alcohol growing up, and twenty eight per cent reported sometimes and ten per cent reported they had not seen any drinking of alcohol. In regards to themselves, forty seven per cent reported they drink alcohol and thirty one per cent reported that they do not drink, and 17 per cent reported they no longer drink alcohol.

The majority fifty one per cent reported to never consume alcohol, and 17 per cent reported drinking monthly or less. Fourteen per cent reported drinking 2-4 times a month and 12 per cent reported drinking 2-3 times a week. In response to how many standard drinks; 12 per cent reported to drink 1-2 drinks; nine per cent reported 3-4 drinks; and eleven per cent reported 5-6 drinks. In response to the question how often do you have six or more standard drinks; the majority of participants 54 per cent reported never; fifteen per cent reported less than monthly; twelve per cent reported monthly and eleven per cent reported weekly. In response to the question how often do you drink with a partner; the majority forty seven per cent reported never and fifteen per cent reported less than monthly. Please see table 10 below.

Table 10: Alcohol (n=180)

Item description	Frequency	Percentage
Growing up did you see any drinking of alcohol		
A lot	106	58.9
Sometimes	52	28.9
A little	19	10.6
No	3	1.7
Do you drink alcohol		
Yes	85	47.2
No	56	31.1
Never drank	7	3.9
Not any more	32	17.8
Family members and consumption of alcohol		
Mum	71	39.4
Dad	104	57.8
Nan	34	18.9
Pop	47	26.1
Aunty	113	62.8
Uncle	124	68.8
Brother	63	35.9
Sister	58	32.2
Cousin	85	47.5
Alcohol consumption		
Never	93	51.7
Monthly or less	32	17.8
2-4 times a month	25	14.4
2-3 times a week	23	12.8
4 or more times a week	6	3.3

Standard daily drinks		
1 to 2	23	12.8
3 to 4	17	9.4
5 to 6	21	11.7
7 to 9	7	3.9
10 or more	17	9.4
Not applicable	95	52.8
Six or more standard drinks on occasion		
Never	98	54.4
Less than monthly	27	15.0
Monthly	23	12.8
Weekly	21	11.7
Daily or almost daily	5	2.8
Not applicable	6	3.3
If you have a partner how often do you both have a drink together		
Single (not applicable)	46	25.6
Never	85	47.2
Less than monthly	27	15.0
Monthly	11	6.1
Weekly	9	5.0
Daily or almost daily	2	1.1

Consumption of alcohol during pregnancy

Table 11: Awareness on effects of alcohol on pregnancy and lactation

Awareness on effects of alcohol on pregnancy and lactation	Frequency	Percentage
Perceived adverse effects of drinking alcohol during pregnancy		
Yes	146	81.1
No	15	8.3
Unsure	19	10.6
Perceived adverse effects of drinking alcohol whilst breastfeeding a baby?		
Yes	154	85.6
No	11	6.1
Unsure	15	8.3
Do you know anyone (female) that drinks alcohol during pregnancy?		
Yes	122	67.8
No	58	32.2
Do you think it is common to drink alcohol during pregnancy		
Yes	58	32.2
No	91	50.6
Unsure	31	17.2

Was the woman who drank whilst pregnant?*

Family member	109	60.6
Friend	70	38.9
Other	58	32.2

*Multiple response

Trauma & support

In response to the question have you witnessed or experienced in your family any of the following; the majority of participants 70 per cent reported that they had not experienced or witnessed any of the above trauma or violence. It is important to note here that the wording of the question is somewhat ambiguous with participants being asked to respond to the questions on trauma as either experienced or witnessed. Therefore, as the highest number of participants 70 per cent had not seen or experienced these traumatic life experiences, it would indicate that most participants had not observed incidence of trauma as described in the table. In times of stress and crisis, the majority of participants 79 per cent reported they turn to family, 41 per cent reported friends and 25 per cent reported partner. Twenty two per cent reported counselling services; twelve per cent listed Aboriginal services and the minority four per cent listed other. Please see table 12 below.

Table 12: Trauma & Support (n=180)

Characteristics	Frequency	Percentage
Have you witnessed or experienced in your family any of the following		
Family violence	129	71.7
Family feuding	120	66.7
Bullying	73	40.6
Sexual violence/abuse	66	36.7
Alcoholism	119	66.1
Drug abuse	111	61.7
Eviction/homeless	78	43.3
All of the above	53	29.4
None of the above	127	70.6
Preferred sources of support		
Family	143	79.4
Counselling services	40	22.2
Friends	75	41.7
Partner	45	25.0
Hospital	16	8.9
Aboriginal services	22	12.2
Other	8	4.4

Stolen Generations

In response to the question was anyone in your family part of the stolen generations; the majority 56 per cent reported yes and 37 per cent reported no. For other family members, it was reported that 23 per cent had a grandmother removed under policies, 18 per cent reported Mum, 19 per cent reported Dad, 24 per cent reported Aunty, twelve per cent reported Great grandparents and 13 per cent reported themselves. Please see table 13 below.

Table 13: Stolen Generations (n=180)

Were you or anyone else in your family part of the stolen generations?	Frequency	Percentage
Yes	101	56.1
No	68	37.8
Unsure	11	6.1
If yes, was it?		
Me	24	13.3
Brother	20	11.1
Sister	21	11.7
Nan	43	23.9
Pop	30	16.7
Mum	34	18.9
Dad	35	19.4
Aunty/s	44	24.4
Uncle	36	20.0
Cousin	31	17.2
Great Grandparents	22	12.2

The signs and symptoms of FASD among children in the community

In response to the question have you seen any of the following behaviours consistently displayed by a child in your immediate or extended family; participants responded that 44 per cent had seen all of these behaviours and 91 per cent reported no. Please see table 14 below.

Table 14: The signs and symptoms of FASD amongst children (N= 180)

Characteristics	Frequency	Percentage
Struggles to follow rules/instructions		
Yes	130	72.2
No	50	27.8
Learning problems at school		
Yes	117	65.0
No	63	35.0
Have difficulty remembering things		
Yes	95	52.8
No	85	47.2
Get upset easily at little things		
Yes	116	64.4
No	64	35.6
Difficulty making and keeping friends		
Yes	77	42.8
No	103	57.2
Long term bed wetting		
Yes	74	41.1
No	106	58.9
Ongoing behavioural problems (often in trouble with the law)		
Yes	98	54.4
No	82	45.6
Ongoing health problems		
Yes	85	47.2
No	95	52.8
Acts younger than their age		
Yes	92	51.1
No	88	48.9
Doesn't understand consequences of their actions		
Yes	102	56.7
No	43	43.3
All of the above		
Yes	80	44.4
No	100	55.6
None of the above		
Yes	16	8.9
No	164	91.1

Signs and symptoms of FASD among adults in community

In response to the question have you seen any of the following behaviours by an adult in your immediate or extended family; participants responded that 56 per cent had seen all of these behaviours and 97 per cent reported no. Please see table 15 below.

Table 15: Witnessed signs and symptoms of FASD among adults in community (n=180)

Characteristics	Frequency	Percentage
Mental health problems		
Yes	141	78.3
No	39	21.7
Being homeless or difficulty keeping accommodation		
Yes	105	58.3
No	75	41.7
Long-time unemployed or difficulty getting employment		
Yes	126	70.0
No	54	30.0
In and out of jail (trouble with the law)		
Yes	125	69.4
No	55	30.6
Impulsive behaviour, anger issues, poor social skills		
Yes	123	68.3
No	57	31.7
Alcohol use		
Yes	140	77.8
No	40	22.2
Drug use		
Yes	136	75.6
No	44	24.4
Acts younger than their age		
Yes	111	61.7
No	69	38.3
Poor time management		
Yes	102	56.7
No	78	43.3
Poor self-care		
Yes	109	60.6

No	71	39.4
Kids in welfare		
Yes	102	56.7
No	78	43.3
All of the above		
Yes	102	56.7
No	78	43.3
None of the above		
Yes	5	2.8
No	172	97.2

Further discussion

There were several anomalies in the survey responses that require further discussion and analysis. The majority of participants, 81 per cent indicated an awareness of the adverse effects of alcohol during pregnancy. However, only 10 per cent were confident in their knowledge of FASD. This must also be considered in view of several factors; firstly, the inconsistency of FASD health promotions in WA and intergenerational trauma for Aboriginal people. Twenty nine per cent of participants had experienced significant trauma and 56 per cent were either themselves or an immediate member of their family was part of the stolen generations. Whilst, there was awareness of the adverse effects of alcohol, this is unlikely to transfer to having increased awareness of FASD and the potential irreversible harm caused by PAE. Further, awareness of adverse effects of alcohol in mainstream society, also does not deter women globally from consuming alcohol during pregnancy as indicated in the literature review in Chapter two.

Thanh, Jonsson, Moffat, & Dennett (2013) note previous FASD research identifying a high prevalence of individuals with FASD coming from a low socioeconomic status. The majority of participants 63 per cent in this study were receiving centrelink benefits. The writers suggest that FASD is a result of poverty. Notably, FASD contributes to financial stress within families in terms of lost earning potential for individuals with FASD and for parents/carers who are unable to work full time due to the intense caring demands. Consequently, FASD contributes to the kind of poverty that cannot be escaped by individuals and families. According to Thanh et al (2013) communities disadvantaged by poverty are 16 times more likely to have children born with FASD.

Conclusion

This chapter provided the quantitative results of the survey that included 180 Aboriginal participants. Further, discussion arising from the results of the survey will be included in the final chapter eight. It has been highlighted in the literature review that the lack of awareness of FASD continues to be an issue within the general community. This survey was subsequently designed to explore the level of knowledge and awareness of FASD within the Aboriginal community in the south west region of Western Australia. These results importantly, are useful to informing health promotions and aspects of service delivery. Further, input from the Aboriginal community is critical in informing culturally secure and appropriate service delivery on FASD. The reception by the Aboriginal community was strong and consequently each town requested training in FASD. The following chapter six includes the themes emerging from the six family interviews with families raising children with FASD in the south west region of Western Australia. The Indigenous framework will be applied in analysing the common themes.

CHAPTER 6

Results for Family Interviews

When I found this out, it was devastating to know, because I didn't want to give up on them, and I didn't want them to give up on life, I didn't want life to keep throwing these curveballs at them, I wanted to give them some hope, and I wanted some hope myself, because it seemed so hopeless. (Carer, 2015)

Introduction

This chapter includes the analysis of qualitative interviews undertaken with six families in the south west of Western Australia in 2015 and will outline the key themes and findings resulting from the family interviews. The Indigenous methodological framework as outlined in chapter four was applied as a framework to collect data and to analyse the key findings and themes. This study is the first of its kind in Australia in conducting in depth interviews with relative and foster carers of Aboriginal children living with FASD in Western Australia. Notably, the majority of the families in this study have cared for their children with FASD at a time when FASD service delivery was virtually non-existent in both Australia and Western Australia. This chapter is divided into three parts. Part 1 provides a description of the six families that participated in the study. Part 2 provides an overview of the children, and part 3 describes the Indigenous framework that underpinned the study and outlines the common themes evolving from the interview analysis with the families.

Timeframe of care (1992 – 2016)

The timeframe of care by families in this study (see Table 1), is important to note as prior to the past 10 years, very little was understood about FASD in Australia by health professionals and the wider community. Three of the families involved in this study began caring for their children as infants in the early 1990s, and the oldest child from this study is now aged 23, and the youngest child was 3 years of age. The fourth family cared for their children within the last eight years, and the last two families are currently caring for their young children at the present time. For two families with young adults they continue to live with their relative foster carers, therefore three young adults continue to live at home with their carers. The other relative carers continue to have contact with their young nephews. One family became the adopted

parents at the request of the biological parents.

Table 16: Timeframe of Care

Family	Relative/ Foster Carer	Number of children with FASD	Timeframe of care	Location
Family 1	Adopted	1 male child	1992 - 2007	Country South west
Family 2	Relative Carers	2 male siblings	2008 - 2011	Metropolitan
Family 3	Relative Carers	1 male	1991 - 2016	Metropolitan
Family 4	Relative Carers	2 male siblings	1997 - 2016	Metropolitan
Family 5	Foster Carers	1 male child	2004 - 2016	Country South west
Family 6	Foster Carers	1 male and female sibling	2011 - 2016	Metropolitan

Part 1: Family Descriptions

The children in all six families with the exception of one, came into care as infants and became permanent placements. However, in that particular family their younger siblings came into care as infants and their older siblings included in this study came into care aged 8 and 11 years. Whilst, six families were interviewed, the families in total cared for nine children; and this included 8 males and 1 female. Three of the families cared for two siblings with FASD, and this included two families who were relative carers and one family who were foster carers. The remaining three families each cared for one child, and this included two families who were foster carers and one family who was a relative carer. Six of the children in this study are now young adults ranging from 18 to 23 years of age. The overall age range was 3 to 23 years of age. The Australian literature collectively by (Payne, et al, 2005, Elliot, 2006, Bower & Elliot 2016) identifies that not only was there extremely low awareness of health professionals in Western Australia in the timeframe for these families, notably this had not changed significantly by 2016.

Family 1

The family resided in a south West Country town and had older children when they met baby Carl, and he came into their care at five months of age. His biological father was Aboriginal and mother was non-Aboriginal and after a few months, the parents requested that the family adopt their young baby. The family agreed to this request, as they were aware the parents were distressed as they had seen their remaining children in care experience multiple placements in the system. During the years of his childhood, it was difficult to raise and learn how to parent Carl, despite having many years' experience of parenting and fostering children. It was necessary to have Carl in behaviour therapy for most of his life, and as a young child he was diagnosed with ADHD, however the family did not agree with placing him on medication.

He never was an aggressive child growing up. He was actually passive, but he did actually strike a parent at school when he was four. At other times when he was little he was overtly friendly, and he never wanted to stand on stage and be the centre of attention, and yet his behaviours made him the centre of attention, all these unusual behaviours, eating his clothes.

Family 2

Family 2 were relative carers and were asked to look after their young nephews aged 9 and 11 at the time. The family were given short notice and overnight the family agreed to care for their nephews. The family had one child of their own who was a similar age to his young cousins. The family found physical exercise was one of the best strategies for the young boys, and also worked hard on improving their self-esteem and self-worth. The older brother held down a part time job with a bakery for a few years prior to leaving their care. The impact of the intense needs of caring for the brothers had a significant impact on the health of their Aunty, who was hospitalised several times, and for this reason had to cease caring for the boys after a period of four years and a half years.

The 12 year old within a space of a year was self-harming, the 9 year old within a space of a year, by the time he reached 10 we were at a specialist. So the older one had cognitive problems, the younger one had the physical; it was only because of the physical signs from the younger one that we discovered FASD. What I mean by physical is the skeletal makeup of his body, and the problems and difficulties, the gaps that his body was missing.

Family 3

Family 3 were relative carers who cared for two young nephews straight from hospital.

The young brothers still remain in the care of the same family, and were fortunate to not experience any other placements. The family were not aware of FASD prior to caring for their young nephews. Their biological father and foster father both passed away when the boys were teenagers. Despite the loss of their father and biological father, the brothers have done well in completing high school and the oldest sibling is now working full time. The brothers are now young adults and remain with their relative carer.

Their father was a part of the stolen generations. Just after my husband had passed away, he tried to offer me help, but because he was an alcoholic and a very sick man, I didn't take him up on it. I thought his health was too much for him to handle at the time.

Family 4

At the time these non-Aboriginal foster carers met young Robert aged 2 years they were a young couple with no children and were providing respite weekend foster care for children. At the time of this interview, Robert was now aged 12. The family also grew with three biological children, and Robert is a loving and attentive older brother. This was how they met their foster son who came to them for weekend respite care. One particular weekend the young couple were asked by child protection and agreed to care for young Robert on a long term basis. However, the years ahead in caring for young Robert were briefly interrupted by an unsuccessful reunification attempt back with his biological family. The carer states:

The behaviour was all the way through. By the time he was 6, there was three other children, it got to the point it was affecting too many people. We could change everything to make sure that we could keep him calm. The school issues also came into. Im glad we didn't put him on medication earlier....He is quite a slight child, he only weighs 30 kilos now, and he is 11. That's why we see the paediatrician so often, his weight and height are always checked to make sure he's gaining, and going up.

Family 5

This family were relative carers who were asked to care for a young nephew at birth from the hospital. The baby boy was not expected to live and had heart surgery before leaving the hospital. The family had older children and had one more child after her young nephew came to live with her. A couple of years into caring for the child, the family was asked to agree to a special guardianship order from child welfare. In hindsight this was not the best move in terms of ongoing support for the carer and the

young boy, as no support from the department was provided throughout the years caring for their son. He is now in his early 20s and has a full time job for the past few years. Independent living will not be possible without support services.

I don't think he will ever be able to have independent living, he can't problem solve, he doesn't have cognitive thinking. He works on impulse, so he does stupid things because he's not scared of anything. If someone told him to do something, he just does it. He is different, because his brain isn't at the 23 year old stage of maturity.

Family 6

This family had grown up adult children and began caring for young Mark from birth. His first six months of life were spent in the hospital, where he had to undergo heart surgery. He has the physical characteristics of FASD and he was also diagnosed with global developmental delay and Microphaly and this gave him access to a range of disability services. His older sister was also removed from birth, however, she experienced multiple placements and was in several foster homes prior to the family being asked to care for the sister. This sister also has physical characteristics of FASD. The family receive no respite for their children, however, their adult children play a huge role in providing respite.

The heartbreaking thing about their disability and at times everybody sees them as looking normal and at times they are quite capable. Six weeks ago she was top of her swimming class, Six weeks later she can't swim at all. We just been through the process, so we know we will come back and apart from wanting to pull all your hair out, which has already happened, we have to keep pushing forward and not get down about it.

All Aboriginal children in this study had biological parents that came from the South west region of Western Australian, with the exception of one family and their mother came from the Kimberley region. The biological parents of three of the children included both Aboriginal and non-Aboriginal parents and for the remaining five children parents were both Aboriginal. Three of the families cared for their children under relative care, and three families cared for their children under a foster care arrangement. All relative carers were Aboriginal and all foster carers were non-Aboriginal.

Six of the nine children came into care as infants and avoided multiple family placements that is common with children with FASD, due to behavioural problems and lack of awareness of carers. However, four of the nine children experienced

multiple placements in OOHC, and the carers expressed strongly how traumatic this experience had been for the child, carer states:

He had trauma around the age of 5, it was build-up of your going and you are leaving us. I think that impacted on him as well. If it had worked out and the family had been able to care for him, however, it didn't work. My own family don't want me either. That's where you need to be and he was packed up and moved and it all fell apart, and he was taken out of school and put in a different school. (Carer, 2015 Country)

Part 2: Snapshot of children with FASD 2015

Table 6.2 provides a brief snapshot of the key areas of impact of FASD on the children involved in this study. Health and key issues category describes the most serious impact of FASD on each child. Most of the carers had knowledge of the biological mother, and her consumption of alcohol during pregnancy, and in this case suspected siblings to also have FASD, and this was confirmed in three of the families. The age category indicates the age the children were when they came into OOHC. These ages support the international pattern of children with FASD coming into care earlier and staying longer than other children.

Table 17: Key areas of impact of FASD

	Gender	Age	Carer	Health/key issues	Siblings
1	Male	<1	Relative	heart surgery other surgery	x
2	Male	<1	Adopted	Behavioural, small kidneys	x
3	Male	<1	Relative	Behavioural	x
4	Male	<1	Relative	Short term memory Behavioural	x
5	Male	9	Relative	Short term memory Behavioural	x
6	Male	8	Relative	Skeletal Behavioural	x
7	Male	2	Foster	Grommets, ear, Short term memory	x
8	Female	<1	Foster	Dental, root canal ODD, Behaviour	x
9	Male	<1	Foster	Short term memory Heart surgery Global, development delay, Behaviour	x

Part 3: Use of the Indigenous Framework

The Indigenous framework and philosophy as described in the methods chapter 4, includes the; Social, Physical and Human worlds. Underpinning this philosophy is the understanding that each of these worlds are interrelated and therefore impact on each other (Foley, 2003). The Physical world incorporates the land and the understanding that the land is the mother, culture and identity (Foley, 2003). The human world includes the knowledge, protocols and rules of behaviour and the ability to change. The social world is not based entirely on the spiritual world, rather the foundation of the social is healing of all entities including caring of country, and oral history (Foley, 2003; Kickett, 2011).

The timeframe of care for the families was identified earlier in this chapter, and despite the fact the timeframe for some families began over 20 years ago, the collective themes remained the same. Highlighting little had changed for families recently and in the past few decades. For some families their experiences of raising young children with FASD was retrospective and they had begun raising young children with FASD around early 2000. The remaining families are speaking from their experiences at the present

time of this study in 2015. For all families there has been markedly little to no improvement in services, despite considerable research on FASD being conducted locally in Western Australia.

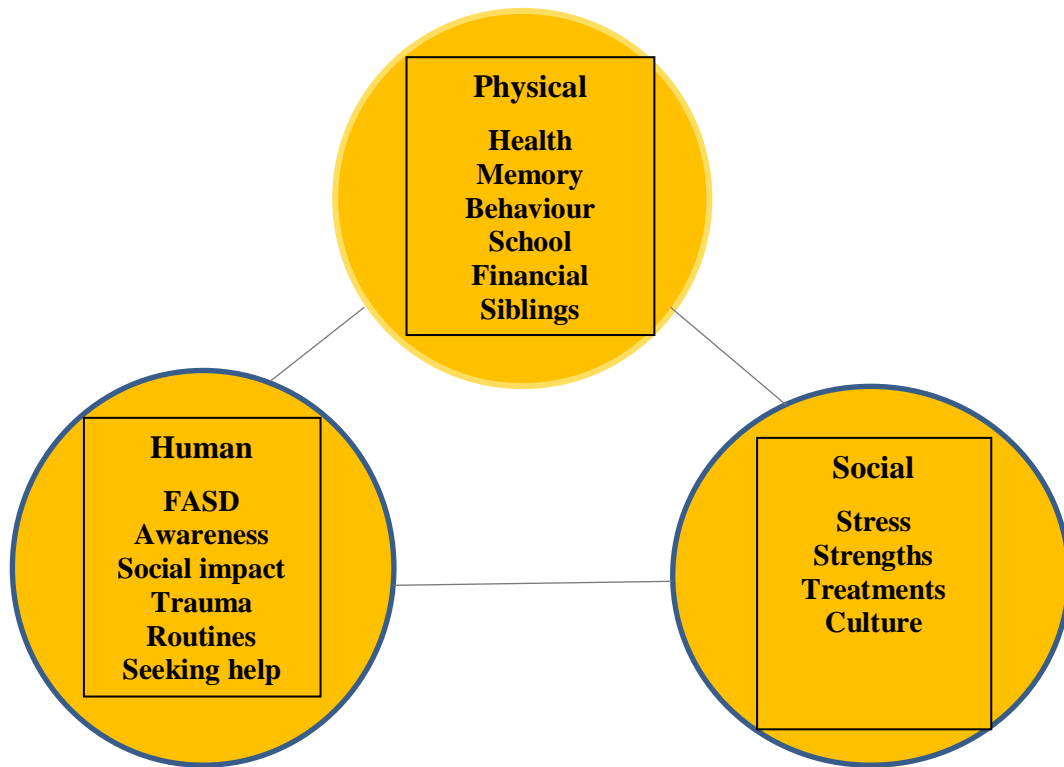


Figure 6.3: Indigenous Framework

Indigenous framework

The Indigenous worldview framework is holistic and each area intersects and impacts on the next area, and Martin (2003) refers to this overlap as interrelatedness and relational ontology. The key themes from the family interviews has been categorized, and, many of the themes also overlap such as sacrifice, trauma and stress, and often this was further compounded by the lack of awareness and support services for children and families.

Physical

Under the category of physical, the following themes emerged; siblings with FASD, health, behaviour, school, and no money.

Siblings with FASD

Three of the families in this study were raising siblings with FASD, and this included two relative carers and one foster carer. Each of the families became guardians of the children at different ages. Only one of the families had both siblings from birth, the second family had the first sibling from birth and the sister from the age of 4 after multiple placements, and the last family started caring for their nephews at the age of 9 and 12.

Relative carers states:

The 12 year old within a space of a year was self-harming, the 9 year old within a space of a year, by the time he reached 10 we were at a specialist. So the older one had cognitive problems, the younger one had the physical problems.

Relative carer makes the following comment:

One brother wouldn't go without the other, wherever one boy went, the other had to go. They had to be together. I don't know whether it's that sibling connection or that because we did everything together. If one was sick and stayed home from school, the other had to stay home too.

Foster carer states:

The only issue for Mark is health issues. Lana is very smart, but she is smart street wise and she has learnt how to manipulate and I think that will affect her long term in how she deals with people. We are seeing that grow and that is a worry, how she is going to cope with it. With Mark, we have not allowed him to blow up all the time, they don't have the monitoring abilities to be able to bring themselves down.

Health

In terms of health, access to an official FASD diagnosis was not available to most families involved in this study. Further, access to FASD remains problematic in other countries besides Australia (Brown, 2015). This was despite most of the children in families having the physical characteristics of FASD. Of the nine children involved in this study, five children had physical characteristics of FASD and four did not. Notwithstanding, the pathway to diagnosis was largely non-existent particularly for those families in this study who began caring for their children in the 1990s in Western Australia. For one family who began caring for their children in 1997, and 1998, there was no access to a diagnosis of FASD at the hospital, and the babies came straight from the hospital to the relative carer who states:

We were in the process of getting it done, but nothing was ever followed up from PMH. A few years ago I ran into someone who was giving a talk on FASD at Subiaco oval, we were up there for work, speaking with him and talking about the boys, it really hit home. These boys had FASD but were not diagnosed.

The pathway to diagnosis was also hampered by lack of national FASD diagnostic tool in Australia until 2016. Further, this was also compounded by the lack of FASD awareness by health professionals. A carer from the country describes why an official FASD diagnosis was never provided for her young son:

The paediatrician actually delivered him and off the record he told me the mother was intoxicated a lot throughout the pregnancy. He said he 100% believes this child has FASD however he was reluctant to do any assessments on him, as doing the assessment won't do anything. He said the behavioural things, and the ADHD is a result of the FASD.

For another relative carer who was asked to care for her young relative as a baby, this was the advice of the FASD diagnosis:

When DCP bought him to me they said he had FASD and that he probably wouldn't walk or talk, so throughout his whole life we have been in and out of PMH doing tests, fighting infections, checking brain waves.

Impact of FASD on the health of the child (physical)

The impact of FASD on the health of the children in this study ranged from serious at birth to ongoing health problems throughout their childhood. A relative carer from the metropolitan area describes the painful impact of FASD on the health of her child:

The younger one in my care was supposed to get a hip replacement; he had bone on bone, crunching against each other, could you imagine a young man walking around in that kind of pain?

Another relative carer describes the ongoing serious health challenges for her child when he was young:

Gary had open heart surgery because he had a hole in his heart... We did a lot of speech therapy with him because he couldn't talk properly. He was in pull ups right up until about 14, his bladder wasn't telling his brain to go to the toilet, and also Gary had vitamised food up until his teenage years because couldn't swallow properly.

A foster carer describing the impact of FASD on the health of his young foster daughter aged 5 years:

Lana has cleft palate, that will be ongoing until I think she is in her 20s. She has

ongoing ear issues, This is her 4th amount of grommets. She has had root canals and crown work. She has had more dental work than the average person in a lifetime.

Memory

All carers expressed their concern with their children's ongoing problems with short term memory. Further, this did not appear to improve as the children aged, as the carer has cared for her son from birth. The son is now a young adult, and the carer states:

I can tell him to do something and he'll sit down and completely forget about it. I can see it going in and out, he can remember things backwards, his mother's passed away now, but he can remember all the times with his mum. But right here and now he forgets what I've said. He just doesn't remember, and it's very frustrating, for us and for him because he knows he can't remember.

Another carer expressed her concern as her now adult son now in his early 20s was himself concerned about his own memory and losing his social communication skills:

They can lose the skills, and even conversation skills; they have to live it, breathe it, and do it. He must know it to, as he said I think I might go back and do year 10, 11, and 12. His desire may not be enough to get him there. He is losing a lot of the skills that he had. He doesn't have the good conversation ability that he used to have.

Another carer describes how they would use posters and visual signs to aid in memory in the weekly school routines:

I had a poster on the wall that used to say sports days were Mondays, Wednesdays and Fridays, and the younger brother every Monday, Wednesday and Friday would ask if it was sports day. I had posters everywhere for instructions, because it's the only way they knew. He would get overly frustrated and even angry, and he would ask me what's wrong with them. It can be a frustrating thing to be so repetitive, they require the constant repetitiveness, and like I said you can tell them something, and then 5 minutes later they've forgotten.

Behaviour

A dominant theme expressed by all carers was the challenging behaviours and for carers having to learn themselves as a family how to address and deal with challenging behaviours. A carer from the country described the challenges of this behaviour as follows:

When he is at home he is diabolical, like it is all about creating a safe environment when he is raging, so his bedroom had to be safe when he is raging. At his worst he was raging weekly if not every couple of days. I used to joke that it was a wonder that my neighbours didn't ring DCP.

Another carer from the country stated the following regarding her son's behaviour when he was younger and some of the impact on the family:

He nearly did us in, because he was so hard to manage. Everything was an everyday struggle, especially in conjunction of raising other children because they'd have places to go, and you needed to be there as well. There were concerts and things and you weren't able to take him, and it sort of fractured the family because you want to do everything together.

The following carer from the metropolitan area describes challenging behaviour of her foster son who is now an adult:

Even now that he's getting older, we still have challenging behaviours with him. He doesn't understand why he can't have a driver's license, or that he can't drink, or go out clubbing, or even go to pubs, he says well I'm 23 and I can do what I want now.

School

According to Roberts, (2015, p.237)

Often parents or carers of affected children know the child and how they react best. They are a key educational resource that schools need to cultivate, not blame

A strong theme expressed in all interviews was the challenges for their children in attending school. School and the education system is often the first place that children with FASD will experience ongoing adversity and challenges (Millar, et al 2017). The challenges for children ranged from issues such as behavioural problems and having problems with memory in retaining information; and being perceived as not having the ability to succeed. (Swart, et al 2014).

Special education was the best option for one child. One of the most important strategies that all carers chose and that was to have their children changed from public to private schools. Carers found that private schools were more willing to work with their children. One carer from the country had to advocate strongly to have private school fees paid for by child protection and this child also benefited from further afternoon tutoring three times a week.

His numeracy is about 12 months behind. His literacy is just scraping in. He is terrible in getting it down onto paper. He has been lucky in the last couple of years, that he has great teachers. I was starting to get a bit panicked because he's getting into high school next year. His literacy is C, year 1 and 2 he was

averaging C and then dropped down to D. He attends learning support 3 times a week that focuses on repetition which I think has helped greatly. The school do that 3 times a week. A lot of hard work, it's a massive struggle.

Another carer found a combination of strategies to assist her child with school including ongoing behavioural therapy; private school combined with home schooling.

I had an agreement with the school that he wouldn't be going a couple of days a week, and that was for their (school) benefit as well. He found it very hard to be appropriate, and it was private school all the way through. We knew that the state school wouldn't be able to offer him very much at all. He went to a very small private school, we actually started him in another school, and the school had a high school but it was too big, and he was being labelled, and I didn't like it. In a smaller school they were more willing to work with us. He never interacted with adults properly, he could play with other children but it would only last for a short period of time. (Carer, Country)

One carer from the metropolitan area found that the biggest challenge has been for their child commencing school, and the school continually ask the carer to come to the school at least 3 times a week and sometimes every day as shared in the quote below.

Support for school, that is what we are finding at the moment, really the critical thing is you have to have some kind of training in the educational system so parents and carers understand what they are dealing with, and number two got to get to the education department and make them understand..... She creates so many problems she needs a full time aid. I find it hard that they can't deal with her. But I have been in the classroom. They don't really understand, they have never had any real training. She sees the principal two to three times a week. (Grade 1: Carer, metropolitan)

Financial Impact

Another common theme was the level of financial sacrifice borne by the family. Research findings by Bobbit (et al, 2016); and Koponen (et al, 2009) provides evidence of the financial stress on carers as extremely high for families. The demands on parenting a child with FASD meant that each family had the ongoing sacrifice of having to having a full time primary care giver remain at home due to the intense needs of the child. This included the extra demands such as ongoing medical appointments; in one case having to visit the school every week.

None of the six families were able to have two parents working consistently regardless of the age of their children with FASD. At times some of the parents were able to attempt part time employment. A carer describes the change of income as:

So instead of having the two full wages that we managed with our son and afternoon childcare, we had to both go down to a part-time wage each, which was basically like one of us pulling out of work, and having just the one income. So we went from being a two income family, to a one income family.

Carer from the country describes the financial impact as:

Massive, going through extra clothing because his is chewing holes through everything. Ray's medical costs would be huge but thankfully we can afford private health care insurance so a lot of it is covered. He has got special dietary needs in the fact that we are trying to help him gain weight.

Another carer from the metropolitan area shared the following sentiment on the financial impact:

it's massive, a pair of orthotics cost \$600, and Doug got 3 pairs in 1 year, that's \$1800, that's just for the ability for him to walk without his feet killing him, at just 9 years old, and that went on for the next 4 years, that's how much it cost in orthotics, let alone food.

Lack of financial support

When carers were advocating for their children, they were often told there was no money available from key agencies. Without private health insurance, families raising children with FASD will not access services that are critical to early intervention. A carer shares her experience:

So they all say to me you're going public, you will have an 18 month wait and I'd say no he's on our private health insurance, and then we would get an appointment the next week, which makes a difference. DCP now are very determined that they will not pay for any out of pocket expenses, you have to go through the public system. So kids are waiting.

Human

Under the category of human within the Indigenous framework, the following themes emerged - FASD awareness, social impact, trauma, routines and seeking help.

FASD Awareness

The theme of lack of FASD awareness was a strong theme for both the carers in caring for children with FASD; and secondly having to navigate the lack of awareness of the wider community. Learning to understand behaviours of children with FASD took considerable time and energy. No carers/family were provided access to any FASD training during the years they have cared for their children. A carer who raised two siblings with FASD describes the lack of training provided on FASD:

The only training that was offered was from Yorgonup, but it wasn't to do with FASD, it was about children in care. How to deal with things, but there was nothing specific on FASD, which I would have loved.

The lack of awareness of FASD by previous carers for this young child contributed to multiple placements by the age of 5, Carer states:

She has had three homes, the first people had no idea, never heard of FASD, had limited experience dealing with any children let alone a child with disabilities. The second people clearly knew about FASD, and clearly recognised there was a problem and were trying to do something about it, but then became very frustrated because of their inability to know where to go or how to go about it to get any help for her, because they were told she didn't have any issues. They got this child with highly emotional issues plus the FASD, with no help at all, and it actually broke them, and it was very sad when it broke their family. That is how Lana ended up with us.

Advocating for a young adult is made more difficult by society having no awareness of FASD. A carer describes some of the challenges that have confronted her young adult son recently in his full time job:

Where he's working, I've had to argue with them a lot of times, because they don't understand what fetal alcohol syndrome is, and they say we treat all our staff the same, and I told them he's not the same. They have been arguing for him to get his manual license so he can drive the cars around the grounds. They won't listen to me about what fetal alcohol is, so it is difficult for him to get his license.

Social impact

Carers expressed their concern about the social impact of FASD on the children they were caring for, and this ranged from the children having difficulty making and keeping friends and their difficulty in understanding social cues with their peers. Stade (et al, 2011) found the same results amongst children with FASD in their study, of feeling alone and finding it constantly difficult to make friends. A carer from the metropolitan area, mentioned that it was difficult for her son to form friendships in school and growing up:

He never really attached to anyone. That's another thing with these kids, they have attachment disorders. He brags sometimes and says he had 20 girlfriends in high school, but he had a new friend every week, because he didn't attach.

A Carer from the country describes her distress in not being able to invite "friends" to her child birthday parties growing up and states:

We used to cry over it because on birthdays we didn't know who to invite; I mean

having our family around is an instant party, but kids need friends. Now that he's grown he actually has linked up with people he used to go to school with, he's got his brothers, but it's not that they are friends. The ones that he does link up with they seem unreliable, or what he can deal with.

A Carer from the metropolitan area described how her now adult son found it challenging in being social within the family:

Like an argument, we know when we're not going to win an argument, so we all back down, but Gary keeps going, that's when he will argue with the big boys, he just keeps going and then forgets what they were arguing about in the first place, and he will get himself into a big fluster. We tell him if he's arguing with someone to just back down after 20 minutes.

Impact on family

Caring for their children had an impact on both the carer and other children in the family, this carer from the country describes the impact on her health:

It was migraines every couple of months probably. I was run down a lot, sinus infection after sinus infection. My dental health suffered. When I get migraines I had to go to the hospital, but they were never as bad as when we were raising Carl.

Another carer who had a child similar age to the young children they were caring for at this time states:

My son had to do grow up very quickly, from 10 to 14 he co-parented these children, especially on camps. He would tell them what appropriate behaviour was.

A foster carer who had raised her son from six months of age explained the impact on her health:

My health is really my stress, because I just keep on going, I don't have time to go to the doctors, but I think it's just my own mental wellbeing with Gary, it's just stress, because he's very challenging.

Another relative carer spoke about the impact of stress on the health of both her husband and herself:

My husband had a heart attack this year, the diabetes just spiked, you know all of our chronic diseases. The health impact on me was that I had a proper physical breakdown. When you have a physical breakdown; it takes a year and a half to recover. I was out of work for that long; I wasn't functioning emotionally, physically or mentally.

Trauma

Trauma was also a common theme with families, particularly as none of the children in this study were raised by their biological parents. Three of the children also experienced the loss of their biological parents whilst the children were still young. In some families there was also a strong suspicion of generational FASD, in that at least three parents displayed behaviours that are common to FASD. A carer shared the following background on the biological mother:

His mother had been bashed prior to giving birth, when he was born he was actually a healthy 8 pound baby, and she had 3 babies in 3 years. She had very rocky relationships, and she was very proud to show the alcohol bottles that she was drinking when she was visiting the sailors. She is relieving pain of her childhood.... Her childhood was shocking, the biological mother was white Australian, and biological father was Aboriginal.

In this respect carers, also expressed their empathy towards biological parents, a relative carer from the metropolitan area states:

I tried to encourage her, I told her to come home and spend time with them. I said even if she didn't have a place of her own, I was willing to go beyond DCP and give her some sort of connection. Having my own kids I could see how I would have felt, if I wasn't connected to them if it had happened to me. I tried everything, even up to today.

Other family experiences also included intergenerational trauma, both from impact of colonisation, oppression and the stolen generations. Loss and grief was also common in families and a carer from the metropolitan area states:

Yes, their father was a part of the stolen generation. Just after my husband had passed away, he tried to offer me help, but because he was an alcoholic and a very sick man, I didn't take him up on it. I thought his health was too much for him to handle at the time.

Daily Routine

All carers strongly supported the importance of strict routines for daily living. To the point that any movement from strict routines resulted in behaviour meltdowns for the children, that would last anywhere up to a couple of hours. A carer from the metropolitan area looking after siblings made the following comments about strict routines:

The one thing I found that worked well, was routine, and structure. It allows them to grow, in fact, they more than grow, and they flourish. They absolutely fly if there are rigid, set boundaries, I had rules, I had regulations, and bedtime

was a certain time every night. They had real structure, so they functioned well within those structures, and they were quite strict, they were stricter than I normally had.

Another carer also reiterated the importance of routines in looking after their young children and state:

It is quite difficult, it has changed how we are, we have to be very strict and have a strict structure at home, where we didn't used to be that strict. We bring these kids up different to our kids. We find if we try and have a soft day, it doesn't work. It is really interesting, if we think we will have a day off, by 4pm your saying that was really a bad decision.

Seeking help

Literature identifies the common theme of carers having to constantly advocate for services for their child (Petrenko, et al, 2014). All carers described how much time and energy was required to advocate for their child in obtaining the services they urgently required. However, carers also expressed they were tired and to the point of almost burning out from the intense caring of their children, particularly when most did not have access to respite care.

A foster carer in the country made the following statement:

"I would be saying jump up and down as loud as you can for the child.... stay strong in your instincts, trust yourself, and ask for help, and especially with medical professionals, if at first you don't have success try a different doctor; don't stay with a doctor if you are not happy. Find someone who is actually going to help you and your child"

A relative carer made the following statement in regards to the importance of seeking services:

get on to every single service that you can, that's Aboriginal and non-Aboriginal, especially the ones that claim to help people with disabilities, because this is a real disability, no matter what anybody says, no matter whatever box you try and put it into. You have a child that has a mental disability, they have inability to cope or function that normal children do, from a young age it's obvious, that cause and effect stuff is not there with cognitive, they don't understand right or wrong, that they're actually doing wrong, that's why half of the prisons are filled with them, because they don't know what they've done.

This carer from the metropolitan area shared his recent experiences with seeking help:

The biggest issue is that there are no services in place, there is no understanding

of it, there is no support. Therefore, you have to try and cheat the system to get what she needs; what the diagnosis has given us, is help to make the doctors and the people, see she clearly has got FASD, but we have to give her something else so she can get the assistance for what she has got. I find this very frustrating.

Another carer shares her experiences:

I think he copes well with life, from what he has been through, he has been lucky to have a permanent placement, in that my husband and I were willing to fight for him, I see many other kids that jump from placement to placement and then end up in wrap around programs because nobody can control them. I have had to jump up and down for him to get where he is now. I think he is doing really well but that is through hard work and determination, and a good team around him.

Attitudes and lack of awareness made it difficult for carers as the following carer from the country shares her experiences of seeking help but feeling judged along with her son:

It's cruel, and it's cruel on the whole family. You're in pain because your child is suffering. And nobody realises that, it is just you need to be a stronger parent, and you need to put more guidelines in, hold him accountable for what he's doing, and you do those things as a parent. We're not stupid, people aren't silly about that, most people don't lead their children into a situation that they're not capable of. You don't set your kids up. So those sorts of comments from schools just aren't helpful. This is not ADHD.

Social

The social aspect of the Indigenous framework includes all elements that contribute to the emotional and social well-being in both a positive and negative manner. In identifying these areas, it facilitates a pathway to appropriate interventions and treatments for children with FASD; and support for their families. Under the category of Social, the following themes emerged; stress, strengths, treatments, and culture.

Stress

All carers in this study spoke of the ongoing demands and stress associated with caring for their children. For those families with children at the time of raising children with FASD, they reported of being close to burn out. All carers had little or no knowledge of FASD when they began caring for their children. Stress was also associated with having no support from agencies and the lack of awareness by the wider society of FASD. Further, no carers were provided with training on FASD, and generally did not receive any extra financial funding for special needs. Finally, lack of respite was

rarely provided for these families. A carer raising two children with FASD in the metropolitan area describes the frustration of receiving no support or respite:

Well I wish I did have a bit more support for them actually, but I never did. Because my husband was alive at the time so we did it together. The crying was an issue for the first 8 months. When we did ask for help, we didn't get it; some other excuse would come up saying they didn't do that now. The only thing DCP did provide was a washing machine and a fridge. Never did have respite offered at all.

Another family describes the one weekend of respite offered for their two nephews and why it was not ongoing for the family:

DCP gave me one weekend, and do you know what happened in that weekend? Let me tell you the horror story that the boys came back and told me. They were taken to a country town not far, by an elderly lady and gentlemen, and they spent the entire weekend digging out his pool, they were nothing but slave labour. They came back to me and said Aunty don't ever let us go on respite ever again, and for 2 years I didn't.

Strengths

All the children involved in this study had strengths ranging from doing well in sport, art, and knowledge of wildlife and their nature was often described as generous, loving and kind with family members. A carer from the country describes her son's artistic ability:

He is very gifted at drawing, art he is amazing. He is getting his marks in creative writing, and he likes to read.

Foster carer from the country described her young son's knowledge on Australian wildlife:

His knowledge about wildlife, wherever we went to the theme parks, like Australia zoo, he could answer any question about any animal, or their habitat, what they do, their feeding systems, the ecosystems. He was 8 or 9, and all we could think was you never put this down on paper.

Relative carer describes how her young nephews were doing well within the private school system:

Their achievements were massive; they can compete with anyone on any level given the right environment, given those structural and support systems. There are a lot of things that they can do as long as they're supported.

The foster carer comments on her young adult son and how he copes as a parent:

They live in a complex where there is a lot of bad judgements by other families.

They ring me when they are in a tight situation, they put their kids out of danger. So I know they have enough skills to do that.

Culture

Culture is often described as being integral to identity and resilience (Kickett, 2011). Three families in this study included non-Aboriginal foster carers raising Aboriginal children and most were from infants. Two of these families resided in the same town as the family of the children. This made it easier for the children to be visited by their extended families. The foster carer states:

We do our best. I hope that we are doing enough for him. But I do believe that he's got connections there when he's ready and he is aware that he is Aboriginal, and he understands that he's from the local community group, we know the names of his family members, so he knows.

Another carer who is non-Aboriginal made the following comments about raising her son:

He has always been a proud Aboriginal boy growing up, but he's never thought much about it, this is where I think the FASD comes into it, because he's never been able to actually grasp it. He's known of his situation all along, and he's known of his family.

One family had two siblings who were being raised along way from the town they were born, making it difficult for their extended family to visit. However, at the same time the department of child protection had not been able access any details relating to their birth mother other than her name. The carers attempted to learn about the region that their children came from, and were keen to take the children back to visit, however, the biological mother has not been located since the birth of the youngest child. The carer states:

Yes, DCP have given us the family tree. They are also trying to trace family for us, so we can take them back to country. We try and read as much as we can about the region and anything cultural.

For Aboriginal relative carers, culture also included the obligation to care for family members and to share this responsibility, a relative carer makes the following statement:

The agreement was that when Gary was 12 or 13 his Uncles take him on, and could look after their nephew, my 2 cousins passed away, so I was left with Gary.

Treatments

Treatments that families felt were useful for the children ranged from behaviour and speech therapy, alternative therapies; and medication for children involved in this study. However, as behaviour therapy was expensive therapy it was only accessed by two families in this study. For one family this was covered by private health insurance and the other family was able to access behaviour therapy through disability access. The carer from the country describes the importance of behaviour therapy for her child and this was a therapy they continued with throughout his childhood to help regulate his behaviour:

We ended up with a Behaviour Therapist and her programme suited him to a t..... It was heavy work and he was 100% engaged. But If he was in the care system he would not have been afforded that, that was the biggest thing and was a lifesaver, and I remember the first time he actually did as he was told, and it was mind blowing, I remember thinking oh wow.

Another carer from the country described how she believed medication had worked for her young child:

It is a lifesaver, he is a different child. He also has catapressin and melatonin at night-time to help him sleep, because he wasn't able to get himself to sleep, it gives him a better quality of sleep. So he has a vyvanse in the morning and dexamphetamine as well.

Carer with siblings described how regular exercise for her young nephews was critical for routine and helping with school:

The great thing about some of these private schools is they did two hours of sport every day, and for a kid with FASD in that environment it was the ticket. I had a straight A child, the youngest was a straight A student.

The inadequate term “Carer”

At the conclusion of the family interviews, it was clear how inadequate the term “Relative Carer or Foster Carer” has become when raising children and particularly children with a disability such as FASD. Historically, the carer role in mainstream society is generally not valued for the sacrifice and commitment required for caring for children with disabilities. Societal lack of value for carers as well intersects with a significant lack of awareness of FASD by services. To this end, the experiences of carers are often subjugated and dismissed by agencies. Their urgent concerns were often minimised by agencies, contributing to a power imbalance and difficulty and frustration for carers to feel confident in advocating for their children. If the carer

feels disempowered, this will not lend to them to being able to advocate for their child. Carers both Aboriginal and non-Aboriginal felt not valued as carers. A non-Aboriginal carer describes her experience and challenges as follows:

When Ray was taken from us, we were dragged to a panel up Perth, it was horrendous. It's not practical, for us. We went up through the panel, I was told that I wasn't allowed to have someone with me. They family were allowed to have people, 10 people with them. I was pregnant, my child is the most anxious child you will ever met. I honestly believe I was in such a state, I was grieving, I was in chronic stress. My daughter is the most anxious child, she worries about things she doesn't need to worry about. I had my thyroids out. I would say absolutely my health has been impacted. I remember going into the doctors and just bawling my out, saying I can't do this, I was prescribed antidepressants.

Ongoing therapy such as behaviour therapy is expensive, and only two families were able to access this therapy on a regular basis. Private health insurance was critical for families to be able to afford ongoing behaviour therapy for their child. All Aboriginal children in this study were not raised by their biological parents, and the majority came into care as infants. The timeframe of care ranged from 1992 to 2015. Three young adults remain with their carer. Whilst, there has been considerable Australian research and reports undertaken in the past 10 years, this has not yet translated into practice and service delivery. This study highlights that very little has changed from early 1990s to 2015, for families raising children with FASD in Western Australia.

Conclusion

This chapter has discussed the key themes from the qualitative interviews with the six families caring for Aboriginal children with FASD in the south west region of Western Australia. The key themes were analysed under the categories of the Indigenous framework. Applying an Indigenous framework was critical, particularly as the area of interventions in FASD globally continues to be an emerging field. Furthermore the literature highlights that interventions for Indigenous people must be decolonised (Salmon, 2011). This chapter has provided a snapshot of the impact of FASD on the child, and the family, including a table that describes the impact on health, and whether there are also siblings with FASD, and secondary disabilities. Three of the families involved in this study were caring for siblings with FASD, and this highlights the

urgency of addressing FASD and the lack of support for children and families. The next chapter 7 provides the case narratives of each family, including reflective interpretive commentary and secondary disabilities.

CHAPTER 7

Case study Narratives

Stories have been used at the healthcare “front line” to promote healthy behaviours.....there is a growing realization that patients and service users are a rich source of healthcare-related stories that can affect, change and benefit clinical practice (Haigh & Hardy, 2011, p.410).

Introduction

This chapter includes the case study narratives of each of the six families caring for Aboriginal children with FASD in the south west region of Western Australia. The first section of this chapter will briefly introduce some of the evidence on the critical role of Indigenous stories and stories per se for informing service delivery and policy. The second part of this chapter will include the family interviews undertaken in 2015 and includes a reflective commentary on each family. Finally, the common theme from the family interviews of “sharing the load” is provided towards the end of this chapter.

Evidence base: Indigenous Stories/Narratives

Indigenous communities have always undertaken research...their research approaches are rooted in a process of storytelling, community consultation, collaborative analysis and evaluation, all guided by traditional protocols, ethics, and relationships (de finney et al, 2009, p.163)

Goulding, Steels & McGarty, (2016) and Sium & Ritskes (2013) asserts that narrative approaches and the medium of Indigenous storying telling plays a critical role in the decolonizing of western paradigms in the production of knowledge. Further, Goulding et al, (2016) note that narrative stories are imperative to influencing social change. Storytelling within Indigenous communities has indeed survived and remains an important medium with a rich diverse role encompassing political resistance, empowerment and therapeutic healing. Sium & Ritskes (2013, p.II) remind us that Indigenous stories are always more than just personal narratives and make the following statement.

“Story” is far too simple for the complex and rich understandings that each of our contributors bring.....Stories in Indigenous epistemologies are disruptive, sustaining, knowledge producing and theory-in-action. Stories are decolonization theory in its most natural form

Australian Indigenous academics Walker (et al, 2013), agree the process of storytelling and yarning is critical to decolonizing western methods of research, as previously noted in chapter four. Further, these writers stress western methods of research has had little impact on the health disparities for Indigenous people (Walker, et al 2013). Rather the sharing of stories facilitates a genuine transfer of knowledge that is respectful to Indigenous people.

Bennett (et al, 2011) supports the medium of Indigenous stories and expands on the importance of deep listening to the storytelling with due respect. Hence, silence given to the storyteller is validation and respect for what they have to share without interruption. Australian Indigenous elders Bacon, (2007) and Wingard & Lester (2001) describe how the use of storytelling and adapting narrative therapy has become an important culturally appropriate therapeutic tool in working with Indigenous communities throughout Australia. Further, the use of storytelling and drama has emerged as an appropriate therapeutic tool in working with children and adults with FASD.

Perry in Malchiodi (2008) also agrees the practice of storytelling remains a critical part of therapeutic practice, however, this is based on the caveat that the participant has the right cultural environment in sharing their story. Perry (2008, p.9) states

These Aboriginal healing practices are repetitive, rhythmic, relevant, relational, respectful, and rewarding; they are experiences known to be effective in altering neural systems involved in the stress responseThese practices emerged because they worked. People felt better and functioned better, and the core elements of the healing process were reinforced and passed on.

Further, the cultural environment includes setting the context naturally through the understanding of yarning in combination with cultural protocols, and establishing connections through relationships (Bennett, et al, 2011). For Indigenous people cultural environment also includes the telling of a story also through the provision of appropriate cultural modalities such as art, storytelling, drama and music. Similarly, Australian Indigenous Psychologist Judy Atkinson has developed an evidence based approach of healing intergenerational trauma through the practice of sharing and listening to the story of participants that incorporates these key components (Atkinson, 2009).

A Snapshot of Families:

The next part of this chapter provides an overview of each of the families and concludes with a reflective interpretive commentary and discussion on secondary disabilities. Four of the families resided in the metropolitan area and two resided in a large country town in the South West region. The families included three families caring for Aboriginal children under kinship care, and three families caring for Aboriginal children under foster care. To date, limited qualitative research has been undertaken both globally and within Australia on families experiences caring for children with FASD. It is well documented that the expertise of carers and families is critical to informing service delivery on FASD. Further, the literature review, identifies that interventions to support children and adults living with FASD continues to be an emerging field. All names have been changed in this chapter.

Brother and sister

Mark and Lana, two young siblings both came into the care system as babies. Whilst, Lana is older than Mark, she experienced two foster placements before eventually been placed with the same family as her younger brother at four years of age. The two previous placements were traumatic for Lana, and at the age of 4, she has entered her third placement with her current family. Mark is now aged 4 and he has been with his foster family since he was discharged from hospital at approximately 6months of age. From birth, Mark was born with serious health problems and was not expected to live.

Both children have had to overcome serious health problems, and still require ongoing specialist care. The parents advise that there are disturbing differences in the amount of services that the brother and sister are able to access. As a baby at Princess Margaret Hospital (PMH), Mark was diagnosed with Microcephaly and global development delay at birth. Lana had ODD and has experienced a great deal of invasive and painful dental work as she was born with a cleft palate, and this has contributed to her already having to undergo more dental work than most adults in a lifetime, including several root canals. There has been no formal diagnosis for either children, however, both children have the physical features of Fetal Alcohol Syndrome. At times the response by agencies to the siblings disability, has been frustrating, as once agency has written to the carers enquiring as to whether the children have “grown” out of their disability.

The previous placement was also traumatic for the family caring for Lana, as they had good awareness of FASD, but were frustrated and extremely stressed that they were not able to provide the care and assistance that they knew she urgently required. The children's mother is from the Kimberley region, and despite efforts from child welfare, there has been no contact with the biological mother. Both children display significant dysmaturity and act far younger than their chronological age. Lana is now in grade 1 and her Dad is requested to attend to the school, generally 3 or 4 times a week, sometimes every day. Mark as yet is not attending school, most of Lana problems at school are based on her not being the developmental age ready for school. This is further compounded by the school not having a good awareness of FASD.

The family have received very little support, and have little energy and time to seek help, after caring for the children. Following strict routines is critical for the siblings, and the parents have found that any slight changes to the home routine can result in meltdowns. These meltdowns can involve hours of screaming and have sometimes occurred up to 3 times a day. The family received no respite care, other than what their own family is able to offer from older adult children within the family.

Reflective interpretive commentary:

These two siblings aged 3 and 5 were the youngest children involved in this research project. Disturbingly, there are contrasting differences between access to services that was likely influenced by several factors, firstly that the young brother was diagnosed with other disabilities providing access to services from birth, and has been with the same carer from birth. In contrast, the older sibling was significantly disadvantaged by two different placements from birth without consistent access to appropriate specialists. This has contributed to the current status of the older sibling not having access to the same amount of services, despite both children having clear physical characteristics of FASD.

In 2015, the oldest child Lana has now commenced year 1 and the school does not understand or attempt to address FASD as a disability. Despite the amount of local Western Australian research on FASD and advocacy this has not made an impact to critical services such as the education system. Lana as a student with FASD is at huge disadvantage within the classroom every day. Further, school teachers will expect

Lana to have the emotional development of her peers at the age of five. Millians (2015) also reported qualitative findings of carers having to have frequent contact with the schools due to having to educate teachers and the school system on FASD.

Secondary disabilities:

In terms of secondary disabilities, both children were still quite young at the time of this research, however, for Lana in year one, the secondary disability of problems at school was already quite well established, and her engagement with school was further complicated by short term memory that Lana experiences. In terms of dysmaturity, Lana probably has the emotional development of around 3 years of age, and this creates problems on a weekly, sometimes daily basis for Lana and her carer.

Young family

Young Ray lives in a country town and has been with his foster carer for the past 9 and half years. In the first few years of his life, Ray experienced multiple placements within his biological family and was in and out of care, before coming into long term foster care at the age of two. His foster carers were a young couple with no children of their own, and they met Ray as his respite carers. One particular respite weekend, the current placement had broken down, and the respite carers agreed to care for Ray on a long term basis. Three years later, at the age of 5, Ray was moved back to his biological family and changed schools. This attempted reunification with family did not work, causing Ray to become quite traumatized after the event.

As a younger child, Ray used to have frequent periods of raging (meltdowns) and this was exhausting for both Ray and the carers. With experience of his behaviour, the carers were able to learn how to divert his attention and de-escalate his behaviour and this had a positive impact on his raging. At the worst, the raging would occur a couple times a week and he would spend hours screaming. His carers would make sure that his environment and bedroom was safe during his rages. At the age of 12, the rages had begun to dissipate and the carers believe they have come a long way in now managing Rays behaviour, as Ray now seems to be able to settle. The carers found a strategy of diversion helps with his rages, and includes things like bear hugs, or suggesting he does something he likes. The couple have also had to work strongly as a team, and step in when the other parent needs a break. This also involves trying to

remain calm for as long as possible. Changing the routine of the family has to be approached differently with Ray such as planning family holidays, as Ray often becomes fixated and unable to cope with change to his routine and environment. He cannot handle excitement and changes to routine must be introduced in gradual steps.

Ray has had ongoing problems with his ears and has had glue ear and grommets and also had surgery to remove the grommets. Ray presents with dysmaturity and has the behaviour of a child younger than his chronological age. He is a well-liked child at school, but does not have any close friends. Ray is now aged 12, and will happily play with his foster sibling aged 6, and still believes in Santa. The carers now have three children of their own and Ray loves his siblings and is the first one to make sure they are okay, if one of them gets hurt. The carers have found that having a Paediatrician in the town who was well informed and experienced with FASD has been a godsend for the family. The specialist is also emphatic to the challenges that confront many foster carers in liaising with the child protection system.

Schooling has been a massive struggle for Ray and he also attends learning support three times during the week that focusses on repetition and this has a huge positive impact on his learning. Ray's foster mother is also a qualified school teacher and understands first-hand what is important in his learning at school. In terms of school work, Ray is very gifted at drawing and his art is amazing. Maths is where he struggles the most and can never remember his math's times tables. Based on the earlier challenges with school, the carer advocated strongly and was later successful with child protection for Ray to be schooled in a private school. The private school system has provided more support with his learning needs.

Reflective interpretive commentary:

In hindsight, young Ray and his family have had to endure further trauma caused by lack of understanding and awareness of FASD by child protection. This inadvertently contributed to the failed attempt of re-uniting with family that occurred too quickly, and then did not work. The biological family were not prepared or given any insight into the disability of FASD and how it impacts on the child and how parenting practices must be altered. Further, a transition period of slowly reacquainting Ray with natural family did not happen. This event was traumatic for Ray and both families

as reunification failed almost immediately and lack of understanding and preparation meant that it was doomed to failure. The other consequence was further trauma for Ray who had already experienced multiple placements as a very young child.

The carer has had to advocate strongly and consistently for Ray with the key agency and this included giving ultimatums of having Ray in their care on the provision that private schooling would be paid for by the department. Support received from department of child protection has been both positive and negative. Positive in the support received from a department case manager who has been quick to respond to requests for the family. However, at times the family has found the expectations from the department to be unrealistic. The social and emotional sacrifice for this family has been profound, the primary care giver is not able to work full time, despite Ray being upper primary school age. The family also do not seek outside respite, and have had to look within their own family networks to receive respite for Ray.

This family were the only carers who did not have their own children prior to raising Ray. The family found it was more difficult to manage his behaviour when the parents had their own children. Whilst, there is a significant age gap between Ray and the younger children, as the children have grown it has made the dysmaturity of Ray more obvious.

Secondary disabilities:

Despite the support of his foster carer as a qualified and experienced teacher, Ray demonstrated the secondary disability of ongoing problems with school. Similar, to the other children in this study, his problems with schooling were mainly caused by his short term memory, and consequently, being unable to remember and recall maths times table. Considerable effort and time went into supporting Ray with education, including better support at a private school and attendance at learning support classes three times a week.

Case study 3: Our nephews

Brothers; Trevor aged 12 and Darren, aged 9 came into kinship care in 2007 and were cared for by an Aunty and Uncle for approximately 4 and half years and left the care of the family in 2011. At this time both carers had no awareness of FASD, and it was

not long before the carers realised that parenting styles for the two brothers had to be different to the raising of their own son who was only a few years younger at this time.

The youngest nephew Darren had health problems that required expensive orthodontics. Doctors recommended that at some stage in his life, Darren would need to have a hip replacement surgery. This caused young Darren a lot of pain and discomfort during his childhood. Added to this stress was that the family were not reimbursed by DCP for a considerable period of time for health related expenses. The carers attempted to learn as much as they could about FASD, but felt distressed and frustrated by the lack of services available to support the young nephews. Compounding this was the realization that FASD is a lifelong disability. This knowledge was traumatizing for the relative carers in having to on one hand learn about FASD, and then attempt to navigate support from services. No formal training on FASD was available for the carers.

For this family, awareness of FASD became an enormous turning point in their lives, and the family, and the carers also suspected that the other siblings of the young nephews had FASD. The carers found that strict routines had to be followed, and these routines were displayed visually and colour coded for the young brothers to check against each day. Short term memory was a significant problem for the young brothers, and an issue that the carers had to understand quickly and constantly address. As the relative carer's knowledge on FASD increased through their own efforts in talking with experts such as Lorian Hayes, and reading on FASD, they quickly adapted their style of parenting the young brothers. This routine had a positive impact on the boys, and the boys began to thrive. They achieved better grades at a private school, and the carer strongly believed the boys did well at this particular high school, as each day included two hours of sport. Further, the oldest nephew Trevor went on to make the state rugby team for his age group and played interstate.

Trevor also had a part time job with the local bakery, and thrived in his job, and the owner of the bakery was impressed and happy with Trevor. Before long, Trevor was promoted to the position of Assistant Manager in the bakery. This job was important for Trevor, and had a positive impact on his self-worth and self-esteem. With support from his Aunty, Trevor had no problem keeping the job, and managing his money from

his part time job. When he left his Aunties care, he also ceased working at the bakery. After he left his Auntie's care several years later, he went back to the bakery and asked for another opportunity to work in the bakery, and the Manager agreed. However, Trevor's second time working at the bakery was short lived as he did not have the support of other family members understanding of FASD and providing support to him at that time.

The social impact on the relative carers was significant not only in terms of the financial sacrifice, but also for the primary care giver having to place her promising career on hold during the years of raising the nephews. The carers received respite once during these years, and when it was provided by DCP, the young brothers came back extremely traumatized from the experience, begging their aunty to never send them back to the respite home again. The boys complained that they had spent the whole time digging holes in the backyard for the respite carers.

The challenges of raising the young brothers were compounded by significant factors as: lack of understanding on FASD by the health services and child protection, no training on FASD provided to carers; lack of recognition of FASD as a disability, and overall a lack of support. For the carers there was also the ongoing grief and the emotional rollercoaster of understanding the young brothers had an irreversible disability for life. This continues to have a profound impact on the Aunty, and she has developed a good understanding of FASD as a disability. Since leaving the care of the Aunty, the young nephews have now developed serious addictions with alcohol and drugs, and have not been able to gain employment as young adults. The Aunty continues to worry for the future of her young nephews, and believes that without consistent support and services, the young men will never reach a good quality of life.

Reflective interpretive commentary:

Engaging the boys in regular outside physical activity became an important part of the daily routine. The brothers both participated in sporting teams and the oldest brother was selected for the state Rugby team. Private schooling worked and the boys with intense support from the carers were able to thrive with their schooling. The constant personal and financial sacrifices by the carers was profound. The Aunty during these years was not able to work, and had to forgo a second family income and career

opportunities. Consequently, the financial and emotional sacrifice was significant to the carers and their family.

Whilst the carers have extensive experience in parenting and raising children, the experience of raising children with FASD was a constantly challenging experience that was not minimized with any external support. The result for the carers was that the Aunty experienced severe burnout and was hospitalized several times in the last year of the children being with the family. Impact on chronic health issues, was significant and the carers had to cease caring for the young brothers after four years. Despite, this the relative carers continue to offer support and advocate for the young nephews. The aunty worries for the future of both young men, and recognizes that they will live with ongoing adversity for the rest of their lives. As the aunty suspects generational FASD, this heightens her fear, as she recognizes the challenges of extended families to firstly understand FASD in the family and then to be able to support family members.

Secondary Disabilities:

The extended family provided considerable support, love and advocacy for the young brothers in the four years they lived with the family. The boys did not experience as many problems with schooling in comparison with the other children in this study, and the only issue that impacted on the boys was both had ongoing problems with short term memory. The boys experienced multiple placements within the extended family. In the first year of this placement, both boys demonstrated extremely low self-esteem and depression. Consequently, the carer arranged for the nephew to have ongoing counselling at a mainstream counselling agency.

After a period of time, the counselling agency advised they were no longer able to assist the young nephew, as they recognized his younger emotional age, and they believed he would not progress any further in counselling as described to the carers. The carers were devastated the agency were not willing to adapt their counselling for his disability. After the nephews left the care of the relative carer, issues with alcohol and drug use began to emerge within the first 6 months while the nephews were still quite young. Both nephews are now young men and continue to struggle to live independently, and both now have the secondary disability of alcohol and drugs issues. They have not been involved in the criminal justice system.

Case study 4: Brothers

Two young brothers were placed with an Aunty and Uncle from birth in 1997, and 1998, and they are now aged 18 and 19 years of age. In the Nyoongar extended kinship system, these two young brothers are viewed as grandchildren and not nephews as they are the children of the husband's nephew. The biological parents of the children were heavy drinkers, and the father was Aboriginal and the mother non-Aboriginal. The mother had six children, all but the sixth child was removed from her custody, and one of the babies passed away. The Aunty has always encouraged the biological mother, to have contact with her children. However, this opportunity has not been taken up by the mother.

The relative carers had four children of their own, and at the time of placement their youngest child was 10 years of age. Both carers had never heard of FASD, or received any training on FASD during the years caring for the children. The brothers were never assessed for FASD and the process of having a diagnosis was attempted but not followed up by the Children's hospital. The family were later advised that it was too difficult at that time to have the young brothers assessed for FASD in Australia. Despite the lack of assessment, both brothers had physical characteristics of FASD, such as pigeon chest. In the first few years, frequent crying was an issue for the family. During the years of care, no respite was ever offered to the family. The biological father of the brothers offered help upon the passing of his Uncle, however, at this time he also had health problems and died three years ago.

The Aunty has now cared for the brothers for the past 18 years and they still reside with the family. The husband passed away when the boys were adolescents, and the Aunty has since cared for the brothers on her own. Schooling was challenging, and the boys struggled to remember new information that was taught, and they had to be told around three times to retain information. The boys were also subjected to a lot of bullying in primary school. This resulted in the family moving the boys to a local private school, who were more supportive of their educational needs. At school, the brothers both enjoyed and were good on computers for their schooling, however, their Aunty was rightly concerned that not practicing writing on paper was not good for their overall memory and keeping their literacy skills. Both brothers completed their secondary education at the private school, and this was focused more on practical work

readiness.

Reflective interpretive commentary:

The boys were born in the early 1990s and were raised at a time when very little was understood about FASD (Payne et al, 2005; Bower & Elliot, 2016). Whilst it was clear that the boys were born with physical characteristics of FASD, the specialists were unable to provide a diagnosis of FASD. The relative carers raised the children under enormous adversity; lack of awareness and support at significant social and financial cost to the relative carers. The young brothers will most likely never live independently. Recent literature in countries such as the UK identified the same reports by carers in not being supported by agencies and continuously having to fight for services, including diagnosis (McCormick, 2014).

During the years of raising the children, the carers did not receive any respite or support in caring for the children. Further, there was no financial assistance provided for the children. In retrospect, the primary carer wished there had been more support provided, particularly after her husband had passed away. Here it is important to acknowledge the husband was only in his early 50s when he passed away. The loss of the carer as father to the young brothers was devastating, and not long after his passing, they also suffered the early death of their biological father. Furthermore, the couple had been a strong team in approaching the care needs of the young grandsons and his early passing left the wife with the full responsibility.

The chronic health conditions of Aboriginal people are important to consider and address, particularly in terms of adding further stress to any families without offering social and financial support. Many Aboriginal relative carers have chronic health problems as highlighted by the case studies in this research project. The intense care giver needs are likely to contribute to all carers both Aboriginal and non-Aboriginal neglecting their own health, at serious risk of their own health. The stability of placement and profound sacrifice by the relatives carers, has provided the young brothers with quality of life as young men. The oldest of the brothers has now been working full time in a gardening position.

Secondary Disabilities

Both young brothers did not experience multiple placements and were with the same relative carers from hospital to the present time. In terms of secondary disabilities; the boys experienced problems with schooling and this was impacted by short term memory problems. As young men, the brothers did not develop secondary disabilities of alcohol and drug misuse; involvement in the criminal justice system and mental health issues. The stability and enormous sacrifice provided by the carers and extended family has saved significant amount of expenditure to the Australian government during the raising of these two young brothers. Furthermore, the financial and personal sacrifice has not been recognized by any particularly agency, and the only support provided to the carers was a fridge and washing machine, no training on FASD, which the Aunty stated she would have loved.

Case study 5: My Baby boy

Young Gary was raised by relative carers and came into care at the age of 6 months of age. Gary was a very sick baby and was not expected to live, and Gary had open heart surgery as he had a hole in his heart, and used to catch a lot of infections. Gary was removed from his mother's care as she was homeless. His biological mother was also suspected of having FASD and had three children, who were all removed from her care. Gary's sister also had FASD and was raised by another family member. At the age of 2 and half years the carer was talked into taking out a special guardianship order for Gary. As a child he had to have a lot of speech therapy as he could not talk properly. He had to wear pulls up until the age of 14, and had to have vitamised food up until his teenage years as he had difficulty swallowing food properly. In the early stages, within the extended family, it was agreed that the Aunty would raise Gary in his early years, and then his Uncles, would then raise him as a teenager to adulthood. At the time that Gary became a teenager, both Uncles passed away in the same year. Consequently, the Aunty then continued to raise Gary to adulthood.

The relative carer was not aware of FASD and did not receive any support during his childhood. Gary is now a young adult in his early 20s, and it has been an extremely hard road for both Gary and his carer. Gary still resides with his carer and has a full time job gardening which he has had for the past several years. In hindsight, the carer regrets agreeing to special guardianship of Gary as it meant she received no

departmental support in caring for him during childhood. During his time at school an incident occurred where another student told Gary to expose himself and he did at school. This resulted in Gary getting into a lot of trouble, as he does not have the ability to say no, and being placed on the sexual offender registry. The fact that Gary has a disability was never taken into consideration by the school.

Whilst, Gary has a full time job gardening, at the age of 23 he currently remains living with his carer. His carer does not believe that Gary is capable of independent living as he cannot problem solve and does not have cognitive thinking. He still works on impulse and will do things without thinking, and is not afraid of anything. He makes poor decisions based on what he thinks is right. Gary is different as he does not have the maturity of a 23 year old, and struggles with short term memory. In his payment with his full time job, Gary would be paid his salary one day and by the time, he had returned home, had no money left. The family are not aware of where his salary was going, and in order for Gary to have money over the fortnight, have had to quarantine an amount out of his salary to cover his expenses of getting to work. As Gary has been working now for quite a few years, it is likely he will require this level of support with finances.

Reflective interpretive commentary:

Gary is another case study from birth to early adulthood and he has remained with his relative carer from the time he left hospital after surgery on his heart. As highlighted respite was not offered to his carer, and had to be organized by his carer upon the birth of her last child. As an adult, the impact of the disability remains a challenge in his life. As outlined by the carer, Gary was born with severe health problems, and had several surgeries during his childhood. The level of intense care for young Gary was consistent, and he required vitamised food until he was fourteen years of age. In relation to the incident that occurred at school when the fellow student asked Gary to expose himself. It is likely that the school had no understanding of FASD, and furthermore, Gary himself would have been likely to have been younger emotionally than the other student.

The passing of Gary's two uncles highlights the early mortality rates of Aboriginal people, and how this ultimately impacts on the extended family. Further, it raises

again the urgency of providing external support for carers, as many Aboriginal people have chronic health issues. The high stress levels and lack of respite to carers must be urgently addressed, particularly in view of the ongoing stability they provide to children with special needs. The ongoing stable nurturing home environment is now evidence based as being one of the most protective factors for the prevention of further secondary disabilities with FASD.

Secondary disabilities:

The intervention of stability and support by the extended family has contributed in limiting the onset of secondary disabilities. The secondary disabilities problems were with schooling. As a young adult, Gary has not developed the secondary disabilities of alcohol and drug misuse, mental health and criminal justice system. However, the Aunty remains vigilant with Gary as a young man, and continues to remind him on the safe levels of alcohol consumption and safety when he leaves the home. This family as well saved the Australian government significant expenditure, as the family took the full brunt of the disability with no financial support or respite as relative carers.

Case study 6: Adoption for Carl

At birth, Carl weighed a healthy 8 pounds and was born with small kidneys and no facial characteristics of FASD. As a baby Carl was severely neglected and came into care so malnourished that he had been close to death. He was raised in a south west country town and was placed with his foster family at five months of age. His biological mother is non-Aboriginal and father is Aboriginal. The biological mother herself had a traumatic childhood and all her children were removed from her custody, and to this day, she remains a heavy drinker. The siblings of Carl displayed behaviour problems that was worse than Carl, as a result foster care placements would break down resulting in multiple placements. Out of concern for Carl, both the biological parents then asked the foster parents to adopt Carl at 18 months of age. The foster parents agreed to this request as they wanted stability for Carl. At the time the carers had little knowledge of FASD.

As a young child, Carl had the behavioural and emotional problems that is common to FASD. At the age of four, Carl was diagnosed with ADHD, and medication was recommended. The Paediatrician also was aware of the family and advised that it was

also very likely that Carl had FASD. This form of assessment was the closest that was available to having a formal diagnosis of FASD in Australia at this time. The carers did not agree with placing Carl on medication at this young age. Carl is now a young adult in his early 20s and his family still look out for Carl, who is now the father of two young children.

Schooling was very difficult for Carl, and teachers were quick to label Carl as a “child who was never going to amount to anything”. This attitude by teachers was distressing for the foster carers, and as a result the carers chose to enrol Carl in a private school. The carer and the private school agreed to an arrangement where Carl could attend school and also be home schooled. This was an arrangement that suited both the school, and the family. The private school were more willing to work with the family, as Carl found it difficult to interact with adults. Whilst, Carl was able to play with other children, it would only last for a short period of time. The issue of home schooling was captured in research by Hellerman (et al, 2009) who recorded some parents had little option but to home school their children, as schools were unable to cope with the behaviour.

Carl was a difficult child to care for, and the carers found having regular sessions with a Behaviour Therapist was critical for both Carl and the family. At this time, Carl’s behaviour had become defiant and he would not do as he was told, after regular sessions with behaviour therapy, Carl had learned to listen and for the first time do as he was told. The carers were impressed with the results they saw from the therapy, and most of the therapy was visual and importantly the therapist taught the family in the way that Carl needed to be taught. Carl’s mother can still recall the first time Carl listened to an instruction and did what he was told. The family could not sing the praises of this therapy enough and through the years the therapy helped Carl regulate his behaviour and he remained completely engaged. The therapy helped Carl be able to remain at school, as he was able to use the skills. The therapy continued for most of his childhood over approximately a 6 year period, at a cost of \$110 an hour and was medicare rebatable, however this was based on having private health insurance. At 6 years of age, Carl demonstrated the behaviours of a 3 year old child. The carers had also never received any training on FASD.

As an adult Carl is now in a relationship with the mother of his two children and residing in the same town. Both he and his partner do not drink alcohol. Carl is a loving and attentive father to his two young children. He has retained his cooking skills and cooks for his children as this is done on a daily basis. As a young adult, it has been difficult for Carl to be employed and now as a 22 year old he had forgotten how to write. Without ongoing practice, Carl is losing these important skills at a young age. He also now does not have the conversational ability that he used to have. For this reason, Carl finds it even more challenging in dealing with strangers or agencies such as Centrelink. This is further compounded by having to deal with different people at agencies. It is a constant challenge for both Carl and his partner who also has an intellectual disability to navigate the process at Centrelink. Compounding this as well is the short-term memory problems. As a result, they often have the Centrelink payments stopped. He also says he doesn't remember his childhood and that really worries his carer. Recently, Carl and his partner have begun to access the South West Aboriginal Medical Service (SWAMS) in the town and this has been another godsend for the family. Prior to SWAMS, Carl and his partner would not engage with any services.

Reflective interpretive commentary:

Carl was the youngest child in the family, and his adopted siblings were considerably older than him, at the time of placement. Therefore, his parents were able to provide Carl with considerable attention, particularly as his private school frequently requested that Carl spend considerable time being home schooled. To this end behavioural therapy was an ongoing treatment accessed and paid for by the family for the majority of his childhood. This therapy was critical in providing assistance for Carl to help self-regulate his behaviour. Further, the parents chose not to place Carl on any medication, as he had been diagnosed with ADHD. There appeared to be signs of generational FASD for his mother, as all her children were removed from care, and his mother still drank at the time of this interview.

Carl is now in his early 20s and is the father of two young children and is an attentive and loving father. With his partner they both live not far from his adoptive family. Herrick (et al, 2011), agree parents with FASD with support can achieve successful parenting. As a young adult, it is challenging for Carl to navigate now through life, in

terms of being able to hold down full time employment, or to deal with agencies such as Centrelink. Carl has problems now with memory, and to the point that he has forgotten how to write. His mum continues to provide emotional support and tries not to be too invasive in her support. This also highlights the critical gap of lack of services for adults living with FASD.

Secondary disabilities

Early intervention and ongoing intervention was provided through consistent behavioural therapy in his childhood, combined with home schooling, as requested by the private school. As a young adult today, there are no signs of the onset of secondary disabilities such as alcohol and drug misuse; involvement in the criminal justice system, and mental health. The interventions put in place by the family were expensive, and time intensive for the family, however, anything less would not have allowed Carl to now have the level of quality of life, in being able to live with his partner and successfully raise his children.

Sharing the load:

Carers described the importance of sharing the load, and each of these families were two parent families at the commencement of placement. Three of the families cared for siblings with FASD. One carer passed away, when the children were young adolescents and in another couple the marriage later ended, resulting in two of the families subsequently raising their child/ren as single parents. Families did not have access to respite, and two of the families received support from their older children in sharing the load. Herrick (et al, 2011, p.49) remind us of the critical role provided by carers, and the need to care for the carers:

Working with someone affected by FASD is a difficult and taxing full time job. It requires patience and persistence, devoted attention, and despite a lot of effort, it can often feel as though there is no progress. Because a caregiver is so important in the life of a person with FASD, it is critical to make sure the caregiver is cared for as well. Physical and mental breaks should occur regularly (Herrick, et al, p.49)

The sharing of the responsibility between caregivers was critical in being able to cope with the intense care demands. Similarly, there are parallels in the Australian study by Chamberlain (et al, 2016); of caregivers feeling unsupported and alone in caring for children with FASD; having problems accessing services for their children and

reported lack of knowledge of FASD by health professionals. A foster carer looking after siblings with FASD describes how both parents shared the load between themselves:

You need each other to bounce off.... She would have meltdowns four times a day and some of the meltdowns could last 2 to 4 hours and you would get to that breaking point. The other person would then take over. Mentally you had to be very strong. (Carer with siblings, 2015).

One of the relative male carers of two young siblings passed away when the boys were adolescents and they remained in the care of his wife. The brothers were naturally devastated for a long period of time by his death, and would not allow their Mum out of their sight after his passing for a long period of time. The relative carer with siblings as babies shares her experience:

Once they got into primary school, it was alright. Because I had to say to them school tomorrow, we need to go to bed early. The routine of getting them to bed and getting them up was hit and miss. There was many times where I used to sit up with them, while they played on the floor, tired as. Otherwise it was my husband sitting up... in the end we did it as one baby was mine and the other was his (Relative carers with siblings aged a year apart as babies, 2015).

Most carers themselves had children at the time of placement and the children were generally older; and, only in one family were there no other children at the time of placement. In another family, the carers own son was aged in the middle of his two cousins. A wife describes the important role of her husband in caring for siblings with FASD:

Massive, the older boy was used to having one on one time with his father's attention and he demanded it from my husband. My husband was very generous in that he was able to give them all attention. Im sure it is what brought on his chronic health problems earlier than later.

The challenges of parenting children with FASD appeared as difficult to experienced parents and foster parents as they were to the young couple with less parenting experience and no children. As previously stated none of the carers were provided with training in FASD whilst raising their children. Rather, all families were for the most part two parent families, and were able to equally share the parenting for the child or children with FASD. The common theme here is that all families, regardless of age and parenting experience all started with relatively the same level of awareness of FASD, which ranged from none to very little. The majority of the families involved in

this study had many years' experience as parents, however, this was no real preparation for the different style of parenting for children with FASD.

Initial Placement in OOHC

The majority of families in this study, generally did not see the initial placement for the children as potentially long term, as this was not articulated to the carers at the time of placement. Nor did any in-depth discussion on FASD occur between the families and OOHC, and in some families, there was no mention at all of FASD at the time of placement. Parkinson & McLean (2017) assert the lack of awareness of FASD of carers will likely contribute to placement breakdowns, and this was experienced by four of the children in this study. In one family, the placement ceased after four years, and another young child had experienced two placements before coming to her third placement under the age of 5. Further, a reunification for one of the young boys in this study was unsuccessful as the reunification to the biological family did not consider FASD in the transition process. In a study undertaken by Paley (et al, 2006, p 402.) the following response was provided by carers describing what were their urgent needs to maintain a successful placement;

Foster parents highlighted...social, instrumental, and professional support and services, and an understanding of FASDs, including knowledge and skills related to behavioural management and parenting children with disabilities and knowing "what you are getting into".

One relative carer was advised the baby was not expected to live past 12 months due to the serious health problems at birth. Two of the foster care families were respite foster carers when their child came into their care, and were then asked after a period of time to consider having the child on a long term basis. The long term placement of the child only appeared to be clear to only two of the families, who had the children from infants. This is likely to have placed the carers and the child at a disadvantage in terms of advocating for ongoing support. As most carers were not aware of FASD in the first instance, and consequently did not negotiate for further support from the relevant agencies during the initial placement.

One family was able to negotiate for further support in the form of private schooling after an attempted reunification with the biological family failed. However, by this time, the family had cared for the child for several years, and then had a clear

understanding of the impact of FASD on the child and the family. Further, the failure of reunification likely occurred as the case management process was not FASD informed, as in there was no transitional process, and no training on FASD for the biological family.

Conclusion:

This chapter has provided an overview of each of the families that participated in this study. As previously highlighted the majority of literature on FASD has been dominated by scientific studies relating to prevalence rates of FASD within society. Subsequently, the experiences of carers are imperative to informing interventions, policy and service delivery on FASD. Each family commentary has also included discussion on the secondary disabilities, that notably did not emerge for the majority of children in this study. This is largely due to carers and the stability of a loving stable home as the first part of intervention required to minimize onset of potential secondary disabilities. However, as highlighted in this chapter, these families were constantly challenged by the intense care giving needs, along with personal and financial sacrifice. Further, literature highlights financial pressure further compounds the stress of caregivers. The next chapter eight is the concluding chapter of this study and includes further discussion and recommendations for policy and service delivery.

CHAPTER 8

Discussion, Recommendations & Conclusion

The ultimate cost on the wider community is going to be far more, put the hard yards in now, and spend the money now whilst they are young, put infrastructures in place to support them, and encourage them and look after them. Why are they forced onto families who can't cope? Why have they not been made a part of a disability safety net? That catches them, and looks after them, and cares for them. (Perth Carer, 2015)

Introduction

This chapter will provide an overall conclusion for this study, and is divided into several parts including an overview of the research methods; discussion in response to the research objectives, including additional information in the appendices and recommendations. The recommendations on FASD are designed for the community sector; health workers; policy and practice; and future research required in this area. Finally, the significance of this study will be outlined and discussed, along with the study limitations and concludes with an epilogue.

Brief overview of research design

This study has included a mixed methods qualitative and quantitative approach, and the methodology applied was underpinned by Indigenous standpoint theory. The study sites included Perth and five country towns in the south west region. A CRG for expert consultation was established including both Aboriginal and non-Aboriginal people with expertise in FASD; community development and research. The CRG were consulted for the development of the family interview questions and the survey tool titled; Our Gurlonngas, Our future. Additionally, extensive peer review of the survey tool was undertaken with senior researchers from the National Drug Research Institute, Telethon Institute for Kids, and Curtin University. Indigenous standpoint approach was applied throughout this study, and this included the strict adherence to Aboriginal protocols. At each site, the researcher met with an elder from the town and introduced the survey tool, and gained permission before commencing any surveys. Ethical approval was obtained from both the Western Australian Aboriginal Health Ethics Committee, Curtin University and the Department of Child protection.

An intensive international study tour on FASD was undertaken for five weeks in 2014, in North America and Canada. This included training on FASD by leading international experts Diane Malbin, Dr Dorothy Badry and Donna Debolt. The researcher also attended two international FASD conferences during this timeframe in Canada; and attended a meeting of the Canada National FASD network. A presentation on this research project titled “Our Gurlonngas, our future; Fetal Alcohol Spectrum Disorder (FASD): how relevant is a trauma informed approach in Perth, Western Australia?” was delivered at the International Conference, Living Well FASD and Mental Health 2014.

Response to the research objectives/questions:

1. Develop and administer a survey to capture the range of understandings and knowledge of FASD of Aboriginal people in the South West region of Western Australia

A total of 180 Aboriginal people, aged from 16 – 67 years of age, participated in the survey, and this included 109 females and 71 males, the median age was 14 years. The majority of participants 78 per cent had children. Whilst, the majority 61 per cent reported to have heard of FASD, 55 per cent rated their awareness as low, and 34 per cent reported to have no awareness of FASD; and only 10 per cent reported to have considerable knowledge on FASD. Sixty seven per cent indicated they were interested in receiving information on FASD. The majority 55 per cent, indicated their preferred delivery of FASD was in community forums and 45 per cent also indicated small groups, and 18 per cent selected on a person to person basis, the minority 14% indicated online. As previously, discussed the survey acted as an icebreaker and facilitated yarning on FASD within the community.

The majority of participants in this study did not drink alcohol, and 47 per cent of participants reported to consume alcohol. Growing up, the majority, fifty eight per cent had seen a lot of consumption of alcohol. Sixty seven per cent reported to know a female who drank alcohol during pregnancy and thirty two per cent had not witnessed a female consuming alcohol during pregnancy. Thirty two percent felt that it was common to drink alcohol during pregnancy and the majority 50 per cent believed it was not common. Sixty per cent in this study, indicated the females who consumed

alcohol during pregnancy were a family member. In response to the question do you consume alcohol with a partner, 27.2 percent drank alcohol with a partner, whilst the majority 47.2 per cent did not. Similarly, the findings in the study of first nations women consumption of alcohol during pregnancy was estimated at 36 per cent in Canada, and 42 per cent in the US (Popova, et al, 2017). Further, Popova et al, (2017) reported a prevalence rate for Australian Aboriginal women at 34 per cent in consuming alcohol during pregnancy. Research by McBride & Johnson (2016) found the mainstream population reported as high as 75 per cent of women consumed alcohol with a partner in Western Australia.

In response to the question, do you think anyone in your family possibly has FASD, thirty seven per cent stated yes, the majority forty seven per cent were unsure, and fourteen per cent reported no. In response to the question relating to signs and symptoms of FASD amongst children in the community, 44 per cent indicated that they had witnessed symptoms and 55 per cent had not. In the same question relating to adults with symptoms common to FASD, 56 per cent had witnessed symptoms and 43 per cent had not. In questions relating to the stolen generations, fifty six per cent were either themselves, or had a family member who was part of the stolen generations. The majority 79 per cent indicated their preferred sources of support was their family, 41 per cent indicated friends and 22 per cent indicated counselling services.

2. To document and record the experiences of parents/caring for Aboriginal children with FASD using a case study approach

At the time of placement, none of the carers had heard of FAS or FASD. This is likely to have placed the families at a disadvantage in negotiating for services in the first instance. In total, the six families cared for nine children with FASD, including eight males and one female child. Three of the families cared for siblings with FASD. The interview questions were semi structured and included yarning about the experiences of the carers and their families. All families had experience in parenting, however, this did not prepare the carers for the different parenting style required for children with FASD. None of the carers were provided with training on FASD, or support groups. Furthermore, this was exacerbated by lack of awareness of health professionals, and lack of services. For most of the families, respite was not offered,

and on the occasions it was offered, it proved to be too traumatic for the child, and the carer had to spend several weeks in getting the child back to normal routines. In this case it is likely that respite was not successful as routines must be similar.

From the families in this study, four of the nine children are now young adults and in their early 20s. Two of the young men have been working in the same position long term. The second eldest young man in his early 20s is successfully raising his child, and the fourth young man has just finished high school. Likewise, Bell (et al, 2015) reported findings of success for children and adolescents with FASD who had received advocacy and good parental support. Therefore, the stability and sacrifice of families has arguably played an instrumental role in preventing secondary disabilities. The secondary disabilities that these young adults do not have includes; alcohol and drug problems; involvement in the criminal justice system, and mental health. Literature supports that family stability is one of the most important aspects of ongoing intervention for children with FASD. These four young men have been with the same family since birth highlighting the critical factor of stability for children with FASD.

3. Explore carers the impact of FASD on the health and economic status of families caring for children

Within this study, none of the nine children were raised by their biological parents and all nine children were raised in OOHC. The impact of caring for children with FASD on carers in Perth, and in country towns of Western Australia was profound both socially and financially. Both relative and foster carers took on this responsibility and role with non-existent to little support.

The impact on the health of carers was significant; and one carer passed away in his early 50s from a coronary attack. Another family, ceased care after four years, as the intense needs of caring for two young siblings without respite and support had escalated the chronic health problems of both carers. Not long after ceasing the placement, one of the relative carers suffered a coronary attack and the other relative carer was hospitalized several times within a year.

The social impact and adversity for the children living with FASD was ongoing and was difficult for their families and carers to observe in their children. The majority of

the children all had significant memory problems that were distressing to the carers as well to themselves. For one participant now a young adult, this included forgetting the skills of reading and writing. Carers also expressed with distress and sadness, the lack of friends their children had growing up at school. Likewise, Bell (et al, 2015) and Stade (et al, 2011) reported the same in their studies of children with FASD finding it difficult to make friends at school. Therefore, indicating the children begin to feel isolation at a young age during their childhood. The majority of the children in this project had dysmaturity and therefore acted younger than their chronological age and this made it difficult for the children to maintain friendships with their peers. Further, carer support groups were only newly established at the time of this project. Therefore, the majority of families had no access to carer support groups.

According to Bobbit (et al, 2016) in their study findings on caregiver stress, found higher stress levels with families caring for children with FASD with lower incomes. None of the families involved in this study were able to remain a two income family due to the intense care needs. The financial impact of raising a child with FASD must be considered, as appropriate treatments such as behaviour and speech therapies are costly therapies, particularly when required on an ongoing basis. For one of the families, their son continued to have behaviour therapy throughout his childhood. Only one of the families was financially able to have their child in ongoing therapy throughout childhood, and this made a significant impact on self-regulating his behavior. This is important to note as without this therapy it was unlikely that the family would have been able to cope long term. Another child had ongoing speech therapy. This study has also highlighted the ongoing financial disparity between relative and foster carers in caring for their children. Relative carers in this study did not receive the same amount of money as foster carers. Another family chose adoption and then with private insurance personally covered the costs of therapies.

Two of the carers of adult young men both shared common stories on the difficulties the young men now have in managing their own money. According to Egerton, (2014) this is a common problem for many adults with FASD in budgeting money, and often this has serious consequences, such as not being able to pay for rent. The first carer now quarantines part of his income for off pay week to last him for the fortnight. The second carer, provides support and at times financial support in small amounts, as her

son now is a young father and lives not far in his own home with his young family. At the moment, the adult son does not have a job and now has problems with literacy and numeracy, making it extremely challenging to gain and hold employment.

Significant outcomes from the study:

There were significant outcomes resulting from this study and these included; development of the survey tool Our Gurlongas, our Future, participation of 180 Aboriginal people in the survey, thematic analysis of the six family interviews; and the development of a FASD training package incorporating the data results of this project. The researcher was invited on several occasions to be a keynote speaker at the State Aboriginal and Alcohol and Drug forum in 2015 and the SNAICC AGM in 2016. In 2018, presentations of the results from this study were made to the National Judiciary Association in Canberra, and at the National Indigenous Incarceration Conference in Brisbane.

FASD training package for workforce and families.

Whilst, the development of the training package was not part of the original aims of this project, it demonstrates the study was immediately responsive to the needs identified by the Aboriginal community in the south west region. Further, the training package was also critical in providing translation of the findings of this research project to the community and the workforce sector in Western Australia. The development of a FASD training package evolved during the data collection in Perth and country areas, and the request for FASD training was made at each site, from both the community and community organisations. Further in being informed by cultural security; Indigenous approaches and the literature on FASD; this training promotes understanding and highlights the stigma associated with FASD, and promotes a nonjudgmental approach in understanding FASD. To this end, the researcher developed a FASD training package informed by the following; FASD training received during the international study tour of 2014; literature review; results from the family interviews and the inclusion of the results of the survey.

The aims of the FASD training package were as follows:

1. An overview of FASD as an irreversible lifelong disability, and how it affects children and adults who are living with FASD and the implications for their

- families and the wider community
2. Approaches for intervention and treatment
 3. An understanding of the urgent need for ongoing professional advocacy and raising awareness in our community

By July 2016, the researcher had been requested and delivered training on FASD to key Aboriginal and non-Aboriginal agencies in Perth, Albany and Victoria. Evaluation forms for each training session were completed by participants, to encourage feedback and for the researcher to continue to improve the content and delivery. Training on FASD in 2016 was requested and delivered to the following agencies in Western Australia and Victoria: WA Country Health Service and Palmerston Rehabilitation Service (Albany); Derbarl Yerrigan Health Service (DYHS); Yorgum Aboriginal Counselling Service; Aboriginal Alcohol Drug Service (AADS); Society of Professional Social Workers and Secretariat of National Aboriginal and Islander Child Care (SNAICC), Victoria.

Narrative role play: Externalising FASD

Included in the FASD training package is a role play based on the narrative therapy approach of externalizing. Externalising of health issues such as diabetes has been used within community forums as an icebreaker, and has been successfully applied by Australian Indigenous elder Barbara Wingard (Wingard & Lester, 2001). In this context, externalizing is an extremely effective and culturally appropriate tool for health promotions (Wingard & Lester, 2001). The externalizing of FASD allows the audience to meet FASD as a visual character. In some role plays a mask is worn by the person acting as FASD, and this visually promotes the fact that FASD transcends all races, and class. The role play was used with both Aboriginal and non-Aboriginal audiences and the language in the role play is easily adapted for audiences. In this respect, the role play was well received by both Aboriginal and non-Aboriginal audiences and the diverse age groups. The role play takes only approximately four minutes to complete, and volunteer participants receive the script prior to delivering the role play.

The medium of role plays is also supported by literature as being an important tool in working with children and adults with FASD. Particularly, for an Indigenous

audience, as the use of narrative therapy and storytelling is a key element within Indigenous Australian cultures (Wingard & Lester, 2001). This role play was also designed using Nyoongar vernacular and includes Nyoongar words and humour. As the content on FASD training is at times confronting, the role play provides participants with some light relief, whilst consolidating their learning on FASD. The role play has been successfully used as an icebreaker, and promotes further engagement during FASD training by participants, and feedback from the evaluations forms relating to the role play was extremely positive.

Presentations of results from thesis:

During the study of this research project, the researcher was successful in having abstracts accepted for presentations at two international conferences in Canada in 2014. Presentations based on the results of this study were also requested at the Social and emotional wellbeing workforce support unit combined regional and statewide forum in 2015. In 2016, the researcher was invited to provide two key note presentations in Australia; including the National AGM of SNAICC in Victoria and the WA Aboriginal Alcohol and other Drug Worker forum in Western Australia in 2016.

Recommendations from the Study

The next section of the chapter includes recommendations resulting from this study. The various recent Australian national and state reports on FASD highlight major reform is urgently required to support individuals and families living with FASD. Therefore, recommendations in this section target the following areas; policy and practice; children in OOHC; interventions and service delivery (community organisations, community health workers); mental health and co-morbidity; education and future research.

Recommendations for policy and practice

Recommendations for policy and practice, considers the fact dedicated services on FASD were largely non-existent at the present time of this study. The following recommendations are aimed at policy and practice in the design of service delivery for FASD; The Western Australian model of care (2010) includes 33 recommendations to address FASD within Western Australia. Subsequently, a taskforce should be

established to urgently review progress of these recommendations to identify which recommendations have been implemented. Further, the taskforce should monitor and review on an annual basis any recommendations that have not been implemented. FASD must be recognized as a disability in Australia and therefore supported as a lifelong disability. Understanding of FASD must be consistently incorporated into policy as both prevention and across the lifespan for individuals living with FASD.

FASD training must be included for all relevant workforce, and this includes an ongoing role in health promotions. In order to address stigma and misconceptions surrounding FASD, it is imperative for FASD training to be delivered in face to face, rather than online training. The issue of employment for adults with FASD must be identified as an area of priority and supported, and the reintroduction of Aboriginal employment programmes such as CDEP. These programmes would assist adults with undiagnosed FASD in their day to day skills, and protect their income stream. AOD Treatment programs need to be adapted for adults with FASD, or suspected of having FASD. Treatment programmes must be FASD informed and trained. Further, case management in service delivery must be FASD informed and adapted for clients to avoid unintentional discrimination of the client.

Children in OOHC

The literature identifies children with FASD are over represented in OOHC; and are at considerable risk of remaining undiagnosed, and this potentially will have serious consequences for the child and the family. All relevant recommendations made from the WA FASD Model of Care (2010) for children in out of home care must be implemented within the Department. Early intervention must incorporate FASD and this includes access to early diagnosis, and ongoing support. Children with suspected FASD must be given urgent access to diagnosis, and early intervention. Treatment programmes such as speech and behaviour therapy must be provided on a regular basis, particularly to assist in self-regulation of behaviour. Policy on FASD must be included in all relevant areas of child protection, particularly in the areas of early intervention with young children. Case management practices for children with FASD must be FASD informed and applied consistently in case practice, and adopted into policy and practice. Consideration should be given to the existing number of children in a home, before placing a child with FASD, in order to protect long term placement.

Special Guardianship orders must be urgently reviewed and adapted for children with FASD, in order to provide support for the child and the family in terms of treatment expenses and social support. The financial disparity between relative and foster carers must be addressed urgently, and relative carers should be paid the same amount of money and have access to training and services as available to foster carers. Department Staff must have ongoing training on FASD, and clinical supervision of staff should also be FASD informed.

DCPFS should only refer children with FASD or suspected of FASD to other specialists such as psychologists who are FASD informed, including General practitioners, to prevent further misdiagnosis. Respite care must be well co-ordinated to properly support the families and must be consistently offered to families to protect the long term placements for children and to prevent burn out for carers. Furthermore, respite carers must be FASD trained and able to follow the same instructions of routine for respite care. Transition planning of leaving care for children, requiring extended time within OOHC and case management including referrals made to disability adult services.

Interventions, Cultural Security and service delivery

It is well documented that early intervention is critical for the prevention of secondary disabilities and improving the quality of life for the individual and their families, particularly in the transition to adulthood. There, was strong evidence on the effectiveness of the PCAP intervention that has now been replicated in three countries; Canada, US and New Zealand. Further, this model has been found to be effective with Indigenous populations and marginalized communities. Therefore, the Parent Child Care Prevention (PCAP) intervention models from Canada and North America should be adapted to suit populations of Western Australia in support of both families who are at risk and families who are living with FASD. This should be facilitated through workshop consultations in how PCAP should be adapted for local population. The model provides a three year intensive case management approach for families who are perceived as high risk.

Cultural security in FASD service delivery must be evident in all aspects of

interventions and case management practice of working with families in support of FASD. The involvement of Indigenous led and supported interventions is critical for several reasons as highlighted in the literature review. This includes the need to firstly decolonize service delivery for Aboriginal people, and secondly the trauma and intergenerational trauma experienced by many Aboriginal people requires a cultural and professional set of skills that many non-Aboriginal agencies generally do not have, and further cannot be serviced by only one or two Aboriginal staff members employed at an agency. Cultural secure frameworks encompass an Indigenous workforce of at least 50% of service delivery. The literature supports that most interventions are based on holistic service delivery and this service approach has been applied by Aboriginal community agencies since their inception.

The urgent establishment of dedicated services to support the individual child/adult with FASD and the family. Training of FASD to all workforce to include: Child protection; Education departments; criminal justice; health and allied professionals. Training of FASD must remain at a high quality standard, given the evidence of lack of awareness and knowledge of FASD. Additionally, an Aboriginal rehabilitation and healing centre be established in the south west region, that is FASD informed and also provides support for pregnant women attempting to withdraw from alcohol.

Recommendations for community organisations

FASD must be a consistent part of all health promotions, and this must include the input of the local community. Further, it is also critical to include the input of young people in the design of health promotions. The preferred delivery of information on FASD to the Aboriginal community in the south west regions is in community forums and small groups (Our Gurlonngas, Our future data results). Supervision for counsellors must also include FASD informed supervision, and this would allow counsellors to continue to increase their awareness of FASD. Organisations should also utilize FASD consultants who have in-depth expertise and training in FASD with case management, whilst staff build their awareness and capacity of FASD.

Recommendations for community health workers

Ongoing education on FASD must be included in the training of community health workers, who are the front line to those most at risk of FASD. The introduction of

dedicated FASD workers similar to the PCAP programmes in Canada. Supervision for workers should also be FASD informed to support workers with intense clients.

Mental Health and Co-morbidity:

The complexities of FASD and mental health must be included in policy, and service delivery. This includes the immediate adapting of treatments for adults that are suspected of FASD. Urgent review of children and adults with FASD who have co-morbidity of mental health problems and adapting treatment plans. Suicide interventions approaches must be adapted for youth and adults suspected of living with FASD, and include comprehensive training on FASD for all relevant workforce.

Education:

The education system within Western Australia must include FASD training for teaching staff. Comprehensive planning must include catering for students with FASD in each school region. Further, university curriculum for relevant professions; teachers, social workers, health professionals, psychologists, include a dedicated unit or inclusion of FASD in course curriculum. Additionally, extra support provided for students with FASD in the school system. Carers need to be given training on the educational needs of their children, and how best to advocate and provide support in the school system.

Recommendations for future research

In consideration of the social discourse on FASD, research on FASD should have a methodological approach that has a clear decolonization framework when applicable to Indigenous populations. Research undertaken in settings where Aboriginal people are over represented, must include Aboriginal researchers. Research undertaken on Aboriginal people should include Aboriginal methodological approach, including the adherence to Aboriginal protocols. Research is urgently required in exploring the needs of parents with suspected or diagnosed FASD in parenting their child/ren. This is urgent to identify any potential deficits in parenting, but also highlighting strengths in adults with FASD; and identifying supports within extended family. Research on parenting programmes for adults with FASD; to explore what adaptations are required in traditional parenting programmes.

FASD prevalence studies need to be conducted in non-remote areas, to explore the prevalence rates in the mainstream Australian community. Further qualitative research is critical and urgently required on the experiences of carers, including foster carers and relative carers looking after children both Aboriginal and non-Aboriginal children with FASD. This needs to include any financial disparity between relative and foster carers. Research that includes qualitative longitudinal research on young adults who have been diagnosed with FASD in Australia, in order to capture what strategies and interventions are critical for the prevention of secondary disabilities and improving quality of life. Further, research that looks at correct interventions and treatments across the lifespan, with a focus on providing evidence on employment programmes such as Community Development Employment Programme (CDEP). Currie (et al, 2016) also argued the urgency for research on vocational employment needs for adults with FASD.

Research on the educational needs of children with FASD in WA is urgently required, particularly on the experiences of interventions for children with FASD, and identifying appropriate strategies that cater for behavioural and academic challenges. Research on the impact of FASD on children, relating to their self-esteem in Western Australia is urgently required.

Significance of the study

The following section discusses the significance of this research project for the community, and academia in challenging the current social discourse on FASD.

Community

This project and engagement with the Aboriginal community, was significant as it was the first research in Australia to explore the awareness of FASD amongst Aboriginal people in both urban and rural areas. Furthermore, this study recorded the experiences of carers looking after Aboriginal children with FASD. To the knowledge of the researcher, no other study in Australia has recorded the stories of both relative and foster carers. This is an area that requires urgent attention by all sectors, as relative carers do not receive the same remuneration as foster carers and access to training. This disparity between foster and relative carers was previously highlighted in the Western Australian Ford Review report (2007), and a decade on still remains an urgent

issue that has not been addressed.

There is an urgency to build capacity within the Aboriginal community on FASD for several reasons. Firstly, the Aboriginal community as previously highlighted is a young population and the majority under the age of 25 years and with a birth rate significantly higher than mainstream population. The younger population must be considered in terms of intergenerational trauma, families with possible generational FASD, and with more than one sibling in the family with FASD. Building capacity in communities on FASD is paramount to breaking the cycle of what has been anecdotally described as patterns of generational FASD within some families. In discussing the strengths of Aboriginal families and approaches to parenting with FASD; Rutman & Bibber, (2009, p2), argue the following:

In Aboriginal communities, challenges in parenting with FASD are compounded by the effects of colonization. However, the unique strengths of Aboriginal communities are reasons to approach parenting with FASD from a wholistic and indigenous perspective. FASD finds its roots in the colonial history of Canada.

The statement by Rutman & Bibber (2009) above, also applies to the strengths of Australian Indigenous families. Further, the Aboriginal community and agencies must play an instrumental role in adapting and decolonizing service interventions for Aboriginal children and adults with FASD. Salmon (2011) asserts that it is critical any interventions on FASD for Aboriginal people are Aboriginal led and are trauma informed to address the systemic challenges of racism and marginalization.

According to literature, Aboriginal agencies are best placed to deliver FASD interventions for Aboriginal people based on the premise of holistic service delivery. The community results gained from the survey are also significant as it informs the development of health promotions strategies on FASD for the Aboriginal community, in a manner that is sensitive and culturally secure. Health promotions of FASD has occurred on an ad hoc basis due to the limited knowledge of Australian health professionals and the general community. In order to design culturally sensitive promotions on FASD, it was critical and culturally appropriate to have input from the Aboriginal community on their preference of delivery. The results indicate that the preference of delivery was in community forums and small groups and in one on one. This is important to note, as it also allows the community to engage and build their

awareness of FASD.

Further, being informed by the Aboriginal community will facilitate engagement and this is a strong position to address the pervasive stigma relating to FASD. To the knowledge of the researcher, the non-Aboriginal community, and those families at risk have not been consulted on their preferred methods of delivery of FASD in Australia. Raising awareness of FASD is critical in the Australian community, and raising awareness of FASD within the Aboriginal community is critical, particularly due to poor social health determinants.

Whilst literature identifies the untapped expertise of carers of children with FASD, it remains a paradox as carers express their frustration in not receiving the respect, appropriate support and respite from all relevant agencies. Furthermore, this is critically needed to protect the social well-being of the child and protect the long term placement to prevent secondary disabilities. Indeed, this has been reported as a great source of distress for carers in having to educate the professional people.

Academia

Structural inequalities, which underlie and perpetuate poverty, are prevalent in most Aboriginal and Torres Strait Islander communities and inequality in Australia is increasing (Libesman, 2016, p.54)

FASD for Indigenous children and families exists against the backdrop of colonization, human rights violation; marginalization, oppression, systemic racism, removal of children (sexual and physical abuse), intergenerational trauma, and poverty. Furthermore, Aboriginal people in Australia, US and Canada, are systematically prevented from developing their own agency and this is further compounded and complicated by neoliberalism and lack of adequate service delivery in addressing FASD (Cuneen, 2016; Libesman 2016). Sagers (2011) argues history and race remains a powerful determinant of health, and Indigenous people globally continue to suffer mortality and morbidity rates well below mainstream society. FASD is not solely an Indigenous problem, but for Indigenous people it arguably has a different history and is compounded by the contemporary eurocentric social context challenging the agency of Aboriginal people to be able to respond to FASD within families and the community.

Research on FASD interventions must address factors including white privilege and neoliberalism that actively prevents agency and self-determination of Aboriginal people, and communities in the design and evaluation of services on FASD for their communities. Further, compounding this is the era of neoliberalism and the shift of blame from society to the individual (Cunneen, 2016). Under the banner of neoliberalism, mainstream NGOs are funded to provide services in preference to Aboriginal agencies. Writers such as Ranzijn (et al, 2009) comprehensively outline the systemic and racist inequalities that continues to impact on Aboriginal people.

Literature argues that the powerful role of stigma, blame and discourse plays a pivotal role in preventing awareness and appropriate services. Garond (2014) provides a compelling critique on the misuse of the term “Aboriginal dysfunction” and the subtle way in which it has crept into the Australian debate on Aboriginal issues since the 2007 Northern Territory intervention. According to Garond (2014), the concept and term Aboriginal dysfunction gained momentum largely due to the work by anthropologist Sutton, who was of course an advisor to the Northern Territory government intervention of 2007 (Garond, 2014). Further, the timing of Sutton’s work came after commencement of the political term of the Howard liberal government, and the major reforms that occurred in Aboriginal policy and services to Aboriginal people throughout Australia. The writer asserts Aboriginal dysfunction has now become a common discourse in discussing individual and social behaviour of Aboriginal people. Critically, this also extends to economic and health issues confronting Aboriginal Australia. The ideology of Aboriginal dysfunction then lays the justification and premise for punitive measures in basic service delivery.

Rarely acknowledged is the levels of chronic stress Indigenous people live with relating to systemic challenges and lack of appropriate services. Tragically, such disparities in fact continue to grow, and the number of Indigenous children in OOHC within countries such as Australia, Canada, US and New Zealand is increasing (Libesman, 2016). Cunneen (2016) and Libesman (2016) within Australia both argue the impact of neoliberalism within the past two decades has increased the social inequalities for Aboriginal people within Australia. Hence, contributing to the lack of services for Aboriginal families at risk, and the escalation of rates of Aboriginal

children in OOHC and in juvenile detention centres. Notably, prevalence studies conducted at juvenile detention centres will generally find an overwhelmingly high Aboriginal population incarcerated.

Limitations

There are several limitations within this study, and the sample size of 180 participants in the qualitative survey is a not representative sample, and therefore cannot be applied to the overall Aboriginal community in the south west region. It does however, provide a snapshot of the level of awareness of FASD within the Aboriginal community. Likewise, the same size of the family interviews was only six. This study has only focussed on Aboriginal children living with FASD, and did not include non-Aboriginal children. Further, the eligibility criteria for this family case studies also included those children who did not have a formal diagnosis of FASD, however, five of the nine children had the physical facial characteristics of FASD, and one child also had microcephaly common to children born with FAS.

Previous international qualitative studies have frequently involved children without a formal diagnosis of FASD, due to the challenges in access to formal diagnosis for FASD (Bobbit, et al, 2016). Such literature also asserts that to exclude children without a formal FASD diagnosis, is to also further subject them to further marginalization. Indeed, it was during the timeframe of this thesis that the Australian government has agreed on national diagnostic tool for FASD in 2016. Each of the families had been informally informed of their child's diagnosis by clinical staff, and at times paediatricians and OOHC. In each of the families, it was also confirmed and observed by family members there had been PAE during pregnancy.

The time span for each family was not the same for every family and child involved in this study. Seven of the nine children are now adults and only two of the children were still quite young at the time of this project. However, very little has changed in terms of policy and services in Western Australia during the past 20 years in Western Australia. The responses by Aboriginal participants to the survey are subjective, however, it is likely their responses to survey questions were informed by their own observations of alcohol consumption by women during pregnancy. Further, research by Popova (et al, 2017) supports the prevalence rates of PAE during pregnancy of

Aboriginal women, as identified in these findings. Again, it does provide some important insight into the possible numbers of individuals with FASD within the Aboriginal community. Further, it is only recent years in Western Australia, that there has been access to FASD diagnosis.

Conclusion

FASD is another tragic far reaching consequence of the oppressive historical past for Indigenous people in Australia, and throughout the world. For many decades now, Indigenous people have medicated their trauma with alcohol, without the knowledge of the potential harm to their children. Indeed, lack of awareness of FASD still exists in not only the Aboriginal and non-Aboriginal community, but disturbingly amongst health and social services professionals. Whilst, FASD is indeed a serious mainstream global health issue, it is heightened in the Aboriginal community by several factors. The devastating impact of colonisation; intergenerational trauma, poverty and the fact that the majority of the Aboriginal population are under the age of 25 with a higher birth rate than mainstream population. Compounding this further is systemic racism and the lack of appropriate services for Aboriginal people. The literature has clearly identified that FASD interventions for Aboriginal people must be decolonised and delivered by the Aboriginal community.

This project was therefore significant for several reasons, firstly there are considerable gaps in the knowledge of FASD within the Australian community; and attempts to address this have been mostly sporadic and ad hoc within Australia. The literature review highlights the extremely limited qualitative research undertaken on families caring for children with FASD. This project was the first of its kind to explore the level of awareness of FASD in the Aboriginal community, in the south west region of Western Australia. This research was important in providing a voice for families and carers looking after children with FASD in Western Australia, and for providing critical insight into the ongoing adversity impacting on Aboriginal children with FASD and their families. The results of the qualitative study highlight that each of the nine children were raised in OOHC, and half of the families were caring for siblings with FASD.

The Western Australian FASD report of 2012, highlighted FASD is also at times

generational within a family. Further, Elliot (2015) found in Australia, we are missing the opportunity to prevent further cases of FASD within sibling groups. Moreover, whilst many writers attest to FASD being a preventable condition, not a great deal is known about prevention of FASD within the population who are living with FASD. Forty per cent of adults with FASD will have children with FASD, indicating FASD is transgenerational as argued by O'Malley (2014). Furthermore, many will be misdiagnosed and remain undiagnosed both as children and adults.

The majority of children with FASD will not be raised by their biological parents and are often raised by grandparents, relative and foster carers. Following from this is the urgent recognition that children in OOHC remain at risk for not being assessed for FASD and properly supported, particularly if there is a series of placement breakdowns. Children with FASD come into care earlier and stay longer than other children. The study findings have highlighted families are caring for children with FASD with none to minimal support from services. These systems remain ill-informed and equipped in providing for the special needs of this disability. It is unacceptable and unforgiveable that carers and grandparents are receiving no training on FASD and support. As this thesis has reiterated the parenting style of children with FASD is very different to traditional parenting styles. Many grandparents and carers already struggle with chronic health issues themselves, as identified within this study.

Whilst, the literature review identified gaps in expertise such as supporting adults with FASD and interventions; there was clear consensus within the literature that access to FASD diagnosis and early intervention is critical in the prevention of secondary disabilities. Ferguland (et al, 2012) argues children and adolescents with FASD often have the poorest adaptive skills in behaviour. Further, interventions to date have been adapted from the disabilities field, with little empirical evidence on effective interventions critical in preventing the onset of secondary disabilities. To this end, whilst a great deal of research has been undertaken internationally on FASD, the critical areas of appropriate interventions has only received attention in the past decade.

Whilst, the incidence of mental health as a secondary disability is well documented within the literature, there are gaps in the expertise of FASD and mental health. This

is disturbing as adults with FASD remain a vulnerable population, and at risk of suicide attempts. The context of extensive trauma as a factor for risky drinking by women is often applied as an afterthought, when it should be flagged as one of the most significant factors. Disturbingly, the lack of awareness and support also contributes to more than one sibling in the family having FASD. Within the family studies in this thesis, 50 per cent of the families were raising siblings with FASD.

There was a number of significant outcomes from this research project, including knowledge translation to the community with the request for the development of a training package on FASD and the completed FASD training for several key Aboriginal agencies. This project was underpinned by Indigenous methods and responded to requests from the community for a FASD training package that provided knowledge of FASD across the lifespan. At the time of this project no FASD training had been established that included training other than prevention and across the lifespan. This training also promotes the need for community engagement and direction in strategic planning of FASD for the community.

This research has highlighted the impact on the family is profound and this has been rarely acknowledged outside of the literature on FASD. A stable home placement is integral to preventing the secondary disabilities, including involvement in the criminal justice system, mental health, educational problems and alcohol and drug misuse. Six of the children involved in this study are now young adults, two are working full time and have been for a number of years. One adult is raising his two young children and is a loving and attentive father. It is full credit to the enormous sacrifice of their carers that these young men have not developed the common secondary disabilities and have quality of life. However, it is not reasonable to expect that every family will have the capacity socially or financially to care for a child or children with FASD without ongoing intensive support. The profound social and financial impact of FASD on the individual, carers and family is immeasurable, and families carry this burden alone, due to the lack of services; access to diagnosis and awareness within the overall Australian community.

EPILOGUE

This PhD was undertaken at a time when awareness of FASD was minimal within the wider Australian community. Awareness on FASD ranged from absolutely nothing to some vague understanding and misconception. This has been compounded by societal denial, stigma and judgement of women. Another critical layer here is the misconception and social discourse on FASD and Aboriginal people. Added to this is the sentiment that, FASD is easily dismissed based on the message that it is completely preventable. The concept of being preventable is interesting, whilst a theoretically accurate statement it has to be considered in view of the high rate of unplanned pregnancies in affluent western countries such as America and Australia; and suspected generational FASD that does occur in many families.

On a personal level, knowledge and awareness of FASD has been life changing for this researcher in the realization of my own previous wrong judgements and misinterpreting patterns of observed behaviours in close family members with undiagnosed FASD. Learning about FASD was a defining moment in my personal and professional life. It was an epiphany to begin to understand certain family members. In retrospect, this process occurred over 8 years, and due to lack of awareness, training and support, happened too slowly for our family in being able to clearly understand FASD, and what knowledge and tools we required. It is hoped that this study will expedite the learning and awareness stages of FASD for other families in Australia.

For my brother Marja man, I am late in knowing about FASD, and his life and early death in 2013, reminds myself and my family of how wrongly he was judged based on his behaviour. For the majority of his life, nobody understood his patterns of behaviour (sometimes bizarre), mood swings, and addictions. In chapter 1, I told the story of our baby nephew who died tragically at the age of 3, and he was the nephew of Marja man. In this one family, FASD contributed to the early deaths of an Uncle and his baby nephew. Further, compounding this tragedy is how easy it is to even miss this critical fact that FASD played an instrumental role in their premature deaths. In sharing stories with my younger sister Karen, I am also reminded of the many stories of our

brother and of his talents as a great artist and his strengths. It was his strengths that saw him live his final years with some peace as he had finally come to have his own little home. This gave him the opportunity to live these years with an enormous sense of pride in himself. His undiagnosed FASD had been recognized as mental health, providing him with a case manager to advocate for him and this provided him housing and ongoing support. Hence, it was the secondary disability of mental health that finally provided case management and support. As a family, and society, this should be enough to motivate us to address FASD in our families and community, and to provide support that is free from judgement and stigma.

The cliché of knowledge being powerful becomes such a true sentiment and catalyst for action when understanding you have family members living with FASD. It is also a reminder of the tragic fact that many people in Australia both Aboriginal and non-Aboriginal have lived with this disability undiagnosed, unsupported and unrecognized. Australian society as with other countries has not been informed well enough of the fact that many families both black and white are struggling with FASD, and often have generational FASD within the family. From the outset then the capacity within a family has been determined by an undiagnosed disability. This is a painful and traumatic notion indeed to understand; support and attempt to address. Further, compounding this is the early mortality rates of Aboriginal people throughout Australia.

Understanding FASD involves a significant paradigm shift and ongoing commitment, recognizing a level of personal denial in some circumstances. It requires the urgent understanding of FASD across the lifespan. It also requires the acknowledgement and recognition that FASD is in fact a mainstream problem, and not one that can be again thrown onto just the Indigenous space. The leadership of Aboriginal people such as Lorian Hayes, Dr Janet Hammill, June Oscar and the community at Fitzroy Crossing should be seen exactly for what it is, courage and leadership for advocating for their families and communities. Finally, it is with great respect and acknowledgement to the many unsung heroes caring for children with FASD, this research project gives the final words:

(Foster carer, 2015)

By the time he left my care he needed a hug every day from me, it was to make him feel good, telling him he was loved, and he was in the right place, and he was going to do well, and grow up and be brilliant. Always be positive, and that is all I had to give in the end, because I was so frustrated with the system, they really let me down, more importantly they really let them down. (Perth Carer, 2015)

(Relative carer, 2015)

Learn as you go - no manual. That was the hardest bit because I was always conscious of how they would turn out, what type of lives they would grow up to lead, how they would cope, how they would get on in the world on their own

(Adopted mum, 2015)

We ended up with a Behaviour Therapist and her programme suited him to a t..... It was heavy work and he was 100% engaged. But If he was in the care system he would not have been afforded that, that was the biggest thing and was a lifesaver, and I remember the first time he actually did as he was told, and it was mind blowing, I remember thinking oh wow.

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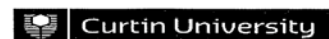
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Appendices

Ethics Approval – Curtin University



Memorandum

To	Associate Professor Dawn Bessarab, Health Sciences - CHIRI - Indigenous
From	Professor Stephan Millett, Chair, Human Research Ethics Committee
Subject	Protocol Approval HR 175/2013
Date	13 November 2013
Copy	Ms Robyn Williams, Health Sciences - CHIRI - Indigenous Associate Professor Marion Kickett, Curtin Teaching and Learning

Office of Research and Development
Human Research Ethics Committee

TELEPHONE 9266 2784
FACSIMILE 9266 3793
EMAIL hrec@curtin.edu.au

Thank you for your application submitted to the Human Research Ethics Committee (HREC) for the project titled "*Understanding Fetal Alcohol Spectrum Disorder (FASD) through the stories of Nyoongar families in the South West and how this can inform policy and service delivery*". The Committee notes the prior approval by Western Australian Aboriginal Health Ethics Committee (WAAHEC) (reference number : 484) and has reviewed your application consistent with Chapter 5.3 of the *National Statement on Ethical Conduct in Human Research*.

- You have ethics clearance to undertake the research as stated in your proposal.
- The approval number for your project is **HR 175/2013**. Please quote this number in any future correspondence.
- Approval of this project is for a period of four years **14-11-2013 to 14-11-2017**.
- Annual progress reports on the project must be submitted to the Ethics Office.
- If you are a Higher Degree by Research student, data collection must not begin before your Application for Candidacy is approved by your Faculty Graduate Studies Committee.

• The following standard statement must be included in the information sheet to participants: *This study has been approved by the Curtin University Human Research Ethics Committee (Approval Number HR 175/2013). The Committee is comprised of members of the public, academics, lawyers, doctors and pastoral carers. If needed, verification of approval can be obtained either by writing to the Curtin University Human Research Ethics Committee, c/- Office of Research and Development, Curtin University, GPO Box U1987, Perth, 6845 or by telephoning 9266 2784 or by emailing hrec@curtin.edu.au.*

Applicants should note the following:

It is the policy of the HREC to conduct random audits on a percentage of approved projects. These audits may be conducted at any time after the project starts. In cases where the HREC considers that there may be a risk of adverse events, or where participants may be especially vulnerable, the HREC may request the chief investigator to provide an outcomes report, including information on follow-up of participants.

The attached **Progress Report** should be completed and returned to the Secretary, HREC, C/- Office of Research & Development annually.

Our website https://research.curtin.edu.au/guides/ethics/non_low_risk_hrec_forms.cfm contains all other relevant forms including:

- Completion Report (to be completed when a project has ceased)
- Amendment Request (to be completed at any time changes/amendments occur)
- Adverse Event Notification Form (if a serious or unexpected adverse event occurs)

Yours sincerely

Professor Stephan Millett
Chair Human Research Ethics Committee



DERBARL YERRIGAN HEALTH SERVICE INC.

ABN 60 824 221 416

156 Wittenoom Street, East Perth W.A. 6004

Phone: (08) 9421 3888 Fax: (08) 9421 3884

Email: dyhs@dyhs.org.au Website: www.dyhs.org.au

27 March 2013

Ms Tammy Prouse
Chairperson
WAAHEC (Aboriginal Health Council)
450 Beaufort Street,
PERTH WA 6003

Dear Ms Prouse,

Re: Letter of support for Robyn Williams PhD program

This is to inform you that at a Board of Directors meeting on the 14th March 2013, the board of the Derbarl Yerrigan Health Service (DYHS) agreed to support the Phd project to be undertaken by Robyn Williams. In seeking support, Robyn previously consulted with the CEO Barbara Henry DYHS staff on this research project and provided a copy of her Phd research proposal.

Robyn Williams is well known to the DYHS having successfully coordinated a three year community based Aboriginal youth health research project in the Aboriginal communities of Perth and the south west towns of Albany, Bunbury and Northam. Robyn has a maturity and understanding of Aboriginal culture which will aid her in this sensitive topic.

DYHS considers research into Fetal Alcohol Spectrum Disorder (FASD) in the Aboriginal community a priority. Research projects such as Robyn's have the potential to inform health promotions, policy and service delivery to Aboriginal people. The stories of parents/carers who care for Aboriginal children with FASD can inform health service providers and government of the dire need for advocacy and interventions around alcohol and its impact on families who care for children who are born with FASD.

Yours sincerely

*Barbara Henry – Chief Executive Officer
Derbarl Yerrigan Health Service Inc
PH 9421 3814 Fax 94213873
henryb@dyhs.org.au - www.dyhs.org.au*

To Whom This May Concern

I am a female Aboriginal Elder (Nyoongar/Yamatji) who has worked in Aboriginal Affairs for over 30 years. I have an extensive background in Aboriginal health and social welfare in both Government and Aboriginal community based agencies. From 2009 – 2012, I worked with Robyn Williams at Derbarl Yerrigan Health Service, where I was employed as the Site Manager at East Perth and Robyn co-ordinated an Aboriginal youth community based research project.

During this time, Robyn consulted with me extensively on her proposed research into Fetal Alcohol Spectrum Disorder (FASD) in the south west, Western Australia. I had the opportunity to have input and give feedback to the development of her proposal. Further, from my observations of Robyn's work as an Aboriginal researcher, I am confident in her ability to approach this topic with maturity, sensitivity and strong ethical approach, whilst maintaining cultural security.

I strongly support Robyn and congratulate her on choosing FASD in the Aboriginal community for her PhD topic. I look forward to seeing her complete her PhD with some well researched and well written papers on the experiences of Aboriginal parents/carers of Aboriginal children with FASD. This is well overdue in Western Australia.

Yours sincerely,

Margaret Gidgup
Community Engagement Officer
Growing Solid Aboriginal Communities Project
Suit 3 Anderson House, Cnr Brookman & Porter St,
KALGOORLIE WA 6430
Mobile: 0403 464 349
Email: Margaret.gidgup@tccp.com.au

March 28, 2013

28th March, 2013-03-28

Letter of support for Robyn Williams

To whom it may concern,

As the founder of the National Indigenous Corporation for Fetal Alcohol Syndrome Education Network (NICFASEN), I realised that I have been a lone voice in my efforts to raise the awareness of Fetal Alcohol Spectrum Disorder (FASD) in communities throughout Australia.

During the past two decades I have been lobbying and advocating for the recognition of FASD and have now been joined by a choir of voices, Aboriginal and non-Aboriginal alike to address the FASD debate, these voices can no longer be silenced or ignored.

Robyn has shown such a strong desire to become involved in the FASD field it is with appreciation and admiration that I recommend and support Robyn on her journey to identify and support conditions where maternal and infant health will flourish, to identify and work with persons at risk, such as pregnant women; women in their child bearing age who drink alcohol; their partners and the community in order to reduce the risk of FASD births, to increase community awareness of FASD and to inform community members of the dangers of maternal alcohol consumption during pregnancy as an important health issue.

All the very best Robyn, I'm sure that I will be quoting your articles on FASD in the near future.

Sincerely

Lorian Hayes MAE, BAppHsc (Hons)

FASD Educator/Consultant

Centre for Chronic Disease

School of Medicine

University of Queensland

Mobile: 0447234171

Email: l.hayes3@uq.edu.au



8th May 2013

Dear Robyn,

RE: HREC Reference number: 484

Project title: Title: Understanding Fetal Alcohol Spectrum Disorder (FASD) through the stories of Noongar families in the South West and how this can inform Policy and Service delivery.

Thank you for submitting the above research project which was considered by the WAAHEC at its meeting held on *2nd May 2013*.

I am pleased to advise that the WAAHEC has granted approval of this research project.

WAAHEC approval is granted from *2nd May 2013* pending your agreement of the following conditions:

1. Conditions

- The WAAHEC will be notified, giving reasons, if the project is discontinued before the expected date of completion.
- The Coordinating Investigator will provide an annual report to the WAAHEC and at completion of the study in the specified format. This form can be found on the AHCWA website (www.ahcwa.org).
- The approval for studies is for three years and the research should be commenced and completed within that period of time. Projects must be resubmitted if an extension of time is required.
- Publications that arise from this research are to be provided to the WAAHEC for review prior to submission for dissemination.
- That the Aboriginal and Torres Strait Islander community are formally acknowledged for their contribution to this research project.

Western Australian Aboriginal Health Ethics Committee



AHCWA
Aboriginal Health Council
of Western Australia

2. Amendments

If there is an event requiring amendments to be submitted you should immediately contact ethics@ahcwa.org for advice.

Should you have any queries about the WAAHEC's consideration of your project please contact ethics@ahcwa.org.

The WAAHEC wishes you every success in your research.

Kind regards

Chelsea Bell
For
Tammy Prouse
Chair, WAAHEC

This HREC is constituted and operates in accordance with the National Health and Medical Research Council's (NHMRC) *National Statement on Ethical Conduct in Human Research (2007)*, *NHMRC and Universities Australia Australian Code for the Responsible Conduct of Research (2007)* and the *CPMP/ICH Note for Guidance on Good Clinical Practice*. The process this HREC uses to review multi-centre research proposals has been certified by the NHMRC.

Understanding Fetal Alcohol Spectrum Disorder (FASD) through the stories of Nyoongar families in the South West and how this can inform Policy and service delivery

Consent form

I(your name) give permission to take part in a survey/interview. I understand that my details will not be provided to anybody and that any comments that I make will be treated as strictly confidential. I have been provided with a copy of the Information sheet for this research project.

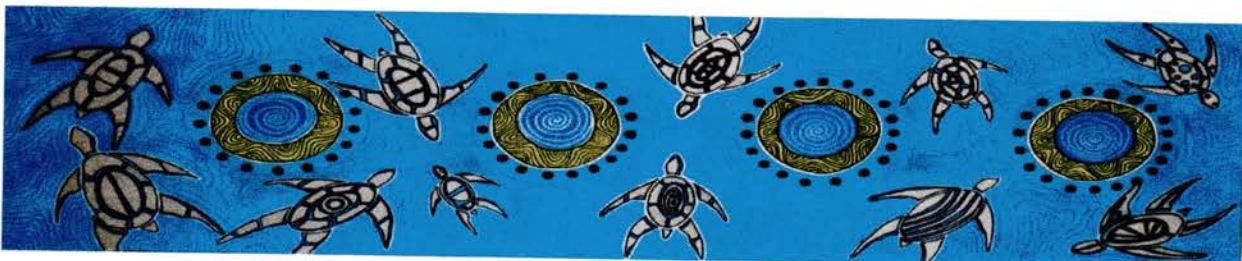
I understand that I can withdraw from the survey/interview at any time.

Signed:

Date

The researcher, Robyn Williams is undertaking this research as part of a PhD study with Curtin University, Health Sciences. This project is being supervised by A/Professor Dawn Bessarab; and Dr Marion Kickett (Curtin University). If you want further information on this project, please contact the researcher Robyn Williams on mobile: 042 474 3747 or email: robynwilliams2011@live.com.au. If you have any concerns about this project or how it is conducted, please contact :WA Aboriginal Ethics Committee on (08) 9227 1631.

.....
Initialed/ticked by participant for receipt of gift voucher for participation in survey



**Understanding Fetal Alcohol Spectrum Disorder (FASD) through the stories of
Nyongar families in the South West and how this can inform Policy
and service delivery
Information Sheet**

Purpose of this research: This research will explore the knowledge and understanding of Fetal Alcohol Spectrum Disorder within the Aboriginal community in the South West of Western Australia.

Who is carrying out the study? The researcher, Robyn Williams is undertaking this research as part of a PhD study with Curtin University, Health Sciences. This research project is being supervised by A/Professor Dawn Bessarab; and Dr Marion Kickett (Curtin University).

What this study will tell us? Information from this study will tell us how much Aboriginal people participating in this study know and understand what FASD is and how it is caused. The knowledge gained in this research will assist in guiding health service providers on what needs to happen to raise awareness in the Aboriginal community about FASD and the type of support that is needed by Aboriginal families who care for Aboriginal children with FASD. It will help in developing educational material to address the level of awareness of FASD in the Aboriginal community in the south west.

What will you be asked to do if you decide to take part in this study You will be asked by the researcher to take part in a short survey on FASD or interview. You are free to stop your participation in the survey/interview at any time if you choose. Your participation in this survey is voluntary and all information will be treated in the strictest confidence. If you choose not to participate in the study your relationship or participation in any programs or services will not be affected in any way.

Your privacy: Your responses will be kept private and no information will be given to any person or organisation in a way that you could be recognised.

More information:

If you would like further information on this research project, please contact the researcher, Robyn Williams on 042 474 3747 or email robynwilliams2011@live.com.au

If you have any concerns about the project or how it is conducted, please contact:WA Aboriginal Ethics Committee (08 9227 1631) This study has been approved by the Curtin University Human Research Ethics Committee (Approval Number HR 175/2013). The Committee is comprised of members of the public, academics, lawyers, doctors and pastoral carers. If needed, verification of approval can be obtained either by writing to the Curtin University Human Research Ethics Committee, c/- Office of Research and Development, Curtin University, GPO Box U1987, Perth, 6845 or by telephoning 9266 2784 or by emailing hrec@curtin.edu.au.

Our Gurlonngas, Our Future



With Permission of Artist: Peter Farmer 2014



*Your participation today is important. The topic of Fetal Alcohol Spectrum Disorder (FASD) is something that we are **all** still learning about in every community. This survey will help us find out what our community knows and what information is missing. Your answers will stay confidential and no-one will be able to identify you. In this survey Fetal Alcohol Spectrum Disorder is also referred to as Fetal Alcohol Spectrum.*

Date:Location:.....

Section: 1 Demographics

The first set of questions asks some basic information about you

1. How old are you?

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2. Gender

- Male
- Female

3. Are you of Aboriginal or Torres Strait Islander descent?

- Yes, Aboriginal
- Yes, Torres Strait Islander
- Yes, both Aboriginal & Torres Strait Islander
- No, Neither

4. What is the suburb or town where you normally live?
Write the name of the suburb or town in BLOCK letters

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5. Where does your birth mother's family come from?
Write the name of the city or town or community in BLOCK letters in the space below. If you are not sure, write "DK" (Don't know)

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6. Where does your birth father's family come from?
Write the name of the city or town or community in BLOCK letters in the space below. If you are not sure, write "DK" (Don't know)

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7. Who do you identify as?
(Please tick your answer)

- Noongar
- Yamatji
- Wongi
- Noongar/Yamtji etc
- Other (please state)

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8. Who mainly raised you as a child?
(Please tick all that apply)

- Mum & Dad
- Mum
- Dad
- Sister/Brother
- Nan
- Pop
- Aunty
- Uncle
- Cousin
- Foster family/foster carers
- Other (please state)
-

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9. Did this change while you were growing up (primary caregiver)?
(Please tick your answer)

- No
- If Yes - please briefly describe:

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10. Are you currently?

- (Please tick what applies)
- Single
- Married
- Living with a partner (defacto)
- Divorced/widowed

11. Do you have any children?
(Please tick what applies)

- Yes
- No }
- Not sure } *please skip and go to question 14*

12. How old were you when your first child was born?

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13. How many children do you have?

(Please tick what applies)

- 1 child
- 2 children
- 3 children
- 4 children
- 5 children
- 6 or more children
- Not sure

14. What is the highest level of education that you have completed?

(Please tick your response)

- Didn't complete primary school
- Completed primary school only
- Completed early high school (up to Year 9)
- Completed Year 10
- Completed Year 11
- Completed Year 12
- Completed an apprenticeship
- Completed a traineeship
- Completed a Bridging programme
- Completed a degree or diploma
- Completed a Higher degree (Masters, PhD)

15. Are you currently attending or enrolled at any of the following?

(Please tick your response)

- High School
- College
- TAFE
- University
- Other
- None of the above

16. Are you currently?
(Please your tick response)
- Employed Full-time
 - Employed Part-time
 - Employed Casual
 - Not employed, looking for work
 - Not employed, not looking for work

17. Do you receive any of the following Centrelink allowances:
(Please tick your response)
- Pension
 - Newstart
 - Disability
 - Abstudy
 - Carers pension
 - none of the above

18. In your accommodation are you currently:
(Please tick your response)
- Buying your home
 - Renting your home
 - Boarding
 - Homeless – Looking for somewhere to live
 - Other

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Section: 2 *This set of questions asks about your understanding of Fetal Alcohol Spectrum Disorder (FASD). Don't worry if you don't know the answers. Please do your best to answer all questions.*

19. Before today have you ever heard of "Fetal Alcohol Spectrum Disorder (FASD)"

(Please tick your response)

- Yes
- No } *Please skip and go to question 22*
- Unsure }

20. If yes, how long ago did you hear about FASD?

(Please tick your response)

- Recently, within the last 12 months
- Between 1-2 years ago
- Longer than 2 years ago

21. Who told you about FASD?

(Please tick any that applies)

- Family member
- Health professional (Nurse), (Doctor), (Health Worker)?
- Health promotions
- School teacher
- Social Worker
- Police
- Media
- Aboriginal organisation (please state)

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- Other (please state).....

22. How much do you know about Fetal Alcohol Spectrum Disorder? (FASD)?

(Please tick what applies)

- A lot
- A little
- None

23. What do you think Fetal Alcohol Spectrum Disorder (FASD) is?

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24. Do you think it is important for the community to know more about FASD?

(Please tick your response)

- Yes
- No
- Unsure
- Please tell us why?

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25. Have you ever received any information about FASD? (Please tick your response)

- Yes
- No } *please go to question 27*
- Unsure }

26. If yes, was the information you heard or saw on FASD by?

(Please tick what applies)

- Pamphlet
- On the radio
- Advertising on the tv
- Attended a forum/workshop
- Training
- Verbal (discussion with another person)
- Online

27. As far as you know, has a member of your immediate or extended family ever received any information on Fetal Alcohol Spectrum Disorder?

(Please tick your response)

- Yes
- No
- Unsure

28. Have you seen any of the following behaviours consistently displayed by a child in your immediate or extended family over several years?

(Please tick all that apply)

- Struggles to follow rules/instructions
- Learning problems at school
- Have difficulty remembering things
- Get upset easily at little things
- Difficulty making and keeping friends
- Long term bed wetting
- Ongoing behavioural problems (often in trouble with the law)
- Ongoing health problems
- Acts younger than their age
- Doesn't understand consequences of their actions
- All of the above
- None of the above
- Any comment

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29. Have you ever seen any of the following behaviours consistently displayed by an adult in your immediate or extended family over several years:

(Please tick all that apply)

- Mental health problems
- Being homeless or difficulty keeping accommodation
- Long time unemployed or difficulty getting employment
- In and out of jail (trouble with law)
- Impulsive behaviour; anger issues, poor social skills
- Alcohol use
- Drug use
- Acts younger than their age
- Poor time management
- Poor self care
- Kids in welfare
- All of the above
- None of the above
- Any comments

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30. Do you think anyone in your immediate or extended family might have FASD?

(Please tick your response)

- Yes
- No
- Unsure
- If yes, why?

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Part 3: These questions are about alcohol, and these are not to shame or blame, there are reasons why people drink alcohol and not all are negative, including celebrating, relaxing, and being social.

31. Growing up did you see any drinking of (alcohol) in your family?
(Please tick what applies)

- A lot
- Sometimes
- A little
- No *(if no please skip to question 33)*

32. If yes, who were the family members that drank alcohol?
(Please tick any that applies)

- Mum
- Dad
- Nan
- Pop
- Aunty/s
- Uncle/s
- Brother/s
- Sister/s
- Cousin/s

33. Do you drink alcohol? (Please tick your response)

- Yes
- No
- Never drank
- Not any more (can you please tell us why) *(please skip to question 38)*

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34. How often do you have a drink containing alcohol?
(Please tick your response)
- Never
 - Monthly or less
 - 2 – 4 times a month
 - 2 – 3 times a week
 - 4 or more times a week
35. How many standard drinks do you have on a typical day when you are drinking?
(Please tick what applies)
- 1 or 2
 - 3 or 4
 - 5 or 6
 - 7 to 9
 - 10 or more
36. How often do you have six or more standard drinks on one occasion?
(Please tick what applies)
- Never
 - Less than monthly
 - Monthly
 - Weekly
 - Daily or almost daily
37. If you have a partner, how often do you both have a drink together?
(Please tick your response)
- Not applicable - single
 - Never
 - Less than monthly
 - Monthly
 - Weekly
 - Daily or almost daily
38. Do you think there are any effects of drinking alcohol during pregnancy?
(Please tick your response)
- Yes
 - No
 - Unsure

39. Do you think there are any effects of drinking alcohol whilst breastfeeding a baby? (Please tick your response)

- Yes
- No
- Unsure

40. Do you know anyone (female) that drinks alcohol whilst pregnant? (Please tick your response)

- Yes
- No
- If No, *please skip to question 43.*

41. If yes, do you think it is common for women to drink alcohol during pregnancy? (please tick your response)

- Yes
- No
- Unsure
- If yes, why do you think so

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42. Was the woman who drank alcohol whilst pregnant a?
(Please tick what applies)

- Family member
- Friend
- Other
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- All of the above

43. Are there any comments you would like to make about FASD?

- No
- Yes, please describe

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Section 4: history and family

These questions are about family and history, it would be greatly appreciated if you could answer these. It is well known that the past has played a big role in where many of us are today, both good and bad.

44. Were you or anyone else in your family part of the stolen generations?

(Please tick your response)

- Yes
- No
- Unsure
- If Unsure or No, *skip to question 46.*

45. If yes, was it? (please tick all that apply):

- Me
- Brother/s
- Sister/s
- Nan
- Pop
- Mum
- Dad
- Aunty/s
- Uncles
- Cousins
- Great Grandparents

46. Have you witnessed or experienced in your family any of the following:
(Please tick all that apply)

- Family Violence
- Family fueding
- Bullying
- Sexual violence/abuse
- Alcoholism
- Drug abuse
- Eviction/homeless
- All of the above
- None of the above

47. In times of stress or crisis, who do you turn to for support?
(Please tick all that apply)

- Family
 - Counselling services
 - Friends
 - Partner
 - Hospital
 - Aboriginal services
 - Other (please describe).....
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Section : 5: Information on FASD:

48. Would you like any information on Fetal Alcohol Spectrum Disorder (FASD)?

(Please tick your response)

- Yes
- No
- Unsure

49. If yes, what kind of information on FASD would you like to receive?

(Please tick any that apply)

- Basic information
- Referral for diagnosis
- Referral for help with other services like Justice, Mental Health
- Supporting a family member with FASD
- Prevention
- All of the above
- Other

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50. How would you like the information on FASD delivered?

(Please tick any that apply)

- Small groups
- One on one
- Community forums
- Online
- Not sure

The End

That is the end of the survey – thank you very much for your time and for providing us this important information. Do you have any questions or comments?



Robyn Williams
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Health Sciences
Curtin University 2014

Case study questions:

Awareness:

1. Have you heard the term Fetal Alcohol Spectrum Disorder (FASD)?
2. If so, when and where did you hear about FASD?
3. Can you tell me what you know and understand about FASD?
4. Are you caring for any children that you think have FASD? (If yes, what makes you think they have FASD?)
5. Have they been assessed?

Health:

1. If assessed, can you tell me how they came to be assessed for FASD. You might like to tell me:
 - a. Did you seek help, if yes how long did this take?
 - b. When and where were they assessed?
 - c. Who did the assessment?
 - d. What has happened after and since the assessment?
2. If not assessed, what has been some of the problems getting your child assessed?
3. Are there any other health issues affecting your child? If so what are they?
4. Do you think your child is different to other children their age? If so how?
5. Why do you think they are different?

Resources/Support services:

1. Have you received any support/information about FASD that has helped you in caring for your child?
2. How long have you cared for the child? Are they still in your care? (Are you aware of how often the child has moved homes?)
3. What type of support was this, and where from?
4. What kind of support (for both the child and family) do you think is important in caring for a child with FASD?

Family/general:

1. What do you feel comfortable in telling me about the background of the family (cultural, stolen generations) etc.
2. What has been the impact (good/not so good) of caring for your child by yourself and your family?
3. How has your child coped with school/training, has there been issues that have emerged? (younger child)
4. How has your child coped with life, has there been any issues that have emerged?
5. What kind of advice would you give a parent who has just found out their child has been diagnosed with FASD?
6. Is there anything you want say about your experience of caring for a child with FASD?

Generational :

1. Is there an alcohol story in your family, ie, If so how far back can you remember in terms of parents, grandparents, What can you tell me about the alcohol use in the family that this child comes from?
2. Do you know or think that there are any other members in the family that has FASD?

Economic and Social cost:

1. What can you tell me about the economic costs of caring for a child with FASD?
2. What can you tell me about the social costs of caring for a child with FASD?