School of Psychology and Speech Pathology

Talking about health, wellbeing and disability in young people: an Aboriginal perspective

Caris Lae Jalla

This thesis is presented for the Degree of

Master of Philosophy

of Curtin University

February 2016

DECLARATION

To the best of my knowledge and belief this thesis contains no material previously published by any other person except where due acknowledgment has been made. This thesis contains no material which has been accepted for the award of any other degree or diploma in any university.

Signature:

Caris Jalla

Date:

ABSTRACT

In many Indigenous languages globally, there is often no directly translatable word for disability. For Australian Aboriginal and Torres Strait Islanders, the prevalence of disability is greater compared to non-Indigenous populations. Despite the gap in rates, access to disability supports and services are lower and disproportional. One factor impacting low service access may be the differing views of disability between Aboriginal and Torres Strait cultures and mainstream Western perspectives.

The objectives of this research were to investigate the meaning of health, wellbeing and disability from the viewpoint of Aboriginal and Torres Strait Islander youths and to describe the facilitators and barriers to health and wellbeing for people with disabilities. These investigations also identified Aboriginal and Torres Strait Islander children and young people's perceptions on the causes of disability and explored concepts associated with living with disability. Aboriginal and Torres Strait Islander youths, both with and without disabilities, residing in Perth, Western Australia (WA) and aged nine to 26 years were invited to participate in qualitative research. Yarning circles were conducted in various home and community settings around the metropolitan area. The research incorporated the voices of Aboriginal and Torres Strait Islander children and young people with and without a diagnosed disability.

Results depict the holistic understanding of wellbeing, with health identified in terms of coexisting components – the physical, mental and spiritual/cultural self. Enablers and inhibitors to health and wellbeing for people with disabilities were discussed, with these facilitators and barriers later categorised as social and cultural, physical and medical, or material and environmental. The three categories provide a framework for the facilitators and barriers to health for Aboriginal and Torres Strait Islander people with disabilities. Participants also identified several beliefs on the causes of disabilities. Further discussions on disability explored varying emotions linked to living with disability. The results give a unique perspective on health, wellbeing and disability from Aboriginal and Torres Strait Islander youths.

This research provides new insights for health professionals working with Aboriginal and Torres Strait Islander families caring for children with disabilities. The results identified can be used in recommendations for better service delivery in the health and disability sectors. Findings can be applied by service providers and policy makers to create a shift towards a more holistic approach to health and disability.

AWARDS, PUBLICATIONS AND PRESENTATIONS

❖ Hayden, G. and Jalla, C. (2015). 'Communicating for quality and safety in Aboriginal health care', in R. Iedema, D. Piper and M. Manidis (eds) *Communicating Quality and Safety in Health Care*, pp. 230-44. Melbourne: Cambridge University Press.

❖ Jalla, C. and Hayden, G. (2014). 'Aboriginal health research is not black and white – lessons from the field', *Australian Indigenous HealthBulletin* 14(3), 1-4.

❖ 'Yarning about Disability', National Student Award, *Endowment Challenge Fund,* Endeavour Foundation (May 2015).

❖ 'Talking about health, wellbeing and disability in young people: an Aboriginal perspective', Aboriginal and Maternal Child Health Conference, Perth (May 2015).

❖ 'Disability as a Social Construction: Exploring Australian Aboriginal and Torres Strait Islander perspectives', International Disability Conference, Kuching, Malaysia (November 2014).

❖ 'Disability as a Social Construction: Exploring Australian Aboriginal and Torres Strait Islander perspectives', Building Mental Wealth Through Innovation Conference, Curtin University, Perth (December 2013).

❖ 'Talking about health, wellbeing and disability in young people: an Aboriginal perspective', Dennis Glencross Seminar, Curtin University, Perth (July 2012).

TABLE OF CONTENTS

LIST OF ABBREVIATIONS

ABS   Australian Bureau of Statistics

ADHD   Attention Deficit Hyperactivity Disorder

AIHW   Australian Institute of Health and Wellbeing

APY   Anangu Pitjantjatjara Yankunytjatjara

CCYP   Commissioners for Children and Young People

CP   Cerebral Palsy

DSC   Disability Services Commission

DV   Domestic Violence

DVD   Digital Versatile Disc

FAS   Fetal Alcohol Syndrome

FASD   Fetal Alcohol Spectrum Disorder

FPDN   First Peoples Disability Network

HREC   Human Research Ethics Committee

ICF   International Classification of Functioning, Disability and Health

NDIA   National Disability Insurance Agency

NDIS   National Disability Insurance Scheme

NHMRC   National Health and Medical Research Council

NT   Northern Territory

OM   Otitis Media

SDAC   Survey of Disability, Ageing and Carers

SES   Socioeconomic Status

TSI   Torres Strait Islander

WA   Western Australia

WAAHEC   WA Aboriginal Health Ethics Committee

WHO   World Health Organisation

ACKNOWLEDGEMENTS

Acknowledgements and gratitude are due to a number of people who have joined me along this journey. The first steps began with my supervisors Dr Jillian Pearsall-Jones, Dr Cori Williams, Dr Marion Kickett and Professor Jan Piek, whose entries into this melody were individually timely and harmonious. Thank you for your on-going support, your guidance and kindness has continued to kindle my passion for research. Aboriginal colleagues and mentors have influenced my learning; many thanks to George Hayden, Professor Dawn Bessarab, Michelle Webb and Dr Marion Kickett for your time and wisdom over the years. George, I've enjoyed learning the big and small lessons, such as 'kaya' (hello), and 'boorda' (later). The Aboriginal Reference Group was one of the first steps in the conception of this story; thank you, Jonathan Ford, Michele Sultan, Rachel Visser and Dr Rhonda Marriott for your time and interest. A quiet, but consistent mentor has been my colleague and friend, Dr Marie Blackmore. You have added richly to my life in many ways; I am eternally grateful. Acknowledgements and love to my extended family living in almost every continent in the world; our global longhouse and tribal roots keep us forever connected. A special mention to James Hodierne, who has been a wonderful encourager during the final sprint of this journey. Last but not least, thank you to all the Aboriginal youths who so enthusiastically and willingly shared their stories and ideas. Each one of you adds a unique thread to the tapestry that is Australia's future. May your journeys be filled a light that will shine for generations to come. Boorda!

PROLOGUE

Pu'un Beruh – 'New beginning'

Introductions by Indigenous people often begin with a mutual exchange of family connection, cultural identity and country; therefore I would like to begin by sharing my story and position with readers. I was born in East Malaysia to a Singaporean mother and a Malaysian father. My early childhood memories are mostly of close relationships with my father's extended family. I spent a good part of my growing up years in my town of birth Miri; an oil town situated east of Sarawak's capital city, Kuching, and west of the Bario Highlands.

Sadly with the early passing of my maternal grandfather in Singapore and the geographical distance, I did not have much connection to my 'Peranakan' side of the family in Singapore, Malacca and Indonesia until my later years. And so it is, despite my family's migration to Australia when I was six, the mainstay of my identity is my Kelabit tribal heritage; a minority tribe comprising of no more than 7,000 people living in the heart of Borneo – the Bario Highlands.

My father was born into a prominent Kelabit family. My grandfather, Tepu' Napuun Beruh (lovingly known as Tepu' Puun), was among the first Kelabit to have received an education. He was trained as a teacher and throughout his lengthy career as a pioneer teacher; he founded many schools in the Highlands. When he retired from service, he assumed the role Penghulu and Pemanca (Judge and Paramount Chief) of the Kelabit community. On the 22 of March, 2016, Napuun Beruh passed away peacefully at home, surrounded by his loved ones. I would have to acknowledge that it was due to the old man's far-sightedness and emphasis on education, that my father, along with a good number of his contemporaries, went on to receive a university education. The introduction of education into this niche tribe was facilitated through globalisation and the impact of missionaries establishing education systems in the 1940s. The impact of globalisation also meant to some degree that the old system of tribal roles have dissipated as families continue to migrate from rural to urban areas. Through the opportunity of a Colombo

Plan scholarship to Australia, my father met my mother who was studying to become a pre-school teacher in Perth. Over the next decade, married life for my parents included living in both Malaysia and Australia. Our young family of five eventually settled in Perth, a move that was probably harder for my older brother and sister.

Perth is in Whadjuk Country, part of the Noongar Nation, and with my citizenship confirmed is where I now call home. Not unlike many of my tribal cousins who live overseas – I also call Bario 'home' despite never having lived there. Identity, as I have learnt, is entrenched in culture, family, land and language. English is my first language and is the only language spoken at home. Despite my loss of the Kelabit language there is a strong family connection, particularly with a growing number of extended family members living in Perth.

After completing my Health Science and Economic degrees at the University of Western Australia, I worked in my chosen field of study at Ability Centre (formerly known as The Centre for Cerebral Palsy) and Telethon Kids Institute (then Telethon Institute for Child Health Research). Through my research and experience, it became obvious to me the worldwide disparities of Indigenous groups in health, education etcetera, were a common tale too for Aboriginal and Torres Strait Islander people.

My initial investigation into Aboriginal health revealed that there is no directly translatable word for disability – in Noongar or other Australian Indigenous languages. Some language groups have affiliated words such as 'sick' to depict the meaning of disability. In Noongar, the word 'winyarn', meaning 'sick', 'sad' or 'poor fella', is a generic term used to describe a person with a disability, mental health issue or chronic health problem. As in the Kelabit language the word 'ma'it', meaning 'sickness', is used interchangeably for all kinds of disabilities.

Another interesting observation on how cultural values shape language is illustrated by the adoption of the words thank you by the Kelabit people. In Kelabit, for instance, there are no direct words for 'please' or 'thank you'.

Today the Bahasa Malaysia words 'terima kasih' are commonly used by Kelabits for 'thank you'. The traditional cultural value esteemed in this example is the fact that a giver of a gift should be motivated to give the gift regardless of a person's verbal expression but motivated by seeing the joy that the gift elicits. Giving and sharing is naturally expected from family and community. This foreign concept of having to say thank you reminded me of a story of an Australian Aboriginal woman recounting one of her first memories of forced assimilation education. She was awarded a pencil case as a prize for an academic achievement. However, when she went to receive her prize she failed to say her thank yous. Needless to say, this was interpreted as rude and stubborn, and as a result, she forfeited her prize. The narrator goes on to confide how this experience conflicted with her cultural values and had left her upset and confused. In her reflection, she felt she had earned that gift. It was promised, and her delight in receiving it should have been the motivation of her teacher. Anthropologist and activist David Graeber (2011) has this to say in his book 'Debt: The first 5000 years':

> "All human interactions are not forms of exchange. Only some are. Exchange encourages a particular way of conceiving human relations. This is because exchange implies equality, but it also implies separation."

Perhaps in collectivist Indigenous cultures, exchanges that may imply a separation between two people is counter-intuitive. Politeness as we know it in Western society has roots in European languages such as French ('si il vous plait') and Spanish ('por favour'), with the literal meaning to be 'you are under no obligation to do this'. These terms gained popularity during the commercial revolution in the 16th and 17th centuries (Graeber, 2011). The individuals of the exchange are under no obligation – while it may be in Indigenous cultures that family obligations are non-negotiable.

On my maternal side, I learnt that there are particular Chinese words to describe family kinships. For example, there are distinct names for your uncle (father's elder brother, father's younger brother, father's sister's husband or mother's brother), aunt (father's elder sister, father's younger sister, father's

elder brother's wife, father's younger brother's wife, mother's elder sister, mother's younger sister or mother's brother's wife) or your cousin (paternal or maternal). These distinctions emphasise the importance of males in the culture, order of birth and whether these relations are by marriage or blood. In Indigenous cultures, family connections and obligations are strong. Many aunties and uncles in Aboriginal and Torres Strait Islander groups are considered as close as a mother or father, and cousins like brothers and sisters.

Disability as a construct is not unlike simple words such as saying 'please' and 'thank you', which are culturally weighted words. Being an Indigenous migrant in a multicultural Australia has given me a unique window to appreciate the cultural sensitivities in exploring disability among Aboriginal and Torres Strait Islander youths. Although I cannot predict with certainty where this journey will take me, one thing is for sure, it will be one of ongoing challenges and personal growth. I would like to extend a sincere thank you (as custom in this Western culture), for the courageous and generous contribution that has been afforded to me in the course of my research. If anything, it is my sincere hope that the narration in the following pages will highlight the need to incorporate cultural context in the study of disability and at the very least point future researchers in the right direction. And to you, as a reader of this work, I extend a heartfelt thank you for being connected to this narration.

Kelabit words

beruh = beginning, **ma'it'** = sickness, **puun** = new, **tepu**' = grandparent

Noongar words

boorda = later or later on, **kaya** = hello, **winyarn** = sick, sad or poor fella

1 CHAPTER 1 – INTRODUCTION

1.1 Background

Health, according to the World Health Organisation (WHO), is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity. Traditionally in countries like Australia, the health system and current clinical interventions are often based on a medical model. Health from an Aboriginal point of view sits within a larger holistic model with elements beyond the physical such as spiritual, cultural, emotional and community capacity (National Aboriginal and Torres Strait Islander Health Council, 2003). Health initiatives must be designed based on Aboriginal worldviews, and not Western health understandings alone. The need to understand differing perspectives and fundamental definitions has been advocated for many years (Phillips, 2003). The holistic Aboriginal worldview on health and disability challenges the response service providers employ when engaging with Aboriginal communities.

The Australian Bureau of Statistics (ABS) identified Aboriginal Australians as constituting 3% of the Australian population (ABS, 2013). In WA Aboriginal Australians were identified as constituting 3.8% of the population (ABS, 2013). In March 2015, WA had an total population of 2.6 million, the fourth largest state or territory in Australia (after New South Wales, Victoria and Queensland) (ABS, 2015). The ABS also identified WA as the state or territory with the third largest proportion of the total Aboriginal and Torres Strait Islander population. Although the percentage of Aboriginal Australians is small nationally, the gaps in health outcomes remain large.

In Australia the majority of Aboriginal people are under 26 years of age (ABS, 2013). Therefore engagement with children, adolescents and young adults is necessary. There is a plethora of research emphasising the health disparities between Aboriginal Australians and other Australians; however there is a dearth of literature that explores the concepts of health, wellbeing and disability from the viewpoint of Aboriginal children and young people.

Although gaining a clearer understanding of health and disability will not heal the health discrepancies experienced by Aboriginal people, it is essential to conceptualise policies and systems. An understanding of Aboriginal views on health and wellbeing often guide and shape service delivery for the community. Over the decades, an increasing number of research studies and service delivery models have begun to incorporate this holistic health view into their methods and approach to Aboriginal health and wellbeing. A holistic view of health encompasses spiritual, social, emotional, cultural, physical and mental wellbeing.

The health status of Aboriginal people in Australia is often described as a gap that needs to be closed (ABS, 2014). Equality of life expectancy and disability statistics between Aboriginal and non-Aboriginal populations are highlighted as an international and national priority. On average, the rates of Aboriginal people with disabilities are twice as high compared to non-Aboriginal people, for many complex reasons (ABS, 2012b). Inequitable gaps also exist in education, housing, and child health indicators. Aboriginal views and definitions of disability differ from Western worldviews (Ariotti, 1999). The rates of disability in Aboriginal populations may be underrepresented as a result. These differences affect the way Aboriginal people with disabilities engage with health and disabilities services. In addition, these cultural differences impact the way mainstream disability services are provided. How then can disability services provide support when the meeting place between Aboriginal service users and service providers begin on differing planes?

Current literature does not explore the narratives around disability from an Aboriginal youth's perspective. Furthermore, the participation of Aboriginal people with disabilities in research has to date been underrepresented. In a cohort where more than half (56%) the population are under the age of 26 years (ABS, 2010), there is a need to understand youths' understanding of health and wellbeing. Voices of people further disadvantaged, such as children and young people and people with disabilities, are often excluded. The aim of this research is to explore Aboriginal youth's perspectives on health, wellbeing and disability. The research objectives are also to

investigate the facilitators and barriers and the beliefs about the causes of disabilities. Key differences and similarities between Aboriginal children and young people with and without disabilities are reported. The study adds to the existing qualitative studies on Aboriginal health by sharing the perspectives of Aboriginal youths. This unique research includes the voices and experiences of those both with and without a disability. Aboriginal children and young people with disabilities are the key informants of health and wellbeing and disability and future research has a duty to engage more Aboriginal youth with disabilities.

Perth is the capital city of WA, which is the largest geographic State in Australia. The main Aboriginal group in Perth is the Noongar (or Nyoongar) people and the land surrounding the metropolitan area of Perth is known as Whadjuk Country. In WA, 32% of the Aboriginal youths live in the Perth metropolitan area, 22% per cent live in regional areas and 46% in remote areas (CCYP, 2010). It is estimated that there are more than 40,000 Aboriginal youths under the age of 19 years, with 15,402 living in the Perth region (CCYP, 2015). Therefore, approximately 60% of Aboriginal youths, birth to 18 years old, live outside of the Perth metropolitan area. Compared to non-Aboriginal youths, this is significantly higher, where only 22% of non-Aboriginal youths live outside of Perth. Although collectively, the majority of Aboriginal youths live outside of Perth, the largest single concentration of WA Aboriginal children and young people is within the metropolitan area (CCYP, 2015). In WA, the majority of people with a disability reside in the Perth and South West regions of the state.

1.2 Objectives of the Study

This study expands beyond current research to gain a unique view of Aboriginal youths living with a disability. There is an increasing trend to include the perspectives of children and young people in health policies, yet there is a gap in youth consultation in this area. Furthermore, the participation of Aboriginal children and young people with disabilities has not

been previously explored. Therefore there was a need to purposefully describe perceptions of health and wellbeing from the viewpoint of Aboriginal youths with and without diagnosed disabilities.

The research aim was to determine the meaning of health, wellbeing and disability from the viewpoint of Aboriginal children and young people, with or without a diagnosed disability, living in the Perth metropolitan area in WA. The objectives of this research were to:

- investigate the meaning of health, wellbeing and disability from the viewpoint of Aboriginal children and young people both with and without disabilities,
- explore the facilitators and barriers to health and wellbeing in Aboriginal children and young people and
- report on key differences and similarities between Aboriginal children and young people with and without disabilities.

This qualitative study investigated the contemporary constructions of health and wellbeing as framed by young Aboriginal people in Perth. The findings identified the enablers and challenges to health and wellbeing in the context of disability.The aim of this study was not an attempt to further categorise and label new constructions, but to assist both Aboriginal and non-Aboriginal Australians to understand how best to navigate the current health system in order to receive the best benefits available within the cultural context. Findings identified the meaning of health, wellbeing and disability of Aboriginal children and young people, both with and without disabilities. Social constructions of health, wellbeing and disability of Aboriginal youths with disabilities can inform better practice of disability services providers.

1.3 Significance of the Study

A greater understanding of this perspective has significant implications for service delivery by mainstream health and disability systems. Results of this study can assist in educating Western disability service providers, including

the education sector, about cultural perspectives of young Aboriginal youths who are at the forefront of change in this generation. Findings may also be used to inform policy and procedure of service providers working with Aboriginal families caring for people with disabilities. Currently there are limited theories for understanding Aboriginal youth perspectives of health and wellbeing, the challenges and enablers of disability and frameworks on the children with disabilities. There is a gap in current research that describes the above areas from all perspectives – that is, Aboriginal views, youth perspectives and the voices of people with disabilities.

1.4 Summary

In this dissertation, Chapter 2 provides a literature review on Aboriginality and disability within an international context. Chapter 3 further describes the rationale and the research objectives, the methods undertaken as well as participant characteristics. Chapter 4 presents the findings and summarises the key themes generated from the data. Discussions on these results are provided in Chapter 5. The results discussed are compared to and referenced with relevant existing data and theoretical frameworks. A short section on the research study strengths and limitations is covered. In Chapter 6, comments for the future directions and implications for this field are raised. This chapter also provides a summation of the research with concluding remarks on the recommendations.

2 CHAPTER 2 – LITERATURE REVIEW

2.1 Introduction

This literature review provides an overview of Indigenous people and health outcomes in a global context. Barriers to service access for Aboriginal and Torres Strait Islander people in Australia are discussed. The chapter then summarises Indigenous constructs of disability, with a focus on Aboriginal and Torres Strait Islander cultures. In this literature review 'Indigenous' refers to Indigenous or First Nation groups, and within the context of Australia, 'Indigenous' groups are described as Aboriginal and Torres Strait Islander people. Torres Strait Islander people are the Indigenous people of the Torres Strait Islands.

To note, for many Aboriginal people in WA, the term 'Aboriginal' is preferred over 'Indigenous'. 'Indigenous' is used more commonly in national and in Federal Government documents and less frequently in WA. These organisations do however include and engage Torres Strait Islanders and the phrase 'Aboriginal' is often used for brevity to mean Aboriginal and Torres Strait Islander. Government reports, such as those by the Australian Bureau of Statistics, and national studies, have been cited throughout this paper. In these instances the phrasing remains consistent with the sources. For studies that engaged Aboriginal groups, the term 'Aboriginal' has been used to maintain consistency with the source of literature. In some research papers the title 'Aboriginal' in fact refers to both Aboriginal and Torres Strait Islanders and has been used for ease of the reader. This thesis will predominately use the preferred term 'Aboriginal' to describe the WA population. The study did engage participants who identify as Aboriginal or Torres Strait Islander. This paper acknowledges persons from Torres Strait Islander backgrounds as part of Australia, and WA's diverse Indigenous people groups.

In Australia, there are an estimated 713,600 Aboriginal people, representing 3% of the total population (ABS, 2013, 2014). Of these, 90% identify as

Aboriginal only, 6% as Torres Strait Islander, and 4% as both Aboriginal and Torres Strait Islander (ABS, 2010). The population is relatively young compared to the non-Aboriginal population with 57% of the Aboriginal population aged under 26 years (ABS, 2013). The median age of Aboriginal people is 22 years compared to 38 years for the general population (ABS, 2010). This reflects the higher rates of fertility and lower life expectancy among Aboriginal people (ABS, 2013).

2.2 Indigenous People

There are up to 500 million Indigenous people globally in over 70 countries with more than 5000 languages and cultures (Westby & Inglebret, 2012). The original inhabitants of a continent prior to colonisation are categorised as Indigenous, Aboriginal, tribal or First Nation people (Stephens, Nettleton, Porter, Willis, & Clark, 2005). These include Aboriginal and Torres Strait Islander groups of Australia, Maori people of New Zealand and Native Indians of Canada and America. In developing countries such as Asia and Africa, many tribal groups consider themselves Indigenous if they have achieved decolonisation from colonial powers (Westby & Inglebret, 2012). Within each Indigenous group there is a rich and vast diversity of culture, language, tradition and spirituality (WHO, 1999).

Culture refers to learned and shared sets of beliefs, values, norms and ways of thinking (Kreuter & McClure, 2004). The cultures of the world are often broadly categorised into two groups, individualistic and collectivist, with the latter often associated with Indigenous groups. Western and dominant European cultures strongly reflect individualism where self-expression and choice are highly valued (Triandis, 1995). In collectivist cultures, there is a greater emphasis on group cohesion, cooperation and community (Triandis, 2001). Indigenous cultures are commonly described as collectivist (Westby & Inglebret, 2012). A collectivist worldview impacts parenting styles and behaviours that mainstream services may interpret as neglectful, uninvolved or alternatively overinvolved, depending on one's cultural orientation relative

to expectations (Payne, 2008). Parallel to individualism and collectivism, these cultural categories have also been described as 'doing' cultures versus 'being' cultures, with Indigenous groups representing the latter (Westby & Inglebret, 2012). In this position, individuals are valued not for their accomplishments but rather simply for being, with the result that age or disability does not diminish the worth of a person.

Interestingly, individualism as a concept itself is a relatively young construct within Western society. During periods predating industrialism, people were identified by their family, role in community and religious faith or spirituality. Control was determined by luck, nature, the monarch, the tribe or a supernatural or external force (Etzioni, 2002). With industrialism, science, technology and secular humanism, the perceived value of self is manifested from within rather than externally. Ideas such as individual rights and autonomy gained popularity, particularly in opposition to the restraining powers of government (Etzioni, 2002). Historically, most of the world's cultures originated with a more collectivist viewpoint, with decision making and self-worth linked to community. Social isolation in exaggerated individualism has ill effects physically and psychologically (such as depression), whereas social bonding associated with collectivist cultures develops morality and social virtues such as caring for others (Etzioni, 2002; Putnam, 2000).

2.3   Indigenous Populations and Health Outcomes

Indigenous people have poorer health outcomes relative to non-Indigenous people (Bramley, Hebert, Jackson, & Chassin, 2004; WHO, 1999). There are culturally determined discrepancies in key health outcomes such as life expectancy and child mortality. Health indicators are poorer for Aboriginal and Torres Strait Islanders, Maori people, Inuit people and Pacific people. Overall life expectancy in Indigenous people is up to 20 years less compared to the general population (Bramley et al., 2004; Ring & Brown, 2003). The World Health Organisation states that globally, infant mortality rates in

Indigenous cultures are 1.5 to three times greater than the national average (WHO, 1999). Common disabilities associated with communicable infections include otitis media, which leads to hearing problems, and trachoma infections that lead to vision loss. The disease otitis media is preventable and is considered as one indicator of poverty in developing countries such as India, Malaysia, Thailand and Africa as well as in Indigenous populations in Australia, New Zealand and America (Berman, 1995; Vergison et al., 2010). Temporary or permanent damage to sensory organs such as the ears and eyes have lifelong impacts on communication, education, employment and health.

With colonisation came the introduction of harmful substances such as alcohol and tobacco (Gracey & King, 2009). Substance abuse has been reported to be a common experience in Indigenous communities; with the burden of alcohol and drug use leading to death, disability and disorders (King, Smith, & Gracey, 2009). Fetal Alcohol Spectrum Disorder (FASD) encompasses the following three categories: Fetal Alcohol Syndrome (FAS), partial FAS and alcohol-related neurodevelopmental disorder (Committee to Study Fetal Alcohol Syndrome Division of Biobehavioral Sciences and Mental Disorders Institute of Medicine, 1996). The umbrella disorder, FASD, is a pattern of physical abnormalities resulting from excessive alcohol consumption during pregnancy (Westby & Inglebret, 2012). The syndrome, FAS, is characterised by a pattern of facial dysmorphology, neurodevelopmental abnormalities and growth retardation (Clarren & Smith, 1978). The criteria for diagnosing FAS, methods of case ascertainment, and access to specialised paediatric services, also influence the rates of prevalence (EJ Elliott & Bower, 2004). Overall, FASD is higher in Indigenous populations compared to the dominant cultures of a country (Szlemko, Wood, & Thurman, 2006). Foetal Alcohol Syndrome caused by alcohol abuse is common to Indigenous groups in Australia, America, Canada and South Africa (EJ Elliott, Payne, Morris, Haan, & Bower, 2008). In Australia, a study exploring FASD, is the community-led Lililwan Project in the Fitzroy Valley, WA. In parts of very remote Australia, such as this, rates of prenatal alcohol exposure are high (Elizabeth Elliott, Latimer, Fitzpatrick, Oscar, & Carter,

2012; Lucas et al., 2016). There are a growing number of research studies exploring the impact on FASD on health, education, employment and the correctional system. Researchers such as Douglas and colleagues are advocating for greater awareness of FASD in the criminal justice sector in Queensland, Australia (Douglas, Hammill, Hall, & Russell, 2013). The misdiagnosis of disability in the classroom or prisons fails to address underlying issues which often exacerbate health problems.

Over 1 billion people in the world, or 15% of the world's population, have a form of disability (WHO, 2012). The WHO Disability Assessment Schedule 2.0 (WHODAS 2.0) is grounded in the conceptual framework of the International Classification of Functioning, Disability and Health, known as the ICF (WHO, 2010). This schedule comprises six major life domains: (i) cognition (understanding and communication); (ii) mobility (ability to move and get around); (iii) self-care (ability to attend to personal hygiene, dressing and eating, and to live alone); (iv) getting along (ability to interact with other people); (v) life activities (ability to carry out responsibilities at home, work and school); and (vi) participation in society (ability to engage in community, civil and recreational activities). The development of this instrument focussed on its adaptability across cultures, sexes, age groups as well as different health conditions (WHO, 2010). People with disabilities have less access to healthcare due to factors such as cost, availability of services, physical barriers and skills of health workers. Overall, disability is higher in Indigenous populations, with wider gaps for young Indigenous people (Gracey & King, 2009). Indigenous people face barriers to health access, compounding their disadvantage. The health discrepancies between Indigenous and non-Indigenous groups worldwide are well documented (Bodeker, 2008; Cooke, Mitrou, Lawrence, Guimond, & Beavon, 2010; Gracey & King, 2009). Aboriginal people in Australia have some of the poorest health outcomes globally (Australian Institute of Health and Welfare, 2011c). This can be attributed to colonisation, the loss of tradition, systematic racism and poverty, amongst other factors (Bodeker, 2008).

2.4 Disability in Australia

The Australian Survey of Disability, Ageing and Carers (SDAC) defines disability as any limitation, restriction or impairment which restricts everyday activities and has lasted, or is likely to last, for at least six months (ABS, 2009a, 2012a). The *Disability Services Act 1993 (WA)* defines disability as a condition (*"Disability Services Act," 1993, pp. 2-3*):

(a)   which is attributable to an intellectual, psychiatric, cognitive, neurological, sensory, or physical impairment or a combination of those impairments; and

(b)   which is permanent or likely to be permanent; and

(c)   which may or may not be of a chronic or episodic nature; and

(d)   which results in (i) a substantially reduced capacity of the person for communication, social interaction, learning or mobility; and (ii) a need for continuing support services.

Traditionally in Western cultures, disability is defined within a medical model with a focus on the biological – such as impairments of mobility, speech or vision (Rhodes, 1985). Over time, there has been a shift toward function, activity and participation, as described by the International Classification of Functioning, Disability and Health, known as the ICF (WHO, 2001). The ICF defines disability as an umbrella term for impairments, activity limitations, and participation restrictions (WHO, 2012). Impairment is a problem in body function or structure while activity limitation is described as the difficulties encountered by an individual while executing a task or action. Participation restrictions are the barriers experienced by an individual in everyday life situations. The World Report on Disability (WHO, 2012, p. 7) states that:

Disability refers to the negative aspects of the interaction between individuals with a health condition (such as cerebral palsy, Down syndrome, depression) and personal and environmental factors (such as negative attitudes, inaccessible transportation and public buildings, and limited social supports).

Within this framework, people with a disability are defined and categorised and are therefore labelled both medically and socially.

Disability is often associated with an ageing population. However, rates of disability are higher in the Aboriginal population than in the non-Aboriginal population despite the latter being a relatively young population. The *Aboriginal and Torres Strait Islander health performance framework 2010* report estimated that approximately 19,600 Aboriginal Australians required assistance with a core activity, that is, assistance with self-care, communication or body movements (Australian Institute of Health and Welfare, 2011a). In 2008, after age-adjustment, Aboriginal people were 2.2 times as likely as non-Aboriginal people to have a profound or core activity restriction (Australian Indigenous Health InfoNet, 2015). A profound or severe core activity limitation describes people at the severe end of the disability spectrum (ABS, 2014). Of Aboriginal and Torres Strait Islanders over 15 years living in non-remote areas (major cities and regional areas), 60% had some form of disability (ABS, 2009b). This rate of disability is considerably high compared to the total Australian population of approximately 20%. For Aboriginal youths aged between 15 and 24 years, the need for assistance with a core activity was 1.7 times greater than for non-Aboriginal Australians. To exacerbate this, 36% of Aboriginal people with a disability have problems accessing services, such as doctors, hospitals or employment services, compared with 24% of those without a disability (ABS, 2012b). More than one-third of Aboriginal users of specialist disability services had an intellectual disability as their primary reason for activity limitations.

The most common type of disability in Aboriginal people 15 to 64 years old was physical disability (82%), followed by sight, hearing and speech-related

disabilities (42%, and not mutually exclusive) (Australian Institute of Health and Welfare, 2011c). The most common hearing problem among Aboriginal people is OM, a common childhood disease is leading to hearing loss and consequent learning difficulties. A WA study found that middle ear disease affects 42% of the urban Aboriginal population in school children aged between four and 12 years old (Williams, Coates, Pascoe, Axford, & Nannup, 2009; Williams & Jacobs, 2009). This disease has serious implications for permanent hearing loss, impacting language and literacy development in children and young people.

Co-morbidities exist with some disabilities, for example, cerebral palsy linked with epilepsy, scoliosis or vision impairments (Rosenbaum et al., 2007). FASD has associated cognitive and behavioural difficulties including attention deficit hyperactivity disorder (ADHD), learning difficulties, poor impulse control, mental retardation, hearing impairments and speech or communication deficits (Koren, Nulman, Chudley, & Loocke, 2003; Westby & Inglebret, 2012). Individuals diagnosed with FASD also frequently develop associated issues such as disrupted education (61%), mental health conditions (90%), problems with the justice system (60%) and substance abuse (39%) (Fitzpatrick et al., 2012). In Australia, the rates of FASD are underestimated and underreported mainly due to diagnostic inconsistencies. In WA, FAS is estimated to be 100 times higher in Aboriginal populations than in non-Aboriginal populations (Fitzpatrick et al., 2012). There is often an overlay of shame associated with FAS and FASD as the condition is preventable (Fitzpatrick et al., 2012). Shame associated with disability exists in different ways in a variety of Aboriginal communities (Gething, 1994). In general, shame refers to any social situation where an individual has been singled out, and the anonymity provided in a collective setting is compromised (D. Morgan, Slade, & Morgan, 1997).

Families caring for children with disabilities report very high levels of caregiver stress (Fitzpatrick et al., 2012). Anxiety and depression are often comorbid with chronic health conditions and disabilities, such as physical disabilities (EJ Elliott et al., 2008; King et al., 2009; Schuengel et al., 2006).

In the Aboriginal population, people with a disability or long-term health conditions were more than twice as likely as people without a condition to report high levels of psychological distress (ABS, 2009b). Moreover, mental health challenges and stresses are commonly high in Aboriginal populations, particularly in young people (Bodeker, 2008).

Although there are relatively higher proportions of Aboriginal people with disabilities, research describing the geographic distribution is scarce. Figures of the disability distribution, according to gender, can be estimated from the 2011 Census. In WA, the percentage of Aboriginal children with a disability, aged birth to 14 years was highest in the Perth and South West regions (Biddle, Gray, & Yap, 2013). For males and females, the estimations per region are summarised in Table 1.

Table 1. Estimated percentage of Aboriginal and Torres Strait Islander males and females living in WA who reported having a disability

Region	Male (%)	Female (%)
Perth	3.4	1.6
South-West	2.9	1.9
Broome	2.6	1.5
South Hedland	2.1	0.3
Kununurra	1.8	0.5
Geraldton	1.4	1.4
Kalgoorlie	1.0	1.0
West Kimberley	0.5	0.6

The numbers in Table 1 describe the percentage of Aboriginal people who reported the need for assistance with core activities. In all regions and age groups, the proportions of disability were higher than in non-Aboriginal populations (Biddle et al., 2013).

The *United Nations Convention on the Rights of Persons with Disabilities* recognises the rights of people with a disability to be decision makers in their lives, participating to the fullest extent in communities. The National Disability Insurance Scheme (NDIS), recently adopted by Australia, promotes choice and self-directed services for people with disabilities. (National Disability Insurance Agency, 2016). Since 1 July 2014, WA has participated in a trial of the Australia-wide NDIS as well as the WA NDIS (State version). These WA trial periods and geographical sites have been expanded and it is anticipated that the State and Federals sites will be compared and evaluated 2017. The commencement of the *Disability Services Amendment Act 2014* amends the *Disability Services Act 1993* in WA. More specifically to the Aboriginal population, the *Implementation Plan for the National Aboriginal and Torres Strait Islander Health Plan 2013–2023* outlines strategies addressing disability (Department of Health, 2015). Some noted strategies for the future of Aboriginal people with disabilities include: i) supporting National Aboriginal Community Controlled Health Organisations in the prevention of disability, ii) creating mainstream services that are inclusive and accessible to Aboriginal people with a disability, and iii) culturally appropriate support for older Aboriginal people caring for family members with a disability.

The Report of Audit of Disability Research in Australia summarised Australian research studies exploring Aboriginal people and disability (University of Sydney, 2014). They found that only a small number of papers were published, 39 scientific reports and a further 30 papers in grey literature. This audit recognised focus groups as a common and suitable method within Aboriginal research. The report stated that in comparison to Australian strategic policy documents available, the size of the body of research remains disproportionately small. This literature review confirmed that there is a significant gap in research that engages Aboriginal carers.

2.5 Australian Children and Young People

The Survey of Disability, Ageing and Carers (SDAC) conducted by the ABS measured the prevalence of disability and the need for support by people with disabilities in all age groups (ABS, 2014). In this survey disability was defined as any limitation, restriction or impairment which restricts everyday activities and has lasted or is likely to last for at least six months. For all Australian children aged 5 to 14 years, the percentage of disability was 8.8% (ABS, 2012a). Aboriginal children (0–14 years) were more than twice as likely as non-Aboriginal children to have a disability (15.2% versus 6.6%) (ABS, 2014). Aboriginal boys (0–14 years) were 2.5 times more likely to have a disability than Aboriginal girls (21.1% versus 8.5%). For young adults aged 15 to 24 years, disability affected 7.8% of the population. A profound or severe core activity limitation describes when a person requires constants assistance with either self-care, mobility or communication (ABS, 2014). Aboriginal people were 1.7 times more likely as non-Aboriginal people to have a profound or severe core activity limitation. The prevalence of profound or severe core limitations of children birth to 14 years were 6.8% and 3.9% for Aboriginal and non-Aboriginal people, respectively. In WA, an estimated 2% of Aboriginal children aged 4 to17 were reported by parents or carers to require help with activities of daily living (e.g., eating, dressing, bathing and going to the toilet) (AIHW, 2008).

An Australian study on FAS found that the number of children with FAS increased between 2001 and 2004 (EJ Elliott et al., 2008). Of these children, 48.9% had an intellectual impairment, 59.8% had language and speech problems, and 5.4% had sensorineural hearing problems. The majority (65%) of mothers were Aboriginal or Torres Strait Islander. High rates of FAS can be linked to factors such as low educational attainment, binge drinking in young women, drinking during pregnancies, unplanned pregnancies and low access to antenatal care (EJ Elliott et al., 2008).

The *Western Australian Aboriginal Child Health Survey* is a comprehensive survey of the health, wellbeing and development of Aboriginal children in WA (Zubrick et al., 2004). The survey included questions about restrictions to

core activities of self-care, mobility and communication. It reported that more than a quarter (27%) of 4 to 17 year-old Aboriginal children were limited in one or more sensory functions (vision, hearing or speech) or experienced pain (Zubrick et al., 2004). Approximately 8% of these children did not have normal vision in both eyes, and 7% did not have normal hearing in both ears. Additionally, an estimated 49% of these children were deaf or partially deaf in one ear while 24% were deaf or partially deaf in both ears. An estimated 10% of children were reported to have trouble saying certain sounds. These statistics are consistent with the *National Aboriginal and Torres Strait Islander Social Survey* that reported almost one in ten Aboriginal children had an eye or sight problem (ABS, 2009b). The survey also reported an estimated 35% of Aboriginal children aged from birth to 14 years had otitis media and 9% experienced hearing loss, leading to 4,200 cases of hospitalisation (ABS, 2009b).

According to Watson, Blair and Stanley (2006), cerebral palsy (CP) rates are consistently higher in the Aboriginal population than in the non-Aboriginal population. Among children born between 1980 and 1999, 120 Aboriginal children with CP were recorded in WA, contributing to 8.4% of all cerebral palsy cases, although Aboriginal people constitute only 3.8% of the state's population. This rate is considerably higher than the WA incidence of 0.2% as reported by Watson and colleagues. There is evidence that the health of children in Aboriginal communities is severely disadvantaged, even from the start of life (Freemantle et al., 2006). For many disabilities, the prevalence of disability is estimated to be higher in Aboriginal populations than non-Aboriginal populations. Nevertheless, research also indicates that children with disabilities are highly resilient, with the ability maintain positive self-worth and resilience (Schuengel et al., 2006).

In 2009, the Commissioner for Children and Young People (CCYP) WA conducted statewide consultations with 959 youths exploring important factors to their wellbeing (CCYP, 2009). Of these, 10% were Aboriginal respondents and 6% had a disability. Participants identified family as the fundamental source of wellbeing by support through stressful situations.

Family included references to brother, sisters, pets and extended family. Aboriginal participants noted that they would rather speak to family than friends about things that concerned them (CCYP, 2010). Aboriginal youths also reported family as a source of ill health with issues of bereavement, imprisonment and conflict (often associated with substance abuse). Aboriginal children and young people perceived the acceptance and acknowledgment of their culture in the wider community as being a necessary facilitator of wellbeing (CCYP, 2010). Respect for their culture is important for Aboriginal youths.

The CCYP also conducted an *Inquiry on Mental Health* (CCYP, 2011). This Inquiry recognised that Aboriginal people have a holistic view of mental health, a view which incorporates the importance of connection to the land, culture, spirituality, ancestry, family and community (CCYP, 2011). Common concerns included domestic violence and feuding, substance abuse, involvement with the justice system and coping with suicide and loss. The Inquiry also explored the views of youths with disabilities, however the report amalgamates the views of Aboriginal and non-Aboriginal children. Therefore clear themes of Aboriginal children with disabilities could not be ascertained.

In August 2015, the CCYP conducted further investigations of the views of WA Aboriginal youths and explored suggestions to improve wellbeing and service delivery (CCYP, 2015). Major determinants of wellbeing included social, physical and economic factors, as well as individual characteristics and behaviours. Holistic wellbeing included the connection to family, community, education, recreational activities, reconciliation and culture, land, spirituality and ancestry (CCYP, 2015). These protective factors were threatened by barriers such as racism, historical experience, intergenerational trauma, disadvantage and marginalisation. Mohajer and colleagues undertook a study on health in Aboriginal adolescents (Mohajer, Bessarab, & Earnest, 2009). They ran focus group discussions with 99 Aboriginal children (aged between 12 and 18 years) in rural Australia (Mohajer et al., 2009). Their views on health promotion, significant health problems and support networks were documented. The study identified

alcohol, drugs and violence as the biggest problems. Boredom, racism and bullying were also large issues that had adverse effects on school attendance. Adolescents interviewed felt that family members were the primary people to turn to for help and support. Many adolescents were proud to be Aboriginal and identified strongly with sports. Like many adolescents, Aboriginal children in this study wanted a fun and safe place to socialise in the evenings. To date, there are still gaps in research that explores the views of health and wellbeing from the perspective Aboriginal youths with disabilities.

It is probable that the prevalence of disability in the Aboriginal population is still markedly underestimated (Productivity Commission, 2011). Surveys in the Aboriginal population are affected by high non-response rates. Reasons for low participation rates of Aboriginal people in past data collection surveys include unfamiliarity with forms, low levels of literacy, reluctance to reveal Aboriginality, frequent change of dwelling place, lack of cultural awareness by data collectors and a distrust of the government (Gething, 1994). The incidence of disabilities in Aboriginal children and young people remains high, yet many disability service providers have not been effective in consistently engaging Aboriginal families and communities. This is due to a number of complex reasons, with the barriers to service access in Australia further described in the following section.

2.6 Australian Aboriginal Constructs of Disability

Australian Aboriginal and Torres Strait Islanders are an Indigenous group with the oldest living culture, surviving up to 65,000 years on Country (Queensland Studies Authority, 2013). Although there is vast diversity within the tribes, similarities include values of Country, kinship, lore and the holistic views of health and wellbeing. Long and colleagues tell stories of healthy communities in remote Australia (Long et al., 1994). Elders, including men and women with disabilities, have a distinct role – to teach the children and young people song, art and dreaming stories. People with and without

disabilities take part in ceremonies and live near their Country. People with disabilities stay living with their family. Where a person could not look after themselves, family naturally cared for one another (Long et al., 1994).

Disability, as a social construct, is a Western concept that was first introduced to Aboriginal groups during colonisation. Literature referring to early constructs of disability reveals that Western notions of disability did not exist prior to colonisation (Ariotti, 1999). It is true, that like many Indigenous languages across the world Aboriginal languages do not have a word for 'disability' as found in Western society (Ariotti, 1999; Productivity Commission, 2011). In some Aboriginal translations, words such as 'slow' or 'incomplete' were used to describe impairments and disability as constructed by Western cultures (Westby & Inglebret, 2012). Other terminology in remote communities may include, 'can't walk', 'cripple or maimed', 'can't speak well', 'don't think or learn right', 'don't listen' and 'can't hear' (Pidgeon, O'Kearney, Johnston, Greenstein, & Pilikington, 2015).

Many Aboriginal communities do not differentiate between ageing, disability and mental illness (John Gilroy, 2008). As there is no distinction between disability issues and health issues, people with disabilities would not see themselves as having a disability (Mokak, 1997). Often Aboriginal people are not aware of how much their condition limits them, and typically communities recognise and accept the person as they are (Senior, 2000). Expectations of health and their perceptions of what is normal and expected varies between different clans of Aboriginal groups (Senior, 2000). Attitudes also differ between mental and physical disabilities, with intellectual or behavioural problems being attributed to supernatural and medical causes. In some Indigenous populations disability only became an issue if the condition became a handicap, meaning participation restriction or activity limitation (O'Neill, Kirov, & Thomson, 2004).

One of the most cited Australian research studies on Indigenous constructs of disability is a 1999 paper by Ariotti. In this research Ariotti shares the views of the Anangu people who live in the region where WA, South Australia and the Northern Territory converge. It was discovered that within the

Pitjantjatjara language there was no word for disability. Anangu people tended to name health conditions that were descriptive of the affected body part, for example, blind, deaf and crippled. There existed no overarching umbrella term that segregated these individuals away from community. Contemporary Anangu people adapted the word *nyumpu*, meaning crippled or maimed (which is used to describe an individual who walks with a limp) to understand the term 'disability', however some objected to its use as they believed it 'labeled and stigmatised, not about their personal limitations, but about their perceived social standing' (Ariotti, 1999, p. 219). To this day 'disability' is a foreign dialogue in many communities.

Ariotti also reported that the community found that people with impairments were 'treated and cared for no differently from other members of the group or clan' (1999, p. 218). This echoes Long and associates' paper that tells of ageing men and women and people with disabilities. Women with a physical disability would continue to teach younger members how to paint, sing and dance their dreaming stories (Long et al., 1994). Similarly, the men would pass on sacred cultural knowledge and participate in ceremonies. Carnegie's (1898) early observations also concluded that members of the community with a disability were treated much the same as other members in the community. In these examples, there is no 'disability'. The elderly and those with a disability traditionally lived a good life within their community.

Other research into Indigenous cultures has found that a person with a disability was often the responsibility of the family, not the whole community, and that he or she was included within the kinship link of the extended family (Elliot, 1984). In Australian Indigenous culture, inclusion and participation are often measured by an individual's ability to engage with their family and fulfil their role in their kinship system (Senior, 2000). Having a disability does not necessarily separate individuals from their community, and limitations are not understood in the way of Western culture. Aboriginal families may consider themselves more accepting of disabilities where family members with a disability remain included in their extended families (O'Neill et al., 2004). As much as a person is able, they will continue their typical roles and

responsibilities within the community. However, there are also cases in which the breakdown of traditional family structures, due to poverty, alcohol misuse, grief and stress, for example, has led to neglect (O'Neill et al., 2004). Hidden disabilities, such as mental health or intellectual difficulties, can be left unidentified if they have no adverse effect on group inclusion (Gething, 1994). Therefore, some individuals may not have any perceived limitations, as defined by Western standards, if they fulfil their family role.

As in other Indigenous groups, infanticide occurred in some Aboriginal and Torres Strait communities where an infant had severe impairments (Ariotti, 1999). It has been suggested that within a nomadic way of life physical disabilities and congenital malformations may have jeopardised some communities (Blainey, 1975). Furthermore, the infant with a disability would not be able to become an adult who completed relational and kinship obligations. Infanticide, however, was not thought to be a widespread phenomenon (Webb & Thorne, 1985). Anthropologists discovered skeletal remains of Aboriginal adults with congenital disabilities in the north-west of New South Wales (Webb & Thorne, 1985). This evidence added to the understanding that a number of Aboriginal adults had disabilities such as spina bifida, cleft palate and hydrocephaly. It was concluded that not all congenital anomalies resulted in infanticide, alternatively it was determined by the ability of the group to support their members with a disability, to what extent the community was nomadic and the level of inability of the individual (Webb & Thorne, 1985).

Australian literature has identified differences in attitudes to mental and physical disabilities. For intellectual disabilities or behavioural problems there appears to be a greater attribution for supernatural causes (O'Neill et al., 2004). Physical disability is the most common category of disability for Aboriginal people with severe or profound core limitation (82%) (Australian Institute of Health and Welfare, 2011b). Other types of disability were sight, hearing, speech (42%), intellectual (29%) and psychological (28%), with these categories not mutually exclusive. These national figures are based on people aged 15 to 64 years. With the epidemic of otitis media, it is anticipated

that the inclusion of children 0 to 15 years would markedly increase the prevalence of hearing disabilities. In an Australian study of Aboriginal people, 102 participants were clinically assessed as disabled; however only eight individuals were described by their community as having a disability (Handicapped Programs Review Australia, 1985). Traditionally, most Aboriginal people tend to regard more visible disabilities, such as physical amputations, as disabilities (Gething, 1995). In some Aboriginal populations, disability only became an issue if the condition became a handicap, meaning participation restriction or activity limitation (O'Neill et al., 2004).

Perceptions of disability vary between regions as well as between urban and rural areas (Maher, 1999a; Senior, 2000). For example, there are different understandings of the term disability within rural communities. Curry (1993) found that the term 'handicap' held a significant stigma in various communities across the Northern Territory (NT) while contrary to this Westerman (1995) found the term 'handicapped' and 'crippled' were accepted terms used in East Arnhem communities in NT. Traditionally the concept of disability was somewhat irrelevant as Indigenous people with disabilities were neither stigmatised nor excluded from their communities (Ariotti, 1999; Productivity Commission, 2011). This sense of shame transpires when the individual is singled out by the group and experiences community isolation (D. Morgan et al., 1997). This labelling of a condition can, in fact, stigmatise and erode cultural identity (Bostock, 1991). Kuppers states (2013, p. 177):

> "I have been told by the organizer of the then Aboriginal
> Disability Network, now First Peoples Disability Network,
> Damien Griffis, that Aboriginal cultures do not have words for
> conditions like Down Syndrome, and I also realize that a
> society that values elders creates different systems of stigma
> around issues such as "the sugar" (diabetes) and resulting
> amputations. But I do not really know, beyond individual
> encounters, how younger people with mobility or cognitive
> impairments (for instance) fare in traditional value systems."

Kuppers also acknowledges the diversity and heterogeneous nature of Aboriginal communities, particularly between contemporary groups in urban areas versus groups within smaller rural communities (2013).

2.7 Barriers to Service Access in Australia

Consistently in Aboriginal cultures, rates of disability are higher than non-Aboriginal populations but the utilisation of services often remains relatively low (Gracey & King, 2009; Kendall & Marshall, 2004). In Australia, access to general healthcare by Aboriginal people has social (e.g., family situations), cultural (e.g., shame) and structural (e.g., inflexible health systems) barriers (McBain-Rigg & Veitch, 2011). Barriers for Aboriginal people with disabilities include shame, stigma, family allegiances, geographic isolation, differences in language, lack of culturally appropriate information, gender roles, cultural trauma from past experiences, grief and stress, abuse and vulnerability, lack of awareness, low educational attainment and health literacy, low income, poverty and high financial cost (Bostock, 1991; DSC, 2006; O'Neill et al., 2004).

Shame is a significant factor in many Aboriginal people's experience of disability (Ariotti, 1997; Maher, 1999b). The term shame is used to describe the stigma associated when an individual is singled out, where group cohesion would usually provide anonymity (Maher, 1999b). In collectivist cultures, such as Aboriginal cultures, there is a higher emphasis on group cohesion, cooperation and community (Triandis, 2001). Shame can also be experienced when people are forced to act in a way that is in conflict with social roles and obligations (Kendall & Marshall, 2004). The effect of shame is powerful, and any action that would separate oneself from the community and elicit shame, would be avoided (Kendall & Marshall, 2004). Shame is one barrier for Aboriginal families and individuals accessing disability services (O'Neill et al., 2004).

In some tribes, visible conditions, such as amputations, were often more likely to be identified as a disability (Maher, 1998; Senior, 2000). Disabilities

caused by accidents and congenital disability were treated differently, with genetic anomalies often attributed to maternal wrongdoing (Maher, 1998; Senior, 2000). In some rural and remote communities a child born with a physical disability may be considered to be a result of the child's mother doing something ill-advised when pregnant, such as treading on the back of a goanna (DSC, 2006). Accidental lore transgressions, such as these, do not result in discrimination against the child and are more or less accepted by the community. Eating certain foods or doing certain activities while pregnant or 'marrying wrong' were also thought to lead to congenital anomalies (Senior, 2000). These reasons can be a potential cause of shame that leads to low engagement in disability supports and services. For some families, there may also be stigma associated with accessing a disability or non-Aboriginal service (O'Neill et al., 2004). In addition, accessing services from Aboriginal medical services delivered by opposing family groups can be a barrier to access. Family allegiances and feuding between groups can prevent families from accessing services (O'Neill et al., 2004). These factors and other barriers are further described below (DSC, 2006; Nelson & Allison, 2004; O'Neill et al., 2004):

- **Shame:** Shame was identified as a barrier to accessing hospitals, clinics and rehabilitation, especially in non-Aboriginal settings. Children experienced a sense of shame when being singled out of the class by a non-Aboriginal therapist. When this occurs, group therapy sessions have been effective in reducing the shame experienced by some students. School-based therapy also reduced the shame felt by parents accessing mainstream services.
- **Stigma:** Some Aboriginal people feel that there is stigma associated when registering with a disability services agency and may desire alternative supports. Others have a misconception that some services are only available to non-Aboriginal people.
- **Family allegiances:** Family allegiances and feuding can make accessing services difficult. Families may choose services in another town due to feuding family members.

- **Low income:** Many Aboriginal families live in poverty and often cannot afford to care for more needy members of their group. Added expense in caring for a person with a disability can disadvantage other members of the family.
- **Gender:** Aboriginal women usually care for older parents, children and grandchildren. Aboriginal women may not be permitted to offer physical aid to men, which poses a difficult situation as caring is not regarded as part of the man's role.
- **Abuse:** People with a disability can be very vulnerable to exploitation in environments where alcohol misuse and family breakdown occurs.
- **Grief:** The burden of grief and stress carried in many communities can lead to inconsistencies in care.
- **Lack of awareness:** Many people are disadvantaged by not knowing how to care (e.g., behaviour support for people with Autism) or where to go for help. Aboriginal family carers do not have sufficient support and are unaware of available services.

Poor educational attainment is linked to poor health literacy and low income. Higher health outcomes are positively correlated with higher levels of educational attainment. Aboriginal people aged 15 to 64 years are less likely to complete Year 12 in comparison to non-Aboriginal Australians (ABS, 2012b). The level of household income and educational attainment tend to be lower in remote areas. Furthermore, supporting a family member with a disability comes with greater financial demands than faced by the average household. The *National Aboriginal and Torres Strait Islander Social Survey* reported that barriers to service access for Aboriginal people aged from 15 years include insufficient services (15%), long waiting times (13%) and cost of services (11%) (ABS, 2012b). Trust of service providers and availability of transport were other key factors adversely influencing the utilisation of health services. Common barriers to service access include complex and fragmented service provision, and professionals who operate in isolation from one another (Green et al., 2014).

In general, there is a socioeconomic disadvantage of Aboriginal people which impacts factors such as education, place of residence, occupation, income, access to health services and health beliefs (ABS, 2012b). Furthermore, Australian research has explored the link between socioeconomic status (SES) and Aboriginal child health outcomes. It was concluded that within Aboriginal populations, the link between SES factors, such as household income, and health, produce a proportional relationship with a flatter gradient compared to the strong positive upward correlation seen in Western societies (Shepherd, 2012). A flatter gradient indicates a weaker correlation between household income and health. This may be partly attributed to the larger family demands and links to extended family obligations. Therefore, for many measures that improve health in non-Aboriginal populations, such as household income, there is less benefit for Aboriginal populations.

For Aboriginal people, geographic isolation and lack of specialised services, such as respite and equipment provision, in regional areas continue to be a barrier to service access for rural and remote families (O'Neill et al., 2004; Senior, 2000). Associated with geographic isolation is the issue of language and lack of information provided in culturally appropriate ways (O'Neill et al., 2004). For example, the lack of interpreters available, or English not being the primary language, can lead to misunderstandings. Prior to colonisation, it is reported that there were over 250 Aboriginal languages in Australia. In 2008, 13% of Aboriginal people aged 15 years and over spoke a language other than English as their main language at home (ABS, 2012b). This was higher in remote areas (46%), of which 15% had difficulty communicating in English and being understood by English speakers. Although the majority of the traditional languages are extinct, many Aboriginal groups speak Aboriginal English, a non-standard dialect that differs on various levels from Standard Australian English (Austin, 2006; O'Neill et al., 2004). Moreover, low literacy levels in Aboriginal populations are proportional to geographic isolation, that is, poorer in more remote areas.

Maher (1999b) categorised traditional Aboriginal health beliefs into five causations. These are: natural (e.g., dietary factors), environmental (e.g.,

climate), direct supernatural (e.g., breach of taboos), indirect supernatural (e.g., singing and religious offences) and emergent or Western conditions (e.g., post colonisation). The view that disability is caused by direct supernatural and indirect supernatural versus Western causations can impact the way services are sought. Families may be more inclined to seek medical support for illnesses believed to have non-supernatural causes. Danseco (1997) documented the ways in which parental beliefs on disability affected decisions on treatment and intervention. It was found that parents who believed that divine intervention caused their child's disability pursued non-medical interventions (for example pilgrimages, religious rituals, or fulfilling vows to remove divine displeasure) and parents who regarded disability as having supernatural causes were more inclined to seek cultural prescriptions over professional advice. Danesco (1997, p. 47) states:

> Parents who believed that the disability was caused by evil spirits sought ways to drive such demons away or sought the help of folk healers to achieve this end. Parents who believed that the disability was caused by their past transgressions or negative habits, changed their behaviour to alleviate their child's condition.

However parents who accepted biomedical perspectives were more inclined to follow professional advice, but often also performed various cultural prescriptions to find a cure for their child's disability.

The care of a person with a disability was often seen as the responsibility of family, and people outside of the family was seen to be interfering with personal business (Ariotti, 1999; Elliot, 1984). Therefore, parents and carers who view disability as a family matter may also be reluctant to actively seek help. Aboriginal people are also less likely to speak up about their needs to another person and usually hold a fatalistic view in which hardship is something to be endured (Kendall & Marshall, 2004). Differing constructions of disability held by Aboriginal people also impact on the uptake of services as well as compliance (Maher, 1999b). Those with a disability who saw no limitation as a result of their condition were also unlikely to access service

providers. In Aboriginal culture, the foreign word and concept of the term disability would mean that those who did not identify as having a disability would not seek services (Ariotti, 1999). From a Western perspective, function and participation dictate the success of health and wellbeing; however participation from an Aboriginal perspective is associated with an individual's ability to fulfil their relational obligations and hold a legitimate role in society (Ariotti, 1999). The underestimated prevalence of disability can be attributed to differing definitions of disability from Western and Aboriginal views, and the irrelevance of the concept of disability itself. Aboriginal constructs of disability are further discussed in the following sections. Research into Indigenous cultures and disability has found that in many Indigenous languages no word for disability exists (Ariotti, 1999; Whyte & Ingstad, 1995). As a result of cultural barriers to service access, Aboriginal people with disabilities are at a double disadvantage (Bostock, 1991; Gething, 1994).

O'Neill and colleagues (2004) identified barriers to service access for Aboriginal people with disabilities. Their study categorised four broad issues that impacted Aboriginal people accessing disability services. These were i) cultural, social and other aspects; ii) lack of knowledge about disability rights and services; iii) limited access to services and, iv) workforce issues (O'Neill et al., 2004). Factors that impact low service access can include family allegiances, geographic isolation, differences in language, lack of culturally appropriate information, gender roles, grief and stress, abuse and vulnerability, lack of awareness, low health literacy, low income, poverty, high financial cost and geographic location (O'Neill et al., 2004). Interestingly, the rate of service use for Aboriginal Australians with disability is highest for 15 to 24 year olds (Australian Institute of Health and Welfare, 2011b).

Table 2 illustrates further the factors that impacted Aboriginal people accessing disability services as identified by O'Neill and colleagues (2004).

Table 2. Issues affecting access by Aboriginal people to disability services (adapted from O'Neill et al. 2004, pp.6-14)

1. Cultural & Social Aspects	2. Lack of Knowledge	3. Limited Access	4. Workforce Issues
1.1 Different understandings & values • Concept of disability not identified or familiar • Shame and stigma • Underestimation of cultural beliefs and assumptions by services • Diversity of cultures	*2.1 Lack of knowledge about disability rights and services* • Lack of knowledge of entitlements and rights • Unaware of services due to communication, distance, information or advocacy • Lack of culturally appropriate information material	*3.1 Cost* • General cost of living, and higher in rural areas • Cost of providing health services increases with increasing distance from major urban areas (labour costs, freight costs, airfares and travel allowances/ subsidies etc.)	*4.1 Recruitment & retention* • Low support for professional staff • Staff turnover and loss of informal knowledge • Recruitment and retention leads to failure to goal delivery and poor continuity of care
1.2 Language barriers • Australian Aboriginal language (in very remote areas, 55%) • Aboriginal English is common in metropolitan, regional and remote • Language barriers and different understanding of words e.g., rehabilitation associated with prison; disability to mean sickness		*3.2 Availability* • Low numbers of allied health professionals • Difficult to provide home help, personal care • Respite care options are usually inappropriate • Difficulty accessing education for children with disabilities (availability, accessibility, affordability and acceptability)	*4.2 Inadequate training* • Where there is high turnover and staff may not be replaced immediately and a lack of hand-over and training • In regional areas distance makes it difficult to organise training provision and supervision
1.3 Socioeconomic circumstances • Poverty and lower income (increases with remoteness) • Households larger (3.5 vs. 2.6 people) • Lower motor vehicles registered		*3.3 Attitudes* • Reluctance due to past policies and experiences with mainstream services • Some fear abuse, shame or being exploited	*4.3 Insufficient number of Aboriginal staff* • Some have a preference for Aboriginal staff • The need and lack of Aboriginal staff and services in disability
1.4 Mobility • Mobility between communities can lead to instability and fragmentation in the care of people		*3.4 Establishing need for services* • Services face difficulties gauging the need because of high mobility, communication barriers and access in remote regions	*4.4 Racism* • Racism can occur at all levels of service provision. It can range from misinformation, fear, and stereotyping to exclusionary racism
1.5 Alcohol & drug use • Substance abuse can contribute to dysfunction and may lead to neglect		*3.5 Transport problems* • Vehicle ownership, poor conditions of vehicles, inadequate or no public transport, rough terrain	
1.6 Family Feuding • Families may choose services in another location due to feuding family members		*3.6 Bureaucratic requirements* • Some people are not referred onto services • Some tend to use services in a crisis • Health professionals unaware of services • Referrals and application may be inappropriate.	
		3.7 Lack of coordination • Insufficient coordination between services and programs	

Gilroy and colleagues outline twelve factors that can influence the participation of Aboriginal people in disability services (J Gilroy, Donelly, Colmar, & Parmenter, 2016). These factors are:

- Conceptualising Disability,
- Family and Kin,
- Colonisation and Trauma,
- Racism,
- Choice of Workers,
- Choice of Organisations,
- Community Connections,
- Trustworthiness of mainstream services,
- Multiple Agency Intervention,
- Trusting Workers,
- Mobility, and
- Affirmative Action Policy.

A study by the Anangu Pitjantjatjara Yankunytjatjara (APY) Women's Council provides useful information on the barriers to disability services in remote Australia. The identified barriers were accessibility, bedding, respite, coordination or supports, paperwork and mobility (Ngaanyatjarra Pitjantjatjara Yankunytjatjara Women's Council, 2014). Their results include data about children; however the findings reported are from the perspectives service providers and Aboriginal carers – not from the children and young people themselves.

Facilitators of service access for Aboriginal carers of children with disabilities was explored by DiGiacomo and colleagues (2013). Enablers identified were, increasing awareness of services, facilitating linkages and referrals, eliminating complexities to accessing support, and working with families and Aboriginal community organisations. Working together was founded within a framework of resilience and empowerment improving support and care for Aboriginal children with a disability.

2.8 Indigenous Perceptions of Health, Wellbeing and Disability

Biomedical or socio-cultural beliefs impact on the way health is framed, with the latter construction associated more with non-Western cultures (Danseco, 1997). Biomedical refers to a professional or scientific basis while socio-cultural beliefs include lay conceptions such as supernatural and religious explanations. Perceptions of health from an Indigenous perspective are often more holistic than Western biomedical standards as they consider the interactions between social, emotional, mental, physical and spiritual factors (Mussell, Nichols, & Adler, 1993).

Health, both physical and mental, is viewed by Indigenous people within a holistic and community lifestyle framework, linked to the past and present issues, not necessarily individualised (Brown, 2001). For Aboriginal and Torres Strait Islanders in Australia, the wellbeing of the whole community affects the health and wellbeing of the individual. That is, the welfare of the individual is relative to community within the cyclical concept of life-death-life (Swan & Raphael, 1995). The holistic view of health also encompasses the spiritual connections to the land or country of a tribe.

Westby and Inglebret (2012) contend that fatalistic perceptions coupled with an attitude that accepts differences in an individual indicate that Indigenous communities are less motivated to change a circumstance than is the case in Western cultures. Indigenous worldviews that recognise the harmony that exists between human life, nature and the supernatural mean that families are often less inclined to take up health services such as disability support (Westby & Inglebret, 2012). Furthermore, decision making pertaining to the child or family member with a disability would usually involve the extended family group. The social construction of disability is interrelated with a worldview of holistic acceptance.

Historically, in individualistic Western societies the institutional care of people with disabilities was supported by government assistance and religious organisations (Selway & Ashman, 1998). In many Western countries, persons with disabilities were cared for by family members or by institutions

such as schools for the disabled and residential care facilities. Over time there has been a shift toward integration into the wider community, for example, education support centres within mainstream schools and community based residential care homes.

In collectivist cultures, people with disabilities were not traditionally institutionalised. Instead, the elderly and those with disabilities in Australian Aboriginal cultures were often cared for by members of their family or community (Long et al., 1994). Generally in collectivist cultures a high sense of community care meant that there was a natural integration of individuals with disabilities within society. In collectivist cultures outside of Australia, some people with disabilities were sometimes rejected by their family or community, therefore were neglected, abandoned or forced to beg (Bourquia, 2007). There are a number of social and cultural influences that result in the marginalisation of people with disabilities. Common factors for collectivist cultures include spiritual beliefs and religion, family pride or shame, financial stress or limited resources and a lack of education (Bourquia, 2007; Miles, 1996; O'Neill et al., 2004). These attitudes are often still held by their cultural groups, although, in colonised countries, there has been a trend towards dominant Western influences. For example, in India there has been a tendency to adopt Western worldviews on disability despite its contradictions with traditional values and beliefs (Ghosh & Talbani, 1992).

Many Indigenous cultures across the world have held similar views on disability. A majority of these cultures perceive strong links between spirits and supernatural with the conditions, particularly those with a physical defect. 'What is the point of feeding him, he is a spirit' a father of the Punan Bah tribe of Sarawak remarked of his son with a physical and intellectual disability (Nicolaisen, 1995). In Africa, the Dogon and Bantu people believed infants born with congenital disabilities were conceived between the mother and bush spirits, or within incestuous relations (Paulme, 1940; Wagner, 1956). Similarly, the Hopi and Ainu people, indigenous to America and Japan respectively, saw links between disabilities and evil spirits or parental transgressions (Munro, 1963; Titiev, 1971). The Punan Bah people attributed

different causes to different disabilities (Nicolaisen, 1995). Generally fathers were held responsible for congenital disability while mothers were also held part responsible for their behaviour during pregnancy. A child, for example, with blindness, was considered a result of the mother having intercourse during her pregnancy and not maintaining self-control. Intellectual disabilities were often said to be due to the soul in the body being bad; thus the person was subhuman. Punan Bah newborns with spasticity and limited head control were said to be a direct result of the father cutting off a tortoise's head during the mother's pregnancy (Nicolaisen, 1995). In these scenarios, the individual is not responsible for their condition. Blame is often dependent on a number of complex social opinions.

In almost all Native American communities, disability is not a physical concept but rather framed as a disharmony of spirit (Locust, 1985). There are Indian spiritual beliefs that are linked to wellbeing with the human as a three-fold being made up of a body, mind, and spirit. Humans are considered part of the spirit world and illnesses affect the mind and spirit as well as the body. Wellness is associated with harmony in body, mind, or spirit and unwellness with disharmony in body, mind, or spirit. Other spiritual beliefs state that natural unwellness is caused by the violation of a sacred or tribal taboo while unnatural unwellness is caused by witchcraft (Locust, 1985). Within this spiritual framework, it is not difficult to understand why there are few parallels to Western constructs of health and wellbeing.

Infanticide of babies born with a disability and invalidicide occurred in some nomadic groups (Scheer & Groce, 1988). The Nuer group in East Africa viewed infants with a physical disability as representing an animal, such as a hippopotamus, and were therefore returned home by leaving them in the river (Scheer & Groce, 1988). Infanticide and abortion are often socially accepted where belief systems define newborns as nonpersons. Some tribes consider a newborn only as human after an ancestor spirit takes permanent residence in the body (Nicolaisen, 1995). This is usually marked by the infant's ability to turn its body or break its first tooth. Only at this developmental milestone is the child given a name, rights and a position in the family. Any infant child

before this time is merely a physical shell, and any burial of a nonperson will be conducted without proper death rituals. Within the Inuit community, ageing Elders were abandoned when traditional lore determined their spirit had moved on and left their physical body (Scheer & Groce, 1988).

Those children who survived often lived in the community and were included and cared for by family members and extended family (Nicolaisen, 1995). Maori cultures, like many other Indigenous groups, attribute their low uptake of disability services to their normalising attitudes of disability within their communities (Fitzgerald, 1997). The way disability is framed and categorised is intrinsically linked to the values attached to it. A culture's worldview influences how society accepts individuals with a disability. It impacts the varying levels of expectation and participation that shape the identity of a person with a disability.

2.9 Summary

Health for Aboriginal people is viewed within a holistic and community lifestyle framework (Brown, 2001; Swan & Raphael, 1995). Health does not just mean the physical wellbeing of the individual but also refers to the social, emotional and cultural wellbeing of the whole community (National Aboriginal Health Strategic Working Party, 1989). A whole of life view includes the cyclical concept of life-death-life. Therefore, healthcare services must strive to achieve a state where individuals can achieve full potential as human beings, bringing total wellbeing to communities (National Aboriginal Health Strategic Working Party, 1989).

> Aboriginal people perceived mainstream mental health services as failing them, both in terms of cultural understanding and response, and repeatedly identified the need for Aboriginal mental health services, which took into account their concepts of the holistic value of health and their spiritual and cultural beliefs, as well as the contexts of their lives. (Swan & Raphael, 1995 p.8).

Past studies have reported on Aboriginal adults' perspectives on health. Priest and colleagues explored Aboriginal parents' views on health but not children's views (Priest, Mackean, Davis, Briggs, & Waters, 2012).

This chapter provided an overview of Indigenous perceptions of health and disability, with a focus on Aboriginal and Torres Strait Islanders. This review of literature outlined the challenges and enablers of wellbeing and service access for people with disabilities. The disproportionate statistics of health and disability in Australia between Aboriginal and non-Aboriginal populations is evident. To intensify this inequality, the level of access to disability services by Aboriginal people is underrepresented relative to the prevalence. The paucity of literature that includes the perspectives of Aboriginal people with disabilities has been highlighted.

3   CHAPTER 3 – METHOD

3.1   Introduction

Traditional teachings of Aboriginal knowledge are often passed down through generations through oral stories. Knowledge obtained via visions and intuition is sometimes regarded as spiritual knowledge or 'blood knowledge' and is not observed physically (Lavallee, 2009). Aboriginal ways of knowing are in both the physical and nonphysical realms of reality which are not always measurable in a quantifiable way. Research on perceptions, experiences and belief of Aboriginal Australians requires a qualitative approach (Shahid, Bessarab, Howat, & Thompson, 2009). Historically, some Western research methodologies with Aboriginal people often adopted principles that viewed Aboriginal populations as 'requiring civilisation' (Smith, 2012). Decolonising these methodologies is about the emphasis of Aboriginal principles in research methodology. In today's day and age, research practices affirm Aboriginal people's rights and sovereignty (Smith, 2012).

Qualitative research examines people's experiences and can often bring insights that are limited in quantitative research methods (Al-Busaidi, 2008; Patton, 2001). Qualitative research data are collected from a variety of sources such as fieldwork observations, in-depth interviews, open-ended interviews, focus groups and written documents (Patton, 2001). In-depth interviews are defined by Kvale (1996) as conversations which attempt to understand the world from the subjects' point of view and that unfold the meaning of people's experiences. In interview type methods, the same sets of questions are asked of all participants in order to determine common themes and differences. Krueger defines a focus group as a "'carefully planned discussion designed to obtain perception in a defined area of interest in a permissive, non-threatening environment" (Krueger, 1988, p. 18). Focus groups are identified as suitable for children and young people, as they create a safe environment in which participants share beliefs, experiences and ideas (M. Morgan, Gibbs, Maxwell, & Britten, 2002). Group

discussions may boost participants' safety and comfort, and also increase the number of participants. Group discussion also fosters attitudes and perceptions in an interactive forum rather than in isolation (Morse & Field, 1995). This method of qualitative research is often adopted as a strategy for working with young people and marginalised populations.

Fielder, Roberts, and Abdullah (2000) outlined strategies for non-Aboriginal researchers working with Aboriginal people. They summarise four major elements that are fundamental to successful research. The first element is to engage an Aboriginal Reference Group to steer the research. Secondly, identifying key Aboriginal stakeholders and including them throughout the research process is essential. Thirdly, Aboriginal health research must be owned by Aboriginal people, and lastly for all Aboriginal participants to be acknowledged and valued for their participation. This process is reiterated by Vicary and Bishop (2005) who strongly suggest that forming an Aboriginal Reference Group is one of the first steps of cross-cultural research. This process allows continuous self-reflection and accountability with key members of the community.

This research used a qualitative research method, yarning circles, which was chosen for its cultural appropriateness. Meetings with the Aboriginal Reference Group, Cultural Consultant and Aboriginal Associate Supervisor discussed a number of different methods and approaches for the yarning circles. This chapter describes the methods adopted to explore Aboriginal youth's experiences and their perspectives on health, wellbeing and disability. An explanation of the Aboriginal Reference Group is provided as well as the values adhered to under the ethical guidelines. The process of the pilot yarning and the procedure is described, followed by sections outlining the recruitment and data analysis.

3.2 Aboriginal Reference Group

Ongoing advice and consultation was sought from the Aboriginal Reference Group, a Cultural Consultant and an Aboriginal Associate Supervisor. The

role of these Aboriginal stakeholders included the provision of advice on research methodology, cultural guidance, and support with the recruitment of participants. The Cultural Consultant was a Njaki Njaki Noongar man affiliated with the National Health and Medical Research Council 'Building Mental Wealth: Capacity Building Grant' team at Curtin University. The Associate Supervisor was a Noongar woman with a doctorate in Aboriginal health and is affiliated with Curtin University. The input from each individual was integral to the research process.

An Aboriginal Reference Group was established at the foundation of the study, as stipulated by good practice in Aboriginal research, to assist throughout the entire study (Vicary & Bishop, 2005). Invitations onto the Aboriginal Reference Group were facilitated by the Cultural Consultant and Associate Supervisor. The Aboriginal Reference Group was made up of four Aboriginal individuals each of whom represented a key and unique perspective towards the research the process. The four members included a researcher affiliated with a peak research organisation, a mother/carer and person with a disability, a youth representative and person with a disability, and a manager of a local Aboriginal health organisation. The Aboriginal Reference Group identified three visions and outcomes for the research study. These were to:

I.   create strength-based research which will help support families and build strong children,
II. help children and young people learn to accept who they are and have self-confidence, and
III. help children and young people to grow in self-acceptance and have confidence in all aspects of life (a strong home, family, school, friends, work, post-school options).

During the first meeting, the Aboriginal Reference Group set their Terms of Reference such as frequency of the meetings, role of the Aboriginal Reference Group, expectations and preferred mediums of communication. Agenda items included discussions such as the appropriateness of the information sheet, yarning questions, visual resources, counselling referral

process and recruitment of potential participants. The Aboriginal Supervisor and Aboriginal Reference Group also provided suggestions about culturally appropriate methods and guidelines to the process, for example, an established referral process to counselling support before data collection. The Aboriginal mentors and peers supporting this research were from diverse cultural backgrounds across Australia, adding to the richness of a personal experience and position as an Indigenous migrant and citizen. Throughout the entirety of the study, these relationships assisted with personal development and reflectivity practices. Mutual respect, learning and openness allowed growth which has enriched life past the research process.

3.3 Ethics

This study was approved by the Curtin University Human Research Ethics Committee (HREC), the WA Aboriginal Health Ethics Committee (WAAHEC) and the Department of Education. Although ethics from the Department of Education was gained, recruitment from schools was not utilised for data collection due to time constraints and low attendance of Aboriginal children with disabilities in the schools. This research was conducted with the values identified by the Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research (National Health and Medical Research Council, 2003). These guidelines include the values of i) Reciprocity, ii) Respect, iii) Equality, iv) Responsibility, v) Survival and protection, and vi) Spirit and integrity (National Health and Medical Research Council, 2003). These values are represented in diagrammatic form in Figure 1 and expanded further in the five statements following.
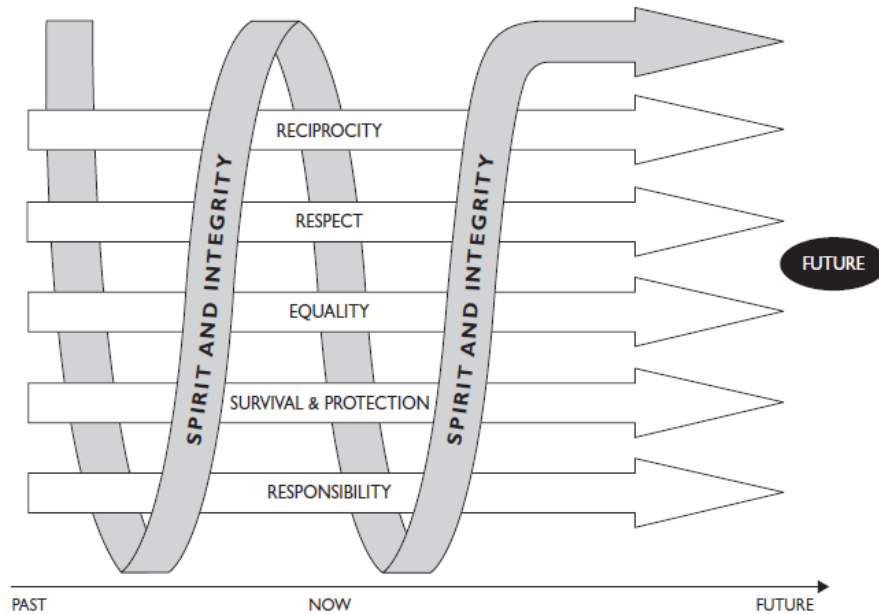
Figure 1. Aboriginal and Torres Strait Islander Peoples values relevant to health research ethics (National Health and Medical Research Council, 2003)

3.3.1 Reciprocity

Contribution to the health and wellbeing of the community: The aim of the research was to capture the unique perspective of health, wellbeing and disability from Aboriginal children and young people. The broader objective was to improve service delivery by disability organisations by building stronger relationships between agencies and families by enabling these organisations to deliver culturally appropriate support. The process and results of the study assist in educating mainstream services to meet the cultural and holistic needs of Aboriginal families and their children and informing families of the services and support available.

Links to the community: This project was developed with the continual consultation with members of the community. The Associate Supervisor, an Aboriginal Noongar woman, and cultural consultant, an Aboriginal Noongar man, heavily influenced the process and direction of this journey. The researcher also made links with Aboriginal Reference Group members.

Benefits and ownership: These yarning circles gave children and young people an opportunity to have their voices heard as they represent Aboriginal youth in Perth. Members of the Aboriginal community supporting the project were beneficiaries of reciprocal acts such as thank you gifts and outings, volunteer work (e.g., event evaluation for Aboriginal community organisations) and other acts of gratitude. Acknowledgement of participants and other Aboriginal stakeholders are noted and thanked in publications related to this research.

Provision of services: The researcher provided links to appropriate services for any individual, according to their requests and needs. The proposed protocol was selected in consultation with members of the community.

Flexibility: The researcher recognised the uniqueness of each individual and tailored the protocol for each person to minimise any potential risk or discomfort.

3.3.2 Respect

Respectful engagement and individuality: The yarning process used was adopted from the traditional Aboriginal way of sharing and communicating, that is, open ended (yarning) with indirect forms of communication. It was approached on an individual needs basis.

Anonymity and recognition: The researcher respected the confidentiality of each person involved. In this dissertation, participants remain anonymous but their contribution is recognised. Final results are to be disseminated through a story book and individuals acknowledged.

Inclusion and authorship: The wishes of the family of the participants involved will also be considered and respected. The safe storage of data was maintained.

Voluntary: All persons and their families involved were informed and able to make an informed choice to participate. Informed assent was gained from all

children and young people, as well as consent from their parents and guardians. Any child or young person who did not have capacity to make an informed decision was not included. The researcher respected the right of any individual to withdraw from participation in the study at any time. Individuals were informed that they could refuse to participate and give no reason for their decision. A plain English Information Sheet and Consent Form were designed with the aid of the Cultural Consultants.

3.3.3 Equality

Equality and benefits: The researcher respected equal partnership and maintained equality in the distribution of benefits to those involved. The researcher ensured that all information provided was presented in a way that was understood, and that ensured that informed decisions could be made.

Representation: Potential participants were recruited mainly via word of mouth. The researcher and Aboriginal Reference Group also ensured that the participants involved were from various groups and invited Aboriginal youths from across Perth.

Non-discriminatory: Participants invited were not discriminated against on the basis of race, age, sex, disability or religious or spiritual beliefs except where the exclusion of inclusion of particular groups was essential for the purpose of the research.

Consultation: Members of the Perth Aboriginal community were engaged from the beginning of the project, and were continually consulted. An Aboriginal supervisor and Cultural Consultant provided direction and advice from its conception. Furthermore, the Aboriginal Reference Group was established to ensure that the research process demonstrated equality at all stages.

Oneness and wisdom: The stories that were shared are acknowledged to be individual experiences but also part of a larger story, past and present, interwoven over time.

3.3.4 Responsibility

No harm: The researcher was committed to doing no harm. One of the first responsibilities of the Aboriginal Reference Group was to develop and agree on terms of reference (or ground rules). These terms covered aspects such as establishing authority, decision making, communication and feedback protocol, conflict resolution and transparency.

Accountability: The researcher was accountable in providing information that was usable in decision making, and adhered to the ethics and spirit of the community. The researcher was also accountable to the individuals, families and communities, particularly in the domains of cultural and social aspects of life.

Decision making: Reference Group members assisted in inviting participants, and in decisions regarding protocol of yarning groups.

3.3.5 Survival and Protection

Protect: The rights of participants and their families were protected throughout the project. Both written and verbal information were gained and potential risks and responses considered. For example, links to Aboriginal counselling services, and a referral protocol were established.

Aboriginal values: The process of this project allowed youths to participate in a culturally safe environment. The researcher also participated in Aboriginal cultural awareness training and is committed to continually learn and develop cultural competency.

Cultural distinctiveness: The method (yarning) was conducive to Aboriginal values. This unstructured format allowed those involved to enjoy their cultural distinctiveness. The researcher was committed to providing opportunities where participants were able to enjoy and celebrate their uniqueness (e.g., participate in the storybook process).

Unite: The yarning process allowed individuals the opportunity to share similar stories of past experiences and therefore connect to other members of their community. Outcomes of the study were stronger bonds between individuals, both Aboriginal and non-Aboriginal, involved in the journey.

Cultural bond: The researcher's professional role with a peak disability service provider has fostered stronger links of Aboriginal culture and history in the sector. The research has also provided links to the disability sector for various participants and stakeholders of the study.

3.3.6 Spirit & Integrity

Values: Procedures were guided by Aboriginal Cultural Consultants and reflected the values and spirit of the community. The researcher acknowledges the continuity of the spirit and culture, in the past, present and future as one.

Diversity: The researcher recognises and respects the diversity within the Aboriginal community. Each individual has differing values, norms and aspirations. Any publications will include a statement that recognises the diversity in Aboriginal communities. For example Perth is predominately home to the Noongar Nation, a people group that has several more clans or tribes within the Nation.

Reflection: Throughout the project, the researcher was continuously reflective. The researcher was accommodating and flexible to the cultural and spiritual identity of the Aboriginal people.

Dissemination: The final stories are shared and communicated in an ethical and honest way. The researcher values the welfare, rights, beliefs, perceptions, customs and cultural heritage of both the individual and collective, at all levels – from commencement to dissemination and into all future work with Aboriginal and Torres Strait communities across Australia.

3.3.7 Counselling Support & Reducing Risks

The yarning process itself has often been said to be an empowering journey (Bessarab & Ng'andu, 2010). Therapeutic yarning occurs when personal or traumatic information is disclosed. During this type of story sharing, having a story affirmed can aid in the healing process of past traumatic experiences. During this process, the researcher switches from researcher to listener, supporting and empowering the story teller. It is important however that the researcher does not become a counselor, but ensures that access to appropriate counseling services is made available. Before yarning commenced, efforts were made to ensure that participants were referred to a counselling service if requested. Contact with two Perth organisations was established before the yarning circles began. Yorgum Aboriginal Family Counselling Service and YouthLink Mental Health Service were deemed by the Aboriginal stakeholders to be appropriate. Meetings with staff members at both organisations reaffirmed the appropriateness of these services.

Yorgum is an Aboriginal Corporation that offers psychology and counselling services to children of all ages. The researcher and Cultural Consultant had a number of telephone and email conversations with staff at Yorgum and also met with the Chief Executive Officer. Yorgum supported the study and referral process and featured the research invitation in their newsletter. Their counselling program was the service referred to for children and young adults.

YouthLink is a statewide mental health program that assists young people aged 13 to 23 years old. Their service has a focus on enhancing the mental health and wellbeing of young people who are marginalised or disadvantaged. The researcher also made contact with two Aboriginal Mental Health Practitioners at YouthLink and met with them face-to-face. Where emotions, anxiety or distress occurred, the researcher stopped the session immediately. Previous arrangements with an Aboriginal counselling service were made so any referrals were a smooth process. The researcher offered these services to two of the participants, of whom one took up the invitation.

In this case the contact details of the organisation were provided as well as a referral made by the researcher.

The researcher holds a Working with Children Check (Notice Number 910021). As outlined by the National Health and Medical Research Council Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research, the researcher continually strived for the values of reciprocity, respect, equality, responsibility, survival, protection, spirit and integrity. In the spirit of reciprocity, the researcher volunteered for the Indigenous Communities and Education Awareness organisation. This group is a youth led initiative fostering experiences, relationships and awareness in order to support reconciliation in WA. The researcher also participated in various workshops and forums as a commitment to continually develop cultural competency. The researcher's parallel cultural background of indirect communication also provided some benefit throughout this study. Over the years a number of events were attended with more notable workshops including:

- 'Aboriginal Leadership Program' (conducted by Australian Institute of Management)
- 'Nyoongar Language Workshop' (hosted by Fremantle Cultural Art Centre)
- Working with Aboriginal Communities (by the WA Council of Social Services)
- 'Yarning: the art of communicating with Aboriginal People' (lecture by Professor Dawn Bessarab)
- National Health and Medical Research Council consultation – Aboriginal and Torres Strait Islander Health Research Ethics Evaluation (NHMRC hosted by Derbarl Yerrigan)

The researcher acknowledges that workshops and programs such as these are primarily tools to aid in successful engagement, and are not by any means qualifications.

3.4 Yarning Circles

Yarning is a credible and accepted qualitative research method in an Aboriginal context (Bessarab & Ng'andu, 2010). Yarning circles are similar to a semi-structured in-depth style of interview or group conversation that is conducted face-to-face. Yarning circles (both in groups and one-on-one), is a cultural and age relevant method for Aboriginal children and young people. Past researchers have utilised semi-structured yarning and found it to be an acceptable method of qualitative research when engaging Aboriginal people from the Kimberley region (Vicary, 2002). This emphasis on narratives and storytelling creates a culturally safe method of engagement (Bessarab & Ng'andu, 2010).

Yarning circles are relevant in addressing the research question because the four interrelated features are culturally appropriate. Yarning includes social, research, collaborative and therapeutic yarning (Bessarab & Ng'andu, 2010). Social yarning occurs before research yarning and is informal and unstructured – following an organic meandering course. Topics usually include news, humour or advice and it is during this phase that trust and rapport develops. Research yarning is the unstructured or semi-structured research interview phase. It is relaxed and interactive but has a distinct purpose. The purpose is to gather information related to a topic through stories. Research yarning has a defined beginning and end point. Collaborative yarning is when two or more people are actively engaging in information sharing. During this phase discussions confirm common understandings, or lead to new discoveries, also aiding in rapport building. The yarning process itself has often been said to be an empowering journey and it is common for therapeutic yarning to occur. This process, which assists the participant to make sense of or have story affirmed, can aid in the healing process of past traumatic experiences (Bessarab & Ng'andu, 2010).
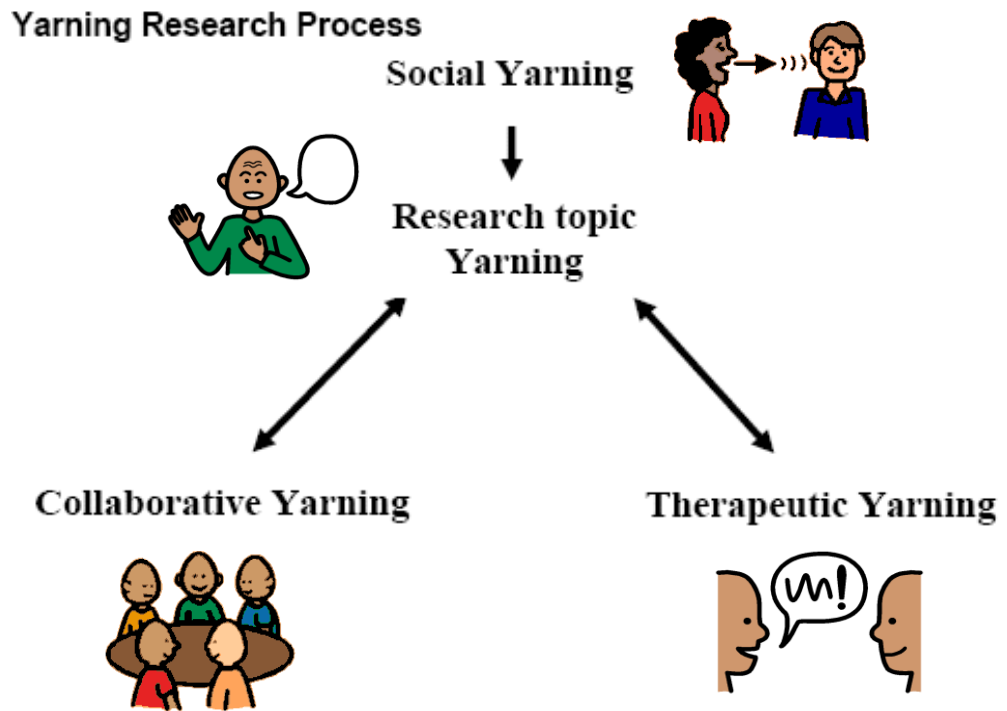
Figure 2. The Yarning Research Process as described by Bessarab and Ng'andu (2010)

Yarning circles needed to engage children, particularly those that may have learning, reading or attention difficulties. Images are evocative and allow access to the subconscious (Prosser & Loxley, 2008). The rationale of the yarning circle and the assisting tools were chosen with guidance from the Aboriginal Reference Group. Methods that involve drawing can assist participants to quietly reflect on the topic being explored and contribute more thoughtfully to conversations (Gauntlett, 2007). Art-based approaches, such as drawing and mapping, are often used with children and in cross-cultural settings (Bagnoli, 2009). Drawing can also help children with disabilities express themselves verbally. Visual methods can also foster discussion on a topic that may be sensitive, such a disability (Gauntlett, 2007).

The initial methods considered included drawing a self-portrait, describing themselves in three words, a health timeline and a genogram. Consideration of the participants' ability, in terms of physical participation and age

appropriateness, were important. Drawings are useful as 'openers' and 'icebreakers' (Morrow, 1998) and were used in the pilot yarning, as well as in the yarning circles (see section 3.7 for greater detail on the procedure). The Aboriginal Reference Group affirmed that accompanying yarning circles with visual tools and other methods such as art and storybooks to be culturally appropriate. The use of visual prompt cards such as *Stones Have Feelings Too* (St Luke's Innovative Resources, 2010) and *Talking up Our Strengths –* cards (St Luke's Innovative Resources and SNAICC, 2009) can be used to help to share emotions. *Stones Have Feelings Too* is promoted to be relevant to discuss mental health with children and young people. Using multiple methods in qualitative research, such as focus groups with drawing, has been found to engage children to be active agents (Darbyshire, MacDougall, & Schiller, 2005). It has practical value in helping participants provide data and creates richer discussion that may have been missed using a single method approach. *Talking up Our Strengths* is a resource that is specifically designed for the use with Aboriginal and Torres Strait Islander people with people from diverse backgrounds. This resource can be used to assist summarising themes at the close of a yarning circle. Summarising key themes at the end of the session also ensures the accuracy of the discussion (Fereday & Muir-Cochrane, 2008).

3.5 Pilot Yarning

The pilot yarning questions and suggestions were drafted in collaboration with the Aboriginal stakeholders. These initial questions were further refined via two pilot yarning circles with Aboriginal youths, and with one-on-one discussions with Cultural Consultants. Where the term 'disability' does not exist in many Aboriginal languages, disability stories and a DVD assisted in the discussion without explicitly using the word 'disability' in the yarning questions schedule. Three Aboriginal youths were invited to participate in a pilot yarning circle and to suggest descriptive feedback on the procedure. The first pilot was conducted with a pair of siblings and the second as one-on-one yarning circle with a young person with a disability. The pilot yarning

process further refined the methods, approach and tools. For example, the initial timeline activity requesting youths to highlight the positives and negative times in their health over the course of their lives was modified. This activity was said to be complex for young participants and for older participants somewhat time consuming. In addition, the linear construct of time may be in opposition to some Aboriginal cultural frameworks of circular time. The timeline activity was adapted and the essence of this activity was modified into the social yarning, or icebreaker, activity.

The social yarning activity was a drawing activity in which the researcher both conducted and participated. Participants were directed to write their name on the top and to divide the paper in half. On one half participants drew a happy face and on the other half, a sad face. Under the happy face youths were instructed to draw or write the positive things in their life (*Write or draw the positive things in your life, what makes you happy?*) and under the sad face, the negative things in their life (*Write or draw the sad or hard things in your life, what makes you sad?*). After a short period of time each individual shared their drawing with the group, with the researcher facilitating and initiating the sharing group discussion. During the pilot yarning participants affirmed the effectiveness of the social yarning activity, commenting *"It's helpful because you're making it about them and they hear about you, so it's a good icebreaker. And then putting the happy/ sad faces helps you see when you were happy and sad, and associate."* The pilot yarning confirmed, modified or rejected initial methods. The pilot study identified the need to further incorporate the use of illustrations, stories, a DVD and evocative cards for the needs of the targeted population.

Ongoing engagement with the Aboriginal stakeholders developed the final data collection instrument and process. These consultations assisted in the choice of language terms that were age and culturally appropriate, for example, *'what is the hardest thing?'* (rather than *'worse thing'*), *'what makes a strong or solid life?'* (rather than *'good life'*) and *'picture yourself as this young bloke; if that was you in the story'* (rather than *'put yourself in his shoes'*). Open questions were also utilised to foster greater discussion, such

as, *'tell me about this young girl'*. In the final yarning process, drawing activities were utilised primarily as a part of the social yarning stage or icebreaker. The yarning circle schedule shifted from an activity based session to focus more on a conversation assisted with visual prompts in order to accommodate youths with different abilities. The final yarning circle schedule and prompt questions are included in the appendices (see Appendix D). The final yarning sessions were supported via the use of illustrations, stories, a DVD and card resources. The five resources are described below.

3.6 Visual Supports and Aids

Yarning circles were supported by a number of visual supports or aids. The statement by the Aboriginal Reference Group '*to create strength-based research which will help support families and build strong children'*, assisted in determining the content of the visual aids used. The following resources were used during the yarning circles:

- *Don't be Shame – Staying Strong Stories* (Howard, 2012)
- *Two Mates* – storybook (Prewett & Prewett, 2012)
- *Inspire, Include, Increase* – DVD (YouthWorX NT, 2009)
- *Stones Have Feelings Too* – cards (St Luke's Innovative Resources, 2010)
- *Talking up Our Strengths* – cards (St Luke's Innovative Resources and SNAICC, 2009)
- *Journey Girls* – doll (Toys "R" Us)

The *Staying Strong Stories* are Aboriginal vignettes that describe how people remain strong during hardships, such as living with a disability. *Don't be Shame* (Figure 3) illustrates the challenges of a student with hearing problems and encourages people to 'don't be shame, ask again'.
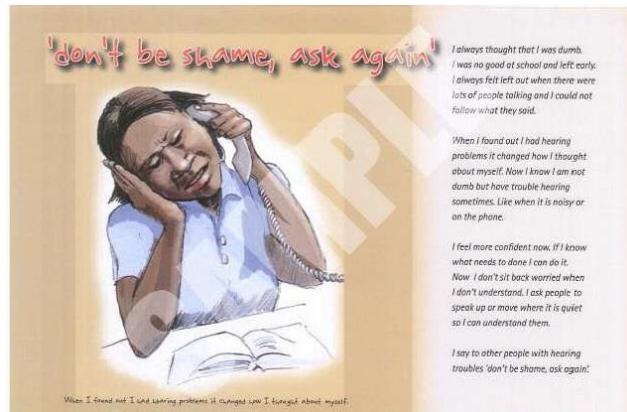
Figure 3. 'Don't be Shame' case study sample

Two Mates (Figure 4) is based on a true story of an Aboriginal boy and his friend. This story focuses on the positive elements of participation and the social life of a young boy with spina bifida.

Whatever Raf and I do, we always have fun.
I'm glad we're mates.
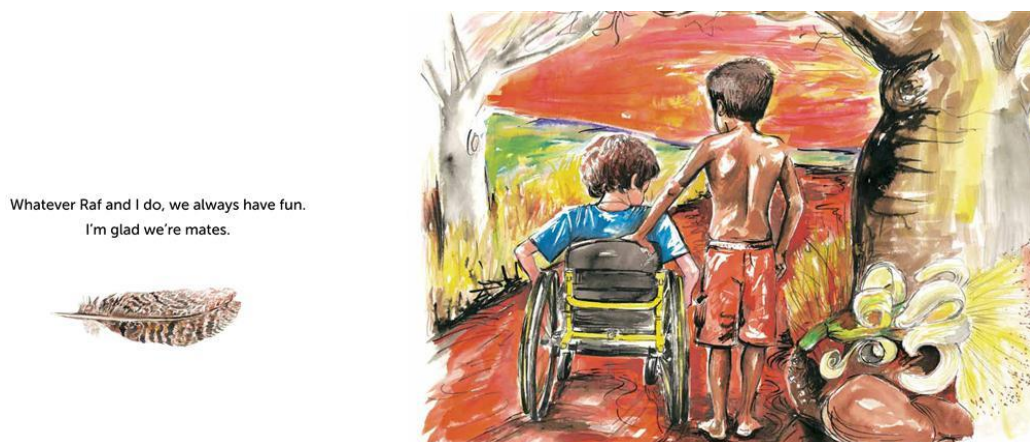
Figure 4. 'Two Mates' storybook sample

The *Inspire, Include, Increase* DVD (Figure 5) shares six real life stories of Aboriginal people with a disability. Their tales highlight how disability is perceived and accepted within their community.

Figure 5. 'Inspire, Include, Increase' DVD Cover

The two card resources *Stones Have Feelings Too* (Figure 6) and *Talking Up Our Strengths* (Figure 7) are evocative cards to assist in raising sensitive issues, validating topics and assisting in articulation of emotions or ideas. Sharing thoughts on a topic is an activity that is often undertaken, for example, in a classroom and in social situations. Revealing feelings and emotions can be a more personal exercise. The *Stones Have Feelings Too* cards set illustrate 52 different emotions and can be used to open conversations about a difficult problem. The *Talking up Our Strengths* cards is a set of 22 photomontage cards that depict the strengths and values of Aboriginal cultures, fostering recognition and celebration of Aboriginal people. This resource was used at the end of each yarning circle to affirm, or validate the topics raised during discussions. A *Journey Girls* (Figure 8) doll was also used in yarning circles when age and gender appropriate.

Figure 6. 'Stones Have Feelings Too' cards (left)

Figure 7. 'Talking Up Our Strengths' cards (right)

Figure 8. 'Journey Girls' doll

The use of these visual resources was to engage participants and introduce the topic of disability without highlighting a participant's disability and to complement the yarning questions without using the term disability (e.g., *Why do you think kids like Raf are born this way?*). Although thoughts on a topic are usually freely shared, identifying the emotions on a topics such as disability are often more difficult to discuss. Moreover, people with disabilities often have greater difficulty identifying and articulating emotions (Gresham, 1981). The *Stones Have Feelings Too* resources were therefore used to help participants articulate their emotions or feelings. The faces of varying emotions helped participants to discuss the sensitive and personal topics of disability and help express their feelings experienced throughout the session. The social yarning drawing activity and the *Talking up our Strength* cards were also utilised in order to summarise and validate findings.

3.7 Procedure

The key feature of yarning circles which differ from focus groups is the laxer approach to the questions on the schedule and the meandering nature of the discussion. Similarities of yarning circles to focus groups are the number of participants in each group, the physical arrangement of the group and the number of yarning circles for data collection. It was predetermined that a maximum of six participants would be suitable to maintain equal opportunities

to contribute to the yarning circle, similar to the rationale of focus groups. The rationale for the size of groups range, with some researchers noting four to six people while others affirming ten to twelve as optimal (McLafferty, 2004). Morgan states that the benefits of smaller groups are that they enable the researcher to better manage participants and that it allows greater interaction between participants (1996). Although small groups can also be somewhat more labour intensive, larger groups may be more unwieldy (McLafferty, 2004). While groups of fifteen to twenty can generate more concepts, some ideas may be lost as participants' voices become diluted. With consideration of the topic, gender and possible tribal dynamics, an optimal number of six participants, was determined by Aboriginal stakeholders to be appropriate.

All yarning circles were conducted at a table. When seated around a table participants, particularly reserved youths, may feel more comfortable. The table barrier assists in creating a sense of security and for mixed gender groups it provides a shield for legs which may be a distraction for boys and girls (Stewart & Shamdasani, 2014). Although seating in focus groups encourages eye contact, for some Aboriginal people, avoiding eye contact can be considered culturally appropriate and respectful. Direct eye contact can be interpreted as rude, particularly with a person who is older or between male and females (Eades, 2013). In many circumstances it may be more appropriate for males and females to sit side by side, to avoid direct eye contact. Appropriate dress code of the female researcher was also a consideration, particularly with male participants (Jalla & Hayden, 2014).

The suggested number of focus groups for sufficient data collection ranges. In literature, various researchers have proposed that a minimum of three and maximum of twelve is ideal, while others state data generated after ten focus groups to be redundant (McLafferty, 2004). In this research, data collection ceased once data reached saturation or the key common themes were continually repeated. Saturation usually occurs when no new data emerges, however it also denotes when no new categories are developed (Corbin & Strauss, 2008). Saturation is a standard by which purposive sample sizes are determined (Guest, Bunce, & Johnson, 2006). Although new data may

always be revealed with ongoing yarning circles, key common categories emerge, and when the related data are reiterated with less themes appearing, data collection ceased. Practical guidelines on saturation and sample sizing are somewhat lacking in the literature. Guest and colleagues discovered in a systematic review of qualitative data that saturation occurred within the first twelve interviews, and early meta-themes were present as early as six interviews (Guest et al., 2006). When the research concepts are well defined and explained theoretical sampling can cease. Furthermore, theoretical sampling is based on the premise that data collection and analysis are conducted in parallel and in an ongoing fashion. Data analysis commenced during data transcription, which was conducted very shortly after each yarning circle. The analysis, coding and re-coding continued throughout the data collection process. This is discussed further in the next section (see 3.8).

Before research yarning could commence, participants were engaged in the social yarning icebreaker activity. The social yarning that preceded the research yarning was facilitated through an icebreaker art activity. Social yarning assists to build rapport with individuals.Participants identified people or activities that made them happy and sad. The researcher also participated in sharing personal stories of the positive and negative aspects of life. The ideas shared during this discussion assisted in probing and deeper conversations of the research yarning. The research yarning featured several key ideas for exploration. These ideas were captured by the following phrases *'What does it mean to be healthy?'*, *'What makes a strong life?'*, *'Who can help you live a strong life?'*, *'What/ who stops you from living a strong life?'* Using visual prompts assisted participants to explore further the facilitators and barriers of a 'strong life' e.g., '*Tell me about this young girl/boy? What would be the best/hardest thing about her/his life?* An initial yarning circle schedule was developed in consultation with an Aboriginal Reference Group, Cultural Consultant, Aboriginal Associate Supervisor and pilot yarning circle participants.

A total of ten yarning circles were conducted, of which four were one-on-one discussions, and six were group discussions. Within each session, the number of participants ranged from one to five participants per group. The four one-on-one discussions were all with youths with a diagnosed disability. For the six group discussions, those of similar ages were grouped together. For example in one yarning circle, there were five youths, all aged between 11 to 16 years. Another group of three participants were aged 22 to 25 years old. These participants were grouped with the guidance of the relevant Health Worker or Cultural Consultant. All yarning circles were conducted face-to-face. The average duration of a yarning circle was one hour and was carried out in a variety of settings. They were conducted in participant homes, community settings and disability organisations. Participants had the option of being supported by the presence of parents, siblings or a Cultural Consultant. All audio was recorded using a non-invasive Echo SmartPen with participants' permission. The SmartPen records what is spoken and written (on the specifically developed Livescribe dot paper notepad). Visual and audio files capture the data which is later transferable to computer via USB cable. The Livescribe software that comes with the SmartPen enables the researcher to view and hear the audio in real time to the dot paper screen capture. The audio playback speed can be reduced and increased, assisting with the efficient transcription of audio. This device was subtle and well received by the pilot yarning participants, Aboriginal community stakeholders and the participants themselves.

A yarning circle schedule was used to guide the conversation. Specific research questions were asked, however the flow and the order of the conversation were not constrained to the list (see below). Probing questions were also listed on the yarning circle schedule in order to clarify points and deepen ideas (Kvale, 1996). Prompting questions and visual aids were added where necessary and when participants opened up to discuss their disability the conversation was naturally continued in an organic manner.

Participants were asked the following:

- *What makes a strong life?*
- *What does it mean to be healthy?*
- *Tell me about this young girl/fella?* (After reading the stories)
- *What would be the best thing about her/his life?*
- *What would be the hardest thing about her/his life?*
- *Who or what can help Raf live a good life?*
- *Why do you think people like <character's name> are born this way?*
- *If that was you in the DVD, how would you feel?* (utilising the *Stones Have Feelings Too* cards)
- *Thinking about today, did we talk about <e.g., 'our struggles', 'our identity'>….* (utilising the *Talking up Our Strengths* cards)

Prompting and probing questions included phrases such as *'do you think s/he always thought like this?', 'can you think of any stories mum or dad taught you?'* Challenging questions such as *'what do you mean by…?'* or *'what else?'*, and calling on quiet participants to speak up, was valuable in guarding against 'premature closure' (Beck, 2003). See Appendix D for the final yarning circle schedule and prompt questions.

The final part of the formal research yarning was to engage participants in describing emotions and perceptions about the disability stories (*Two Mates* story and *Inspire, Include, Increase* DVD). Using the *Stones Have Feelings Too* cards participants were asked, '*If that was you in the DVD, how would you feel?'* Each youth passed around the cards in a circle and placed in the middle of the table the ones which resonated with them. After all the cards were distributed the researcher probed *'who chose this card and why?'* Participants were prompted to describe the emotion or the picture. For this latter question ('*Thinking about today, did we talk about…'*) the *Talking up Our Strengths* resource held 22 cards with the following themes, our: struggles, music, connection, children, men, women, elders, heroes, humour, identity, health, stories, sport, tucker, knowledge, language, land, pride, past,

present and future, celebrations, colours and mob. This final part of the yarning circles was part of the participation validation process. During this activity the researcher summarised key yarning circle themes inviting participants to confirm or alter the ideas discussed. The cards prompted participants to join in a group consensus to ensure accurate interpretations of the discussion. Some ideas were unclear to the researcher; they were affirmed or corrected during this process. Participants with and without a disability were asked the same set of questions. Yarning circles were undertaken from mid-2013 to early 2015. During this time period, the age reported was the age of the participant at the time of the yarning circle. The development of the process was guided by national standards and conducted in consultation with Aboriginal stakeholders (Jalla & Hayden, 2014).

3.8 Recruitment and Participants

Recruitment for the study included purposive and snowball sampling (Patton, 1990; Priest et al., 2012).(Patton, 1990; Priest et al., 2012) The researcher recruited purposefully and invited Aboriginal youths with and without disabilities to participate in order to develop a well-rounded theory of internal comparison. Potential participants were identified via Aboriginal health services, community-based organisations, networks and disability services. Participants were further recruited with purposive and snowball sampling (Patton, 1990; Priest et al., 2012). All participants in this study were children and young people that lived in Perth. To ensure some element of homogeneity in very diverse population, participants with a diagnosed intellectual disability were excluded. Although participants were youths living in Perth, participants came from a variety of tribal backgrounds including: Noongar, Bardi, Indjabandi, Nyul-Nyul, Torres Strait Islander, Wongatha and Yamatji.

A total of 24 children and young people aged 9 to 26 years, eight of whom had a diagnosed disability, were recruited (see Table 3. Participant characteristics). Disabilities were physical, sensory or Fetal Alcohol Spectrum

Disorder (FASD). Diagnosis included cerebral palsy, congenital amputation, deafness (or hearing difficulties associated with otitis media) and FASD. Some of the youths had associated conditions such as depression, anxiety and Attention Deficit Hyperactive Disorder (ADHD). A range of undiagnosed conditions pertaining to learning difficulties and mental health problems were also noted by parents, teachers or youth workers supporting these participants. In total there were 17 male and 7 female participants. The gender distribution of the participants somewhat reflected the statistics of disability prevalence, which indicates that Aboriginal males are 2.5 times more likely to have a disability than Aboriginal females (ABS, 2014). The characteristics and demographics of participants are outlined below.

Table 3. Participant characteristics

Participants	With a disability	Without a disability
N = 24	8	16
Gender	M = 5, F = 3	M = 12, F = 4
Age range	9 to 22	10 to 26
Mean age, SD Mean 15.9, SD 4.9	Mean 13.7, SD 4.6	Mean 16, SD 4.6
Disability	3 sensory disability	
	2 physical disability	
	3 fetal alcohol spectrum disorder	
Aboriginality	Noongar, Bardi/ Indjarbandi, Nyul-Nyul	Noongar, Wongatha, Torres Strait Islander (TSI), Noongar/Yamatji, Yamatji/TSI

Note. N = number of participants, SD = standard deviation, M = male, F = female. (Sensory = otitis media and associated hearing difficulties leading to permanent hearing loss. Physical = congenital amputation, cerebral palsy).

3.9 Thematic Analysis

Thematic analysis is a tool in qualitative analysis that is flexible and enables the researcher to consolidate rich yet complex data (Braun & Clarke, 2006). Morse and Field (1995) define thematic analysis as analysis which "involves the search for and identification of common threads that extend throughout an entire interview or set of interviews" (p. 114). Thematic analysis is a search for themes that emerge to describe a phenomenon and where patterns are formed within the data for these themes to create categories (Fereday & Muir-Cochrane, 2008). These themes are usually abstract notions implied by the data. Moreover, the researcher plays an active role in identifying themes and interprets the various aspects of the research topic (Boyatzis, 1998). Although thematic analysis and thematic coding are used as a process in other qualitative research methods, Braun and Clarke advocate thematic analysis a method within itself. Braun and Clarke (2006) outline this method of analysis as guided by the six phases: (i) familiarising yourself with data; (ii) generating initial codes; (iii) searching for themes; (iv) reviewing themes; (v) defining and naming themes; and (vi) producing the report. The first step involves immersing oneself into the data, and it is the process of transcribing data verbatim, that instigates this phase. Initial coding organises data in meaningful groups that are later combined into overarching themes (Braun & Clarke, 2006; Tuckett, 2005). This coding process identifies a 'good code' as one that captures the depth and richness of the phenomenon (Boyatzis, 1998). After collating codes into major themes and reviewing these, the final two phases involves refining the analysis and telling a story in a logical approach.

Yarning circles as a method is a flexible process that follows a meandering path of storytelling. So it should be that the method of data collection continues with an organic approach. Furthermore, Aboriginal ways of communication are generally more indirect than non-Aboriginal ways of communication. In cultures of direct communication, the emphasis is on the speaker to speak well. The speaker is expected to provide all the information needed for the listener to understand. In cultures of indirect communication,

the emphasis is on the listener to 'read in between the lines'. Euphemisms, implied meaning and slang words may be better coded under a less rigid method of analysis where transcriptions adopt a denaturalism approach (Davidson, 2009). As conversations from the yarning circles featured indirect styles of communication, it was important for the researcher to consistently conduct the yarning circles, transcribe the audio recordings and analyse the data.

Data collection and analysis continually intertwine, that is, from the collection and transcription of data, open coding commences. This approach is an iterative process which leads the researcher to theoretical saturation and thus the theory generation. Saturation occurs when sufficient data has been collected to gain an understanding of the concepts and themes that have emerged (Watling & Lingard, 2012).

3.10 Data Analysis

Data analysis occurred concurrently with data collection. Data collection addressed the core phenomenon (the meaning of and characteristics of health and wellbeing), causal conditions (beliefs about causes), strategies (e.g., what or who are the facilitators and barriers) and the outcomes (e.g., what emotions are associated with disability). The data was analysed using thematic analysis, as defined in section 3.9. The initial codes and comparisons transpired first informally during the yarning circles and throughout the transcription process. Identifying initial codes occurs subconsciously and consciously (Boyatzis, 1998), thus is was important for the same researcher to conduct the yarning circles, transcriptions and analysis.

Audio-recordings were transcribed verbatim with the assistance of voice to text software DragonSpeak. Transcriptions were conducted by the researcher shortly after the yarning circles occurred and usually before the next yarning circle. Semicolons and dashes were used to depict long and short pauses during the yarning. The transcriptions retained the natural and

original features of the oral language, with the 'ums' and 'ers' transcribed. This denaturalized approach accentuated that the meaning in speech is in the said and unsaid, with perceptions impacting the constructs of reality (Davidson, 2009). This approach also holds more transparency and may be more relevant in the context of collectivist cultures that tend to be more indirect communicators than direct. Nevertheless selectivity does occur as it is impossible to transcribe all the features of speech (Davidson, 2009). The transcriptions of the yarning circles required the researcher to listen to the audio recording multiple times over a number of transcription sessions. This allowed a deeper understanding of the data throughout the entire process. Transcribing by the interviewer not only served as part of the analysis process, but it allowed the researcher to determine when the data reached saturation. Ten transcripts were imported into NVivo10 software where the initial codes and themes were noted. Data collection, transcription and analysis were conducted by the same researcher for consistency and continuity.

Thematic analysis was adopted to search for common codes within the transcripts. This method of data analysis undertook the following stages: familiarising self with data; generating initial codes; searching and reviewing themes; defining and naming themes; and reporting (Braun & Clarke, 2006). As the transcriptions were read as a whole, unusual issues and events were noted. Coding and identifying themes involved reviewing and re-reading the data with constant comparisons between transcripts. Chunks of texts were indexed or assigned initial themes. During this coding process, comparisons identified the relationships between codes. Comparisons of the codes and themes emerging occurred both within and between the data transcripts. As more data was gathered, and audio transcribed, similar codes were combined to eliminate repetition. In addition, the relation of the codes to the research question, were part of the analysis process. The analysis process was also a reflective process, where codes were analysed to concepts during a deeper thoughtful process (e.g., what did participants mean when they said <data>?). The core themes of the data set were identified through the coding and re-coding throughout data collection. As data reached saturation and

themes expanded, similar themes were further combined as major themes, with minor details of the key themes categorised as subthemes. Saturation of major and minor themes was attained at 24 participants, during the tenth yarning circle.

Transcripts and notes were stored in a secure cabinet and electronic versions were retained in the qualitative data analysis computer software program NVivo10. Audio files were transferred via the USB cable from the Echo SmartPen to the Livescribe software. All audio files and transcribed yarning circles were saved on a password protected computer that was regularly backed up. The software package, NVivo10, assisted in the complex organisation and retrieval of data. Visualisations, figures and models were illustrated with assistance from the NVivo10 analysis software. The relative importance of themes was determined by grading the frequency of highlighted references in each transcript and source (or yarning circle). That is, the word frequency clouds depict the relative font size to the terms that are most frequently mentioned.Word frequency cloud queries were utilised to illustrate the feeling and emotions raised by participants.

Transcripts of every interview were made available to participants for verification, with one young person requesting an electronic copy of their document. Participants were invited to validate the content, with the older participants more engaged in this validation process than the younger children. All participants were satisfied with the yarning circle process. To note, another activity undertaken by the researcher after yarning circles was reflective journaling. Comments of the process and personal reflection gave height to self-awareness. This task assisted the researcher to be continually respectful and responsible to the ethical guidelines and stakeholders. After the yarning circles where the male Cultural Consultant was present (with the all-male yarning circles), feedback and reflection occur face-to-face. There were no points of concern for either the researcher or the Cultural Consultant during these feedback conversations. Further to the formal research process, a number of stories and experiences of participants with a disability were distilled to create a disability children's resource. This side project was

undertaken to engage the younger participants in a more age-appropriate manner to the content validation process. These participants and their families were engaged via phone conversations, face-to-face meetings and art sessions to confirm that these representations of their experiences reflected their stories. Although the disability stories were not formally part of the research process, it was a unique avenue to engage participants with the data and affirm ownership after the data collection process. This resource was funded through a national disability scholarship and will be made available by the end of 2016 (see E.iii).

3.11 Summary

Health from an Aboriginal point-of-view sits within a larger holistic model with elements beyond the physical such as spiritual, cultural, emotional and community capacity (National Aboriginal and Torres Strait Islander Health Council, 2003). It is recognised that the way initiatives are designed must be based on Aboriginal worldviews, and not Western health understandings alone (Department of Families, Housing, Community Services and Indigenous Affairs, 2009). The establishment of the Aboriginal Reference Group ensured that the pilot research and final procedure undertaken were culturally appropriate to the population engaged. This group was integral at all stages of the research; from creating the wording of the questions to the assistance of the final children's book resource (see Appendix Eiii). The relationships formed within the group were also supportive for the researcher to continually self-reflect and remain aware of the personal position, as shared in the prologue. The holistic Aboriginal worldview on health and disability challenges the response medical professionals and service providers employ when engaging with Aboriginal communities. These holistic views should also be considered throughout the design of any research engaging with Aboriginal communities. An Aboriginal Reference Group and the Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research are good standards in the methods of Aboriginal research, The need to start understanding perspectives and basic definitions has been

advocated by Phillips (2003, p. 30), '…diagnostic and treatment regimes used are still inherently Western and there has been no attempt to start defining the specific basis of Aboriginal and Torres Strait Islander wellbeing, or at the very least, to integrate the two differing worldviews'.

4 CHAPTER 4 – FINDINGS

4.1 Introduction

Participants were engaged in discussions about health, wellbeing and disability with four main ideas explored. The four sections of the results cover: A) definitions of health and wellbeing by Aboriginal youths, B) facilitators and barriers to health, wellbeing and disability, C) beliefs on the causes of disabilities and D) emotions associated with living with a disability. Presented within each section are subsections that describe the themes identified within the issue in focus. The themes that emerged are the cultural perspectives of participants and their lived experiences. Relevant quotes for the themes are included, and comparisons between participants with and without disabilities are outlined.

4.2 SECTION A – Aboriginal Health and Wellbeing

Health and wellbeing were explored by participants responding to '*what does it mean to be healthy?'* and *'what makes a strong life?'* In this study, responses were categorised into three key themes a: 1) *strong body,* 2) *strong mind* and 3) *strong spirit or culture.* First and foremost, youths described health in terms of the physical aspects of having a strong body such as physical activity. When talking about living a strong life, participants spoke about having a strong mind, spirit and culture. These three areas were not separate; instead, health and wellbeing comprised a relationship and balance between all three aspects.

4.2.1 Theme A1: Strong Body

Good nutrition and engagement in physical activity were seen as major contributors to physical health. Other features of a *strong body* included sleep, abstaining from an unhealthy diet and the absence of alcohol or drugs (including smoking). In summary having a strong body meant *"treating your*

body properly" (Male, 16, FASD). Although physical health was usually the first description of health raised during the yarning circles, all participants acknowledged the holistic nature of health with the identification of mental health, a strong spirit and culture.

> *"Eat most of the healthy stuff; like apples and vegetables… Doing fitness running and that like going out for a jog and that, and staying active instead of sitting on the couch and watch TV."* (Male, 10, sensory disability)

> *"Having support; friends and family… Setting a goal with your fitness and like… Eating the right foods and drinking the right things; not drinking [alcohol]."* (Female, 14)

> *"Well first of all yeah, physical activity. Make sure you're having regular exercises, you eat healthy, that leads to having a good mental – having a good mentally; emotionally. Probably just like socialising, always be positive and believe in yourself."* (Female, 22)

> "*Well I guess health for me is like is your physical, mental and social, I mean it's not about all of those things being perfect because there's always times where you have a sore back or a sore leg but you still feel healthy. Or you're a bit worried about something but I still feel mentally quite healthy and strong, and maybe not all my social relationships are perfect, but… When all of those are fairly balanced, I feel good.* (Female, 26, sensory disability).

The social aspects of physical activity were also important as it created a sense of acceptance, belonging and inclusion (e.g., in a sports club).

4.2.2 Theme A2: Strong Mind

Health and wellbeing were also defined as having a *strong mind* or good mental health. Mental health was marked by positive self-worth or self-perceptions, acceptance and resilience (against bullying for example).

Influential relationships with family, friends, teachers and mentors impacted a young persons' perception of self. Family connections were overall, the most influential for children and young people.

> *"Well, to do exercise often, and be strong emotionally, physically and um to make sure that if people do bring you down to tell someone about it and not leave it inside you because it can just build up and build up, and make you mentally unstable… I like it that I can talk to my friends and my family and tell them what's going on and if I feel that I don't feel comfortable telling my friends or family what's going on at just go outside and pet my pets and tell them secrets that I don't like to tell anyone else because they can't talk. So if I'm afraid of telling someone then them telling someone else, then I just go and tell my dog."* (Female, 10, physical disability)

> *"I go tell the teacher [and then] click off, turn off, walk off that's our rule… Like you click your fingers and walk off. [You say to them] stop it; stop bullying me… Because I don't like it…. [My dad says] don't listen to what other people say and you can do it!"* (Male, 9, physical disability)

> *"Like be positive of yourself… just enjoy yourself; I just enjoy myself; just kick back at home, play games; relax… Don't worry about anyone but yourself; and your family."* (Male, 18)

Education and knowledge were also associated with having a *strong mind.* A strong mind or brain included learning (e.g., to use positive affirmations) and gaining information, particularly about one's own disability. Understanding the disability or condition enabled youths to self-regulate, accept and adapt accordingly; leading to a stronger spirit.

> *"School can keep you healthy; you can keep your brain healthy by learning."* (Female, 14)

> *"I used to really beat myself up because of my disability. And watching documentaries about other people [with] fetal alcohol*

spectrum and understanding them, there's a native Indian, who did a video of himself and why he has it and how you can understand it… So the guess the more I watch him and saw it, the more I wanted to understand myself a lot more." (Male, 22, FASD)

"Having positive people that just; and helping her to learn how to use self-affirmations and realise that she's valuable… But then I find looking inward too much, like self-affirmations, not that that's a bad thing; but focusing too much on the issue or, that can just send you a bit crazy." (Female, 26, physical disability)

Education was also identified as an important facilitator to a strong life.

"Sometimes I'm happy when I don't go to school but sometimes I just want to go to school and get a good education." (Male, 14, sensory disability)

"The positives I have, University, scholarship I got accepted into scholarship which makes it easier." (Female, 22)

Participants spoke of walking as a way of calming down or building resilience and having a strong mind.

*"C*lick off, turn off, walk off that's our rule."* (Male, 9, physical disability)

Self-worth or positive self-perceptions were commonly raised by participants. Self-worth was often associated with resilience, with participants using positive affirmations and phrases throughout discussion, such as *'be positive'*, *'be strong emotionally'*, *'believe in yourself'*, *'conquer'*, *'don't dwell on things'*, *'strong minded'*, *'strong heart/soul'* and *'think positive'*. For youths with a disability, family and other strong relationships assisted in acceptance and emotional support. Self-worth, acceptance, resilience and respect are linked to identity and a sense of belonging; all of which are inherently connected to family, culture and Country. Acceptance, confidence and resilience were traits that grew over time through knowledge (of self and culture) and maturity.

"I was looking for it [information] because I was so desperate at the time… Yeah it helped me a lot." (Male, 22, FASD)

"I guess growing up and being a little bit more emotionally intelligent and that kind of stuff, you become a little bit more confident and realise this doesn't make me a lesser person. I think when you're little… You kind of put yourself in that box, 'oh yeah I feel a little bit different'; but growing up, it's not even an issue." (Female, 26, sensory disability)

A *strong mind* was important to maintain emotional stability. Mental and emotional health was facilitated by family, knowledge and self-love. Facilitators and barriers to health and wellbeing are further discussed in Section B.

4.2.3 Theme A3: Strong Spirit or Culture

Intertwined with physical health and mental wellbeing were links to a *strong spirit or culture*. A *strong spirit/culture* was achieved by being connected to family, friends, mentors and role models. Family allowed youths to connect to culture, and friendship engaged youths in social participation and inclusion. Connection to culture also had benefits of physical and spiritual healing.

"Respect makes a strong life… the Elders, your Elders... [respect] everyone." (Male, 16)

"When you spend time out in the bush and that. It makes it feel like I'm home… We call it spiritual healing. You go out countryside; you help out in the countryside… Hunting, just because you have a good day, like it takes the stress off you, yeah… I feel relaxed, happy to keep going, a lot more motivated." (Male, 22, FASD)

Spirituality was connected to both traditional Aboriginal culture (e.g., Country) and religion (e.g. Christianity). A *strong spirit/culture* was connected to both

physical and mental health. Further excerpts summarise spiritual health as necessary for a strong spirit.

> *"You got to be holistic about it, for me in particular is just, it's exercising, socialising, um, making time for family really, and because I used to be quite a hermit, quite a bit of hermit – so I was slowly getting into a downward spiral, so it was good to snap myself out of that… [I] literally just snapped, I started praying a lot more, I became more proactive. It more or less just happened overnight."* (Male, 24)

> *"Spiritually, wake up every day, thank God for the life that you live. I know some people aren't into Christianity, but even though I don't preach it, I still wake up and thank God for the life that I live, and pray. I usually go for run in the morning and it's beautiful when you see the sun comes up, and you're like thank you God… And the main thing is probably know your identity. Like, my dad used to say to me, it doesn't matter where you go in life as long as you know your identity, you should be good."* (Female, 22)

> *"The most important thing on the left is God, definitely… Negative; thoughts and fears, where you just get worried… God's really teaching me that I don't have to believe everything that comes into my head and the truth is that we are really blessed and we have hope no matter what situation we're in; and so that's been really good… For me, because I am – really believe in God, and um, spend like most days talking to Him and praying and that kind of stuff... I would struggle without faith, yeah definitely."* (Female, 26, sensory disability).

A *strong mind* and *strong spirit/culture* were both significant facilitators for youths, however particularly for individuals with a disability. A *strong mind* was also linked to a *strong spirit*, which was implicitly linked to family and culture. Having a *strong spirit/culture* meant belonging, identity, respect and resilience. These subthemes were all linked to family. That is; a place of belonging in family and community; identity linked to family and culture; respect (of family, Elders and self) and resilience as a family value and

cultural virtue. There are three distinct categories which make up the totality of health and wellbeing, but common to each area are common concepts, such as family and respect, for example. This is summarised in the following discussion.

4.2.4 Section A Summary

The holistic nature of health was described as harmony between *body, mind and spirit/culture.* In discussions of health and wellbeing a *strong body* included factors such as nutrition, physical activity and sleep. A *strong mind* was facilitated by self-worth, acceptance and resilience and a *strong spirit/culture* encompassed identity, respect and faith or Aboriginal spirituality as depicted in Figure 9 below.

Strong body
1
- Exercise
- Good nutrition
- Avoiding substance abuse
- Sleep

Strong mind
2
- Self-worth
- Acceptance
- Respect
- Resilience

Strong spirit /culture
3
- Culture
- Elders
- Country
- Identity
- Spirituality
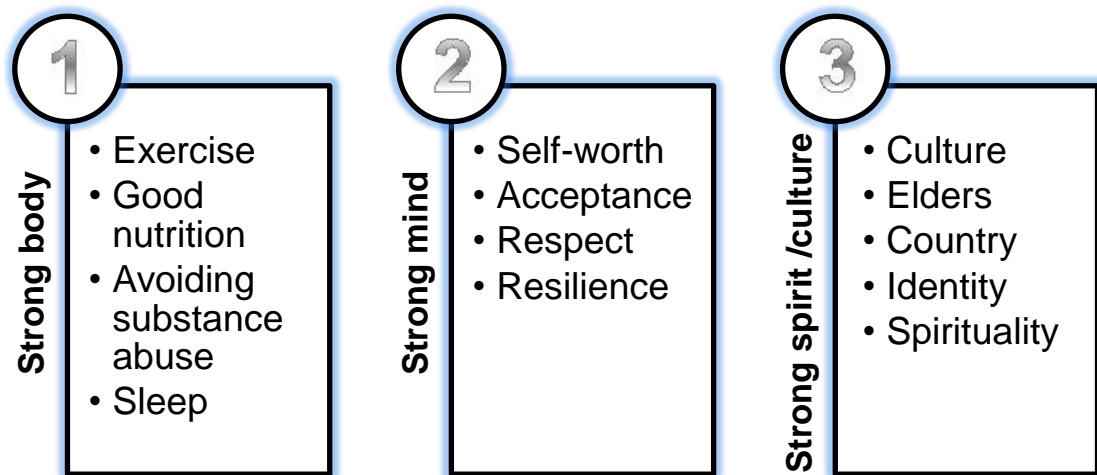
Figure 9. Subthemes within a strong body, mind and spirit/culture

Across these three factors were a number of concepts which were common. These included family, participation, relationships, resilience and respect (e.g., respect for your body, mind and culture). For example, family members were enablers of providing good nutrition, self-worth and connection to culture. Aboriginal culture had strong links to traditional spirituality, for example spiritual healing and spending time on Country or in nature (*'out in the bush'*). Health and wellbeing included participation in activities, physical activity, social inclusion and strong links to family and culture – *"Keep*

occupied… Like exercising really well… You can get healthy by um, like walking… enjoying time with your friends… Family… Learning about your culture." (Female, 10, sensory disability). Participation meant not only physical activity, but being included in activities with peers (e.g., sport, education) and family (e.g., cultural activities). Participation in social activities was connected to having meaningful relationships. Meaningful relationships included connections with family, friends, mentors or having role models. All of the subthemes mentioned have links to family and culture. Overall, a significant contributor to health and wellbeing for youths both with and without a disability was family. The following quote summarises the importance of family as well as other factors contributing to health and wellbeing.

> *"The things that make me happy are spending time with my family, friends, my pets and doing fun activities with them… My family [is the best thing in my life]... To have loving and supporting family, caring friends as well… Going out to do fun things once in a while, and just basically having fun and having loving and supporting people around you, they're all there to help you."* (Female, 10, physical disability)

Ill health was described as the opposite of the above subthemes, for example; poor nutrition, use of alcohol and drugs, social isolation and not being connected to culture and family. Main sources of ill health included social and cultural factors such as loss of culture, lack of disability awareness and stigma, poverty, poor education and family death or breakdown.

Health and wellbeing was described as having a strong connectedness between *strong body, mind, spirit/culture*. These elements were holistic and in its totality made up wellbeing Factors of a *strong body* included the physical aspects of health. Family and self were two key enablers and inhibitors of youths achieving a healthy body. Family was a source of support for young people however the role of friends and mentors was also important to strengthen mental health, spirit and culture. A *strong mind* included self-worth, acceptance and resilience – linked to identity from culture and family.

Factors of *strong spirit/culture* included identity, respect and spirituality – all of which are also linked to family. Family was the primary source of culture and Country. Having a *strong body, mind, spirit/culture* was ultimately linked to family.

4.3 SECTION B – Facilitators and Barriers

Participants identified several features of a strong body, mind and spirit. A lack of these features played a role as inhibitors to health. The enablers and inhibitors of a strong life included physical health and development, social acceptance and participation, meaningful relationships, self-worth, resilience, identity, and connection to culture. Participants were further engaged in a discussion about the facilitators and barriers of a strong life for people with disabilities. Their responses can be categorised into one of three aspects: 1) S*ocial and Cultural,* 2) *Medical and Physical* or 3) *Material and Environmental.* The S*ocial/Cultural* factors were the most frequent facilitators raised by participants. S*ocial/Cultural* facilitators included strong family connections, friends, disability awareness and social participation. *Medical/Physical* factors included physical health and access to healthcare. *Material/Environmental* factors included disability modifications, accessible environments as well as financial security and access to education.

4.3.1 Theme B1: Social and Cultural Aspects

Social and cultural aspects included a number of protective factors. Relationships, culture, resilience and social participation were common subthemes for all participants. Relationships included connections with family, friends and mentors. For youths with and without disabilities, family was the most meaningful connections. This included extended family such as grandparents, aunties, uncles and cousins. Other important relationships were those with friends and mentors, such as teachers and role models. Below are excerpts illustrating the commonalities between children and young people with and without a disability.

Participants with a disability:

"A family… support, and they make you feel better… with their heart and love." (Male, 9, physical disability)

"His schoolteacher and his parents and that." (Male, 14, sensory disability)

"Well the main supports of my life are my mum, my dad and my nanny… And I call my other grandma Nan." (Female, 10, physical disability)

"The teachers and the class and friends, if they say something to you they come up to you and say it, they don't shout across the room, so I understand what they're saying and it's easier for me." (Female, 10, sensory disability)

"[Socialising] keeps me from whatever is annoying me or frustrating." (Male, 16, FASD)

Participants without a disability:

"Your brothers and sisters… teachers… close friends… supporting others if they're going through the same thing you are." (Female, 14)

"Immediate family, like my dad… We weren't so close but we are getting very close now, so that's very nice. My mum and Nan is very special." (Male, 24)

Strong relationships provided love, support, identity, knowledge, empathy and advocacy. Where family may have been a source of poor health, youths also found support through mentors and role models.

"Support… [from] family, any adult that would listen." (Female, 11)

"A good attitude… Support…[from] famous people, what are they called – idols." (Male, 15).

"I've got a book about a man with a disability if you want me to get that… Nick Vujicic, Life Without Limits… In the back it's also got your own personal action plan, I haven't done it yet, I'm going to go and use it, see, it's got questions." (Female, 10, physical disability).

"Michael Johnson – I got a photo with him he gave me advice too… I'm in this Aboriginal program… we go in the class with our teacher whose Aboriginal… he teaches us… in our own time, instead of being in a crowd, because there's only a little bit of us… We have a day with the David Wirrapunda foundation and they teach us about alcohol and drugs and not to do it and how it affects your life… I learnt a lot, Troy Cook does it with us… [and] this Aboriginal lady at school, Tanya, she helps – sometimes comes in my class and helps me with schoolwork." (Male, 14, sensory disability).

I was doing my apprenticeship; I was finding it hard to understand… I wanted lecturers and that to know that I'm not just a student, not like any other student. I'm a student who wants to do things, just needs to understand it at his own pace and you just need to understand you got to give some students a go… I had a tutor are helping me… Some of the lecturers helped me understand… I explained to one of them about my health and how hard it was for me and they understand." (Male, 22, FASD)

Strong family connections incorporated culture, belonging, identity, resilience, spiritual healing and a way of life for participants.

"Learning about your culture." (Female, 10, sensory disability)

"[Culture] it keeps you; like it reminds you about who you are... just being strong about who you are and your culture and being strong with people teasing you and all, and powerful because you can overcome other people's negativity." (Female, 14)

"*And the main thing is probably know your identity. Like, my dad used to say to me, it doesn't matter where you go in life as long as you*

know your identity, you should be good. And one time he talked about culture, and I'm like 'oh man, stuff this culture', and he laughed at me, and he was like 'your culture is your backbone'." (Female, 22)

"If you're having trouble with something you should ask someone about it or tell them about it and take action and if it tried taking action and it doesn't work maybe tell your family about it and see if there's something you can do to help it, if they have any ideas." (Female, 10, physical disability)

"Family… Help you out… Like if you're having trouble with anything just talk to them, make them understand from your point of view." (Male, 16, FASD)

"What they teach me in the desert, which was just to sit still and, sit in the presence… This was the problem with white people; I was living like a white man." (Male, 25)

Another cultural subtheme was traditional healing and Aboriginal spirituality.

"Nanna helped him, and Pop they helped him…Pop put [inaudible] on his legs hey?... Black magic… Yeah [my pop is a medicine man]." (Male, 10)

"You can go to them Wongi… You know that one… You go there, and their legs fixed… Yeah [a healing doctor]… Better than a doctor." (Male,16)

"I know a few stories but nothing close to mental handicap or disabilities in general. There's many [stories] about physical sicknesses where people can get cured." (Male, 24)

Resilience was a significant social factor and included ideas such as respect, self-worth and a positive attitude. Resilience was seen in youths both with and without a disability. Resilience for youth without a disability included

protection against mental health issues linked to disenfranchisement and negative relationships.

> *"Treat everybody else with respect, so it goes both ways."* (Male, 15)

> *"Always remind myself that there's people that love me and that not everyone in the world is bad, there's more good people than bad people in the world, and like when I'm feeling down I'll give myself a compliment."* (Female, 10, physical disability)

> *"You got to have a good feeling. You got to think positive… Be positive, about yourself, have a positive attitude, get along with people."* (Male, 16)

> *"You shouldn't hover over the past and think about all the bad things that people have said to you, you should look into the future and think about the good things that will happen to you, and all the good things that will be said to you by your friends and family."* (Female, 10, physical disability)

> *"Don't dwelling on things, because I have quite a problem dwelling, um, it's best, not try and block it out, because it's sort of hard to move on from things. But just manage with it, it's easier said than done obviously, but just, find other ways to cope with it."* (Male, 24)

As with the facilitators, the key barriers for all participants were predominately *Social/Cultural* aspects. Barriers included boredom, lack of participation (in culture, family and social activities), bullying (including social media), peer pressure, death and family breakdown (including loss of culture). Participants also noted issues of low education and limited job opportunities, leading to concerns of financial insecurity and poverty. All of these factors can lead to substance use or abuse and antisocial behaviours. Barriers categorised as *Social/Cultural* features were common for all youths. Participation meant inclusion in social situations (e.g., with family, friends and peers) and activities (e.g., hobbies, interests). Excerpts below highlight the themes and

subthemes identified. Participants with a disability speak about social barriers in their lives:

> *"We play a game…Sometimes we're left on the side."* (Male, 9, physical disability)

> *"Well sometimes when I get back from my, from seeing my mum [who I don't live with], I get angry at people, because I take it out on them and I'm not allowed to and that's what nanna Sal told me. So um when I get like angry, I take it out – shout, slam doors."* (Female, 10, sensory disability)

> *"When I had arguments with my family, I don't like it. Or when one of my pets passes away or one of my family passes away… Sometimes when my um, my family or friends they say hurtful things in an argument, feel like breaking apart and I feel like there's parts of me falling off… And yes, sometimes I hate it when people give me the silent treatment it makes me feel like I'm invisible."* (Female, 10, physical disability)

> *"I've got a couple friends like to go out and party, and they always ask me, but I said no I don't like doing that… They don't really care; but I do and I don't really want to do that… All my family tell me you don't worry about drinking now and all that… Because then you succeed in life – can do what you want when you're older, not sitting bored or nothing…You can get drunk and can't control your anger… Start fights and you could probably go to jail, you could get into trouble. You'll be like, what am I doing here?"* (Male, 14, sensory disability)

> *"And my worst one is being bored, being sick, wasting my time."* (Male, 15, FASD)

> *"People getting you to get involved in what they're doing… Alcohol."* *"Parents [can] hold you back."* (Male, 16, FASD)

Participants without a disability spoke about the social barriers in their lives:

"Back stabbing friends and two-faced friends… Your family, if your family does drugs and alcohol… Starting fights with people." (Female, 14)

"I guess challenges… Conquer something, then it's hard for me but I just try and keep trying, just try the best that you can to overcome that… Like parties and that." (Male, 16)

"It can get addictive… Someone might start chipping you… People can get cheeky on Facebook." (Male, 18)

4.3.2 Theme B2: Physical and Medical Aspects

Participants were asked about other facilitators and enablers to health and wellbeing. Discussion of the characters in the video and case studies facilitated conversations which also led to enablers in their own lives. Other than family, disability support workers and services also assisted people with a disability. Respondents discussed access to health professionals such as doctors, therapists and health workers.

"A doctor would help him at life, and his like, other family members, and some of his friends." (Male, 14, sensory disability)

"Disability workers could help him as he grow older, finding a place, is that what disability workers do? Accommodation, and things he needs in the house, because they would need certain types of things." (Female, 22)

Health workers allow individuals privacy and anonymity that they may require.

"So most people with disabilities have good lives and have good friends and supportive families… If they needed to find help or seek help, I'd suggest like going to talk to family, but if you really think you can't talk to family because it's that bad, my advice would be maybe

ask your parents if you can talk to a therapist maybe. Cause therapists are good and they help people express their feelings." (Female, 10, physical disability)

One participant noted the differences in the type of care that may be received from a paid disability support worker compared to a family member.

Some people might just do it, like my dad is an example, he's a carer but he um, he doesn't do it so much for the fact that he wants to help people. He is a good person but it's more so… it's convenient money. He goes into a home and just cares for people, clean up, cooks meals… He knows how that work is and it just happy with it. He's been doing it for 20 years…. He doesn't really get intimate with clients but he's friendly, he likes to keep a sense of professionalism." (Male, 24)

The unique physical abilities and adaptability of people with a disability were also discussed as an enabler.

"But you can exercise in different ways... He can't speak, and he does sign language and expresses [himself], like drawing." (Female, 14)

"Because you can exercise even if you are in a wheelchair." (Male, 16)

"He's young and it looks like he's very active, and the way he sits here it's like he got off the wheelchair by himself, and the more he practices, he do it, the better he becomes." (Female, 22)

Advocacy and support from charities and not-for-profit organisations were discussed, with a role to provide physical support and, also social support. This included support for families, both emotional and financial, as well as raising the awareness of disabilities in the general community e.g., advocacy.

"For Joseph to improve, he has cerebral palsy maybe he could take speech therapy… So he can learn to control it, and it won't happen so much… Like pausing… if there was anyone with him at the moment so people don't think he's being rude, maybe they could just tell them that

he has cerebral palsy and he's not trying to be rude." (Female, 10, physical disability)

"Community members… their neighbours, local charities… like non-profit organisations or government… Fundraising and build awareness of what other support the family can get; so that he can have those opportunities." (Female, 26, sensory disability).

Health professionals assist by providing or supporting health interventions and therapy. Participants with a disability shared their experience about receiving healthcare:

"PMH; they just put needles into my leg….[to help with my] muscles." (Male, 9, physical disability)

"He [the doctor] said that I might need to get a hearing aid because I have a hole in my ear drum, so um they said I need to patch it up." (Female, 10, sensory disability)

"Well, it's good, cause you know you can trust them [therapists], they won't; most of the stuff that you talk about in therapy room, stay highly classified and like your parents only get to find out a little bit of that information, so you know that you can tell them anything at all, but if they feel that your parents really need to know that, then they'll probably tell them. But they'll probably ask you permission if you want your parents to know… they trained to make kids feel better." (Female, 10, physical disability)

"When I was little I got too much water in my ear, and then I got really bad, and I kept coming in and out of hospital and the last time I was in hospital, I think it was like two years ago, I had grommets or something, and they had stitches in my ears, I'm not sure what they did, but I was in hospital for a like a couple of days, and then I got out and I haven't had an ear problem ever since then." (Male, 14, sensory disability)

"Doctors or carers, people that specialise in it." (Female, 26, sensory disability)

As expected, medical or physical barriers were more inhibiting for those with disability. Participants with a disability share personal barriers associated with their condition, both the physical and social limitations, such as bullying. Those with physical disabilities also experienced social barriers, for example, poor awareness of their condition by peers and feelings of difference.

> *"Well some things I can't do that other kids can because I have one arm, so that's a bit of a disadvantage and I don't like it when – like before I had people come up to me and ask me if I go to school, and I think why wouldn't I go to school just because I have one arm it doesn't affect my brain, like the way they say it – it makes them look like they think that having one arm affects my brain and I can't go to school because I'm all stupid and stuff. And then I try to tell them yeah of course I go to school."* (Female, 10, physical disability)

> *"If you were deaf and they're trying to tell you something and you keep saying 'what?' the person be like I'm not telling you again, and you really want to know, and the person says I'm no I'm telling you… I'm deaf… Yeah it's hard just not being able to hear properly."* (Female, 10, sensory disability)

> *"My heart can't take pressure, because like the doctors didn't really understand and everyone else… I have Fetal Alcohol Spectrum… let us understand our body… I can't take too much pressure, because of my heart, because I'm not breathing the right way, or its cause I'm over doing too much yeah."* (Male, 22, FASD)

> *"If you feel a bit different you don't want to ask people 10 times what they said to you… So if I have to say 'oh pardon?', like more than twice I probably won't say it like past three times. Three times would be max (laughs); because you feel really silly and because if it's a stranger, then I'm not going to say, 'sorry I'm a bit, I can't really hear*

you that well'. But if it's a workmate I definitely will, I'm like 'sorry I really don't know what you're saying, could you just repeat that'; in a nice way." (Female, 26, sensory disability)

After viewing disability stories, participants discussed the physical limitations and associated social challenges of living with a disability. Subthemes included limited independence, social isolation, mental health issues, advocacy and lack of awareness.

> *"They have to wait until they get pushed… What about if they need to go to the toilet… Shower."* (Male, 13)

> *"Watching kids run around… Sitting in a wheelchair and watching everyone run around, you know what I mean… Mentally it would be boring, it would be sad, because everyone else will be walking… It will be boring because you can't walk… If I was in a wheelchair I'd just sit at home so I don't have to see it."* (Male, 14)

> *"Being in a wheelchair and all that, having other people speak for you, because you're not really good at it."* (Male, 14, sensory disability)

> *"When he goes to Princess Margaret Hospital he might be missing out on something really fun when he's going… Maybe he might like feel lots of pain in the middle of the day because of his spina bifida… The hardest thing about Cece's [character in DVD] life is she might need someone to interpret for her all the time… One time she might not have anyone there to interpret for her and people would just walk all over her... It might be hard because people might not be open to learning to sign."* (Female, 10, physical disability)

Medical/Physical barriers were significant for people with a disability, with these themes linked to social aspects such as dependence or social isolation. That is, physical limitations of a person with a disability excluded them from social participation. Important facilitators for those with disabilities included medical intervention and a person's adaptability to their condition.

4.3.3 Theme B3: Material and Environmental Aspects

Facilitators and barriers were also categorised in a third and final area, *Material/Environmental* aspects. Material factors included wheelchairs and hearing aids, and environmental factors included classroom settings, geographic location, wheelchair assessable buildings and community spaces. These categories have links with one another. For example, equipment cost is also linked to social considerations, such as a family's level of income, job opportunities and an individual's ability to advocate. Participants both with and without disabilities raised factors considered to be the material and environmental barriers:

> *"There might be school excursions or something that he won't be able to attend because the bus might not like, there might not be able to fit his wheelchair onto the bus."* (Female, 10, physical disability)

> *"Like stairs, there might not be a ramp so you might have to go around the school."* (Male, 12)

> *"Maybe if you can't get there… To hospital."* (Male, 16)

> *"School would be hard for him because it would be hard for him to get around to each class, like say there was stairs or something you won't be able to get to each class, like say there was stairs or something he probably will have to stay in one class instead of going to each period… The school might be like big or something and he might get lost."* (Male, 14, sensory disability)

> *"Why don't they put something in his back to send signals to his body? It costs too much money."* (Male, 16 and 18).

> *"It is also expensive… You get your medication in the big major cities, you go remote community and you get the bill and you've got $35… And the thing is, job wise, in the remote community, most of them got, there's less opportunities."* (Female, 22)

"Might not be as much care as you could get from somewhere, um… Might not have just the support as immediately, in a much more populated area. Obviously because of their handicap makes it quite hard; remote areas also, there's not many options for jobs." (Male, 24)

"Some of the stuff might be expensive as he has to get a wheelchair as he gets older and that kind of stuff would cost the family a lot probably; if they're not funded… Having access to resources if they are living rural. Um and access to health, I mean there's already that issue for people that don't have a disability anyway, so yeah that would be a challenge." (Female, 26, sensory disability)

Participants with a disability shared their personal experiences with environmental barriers:

"The teachers says that she wants me to get an A but I said I can't get an A if you don't put me up the front, so how am I supposed to get an A if I can't hear properly." (Female, 10, sensory disability)

"Just in class like if I couldn't hear what the teachers was saying, or I couldn't hear what one of my friends was trying to whisper to me, or generally when people are trying to whisper to me, then that's when it feel funny... Or if I'm in class or at work and someone tries to whisper something to me, I'm like 'pardon?', and I really can't hear them that when I'm like agh, I feel – I get a bit frustrated. But it's not a huge issue where I actually feel really down." (Female, 26, sensory disability)

Environmental facilitators, such as an adapted classroom setting were discussed, and also had links to social aspects such as family and advocacy.

"Nanna Mary said that if they want to put me up the front, but I'm at the back…. Cause I can hear properly a little bit. But cause my teachers got me up the back I don't know what she's saying… So my teacher takes the group out and we go work together and I sit next to the teacher so I understand." (Female, 10, sensory disability)

Material/Environmental facilitators discussed included the opposite ideas to the above subthemes, for example, having transport, equipment, modifications and education.

> *"They need good transport."* (Male, 13)

> *"He's got a wheelchair to get around."* (Male, 16)

> *"Maybe if his school, next time they go on an excursion, hire a bus that has wheelchair access or wheelchair mobility… It would be good for maybe people in Dion's life to try and learn, try and learn to sign and give him a chance, and not just say; 'this is too hard I don't want to do this', so give him a chance."* (Female, 10, physical disability)

Material/Environmental barriers were significant for people with a disability and again linked to social aspects. Material or environmental limitations, such as a lack of a wheelchair or wheelchair ramps, excluded individuals from participation. Facilitators to overcome these challenges included finance, advocacy, design and modifications.

4.3.4 Section B Summary

The most common facilitator for Aboriginal children and young people was *Social/Cultural* aspects. For the whole cohort, family was by far the most commonly raised facilitator for assisting with health and wellbeing. Family was a principle source of acceptance, belonging, culture, identity, resilience and self-worth. Friends, teachers and mentors were also raised as assisting self-worth, acceptance and resilience. The feature of relationships, whether with family, friends, teachers or disability health workers, was authenticity and being face-to-face; *"And not just pseudo-socialise like on the Internet or something, but actually face-to-face like right now, like an exchange"* (Male, 24). Significant limitations for participants with a disability were low levels of social participation. The contributors to social isolation were *Social/Cultural* and *Medical/Physical* in nature. These subthemes included bullying, social exclusion, low self-worth, lack of confidence, shame, stigma (*Social/Cultural*),

lack of modified equipment or environment, and physical limitations (*Medical/Physical*). Table 4 includes examples of facilitators and barriers to health and wellbeing within each category: *Social/Cultural*, *Medical/Physical* and *Material/Environmental*. These examples summarise the subthemes raised by all participants on discussions about the facilitators and barriers to health and wellbeing for the case studies and characters with disabilities.

Table 4. Facilitators and barriers to health for Aboriginal people with a disability

Category	Facilitators	Barriers
Social/ Cultural	Cultural identity Disability awareness Diagnosis and acceptance Education, teachers Employment, finance Family Friends, mentors Participation, hobbies, pets Self-worth / self-affirmations Spirituality / healing / faith Resilience Routine	Loss of culture / identity Lack of disability awareness Stigma associated with diagnosis Low education, no mentors Unemployment, poverty Family death, breakdown or overprotectiveness Social isolation, boredom, bullying Low/ negative participation, antisocial groups e.g., drugs Negative self-worth No spirituality Poor emotional regulation Dynamic or unstable lifestyle
Medical/ Physical	Access to professionals and services e.g., surgery Avoiding substances Physical activity, nutrition, healthy lifestyle, sleep	Low access to health and disability services Substance use and abuse Physical inactivity / limitations, poor nutrition / diet, lifestyle, poor sleep
Material/ Environmental	Accommodation Accessible resources e.g., sign language Accessible built environment Modifications and health equipment e.g., wheelchairs	Housing issues Lack of resources Environment with poor access e.g., no ramps at sport clubs Fixed environment, no equipment (financial costs)

The three aspects of the Trichotomy Model, *Social/Cultural, Medical/Physical* and *Material/Environmental,* are not mutually exclusive. For example, violence and drugs impacts all three areas. Alcohol abuse as a social issue has social consequences, such as poverty (via unemployment or poor health) and physical consequences, such as FASD (*Medical/Physical*). This also impacts the childhood learning environment with consequences for future generations (*Material/Environmental*).

Significant barriers to health for Aboriginal youths were *Social/Cultural* factors such as family breakdown and low levels of social participation. A breakdown in family and culture was disabling for all participants, regardless of their physical state of health. Although *Medical/Physical* features were real barriers for participants with a disability, discussions revolved predominately around the *Social/Cultural* aspects. On the inverse, family, identity and connection to culture were active facilitators to health. The key facilitator for health for all participants was family. Family meant belonging, acceptance, culture and identity. Key facilitators for participants with a disability were high self-worth, acceptance and resilience. A sense of high self-worth came predominately from family and culture.

The key difference for children with a disability was the physical and social aspects of their disability. A participant stated *"the things that make me sad are being teased, being left out um, abuse and bullying and the things that make me happy are spending time with my family, friends, my pets and doing fun activities with them"* (Female, 10, physical disability). A lack of social acceptance and participation in social activities was the greatest barrier for youths with a disability with limitations being both physical and social in nature. As a result, resilience was an important feature for participants with a disability; however youths without a disability also exhibited strengths of resilience against peer pressure and family conflict for example. In summary, S*ocial/Culture* aspects were the most important facilitators and barriers for all participants.

4.4 SECTION C – Causes of Disability

The causes of disability were explored using disability stories to elicit conversation. After reading and viewing stories of Aboriginal people with disabilities participants were asked *"Why do you think kids like <character's name> are born this way?"* Discussions regarding the causes fell into one of five key themes. They are, listed in descending frequency, the following: (1) abuse, (2) birth complications and genetics, (3) environmental factors, (4) Aboriginal cultural factors and (5) unknown factors. The ranking of frequency was determined by not only the number of referenced excerpts (quotes or items), but by the number of sources (yarning circles) in which each theme appeared.

4.4.1 Theme C1: Abuse

The theme abuse was the most commonly raised cause of disability as identified by participants. Abuse included either physical or substance abuse experienced by the mother. Substance abuse included the use of alcohol, tobacco and other drugs. This theme also included situations where mothers used alcohol or drugs but were unaware they are pregnant. In these scenarios, parental blame was not as severely associated. It also included being around drugs, such as marijuana smoke, that would adversely affect a pregnant women. Participants spoke about domestic violence, substance use and abuse in the following excerpts.

> *"Mainly alcohol and drugs I guess."* (Male, 16)

> *"Being around too much smoke, gunga <marijuana>… When he's meant to be on the bottle <bottle fed>."* (Male, 16)

> *"His mum might have done something wrong… She might have been drinking alcohol… Smashing speed… A drunken person bumped her… Drunk person might have punched her in the guts."* (Male, 18)

"Like people sometimes have pregnancy when they're on drugs and it spreads." (Female, 10, sensory disability)

"Not knowing your pregnant and like doing stuff [drugs]." (Female, 11)

"The mum could be doing drugs or anything and just forget that they are pregnant, and when they realise they have the baby, then the baby's got brain damage or something." (Male, 14, sensory disability)

"Maybe because of the mumma… I don't know, maybe she was drinking or something, or drugs… maybe mum was eating the wrong food." (Male, 16)

"So it comes back to health… How your parents, look after themselves what you're in the womb… That affects the baby." (Female, 22)

"If the woman is not looking after herself while she's pregnant, and he's doing all those drugs and all that drinking and like she got beaten up by her boyfriend or her husband or something it's not going to be good for the baby." (Male, 22, FASD)

Domestic violence or physical abuse was closely linked to substance use and abuse. Therefore these themes were categorised together, and physical abuse was categorised separately from accidents. A later theme, environmental factors, included accidents such as motor vehicle accidents. This latter theme did not associate any blame or shame. Participants talked about physical abuse in the following excerpts.

"Being beaten." (Female, 11)

"They probably had violent people around." (Male, 18)

"Or if babies are a newborn their heads very delicate so if you shake it too much their brains just like an egg and it will affect their brain if you shake them too much or drop them or something like that." (Female, 10, physical disability)

"Like their parents fight all the time and it hits them in the guts, and they might accidentally hit the baby…When their husbands hit them in the wrong place, in the stomach." (Female, 10, sensory disability)

"Yeah that [physical abuse] happened in my family." (Female, 14)

4.4.2 Theme C2: Birth Complications and Genetics

The second most frequency theme for the causes of disabilities included subthemes of birth complication, genetics, mutations and other natural causes. . Some participants associated genetic or hereditary causes with some parental blame associated, while other participants did not.

"Sometimes it could have been how they were born... How they was produced." (Male, 16)

"Parents born with that disability as well." (Female, 14)

"Passed down from some family member, had some sort of disease..." (Female, 22)

"Could have run in the family or something… Spinal cord could have been around his neck." (Male, 18)

"They were born like that… Natural causes." (Male, 18)

"Some of it can be natural… Sometimes it could sort of be a mistake." (Male, 22, FASD)

"Mutation or something… Genes… Just bad luck really… It can be hereditary… I don't really have any stories on disability either… How things came to be, but nothing on with just disability or mental handicaps. It would be interesting, to find out how it was treated, back like 3000, 8000 years ago. I think that disability still probably existed back then, genetic defects, even though they just lived a much healthier lifestyle off the land." (Male, 24)

"They have a deformity in the face because they have an extra chromosome." (Female, 10, physical disability)

Birth complications included lack of oxygen and premature birth; environmental hazards included noise pollution, food poisoning or poor parental diet. Within this theme there was indirect blame on the parents, but not necessarily shame or stigma for the child with a disability.

4.4.3   Theme C3: Environmental Factors

The theme, environmental factors, included examples such as motor vehicle accidents, animal attacks, non-genetic disease or environmental hazards (e.g., food poisoning, pollution).

"You might have been in a car crash when you were pregnant." (Female, 11)

"Being attacked by something, dog, shark." (Male, 15)

"The baby was just about to be born she might had like food poisoning." (Male, 16)

"Well maybe with hearing problems when the baby is born it's only a newborn, they could be maybe shouting or a really loud noise that can affect their hearing because they're eardrums would only be very… Delicate." (Female, 10, physical disability)

"A deficiency with the body sometimes…. Just the way the body develops... Yeah the health of the woman sometimes, and the environment… Like sometimes it could be an accident." (Male, 22, FASD)

"The mum might have missed heaps of her appointment… For needles." (Male, 9, physical disability)

Factors within this theme were mainly accidents, which by definition did not associate blame or shame. Although the final quote above does not explicitly describe blame or shame on the mother, it may be deduced indirectly as blame, depending on the reasons of medical non-attendance.

4.4.4 Theme C4: Aboriginal Cultural Factors

Aboriginal cultural factors were still prevalent in the views of metropolitan youths. These included payback and curses (or being sung), wrong-way marriage and other violations of traditional lore.

> *"They might have a curse… It does happen… A curse… Like someone could have sung them… Some Aboriginal people can put curses on you… Like Wongi's… They're very spiritual."* (Male, 13)

> "*Cause sometimes it could have been how they were born… Wrong way [marriage]."* (Male, 16)

> *"Sung… They might have done something wrong… Because they might want you… Some of them do it just because they want you… They do it because their family might have done something wrong… Payback and all this."* (Male, 18)

> *"I think in Islander as well, these kind of kids come out when like two cousins are in a relationship… That blood connects together*." (Female, 22)

The cultural causes of disability may have been positive or negative, with the participants theorising that some tribes may have associated a special meaning to disabilities. Other participants associated neither a positive or negative slant, but accepted different abilities to be a natural part of life. The following quotes highlight the relevant themes.

> *"Because they're marrying the wrong skin, like say they were wrong way of marriage, and the wrong skin group… You've got just four*

skins, these two can always marry, and these two can always marry but if this one goes to that one, the kids will be… Now when they marry wrong way their kids will end up affected, they will not be fully all there, they will have like disability… If you were to have sexual relationships, with your wrong skin groups, if I was to have sexual relationships with my cousin, then we would have had a kid that's disabled… I believe, back in the old ancient days… They might have thought it might have been, a very special child." (Male, 25)

"If they were coming from a spiritual sense, that either they're really special, or either there's something, there was like a – and I'm not saying this – but either like really special, or like a curse; or something bad that the family did or something. I have heard that before but I don't know…. I have just heard that if the parents are too closely related. I've heard that… Well with Noongar, I guess because we lost a lot of our… Actual cultural practices, we don't do skin – well I don't know the skin stuff; but yeah too closely related." (Female, 26, sensory disability)

Aboriginal cultural beliefs included curses due to pay-back and wrong-way marriage (of cultural skin groups).

4.4.5 Theme C5: Unknown or Unspecified Natural Causes

Some participants were unable to articulate specific causes, but expressed disability as an expected part of life. This fatalistic notion placed no blame on parental behaviour, health or lifestyle.

"Sometimes it's like the unknowns of the unknowns." (Male, 13)

"It's just the way they were born, so they can't help it if they're in wheelchairs and they can't talk it's not their fault it's the way that they were born." (Female, 10, sensory disability)

"People get sick, and that's just a part of life. So I guess with people having disabilities, it doesn't happen to everybody but it can happen, and it does happen, yeah." (Female, 26, sensory disability)

These unspecified causes of disability placed less emphasis on shame or parental blame.

4.4.6 Section C Summary

The five final themes were compared against each participant. For every participant, their perceptions were categorised and checked off down a frequency list. The list provided the frequency of each theme, with a comparison between participants with and without disabilities conducted. This is illustrated in Figure 10 where the five common beliefs of the causes of disability are listed from least to most commonly considered.

unknown causes*

Aboriginal cultural factors

accidents, hazards and disease*

genetics, birth complications*

abuse (e.g., drugs, DV)

Frequency

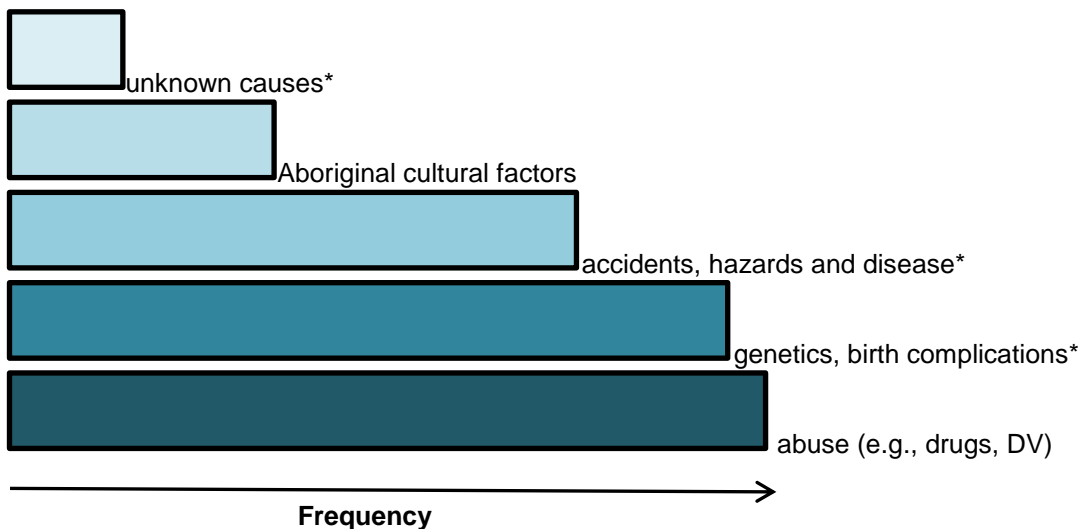**Figure 10.** Beliefs of the causes of disability

* little or no shame associated. DV = domestic violence.

Interestingly, 'unknown causes' were mentioned only by those with a disability. This may be due to personal stigma and shame experienced by those with a disability. The 'Aboriginal cultural factors', subcategory was mainly held by youths without a disability (86% versus 14% with a disability).

114

This may be due to those with a disability having a greater understanding of the medical model of disease and disability. 'Accidents, hazards and disease' were mentioned more frequently by youths without a disability (60% versus 40% with a disability). Participants with a disability were almost as likely to identify 'genetics and birth complications' as their peers without a disability (42% with a disability versus 58% without a disability). 'Abuse' as a cause of disability was identified more frequently by youths without a disability (65% versus 35% with a disability).

It is important to note the beliefs that attribute blame and those that do not. In the above themes, there was a mix of parental blame and no parental blame. No parental blame was linked to items such as car accidents and birth complications. Parental blame was associated with the factors such as poor lifestyle, substance abuse and domestic violence. Some participants identified the root causes of substance abuse as stemming from living a 'hard situation'. This may include historical trauma, breakdown in family and culture and transgenerational violence. However, in cases of drug and alcohol use and abuse, there was some element of parental blame and shame. In the current study the following causes were associated with shame: cultural factors (e.g., transgression of lore by a parent), genetics (e.g., passed down from a parent) and abuse (e.g., alcohol and drug abuse, and domestic violence). The quotes below emphasise parental blame and stigma (emphasis added):

> *"Because their parents weren't really that healthy when they were pregnant so they come out; **because their mum wasn't really good parents when they're pregnant**, the kid wouldn't live a successful life as the mother really wanted him to because she has been doing that stuff; and then they get that, they probably in a wheelchair for the rest of the life and have a disability."* (Male, 14, hearing impairment)

> *"Because their parents been having drugs or drink and they like could have a hard situation in their lives when they grow older, and then something bad could happen and they're just like; then **their mum or dad would get the blame** if they're born too tiny and they come out*

too tiny, and then they could get sick if they got alcohol or drugs in their system… um, like their parents fight all the time and it hits them in the guts, and they might accidentally hit the baby." (Female, 10, hearing impairment)

Yarning circles identified several factors about the causes of disability. Some of these factors had an element of parental blame, while others had none associated. For many Aboriginal people, family issues remain private and within the family or community.

In summary, most participants associated disability with abuse, which associated stigma and shame for the family. Other causes that were associated with shame included Aboriginal and cultural factors. In some cases genetic causes were linked to shame or parental blame, however generally no blame was linked to birth complications. Causes which were due to accidents, hazards or disease had little or no shame associated. These results highlight that cultural beliefs of disability, such as payback, are still prevalent today in Aboriginal urban communities. Lastly, unknown causes of disability placed no shame or blame on the parent or person with a disability. It is important to note that this category ('unknown causes') was only identified by participants with a disability. These five categories of the causes of disability had a varying mixed of shame and no shame associated. Parental blame and stigma can be a major barrier for families accessing disability services. Service providers that are aware of the varying beliefs of the causes of disability will be able to provide culturally safe services and supports.

4.5 SECTION D – Emotions about Disability

During the yarning circles, participants spoke about the difficulties associated with living with a disability. Conversations revolved around the disability case study and stories, with the yarning often unfolding to include personal experiences. This was more explicitly investigated using evocative cards.

Participants responded to a range of cards displaying a variety of emotions. Below is a quote by a participant regarding living with a disability.

> *"Some people when they see someone with a disability or in a wheelchair they point that kid out for his disability like if there was a boy with Down syndrome and they would say 'Oh look at that kid with Down syndrome', they wouldn't recognise him by his name, they'll just say that kid with Down syndrome… I don't think that'll be very nice, because they should recognise him by his name and his personality not the disability that he has."* (Female, 10, physical disability)

4.5.1 Resilience and Loneliness

Living with a disability included topics of bullying, rejection by peers and society, access issues, isolation (both physical and social e.g., poor wheelchair access and games with unmodified rules). The lack of understanding about a disability in mainstream society was raised as causing social isolation and misunderstandings. Emotions with both positive and negative associations were shared by all participants. Positive emotions associated with disability were feelings of love, protection, happiness, and resilience. Negative emotions included sadness, anger, hurt, rejection, isolation, powerlessness, worry and fear. The following word frequency cloud, Figure 11, depicts the different emotions shared by all participants. The words larger in size are the terms more frequently raised.

Figure 11. Emotions on disability stories as shared by all participants

Emotions of youths with and without a disability are again depicted in the word frequency clouds below. Figure 12 illustrates the emotions of participants with disability and Figure 13 depicts the emotions of participants without disability.
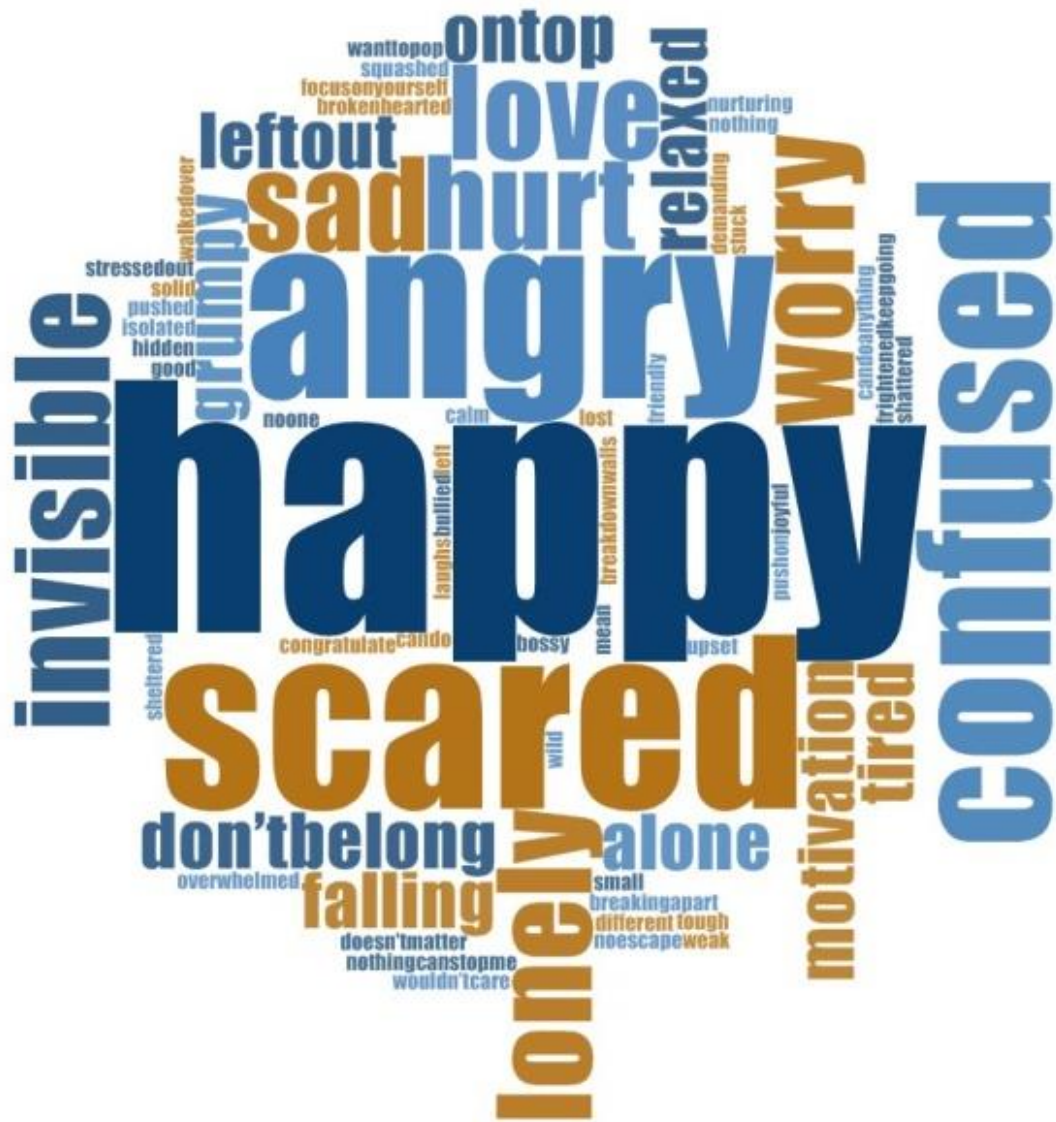
Figure 12. Emotions shared by participants with a disability

During discussion on disability, happiness was featured by all participants which may be attributed to the focus on the strength based stories and visual aids chosen in the study. Notably however, happiness was more frequently mentioned by participants with a disability, which may be associated with the support they receive (from family, friends or services). Other common emotions of youths with a disability included scared, angry, confused, invisible and lonely (Figure 12). These are comparable to the terms shared by youths without a disability: angry, broken, worried and alone (see Figure 13)

Figure 13. Emotions shared by participants without a disability

4.5.2 Personal Experiences

The use of disability stories enabled participants with disabilities to speak about their disability without directly highlighting their condition. Discussions relating to the disability case studies eventually led to conversations about their own disability. In some instances participants were hesitant to explicitly articulate their disability, however towards the end most of the participants with a disability spoke openly about their condition. Some younger male participants did not openly identify themselves as having a disability, which

may be due to the mixed setting with males and females. The excerpts below demonstrate participants' experience about disability and the approaches when talking about disability (emphasis added).

> *"I used to have that because **I had – yeah, problems too**, but now it's like wared [sic] off and I've got better hearing now."* (Male, 14, sensory disability)

> *"Sometimes I do feel **different from the others**… Quirky, strange or sometimes I do feel a bit different."* (Female, 10, physical disability)

> *"It takes a long time I reckon [to gain confidence]. Like in primary school, I didn't, it didn't bother me that much I think, it didn't bother me too much but if I thought about it too much, or if I really couldn't hear things I would feel a bit stupid, but it wasn't a constant, consistent feeling, it was every now and then. **It would rear its ugly head**, 'I can't hear what you're saying'."* (Female, 26, sensory disability)

An underlying sense of stigma or avoidance to use the word disability may be linked to some of the beliefs about the causes of disability which elicit shame or blame (emphasis added).

> *"No one really talks about it that often; unless you ask these questions. You kind of just think, oh it's happened, and people kinda of **deal with – you know – in their own way**. You know, people can be quite private as well about it. But I guess in some communities, they don't see it as really different, or as a disability."* (Female, 26, sensory disability)

Discussions on disability by participants with a disability also had an emphasis on acceptance and resilience (emphasis added).

> *"I was really **desperate to know about my own disability** you know. My mum and dad told me bits and pieces, but my mum told me a lot more… Now I understand why she was so hard on me and that."* (Male, 22, FASD)

121

This participant shared his lack of understanding of FASD and the quest to gain greater self-awareness. It is possible that the stigma associated with alcohol consumption and FASD created a childhood experience in which his disability was not spoken about. Where participants knew more about their condition, they were better able to inform their peers and family. Awareness also assisted participants to better articulate their experiences and regulate their own emotions more positively. Participants with a disability shared their ideas on the word disability:

> *"I think people shouldn't be dissing your ability."* (Female, 10, physical disability)

> *"I don't really mind as long as they care about the disability."* (Male, 14, sensory disability)

> *"For other people [disability] it's, it's a big deal for them, but for other people who want to learn to understand, it's not a big deal… these days, you know. You've got to learn to understand it, take steps… I felt really relieved about it, yeah. I'm really sorry about that [crying]… seeing a video like that… it makes me want to do more… this is the first time I've actually broke down in front of someone because of how relieved I was… just watching the DVD and like to see those guys saying like 'you got to keep pushing on, it doesn't matter how hard life is'… I've been saying that to myself a lot too… disability isn't what you are… you accept yourself for who you are."* – (Male, 22, FASD)

> *"I guess growing up… yeah you don't want to feel different, you wanna feel normal. But as an adult I'm like 'well what's normal?', you know, there's not really any normal… No one's normal (laughs); which is good, a good relief."* (Female, 26, sensory disability)

4.5.3 Section D Summary

The emotions in the word frequency clouds are listed descriptively in Table 5.

Table 5. Emotions associated with disability clustered into similar phrases

Themes:	Youth with disability	Shared terms (exact)	Youth without disability
Happy, loved, protected	Joyful, calm, good, love, lovable, nurturing, sheltered, friendly, relaxed	Happy, loved	Lovely, supported, cuddled, protected
Strong, confident, resilient	On top, tough, break down walls, don't worry, laughs, can do anything, wouldn't care, solid, congratulate, can do, keep going, motivation, nothing can stop me, push on, focus on yourself, doesn't matter		Confident, act normal, dominant, strong, powerful, useful, tough, amazed, overcome, don't care, don't worry, sitting back, laidback, stand up, bounce back, working on small things, looking at the best
Sad, hurt, angry	Demanding, want to pop, wild, shattered, grumpy	Sad, down, upset, angry, hurt, bossy, mean	Sorry, depressed, sick, dumb, bored, cranky, aggressive, mad, annoying, ashamed, disgraced, bitter, nobody, frustrated
Rejected, isolate	Bullied, left out, isolated, don't belong, broken-hearted, hidden, small, walked over, different	Alone, lonely, invisible,	Unprotected, abandoned, transparent, unseen, alone, isolated, in a shell, nobody cares, hiding, judged, different
Powerless, broken, tired	Weak, stressed out, falling	Tired	Drained, rundown, exhausted, faulty, squashed, cramped, trapped, crushed, broken, crumbling, hollow, clumsy, heavy, stuck, wrong track, can't move, pressured, boxed, up, hiding, don't want to be in the world, running away, in the ground, die, weight of the world
Lost, scared, frightened	Overwhelmed, lost, confused, where to start, nothing, no one, pushed, no escape, breaking apart, squashed, stuck	Scared, frightened, worried, don't know	Nervous, under a rock, on edge, all over the place, unsure, whatever, confused, wondering

Table 5 has the similar terms clustered together. This table provides another visual overview of the terms associated with disability that were mentioned by participants with a disability and without a disability. The first two rows of Table 5 are positive associations and the four bottom rows, negative terms. This table reiterates that positive words (e.g., 'loved' and 'resilient') were somewhat more common for participants with a disability; and negative terms (e.g., 'sad' and 'broken') were more frequently mentioned by participants without a disability. Although youths with a disability experienced greater social isolation and lower social participation, there was a stronger sense of resilience and optimism (or happiness).

Under stressful events, positive perceptions can assist as an adapting or coping mechanism against depression as individuals and parents claim control and mastery (Gupta & Singhal, 2004). Hastings and Taunt reviewed existing literature that used positive questions about the perceptions and experiences of families of children with developmental disabilities. It was found that studies suggested that positive perceptions may be a resource factor or outcome for families (Hastings & Taunt, 2002). The strength-based approach of this current research may have also contributed to the high frequency of positive terms noted, particularly by participants with a disability. Moreover, participants with a disability who had positive experiences could have been more likely to engage in this study, compared to those who did not self-identify as having a disability, or experienced negative emotions or shame.

4.6 Trichotomy Model of Facilitators and Barriers to Health

This chapter has outlined the four research areas explored within the yarning circles: A) definitions of health and wellbeing, B) facilitators and barriers, C) causes of disability and D) emotions associated with disability.

The following Trichotomy Model, Figure 14, illustrates the research that explored the definition of health and wellbeing and the facilitators and barriers. Participants in this study emphasised that the most important

facilitators were *Social/Cultural.* A strong family was connected to a *strong body, mind* and *spirit/culture*. Other *Social/Cultural* factors include Elders, Country and identity. Facilitators for Aboriginal youths were predominately *Social/Cultural* in nature, as depicted by the larger base. These factors lead to youths having a *strong body*, *mind* and *spirit/culture* – that is, greater health and wellbeing. Where children and young people were loved by their family, they felt secure in *body*, *mind* and *spirit*. Where they were enabled to build self-worth, resilience and security, they felt strong within themselves. *Medical/Physical* aspects, such as access to medical care were more vital in the provision for a *strong body*. Physical health was an important and obvious pathway to health, with medical facilitators aiding a *strong body*. *Material/Environmental* facilitators included finance, accessibility and the built environment. Although these factors were important in facilitating wellbeing, they were not mentioned as frequently by youths as *Social/Cultural* factors.

Figure 14 illustrates that, as seen with the facilitators, the key barriers to health were also *Social/Cultural* factors. For example family breakdown, lack of meaningful relationships, social isolation, low participation in activities and poor disability awareness were commonly noted as critical barriers. The basic need for security, self-worth and significance are ultimately met within family and culture via belonging and identity. Where these features were missing, participants experienced ill health. Other barriers, *Medical/Physical* and *Material/Environmental*, include inadequate access to healthcare or an inaccessible physical environment. An absence of these barriers (or the presence of the facilitators) indicated health and wellbeing. Although a young person may face challenges and barriers through childhood and adolescence, a strong family created a space of acceptance, belonging and identity. Family was the key subtheme of *Social/Cultural* factors for all participants.
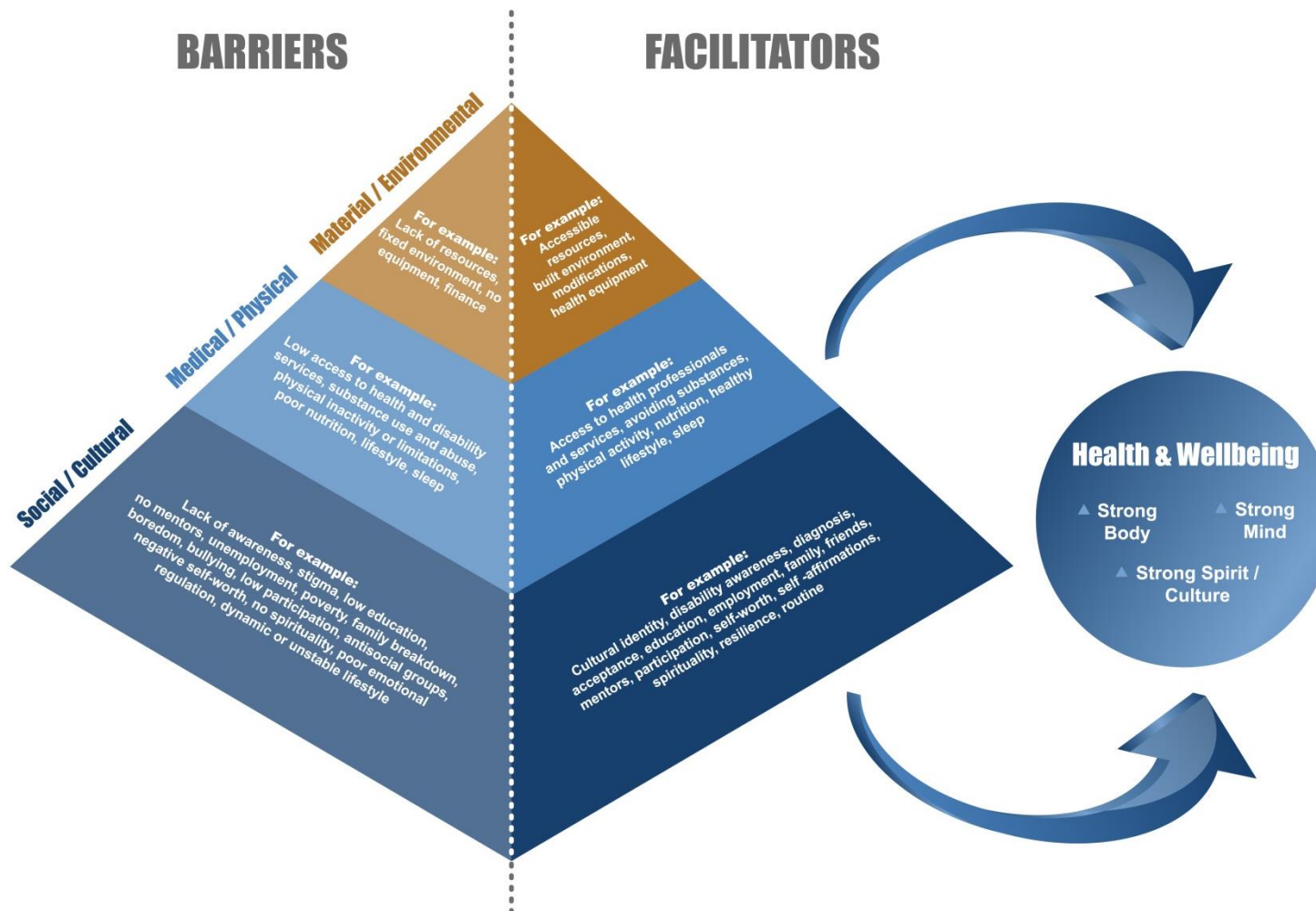
BARRIERS

FACILITATORS

Material / Environmental

For example:
Lack of resources, fixed environment, no equipment, finance

For example:
Accessible resources, built environment, modifications, health equipment

Medical / Physical

For example:
Low access to health and disability services, substance use and abuse, physical inactivity or limitations, poor nutrition, lifestyle, sleep

For example:
Access to health professionals and services, avoiding substances, physical activity, nutrition, healthy lifestyle, sleep

Social / Cultural

For example:
Lack of awareness, stigma, low education, no mentors, unemployment, poverty, family breakdown, boredom, bullying, low participation, antisocial groups, negative self-worth, no spirituality, poor emotional regulation, dynamic or unstable lifestyle

For example:
Cultural identity, disability awareness, diagnosis, acceptance, education, employment, family, friends, mentors, participation, self-worth, self -affirmations, spirituality, resilience, routine

Health & Wellbeing

▲ Strong Body   ▲ Strong Mind

▲ Strong Spirit / Culture

Figure 14. Trichotomy Model of facilitators and barriers to health and wellbeing for Aboriginal youths with a disability

126

Health and wellbeing were categorised into three parts, *body*, *mind* and *spirit/culture,* which interact in unison. The deep connection between Aboriginal culture and spirituality is represented by the mix of these two elements. The spirituality mentioned by participants also included faith and religion, which was not mutually exclusive from Aboriginal spirituality. A *strong body* was associated with the external and physical part of self. A *strong mind* was discussed in reference to mental health, resilience and self-awareness. The *strong spirit/culture* is the invisible part of the personhood that is linked to Aboriginal Elders and Country. This trinity which cannot be divided embodies the person. The three parts in unison make up health and wellbeing, as illustrated in Figure 15.
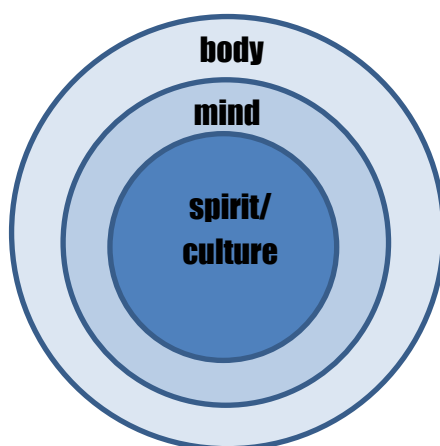

Figure 15. Health and wellbeing: a strong body, mind and spirit/culture

4.7 Summary

While health and wellbeing can be described as three parts, body, mind and spirit, they are not individual states of wellbeing, but something that has a mutual and reciprocal dependency on each other, family and community. Similarly, the Trichotomy Model representing *Social/Cultural*, *Medical/Physical* and *Material/Environmental* aspects are holistic. Although *Social/Cultural* factors are dominant, it is a combination of these three categories that promote health and wellbeing. The connections between and within the items, make up an ecosystem of wellbeing. To propose a single

model of best practice detracts from the fact that people with disability and Aboriginal people have heterogeneous and diverse lives linked to the past and present. Definitions of traditional and contemporary Aboriginal communities are somewhat vague and undefined, as culture is dynamic rather than static. Any model or framework depicting Aboriginal health or people with disability must recognise diversity and promote both personal and collective agency.

To address one of the issues with little concern for the other facets is contrary to holistic wellbeing. Facilitators that were significant to Aboriginal youths with and without a disability were *Social/Cultural* elements, such as participation in activities, strong family and connection to Country. As expected, participants with disabilities experienced greater social barriers such as low participation and social isolation. However, family, positive self-perceptions, culture and spirituality (leading to resilience) were seen as protective factors for holistic health. Where these elements were evident, youths with a disability lived a good life. A variety of beliefs on the causes of disability also impacted acceptance and shame, having negative implications on disability service access. That is, ideas that saw parental behaviour as the cause of disability may lead to shame, which in turn may result in low service access and health outcomes. Other facilitators and barriers, categorised as *Medical/Physical* and *Material/Environmental*, were important in promoting health and wellbeing. Mainstream professionals and the health systems that recognise culture and spirituality together with physical development and mental health can provide a more culturally responsive service.

5 CHAPTER 5 – DISCUSSION

5.1 Introduction

Literature and statistics on Aboriginal populations worldwide share a story of disproportion in major health outcomes, chronic conditions and disability. Within the rich diversity of culture, language and tradition there is a common thread of inequity, injustice and resilience of Aboriginal people. In Australia, although levels of disability in Aboriginal people are said to be nearly twice as high when compared to non-Aboriginal Australians, actual rates remain uncertain as figures may be distorted by non-response, failure to disclose Aboriginality, and bias of respondents. Service providers should develop systems, policy and models based on consumer research including youth and cultural aspects. Recent literature has seen a trend in children and young people's perspectives on health, with their opinions becoming increasingly integral to policy development. These results highlight unique factors to consider when delivering disability services for Aboriginal youths. Essential elements of service delivery models include policy, education and training, systems and infrastructure. Key themes from the findings of this study can assist in the design of future research in this area and guide recommendations for disability service delivery. Findings of the study confirm findings of other studies, including those carried out with adult participants. This chapter highlights the findings that were presented in the previous chapter, with reference and comparisons to existing literature to provide a greater overview of Aboriginal health, wellbeing and disability in Australia.

5.2 Talking about Health and Wellbeing

Participants in this study emphasised the role of family on health and wellbeing. Family members, such as mothers, fathers and grandparents were important in providing the physical and environmental support required. Youths mentioned how the choices of parents (e.g. diet, exposure to drugs

and alcohol) had direct impacts on the physical health – that is a *strong body*. Physical activity and fitness were facilitated through social groups such as football and basketball and had positive impacts on belonging, identity and acceptance. Parents as well as extended family members such as cousins, aunties and uncles were important in fostering a *strong mind* and *strong spirit/culture*. Connection to family was integral for Aboriginal youths to know their cultural links. These links created belonging, identity and acceptance, which were important for the mental health and spirituality of participants. Other relationships, such as friendships and support from mentors or teachers also enabled participants to live a strong life. Negative relationships with family and non-family members had poor outcomes for participant's mind and spirit – or mental health. For example one participant with a disability described a teacher as a bully. This was first identified in the art ice breaker activity and further discussed during the research yarning. Bullying had negative impacts on social attendance and peer relationships in school. Bullying from peers at school was also an issue for participants with and without disabilities. Youths with a disability experienced covert and overt bullying. For example passive social isolation and being excluded from activities to physical bullying. Some participants had family and friends under the 'sad face' column and spoke of the negative impact that fighting and arguing had. Relationship breakdown within family sometimes also isolated children and young people to connect within the immediate family structure. Where this occurred, youths often sought support from other family members or mentors for example. As discussed previously, bullying is a social barrier to wellbeing as it often leads to isolation (see 4.2.2, 4.3.1, 4.5.1). It was also found that youths who had experienced adversity, due to disability, were also in many ways resilient (see 4.5.1).

The drawings during the icebreakers also had family and friends as positive influences under the 'happy face' column. Positive relationships were paramount in facilitating participants to live a strong life. Overall, all participants described health and wellbeing as encompassing physical health and a striving for a strong mind, spirit and culture. Some of these factors are similar to the findings of Fattore, Mason and Watson (2009) who investigated

non-Aboriginal children's views on what constitutes wellbeing in *When Children are Asked about Their Well-being: Towards a Framework for Guiding Policy*. The key factors of wellbeing included relationships with others, agency and control, and safety and security. The point of difference in the current study with Aboriginal participants was the emphasis on a *strong mind* linked to a *strong spirit/culture*. Health and wellbeing were linked to several factors including nutrition, physical activity, sleep, relationships, self-worth, acceptance, culture, acceptance, identity, resilience, respect and faith or spirituality. Family was the key source for strong culture, self-worth, acceptance, identity, resilience, respect and spirituality. In summary, the *Social/Cultural* facilitators and barriers, such as family and other relationships were integral to the wellbeing of Aboriginal youths.

Aboriginal children and young people surveyed in the current study echo the findings reported in existing literature on wellbeing. The Commissioner for Children and Young People (CCYP) conducted a WA state-wide survey with children and young people aged 10 to 17 years (CCYP, 2010). Both Aboriginal and non-Aboriginal youths were engaged in an online survey and focus groups. More than 500 youths participated in an online survey where 6.4% identified as Aboriginal. Of the 300 children and young people engaged in focus groups, 14.8% were Aboriginal. Key themes from these consultations on wellbeing included the importance of a) culture and identity, b) education and c) family. Culture and identity were linked to wellbeing, that is, traditional knowledge and values, respect for Elders, sharing, being close to family, language, law, connection to the land and participating in cultural activities. Having a strong cultural identity was directly related to wellbeing.

The importance of family, culture and identity were found in the CCYP study as well as the current study (as seen in 4.2.2, 4.2.3 and 4.3.1). However, CCYP did not report on the voices of Aboriginal children with disabilities. Family was raised as being important because it allowed a safe home, support, role models and good memories (CCYP, 2010). Extended family members were also active in the care of Aboriginal children and young people. Youths valued family because of parents and family members who

were there to help and support them. Participants identified that parents were the fundamental factor in influencing health and wellbeing for Aboriginal youths. A more recent study by the CCYP engaged 1,271 Aboriginal children and young people statewide, but again did not report specifically on Aboriginal youths with disabilities (CCYP, 2015). Participants highlighted focus areas for health and youth service to consider. These important areas included family, community, culture, education, recreation, racism and reconciliation (CCYP, 2015).

As family and parents are a significant facilitator and barrier to wellbeing, a breakdown in family and a loss of culture has vital implications for Aboriginal children and young people. In WA, more than one-third of Aboriginal families were one-parent families and had a higher percentage of step and blended families than non-Aboriginal families (Zubrick et al., 2004). For all WA families, one-parent families are less than one-fifth of the total population. Colonisation and past practices of the forced removal of Aboriginal children have impacted on family structure (Australian Indigenous Health InfoNet, 2015). It is imperative to note the social and historical context in Australia and its ongoing impact on health, wellbeing and disability. The introduction of alcohol, transgenerational trauma, removal of children and poverty has links to colonisation. These negative implications on the *Social/Cultural* components translate to negative health outcomes experienced today. This is illustrated by the fact that the two most common types of disabilities included in this study were FASD (associated with alcohol use) and hearing loss associated with otitis media (which is influenced by poor living conditions).

Education was identified by the CCYP study as essential for gainful employment and a pathway towards a better life (CCYP, 2010). School was also acknowledged as necessary for literacy and numeracy skills as well as fostering friendships. Distinguished from non-Aboriginal participants, Aboriginal youths saw education as something to aspire to rather than an automatic possibility. Results from the CCYP study identified education and employment as pathways to a secure life (CCYP, 2010). Poor education and

employment were barriers to health and wellbeing. Similar to these findings, participants in the current study, acknowledged school and education as important to overall wellbeing (e.g. via financial security and engaging the mind). Older participants enrolled in universities seem to have more motivation and drive to continue with studies. Youths in both primary and high schools noted homework as a negative part of their day however recognised the importance of education. As one high school participant mentioned: "s*ometimes I'm happy when I don't go to school but sometimes I just want to go to school and get a good education.*" (Male, 14, sensory disability) Some participants were not engaged in education after leaving high school and some struggled to write, spell and read the stories used in the yarning circles. Aboriginal stakeholders involved in participants' lives commented on the possible missed diagnoses of learning disabilities and FASD. Education was an important element for living a strong life.

The facilitators and barriers, *Social/Cultural Medical/Physical* and *Material/Environmental*, are interconnected to a *strong body, mind* and *spirit/culture.* For example, low educational attainment and absence from school can often be exacerbated by barriers associated with a poor home and private life (Priest et al., 2012). Poor literacy translates to low health literacy, unemployment and poor health outcomes (O'Neill et al., 2004). School absence can also be impacted by *Medical/Physical* barriers, such as health complications for people with disabilities. *Material/Environmental* barriers include the environment of the disability sector, for example, policies in disability services that do not provide sufficient support for Aboriginal carers to access services. Other *Material/Environmental* factors (e.g. wheelchair accessible sports centres) can impact social aspects such as participation. Social participation and inclusion are linked to a *strong body, mind* and *spirit/culture.* Success in education and employment is facilitated by family, peers and other *Social/Cultural* factors. These factors are the key facilitators and barriers for Aboriginal youths in current and past research.

Existing literature identified a number of factors contributing to low service access by Aboriginal families, all of which have *Social/Cultural* links. They

included low income, gender, stigma, shame, abuse, grief, family allegiances and lack of awareness (DSC, 2006; Nelson & Allison, 2004; O'Neill et al., 2004): In the current study, participants spoke of low income as a barrier. This was expressed around discussions of Centrelink (welfare payments), the desire for employment and the cost of living with a disability, especially those living in regional areas.

> *"It is also expensive… You get your medication in the big major cities, you go remote community and you get the bill and you've got $35… And the thing is, job wise, in the remote community, most of them got, there's less opportunities."* (Female, 22)

Similar to the existing literature, stigma, grief and shame were barriers for people with a disability as identified in the current study. One participant with FASD shared how his mother provided little information about his condition due to the stigma and grief associated. *"I was looking for it [information] because I was so desperate at the time… Yeah it helped me a lot."* (Male, 22, FASD). It was through his own search for information that he understood his condition and received the support he required.

An Australian qualitative study investigated Aboriginal perspectives of child health and wellbeing in an urban setting (Priest et al., 2012). Key areas identified included: *strong child, strong environment* and *strong culture*; as well as *strength and challenges.* The study engaged Aboriginal adults (parents, guardians and child health workers), but did not involve Aboriginal youths. Figure 16 summarises the key themes identified by Priest and colleagues in their child health and development framework. Their study has elements comparable to the major themes identified in the current study.
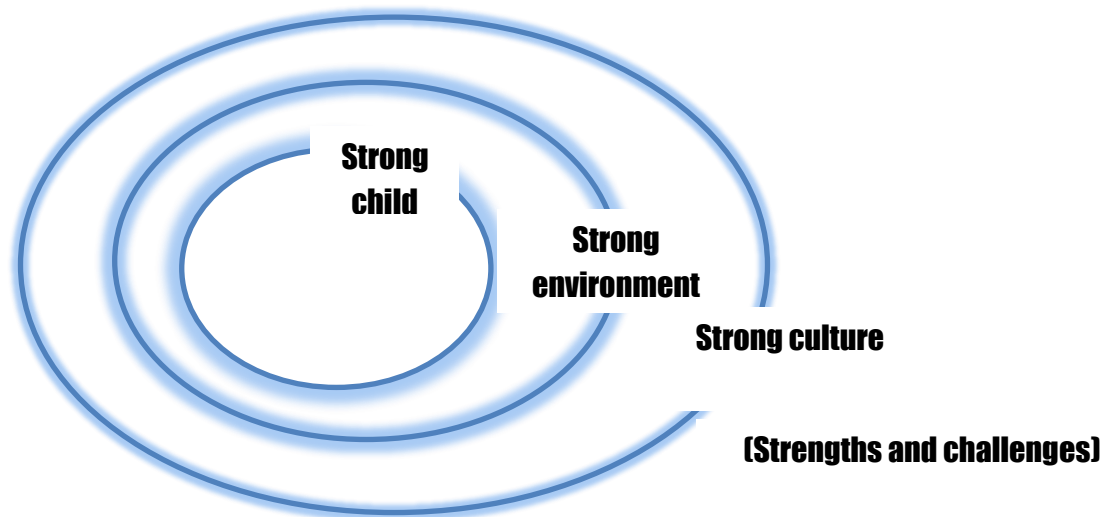
Figure 16. Conceptual framework of Aboriginal child health and development (adapted from Priest and colleagues, p. 183)

The first theme identified by Priest and colleagues, *strong child*, included the following subthemes:

- physical health, development and strong spirit.

The second theme, *strong environment* included the subthemes:

- safety, secure and supported,
- material needs met,
- learning environment.

The third area, *strong culture* included:

- identity, proud, strong, gender and age roles,
- kinship and family connection, respect for Elders,
- connected to community and Country,
- ceremony, art and artefacts, language,
- not tokenistic or superficial (Priest et al., 2012).

The framework developed by Priest and colleagues is a detailed conceptual model of Aboriginal perspectives of early childhood health and wellbeing in an urban context (Priest et al., 2012). Although the study did not include the

views of youths or discuss disability, the framework overlaps with the themes that emerged from the yarning circles of this study and the Trichotomy Model. The topics identified by Aboriginal parents can be integrated into the framework of Aboriginal health, wellbeing and disability. Figure 17 categorises results from Priest and colleagues' paper into the facilitators of the Trichotomy Model of the current study. This visual summary illustrates the importance of *Social/Cultural* factors needed for the wellbeing of Aboriginal youths, with and without disabilities, in an urban setting, as consistent with past and current research.
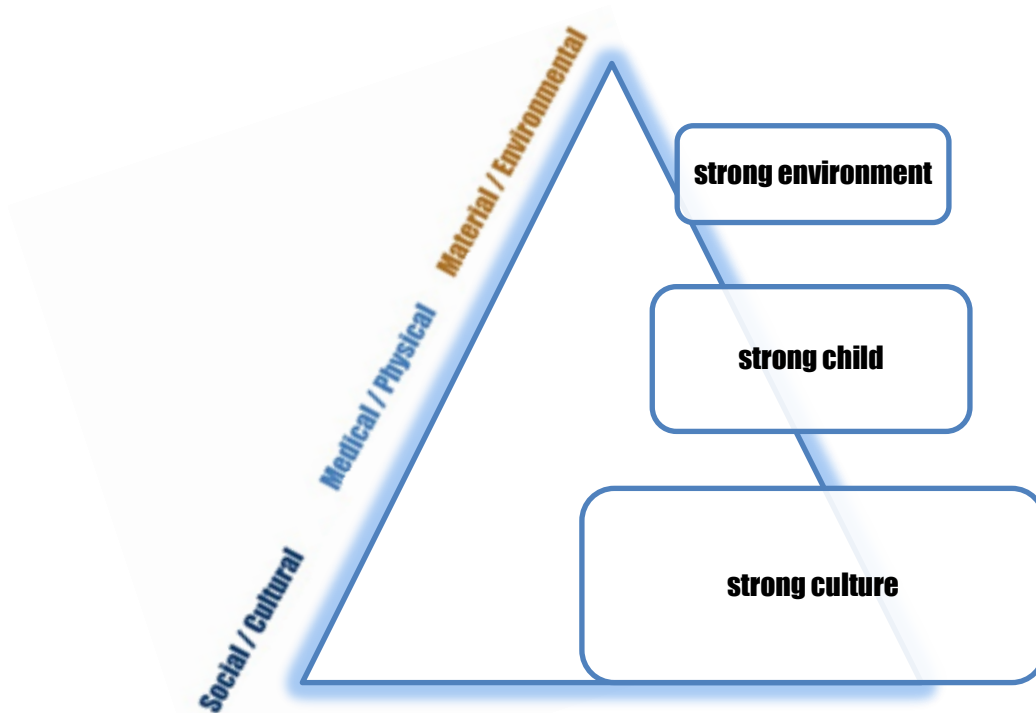

Figure 17. Themes from Priest and colleagues (2012) embedded into the Trichotomy Model

A *strong mind* (4.2.2) can also be described as resilience. Kickett describes the pathway to Aboriginal resilience as a combination of three key factors: i) family connections; ii) culture and belonging; and iii) identity and history (Kickett, 2012). Similarly, Aboriginal healing is facilitated by three elements: i) restoration and community resilience; ii) reconnection and community life; and iii) self-determination and community governance (Dudgeon, Milroy, & Walker, 2014). Although the latter facilitators were identified in the context of the recovery from transgenerational trauma, the model identifies the

elements required for a healthy community and a strong spirit which will support the development of healthy children. Spiritual healing comes from a reconnection to family, culture and community (Aboriginal and Torres Strait Islander Healing Foundation Development Team, 2009). As outlined, previous research has described resilience as embodying ties between family, culture, belonging, identity, social, community and self-determination. These facilitators are predominately associated with *Social/Cultural* aspects – as confirmed in the current study.

The human spirit has also been described as the 'Strong Spirit Strong Mind' or the Inner Spirit concept of Aboriginal culture (Casey, 2013). The 'Strong Spirit Strong Mind' model states the importance of personal connectedness between Inner Spirit and health. The Inner Spirit is the centre of being and the source of emotions (Casey, 2013). When the Inner Spirit is strong, a person's mind is strong. It is the Inner Spirit that keep people healthy and connected to others (Casey, 2013). Pathways to a strong Inner Spirit are connected to culture, beliefs and traditions – that is, health and wellbeing are inherently connected to family and culture. There is a synergetic relationship between spirit, mind and culture. Under the Trichotomy Model, the facilitators identified by Casey (culture, beliefs and traditions), would be categorised as *Social/Cultural* factors. The 'Strong Spirit Strong Mind' principles are also holistic in that a strong body, mind and spirit are all linked to one another. For example, abstaining from alcohol keeps a healthy body and 'Inner Spirit', where connections to family, community and Country can remain high (Casey, 2013). This comparison to existing literature affirms that the *Social/Cultural* factors identified in the current study are the most vital elements of health and wellbeing for Aboriginal people. Although *Medical/Physical* and *Material/Environmental* facilitators and barriers contribute to health and wellbeing, they are secondary to *Social/Cultural* factors, even for those with a disability.

5.3 Talking about Disability and Implications for Service Delivery

The findings outlined the five causes of disability identified by participants in this research. The most persistent belief about the causes of disability was linked to abuse (alcohol, drug or physical). Where a disability was believed to be a result of abuse, transgression of Aboriginal lore or genetics, blame often fell on the parents. Parental shame may or may not necessarily link to shame or stigma of the child, but may still inhibit families to engage in the disability sector. Where the causes of disability implied shame for the parent or child, families may be less open to accessing services, from both mainstream and Aboriginal services (DSC, 2006; O'Neill et al., 2004). Where Aboriginal families do not identify with a disability, they are unlikely to access disability services. The responses in this study and previous research show that for many of the causes of disability identified, there was an element of shame or blame. This finding can help provide culturally appropriate guidelines and recommendations for health professionals working with Aboriginal youths with disabilities, and their families. For example, health promotion messages or resources about the different causes of disability (including factors which incur less shame) may increase the knowledge of disability in Aboriginal communities. Sharing personal stories and experiences of people with disabilities, parents and carers may empower families to seek out support. This capacity building on a micro and macro level will help enable the wider community. Personal stories can be expressed via culturally appropriate resources, parent support groups and awareness in the education systems. Facilitating family members to share personal stories may also be a method to break down experiences of parental blame and create a united community. Raising awareness of disability in the Aboriginal community may assist people with an undiagnosed disability to identify with relevant supports and services. Other positive repercussions of empowerment of Aboriginal communities include the collective impact this will have on the disability sector. Services will have more opportunities to engage Aboriginal people with disabilities and tailor programs and services to the needs of the community in their service delivery catchment area. These recommendations could be concentrated in areas where Aboriginal people are highest.

To complement these approaches, the education of disability workers and professionals about Aboriginal ways of health and disability is imperative. This can be achieved through the creation of Aboriginal specific roles in disability services, cultural awareness training, working with existing Aboriginal service users or collaborations between disability and Aboriginal health service providers. Disability health workers who understand the holistic view of health and disability will have a greater grasp on *Social/Cultural* elements. Knowledge of cultural and historical contexts is part of this *Social/Cultural* approach. Parental blame is a sensitive and relevant area in light of Australia's history of the stolen generation. The events surrounding the stolen generation can have negative impacts on service engagement. For example, where parents are seen to be neglectful, government authorities continue to this day to remove children and place them in other forms of care (Gibson, 2013; Sammut, 2015). Understanding Aboriginal perspectives on disability is important not only for workers in the disability sector but in other overlapping services such as playgroups, Aboriginal parental services, the justice sector and the Department of Child Protection. Aboriginal children across Australia are7.7 times more likely to receive child protection services (Berlyn, Bromfield, & Lamont, 2011). In WA, the ratio is even higher at 12.7. Reasons for the placement of Aboriginal children in protective services include abuse (physical, emotional, sexual), neglect or witnessing domestic violence (Berlyn et al., 2011). This over-representation in child-protection services is due to many complex factors. Some factors may include transgenerational trauma, intergenerational violence, substance use and abuse, different parenting styles and health conditions. Parents who link blame or shame to a child's disability can have fears of the mandatory reporting, perceived neglect and current removal practices. Moreover, the breakdown of family structure impacts the health of the child, family and the wider community for generations to come.

The second most frequently mentioned cause of disability in this study was birth complications or genetic factors. For the latter, some youths attributed parental fault, while others accepted genetic variations as a natural part of life. The third most common perceived cause of disability was environmental

factors (e.g., accidents and hazards). These were associated with little or no blame. Understanding these perceived causes can improve service delivery by, for example, disability and maternal services can campaign culturally appropriate methods of increasing access to health and disability services. Awareness of the correct referral pathways between Aboriginal health workers and disabilities services can increase health outcomes from the start of life. Disability education for expecting mothers and their partners can have positive impact on the child and family.

The fourth and fifth themes of the causes of disability were cultural factors and unknown causes. Although participants in the current study did not always explicitly articulate their experience as shame, it was implied in many ways as highlighted in subsection 4.5.2. Hearing impairments that were not as visible allowed an individual to remain anonymous about their diagnosis. Physical disabilities that were more evident may lead to greater stigma than the invisible conditions. Further research addressing the differences between 'seen' and 'unseen' disabilities can build on existing findings and improve service delivery. Disability service providers require greater awareness of what disability means for Aboriginal communities in their region. Service providers can also adapt therapies or programs to make provision for cultural beliefs of the causes of disability (e.g. wrong-way marriage). Based on the Trichotomy Model, disability interventions may shift from *Material/Environmental* or *Medical/Physical* programs to supports that have a greater focus on *Social/Cultural* factors. For example, a fitness group for children with physical disabilities may be adapted to incorporate physiotherapy with cultural dancing or Dreamtime stories. Or social work support can emphasise building the capacity of not only the individual with a disability but greater inclusion of their important social networks in a culturally sensitive way (e.g. engagement with parents, siblings, grandparents or mentors).

When talking about disability, participants without a disability associated shame and other negative emotions. This was expressed by words such as 'sorry', 'depressed', 'ashamed', 'disgraced' and 'judged'. Youths with a

disability used words which described the impacts of this stigma: 'sad', 'upset', 'bullied', 'left out', 'alone', 'lonely', 'isolated', 'don't belong', 'broken-hearted', 'invisible', 'hidden' and 'different'. These youths however, associated disability with resilience and happiness more frequently than their counterparts without a disability. Positive phrases included: 'happy', 'loved', 'sheltered' 'on top', 'tough', 'break down walls', 'don't worry', 'can do anything', 'solid', 'congratulate', 'can do', 'keep going', 'push on' 'motivation' and 'nothing can stop me'. Past research suggests that this is a result of greater levels of acceptance, adaptation, belonging, coping and resilience experienced as a derivative of living with a disability – factors raised in earlier chapters (see 4.5). Some people who have experienced great loss or suffering may tend to focus on what has not been lost. Hope, gratitude and optimism are often associated with resilience and can strengthen family relationships (Heiman, 2002). Adopting a strength based approach has benefits not only for research but service delivery in the disability and Aboriginal health sectors. This was guided by recommendations by the Aboriginal Reference Group (see the three visions and outcomes outlined in 3.2).

A holistic approach considers health from all points, 'upstream', 'midstream' and 'downstream' (Hayden & Jalla, 2015). 'Upstream' determinants are those that occur at a macro level that includes global forces and government policies; that is education, employment, income, living and working conditions – all of which have been impacted by colonisation. 'Midstream' determinants can be defined as intermediate factors, such as health behaviours and psychosocial factors; and 'downstream' determinants occur at a micro level, including physiological and biological factors such as genetic makeup and gender (Northern Territory Department of Health, 2012). Positive Indigenous experiences in other countries such as New Zealand and Canada have been influenced by broader factors including the establishment of treaties, incorporation of traditional medicine in healthcare and in general, social and government recognition ('upstream' factors). The facilitators and barriers of the Trichotomy Model can be depicted as a stream, with the more significant aspects (*Social/Cultural*) identified as 'upstream'. Figure 18 displays this

premise diagrammatically. Policy, education, training, systems and infrastructure must be designed around *Social/Cultural* facilitators to be most effective.
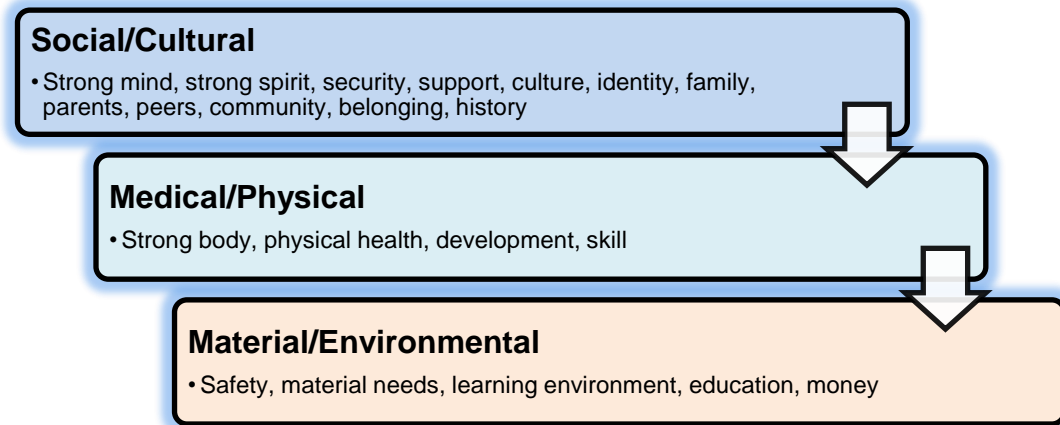

Social/Cultural
• Strong mind, strong spirit, security, support, culture, identity, family, parents, peers, community, belonging, history

Medical/Physical
• Strong body, physical health, development, skill

Material/Environmental
• Safety, material needs, learning environment, education, money

Figure 18. Facilitators to health and wellbeing

The Trichotomy Model and other findings can be applied by service providers and policy makers to create a shift towards a more holistic definition of health and disability. This is particularly timely with the uptake of the NDIS and WA NDIS trials in WA. The NDIS funding model forces changes in the way services are delivered by shifting the funding of services towards an insurance approach. The recipients of government funding under this scheme are individuals and families, rather than disability service providers. Therefore, service providers are adapting from a historical welfare approach to one with a stronger emphasis on business and profit for a purpose. The implications are that services need to be much more relevant and responsive to the real needs of families to capture the market. As rates of disability are higher in Aboriginal populations, understanding Aboriginal perspectives and community consultations are essential. If our health system can evolve to reflect the cultural and historical context, it can provide a more equitable system for Aboriginal Australians. That is, a system where any Aboriginal person can access services offered at a 'walk-in' level – rather than as a navigation exercise through a Western-biased system. There is a dangerous potential risk that the NDIS may disenfranchise Aboriginal people. It is

anticipated that cultural safety and security of service delivery will have positive health outcomes for children and young people with disabilities. A better quality of life for Aboriginal communities can be achieved by understanding and translating into clinical practice, a framework which sees health as an all-encompassing notion.

Research, such as this, and further research must be undertaken by the National Disability Insurance Agency (NDIA), who are the Federal Government representative administering the NDIS. To complicate matters further, WA has recently expanded the State versus Federal trial sites and WA is yet to negotiate with the Commonwealth the final funding arrangement to be adopted. It would be a wise use of scarce resources, for all State, Territories and Federal parties to jointly explore how individualised funding, such as the NDIS, would impact Aboriginal families in Australia under the new world. The current research is one of the few explore this area and should be noted by policy makers and other Government agents. This study should be heard by the NDIA, particularly because of its engagement with Aboriginal youths with a disability in WA – the first of its kind to the knowledge of the researcher. As covered in the literature review, with the Aboriginal population is relatively young, with the majority of the population under 26 years old. Furthermore, the premise of an individualised funding model emphasises that the individual is the agent for self, in terms of choice, control and decision making. Research that directly involves Aboriginal youths and young adults with a disability is sparse, and more research in this area should be supported. It is anticipated that a decision between the State and Federal will be evaluated after 2017. During this trial and evaluation period, engagement with Aboriginal people with a disability and families should be considered at all stages of the trial and transition. The current practices describing how NDIS will be culturally secure for Aboriginal families is not very clear to the wider Australian public or Aboriginal families. It is strongly recommended that greater concerted efforts in the area be undertaken.

For many Aboriginal populations, definitions of health and disability are more holistic than Western standards as they consider the interactions between social, emotional, mental, physical and spiritual factors – with reference to the past, present and future (Mussell et al., 1993). It is known that disabilities in Aboriginal communities are viewed more holistically compared to a Western perspective, with an emphasis on social and cultural factors (Ariotti, 1997, 1999; John Gilroy, 2008; Stopher & D'Antoine, 2008). Some collectivist virtues include the value of being (rather than doing or functioning), group decision making, group cohesion and anonymity. Generally, there are greater blends of cultures in urban areas where the two worlds, Western and Aboriginal, combine more frequently. In countries such as Australia, in which collectivist and individualist cultures co-exist, the disability system currently serves primarily to benefit the dominant culture. A culturally secure disability system for Aboriginal people would be one with collectivist ideologies at the centre. Results from this study show the importance raising the awareness of disability in Aboriginal communities in a relevant and culturally safe approach – with social and cultural facilitators being integral the dialogue.

5.4   Strengths and Limitations

The Trichotomy Model presented, in the context of disability and Aboriginal youths in an urban setting, is comparable to existing literature that describes frameworks on Aboriginal perceptions of health and wellbeing. This new Trichotomy Model does not replace existing models but may be complementary or integrated with similar models to provide a cohesive approach. A strength-based approach that moves away from the traditional deficit approaches used in Aboriginal research can be explored further. Furthermore, there is value in establishing comparisons within an Aboriginal population, rather than the ongoing approach of Aboriginal versus non-Aboriginal evident in past research. Research itself was founded from a colonising approach linked to European imperialism and colonisation. Including people with disabilities within the Aboriginal Reference Group and

the supervising team has reflected proactive efforts to decolonise research methodologies.

A limitation of qualitative research is the emphasis on the recorded voice (Kuppers, 2013). The unsaid or the unsayable is often missed by the inherent nature of audio-recorded studies. Although some qualitative research undertakes statistical analysis of inter-related agreement and quantitative grading, there was no statistical analysis in the current study. Participants engaged were aged across a broad spectrum, 9 to 26 years, and the data were not analysed in age clusters. Doing so, (e.g. 9 to 17 and 18 to 26 years) may have provided different insights. Although qualitative researchers do not often count results, numbers can be useful as in the creation of the word frequency clouds. Numbers can be used for documenting and verifying interpretations or conclusions as counting helps avoid problems in qualitative analysis (e.g. overemphasising experiences) (Beck, 2003).

Other limitations of the study were the sample size, group versus one-on-one discussions and the inclusion criteria. Two yarning circles that were conducted engaged young Aboriginal males involved with a Perth at-risk youth service. This cohort generally had a lower socio-economic status and may have had more exposure to abuse, drugs and alcohol thus impacting some of the results about the perceptions of the causes of disability. Nevertheless, these themes were also raised in all other yarning circles. Ten yarning circles, engaging 24 participants produced reoccurring common themes and saturation was reached. However, existing literature on the guidelines regarding saturation ranges with varying pros and cons for small versus large numbers of participants. Results from small cohorts are not necessarily generalisable, particularly nationally with the great diversity of Australian Aboriginal people. The ideal of saturation as described by Corbin and Strauss (2008) is also generally debated among qualitative researchers with some researchers questioning if saturation as a generic quality marker is inappropriate (O'Reilly & Parker, 2012). Generally saturation is said to be achieved when additional data does not enhance understanding. Like all methods, there are some limitations as seen in this study, such as researcher

bias and position within the research. Purposive recruitment and time of data collection can be time consuming. Analysis can be difficult, particularly with the evolution from traditional positions to the postmodern turn. Lastly to note, a theory based on a small sample of participants always raises concerns of not being generalisable to wider contexts. However, qualitative research is not designed to represent statistical significance.

The participants engaged in the study may represent a biased group. Participants who consented may be families who are more likely to engage with the disability sector, and hence have had more support and positive experiences than those who did not identify as having a disability. Those with an intellectual disability as a primary diagnosis were excluded to ensure that participants could provide informed assent as well as to maintain homogeneity in a diverse group. Experiences of people with an intellectual disability may have contributed different findings. Participants living in regional or remote areas may have provided unique themes, but for logistics, were excluded.

Strengths of this study include the establishment of an Aboriginal Reference Group and ongoing guidance from Cultural Consultants. Cultural sensitivity is necessary to ensure new ways of working together. As a non-Aboriginal researcher, working together with Aboriginal researchers is an integral first step. Without an Aboriginal Associate Supervisor, this study and research topic would not have been pursued. At the commencement of candidacy, support and commitment from a Cultural Consultant was also confirmed. This Cultural Consultant was appointed to a dedicated role in order to work with Aboriginal and non-Aboriginal researchers in Aboriginal health. Funded by the National Health and Medical Research Council capacity building grant (Building Mental Wealth: Improving mental health for better health outcomes 2009-2014), this group of researchers also provided shared cultural knowledge, mentorship and accountability.

5.5 Future Directions

The current study is one of the first to capture the voices of Aboriginal youths with a disability. This research provides initial data where little existed in the area of disability and Aboriginal youths in an urban environment. The suggested Trichotomy Model for holistic health in Aboriginal children and young people in urban settings is comparable to structures reported in existing literature. Future research may explore the similarities and differences of perspectives in metropolitan versus regional and remote areas. Comparisons between families living in other major Australian cities will highlight the similarities and diversities in Aboriginal culture. This may provide further recommendations that would assist national policies and frameworks. An exploration of the beliefs about the causes of disabilities, with probing into different types of disabilities (for example congenital versus acquired conditions) can further inform models of service delivery and policies. New research may also include international comparisons of Indigenous people with disabilities. Perspectives on disability from Aboriginal parents, carers, siblings or disability health workers will also complement these findings. Greater dialogue is needed in this area concerning the various models of disability – the social, medical, moral, cultural and material approaches.

Future directions must continue to be championed by Aboriginal people with disabilities. The national peak body, First Peoples Disability Network (FPDN), is pioneering this undertaking by influencing policy, services, education, training, systems and infrastructure. Closer to home, the FPDN have created a presence in WA via their advocacy State Coordinators. In addition, non-Aboriginal researchers are working with peak stakeholders to discuss, at a State level, the potential establishment of a Disability Research Agenda. These stakeholders include people with disability, carers, researchers, State and community-based organisations and teaching institutes. Research can be better translated into practice at the crossroad of these stakeholders. Collaborative and inclusive networks such as these have the leverage necessary to create change at down, mid and upstream (or primary to tertiary) levels.

5.6 Summary

Perceptions of health and wellbeing by Aboriginal cultures are often linked to physical, mental and spiritual components. The core theme of this research is the holistic nature of health and wellbeing, which encompass the seen and unseen elements. When a person's body, mind, spirit and culture are strong, wellbeing is evident. This was found to be true for Aboriginal youths with and without a disability. The key facilitators to a *strong body*, *strong mind* and *strong spirit/culture* can be categorised into three areas. These three categories, for the facilitators and barriers to health and wellbeing for Aboriginal youths were *Social/Cultural*, *Medical/Physical* and *Material/Environmental* elements. In this Trichotomy Model, *Social/Cultural* facilitators were the most predominant factors. *Medical/Physical* and *Material/Environmental* facilitators and barriers were important, but less significant, as identified by Aboriginal children and young people. However as these three categories have overlapping associations, it is in combination that these factors interact to develop a healthy child. The main differences in wellbeing for participants with and without disabilities were, not surprisingly, the barriers associated with their disability. Despite children and young people with a disability experiencing more social isolation, bullying and health problems, it was found that many of these youths had a more positive outlook on disability than their peers. This may be due to the resilience and support experienced via their disability, coping strategies or the strength-based approach and recruitment process of this research. Although negative perceptions of disability, such as shame, may still be prevalent in the wider community, a positive shift in the social and cultural climates have already occurred, beginning with those living with a disability.

6 CHAPTER 6 – CONCLUSION

Aboriginal culture is highly diverse across Australia yet many families share a common experience of inequitable health outcomes in comparison to non-Aboriginal peers (Westby & Inglebret, 2012). Metropolitan cities harbour a mix of traditional and modern approaches, Western and Aboriginal cultures, which exist in parallel. Although gaining a clearer understanding of disability will not heal the health discrepancies experienced by Australian Aboriginal people, it is essential to conceptualise policies and systems in the context of culture. In Australia, the health gaps between Aboriginal and non-Aboriginal populations are one of global concern impacted by a multitude of complex factors including colonisation, historical trauma and racism. A starting point towards better health outcomes for Aboriginal people with disabilities is to better understand the perspectives of disability, including the views of youths with a disability.

Disability is a Western term used for diagnosing, compartmentalising and labelling. With the introduction of this foreign concept of 'disability', many Indigenous communities, such as Australian Aboriginal people, have been labelled and thus become disempowered. In an attempt to conceptualise these reconstructions, some communities have transferred the Western notion of disability onto Aboriginal words, reorienting traditional language. Colonisation forces old cultural knowledge to be challenged and lost, and imposes new foreign dialogues to be adopted. The process of doing so has created a loss of language, culture and to some degree a shift in family roles and kinship, and community expectations. In turn, this may lead to new behaviours and stigma associated with 'disability', further impacting health and wellbeing.

The suggested Trichotomy Model of the facilitators and barriers provides a framework for health, wellbeing and disability, which are ultimately interrelated and holistic. Concepts of health and wellbeing are approached in a circular and on-flowing manner and do not exist in isolation. Identifying themes within an Aboriginal context assists non-Aboriginal people to work

within a culturally safe space and adapt to new ways of working. This research continues the conversation on disability in Australia, in an Aboriginal context. Aboriginal health and wellbeing and views on disability require a holistic and community driven approach. These findings and the core themes from this research can be used to inform policy and service delivery in the disability sector. The results of this study provide unique insights into health, wellbeing and disability from the perspectives of Aboriginal youths with and without disabilities. Strength-based research studies, informed by people with disability and Aboriginal communities, are part of the social fabric which can enable and facilitate greater wellbeing. To strive towards better health equality in Australia, further conversations on Aboriginal disability must continue with future generations. Future studies that continue this thread will build into the decolonisation of disability and research with Aboriginal families and communities.

"It's more to do with adapting, adapting that's what it's called… and knowing your strengths and your weakness… that's how you learn to do things, and you will adapt to do more things."

~ **Male, 22, FASD** (Aboriginal young person on disability and 'adaptability')

"*Naam daat sarawey* is a general statement and to the Kelabit it has many meanings. *Naam daat sarawey* can simply mean, that that is enough, can we continue the conversation."

~ **Rowland Kebing** (Kelabit philosopher)

REFERENCES

Aboriginal and Torres Strait Islander Healing Foundation Development Team. (2009). *Voices from the campfires: Establishing the Aboriginal and Torres Strait Islander Healing Foundation*. Retrieved from http://www.fahcsia.gov.au/sites/default/files/documents/07_2012/healingfoundationreport09.pdf

ABS. (2009a). *Disability, Australia, 2009* Canberra: Australian Bureau of Statistics.

ABS. (2009b). *National Aboriginal and Torres Strait Islander Social Survey (NATSISS), 2008*. Canberra: Australian Bureau of Statistics.

ABS. (2010). *Population Characteristics, Aboriginal and Torres Strait Islander Australians, 2006.* Retrieved from

ABS. (2012a). *Disability, Ageing and Carers, Australia: Summary of Findings, 2012*. Canberra: Australian Bureau of Statistics.

ABS. (2012b). *The Health and Welfare of Australia's Aboriginal and Torres Strait Islander Peoples, Oct 2010*. Canberra: Australian Bureau of Statistics.

ABS. (2013). *Estimates of Aboriginal and Torres Strait Islander Australians, June 2011* (Vol. 2015). Canberra: Australian Bureau of Statistics.

ABS. (2014). *Aboriginal and Torres Strait Islander People with a Disability, 2012* (Vol. 2015). Canberra: Australian Bureau of Statistics,.

ABS. (2015). *Australian Demographic Statistics, Mar 2015*. Canberra: Australian Bureau of Statistics.

AIHW. (2008). *Aboriginal and Torres Strait Islander Health Performance Framework 2008 Report, Detailed Analyses*. Canberra.

Al-Busaidi, Z. Q. (2008). Qualitative research and its uses in health care. *Sultan Qaboos University Medical Journal, 8*(1), 11.

Ariotti, L. (1997). *The newly planted tree: an exploration of Anangu perceptions of disability* Unpublished Degree of Master Science (Primary Health Care). Flinders University of South Australia. Adelaide.

Ariotti, L. (1999). Social construction of Anangu disability. *Australian Journal of Rural Health, 7*(4), 216-222. Retrieved from http://search.ebscohost.com/login.aspx?direct=true&db=rzh&AN=2000048087&site=ehost-live. doi:10.1111/j.1440-1584.1999.tb00460.x

Austin, P. K. (2006). Australia: Language Situation. In K. Brown (Ed.), *International Encyclopedia of Language & Linguistics, 2nd edition.* (pp. 580-585). Oxford: Elsevier. Retrieved from http://www.sciencedirect.com/science/article/pii/B0080448542017119

Australian Indigenous Health InfoNet. (2015). *Overview of Australian Indigenous Health Status 2014.* Retrieved from http://www.healthinfonet.ecu.edu.au/health-facts/overviews

Australian Institute of Health and Welfare. (2011a). *Aboriginal and Torres Strait Islander health performance framework 2010: detailed analyses*. Canberra: Australian Institute of Health and Welfare

Australian Institute of Health and Welfare. (2011b). *Aboriginal and Torres Strait Islander people with disability*. Canberra. Retrieved from http://www.aihw.gov.au/WorkArea/DownloadAsset.aspx?id=10737418952

Australian Institute of Health and Welfare. (2011c). *The health and welfare of Australia's Aboriginal and Torres Strait Islander people - an overview*. Canberra. Retrieved from http://www.aihw.gov.au/WorkArea/DownloadAsset.aspx?id=10737418955

Bagnoli, A. (2009). Beyond the standard interview: the use of graphic elicitation and arts-based methods. *Qualitative Research, 9*, 547. doi:10.1177/1468794109343625

Beck, C. T. (2003). Initiation into qualitative data analysis. *Journal of Nursing Education, 42*(5), 231-234. Retrieved from http://search.proquest.com.dbgw.lis.curtin.edu.au/docview/203923710?accountid=10382

Berlyn, C., Bromfield, L., & Lamont, A. (2011). *Child protection and Aboriginal and Torres Strait Islander Children*. Canberra. Retrieved from http://www.pdc.org.au/lac/res/file/child%20protection%20Aboriginal%20and%20Torres%20Strait%20Islander%20Children.pdf

Berman, S. (1995). Otitis Media in Developing Countries. *Pediatrics, 96*(1), 126-131. Retrieved from http://pediatrics.aappublications.org/content/96/1/126.abstract

Bessarab, D., & Ng'andu, B. (2010). Yarning About Yarning as a Legitimate Method in Indigenous Research. *International Journal of Critical Indigenous Studies, 3*(1), 37-50. Retrieved from http://www.isrn.qut.edu.au/pdf/ijcis/v3n1_2010/Final_Bessarab_Bridget_IJCIS.pdf

Biddle, N., Gray, M., & Yap, M. (2013). *The geographic distribution of Indigenous disability*. Sydney. Retrieved from http://fpdn.org.au/images/documents/geographic-distribution-indigenous-disability.pdf

Blainey, G. (1975). *Triumph of the Nomads*. Sydney: The MacMillian Company of Australia.

Bodeker, G. (2008). The Health Care of Indigenous Peoples/Nations. In K. Heggenhougen (Ed.), *International Encyclopedia of Public Health.* (pp. 175-180). Oxford: Academic Press. Retrieved from http://www.sciencedirect.com/science/article/pii/B9780123739605004056 doi:http://dx.doi.org/10.1016/B978-012373960-5.00405-6

Bostock, L. (1991). Access & Equity for the Doubly Disadvantaged. *Aboriginal and Islander Health Worker Journal, 15*(4), 10-15.

Bourquia, A. (2007). Handicap in Arab-Muslim culture. *Archives de pediatrie, 14*(1), 1-130.

Boyatzis, R. E. (1998). *Transforming qualitative information: Thematic analysis and code development*. Thousand Oaks: SAGE.

Bramley, D., Hebert, P., Jackson, R., & Chassin, M. (2004). Indigenous disparities in disease-specific mortality, a cross-country comparison: New Zealand, Australia, Canada, and the United States.

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*(2), 77-101. doi:10.1191/1478088706qp063oa

Brown, R. (2001). Australian Indigenous mental health. *Australian and New Zealand Journal of Mental Health Nursing, 10*(1), 33-41. doi:10.1046/j.1440-0979.2001.00189.x

Carnegie, D. W. (1898). *Spinifex and Sand*. London: C. Arthur Pearson.

Casey, W. (2013). Strong spirit strong mind model—informing policy and practice. In P. Dudgeon, H. Milroy & R. Walker (Eds.), *Working together: Aboriginal and Torres Strait Islander mental health and wellbeing principles and practice.* (pp. 419–427). Canberra: Office of Aboriginal and Torres Strait Islander Health, Department of Ageing.

CCYP. (2009). *Speaking out about wellbeing: the views of WA children and young people*. Perth. Retrieved from http://www.ccyp.wa.gov.au/files/Wellbeing%20research%20report%202010/wellbeing-report%5B1%5D.pdf

CCYP. (2010). *Speaking out about wellbeing: Aboriginal children and young people* Perth: Commissioner for Children and Young People.

CCYP. (2011). *Report of the Inquiry into the Mental Health and Wellbeing of Children and Young People in Western Australia*. Perth: Commissioner for Children and Young People.

CCYP. (2015). *"Listen to Us" Using the views of Aboriginal and Torres Strait Island children and young people to improve policy and service delivery*. Perth. Retrieved from http://www.ccyp.wa.gov.au/files/Aboriginal%20consultation%202014/Listen%20To%20Us/Listen%20To%20Us%20-%20Final%20-%20Web%20PDF%20-%20August%202015.PDF

Clarren, S., & Smith, D. (1978). The fetal alcohol syndrome. *New England Journal of Medicine 298*, 1063-1067.

Committee to Study Fetal Alcohol Syndrome Division of Biobehavioral Sciences and Mental Disorders Institute of Medicine. (1996). *Fetal alcohol syndrome: diagnosis, epidemiology, prevention, and treatment*. Washington: National Academy Press.

Cooke, M., Mitrou, F., Lawrence, D., Guimond, E., & Beavon, D. (2010). Indigenous Well-being in Four Countries. *Health Promotion and Quality of Life in Canada: Essential Readings*, 189. doi:10.1186/1472-698X-7-9

Corbin, J., & Strauss, A. (2008). Basics of qualitative research 3e: (London: Sage).

Curry, R. (1993). *Needs assessment report: People with handicaps and the frail aged in five Aboriginal communities*. Darwin: Department of Health, Housing and Community Service and NT Department of Health and Community Services.

Danseco, E. R. (1997). Parental Beliefs on Childhood Disability: insights on culture, child development and intervention. *International Journal of Disability, Development and Education, 44*(1), 41-52. Retrieved from http://dx.doi.org/10.1080/0156655970440104. doi:10.1080/0156655970440104

Darbyshire, P., MacDougall, C., & Schiller, W. (2005). Multiple methods in qualitative research with children: more insight or just more? *Qualitative Research, 5*(4), 417-436. doi:10.1177/1468794105056921

Davidson, C. R. (2009). Transcription: Imperatives for qualitative research. *International Journal of Qualitative Methods, 8*(2), 35-52. Retrieved from http://citeseerx.ist.psu.edu/viewdoc/download?doi=10.1.1.487.9612&rep=rep1&type=pdf

Department of Health. (2015). *Implementation Plan for the National Aboriginal and Torres Strait Islander Health Plan 2013–2023* Canberra. Retrieved from http://www.health.gov.au/internet/main/publishing.nsf/Content/AC51639D3C8CD4ECCA257E8B00007AC5/$File/DOH_ImplementationPlan_v3.pdf

DiGiacomo, M., Delaney, P., Abbott, P., Davidson, P. M., Delaney, J., & Vincent, F. (2013). 'Doing the hard yards': carer and provider focus group perspectives of accessing Aboriginal childhood disability services. *BMC health services research, 13*(1), 326. doi:10.1186/1472-6963-13-326

Disability Services Act, The Parliament of Western Australia (1993).

Douglas, H., Hammill, J., Hall, W., & Russell, E. (2013). *Fetal Alcohol Spectrum Disorders (FASD) within the Criminal Justice Sector in Queensland*.

DSC. (2006). *Aboriginal people with disabilites: Getting services right.* Perth: Disability Services Commission.

Dudgeon, P., Milroy, H., & Walker, R. (2014). Community life and development programs-pathways to healing. In P. Dudgeon, H. Milroy & R. Walker (Eds.), *Working together: Aboriginal and Torres Strait Islander mental health and wellbeing principles and practice (2nd edition).* (pp. 319–334). Perth, WA: Telethon Institute for Child Health Research.

Eades, D. (2013). *Aboriginal English*: [online].

Elliot, D. (1984). *Aboriginal perceptions of disability and the formulation of an appropriate method of providing rehabilitation services to clients on remote communities*. Darwin: Commonwealth Rehabilitation Service.

Elliott, E., & Bower, C. (2004). FAS in Australia: Fact or fiction? *Journal of Paediatrics and Child Health, 40*(1-2), 8-10. Retrieved from http://dx.doi.org/10.1111/j.1440-1754.2003.00281.x. doi:10.1111/j.1440-1754.2003.00281.x

Elliott, E., Latimer, J., Fitzpatrick, J., Oscar, J., & Carter, M. (2012). There's hope in the valley. *Journal of paediatrics and child health, 48*(3), 190-192.

Elliott, E., Payne, J., Morris, A., Haan, E., & Bower, C. (2008). Fetal alcohol syndrome: a prospective national surveillance study. *Archives of Disease in Childhood, 93*(9), 732-737. Retrieved from http://adc.bmj.com/content/93/9/732.abstract. doi:10.1136/adc.2007.120220

Etzioni, A. (2002). Individualism - within history. *The Hedgehog Review, 4*(1), 49-56. Retrieved from http://www.gwu.edu/~ccps/etzioni/A292.pdf

Fattore, T., Mason, J., & Watson, E. (2009). When children are asked about their well-being: Towards a framework for guiding policy. *Child Indicators Research, 2*(1), 57-77. doi:10.1007/s12187-008-9025-3

Fereday, J., & Muir-Cochrane, E. (2008). Demonstrating rigor using thematic analysis: A hybrid approach of inductive and deductive coding and theme development. *International Journal of Qualitative Methods, 5*(1), 80-92.

Fielder, J., Roberts, J., & Abdullah, J. (2000). Research with Indigenous communities. *Working with Indigenous Australians: A handbook for psychologists*, 349-356.

Fitzgerald, J. (1997). Reclaiming the whole: Self, spirit, and society. *Disability and Rehabilitation, 19*(10), 407-413. Retrieved from http://informahealthcare.com/doi/abs/10.3109/09638289709166565. doi:10.3109/09638289709166565

Fitzpatrick, J. P., Elliott, E. J., Latimer, J., Carter, M., Oscar, J., Ferreira, M., et al. (2012). The Lililwan Project: study protocol for a population-based active case ascertainment study of the prevalence of fetal alcohol spectrum disorders (FASD) in remote Australian Aboriginal communities. *BMJ Open, 2*(3). Retrieved from http://bmjopen.bmj.com/content/2/3/e000968.abstract. doi:10.1136/bmjopen-2012-000968

Freemantle, C., Read, A., de Klerk, N., McAullay, D., Anderson, I., & Stanley, F. (2006). Patterns, trends, and increasing disparities in mortality for Aboriginal and non-Aboriginal infants born in Western Australia, 1980–2001: population database study. *The Lancet, 367*(9524), 1758–1766. doi:10.1016/S0140-6736(06)68771-0

Gauntlett, D. (2007). *Creative explorations: New approaches to identities and audiences*. London: Routledge.

Gething, L. (1994). Aboriginality and Disability. *Aboriginal and Islander Health Worker Journal, 18*(3), 29 -34. Retrieved from http://search.informit.com.au/documentSummary;dn=282847910912641;res=IELFSC

Gething, L. (1995). A case study of Australian Aboriginal people with disabilities. *Australian Disability Review, 2*, 77-87.

Ghosh, R., & Talbani, A. (1992). Inequality and education in India: the case of the scheduled castes. In D. Ray & D. Poonwassie (Eds.), *Education and Cultural Differences.* New York: Garland.

Gibson, P. (2013). Stolen futures: the revival of Indigenous child removal. *Overland*(212), 44-52.

Gilroy, J. (2008). Service delivery for Aboriginal People with a Disability and their Families. *Disparity 5*(1), 24-27.

Gilroy, J., Donelly, M., Colmar, S., & Parmenter, T. (2016). Twelve factors that can influence the participation of Aboriginal people in disability services. *Australian Indigenous HealthBulletin, 16*(1)

Gracey, M., & King, M. (2009). Indigenous health part 1: determinants and disease patterns. *The Lancet, 374*(9683), 65-75.

Graeber, D. (2011). *Debt: The first 5,000 years*: Melville House.

Green, A., DiGiacomo, M., Luckett, T., Abbott, P., Davidson, P. M., Delaney, J., et al. (2014). Cross-sector collaborations in Aboriginal and Torres Strait Islander childhood disability: a systematic integrative review and theory-based synthesis. *International journal for equity in health, 13*(1), 126. doi:10.1186/s12939-014-0126-y

Gresham, F. M. (1981). Social skills training with handicapped children: A review. *Review of Educational Research, 51*(1), 139-176.

Guest, G., Bunce, A., & Johnson, L. (2006). How many interviews are enough? An experiment with data saturation and variability. *Field methods, 18*(1), 59-82. Retrieved from

http://www.rincondepaco.com.mx/rincon/Inicio/Seminario/Documentos/Met_otros/Docs_Dra_Fleiz/Lecturas_sugeridas/Guest_data_saturation_interviews.pdf. doi:10.1177/1525822X05279903

Gupta, A., & Singhal, N. (2004). Positive perceptions in parents of children with disabilities. *Asia Pacific Disability Rehabilitation Journal, 15*(1), 22-35.

Handicapped Programs Review Australia. (1985). *New Directions.* Canberra: Australian Government Publishing Service.

Hastings, R. P., & Taunt, H. M. (2002). Positive Perceptions in Families of Children With Developmental Disabilities. *American Journal on Mental Retardation, 107*(2), 116-127.

Hayden, G., & Jalla, C. (2015). Communicating for quality and safety in Aboriginal health care. In R. Iedema, D. Piper & M. Manidis (Eds.), *Communicating Quality and Safety in Health Care.* (pp. 230-244). Melbourne: Cambridge University Press.

Heiman, T. (2002). Parents of children with disabilities: Resilience, coping, and future expectations. *Journal of developmental and physical disabilities, 14*(2), 159-171. doi:10.1023/A:1015219514621

Howard, D. (2012). *Staying strong stories.* Nightcliff, N.T: Phoenix Consulting.

Jalla, C., & Hayden, G. (2014). Aboriginal health research is not black and white – lessons from the field. *Australian Indigenous HealthBulletin, 14*(3). Retrieved from http://healthbulletin.org.au/wp-content/uploads/2014/08/bulletin_report_Jalla.pdf

Kendall, E., & Marshall, C. (2004). Factors that prevent equitable access to rehabilitation for Aboriginal Australians with disabilities: the need for culturally safe rehabilitation. *Rehabilitation psychology, 49*(1), 5. doi:10.1037/0090-5550.49.1.5

Kickett, M. (2012). *Examination of How a Culturally Appropriate Definition of Resilience Affects the Physical and Mental Health of Aboriginal People, PhD thesis.* Curtin University, Perth. Retrieved from research-repository.uwa.edu.au/files/3226223/Kickett_Marion_2011.pdf

King, M., Smith, A., & Gracey, M. (2009). Indigenous health part 2: the underlying causes of the health gap. *The Lancet, 374*(9683), 76-85. Retrieved from http://linkinghub.elsevier.com/retrieve/pii/S0140673609608278

Koren, G., Nulman, I., Chudley, A. E., & Loocke, C. (2003). Fetal alcohol spectrum disorder. *Canadian Medical Association Journal, 169*(11), 1181-1185. Retrieved from http://www.cmaj.ca/content/169/11/1181.short

Kreuter, M. W., & McClure, S. M. (2004). The role of culture in health communication. *Annual Review of Public Health, 25*, 439-455. doi:10.1146/annurev.publhealth.25.101802.123000

Krueger, R. A. (1988). *Focus Groups: A Practical Guide for Applied Research.* Newbury Park: SAGE.

Kuppers, P. (2013). Decolonizing Disability, Indigeneity, and Poetic Methods: Hanging Out in Australia. *Journal of Literary & Cultural Disability Studies, 7*(2), 175-193. Retrieved from https://quote.ucsd.edu/sed/files/2014/04/Kuppers_Decolonizing-

Disability-Indigeneity-and-Poetic-Methods-Hanging-Out-in-Australia.pdf

Kvale, S. (1996). *Interviews: An introduction to Qualitative Research Interviewing*. Thousand Oaks: SAGE.

Lavallee, L. F. (2009). Practical application of an Indigenous research framework and two qualitative Indigenous research methods: Sharing circles and Anishnaabe symbol-based reflection. *International Journal of Qualitative Methods, 8*(1), 21-40.

Locust, C. (1985). *American Indian beliefs concerning health and unwellness*. Tucson: Native American Research & Training Center, University of Arizona.

Long, L. N., Ross, C. J., Williams, M. N., Barker, R. N., Martin, A. N., & Stoll, K. N. (1994). A good life for old and disabled people in remote Aboriginal communities *Aboriginal and Islander Health Worker Journal, 18*(6), 4-5.

Lucas, B. R., Doney, R., Latimer, J., Watkins, R. E., Tsang, T. W., Hawkes, G., et al. (2016). Impairment of motor skills in children with fetal alcohol spectrum disorders in remote Australia: The Lililwan Project. *Drug and Alcohol Review*, n/a-n/a. Retrieved from http://dx.doi.org/10.1111/dar.12375. doi:10.1111/dar.12375

Maher, P. (1998). *The provision of rehabilitation services to Aboriginal people: a qualitative case study.* Unpublished Master of Applied Science. University of South Australia, Adelaide.

Maher, P. (1999a). Disability in the Australian Aboriginal Population. *Australian Journal of Primary Health, 5*(3), 10-20. Retrieved from http://www.publish.csiro.au/paper/PY99029. doi:10.1071/PY99029

Maher, P. (1999b). A review of 'traditional' Aboriginal health beliefs. *Australian Journal of Rural Health, 7*(4), 229-236. Retrieved from http://search.ebscohost.com/login.aspx?direct=true&db=rzh&AN=2000048089&site=ehost-live

McBain-Rigg, K. E., & Veitch, C. (2011). Cultural barriers to health care for Aboriginal and Torres Strait Islanders in Mount Isa. *Australian Journal of Rural Health, 19*(2), 70-74. Retrieved from http://search.ebscohost.com/login.aspx?direct=true&db=rzh&AN=2010986198&site=ehost-live. doi:10.1111/j.1440-1584.2011.01186.x

McLafferty, I. (2004). Focus group interviews as a data collecting strategy. *Journal of advanced nursing, 48*(2), 187-194. doi:10.1111/j.1365-2648.2004.03186.x

Miles, M. (1996). Community, Individual or Information Development? Dilemmas of concept and culture in South Asian disability planning. *Disability & Society, 11*(4), 485-500. Retrieved from http://dx.doi.org/10.1080/09687599627552. doi:10.1080/09687599627552

Mohajer, N., Bessarab, D., & Earnest, J. (2009). There should be more help out here! A qualitative study of the needs of Aboriginal adolescents in rural Australia. *Rural and remote health, 9*, 1137. Retrieved from http://www.rrh.org.au/Articles/subviewnew.asp?ArticleID=1137

Mokak, R. (1997). Aboriginal People and Disability: What are the Issues and Where Do We Go from Here? *Aboriginal and Islander Health Worker Journal, 21*(5), 14-15. Retrieved from

http://search.informit.com.au/documentSummary;dn=2349052758652
93;res=IELFSC

Morgan, D. (1996). Focus groups. *Annual Review Sociology, 22*, 129–152.

Morgan, D., Slade, M. D., & Morgan, C. (1997). Aboriginal philosophy and its impact on health care outcomes. *Australian and New Zealand Journal of Public Health, 21*(6), 597-601. doi:10.1111/j.1467-842X.1997.tb01762.x

Morgan, M., Gibbs, S., Maxwell, K., & Britten, N. (2002). Hearing children's voices: methodological issues in conducting focus groups with children aged 7-11 years. *Qualitative Research, 2*(1), 5-20. Retrieved from http://qrj.sagepub.com/content/2/1/5.abstract. doi:10.1177/1468794102002001636

Morrow, V. (1998). If you were a teacher, it would be harder to talk to you: reflections on qualitative research with children in school. *International Journal of Social Research Methodology, 1*(4), 297-313.

Morse, J. M., & Field, P.-A. (1995). *Nursing research: The application of qualitative approaches*: Nelson Thornes.

Munro, N. (1963). *Ainu: Greed and cult*. New York: Columbia University Press.

Mussell, W. J., Nichols, W. M., & Adler, M. T. (1993). *Making meaning of mental health challenges in First Nations: a Freirean perspective*. Chilliwack: Sal'i'shan Institute Society.

National Aboriginal and Torres Strait Islander Health Council. (2003). *National Strategic Framework for Aboriginal and Torres Strait Islander Health: Context*. Canberra.

National Aboriginal Health Strategic Working Party. (1989). *In: A National Aboriginal Health Strategy*.

National Disability Insurance Agency. (2016). *NDIS in Western Australia.* Retrieved from http://www.ndis.gov.au/about-us/our-sites/wa

National Health and Medical Research Council. (2003). *Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research*. Canberra.

Nelson, A., & Allison, H. (2004). A visiting occupational therapy service to Indigenous children in schools: results of a pilot project. *The Australian Journal of Indigenous Education, 33*, 55-50.

Ngaanyatjarra Pitjantjatjara Yankunytjatjara Women's Council. (2014). *Assisting Indigenous Australians in the Anangu Pitjantjatjara Yankunytjatjara (APY) Lands to Benefit from the National Disability Insurance Scheme (NDIS)*. Alice Springs.

Nicolaisen, I. (1995). Persons and Nonpersons: Disability and Personhood among the Punan Bah of Central Borneo. In B. Ingstad & S. R. Whyte (Eds.), *Disability and Culture.* Los Angeles: University of California Press.

Northern Territory Department of Health. (2012). *Health Promotion Strategic Framework 2011 - 2015 [draft]*. Darwin: Northern Territory Department of Health.

O'Neill, M., Kirov, E., & Thomson, N. (2004). A review of the literature on disability services for Aboriginal and Torres Strait Islander peoples. *Australian Indigenous Health Bulletin, 4*(4), Reviews 2. Retrieved from

http://www.healthinfonet.ecu.edu.au/html/html_bulletin//bull_44/reviews/oneill/reviews_oneill_1.htm

O'Reilly, M., & Parker, N. (2012). 'Unsatisfactory Saturation': A critical exploration of the notion of saturated sample sizes in qualitative research. *Qualitative Research*, 1468794112446106.

Patton, M. Q. (1990). *Qualitative evaluation and research methods*. Thousand Oaks: California: Sage.

Patton, M. Q. (2001). *Qualitative Research and Evaluation Methods (3rd Ed.)*. Thousands Oaks, CA: SAGE.

Paulme, D. (1940). *Social organization of the Dogon*. Paris: Editions Domat-Montchrestien, F. Lovifon et Cie.

Payne, S. (2008). *Aboriginal Cultural Guide for ACT Family Law Practitioners: Second Edition*. Canberra.

Phillips, G. (2003). *Addictions and healing in Aboriginal country*. Canberra: Aboriginal Studies Press.

Pidgeon, F., O'Kearney, E., Johnston, H., Greenstein, C., & Pilikington, C. (2015). *Participation of Indigenous children with disabilities in remote communities*. Paper presented at the 13th National Rural Health Conference: People, Places, Possibilities., Darwin. http://www.ruralhealth.org.au/13nrhc/images/paper_Pidgeon,%20Felicity.pdf

Prewett, M., & Prewett, M. (2012). *Two mates*. Broome, W.A: Magabala Books.

Priest, N., Mackean, T., Davis, E., Briggs, L., & Waters, E. (2012). Aboriginal perspectives of child health and wellbeing in an urban setting: Developing a conceptual framework. *Health Sociology Review, 21*(2), 180-195. doi:10.5172/hesr.2012.21.2.180

Productivity Commission. (2011). *Disability within the Indigenous community. In: Disability care and support: Productivity Commission Inquiry Report Overview and Recommendations*. Canberra: Productivity Commission.

Prosser, J., & Loxley, A. (2008). Introducing visual methods. National Centre for Research Methods. Retrieved from http://eprints.ncrm.ac.uk/420/1/MethodsReviewPaperNCRM-010.pdf

Putnam, R. D. (2000). Health and Happiness *Bowling Alone: The Collapse and Revival of American Community* New York: Simon & Schuster.

Queensland Studies Authority. (2013). *Aboriginal and Torres Strait Islander histories and cultures resources: History - Supporting the implementation of the Australian Curriculum cross-curriculum priorities*. Brisbane.

Rhodes, P. (1985). *An Outline of History Medicine*. London: Butterworth.

Ring, I., & Brown, N. (2003). The health status of indigenous peoples and others: The gap is narrowing in the United States, Canada, and New Zealand, but a lot more is needed. *BMJ: British Medical Journal, 327*(7412), 404. doi:10.1136/bmj.327.7412.404

Rosenbaum, P., Paneth, N., Leviton, A., Goldstein, M., Bax, M., Damiano, D., et al. (2007). A report: the definition and classification of cerebral palsy April 2006. *Developmental Medicine and Child Neurology, 109*(Supplement), 8-14. doi:10.1111/j.1469-8749.2007.tb12610.x

Sammut, J. (2015). The last bastion of aboriginal separatism. *Quadrant, 59*(12), 16-22.

Scheer, J., & Groce, N. (1988). Impairment as a Human Constant: Cross-Cultural and Historical Perspectives on Variation. *Journal of Social Issues, 44*(1), 23-37. Retrieved from http://dx.doi.org/10.1111/j.1540-4560.1988.tb02046.x. doi:10.1111/j.1540-4560.1988.tb02046.x

Schuengel, C., Voorman, J., Stolk, J., Dallmeijer, A., Vermeer, A., & Becher, J. (2006). Self-worth, perceived competence, and behaviour problems in children with cerebral palsy. *Disability and Rehabilitation, 28*(20), 1251-1258. doi:10.1080/09638280600554652

Selway, D., & Ashman, A. F. (1998). Disability, religion and health: A literature review in search of the spiritual dimensions of disability. *Disability & Society, 13*(3), 429-429. Retrieved from http://search.proquest.com/docview/195761911?accountid=10382. doi:10.1080/09687599826722

Senior, K. A. (2000). *Testing the ICIDH-2 with Indigenous Australians: results of field work in two Aboriginal communities in the Northern Territory*. Wollongong: University of Wollongong.

Shahid, S., Bessarab, D., Howat, P., & Thompson, S. (2009). Exploration of the beliefs and experiences of Aboriginal people with cancer in Western Australia: a methodology to acknowledge cultural difference and build understanding. *BMC Medical Research Methodology, 9*(1), 60. Retrieved from http://www.biomedcentral.com/1471-2288/9/60

Shepherd, C. (2012). *The socioeconomic pattern of health and developmental outcomes among Aboriginal and Torres Strait Islander children.* PhD diss. Curtin University, Perth.

Smith, L. T. (2012). *Decolonizing methodologies – Research and Indigenous peoples (2nd Edition ed.)*. London & New York: Zed Book.

St Luke's Innovative Resources. (2010). *Stones have feelings too*. Maryborough, Victoria: Innovative Resources.

St Luke's Innovative Resources and SNAICC. (2009). *Talking up our Strengths*. North Fitzroy, Victoria: Innovative Resources.

Stephens, C., Nettleton, C., Porter, J., Willis, R., & Clark, S. (2005). Indigenous peoples' health-why are they behind everyone, everywhere? *Lancet 366*, 10-13. doi:10.1016/S0140-6736(05)66801-8

Stewart, D. W., & Shamdasani, P. N. (2014). *Focus groups: Theory and practice* (Vol. 20): Sage Publications.

Stopher, K., & D'Antoine, H. (2008). *Aboriginal people with disability: Unique approaches to unique issues*. Perth.

Swan, P., & Raphael, B. (1995). *Ways Forward: National Aboriginal and Torres Strait Islander Mental Health Policy. National Consultancy Report*. Canberra.

Szlemko, W., Wood, J., & Thurman, P. (2006). Native Americans and alcohol: Past, present, and future. *Journal of General Psychology, 13*, 435-451. doi:10.3200/GENP

Titiev, M. (1971). *Old Oraibi: A study of the Hopi Indians of the third mesa*. New York: Kraus Reprint.

Triandis, H. C. (1995). *Individualism and collectivism*. Boulder, CO: Westview Press.

Triandis, H. C. (2001). Individualism-Collectivism and Personality. *Journal of Personality, 69*(6), 907-924. Retrieved from
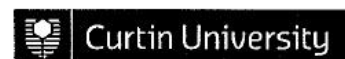
http://dx.doi.org/10.1111/1467-6494.696169. doi:10.1111/1467-6494.696169

Tuckett, A. G. (2005). Applying thematic analysis theory to practice: A researcher's experience. *Contemporary Nurse, 19*(1-2), 75-87.

University of Sydney. (2014). *Report of Audit of Disability Research in Australia*. Sydney. Retrieved from https://www.adhc.nsw.gov.au/__data/assets/file/0013/300091/1a-Audit-of-Disability-Research-in-Australia.pdf

Vergison, A., Dagan, R., Arguedas, A., Bonhoeffer, J., Cohen, R., DHooge, I., et al. (2010). Otitis media and its consequences: beyond the earache. *The Lancet infectious diseases, 10*(3), 195-203. Retrieved from http://www.slipe.org/documentos/otitis-media-lancet-2010.pdf. doi:10.1016/S1473-3099(10)70012-8

Vicary, D. A. (2002). *Engagement and intervention for non-Aboriginal therapists working with Western Australian Aboriginal people.* Doctoral dissertation. Curtin University of Technology, Perth, WA.

Vicary, D. A., & Bishop, B. J. (2005). Western psychotherapeutic practice: Engaging Aboriginal people in culturally appropriate and respectful ways. *Australian Psychologist, 40*(1), 8-19. Retrieved from http://dx.doi.org/10.1080/00050060512331317210. doi:10.1080/00050060512331317210

Wagner, G. (1956). *The Bantu of North Kavirond*. London: Oxford University Press.

Watling, C. J., & Lingard, L. (2012). Grounded theory in medical education research: AMEE Guide No. 70. *Medical teacher, 34*(10), 850-861. doi:10.3109/0142159X.2012.704439

Watson, L., Blair, E., & Stanley, F. (2006). *Report of the Western Australian Cerebral Palsy Register - to birth year 1999*. Perth: Telethon Institute for Child Health Research.

Webb, S. G., & Thorne, A. G. (1985). A congenital meningocoele in prehistoric Australia. *American Journal of Physical Anthropology, 68*(4), 525-533. Retrieved from http://dx.doi.org/10.1002/ajpa.1330680408. doi:10.1002/ajpa.1330680408

Westby, C., & Inglebret, E. (2012). Chapter 5 - Native american and worldwide indigenous cultures *Communication Disorders in Multicultural and International Populations (Fourth Edition).* (pp. 76-101). Saint Louis: Mosby. Retrieved from http://www.sciencedirect.com/science/article/pii/B9780323066990000145

Westerman, T. (1995). *Needs assessment report: People in the remote Aboriginal communities of the East Arnhem District who lack independence in their daily lives due to disability*. Darwin: Commonwealth Department of Human Services and Health and NT Department of Health and Community Services

WHO. (1999). *The Health of Indigenous Peoples*. Geneva: World Health Organisation.

WHO. (2001). *International classification of functioning, disability and health*. Geneva: World Health Organisation.

WHO. (2010). *Developing the World Health Organisation Disability Assessment Schedule 2.0*. Geneva. Retrieved from http://www.who.int/bulletin/volumes/88/11/09-067231/en/

WHO. (2012). *World report on disability: summary*. Geneva: World Health Organisation.

Whyte, S. R., & Ingstad, B. (1995). *Disability and culture: An overview.* Los Angeles: University of California Press.

Williams, C. J., Coates, H. L., Pascoe, E. M., Axford, Y., & Nannup, I. (2009). Middle ear disease in Aboriginal children in Perth: analysis of hearing screening data, 1998-2004. *Aboriginal and Islander Health Worker Journal, 33*(4), 14.

Williams, C. J., & Jacobs, A. M. (2009). The impact of otitis media on cognitive and educational outcomes. *Medical Journal of Australia, 191*(9), S69.

YouthWorX NT. (2009). *Inspire, include, increase: our stories*. Australia: Charles Darwin University.

Zubrick, S., Lawrence, D., Silburn, S., Blair, E., Milroy, H., Wilkes, E., et al. (2004). *The Western Australian Aboriginal child health survey: The health of Aboriginal children and young people*. Perth: Telethon Institute for Child Health Research.

APPENDICES

A. Ethics Approval

Memorandum

Office of Research and Development
Human Research Ethics Committee

To	Professor Jan Piek, Psychology and Speech Pathology
From	Dr Paul Copland, Manager Research Ethics
Subject	Protocol Amendment Approval HR 19/2012
Date	22 August 2013
Copy	Ms Caris Jalla, Psychology and Speech Pathology Associate Professor Cori Williams, Psychology and Speech Pathology Dr Jillian Pearsall-Jones (Adjunct Visiting Fellow), Psychology and Speech Pathology Associate Professor Marion Kicket, Curtin Teaching and Learning

TELEPHONE 9266 2784
FACSIMILE 9266 3793
EMAIL hrec@curtin.edu.au

Thank you for keeping us informed of the progress of your research. The Human Research Ethics Committee acknowledges receipt of your progress report, indicating modifications / changes, for the project *"Talking about health, wellbeing and disability in young people: an Aboriginal perspective"*. Your application has been **approved**.

The Committee notes the following amendments have been approved:

1. Minor updates to Participant Information Sheets. Both amended and original (labelled Appendix 3) attached with this application.

Approval for this project remains until **24-04-2016**.

Your approval number remains **HR 19/2012**, please quote this number in any further correspondence regarding this project.

Please note: An application for renewal may be made with a Form B three years running, after which a new application form (Form A), providing comprehensive details, must be submitted.

Yours sincerely

Dr Paul Copland
Manager Research Ethics

Western Australian Aboriginal Health Ethics Committee
2 Bulwer Street, PERTH WA 6000
PO Box 8493, Stirling Street, PERTH WA 6849

14th September 2012

Dear Caris,

HREC Reference number: 424
Project title: *Talking about health, wellbeing and disability in young people: an Aboriginal perspective*

Thank you for submitting the above research project which was considered by the WAAHEC at its meeting held on 10th September 2012. The Committee has not granted ethical approval for this project at this time.

In order to make a proper determination of the ethical and scientific acceptability of your project, please respond to the following request for additional information/clarification:

- Clarify what regions have agreed to be involved/participate in the study
- Clarify what structures/framework is in place for the focus groups. What information are you trying to gain from the participants? What sort of questions will be asked?

Guidance can be found in the National Statement Section 4.7.

In order to facilitate the HREC's consideration of your project, please provide the requested information as soon as possible. Once this information has been received your application will be listed for the next available meeting for consideration.

Should you require any further information, please contact the ethics@ahcwa.org.

Kind regards

Chelsea Bell
For
Tammy Prouse
Chair, WAAHEC

Government of **Western Australia**
Department of **Education**

Ms Caris Jalla
3/11 Hamilton Street
OSBORNE PARK   WA   6017

Dear Ms Jalla

Thank you for your application received 12 June 2014 to conduct research on Department of Education sites.

The focus and outcomes of your research project, *Talking about health, wellbeing and disability in young people - an Aboriginal perspective,* are of interest to the Department. I give permission for you to approach principals to invite their participation in the project as outlined in your application and subsequent correspondence. It is a condition of approval, however, that upon conclusion the results of this study are forwarded to the Department at the email address below.

Consistent with Department policy, participation in your research project will be the decision of the schools invited to participate, the children in those schools and their parents. A copy of this letter must be provided to principals when requesting their participation in the research. Researchers are required to sign a confidential declaration and provide a current Working with Children Check upon arrival at Department of Education schools.

Responsibility for quality control of ethics and methodology of the proposed research resides with the institution supervising the research. The Department notes a copy of a letter confirming that you have received ethical approval of your research protocol from the Curtin University Human Research Ethics Committee.

Any proposed changes to the research project will need to be submitted for Department approval prior to implementation.

Please contact Dr Adriaan Wolvaardt, Research and Evaluation Officer, on (08) 9264 5512 or researchandpolicy@education.wa.edu.au if you have further enquiries.

Very best wishes for the successful completion of your project.

Yours sincerely

ALAN DODSON
DIRECTOR
EVALUATION AND ACCOUNTABILITY

8 September 2014

B. Information Sheet

WHAT IS THIS STUDY ABOUT?

Information Sheet for 18+ (and parents)

Hello, my name is Caris and I am a Malaysia born Australian who has lived in Whadjuk Country for most of my life.

What am I doing?

We are doing a study titled *"Talking about health, wellbeing and disability in children and young people: an Aboriginal perspective."* With the help of my Aboriginal Reference Group and supervisors, I will be yarning with Aboriginal children and young people about what **health** and **disability** means to them. Here I am with George Hayden (Cultural Consultant) and Marion Kickett (Associate Supervisor). We will be yarning with young people both <u>with</u> and <u>without</u> disabilities. This study has the values of reciprocity, respect, equality, survival and protection; and responsibility.

Guidelines for ethical conduct in Aboriginal Health Research

Why am I doing this?

Health and disability services in Perth can help support families who have a child with a disability (such as blindness, amputations and birth deformities). Often Aboriginal families don't get the support they need because disability services don't understand the way disability is understood by the community.
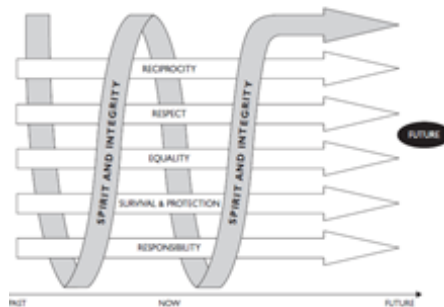
This study aims to capture what 'disability' means to young Aboriginal people so that families with a child with a disability can be **better supported**. We hope that these stories will help health workers (such as disability workers and hospital staff) **understand the community** and work effectively with **Aboriginal families** that need support.

Why have I received this?

We are inviting Aboriginal families living in Perth to be part of this study. Children and young people (**10 years old to 25 years old**) will be part of yarning circles – and we are inviting you (or your child) to be part of this. Youth both with and without a disability are invited. Those with either a **physical** or **sensory** **disability** (problems with ears and eyes for example) will be included.

166
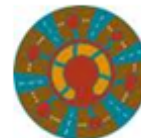
What will I need to do?

We will meet up once or twice to have a yarn, it will be fairly casual. I will talk with you (or your child) about what **health**, **happiness** and a **strong or deadly life** means using stories, art and drawing. Our yarning time will be audio recorded and will go for 1 to 2 hours. A family member or close friend can also be present during the yarning if you wish. It will be at a place that is convenient. You will be asked to give written consent. At a later date, you and will be able to read a copy of the yarning circle to make sure it correctly reflects the conversation.

What are the benefits?

The stories from the yarning can help **educate** health workers, increase **support** for families and build up the **confidence** of young people with a disability. This study will be for my Masters thesis and any published work will acknowledge all participants contribution.

During the yarning circle, refreshments will be made available, and you can receive financial reimbursement for any travelling. A thank you gift voucher will also be given for your time.

If you would like to be involved in this study, you can contact me or my supervisor anytime

Caris Jalla m: 0423 751 993
**e:** carislae.jalla@postgrad.curtin.edu.au
Marion Kickett (Associate Supervisor)
t: 9266 2292
e: Marion.Kickett@curtin.edu.au

Thanks, we hope to hear from you soon ☺

The logo uses the central symbol of a head to represent the field of social and emotional wellbeing. It is surrounded by large circles which symbolize the organisations and community groups which contribute to a combined effort to improve health in Australia. The smaller circles in between the larger circles represent the individuals affected by ill-health and their families. The roads in the outer section of the logo symbolize the many pathways that lead to ill-health and back to restored social and emotional wellbeing. The logo was designed by Allison Bellotte, an Aboriginal artist belonging to the Malgana and Nanda tribal groups from the Shark Bay area of WA.
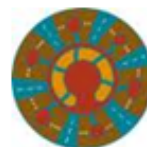
C. Consent Form

Consent Form

For the 'Talking about health, wellbeing and disability in young people: An Aboriginal perspective' Project.

I _____ _____have read and understood the
  <first name>   <last name>

Participant Information Sheet given to me.

- I have been given an opportunity to ask questions
- I understand that the yarning circles will be audio taped
- I understand that my identity will not be revealed
- I understand I have the right to stop participating at any time for any reason
- I understand I will be able to review a summary of my child's/my yarning stories before publications (such as a thesis paper, journal articles and conferences). Any publications will not name anyone. Names will be changed to maintain anonymity.

☐ Yes, I am happy for any artwork my child produces to be shared publically.

Relationship to the child or young person (e.g. mother): _____

Name of child (if applicable):   _____ _____
                                          <first name>   <last name>

I agree to participate in/allow my child to participate in this project as outlined:

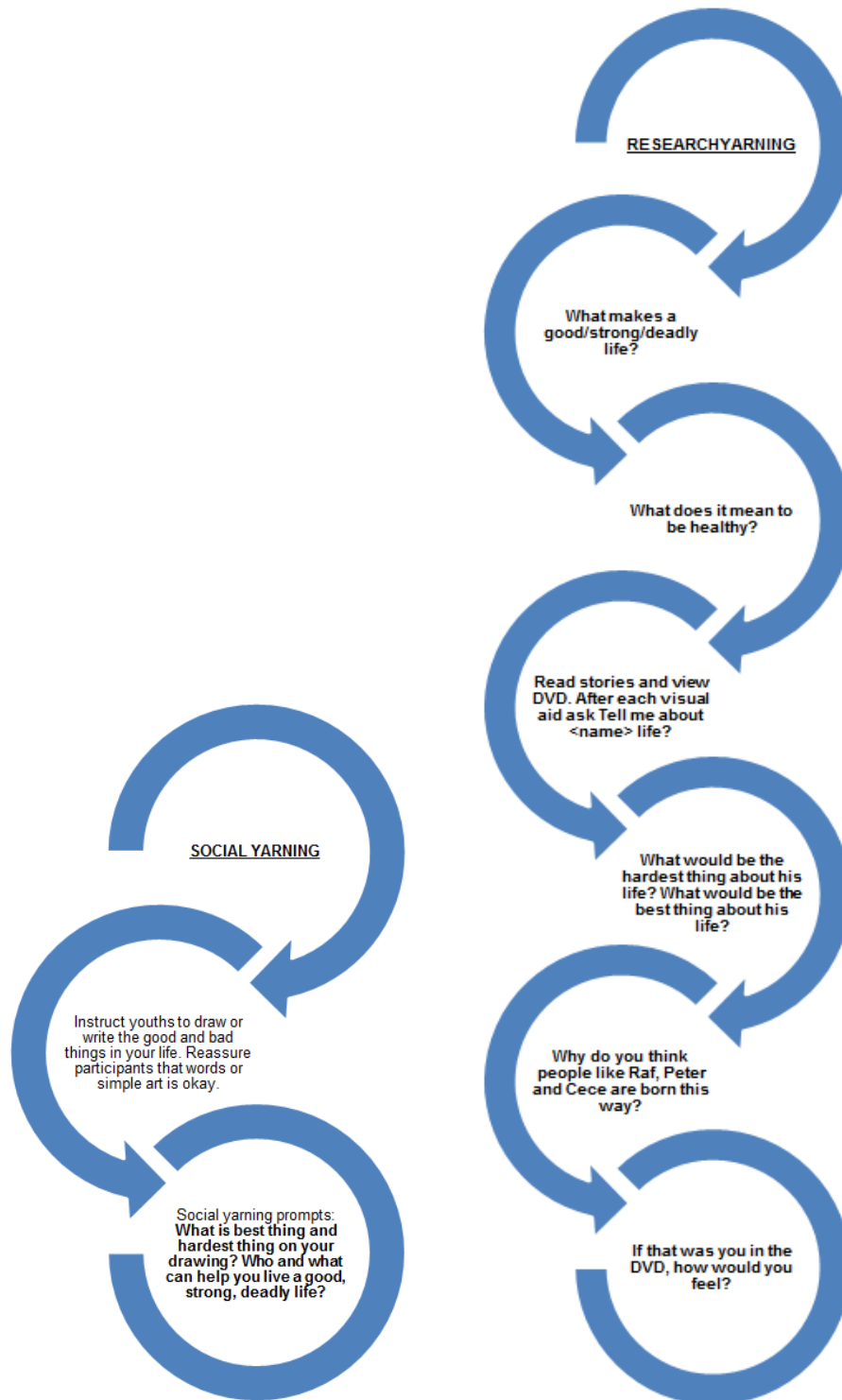_____   _____

Signature   Date

Disability or diagnosis (if any): _____

Aboriginal mob or group I / my child identifies with: _____

168

D. Yarning Circles Schedule

RESEARCH YARNING

What makes a good/strong/deadly life?

What does it mean to be healthy?

Read stories and view DVD. After each visual aid ask Tell me about <name> life?

What would be the hardest thing about his life? What would be the best thing about his life?

Why do you think people like Raf, Peter and Cece are born this way?

If that was you in the DVD, how would you feel?

SOCIAL YARNING

Instruct youths to draw or write the good and bad things in your life. Reassure participants that words or simple art is okay.

Social yarning prompts: What is best thing and hardest thing on your drawing? Who and what can help you live a good, strong, deadly life?

E. Publications

i. Research is not black and white

Jalla, C., & Hayden, G. (2014). Aboriginal health research is not black and white – lessons from the field. *Australian Indigenous HealthBulletin, 14*(3). Retrieved from http://healthbulletin.org.au/wp-content/uploads/2014/08/bulletin_report_Jalla.pdf

ii. Communication Chapter

Hayden, G. and Jalla, C. (2015). 'Communicating for quality and safety in Aboriginal health care', in R. Iedema, D. Piper and M. Manidis (eds) *Communicating Quality and Safety in Health Care*, pp. 230-44. Melbourne: Cambridge University Press.

iii. Yarning about Disability

(Free online book available at https://issuu.com/yarningaboutdisability. Audio version "Yarning about Disability eBook" at https://youtu.be/J-wEmMJrBCU. Also see www.facebook.com/YarningAboutDisability)

(Endeavour Foundation, Endowment Challenge Fund letter included below)

ENDEAVOUR FOUNDATION
Endowment
Challenge
FUND

25 May 2015

Caris Jalla
School of Psychology and Speech Pathology
Curtin University
GPO Box U1987
Perth Western Australia 6845

Dear Caris

Grant Agreement for Student Research Grant $5,000

Congratulations on the success of your recent grant request for the project "Yarning about disability".

Accepting an award from the Endeavour Foundation Endowment Challenge Fund creates a legal duty for you (the recipient) to be accountable for the proper management, control and use of the funds for the purposes set out in your detailed Application Form and other submissions.

The purpose of this document is to provide you with clear guidelines for the reporting requirements associated with your award. These requirements will allow the Endeavour Foundation Endowment Challenge Fund to maintain the high standard of corporate governance required for a Charitable Institution and to ensure accountability in our reporting procedures.

By accepting this grant you agree to:

1. Spend the grant amount of $5,000 (the Grant Funds) only for the purposes stated in your Application Form/Submission, unless approved in writing by the Endeavour Foundation Endowment Challenge Fund, in particular:

    a. Complying with the project details and undertaking the activities specified in Section B of your Application Form/Submission;

    b. Endeavouring in good faith to achieve the expected outcomes for the research project.

2. Document that reasonable steps were taken to ensure that the Grant Funds were used for the purpose stated in the Application Form/Submissions.

3. Provide this documentation in the following manner:

    a. Return a signed Grant Acceptance Form and Statement by a Supplier Form.

    b. Prepare a Final Report (Students) within three months of the project conclusion, 1 October 2016. The report templates can be downloaded from the Endeavour Foundation Endowment Challenge Fund website: http://www.endowmentchallengefund.com.au/guidelines

4. Return to the Endeavour Foundation Endowment Challenge Fund any of the Grant Funds received under this award if the Endeavour Foundation Endowment Challenge Fund determines that such monies are not being used in a manner consistent with the terms and conditions of this grant.