

**Faculty of Education and Social Work**

**University of Sydney**

**THE PARTICIPATION OF ABORIGINAL PEOPLE WITH A DISABILITY  
IN DISABILITY SERVICES IN NEW SOUTH WALES, AUSTRALIA**

**John Alexander Gilroy**

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A thesis submitted in fulfilment of the requirements for the degree of

Doctor of Philosophy



Faculty of Education and Social Work

*Office of Doctoral Studies*

## AUTHOR'S DECLARATION

This is to certify that:

- I. this thesis comprises only my original work towards the <insert Name of Degree> Degree
- II. due acknowledgement has been made in the text to all other material used
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- V. this thesis meets the *University of Sydney's Human Research Ethics Committee (HREC) requirements for the conduct of research.*

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## Dedication

*I want to dedicate the completion of the PhD thesis to my late wife, Danielle Gilroy, and my late daughter, Illa Gilroy, who have inspired me to undertake and continue my PhD studies as a means to empower Aboriginal people and people with a disability. Danielle and I dedicated our lives and careers to empowering the disability rights movement.*

*Danielle's optimism and beauty has helped strengthen me to commence my doctoral studies. At one point when I was going to quit one year into my candidature, Danielle developed the below encouragement note listing the reasons why I started my PhD. She read this and asked me to add to it every time I questioned why I started. It was this note and support from my PhD supervisors, the University of Sydney Faculty of Health Sciences and my loved ones that kept me going after Danielle and Illa both departed to another Universe with our ancestors.*

*When I let go of what I am.  
I become what I might be.*

Tao Tzu



Please add to list

**RESPECT**  
for self & people

To better the lives of so many people in the community

APPRECIATION

Finish whilst young.

Any Job that you want!

cause we are fucking crazy LOL

It's about People.

First Class Honors  
w Deans Merit Award  
w BA Sociology & Ab Studies

# John and his PhD

## Why did you start your PhD??

Give a voice to all

Stay out of Nowra ... HaHa

RESPECT

Because you can

Learn to better PWD

You would be bored otherwise

To Publish in any 1st Grade Journalle you want

World Travel

shaz everyone I can do IT!!

know wdgable

Success

be awesome

Your now getting paid \$1,200 per fortnight to finish the dam thing! (half of your wages)

\$\$\$

Not just a good looking young person with too much enthusiasm

So you had better Keep Going!

## **Abstract**

This thesis identified the factors that influence the participation of Aboriginal people in the New South Wales Government Department of Ageing, Disability and Home Care (DADHC) funded disability services, as described from the experiences of non-government disability service providers and paid disability service workers in New South Wales, Australia. Although it is known that the rates of morbidity are much higher among Aboriginal people compared with the non-Aboriginal population, the participation rates of Aboriginal people in disability services are under-representative. Various authors have examined these phenomena from the view point of Aboriginal people who may be interested in using disability services. However, there is limited understanding on the views of non-government and Aboriginal and non-Aboriginal workers of disability services about the factors that influence the participation of Aboriginal people in disability services. This study aimed to help fill this knowledge gap by achieving the following three research objectives:

1. Identify how and when the participation of Aboriginal people in disability services was identified in documented policy.
2. Identify and describe the factors that influence the participation of Aboriginal people in disability services as perceived by Aboriginal and non-Aboriginal employees in two NSW Government Department of Ageing, Disability and Home Care funded disability services.
3. Develop an Explanatory Framework that adequately encapsulates and represents the factors identified in this study as influencing the participation of Aboriginal people in disability services.

One Aboriginal community controlled organisation and a generic disability organisation were the sites for investigation. Objective one was achieved through a critical historical analysis of policy documents developed by the governments, one Aboriginal community controlled organisation and one generic disability organisation. A rigorous electronic and manual search of publications spanning three decades from 1981 was undertaken. This analysis demonstrated that the disability services sector's strategies to accommodate the needs of Aboriginal people with a disability have made a limited impact on

the service participation rates and have been hampered by Eurocentric models of disability and research. A conceptual framework is proposed to assist disability researchers and policy analysts working with Aboriginal people with a disability. The conceptual framework brings together the strengths of both the International Classification of Functioning, Disability and Health and the Indigenous Standpoint Theory.

The second objective was achieved via a situational analysis of transcripts of interviews, focus groups and field notes that were conducted with Aboriginal and non-Aboriginal paid employees of the same government funded organisations. Twelve factors that influenced the participation of Aboriginal people in disability services were identified from the data. Consistent with objective three, an Explanatory Framework was developed which illustrated the relationships between these factors. This framework demonstrated that the factors that influence the participation of Aboriginal people in disability services are inter-dependent historically, culturally and institutionally. The identified factors and explanatory framework are used to guide recommendations for future research, policy development and service provision in the sector.

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## Glossary

<b>Acronym</b>	<b>Term</b>
ABS	Australian Bureau of Statistics
ACCO	Aboriginal Community Controlled Organisation
ACCHS	Aboriginal Community Controlled Health Service
ACROD	Australian Council on Rehabilitation of Disability
ACT	Australian Capital Territory
ADA	NSW Anti-Discrimination Act 1977
ADD	NSW Government Ageing and Disability Department
ADN	Aboriginal Disability Network
AES	Access and Equity Strategy 2009
AIHW	Australian Institute for Health and Welfare
AOD	Australian Government Office of Disability
CALD	Culturally and Linguistically Diverse
CATSI	Corporations (Aboriginal and Torres Strait Islander) Act 2006
CEO	Chief Executive Officer
COAG	Council of Australian Governments
CPP	Community Participation Program
CSH	Australian Government Department of Community Services and Health
CSDA	Commonwealth State Disability Agreement
CSTDA	Commonwealth State and Territory Disability Agreement
DACA	Disability Advisory Council of Australia
DADHC	NSW Government Department of Ageing, Disability and Home Care
DADHC-APU	NSW Government Department of Ageing, Disability and Home Care Aboriginal Policy Unit. Later called the Aboriginal Service Development and Delivery Directorate
DAP	Disability Action Plans
DCNSW	Disability Council of NSW
DDA	Disability Discrimination Act 1992
DFACS	Australian Government Department of Families and Community Services
DHC	Australian Government Department of Housing and Construction

DMRP	Declaration on the Rights of Mentally Retarded Persons 1971
DoCS	NSW Government Department of Community Services
DOH	NSW Government Department of Health
DOSS	Australian Government Department of Social Services
DRDP	Declaration on the Rights of Disabled Persons 1975
DRIP	Declaration on the Rights of Indigenous Peoples 2007
DSA	Commonwealth Disability Services Act 1986
DSC	Western Australian Government Department of Disability Services Commission's
DSM	Diagnostic and Statistical Manual of Mental Disorders
DSP	Disability Support Pension
FaCS	NSW Government Department of Families and Community Services
FACSA	Australian Government Department of Families and Community Services and Indigenous Affairs
FHCSIA	Australian Government Department of Families, Housing, Community Services and Indigenous Affairs
HACC	Home and Community Care program
Homes Acts	Aged or Disabled Persons Homes Act 1974 and the Aged or Disabled Person Hostels Act 1974
HPAA	Handicapped Persons Assistance Act 1974
HREOC	Human Rights and Equal Opportunity Commission
HREOC Act	Human Rights and Equal Opportunity Commission Act 1986
ICF	International Classification of Functioning, Disability and Health
ICIDH	International Classification of Impairments, Disabilities and Handicaps
IDEAS	Information on Disability Equipment and Aids Organisation
IDPWD	International Day for People with Disabilities
IST	Indigenous Standpoint Theory
IYDP	International Year of People with Disabilities
LGA	Local Government Area
MDS	Minimum Data Set
NACH	National Advisory Council for the Handicapped
NACCHO	National Aboriginal Community Controlled Health Organisation
NAIDOC Week	National Aboriginal and Islander Day of Celebration Week

NDS	National Disability Services
NDIS	National Disability Insurance Scheme
NESB	Non-English Speaking Background
NGO	Non-Government Organisation
NHMRC	National Health and Medical Research Council
NSW	New South Wales
NSWDSA	NSW Disability Services Act 1993
NSWOD	NSW Office of Disability
NT	Northern Territory
ORIC	Office of Registered Indigenous Corporations
QLD	Queensland
RAP	Reconciliation Action Plan
RDA	Racial Discrimination Act 1975
SDA	Sex Discrimination Act 1984
SIDCR	Standing Interdepartmental Committee on Rehabilitation
UN	United Nations
WA	Western Australia
WHO	World Health Organisation
YACS	NSW Government Department of Youth and Community Services

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# Section One: Setting the Scene

## Chapter One: Introduction

...it is academics who represent themselves as 'knowers' whose work and training is to 'know'. They have produced knowledge about indigenous people but their way of knowing is never thought of by white people as being racialised despite Whiteness being exercised epistemologically. Whiteness established the limits of what can be known about the other through itself, disappearing beyond or behind the limits of this knowledge it creates in the other others name. (Moreton-Robinson, 2004, p. 75)

The overall aim of this study is to ascertain the factors that influence the participation of Aboriginal people in disability services in New South Wales (NSW). This chapter provides an introduction to the objectives and purpose of this study. The professional and personal motivations to undertake this study are firstly explained, followed by an outline of the organisation of the thesis.

The Australian Indigenous people are the traditional owners of Australia, representing 2.4% of the Australian population in 2006. The Indigenous people of Australia are also known as the First Nation People. There is estimated to be around 400 different 'clan' groups or 'communities'. The Indigenous people of the Australian mainland are known as the 'Aboriginal people' or the 'Aborigines'. The Indigenous people of the Torres Strait Islands are known as the 'Torres Strait Islanders'. This thesis is only focused on the Aboriginal population living in New South Wales (NSW), whilst acknowledging that many Torres Strait Islander people now live in NSW (Steering Committee for the Review of Government Service Provision, 2009). As such, the phrases "Aboriginal" and "Aboriginal communities" are used throughout this thesis.

One NSW Government funded Aboriginal community controlled disability service provider, known as the *Aboriginal NGO*, and one generic disability service provider, known as the *Mainstream NGO*, were the sites for investigation. The Aboriginal NGO provided a range of disability services specifically for Aboriginal people with a disability and their families primarily in a metropolitan region of NSW. The Mainstream NGO provided a range of disability services for all Australian citizens across NSW. The policy documents from these two agencies and the governments were critically analysed to ascertain how the disability services sector responded to the low disability service participation rate of Aboriginal people. Subsequently, the paid workers of the Aboriginal NGO and the Mainstream NGO were interviewed to learn of their experiences as workers in

supporting and advocating on behalf of Aboriginal people with a disability, their families and communities.

### **Professional Motivation for the Study**

Disability services have a pivotal role to play in supporting people with a disability, their families and carers. Disability service providers have a long history in lobbying and advocating on behalf of people with a disability for over a century. In this context, disability service workers have a mandate to plan, develop and implement services to promote the maximum independence and quality of life of people with a disability. The motivation for the study will be discussed in relation to the defining provider in the sector, prevalence of disability and participation in disability services.

### **Defining disability service providers in New South Wales**

To understand the professional significance of this study, this thesis must first provide a clear understanding of how it defined the NSW disability services sector. As discussed further in Chapter Two, the NSW Government funds government and Non-Government Organisations (NGO) to provide disability services under the *Commonwealth Disability Services Act 1986 (DSA)*, the *NSW Disability Services Act 1993 (NSWDSA)* and a Multilateral Agreement. The DSA sets out the objectives and principles that administer government funded disability service agencies along with the conditions that organisations receive funding. Under the DSA, the state/territory governments have administrative responsibility for the following services:

1. Supported Accommodation
2. Aids and Equipment
3. Behaviour Support
4. Case Management
5. Early Childhood Intervention
6. Post School Support
7. Information and Advocacy
8. Respite
9. Therapy
10. Community Access

Under the DSA, the NSW Government and the Australian Government allocate disability service funding under a 'Multilateral Agreement' called the Commonwealth State/Territory Disability Agreement (CSTDA), later called the

National Disability Agreement (Multilateral Agreement). Under the Multilateral Agreement, the Australian Government and the NSW Government shared the responsibility for funding disability services. The Multilateral Agreement sets out the framework for the planning, delivery and funding of services for people with a disability, their carers and family. The Multilateral Agreement defined disability for government funding purposes by specifying as its target groups those people who have a disability “that is attributable to an intellectual, psychiatric, sensory, physical or like impairment or to a combination of impairments, and that is permanent or is likely to be permanent”, and that the individual requires support to enhance participation in the community (Australian Government Department of Families, Housing, Community Services and Indigenous Affairs (FHCSIA), 2009, p. 2).

In NSW, the New South Wales Government Department of Ageing, Disability and Home Care (DADHC) has responsibility for the administration of NSW Government funded services. Funding is allocated on a state region basis, shown in Appendix A. In 2010/11, the NSW Government restructured the government portfolios for community services. DADHC was merged in with the NSW Government Department of Families and Community Services (FaCS), FACS – Ageing, Disability and Home Care branch. For consistency, this study uses the old departmental structure to reference the NSW Government department responsible for disability affairs as some of the documents reviewed and analysed in this study and the participants interviewed used the acronym DADHC.

In 2009, the NSW Government through DADHC allocated almost \$10 billion in funding to hundreds of government service providers and NGOs (DADHC, 2009c). In 2010, DADHC funded more than 40 Aboriginal-specific programs and services for people with a disability in NSW (New South Wales Ombudsman, 2010). The present study is only focused on disability service providers funded by the NSW Government under the NSWDSA and the Multilateral Agreement.

### **The council of Australian government’s’ reforms**

The Council of Australian Governments (COAG) is reforming the disability and aged care services sector. COAG has separated government responsibility for aged care services and disability services. Effective from 2011, the Australian Government has responsibility for aged care services and the state and territory

governments have responsibility for disability services (COAG, 2012a). Under the reforms, Aboriginal people above the age of 50 years can access aged care services.

The Productivity Commission (2010, 2011) has released a national enquiry report recommending a reform of the disability services sector. COAG and the Productivity Commission have sought comments and suggestions on ways to increase the disability service participation rates of the Aboriginal population, such as developing a service system that is culturally responsive for local Aboriginal people and effective ways to fund services and supports. The Productivity Commission (2010, 2011) recommended that whilst developing a more 'personalised' service system for people with a disability and their families, the government must work to address access and equity barriers to generic services for Aboriginal people with a disability. Such barriers include cultural differences between Aboriginal communities and the disability services system, absence of services in rural/remote regions, lack of Aboriginal workers and fear of disability services that are only staffed by non-Aboriginal workers.

Since the release of the Productivity Commission's inquiry reports, COAG has commenced a number of pilot studies to inform the development of a new national disability services system. These pilot studies aim to test new models of individualised support options for people with a disability (COAG, 2012b).

### **Disability prevalence and disability service participation**

To understand the significance of this research, one must understand the prevalence of disability in the population of Aboriginal people. In 2006, the prevalence of disability is reported to be more than twice the rate reported for the non-Aboriginal population. In addition, Aboriginal people have higher rates of young people caring for people with a disability and higher rates of people with intellectual and psychological disabilities involved in the criminal justice system (Steering Committee for the Review of Government Service Provision, 2009).

Data from the Australian Bureau of Statistics (ABS) (2006b) show that Aboriginal people represented 2.4% of the Australian population in 2006. Table One shows that the greatest number of Aboriginal people resided in NSW, Western Australia (WA) and Queensland (QLD). The Northern Territory (NT) had

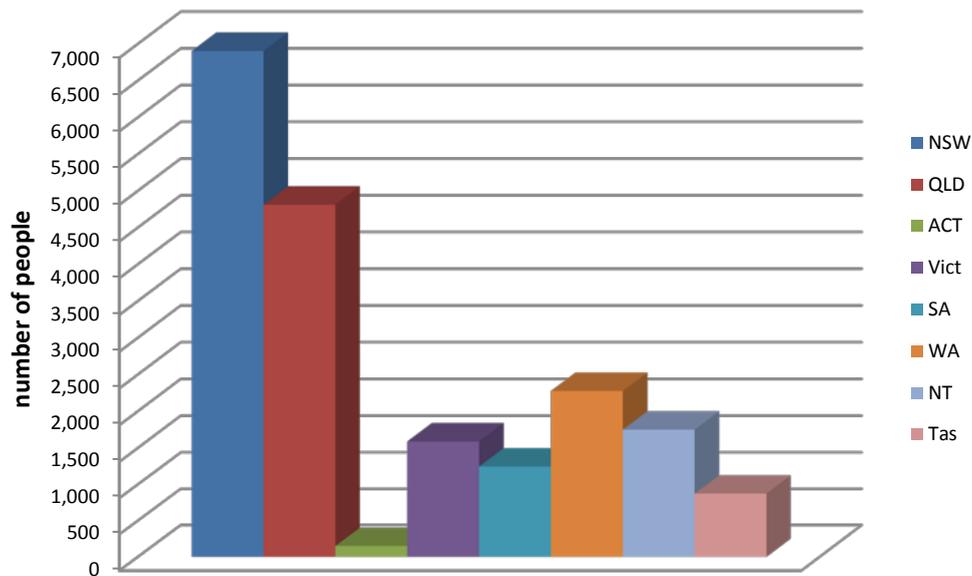
the highest proportion of Aboriginal people within a per state/territory population, representing over 30% of the NT population.

Table 1

*Percentage of Aboriginal People in the Australian Population by State and Territory (2006 Census)*

State and Territory	State/Territory Population	Indigenous Population	Representation of Indigenous People in State and Territory Populations
Northern Territory	210,700	66,600	31.6%
New South Wales	6,817,200	148,200	2.2%
Victoria	5,128,300	30,800	0.6%
Queensland	4,091,500	146,400	3.6%
Western Australia	2,059,000	77,900	3.8%
Tasmania	489,900	16,900	3.5%
South Australia	1,568,200	26,000	1.7%
Australian Capital Territory and Other Territories	334,200	4,000	1.2%
<b>Total Population</b>	<b>20,701,500</b>	<b>514,200</b>	<b>2.4%</b>

Defining disability was difficult due to the high level of subjectivity involved. In Chapter Six, *Conceptual Framework*, this thesis explores how disability is conceptualised. The ABS attempted to defined disability as a multidimensional experience as identified by the World Health Organisation's (WHO) International Classification of Functioning, Disability and Health (ICF) (WHO, 2002). As further discussed in Chapter Six, the ICF identifies disability as a combination of factors relating to impairments of body functions and structures and how *contextual factors*, such as the individual's environment or social structures, and *personal factors*, such as the individual's lifestyle or gender, affects or is affected by the individual's health or impairments. Whilst, the Aboriginal population represented 2.4% of the Australian population, Aboriginal people represented nearly 5% of the population of people with a disability in 2006. Figure 1 provides a state and territory comparison of the number of Aboriginal people with disabilities. The Figure shows that NSW, QLD and WA had the highest number of Aboriginal people with a disability in 2006 (ABS, 2006b).



*Figure 1- Number of Aboriginal people with a disability by state and territory in 2006 (ABS, 2006b)*

Although the level of government funding for disability services has increased, the participation rate of Aboriginal people in disability services has been disproportionate to the reported prevalence of disability in this population. Nationally in 2009, 12,068 Aboriginal people accessed Multilateral Agreement funded services, an increase from 10,633 in 2008. However, these figures were an under-estimate, as around 5% of people did not report their Aboriginality (AIHW, 2008a, 2008c, 2010a).

DADHC (DADHC, 2009c) reported that Aboriginal people represented 4% of all clients of Multilateral Agreement funded services between 2005 and 2009. The majority of Aboriginal people accessed community support, respite and therapy services. Aboriginal people represented less than 3% of community access, day programs and in-home care clients.

### **Personal Motivation for the Study**

The protocol in many Aboriginal communities in introducing oneself to other Aboriginal people is to provide information on one's family heritage so that rapport and connection is established. Consistent with the paradigmatic framework and methodology adopted in this inquiry these details are also important in supporting the reflexive nature of the research undertaken and to make clear the background and experiences of the researcher which have lead me to undertake this inquiry. In

addition as the report of this inquiry unfolds, I will comment on the manner in which this inquiry has informed and influenced me.

I am a Koori man from the Yuin Nation of the NSW South Coast. My father is of Scottish heritage and migrated to Australia as a child. My mother is a Koori woman from the Yuin Nation, whose Aboriginality came through her mother's side.

My interest in this research arose from my personal and professional experiences in the disability rights movement. When I was a child I had a profound speech impairment, which limited my ability to complete a sentence without stuttering, repeating or slurring my words. During my primary school years in the 1990s, I was regularly withdrawn from school classes for speech therapy and counselling to 'correct' and 'address' my speech 'problem'. During a speech therapy session in 1995, I said to my brother "get me a can of coke braaa". The speech therapist responded by correcting me explaining that "it is brother" and counted the syllables, which totally humiliated me in front of my family. The fact is that the word "braaa" is Koori English for "my brother". That event was the final straw for me. I never went back to speech therapy or counselling, skipping school in order to avoid this part of my routine.

When I commenced working for the DADHC Aboriginal Policy Unit, and later the Aboriginal Resources and Pathways projects for National Disability Services (NDS), I learnt that there was a high level of commitment and enthusiasm in the disability services sector to support and work with Aboriginal people with a disability in a culturally responsive manner. It got me thinking about the challenges that might exist for disability service providers in working with Aboriginal communities and developing culturally responsive services. The challenge for disability services was not just a lack of financial resourcing, as the NSW Government's signalled their ten year plan, *Stronger Together*, as the largest investment in disability services in NSW (DADHC, 2006d). The issue cannot just be a lack of a targeted approach, as *Stronger Together* committed a large amount of funding specifically for Aboriginal people with a disability, their families and carers and more effective recruitment and support for Aboriginal workers. This inquiry set out to explore the factors that might be influencing the participation of Aboriginal people with a disability in disability services, from the perspective of disability service workers who are actually engaged in providing services to Aboriginal people.

## Purpose for the Research

The research undertaken in Aboriginal communities over recent decades, discussed in Chapter Two, has helped us understand the challenges Aboriginal people with a disability face in accessing disability services in Australia. In particular, traditional culture and colonisation play an important role in conceptualising disability and supporting people with a disability. This was well demonstrated in relation to many Aboriginal communities' preference for Aboriginal community controlled organisations (ACCO) and Aboriginal workers in the disability services sector.

Little is known about the factors that influence the participation of Aboriginal people in disability services, as understood and experienced by disability NGOs and disability service workers. Does the culture of the service provider or the Aboriginal communities make a difference? Are there differences in the experiences of Aboriginal workers engaging with Aboriginal people with a disability when compared to non-Aboriginal workers? Are there differences between ACCOs and mainstream disability service providers in influencing the participation of Aboriginal people?

There has been limited investigation of the factors that influence the participation of Aboriginal people in disability from the experiences of disability services providers. In particular, there has been limited investigation of the views of the paid disability services workforce about the factors that influence the participation of Aboriginal people in disability services. This study helps to fill this knowledge gap for the current COAG reforms. The thesis provides the disability services sector with knowledge about ways the sector can overcome access and equity barriers for Aboriginal people with a disability, their families and carers. The objectives of the research were threefold:

1. Identify how and when the participation of Aboriginal people in disability services was identified in documented policy
2. Identify and describe the factors that influence the participation of Aboriginal people in disability services as perceived by Aboriginal and non-Aboriginal employees in two NSW Government Department of Ageing, Disability and Home Care funded disability services.

3. Develop an Explanatory Framework that adequately encapsulates and represents the factors identified in this study as influencing the participation of Aboriginal people in disability services.

The research objectives were addressed using two different qualitative methodological frameworks. Objective one was addressed using a critical historical analysis of policy documents developed by governments, the Aboriginal NGO and the Mainstream NGO to identify how these three agencies responded to the disability service participation of Aboriginal people. This analysis traced the history of how each agency has responded to the high prevalence of disability in Aboriginal communities and the low participation rate of Aboriginal people in disability services as a social issue.

The second objective was addressed using open-ended, in-depth interviews and focus groups with Aboriginal and non-Aboriginal workers in the Aboriginal NGO and the Mainstream NGO to identify the factors affecting Aboriginal people's service participation. Objective two sets out to ascertain the factors that influenced the participation of Aboriginal people in disability services as understood and experienced by disability workers and managers of DADHC funded disability services. Objective three was informed by the data collected from the interviews and focus groups with paid workers of disability service providers.

### **Organisation of the Thesis**

This thesis is organised over ten chapters, divided into four sections. Dividing the thesis into four sections helps the reader follow the development of the thesis.

#### **Section one: setting the scene**

Section One includes Chapter One and Chapter Two. Chapter Two sets the scene for the importance of this study. It firstly provides a review of national and international policies and philosophies relating to disability services and people with a disability to illustrate the policy and legislative foundations of the disability services sector. In addition, a profile of the health and welfare of Aboriginal people and people with a disability is provided to demonstrate how Aboriginal people with a disability are one of the unhealthiest and disadvantaged populations in Australia. This chapter also explores three main initiatives undertaken in the disability services sector to help address the service participation rate of Aboriginal people:

person-centred planning, cultural competency and funding ACCOs and Aboriginal services. The chapter analyses the findings of previous research regarding the disability service participation of Aboriginal people.

### **Section two: analysing documents**

Section Two includes chapters Three, Four, Five and Six, which report on the methodology and results of the first objective of this study. Chapter Three outlines the qualitative methodology applied in the collection and analysis of policy documents produced by the governments, the Aboriginal NGO and the Mainstream NGO. A rigorous and exhaustive search of documents from public and private archives, libraries and online databases was undertaken. Documents were obtained from all over the nation. The documents were analysed using a critical historical document analysis. Chapters Four and Five present the findings explaining how the governments, the Aboriginal NGO and the Mainstream NGO have responded to the service participation of Aboriginal people.

Chapter Six proposes a conceptual framework (the Conceptual Framework) that was developed over the course of the policy document analysis because there was no identified culturally appropriate framework available for research and policy development regarding Aboriginal people with a disability. The Conceptual Framework has merged Indigenous Standpoint Theory (IST) and the ICF. IST is often misunderstood as an Aboriginal way of doing research. On the contrary, IST incorporates Aboriginal philosophy and scholarship into Western sciences. The ICF is a globalised taxonomy model of disability developed by the World Health Organisation.

### **Section three: learning from disability service's workers**

The third section includes Chapters Seven and Eight, which address objective two of this study. Chapter Seven presents the methodology used to address the second objective of this study. Data were collected using open-ended in-depth interviews and focus groups with paid staff of the Aboriginal NGO and the Mainstream NGO. Twelve factors were identified from the data collected and are identified and explained in Chapter Eight.

**Section four: factor relationships, conclusion and future implications**

Section Four includes Chapters Nine and Ten. Chapter Nine discusses the findings presented in the previous section of the thesis and proposes an Explanatory Framework on the relationships between the identified factors consistent with the third objective of the thesis. Chapter Ten concludes the thesis and presents the implications and recommendations for current and future policy development and research.

## **Chapter Two: Profile of the Disability Services Sector for Aboriginal People with a Disability in Australia**

This chapter discusses the challenges that Aboriginal people with a disability face in accessing culturally appropriate disability services and sets the scene for the importance of this study. This chapter shows that although Aboriginal people with a disability are one of the unhealthiest and disadvantaged sub-groups of the Australian population, their participation rates are under-representative of the prevalence of disability in the Aboriginal population. Although the disability services sector has attempted to accommodate the needs of Aboriginal people, these attempts have made a limited impact on access and equity barriers to culturally appropriate services for Aboriginal people.

This chapter firstly sets the international and national political and policy scene of the Australian disability services sector. It discusses the policy and legislation development as part of the global Disability Rights Movement and the Indigenous Rights Movement. This segment provides an overview of the United Nations (UN) Declaration on the Rights of Disabled Persons (DRDP), the Declaration on the Rights of Indigenous Peoples (DRIP) and the Convention on the Rights of Persons with Disabilities (the Convention). This is followed by an overview of the purpose of the *Commonwealth Disability Services Act 1986* (DSA), the *New South Wales Disability Services Act 1993* (NSWDSA) and the policies administered under the Human Rights and Equal Opportunity Commission (HREOC) (now known as the Human Rights Commission).

The Chapter then demonstrates how the population of Aboriginal people with a disability is one of the unhealthiest and disadvantaged populations in Australia under the World Health Organisation's (WHO) definition of social determinants of health. Data from the Australian Institute of Health and Welfare (AIHW) are used to demonstrate that the low disability service participation of Aboriginal people has been a longstanding issue in the disability services sector. This chapter then discusses the major strategies adopted by the disability services sector to establish a culturally responsive service system for Aboriginal people.

## **International Disability Policy**

The global Disability Rights Movement has made much progress in helping to liberate Indigenous people with a disability at an international scale since the 1970s. The government policy and legal frameworks guiding and shaping the rights and protections of people with a disability in Australia owe much to the recognition of rights since the UN Declaration of Human Rights 1948. The movement has achieved a global ideological shift in the disability services sector, such as the devolution of large residential accommodation, preventions against abuse of people with a disability, improved employment and living conditions and empowering people with a disability to be independent citizens.

The Disability Rights Movement achieved two major UN declarations in the 1970s. The first declaration, Declaration on the Rights of Mentally Retarded Persons (DMRP) 1971, provided the framework for protecting the rights of people with a disability for countries around the world. The DMRP (UN, 1971) stated that the 'mentally retarded' had "to the degree feasible" the same rights as non-mentally retarded to education, employment, protection from exploitation and to live as independently as possible. The DMRP enshrines the rights of people with a disability to due process of law (i.e. having the same protection of the law as others).

The DMRP paved the way for the development of the protections of rights for people with a disability. The second declaration, DRDP, furthered international protection of the rights of people with a disability. The DRDP reiterated that people with a disability have the same rights as people without a disability. The main difference was the recognition that people with a disability have the same right to economic participation and to become self-sufficient, autonomous and self-determining (UN, 1975). The DRDP (1975) obliges UN member countries to ensure people with a disability have the right to:

1. Protection from discrimination.
2. Access to education, training and employment.
3. Treated with dignity and respect.
4. Form personal relationships, a social life and a family life.
5. Assistance to enable them to become as independent as possible in all aspects of their life.

The DRDP lead the path to the development of the International Year of People with Disabilities (IYDP) in 1981. IYDP commemorated the participation of people

with a disability around the world through festivals, research projects, programmes and policy innovations and reforms. Australian and state/territory governments had committees dedicated to planning and informing the public of IYDP events. IYDP paved the way for the recognition of the relationship between ‘handicap’ and the ‘environment’ in conceptualising disability with the proclamation of 1982 as the Decade of Disabled Persons (International Year of Disabled Persons NSW Steering Committee, 1980). The UN worked with member nations to improve the data collection and reporting on the population of people with a disability to assist countries in policy development and monitoring (WHO, 2002). The UN published many reports on the prevalence of disability, such as:

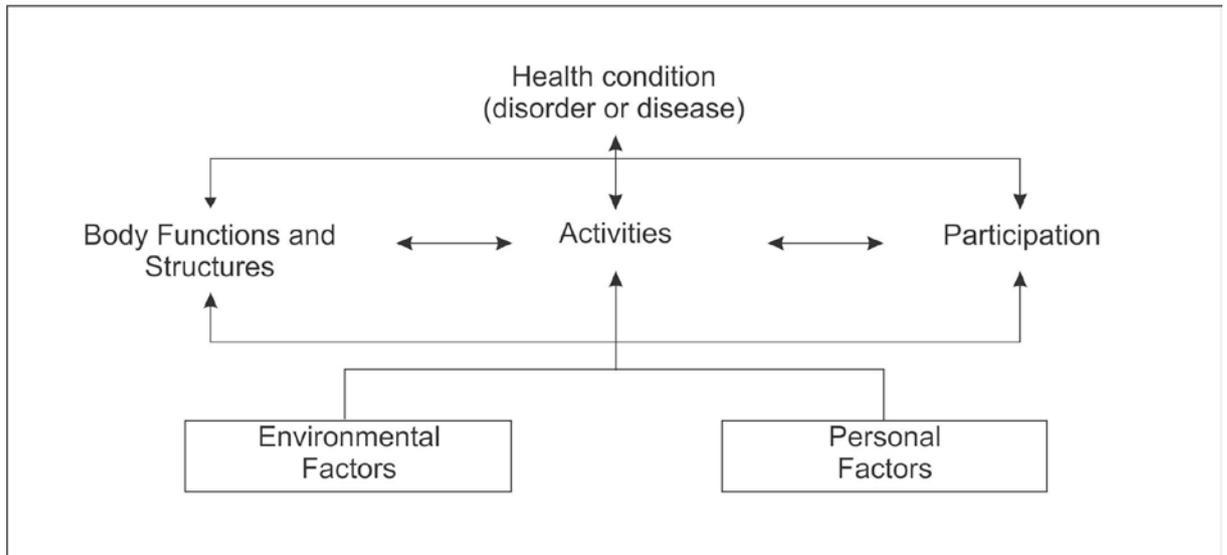
1. International Disability Statistics Data Base,
2. the Disability Statistics Compendium,
3. Manual for the Development of Statistical Information on Disability Programmes and Policies.
4. Guidelines and Principals for the Development of Impairment, Disability, and Handicap Statistics.
5. A Handbook on Census and Survey Methods for Development of Impairment, Disability, and Handicap Statistics is planned by the Division.

In 2007, the UN (2006) ratified the Convention on the Rights of Persons with Disabilities, which further protects the rights and freedoms of people with a disability. The purpose of the Convention is “to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity” (UN, 2006). The Convention better aligns the rights of people with a disability to other UN Declarations. Signatories to the Convention have committed their governments to address “the difficult conditions faced by persons with disabilities who are subject to multiple or aggravated forms of discrimination on the basis of race, colour, sex, language, religion, political or other opinion, national, ethnic, indigenous or social origin, property, birth, age or other status” (UN, 2006).

As discussed further in Chapter Six, in 2001, WHO endorsed the International Classification of Functioning, Disability and Health (ICF). The ICF is taxonomy of functioning and disability. The ICF recognised disability as a multi-dimensional experience (WHO, 2001, 2002):

1. The body functions and structures.
2. The activities people do and the life areas in which they participate.
3. The factors in their environment which affect these experiences.

Each of these factors is defined in the context of a health condition. The ICF conceptualises functioning as the interactions between any or all of “an impairment of body, structure or function, a limitation in activities, or a restriction in participation” as graphically represented in Figure 2 (WHO, 2001, p. 18).



*Figure 2* - Interactions between the components of International Classification of Functioning, Disability and Health (WHO, 2001, p. 18)

Disability is defined as a multi-dimensional experience between personal factors and functional factors. A person’s disability is conceived as an interaction between *environmental* and *personal factors* and *health* and *functioning*. *Environmental factors* refer to the physical, social and attitudinal environments where an individual lives. Environmental factors have an external impact on the person’s level of functioning, including the design of the built environment or the community service system. *Personal factors*, however, refer to the actual lived experience of disability. These factors include gender, sexuality or lifestyle and historical experiences. In addition, personal factors also include socioeconomic status and experiences relating to remoteness and high-risk behaviours and physical functioning (WHO, 2001, p. 18).

The Indigenous Rights Movement occurred simultaneously with the Disability Rights Movement. There was limited to no focus on disability affairs in the global Indigenous Rights Movement. Nevertheless, the biggest achievement of the Indigenous Rights Movement was in September 2007, after a twenty year negotiation by governments and Indigenous people around the world, the UN adopted the DRIP. The Declaration sets out the rights of Indigenous peoples to

self-determination and the practice of traditional laws and cultures and social inclusion. The Declaration helps Aboriginal people to ensure that Indigenous rights are imbedded in legislation, policies and programs that impact on Aboriginal people (UN, 2008).

At the time the UN adopted the DRIP, Australia was one of four countries which voted against it, the others being New Zealand, Canada and the United States of America. However on 3 June 2009, the Rudd Government reversed the Australian Government's decision and gave formal support to the DRIP. In 2011, the Foreign Affairs Minister, Kevin Rudd commented on the principles of the DRIP in a formal presentation to the UN (Rudd, 2010):

The Government which I led as Prime Minister of Australia also overturned the previous Australian Government's opposition to the Declaration on the Rights of Indigenous Peoples.

Since then, other governments have also announced their support for this Declaration.

We have also sought to reflect these principles in our dealings with Australia's own Indigenous peoples.

Again as Prime Minister of Australia, I tendered a formal apology in the Australian Parliament to Australia's indigenous peoples for the centuries of oppression that the first Australians had experienced from European settlers.

### **Australian Disability Policy**

The Australian Government's commitment to the DRIP has further committed the Australian Government to addressing the needs of Aboriginal people with a disability. DRIP pays particular attention to the needs and rights of Indigenous people with a disability. Under Article 22, the DRIP states "particular attention shall be paid to the rights and special needs of indigenous elders, women, youth, children and persons with disabilities in the implementation of this Declaration" (UN, 2008). As such, by signing the DRIP, the Australian Prime Minister committed the nation to meet the human rights needs of Aboriginal people with a disability.

Australia's commitment to the DRIP has informed many national government Aboriginal social and health policies and strategies. For example, the DRIP

influenced the planning and development of the Australian Government's *Closing the Gap* policy, which aims to close the gap in inequalities between Aboriginal and non-Aboriginal populations in education, employment, health and mortality. Although disability is not strongly emphasised in any of the Closing the Gap initiatives, they have the potential to reduce the prevalence of disability acquired through health conditions (COAG, 2011).

The Australian legislative and policy experience did not wholly reflect the international human rights philosophies of the global Disability Rights Movement and the Indigenous Rights Movement. The Australian Government was mostly focused on managing services for people with a disability. Between 1972 and 1986, the Australian Government allocated funding to each state and territory government and many non-government organisations (NGO) for supported accommodation under the *Aged or Disabled Persons Homes Act 1974* and the *Aged or Disabled Person Hostels Act 1974* (the Homes acts) for both people with a disability and people who are ageing. Centre-based day programs were also funded under the Homes acts. Funding for other service types was allocated through the Handicapped Persons Welfare Program under the *Handicapped Persons Assistance Act 1974* (HPAA) to governments and non-government agencies for programs and initiatives covering training, activity therapy, supported employment, residential activities (non-accommodation), rehabilitation and recreation services (Handicap Persons Review Committee, 1985).

The NSW Government allocated funding for disability services similar to the Australian Government under the *Community Welfare Act 1982* and the *Youth and Community Services Act 1973*. The NSW Government managed and funded a range of supported accommodation facilities (including large residentials), vocational counselling, supported employment and day care centres. Some NSW Government disability programs, such as the Young Disabled Children's Programme, were subsidised by the Australian Government (Australian Government Department of Social Security (DOSS), 1984; Handicapped Programs Review Australia, 1985).

Following IYDP, both sides of Federal Parliament initiated the biggest national review of services and support for people with a disability. As discussed further in Chapter Four the report, *New Directions*, reported that the disability services sector was not meeting the needs of people with a disability and government

support for disability services was seriously fragmented and government funding was insufficient and uncoordinated. Furthermore, the rights of people with a disability were not being met by the governments. In 1986, in response to *New Directions*, the Australian Government introduced the DSA to set in legislation the Objectives and Principles for the delivery of government funded services for people with a disability. The DSA (1986) defined a person with a disability as “persons with disability that is attributable to an intellectual, psychiatric, sensory or physical impairment or a combination of such impairments [that] is likely to be permanent”. The DSA enables the Australian Government to make regulations and guidelines that specify the aims and principles for funded disability services.

Each state and territory government was required, under the Council of Australian Government (COAG) agreement to enact complementary legislation to the DSA. In 1993, the NSW Government developed the *NSW Disability Services Act 1993* (NSWDSA). The NSWDSA made a commitment to address the disadvantage experienced by Aboriginal people with a disability, stating that the NSW Government will “meet the needs of persons with disabilities who experience an additional disadvantage as a result of their gender, ethnic origin or Aboriginality”.

The regulations and principles created under the DSA and the NSWDSA focused specifically on service provision and eligibility as opposed to helping people with a disability become independent in society. The principles are broad statements that set the policy framework for funded disability service providers. They are intended to reflect the DRDP to provide people with a disability rights that are equal to the rights of all Australians. People with a disability have a right to make complaints to governments or an advocacy service about a funded disability service or a government agency. The Objectives of the DSA were to clarify the purposes of the funding of services for people with a disability (DSA, 1986).

Under the DSA, the Australian and state and territory governments signed the first Multilateral Agreement for the funding of services for people with a disability. In July 1991, all parties signed the first of three five-year Multilateral Agreements, named the Commonwealth State Disability Agreement (CSDA) from 1991 to 2001 and then changed to the Commonwealth State and Territory Disability Agreement (CSTDA) from 2002 to 2008 (defined in this thesis as the Multilateral Agreement). The Disability Rights Movement was aimed at empowering people with a disability

under a human rights philosophical framework. In comparison, the Multilateral Agreement was not human rights focused as it was focused on funding institutions for people with a disability and, in conjunction with the DSA, regulated service eligibility. The Multilateral Agreement *pathologised* disability as “non-aged people with intellectual disability, psychiatric, sensory or physical disabilities or a combination of such disabilities which is likely to be permanent and substantially reduced capacity for communication, learning or mobility and establishes the need for ongoing support” in the context of accessing a *service* (Australian Government Office of Disability (AOD), 1991). The Multilateral Agreement clarified that the Australian Government holds responsibility for rehabilitation and employment services and the states/territories assume responsibility for the remainder service types. Advocacy and information services are jointly funded by all governments.

Although the DSA did not wholly reflect the pathway of the Disability Rights Movement and the Aboriginal Rights Movement, the Australian Government has enacted legislation to give further effect to the rights of people with a disability and Aboriginal people under Australia’s international treaty obligations. In 1986, HREOC (now called the Human Rights Commission) was established to administer and monitor four pieces of legislation:

1. *Human Rights and Equal Opportunity Commission Act 1986 (HREOC Act)*
2. *Racial Discrimination Act (RDA) 1975*
3. *Sex Discrimination Act (SDA) 1984*
4. *Disability Discrimination Act (DDA) 1992*

These pieces of legislation have influenced and empowered the lives of Aboriginal people with a disability. However, HREOC and the DDA had the strongest impact on the lives of people with a disability. One of the major roles of the Commission is to annually report on how Australia is meeting its obligations under these pieces of legislation within their commitments to the UN declarations and conventions. For example, in 1993 the Commission’s *Report of the National Enquiry Concerning the Human Rights of People with Mental Illness* found major violations of human rights of people with mental illness. This report resulted in a major review of legislation and policies concerning people with mental illness and psychiatric disability (HREOC, 1993).

The DDA is a major piece of legislation that protects people from discrimination based on disability and impairment. It seeks to “eliminate discrimination against people with a disabilities ... [and] promote community acceptance of the principle

that people with disabilities have the same fundamental rights as other members of the community” (DDA, 1992). The DDA has a broader definition of disability than the DSA. Disability is defined as the following:

- (a) total or partial loss of the person's bodily or mental functions; or
- (b) total or partial loss of a part of the body; or
- (c) the presence in the body of organisms causing disease or illness; or
- (d) the presence in the body of organisms capable of causing disease or illness; or
- (e) the malfunction, malformation or disfigurement of a part of the person's body; or
- (f) a disorder or malfunction that results in the person learning differently from a person without the disorder or malfunction; or
- (g) a disorder, illness or disease that affects a person's thought processes, perception of reality, emotions or judgment or that results in disturbed behaviour;

The DDA covers discrimination at work, education, accommodation, access to public premises and the supply of goods and services. The DDA defined two types of disability discrimination. Firstly, direct discrimination is defined as “a person (the discriminator) discriminates against another person (the aggrieved person) on the ground of a disability of the aggrieved person if, because of the disability, the discriminator treats, or proposes to treat, the aggrieved person less favourably than discriminator would treat a person without the disability in circumstances that are not materially different” (DDA, 1992). Secondly, indirect disability discrimination is defined as “a person (the discriminator) discriminates against another person (the aggrieved person ) on the ground of a disability of the aggrieved person if (DDA, 1992):

- (a) the discriminator requires, or proposes to require, the aggrieved person to comply with a requirement or condition; and
- (b) because of the disability, the aggrieved person does not or would not comply, or is not able or would not be able to comply, with the requirement or condition; and
- (c) the requirement or condition has, or is likely to have, the effect of disadvantaging persons with the disability.

The RDA makes unlawful discrimination based on race or culture. Racial discrimination is defined as someone being treated less fairly than someone else in a similar situation because of their race, colour, descent or national or ethnic origin. Similarly the SDA makes it unlawful to discriminate people on basis of sex, gender, marital status, pregnancy or potential pregnancy in a range of areas of public life. Both the RDA and the SDA make unlawful discrimination in employment, government policy, provision of goods and services, public services and advertising (RDA, 1975; SDA, 1984).

Here is an example of how these pieces of legislation protect people from discrimination. Two Aboriginal children were born with talipes, one of whom has Fragile X syndrome. Both of the children were requiring surgery and paediatric treatment. If routine procedures for children born with talipes are surgery and/or paediatric treatment then both children should receive that treatment. It would be deemed discrimination under the DDA for medical practitioners to refuse the child with Fragile X syndrome treatment based on the disability in the absence of a significant medical reason. Furthermore, it would be discrimination under the RDA if treatment were refused purely based on the child's racial background.

### **Bureaucratisation of disability in Australia**

Since the development of the DSA and the NSWDSA, people with a disability have been enveloped in government and non-government agency bureaucracies. Max Weber famously coined the term 'Bureaucratisation' or 'bureaucracy' as an impersonal, rational and efficient routine designed to further the interests of capitalism (Camic, Gorski & Trubek., 2005). In Weber's original theory, a bureaucracy is seen as having technical superiority over any other form of organisation. Bureaucracy exists in government departments, formal institutions, cafes, schools and even universities. Consistent with Weber's (Camic et al., 2005) analysis, legal-rational authority has been adopted in disability services as the basis for meaningful actions that are reliant on an impersonal codification that stipulated the basis for all legitimate decisions. This system operates on the basis of written impartial transparent and abstract rules.

Also consistent with Weberian theory, government funded disability service providers are required to comply with policies and regulations for the delivery of services and support for people with a disability. Submissions and public hearings

to the Productivity Commission's enquiry into a National Disability Insurance Scheme (NDIS), under the Council of Australian Government's (COAG) reforms, reported that vast amount of precious resources are being spent on meeting government regulations, reporting and monitoring that could be better spent on supporting people with a disability (Productivity Commission, 2010).

Bureaucratisation of this nature can undermine the freedom of individuals by ensnaring them in the logic of an opaque, wilful, impersonal even tyrannical system. As bureaucracy in government and in the disability services sector becomes more rigid and complex, the relationships between disability workers and individuals have become impersonal. For instance Parmenter (2004) suggested that:

Society is so complicated now, and the political process tries to reduce us by fitting us into categories. It does not work, and we cannot expect government at higher levels to respond in ways that reflect our needs, when they do not even know or understand what they are. (p. 265)

The instrumental rationality in bureaucracy promises 'objective fairness' in decision making. However, the fairness is lost because the 'person' is lost. As Blatt (1981) stated, the problem with rules and regulations lies not in any perceived 'evil' or 'ablest' intentions of those who work in bureaucracies, but rather in the so-called democratic process of the regulations themselves. People with a disability and Aboriginal people initiated political activism to achieve policy change under the banner of 'rights' and 'social justice'. These same people operated political agencies and institutions with bureaucratic processes, such as membership and grant applications. Over time these same agencies formed alliances with political party members and government agencies, henceforth building more bureaucracy. The actual issues and recommendations that people were protesting about get lost in the process and the regulation of bureaucracy. As Blatt (1981) reported:

Surely there can be no doubt that if 'love thy neighbour' were a federal regulation, it would become meaningless and useless. ... A more serious part of our common problem is that too much of humanism has gone scientific. And too much of our science makes it easier to banish our brothers from our lives. (p. 346)

A good example is the national reform to employment for people with a disability in the mid 2000s. People with a disability protested and lobbied for improved access and support to obtain paid employment outside of the traditional 'sheltered workshop'. The Howard Government created two new programs, typically known as the 'capped' and uncapped' programs, to provide employment support for people with a disability under the reforms to the Disability Support Pension (DSP). If a person wished to access open-market employment support they got their DSP reviewed. As such, people with a disability got more support to obtain employment; however they were at risk of losing their DSP. The fear of losing your DSP was equivalent to workplace insecurity. Furthermore, disability employment agencies were required to submit periodic reviews of each job seeker to government to obtain their quarterly grants. Therefore, what people with a disability were lobbying for got twisted in the bureaucratic process of the disability services sector and government departments (NDS, 2009).

### **Social Determinants of Health in Australia's Population of Aboriginal People**

Despite the positive changes in disability and Indigenous affairs, ABS data on the Aboriginal population and population of people with a disability show that Aboriginal people with a disability are among the most disadvantaged and unhealthiest sub-populations in Australia. WHO (2008) defined the social determinants of health as:

... the conditions in which people are born, grow, live, work and age, including the health system. These circumstances are shaped by the distribution of money, power and resources at global, national and local levels, which are themselves influenced by policy choices. The social determinants of health are mostly responsible for health inequities - the unfair and avoidable differences in health status seen within and between countries. (p. 8)

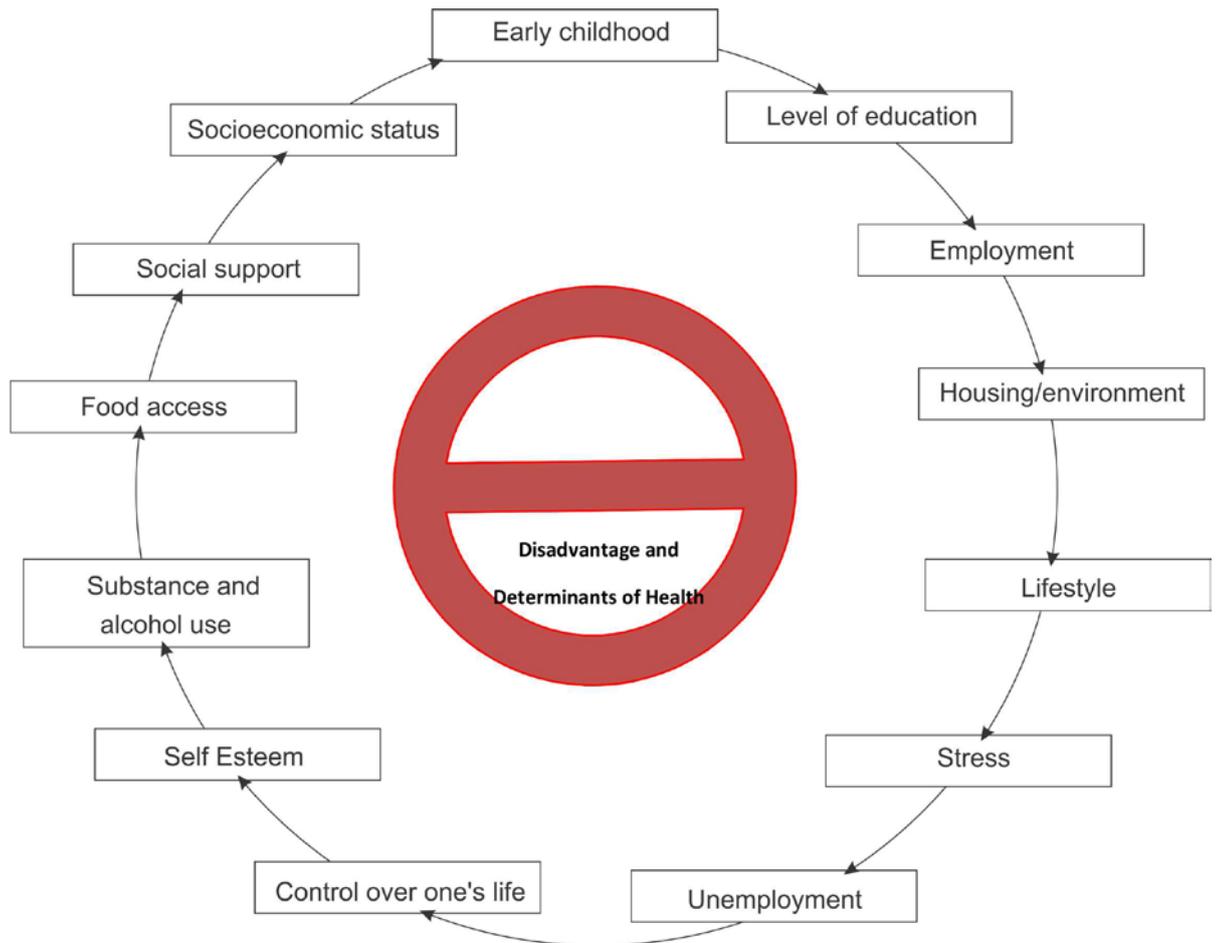
The WHO definition of social determinants of health is used by governments around the world as measures of health and inequality. WHO (2008) concluded in their report on the social determinants of health that:

The poorest of the poor, around the world, have the worst health. Those at the bottom of the distribution of global and national wealth, those marginalised and excluded within countries, and countries themselves disadvantaged by

historical exploitation and persistent inequity in global institutions of power and policy-making present an urgent moral and practical focus for action. (p. 31)

Australian Government reports demonstrated that the social and health statistics were remarkably similar between the Aboriginal population and the population of people with a disability. AIHW (2010a) reported that “despite the overall improvement in population health, the gap between Australians with disability and those without disability remains large. In 2007–08, almost half (46%) of people aged 15–64 years with severe or profound disability reported poor or fair health, compared to 5% for those without disability” (p. 1). Similarly, AIHW (Steering Committee for the Review of Government Service Provision, 2009) reported that Aboriginal people were twice as likely to self-report their health as fair or poor than non-Aboriginal people.

Smith (2007, p. 115) developed an explanatory diagram for the inter-generational relationship between inequality and health modelled on the WHO definition, shown in Figure 3 below. This shows that access to early childhood intervention is linked to a person’s ability to access a good education, employment, housing and the quality of food and nutrition. A person’s unemployment influences their psychological/mental health, which in turn influences social and family relationships and restricts how people interact with society. Smith (2007) suggested that internationally “this whole process of being unemployed becomes a vicious cycle that places us in a certain social class – the unemployed. And this can turn into the ‘cycle of poverty’, which can be passed down from generation to generation – because we know nothing different” (p. 115).



*Figure 3 - The cycle of the social determinants of health in the population of Aboriginal people (adapted from Smith, 2007)*

By using Smith's (2007) figure as an explanatory framework, it is evident that the Aboriginal population and the population of people with a disability are two of the unhealthiest and disadvantaged populations in Australia.

### **Early childhood development**

The foundations of adulthood are established *in utero* and early childhood. Poor maternal diet and life choices, such as smoking, can negatively impact on prenatal and early childhood development. These factors raise the risk of increased cognitive, physical and developmental disability in later life (Smith, 2007; WHO, 2008).

Smoking during pregnancy can lead to miscarriage, stillbirth or premature birth. In 2006, 52% of Aboriginal mothers and 15.6% of non-Aboriginal mothers smoked during pregnancy. There was also a higher rate of alcohol consumption by pregnant Aboriginal women than non-Aboriginal women, leading to foetal alcohol

syndrome and premature birth (Steering Committee for the Review of Government Service Provision, 2009).

There was a higher incidence of low birth weight babies in the Aboriginal population than the general population. Aboriginal mothers (12.9%) were almost twice as likely as non-Aboriginal mothers (6.1%) to have a low birth weight baby in 2006. The average birth weight of babies born to Aboriginal mothers was 3.1kg compared to 3.3kg for non-Aboriginal mothers (AIHW, 2012; Steering Committee for the Review of Government Service Provision, 2009).

### **Level of education**

There is a direct correlation between the level of a person's education and their level of employment and disposable income, which in turn affects an individual's housing, nutrition and health. There is also a link between the level of a person's education and police arrests and incarcerations (Steering Committee for the Review of Government Service Provision, 2009).

Table 2 shows a comparison of the education completion rates of Aboriginal people and people with a disability. It shows that these two population groups have the lowest rates of education completion rates than their counterparts. The decline in school attendance for Aboriginal school students between first grade and tenth grade (2% to 14%) was higher than non-Aboriginal students (3% to 7%) in 2007. Nationally in 2003, the school enrolment rate was slightly lower for Aboriginal students (90.2%) than non-Aboriginal students (93.9%) in the 5-9 year age group. The retention rate of Aboriginal students to year 8 (97%) and non-Aboriginal students (99.9%), however Aboriginal student literacy and numeracy outcomes was still lower than their non-Aboriginal counterparts. Aboriginal people had worse higher education completion rates than non-Aboriginal people in 2001 (ABS, 2001; Steering Committee for the Review of Government Service Provision, 2004, 2009).

Trends in education participation by children and young people with disability reflect the impact of social inclusion in Australia's education sector. Mainstreaming of children with disabilities within the education system has increased substantially in Australia. In 2002, 81% of children with disabilities attended government schools and 91% of children with disabilities who attended non-government schools attended mainstream schools rather than "special schools" (AIHW,

2004a). As shown in Table 2, in 2003 people with a disability were less likely to achieve higher education outcomes than people without a disability, with 30% of people with a disability completing year 12 in school and just over 10% of people with a disability obtaining a bachelor degree.

Table 2

*National Education Completion Rates of People with a Disability*

Level of education	People with a disability	People without a disability	Aboriginal people	Non-Aboriginal people
Complete year 12	30%	49%	39.40%	76.80%
Left school year 8 or younger	16%	5%	3%	0.10%
Complete a diploma or higher qualification*	14%	28%	11.80%	22.70%
Complete a bachelor degree*	13%	20%	4.80%	16.60%

*Note: the data on higher education for Aboriginal people's completion rates were extrapolated from the 2001 Census on Population and Housing as it was the most reliable source (AIHW, 2004a).*

This shows that the participation rate of Aboriginal people in mainstream education was equivalent to people with a disability. Aboriginal people and people with a disability have similar rates of year 12 completions and diploma completions. However, Aboriginal people have lower completion rates in bachelor degrees than people with a disability.

### **Employment opportunities**

Employment prospects are determined by an individual's geographic location and opportunities. People in rural and remote regions of Australia have reduced employment opportunities due to distance, reduced local business investment and low education achievement. The main barriers of employment participation for Aboriginal people and people with a disability were primarily non-vocational, such as physical accessibility and transport. Racial and disability discrimination also contribute to the ability of Aboriginal and people with a disability to obtain employment. Lack of employment opportunities reinforces the poverty cycle by trapping Aboriginal people and people with a disability into a cycle of welfare dependency (AIHW, 2008a; Steering Committee for the Review of Government Service Provision, 2009).

## **Housing/environment conditions**

Recognition that environmental factors can be both a hindrance and an enabler for people's independence is essential to their social and community engagement. An individual's home 'residential' environment, both public and private housing, influences the quality of individual health. The quality of a home environment is determined by factors such as clean water, sewage, food quality and pest control. AIHW (2003a) reported that with regards to people with a disability:

The provision of affordable aids and equipment, support arrangements in educational and workplace settings, mainstream education, accessible public transport and personal assistance all act to facilitate opportunities for individuals to participate in the economic and social world. Furthermore, and just as importantly, they provide people with disabilities an added independence to explore these opportunities (p. xi).

Many people with moderate to profound physical disability require home modifications, such as bathroom and kitchen renovations, to enhance their level of independence and social/community participation. AIHW (2008a) reported that people with profound or severe core activity limitations were more likely to modify their homes than those with a moderate or mild core activity restriction. However, home modifications were more common for home owners who have the financial resources than for people who lived in private rental properties. In 2003, people with a disability were three times more likely to live in government-funded public housing than people without a disability.

AIHW (2008a) found that the increase in some diseases and health conditions (such as diseases of the circulatory system and respiratory system) between the years 1981 and 1998 were influenced by environmental conditions, such as poor accommodation, heating and lack of affordable accessible transport. The incidence of young people with an acquired or lifelong disability residing in hospitals and aged-care facilities, often referred to as "bed blocking", has increased over recent decades (AIHW, 2006c). Without adequate aids and equipment and home modifications, placement in residential accommodation is more likely to continue. The Australian Human Rights Commission (2008) reported that:

... of the 166,668 Indigenous households identified in the 2006 Census, 34% were home owners (with or without a mortgage), 59% were renting and 3% had other types of tenure. In comparison, 69% of the estimated 7 million other Australian households were home owners (with or without a mortgage) 26% were renting and 2% had other tenure types. (p. 300).

Aboriginal communities were four times more likely to live in overcrowded 'rental' housing than non-Aboriginal people. Overcrowding places pressure on the household infrastructure (such as sewage, utilities and washing machines) and can be a contributor to poor health. Overcrowding can also increase family stressors and domestic violence (Steering Committee for the Review of Government Service Provision, 2009). Hospitalisation from health conditions associated with environmental factors was higher for Aboriginal people than the national population. For example, there was little change in the incidence of the below reported hospitalisations between 2004 and 2006 (Steering Committee for the Review of Government Service Provision, 2009):

1. The hospitalisation rate for influenza and pneumonia was 11.7 per 1,000 Aboriginal people, which was four times the rate for non-Aboriginal people.
2. The hospitalisation rate for bacterial diseases was 7.6 per 1,000 Aboriginal people, 3.4 times the rate for the non- Aboriginal people.
3. The hospitalisation rate for intestinal infectious diseases was 4.9 per 1,000 Aboriginal people, 1.8 times the rate for non- Aboriginal people.
4. Scabies is still prevalent in Aboriginal communities (2.8 per 1,000 people).
5. Aboriginal people had a much higher hospitalisation rate for chronic rheumatic heart disease (0.5 per 1,000 compared with 0.1 per 1,000).
6. Aboriginal people had higher reports of acute respiratory infections than non-Aboriginal people (2.9 per 1,000 compared to 1.6 per 1,000).

### **Lifestyle choice**

Lifestyle choices determine the prevalence and onset of chronic diseases and health complications. There exists a growing recognition that personal life choices are greatly influenced by the socioeconomic environments in which people live, learn, work and play (Steering Committee for the Review of Government Service Provision, 2009).

Unhealthy diets, lifestyle and poor nutrition are more prevalent in the populations of Aboriginal people and people with a disability than in the Australian population. Around one of every three Aboriginal people in non-remote regions

and nearly 40% of Aboriginal people in rural/remote regions were either overweight or obese, around twice the rate of the Australian nation (AIHW, 2008c, 2011; Steering Committee for the Review of Government Service Provision, 2009).

AIHW (2010b) reported that in 2008 “among adults aged 18–64 years who were overweight or obese, people with severe or profound disability were more likely than those without disability to report a range of other conditions such as mental and behavioural problems (51% versus 7%), back problems (42% versus 12%), arthritis (38% versus 8%) and cardiovascular diseases (33% versus 12%)” (p. 12). People with severe or profound disability between the ages of 15-65 years were more likely to do a very low level of exercise or no exercise than people with moderate disabilities (43% versus 31%) (AIHW, 2010b).

### **Stress**

Social and psychological circumstances can cause long-term stress. Aboriginal people were dispossessed of their land and traditions as a result of colonisation. Aboriginal people up until the 1970s were forcibly removed from their parents by government agencies under racist assimilation policies, known as the stolen generation. Members of the stolen generation and their communities suffer from post-traumatic stress disorder and inter-generational trauma. Thousands of Aboriginal people still experience the consequences of racism and discrimination from non-Aboriginal people (Reconciliation Australia, 2010). These factors accumulate over generations and impact on the health status of all Aboriginal people within each community (AIHW, 2008c).

People with a disability experience a higher level of social stress than people without a disability. AIHW (2010b) reported that “in 2007–08, of people aged 15–64 years with severe or profound disability, 24% had high distress level and 19% had very high distress level, compared with 5% and 1% respectively for those without disability” (p. 31).

### **Unemployment**

Employment opportunity, discussed above, determines employment participation. Employment is an important indicator of economic participation. Outcomes associated with employment include increased level of disposable income, low stress and increased social participation and better health.

Employment rates for Aboriginal people increased from 80% to 84.4% between 2001 and 2006. Employment rates for non-Aboriginal people increased from 92.7% to 94.9% between 2001 and 2006. Overall, the unemployment gap between Aboriginal and non-Aboriginal people narrowed from 12.7% to 10.5% between 2001 and 2006 (Steering Committee for the Review of Government Service Provision, 2009).

People with disability had lower labour force participation rates than people without disability. Increased participation of people with less severe disability corresponds with recent strong growth in the labour market. However, labour force improvements did not benefit people with severe or profound limitations. The participation rate of people with a disability in employment was much lower than people without a disability. AIHW (2008a) reported that:

People with disability have lower labour force participation rates than people without disability. Over the period 1988–2003, participation rates of people with disability were consistently about 30 percentage points lower for males and 22–25 points lower for females, compared with people without disability. Participation rates for people with severe or profound limitations were lower again than for people with disability generally. (p. 24)

### **Control over one's life**

When considering the ability of an individual to have control over their own life, it is important to understand the types and level of opportunities available to people to make choices (Brown & Brown, 2009; Neely-Barnes, Marcenko & Weber, 2008). Decision making is often discussed in conjunction with self-determination and individual empowerment (Brown & Brown, 2009).

Although the UN Convention on the Rights of Persons with Disabilities (CRPD) and the Declaration on the Rights of Indigenous Peoples 2007 state that people with a disability and Aboriginal people have the right to make their own life choices, such opportunities are often limited by environmental factors such as discrimination, physical environment and public ideologies. Having a low level of disposable income, employment opportunities and poor housing/environment conditions reduces the type and level of control a person has over the events in their life. For example, a person with a physical disability may have their choices

limited in utilising public transport if there is no wheelchair accessible options. As such, their ability to participate in the local community is limited (Brown & Brown, 2009; Neely-Barnes, Marcenko & Weber, 2008; Steering Committee for the Review of Government Service Provision, 2009).

### **Self esteem**

With the lack of control over one's life reduces the level of one's self-esteem. A low level of self esteem contributes to higher levels of poor health choices and can contribute to mental illnesses, such as depression and anxiety.

Aboriginal people had higher treatment rates for mental health issues in community clinics, residential care facilities and hospitals compared with non-Aboriginal people (Steering Committee for the Review of Government Service Provision, 2009). Similarly, low self-esteem and mental health problems occurred at higher rates in the population of people with a disability than people without a disability. "About 42% of people aged 16–64 years with severe or profound disability had seriously thought about committing suicide, including 18% who had attempted suicide, which was associated with their high prevalence of mental and behavioural problems" (AIHW, 2010b, p. 2).

### **Substance and alcohol use**

Alcohol and substance misuse through intoxication (alcohol and drugs) has health and social consequences, dependence and other long term health effects. In addition, long-term use can lead to disease, acquired disability (brain injury) and lower life expectancy. Aboriginal adults were more likely to have consumed an excessive amount of drugs and alcohol on a weekly basis than non-Aboriginal people (Steering Committee for the Review of Government Service Provision, 2009):

1. Aboriginal people are more likely to binge drink at excessive levels: the national drug and alcohol survey suggests that over a quarter of Aboriginal people reported binge drinking at least once in a 12 month period compared with 20% of the non-Aboriginal population.
2. 70% of Aboriginal homicides over the period from 1999 to 2007 involved both the offender and the victim consuming alcohol compared to 22% of non-Aboriginal homicides.
3. Hospitalisation rates for all alcohol related conditions were higher for Aboriginal people than non-Aboriginal people.

4. Aboriginal people were three times more likely to be hospitalised for mental and behavioural disorders caused by drug use. Marijuana, amphetamines and analgesics/sedatives were the most commonly reported drug used by Aboriginal people.

Similarly, in comparison to people without a disability between the ages of 15 and 65 years, people with moderate to profound disability in the same age cohort were more likely to be current daily smokers (31% versus 18%) and consume alcohol at medium or high-risk level in the long term. People with a disability were twice as likely to seek accommodation assistance due to drug, alcohol or substance abuse issues than those without a disability (AIHW, 2010b).

### **Food access**

Shortage of food and lack of food variety causes malnutrition and developmental deficiencies. People on low incomes – older people, people with a disability and unemployed – are least likely to have a nutritious diet. Factors relating to housing/environment and community design all impact on the access to good food and water. Aboriginal people and people with a disability have lower levels of disposable income than the general Australian community, which mean that they have less access to good food. Aboriginal communities in some rural and remote regions have less access to good healthy food choices and have to pay twice as much for food stuffs. Poor nutrition impacts on the long term health and physical development of children and young adults (AIHW, 2008b).

### **Social support**

Support from families, friends and communities builds and maintains community solidarity and protection. In addition, strong community solidarity ensures a collective approach to addressing community and social problems.

Aboriginal people traditionally have a very strong support and family networks. However, dispossession from land, child removal and decades of racial discrimination and government abuse resulting in a high prevalence of inter-generational trauma (Reconciliation Australia, 2010), alcohol and substance abuse has affected Aboriginal community social networks and traditional customs (AIHW, 2008c).

Generally, people with a disability above the age of 65 years reported that they had received adequate support from family and friends for activities of daily living.

However, people below the age 65 years were less likely to report having their needs fully/partially met by family and friends. In 2001, among people aged 0–64 years, this especially affected those needing assistance with self-care (7%), mobility (7%), health care (7%), paperwork (8%) and property maintenance (8%) (AIHW, 2008a).

### **Socio-economic status**

Poor health status, low education achievement and low employment opportunities and participation resulted with Aboriginal people and people with a disability being placed in the bottom of the socio-economic ladder (AIHW, 2008a, 2008c; Reconciliation Australia, 2010; Steering Committee for the Review of Government Service Provision, 2009).

### **Life expectancy**

Life expectancy refers to the average number of years a person of a given sex, gender or cultural group in a given location can be expected to live. Life expectancy is used as an indicator of health and disadvantage (AIHW, 2003b). The poor health and social status of Aboriginal communities has significantly affected the life expectancy of Aboriginal people with a disability.

Based on the data from 2005 to 2007, the estimated life expectancy at birth for Aboriginal males was 67.2 years and for females was 72.9 years. The estimate for non-Aboriginal males was 78 years and females 82 years. The life expectancy gap between Aboriginal and non-Aboriginal people was 11.5 years for men and 9.7 years for women. The mortality rate was 2.1 times the rate of the non-Aboriginal population (Steering Committee for the Review of Government Service Provision, 2009). The rate of prenatal and infant (within one year) mortality rates were two to three times the rate of the non-Aboriginal population. Aboriginal child mortality rates for 1-4 years age groups were between two and four times the rate of the non-Aboriginal population (Steering Committee for the Review of Government Service Provision, 2009).

Measuring life expectancy of the population of people with a disability is very complicated due to the diversity of disability types and the onset of disability. AIHW (2006c) reported that life expectancy for people with a disability improved

markedly between the period 1988 and 2003, but was still lower than non-disabled people. AIHW (2006c) concluded that:

... gains in life expectancy were accompanied by increases in expected years of life both with and without disability or a severe or profound core activity limitation. The proportion of expected years with a disability to total life expectancy increased, especially for older Australians, although this related chiefly to less severe disability. (p. 5)

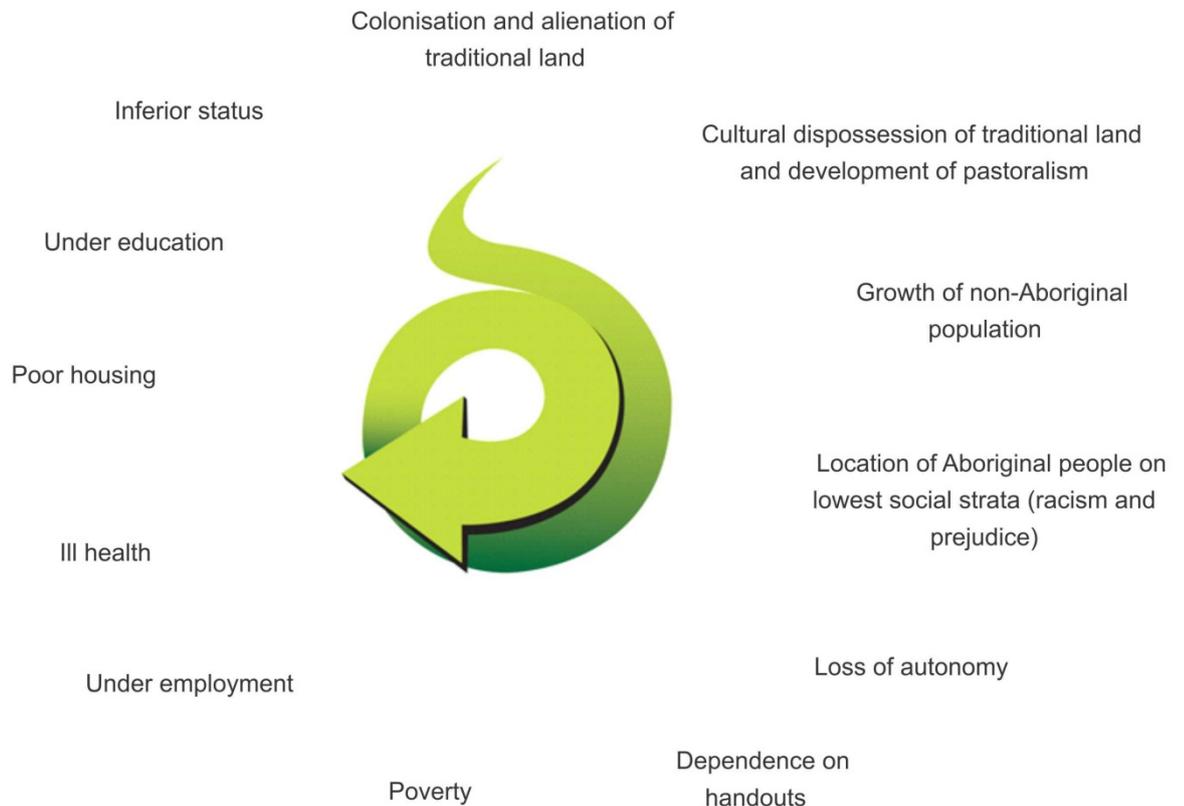
### **Social determinants of health: causes of the causes**

The data discussed above have shown that Aboriginal people with a disability are one of the most disadvantaged and unhealthiest populations in Australia. WHO (2008) made an important point that the emphasis on the social determinants of health must also take into consideration the “causes of the causes” (p. 35) of poor health and disadvantaged in sub-populations of nations. In other words, researchers must ask the question “why are Aboriginal people with a disability one of the most disadvantaged and unhealthiest populations in Australia”? Although Smith’s (2007) explanatory framework covered many of the major determinants of health, it does not recognise two of the major causes of the poor determinants of health in the population of Aboriginal people with a disability: “colonisation and racism” and *the* “vicious circle”.

Firstly, the figure (Eckerman et al’s, 2010) of the social determinants of health, Figure 4 below, shows that there exists an intergenerational link between colonisation, cultural dispossession, racism and social determinants of health in the population of Aboriginal people. The irrevocable loss of land and fragmentation of traditional cultures resulted in Aboriginal people living in poverty and depending on government handouts and living as an inferior social class in poor housing and under-employment. Aboriginal people have experienced the physical and mental health effects of racism as an intergenerational legacy since colonisation.

Aboriginal communities have experienced the consequences of intergenerational trauma since colonisation. Aboriginal people who were removed from their families under racist policies requiring forced removal of children experienced symptoms of post-traumatic stress. Each generation of Aboriginal people inherited the pain and trauma experienced by older generations of Aboriginal people. Recent government publications on the legislated removal of

Aboriginal children reported that many Aboriginal parents struggled to forge positive parenting relationships with their children (AIHW, 2008c; Australian Human Rights Commission, 1997).



*Figure 4 - The spiral of colonisation and alienation in Aboriginal Australia (adapted from Eckerman et al., 2010)*

Secondly, O'Brien's (1980) explanatory framework called the Vicious Circle, displayed in Figure 5, also helps explain the causes of the poor health status of people with a disability. Adopting the deviancy career theory from the sociological sciences, O'Brien (1980) suggested that "the deviancy career is a vicious circle in which a person meets widely held stereotypes and comes to embody them" (p. 5). When a medical specialist labels a person as *disabled* the person automatically becomes a victim of the disability services sector. In fact, people with a disability become 'imbedded' and 'networked' in the bureaucracy of the disability services sector because that is a perspective for access to supports (O'Brien, 1980, 1989, 2003; Voss & Voss, 2005).

The Vicious Circle acknowledged that the values and beliefs of society regarding people with a disability influence the expectations and opportunities available to people with a disability. The cycle of the vicious circle starts off from specialists in the professional and medical professions, who have the skills and knowledge to diagnose and assess ‘disability’ based on a ‘medicalised norm’, and define what is known as ‘disability’. Society perceives and treats people with a disability as unproductive and dependent members of society (Parmenter, 1999). Therefore, people with a disability are viewed as an economic burden on the government and society. Consequently, the devaluation of people based on values and categories they are assigned becomes a self fulfilling prophecy as the subsequent reduction in expectations and limitations of opportunities guarantees that individual performance will be diminished (O’Brien, 1980).

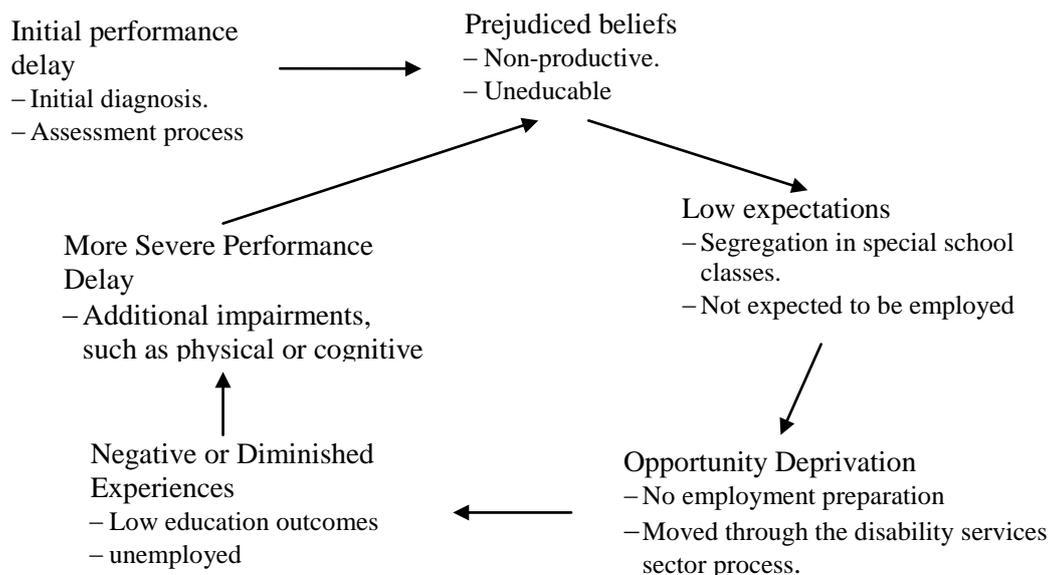


Figure 5 - John O'Brien's Vicious Circle (O'Brien, 1980)

As a consequence, the potential growth of people with a disability is limited and the “person’s label becomes a life sentence” in a rigid bureaucratic system called the disability services sector (O’Brien, 1980, p. 6). Voss and Voss (2005) suggested that people with multiple or ‘secondary’ disabilities are more at risk in being trapped in a vicious circle. When people with a disability rebel against these values, through protest and organised social movements, the emphasis is often placed on reforming the disability services sector as opposed to changing the current operation of the vicious circle. O’Brien (1980, 1989, 2003) stated that attending to the elements of the vicious circle gives more tools and targets for

change in the population of people with a disability, such as changing beliefs and expectations and providing more opportunities for people with a disability.

### Prevalence of Disability and Participation in DADHC Funded Disability Services

Although the data presented above have shown that the population of Aboriginal people with a disability is among the most disadvantaged and unhealthiest sub-population in Australia, their participation in disability services was also under-representative. Figures 6 and 7 provide a state and territory comparison of the representation of Aboriginal people in the population of people with disabilities. The prevalence of disability in the Aboriginal populations in Victoria, Australian Capital Territory (ACT) and NSW was almost three times the representation of Aboriginal people in those region's total populations. Contrary to the general population of people with a disability, the incidence of disability is higher in the age cohorts under 25 years than in the population above 65 years (ABS, 2006a).

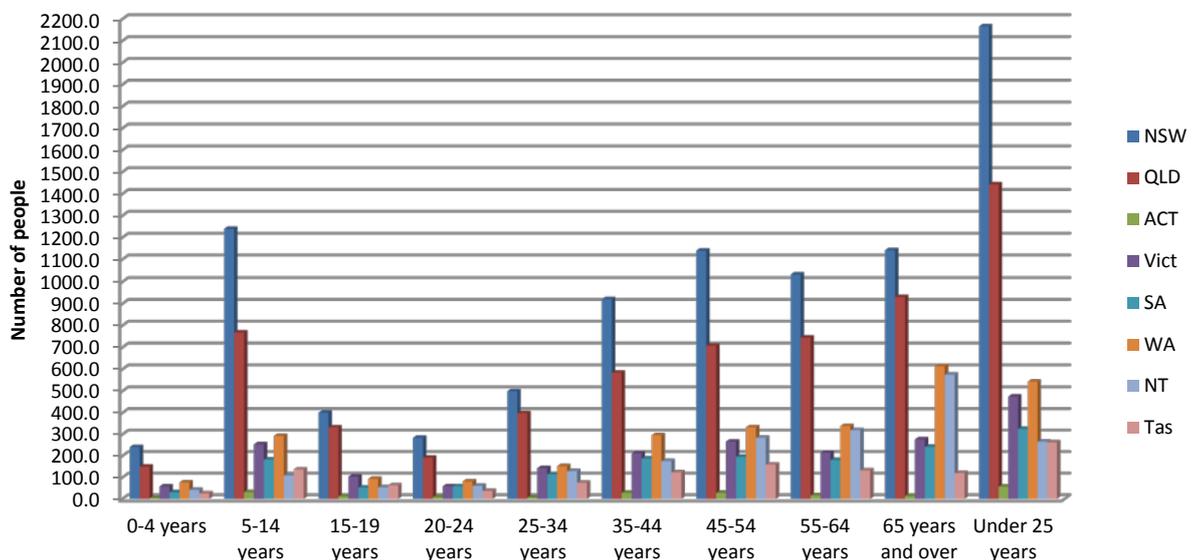
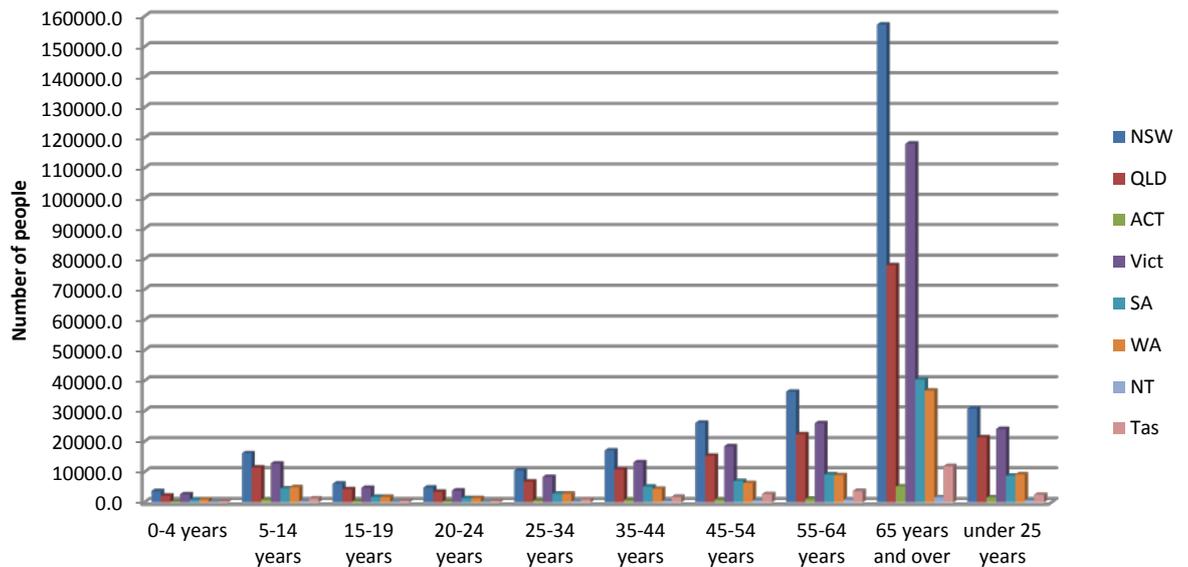


Figure 6 - Number of Aboriginal people with a disability by age, state and territory, 2006 (ABS, 2006a)



*Figure 7 - Number of people reported with a disability by age, state and territory, 2006 (ABS, 2006a)*

The tables at Appendix B (Tables 1 to 6) provide a population profile of each DADHC planning region by Aboriginality and disability, broken down by each Local Government Area (LGA) using ABS 2006 census data. The prevalence of disability was typically higher in the Aboriginal population than in the non-Aboriginal population in most LGAs. In some LGAs, the representation of Aboriginal people in the population of people with a disability was almost double the representation of Aboriginal people in the general population, such as Maitland (4.4% and 2.6%) and Gwydir (5.6% and 2.5%). These tables reveal that the prevalence of disability in the population of Aboriginal people under the age of 65 years was significantly higher than in the non-Aboriginal population, which indicates that the high prevalence of impairments and disabilities occurred much earlier in the lifespan of Aboriginal people. For example, around 50% of the population of people with a disability under the age of 65 years were from an Aboriginal background in the rural communities of Bourke and Brewarrina (ABS, 2006a).

The tables also show that the representation of the Aboriginal population in the population of people with a disability was higher in the rural LGAs than in the Sydney metropolitan LGAs. For example, Aboriginal people in Moree (23.5%), Central Darling (35.2%), Bourke (35.3%), Brewarrina (48.5%) and Coonamble (31.1%) had the highest representation of Aboriginal people in the population of people with a disability. Furthermore, these LGAs also reported a higher

prevalence of disability in the Aboriginal population than in the non-Aboriginal population (ABS, 2006a).

Table 3 shows the number of Aboriginal people with a disability by reported disability type in Australia. Physical disability was the most common disability type among Aboriginal people with severe or profound core activity limitations, consistent with the experience of non-Aboriginal people. Among Aboriginal people aged 15–64 years with severe or profound disability, 82% experience physical disability. Sensory related disability (Sight, hearing and speech) was the next most common, at 42% (AIHW, 2011).

Table 3

*Number of Aboriginal People with a Disability by Disability Type in Australia in 2010-2011 (AIHW, 2011)*

<b>Disability type</b>	<b>Number</b>	<b>Percent of population of Aboriginal people with a disability</b>
<b>Physical</b>	18,061	82%
<b>Sensory</b>	9,167	41.6%
<b>Intellectual</b>	6,362	28.9%
<b>Psychological</b>	6,196	28.1%

Table 4 shows that nationally, the service participation rate by primary disability type among Aboriginal and non-Aboriginal people under the age of 65 years were similar in 2010-2011. Intellectual disability was the most common primary disability among all service users, with 34% of Aboriginal people and 31% of non-Aboriginal service users reporting this as their primary disability. Physical and psychiatric disabilities were also common reported disability types of Aboriginal and non-Aboriginal service users (AIHW, 2010a, 2011,).

Table 4

*Comparison of the Participation rates of Aboriginal People and Non-Aboriginal People in Multilateral Agreement Funded Disability Services by Primary Disability Type in 2010-2011 (AIHW, 2011)*

Primary disability type	Indigenous		Non-Aboriginal		Indigenous status not stated		Total number
	Number	Percentage	Number	Percentage	Number	Percentage	
<b>Intellectual</b>	4,061	33.7	72,102	30.7	1,328	9.7	77,491
<b>Specific learning</b>	533	4.4	8,944	3.8	155	1.1	9,632
<b>Autism</b>	541	4.5	16,145	6.9	311	2.3	16,997
<b>Physical</b>	2,171	18.0	39,495	16.8	821	6.0	42,487
<b>ABI</b>	670	5.6	9,185	3.9	242	1.8	10,097
<b>Neurological</b>	432	3.6	10,661	4.5	342	2.5	11,435
<b>Deaf/blind</b>	27	0.2	453	0.2	21	0.2	501
<b>Vision</b>	234	1.9	5,961	2.5	1,066	7.8	7,261
<b>Hearing</b>	228	1.9	4,682	2.0	266	1.9	5,176
<b>Speech</b>	149	1.2	2,815	1.2	97	0.7	3,061
<b>Psychiatric</b>	1,918	15.9	43,544	18.6	2,379	17.4	47,841
<b>Developmental delay</b>	535	4.4	8,124	3.5	193	1.4	8,852
<b>Not stated/not collected</b>	569	4.7	12,453	5.3	6,473	47.3	19,495
<b>Total</b>	12,068	100.0	234,564	100.0	13,694	100.0	260,326

Although the level of government funding for disability services has increased, the participation rate of Aboriginal people in disability services has been disproportionate to the reported prevalence of disability in this population. Nationally in 2009, 12,068 Aboriginal people accessed Multilateral Agreement funded services, an increase from 10,633 in 2008. However, these figures are an understatement as around 5% of people did not report their Aboriginality (AIHW, 2011).

DADHC (2009c) reported that Aboriginal people represented 4% of all clients of DADHC NSW Government funded services between 2005 and 2009. The majority of Aboriginal people accessed community support, respite and therapy services. Aboriginal people represented less than 3% of community access, day programs and in-home care clients.

To the untrained eye, some reports on service participation may seem to suggest that the participation rate of Aboriginal people in disability services was representative. The ABS has signalled in its data collection over recent years that changes in data collection methods have impacted on the quality of the access rate data. Government statistics showed that the service participation rate of

Aboriginal people is under-representative when compared to the non-Aboriginal *potential* population. The data table at Appendix C (Productivity Commission, 2012) shows that although the participation of Aboriginal people in disability services per 1,000 people under the age of 65 years was higher than non-Aboriginal population between 2003 to 2010, the participation of Aboriginal people per 1,000 people of the total potential population was lower than non-Aboriginal people for accommodation and community access services. In 2009-10, the participation rate of Aboriginal people per 1,000 Aboriginal people was higher in the younger age cohorts than the non-Aboriginal population (ABS, 2006a). Similarly, the participation rate of non-Aboriginal people in 2006/07 was highest for Community Support Services. The participation rate of Aboriginal people from the total potential population was significantly less than the non-Aboriginal potential population in NSW for Accommodation Support Services and Community Access Services. The participation rate of Aboriginal people from the potential population in Community Support Services was higher than the non-Aboriginal potential population (AIHW, 2011; Productivity Commission, 2006). AIHW (2011) reported “that while New South Wales and Queensland have the largest populations of Indigenous people with severe or profound core activity limitations, according to the potential population estimates, their rates of service provision to Indigenous service users, per 1,000 population, fall somewhat below the Australian average” (p. 18).

In 2008, AIHW (2008b) reported that despite some slight improvements in access rates for some services and supports for people with a disability, the participation rates of Aboriginal people in disability services were lower than the reported prevalence of disability. It’s (AIHW, 2008b) research shows a significant under-representation of Aboriginal people participating in disability services, concluding that:

This suggests a higher need for disability services among Indigenous people compared with non-Indigenous Australians. Evidence from other sources supports this view. For example, the 2006 Census showed that, after adjusting for age differences between the Indigenous and non-Indigenous populations, the level of need for assistance with core activities for Indigenous people was almost twice as high as for non-Indigenous people; that this data are indicative

of a need to improve the delivery of services and support for the Indigenous population. (p. 21)

An important factor that influences the participation rate data is that many disability service providers struggle to collect and report on the data accurately. National Disability Services (NDS) (2010) and the Aboriginal Disability Network (ADN) (2007, 2011) found that until disability service providers improve data reporting on service participation rates by Aboriginality, the current client participation rate data must be interpreted as estimations. In saying this, the ABS and AIHW (2011) always take this factor into account when reporting disability statistics.

### **Strategies to Develop a Culturally Responsive Disability Service System for Aboriginal People with a Disability**

In response to the population and health data on Aboriginal people, the disability services sector has developed three major strategies in an attempt to establish a disability service system that addresses the service participation rates. These strategies are discussed under the following three sub-headings: Aboriginal community controlled organisations (ACCO), developing a culturally appropriate service system and the development of person-centred planning.

#### **Aboriginal community controlled organisations**

In response to the Indigenous Rights Movement and the Disability Rights Movement in Australia, the governments continue to fund ACCOs to help address service access and equity barriers to health and disability services for Aboriginal people. ACCOs are primarily non-government, not-for-profit community, human and health service providers for local Aboriginal communities.

The philosophies of Aboriginal community self-determination underpin the ACCO sector. Many Aboriginal people have avoided generic community and health services due to discrimination and cultural insensitivities. Self-determination, in the context of community controlled organisations, implies that Aboriginal community members have a 'human right' to control and determine their community's cultural, social, economic future. For example, the National Aboriginal Community Controlled Health Organisation (NACCHO, 1995) defined an ACCO as:

... a process which allows the local Aboriginal community to be involved in its affairs in accordance with whatever protocols or procedures are determined by the Community. The term Aboriginal Community Control has its genesis in Aboriginal peoples' right to self-determination. (p. 1)

Similarly, as far back as 1986, the National Aboriginal Health Strategy (National Aboriginal Health Services Working Party, 1986) defined community control as:

... the local community having control of issues that directly affect their community. Implicit in this definition is the clear statement that Aboriginal people must determine and control the pace, shape and manner of change and decision making at [all] levels. (p. 2)

In 2008/09 there were 2,723 ACCOs registered under the *Corporations (Aboriginal and Torres Strait Islander) Act 2006* (CATSI Act), with the majority being government funded not-for-profit health and community service organisations (Australian Government Office of the Registrar of Indigenous Corporations (ORIC), 2009, 2010). In 2009, the top 500 ACCOs employed nearly 10,000 people and had nearly \$100m in assets and income nationally (ORIC, 2010). Most ACCOs were located in remote and rural regions of Australia. Table 5 (ORIC, 2009, p. 27) shows the wealth of ACCOs that have provided details on income and assets to the Australian Government. The Table shows that ACCOs were typically small organisations, with less than \$100,000 in income and less than \$25,000 in assets. Almost 50% of ACCOs earned less than \$500,000 of income obtained through government and philanthropic grants and had less than \$500,000 in assets.

There was no known documentation that quantified the number of Aboriginal community controlled disability service providers in NSW. This may be due to many disability type services being provided out of disability service providers and DADHC managed Aboriginal Home and Community Care branches.

Table 5

*Number of ACCOs by Funding Level and Assets in 2008/09 (ORIC, 2009)*

	less than \$25k assets	\$25–50k assets	\$50–100k assets	\$100–500k assets	more than \$500k assets	Total
less than \$100k income	547	25	27	40	44	683
\$100–500k income	10	8	24	91	51	184
more than \$500k income	4	0	1	54	241	300
<b>Total</b>	561	33	52	185	336	1,167

One of the first major government funded ACCOs was an Aboriginal Community Controlled Health Service (ACCHS) in Redfern in 1971, which delivered culturally appropriate primary health care services for Aboriginal people. ACCOs were also developed in the NSW aged care sector, such as Mumbra and the Booroongen Djugun Aboriginal Corporation. From the early 1980s, the NSW Government funded many ACCOs to deliver home and community care services for people with a disability, older people and their carers, such as Kurranulla and Wyanga (DADHC, 2009c).

There are three main differences between ACCOs and generic community and health organisations. Firstly, ACCOs are not controlled by non-Aboriginal ‘specialists’, such as doctors or lawyers. ACCOs are controlled by a Board consisting of Aboriginal community members elected by the local Aboriginal community, some of whom may be specialists. Secondly, ACCOs main priority is the local Aboriginal community that they represent and support, not just people with a disability. Contrary to many generic community and health organisations, ACCOs are theoretically driven by community need and not government funding sources. Thirdly, ACCOs are developed from local Aboriginal community advocacy and not from a government or a mainstream community organisation or health program (Eckerman et al, 2010).

There is no known research on the disability service participation rates of Aboriginal people by ACCOs and disability services. However, there is a plethora of literature demonstrating the benefits that ACCOs have made to the health and

welfare of Aboriginal communities. For example the Australian Health Ministers' Advisory Council (Steering Committee for the Review of Government Service Provision, 2009) reported that 30% of Aboriginal people access ACCHSs on a regular basis than mainstream health services. The main reason was that ACCHSs provided culturally appropriate preventative and curative health care for Aboriginal people. Similarly, ACCOs have helped reduce the prevalence of convicted criminals from reoffending through community justice programs and legal aid programs for Aboriginal people with mental illness or intellectual disabilities (Steering Committee for the Review of Government Service Provision, 2009). Therefore, it can be assumed that the participation of Aboriginal people in DADHC funded ACCOs may be significant.

The growth in ACCOs has posed many challenges for Aboriginal people's participation in DADHC funded ACCOs. Aboriginal scholars Peters-Little (2000), Tatz (2001) and Pearson (1999, 2000, 2002) suggested that the term 'community' was created by government agencies to 'ensure' equitable coverage in the allocation of scarce tax revenue allocated for ACCOs. They claimed that the allocation of scarce government targeted financial resources for Aboriginal 'communities' has created an elitist sub-group of Aboriginal families that dominates some Aboriginal communities. They stated that the concept 'community' has been understood as a romanticised notion that certainly does not entirely evoke the notions of 'connectedness', 'kinship' and 'harmony'. The terms 'community' and 'culture' are often mistakenly used interchangeably during service planning and implementation for Aboriginal people. Peters-Little (2000) purported that 'community' as a concept typifies "notions of an idealised unity of purpose and action among social groups who are perceived to share a common culture" (p. 5). Pre 1970s, Aboriginal assimilation and segregation policies have moved Aboriginal people into institutions in other regions of Australia. Such residential institutions (known as missions) comprised of Aboriginal people displaced from their homelands and forced to socialise with people from other Aboriginal cultural groups.

Tatz (2001) stated that any social cohesion that existed in such communities was institutional and imposed, not cultural, spiritual or linguistic. Changes in policy during the 1970s resulted with Aboriginal people taking control and responsibility for these institutions, forcing them to become 'communities' in name, despite the

lack of cultural and communal uniformity. Philosophies of Aboriginal 'self-determination' and 'self-management' resulted in an Aboriginal community consisting of multiple Aboriginal family groupings fighting for scarce government resources (Pearson, 1999, 2000, 2002; Tatz, 2001). This is often known as 'Aboriginal family factionalism' or 'Aboriginal community politics'. Influence and prestige within the faction or community is based on reputation, government influence and by dominating ACCOs.

Peters-Little (2000) argued that "since that time Aboriginal people across Australia have become so good at playing the community game that many have begun to believe it" (p. 3). Many Aboriginal family groupings dominate the Aboriginal community services sector, with Boards consisting of the same Aboriginal people or 'Elders'. Some Aboriginal people introduced the "proof of Aboriginal identity paper" as a requirement for accessing services through Aboriginal community controlled organisations (Kelly, 2010, p. 23). ACCOs have become the 'gate-keepers' of communities they service to maintain the hegemony over some of the people they 'service' and 'support'.

### **Developing a culturally appropriate service system**

The disability services sector has made efforts to implement Aboriginal cultural protocols and customs into disability service delivery (DADHC, 2005a, 2005b, 2006a, 2009a, 2009b; NSW Ombudsman, 2010). The cultural norms, practices and protocols are essential for members of a cultural group to interact and socialise. However, they also make it difficult for members of a cultural group to engage and connect with a service system that is foreign to them. Many Aboriginal people experience little difficulty in interacting with non-Aboriginal community services workers, including those in disability support services. However, in some cases, differences in cultural background between service providers and Aboriginal people can form an impediment to effective service access and delivery. Cultural misunderstandings can result in Aboriginal people not receiving the support and services they require, which can contribute to family distress and trauma (Productivity Commission, 2010).

The disability services sector has adopted two main strategies to establish a culturally responsive service system for Aboriginal people: cultural awareness and cultural competence. Cultural awareness emphasises the need to recognise how

the differences in cultures, politics and historical experiences between Aboriginal and non-Aboriginal populations impact on service delivery. Over the last few decades, the disability services sector has adopted “cultural awareness” strategies to train workers to recognise and overcome cultural differences between Aboriginal communities and the disability services sector (DADHC, 2009a)

Although acknowledging cultural differences, cultural awareness training has been heavily criticised for not providing the tools, effective strategies and requisite skills to equip non-Aboriginal people to bridge the cultural interface between Aboriginal and non-Aboriginal populations. Consequently, cultural awareness training has made a limited impact in behavioural change in the community and health services sector. In other words, a human and health services sector that is aware of cultural differences does not equip it to deliver culturally responsive and appropriate services for Aboriginal people (Centre for Cultural Competence Australia, 2012).

This is why community and health service agencies are opting for cultural competence training. Cultural competence aims to equip professionals with the requisite skills to work in a cross-cultural context. A culturally competent services sector becomes a culturally safe environment for Aboriginal people. The Australian Indigenous Doctors Association (2004) defined cultural competence as:

... the relationship between the helper and the person being helped, in a cross-cultural context. While cultural safety centres on the experiences of the patient, cultural competence focuses on the capacity of the health worker to improve health status by integrating culture into the clinical context. This last point is important, and demonstrates the importance of moving beyond cultural awareness. Recognition of culture is not by itself sufficient rationale for requiring cultural competence; instead the point of the exercise is to maximise gains from a health intervention where the parties are from different cultures.  
(p. 1)

Over the last decade, cultural competence has formed part of many disability service strategic plans. For example, the Western Australian Government Department of Disability Services Commission’s (DSC) Reconciliation Action Plan (RAP) defined cultural competency as a disability services sector that is aware of differences between Aboriginal and non-Aboriginal communities but is able to

effectively work within the cultural diversity of Aboriginal communities. The DSC's RAP strategies included Aboriginal workforce development, building networks and relationships between Aboriginal communities and funded service providers, strengthening the ACCO sector and breaking down racism and discrimination and involving local Aboriginal communities in the decision making process of government and non-government agencies (DSC, 2010). Similar to the DSC RAP, the NSW Government Department of Family and Community Services (FaCS) Cultural Diversity Strategic Plan 2012 (FaCS, 2012) and its Aboriginal Cultural Inclusion Framework 2011-2015 (FaCS, 2011) has set targets in cultural competence in areas of workforce development and training, cultural capital development and building networks and partnerships between generic community services and local Aboriginal communities.

Although FaCS has committed the NSW Government to implement cultural competence in the disability service sector, reports on progress and initiatives undertaken under the strategic plan was not mentioned in any of their annual reports.

### **Person-centred planning and Aboriginal empowerment**

Recently, there has been a growing shift towards personalised and individualised formal supports and services in the disability services sector (DADHC, 2012b). The ADN reported that individualised supports and services have the potential to support Aboriginal families to establish a service/support mechanism that empower Aboriginal people with a disability within a culturally appropriate framework (ADN, 2012). The primary element of the person-centred approach is person-centred planning, which aims to identify and plan future needs of the individual with their family and friends through developing a service and/or care plan. Person-centred planning is often misunderstood as only a formal service plan connected to the planning and delivery of services through the disability services sector. O'Brien (2003) and Clement and Bigby (2010), however, stated that person-centred planning is, in some aspects, the antithesis of formal service planning as it is centred on the person's whole of life and informal support networks. Bigby (2004) and O'Brien (2003) suggested that person-centred planning includes the resources in the human services sector, the specialist services sector, the citizen sector and the family. Person-centred practice is not a

new paradigm of practice but, rather, adds to the multiple perspectives necessary to understand and support people with disabilities by focusing attention on their gifts, strengths, aspirations and the formal and informal support service systems in a culturally appropriate way.

Early manifestations described such approaches as ‘individualised planning’ in the 1970s and 1980s when the Disability Rights Movement was at its prime. The person-centred approach came into vogue in North America in the late 1980s reflecting the broader ideological approaches to social inclusion, normalisation and social role valorisation. The principles of the person-centred approach refer to a family of approaches to organising and guiding community change in alliance with people with a disability and their families and friends. These include supports that are provided by family, friends, generic and specialist disability service providers and the general community infrastructure (Clement & Bigby, 2010).

Mansell and Beadle-Brown (2003) suggested three distinct characteristics in person-centred planning. Firstly, its emphasis is the aspirations and desires of the person or those family members speaking on their behalf. This characteristic removes the power to define an individual’s goals and outcomes from ‘specialists’ in disability organisations to the individual and their family. The ADN (2012) suggests that by moving to a more personalised approach to service planning, Aboriginal families cultural needs will be addressed as the person has the power to change service agencies and obtain supports from outside the traditional service system.

Secondly, person-centred planning attempts to include and mobilise the resources and finances of an individual’s informal supports, such as family and friends. The level of love and care within an individual’s circle of families and friends is often more personal than that provided by the disability services system. In some cases some disability “services are part of the problem more than they are part of the solution” (Mansell & Beadle-Brown, 2003, p. 2). As such, the cultural capital within the Aboriginal person’s community is utilised. The Aboriginal community’s social network is a richer source of innovation and resources than the formal service system (ADN, 2012).

The third distinctive characteristic of person-centred planning is that it is focused on setting goals as defined by the person as opposed to defined goals that can be managed by disability service staff, such as case workers, within the

disability services sector. In effect, people with a disability are not restricted to the level and type of disability service funding allocated by government and philanthropic agencies. Therefore, people with a disability are self-determining rather than service-dependent for their goal planning and implementation. Aboriginal people with a disability can utilise their government funding to acquire supports from outside of the traditional disability services sector, such as Aboriginal health services and Aboriginal health workers (ADN, 2012; DADHC, 2012c; Mansell & Beadle-Brown, 2003).

Person-centred planning is slowly being mandated in the NSW disability services sector as DADHC edges closer towards an individualised/ personalised funded service model. DADHC funding will be directed to individuals and their families as opposed to funding going directly to disability service providers. For example, the DADHC Community Participation Program (CPP) funding goes directly to the individual, who then chooses a service provider. The CCP Guidelines (DADHC, 2006c) required funded service providers to implement a person-centred approach by identifying the following five key issues:

1. the person is at the centre
2. their wider social network is involved as full partners
3. there is a partnership between the person, their family and the service provider
4. the whole of life is considered
5. there is continued listening, learning and action.

Recently, DADHC (2012c) has funded a person-centred program for Aboriginal families who require high level support, called *Services Our Way*. Aboriginal families can apply up to \$50,000 in annual recurrent funding to use to support a person with a disability. Each family is assessed based on the person-centred approach. Contrary to previous programs for Aboriginal people with a disability, *Services Our Way* funding can be used to purchase commodities and programs outside of the formal disability services sector.

Similarly, person-centred planning was suggested by the Productivity Commission as a key element of a new national disability service system under their proposed National Disability Insurance Scheme (NDIS) (Productivity Commission, 2011). The NDIS suggested that Aboriginal specific programs could be individualised and block funded to ensure an equitable coverage of services types.

## **Research on Barriers for Aboriginal Disability Service Participation**

There has been limited investigation on the views of disability service workers on the participation of Aboriginal people in disability services. Much of the research has been on the views of Aboriginal people themselves. As such there is a need to explore the experiences of paid workers of the disability services sector.

### **What Aboriginal people say**

The research on the views of Aboriginal people with a disability on service access and participation shows that although the disability services sector has attempted to address access and equity barriers, there has been limited improvement made. Much of the research was undertaken by the ADN and non-Aboriginal researchers in disability studies.

As further discussed in Chapter Six, the research shows that every Aboriginal community in Australia has different understandings of disability in comparison to the NSW disability services sector. Many Aboriginal communities interpret the consequences of European colonisation on Aboriginal traditional lands as disabilities. Research undertaken by Gething (1995) found that many Aboriginal people do not differentiate between aged related conditions and lifelong disability as understood by the disability services sector. Furthermore, Gething (1995) and Smeaton (1996) found that many Aboriginal people interpret Aboriginality as a disability.

The concept of disability as understood by the NSW disability services sector is relatively new to many Aboriginal communities. Bostock (2004), a Koori advocate for Aboriginal people with a disability, said that “there is no special category in Koori thinking for physical and intellectual disability” (p. 6). Labelling and categorising people by perceived ‘abilities’ was considered offensive in many Aboriginal communities. The ADN (2007, 2012) found that many Aboriginal families did not understand how the government and disability services defined disability. The ADN (2012) stated that many Aboriginal people do not “identify as a person with a disability when they already experience discrimination based on Aboriginality” (p. 10).

Aboriginal people reported to the ADN (2007, 2012) and the NSW Ombudsman (2010), that in some cases their families were unaware that they were eligible for government funded disability services. Furthermore, many Aboriginal families did

not actively seek information on supports and services for people with a disability due to a long history of service gaps, such as transport and home modifications. The NSW Ombudsman (2010) and the ADN (2007, 2012) stated that one of the causes of the knowledge gap was that the NSW Government and local stakeholders were not effectively communicating with the local Aboriginal communities on services and programs for people with a disability.

Aboriginal communities have a cultural practice of caring for people with a disability within the resources of family and kin. This practice reinforces and maintains a culture of solidarity within local Aboriginal communities, which results with Aboriginal people not actively seeking services. Carers NSW (2006) and the Aboriginal Community Care Gathering (2007) reported that many Aboriginal carers of older people and people with a disability were young people. There were also many reported cases of young Aboriginal people being removed from school to care for a frail older person or a person with a disability.

Aboriginal people reported to the ADN (2007, 2012), Gething (1995) and the NSW Ombudsman (2010) that disability was a major barrier to social interactions, access to health services and employment and education. Many Aboriginal people reported that they were housebound and socially isolated because they did not have the financial resources to modify their properties and utilise accessible transport. Therefore, many Aboriginal people could not access disability services because they could not physically leave their homes.

There is a culture of distrust at the interface of Aboriginal communities and the community services sector. The culture of distrust is a consequence of the past government practice of forcibly removing children from their families based on Western Imperialist ideologies, which created the Aboriginal Stolen Generation. The fear and trauma caused from this practice has impacted on every generation of Aboriginal people in every Aboriginal community. Smeaton (1998), Bostock (1991, 2004), HREOC (1991) Gething (1995) and the Aboriginal Community Care Gathering (2007) found that many Aboriginal families do not trust non-Aboriginal community service workers for fear that their family member may be removed from home and placed into residential care. Consequently, many Aboriginal people with a disability did not access disability services until the resources within the family were depleted. Therefore, Aboriginal families only access disability services in times of family crisis.

Much of the existing research indicated that Aboriginal people felt that the disability services sector is culturally inappropriate for Aboriginal people. Many Aboriginal people with a disability and their families continue to experience racism and discrimination in the disability services sector. For example, the ADN (2012) study on person-centred practice in the Aboriginal communities in NSW reported that Aboriginal people feel that many non-Aboriginal disability workers do not understand Aboriginal culture and practices:

Aboriginal consultation participants advocated for compulsory cultural awareness training for all stakeholders with the disability service system. The cultural awareness must substantially address the consequences of contact history between white and black Australia including the discriminatory laws that were in place against Aboriginal people. (p. 9)

As such, many Aboriginal people prefer to only approach local Aboriginal workers and ACCOs when they need assistance and support. Aboriginal people have reported that Aboriginal workers assist Aboriginal people with a disability and their families through the service entry and planning process. The ADN (2007, 2012), the Aboriginal Community Care Gathering (2007) and the Productivity Commission (2010) reported that the Aboriginal community want an increase in the number of Aboriginal people working in the disability services sector. Gilroy (2009) provided two examples of culturally appropriate Aboriginal disability workforce strategies that have increased the number of Aboriginal people working in the disability services sector. These strategies have merged Aboriginal cultural knowledge and practices with Western knowledge and practices in caring and supporting people with a disability.

Many Aboriginal people reported that the ACCO services sector is under-resourced to effectively address the service needs of Aboriginal people with a disability. They have reported that disability is a low priority area in their communities in comparison to other social and health issues, such as suicides and poor health outcomes (ADN, 2012; Maher, 1999; National Disability Administrators, 2004; Productivity Commission, 2004; Smeaton, 1998; Thompson & Snow, 1994). In many cases, disability was interpreted by Aboriginal communities as a direct result of the poor social and health rates and disadvantage in Aboriginal communities, which is discussed further in Chapter Six

(NSW Ombudsman, 2010). Sackley (2003), an Aboriginal advocate for people with a disability, said that “these are communities where standards in health, education, employment, housing, communication and transport systems are still inadequate and where issues affecting people with a disabilities are not a priority due often to the unacceptable conditions still being experienced by the general community” (p. 19).

### **What disability service workers say**

There has been limited research on the views of disability service workers on the participation of Aboriginal people in disability services. The research on Aboriginal disability service participation suggested four major factors that may contribute to service participation rates of Aboriginal people. The views of disability service workers reflect some of the issues shared by the Aboriginal communities.

Firstly, AIHW (2008), the Steering Committee for the Review of Government Service Provision (2009), Carers NSW (2006) and NDS (2010) suggested that Aboriginal people with a disability often utilised the existing resources within their family and kin networks before accessing formal supports funded by DADHC. NDS (2010) reported that disability service providers that had Aboriginal workers had a higher number of Aboriginal clients than disability service providers who did not have Aboriginal workers. The main reason stated by disability service providers was that many Aboriginal clients trusted Aboriginal workers more than non-Aboriginal workers.

Secondly, there may not be enough service types appropriately tailored for people with a disability or Aboriginal people in the geographic region of some Aboriginal families, such as people living in rural and remote regions of NSW. A large proportion of Aboriginal people live in outer-metro regions of NSW. According to AIHW (2008), the ADN (2004) and NDS (2010), Aboriginal people in rural regions experienced greater difficulty in accessing services than Aboriginal people in metro regions. Similar to the research with Aboriginal people, many Aboriginal people preferred to access services provided by an ACCO (ADN, 2007; NDS, 2010; Steering Committee for the Review of Government Service Provision, 2009).

Thirdly, some Aboriginal people did not wish to report their Aboriginality to disability service workers. NDS (2010) reported that many Aboriginal people did

not report their Aboriginality to disability service workers for fear of being stereotyped and treated differently to non-Aboriginal people. Furthermore, many disability service workers did not ask clients about their cultural background for fear of offending clients and their families.

Fourthly, similar to the research that involved Aboriginal people, disability service providers found that every Aboriginal community had their own distinct understanding and conceptualisation of disability that may be contradictory to the government and the disability services sector. As such, there was a culture clash between the non-Aboriginal and Aboriginal populations in defining and quantifying the prevalence of disability in Australia. This topic is discussed further in Chapter Six.

NDS (2010) found a high level of commitment amongst the disability services sector to address access and equity barriers to disability services for Aboriginal people. The challenge that many provider groups faced was the lack of knowledge on how to overcome barriers to participation for Aboriginal people and forge relationships with Aboriginal community service stakeholders. NDS has made attempts to support disability service providers to improve the service participation rates of Aboriginal people by improving relationships and networks between Aboriginal communities and government funded disability service providers. From 2006, NDS has developed many new local networks of disability service providers and Aboriginal communities to help foster relationship and network building, service planning and identifying unmet need for Aboriginal people. NDS concluded that over time these relationships have resulted to new projects and programs being formed to support Aboriginal people with a disability, families and carers (NDS, 2010).

## **Conclusions**

Although Aboriginal people with a disability are one of the most disadvantaged and unhealthiest populations in the Australian population, the disability services sector has made a limited impact in addressing the disability services participation of Aboriginal people. Aboriginal people with a disability and disability service providers have made similar reports on the reasons behind the poor service participation rates of Aboriginal people.

The definition of disability in the NSWDSA, the DSA and the Multilateral Agreement did not reflect the definition of disability defined in the ICF or the social

rights philosophies of the Disability Rights Movement. Rather, the Australian Government adopted an individual pathological conceptualisation of disability for the formally funded disability services provision. DADHC has funded ACCOs under the DSA and the Multilateral Agreement, which shows that the NSW Government supports Aboriginal communities to be self-determining and autonomous within an individual pathological approach to disability. Interestingly, since committing to the DRIP, the Australian Government has committed to addressing the health and social inequalities between Aboriginal and non-Aboriginal populations through the Close the Gap initiative.

The bureaucratic processes of the governments have created an opaque disability support system that suppresses and subordinates the population of people with a disability to one of the lowest classes of society. The bureaucratisation of disability has depersonalised people with a disability. The needs of people become lost in a system that prefers to label and categorise people into programs and services. Human relationships between disability workers and people with a disability are of an impersonal nature.

The statistical profile of Aboriginal people and people with a disability presented in this chapter has demonstrated that Aboriginal people with a disability are one of the unhealthiest and disadvantaged populations in Australia. Racism, colonisation and the “vicious circle” are some of the causes of the poor social and health status of Aboriginal people with a disability.

Although Aboriginal people with a disability are among the most disadvantaged and unhealthiest populations in Australia, Aboriginal people’s disability service participation rate was under-representative. Some of the major causes of the low service participation rates include services not culturally appropriate for Aboriginal people and Aboriginal communities having a different understanding of disability and support system. Many Aboriginal families have a strong family and kinship support network that they were not in need of a formal support system. Thus, many Aboriginal people access the service system when the resources within their family support network were depleted.

The disability services sector has adopted three major approaches to establish a culturally responsive service system to address the low participation of Aboriginal people. Firstly, the government funds ACCOs to support Aboriginal communities to be self-determining. Cultural awareness, in essence, aims to help

non-Aboriginal community and disability workers to be aware of cultural and lingual differences between Aboriginal and non-Aboriginal communities. DADHC workers have undertaken training courses in cultural awareness since 1997. The principles of cultural competency has worked to build a culturally responsive community service system for Aboriginal people by focusing on changing the actual behaviours of community and disability workers. Supporters of cultural competency acknowledge that cultural awareness has achieved very little to establish a culturally responsive community services sector.

Person-centred planning is being introduced into the NSW disability services sector. DADHC is edging closer towards implementing an individualised/ personalised funded service system, which means that DADHC funding will be directed to individuals and their families, empowering Aboriginal families to develop a culturally appropriate service mechanism for people with a disability.

Research suggests that the disability services sector's strategies to accommodate the needs of Aboriginal people with a disability have made a limited impact on the service participation rates. Aboriginal people have reported that the disability services sector is not culturally appropriate for Aboriginal people. Disability service providers have reported that they did not have the knowledge on how to address the cultural needs of Aboriginal people. Aboriginal people reported that they prefer Aboriginal workers over non-Aboriginal workers. In addition, the ACCO sector is under resourced to accommodate the needs of people with a disability. As such, family members with a disability are supported and cared for within the resources of family and kin.

This thesis sets out to identify and examine the factors that influence the participation of Aboriginal people in disability services funded by the NSW Government under the NSWDSA and the Multilateral Agreement. This study will contribute to the COAG reforms of the disability services sector and provide disability service providers knowledge on ways that they can improve the service participation rate of Aboriginal people. The following section is dedicated to achieve the first objective of this study, which is to identify how and when the participation of Aboriginal people in disability services was identified as a social problem in documented policy. The next chapter outlines the methodology of how this was achieved.

# Section Two: Analysing Documents

## Chapter Three: Critical Historical Documents Analysis

The aim of this study was to identify the factors that influence the participation of Aboriginal people in disability services in New South Wales (NSW). One major question that emerged from the first two chapters of this study was: how and when was the participation of Aboriginal people with a disability in disability services identified as social problem for the disability services sector in NSW? Furthermore, what strategies were adopted to influence the participation of Aboriginal people in disability services?

The purpose of this section was to ascertain the history of government and government-funded agencies in identifying and responding to Aboriginal people with a disability as a 'client group'. To understand the *present problem* one must critically analyse the *evolution of the problem*. This chapter discusses the method that was adopted for this phase. The real names of the two participating non-government organisations (NGO) have been replaced with pseudonyms to protect the identity of the agencies. The generic NGO disability service provider is named the Mainstream NGO. The Aboriginal community managed NGO disability service provider is named the Aboriginal NGO.

### Operating Paradigm

Nakata (1997, 2007) noted that adopting a traditional literature review would only give the Western sciences the authoritative status as 'knowledge holders' and reinforce the oppression of Aboriginal people under the Western sciences. A traditional literature review will not uncover the complexities of the contestation at the intersection of historical trajectories between Aboriginal communities, government and disability service providers in relation to addressing the low participation rate of Aboriginal people in disability services. Similarly, Munslow (2006) stated that "history cannot claim to be straightforwardly scientific in the sense that we understand the physical sciences to be because it does not share the protocol of hypothesis testing, does not employ deductive reasoning, and neither is it an experimental and objective process producing incontrovertible facts" (p. 5).

Concurring with Nakata (1997, 2007) and Munslow (2006), Aboriginal scholar Moreton-Robinson (2004) argued that epistemologies on Aboriginal people are inherently influenced by Western Imperialism. She proposed that Aboriginal researchers should focus on how Whiteness operates to subjugate Aboriginal people as the 'cultural Other' in the Western sciences.

Munslow (2006) suggested that simply revisiting history as abstract 'events' reinforces any existing urban myths created and generated either through politics, science or societal power-relations. Supporting Munslow, Nakata (2007) recommended that the focus of a historical exploration on the relations between Aboriginal people and non-Aboriginal people must be on the:

...multilayered and multi-dimensional space of dynamic relations constituted by the intersections of time, place, distance, different systems of thought, competing and contesting discourses within and between different knowledge traditions, and different systems of social, economic and political organisation. It is a space of many shifting and complex intersections between different people with different histories, experiences, languages, agenda, aspirations and responses. (p. 195)

Simply revisiting and discussing the past events and findings of past research will reinforce the subordination of Aboriginal people as the 'cultural Other'. By adopting Martin Nakata's strategy, this study does not regurgitate history as depicted or represented by non-Aboriginal researchers. In addition, by not adopting an 'Us versus Them' method of analysis, other influencing discourses were not excluded. Rather, the multilayered discourses that create and represent Aboriginal people in their interactions with the disability services sector were critically explored.

### **Method**

Undertaking a historical critical literature analysis is a step process. Three institutions were selected as the fields for this part of the enquiry: the government agencies that had jurisdiction for disability services, the Mainstream NGO and the Aboriginal NGO. The Mainstream NGO was a generic disability service provider and the Aboriginal NGO was an Aboriginal community controlled organisation (ACCO).

Government agencies were selected on the basis of the current NSW Government's jurisdiction under the 2009 Multilateral Agreement. The NSW Government has responsibility for respite, accommodation, community access, therapy and recreation services for people with a disability. Advocacy and information services were also included because these are managed by both the NSW and Australian governments. Disability employment services were excluded as they are managed by the Australian Government.

The Mainstream NGO was selected based on their age (over thirty years old) and the fact that they delivered all of the services under the NSW Government's jurisdiction under the Multilateral Agreement across NSW. The challenge I had was that the Mainstream NGO also provided employment support, which may have influenced how they engaged with Aboriginal communities on a day-to-day basis. The assumption, however, was that given that government funding accountability processes were separated for all service types, there would have been a clear delineation between the Australian government and NSW government-funded programs and service staff and protocols.

Another benefit in selecting the Mainstream NGO was that they had employees who were also in receipt of disability services. Therefore, the documents collected for the research library may have been influenced by both service 'recipients' and the 'staff/management' of the organisation.

It was challenging to find a suitable ACCO in NSW for this study. There was no state-wide Aboriginal community managed disability service provider. For instance, there was an Aboriginal community managed respite service in the Riverina Murray region. However, this service provider was a relatively new DADHC funded pilot at the time this study commenced. There were many disability service providers that had Aboriginal specialised services (such as in Coffs Harbour and Moree). These NGOs were not ACCOs. I discovered that there were many Aboriginal community managed Home and Community Care (HACC) funded services across NSW. In Sydney, for instance, there were less than five Aboriginal community managed HACC funded service providers. However these organisations were mostly targeted towards older people and the frail aged.

For this study, an Aboriginal NGO was selected as they provided a range of disability services specifically for Aboriginal people spanning almost a decade. Although the Aboriginal NGO primarily provided a small number of services in one

region of NSW, it provides outreach support for Aboriginal families in crisis. As such, the Aboriginal NGO provided valuable comparable data for this research. I commenced this study with a different Aboriginal community-managed disability and aged care provider. However, this organisation faced governance and organisational dilemmas, resulting in significant management and staff changes and upheavals that precluded involvement in this inquiry.

Scott (1990) suggested that sometimes there is no need to ask people for their opinions as all written texts are evidence of the thoughts, aspirations, concerns and beliefs of any individual, institution or community regarding issues or events that are of interest to social research. The non-intrusive nature of using documents as evidence means that people cannot react directly to the researcher. It must also be acknowledged that documents do not always reflect the true thoughts and perspectives of the author. There may be times where the author's objective may be to deceive the audience of the document. This is why sections two and three of this study complement each other (see Chapter Seven).

Although documents can provide a rich source of evidence for social enquiry, documents provide access only to those individuals who are literate. Data from the Australian Institute of Health and Welfare (AIHW) (2008c) shows that due to high non-attendance rates at primary and secondary schools, the high prevalence of diseases, such as glaucoma and inner-ear infections, and poverty, Aboriginal people have English literacy competencies lower than the Australian average. However not all people are illiterate, live in the bush, live in poverty or are unemployed. The Aboriginal people who work in the institutions I studied were highly educated and skilled professionals who work within their communities. These people had a high level of understanding on the issues regarding Aboriginal people's participation in disability services.

Scott (1990) suggests that documents are the most accessible and readily available source of empirical evidence for social research. Scott (1990) defined documents as:

... involv[ing] the use of a pen, pencil, printing machine or other tool for inscribing the message on paper, parchment or some other material medium. The introduction of...printing as a supplement to handwriting created the archetypical document: the text printed or written on paper.  
(p. 11-12)

The library of documents included conference papers and research publications, interview transcripts, media publications, government annual reports, disability service provider's annual reports, government tender submissions and reports. In addition, research publications, policies and government reports and parliamentary Hansards were also used in this study.

A thorough search for documents published by these three institutions was undertaken. This study developed rigorous assessment guidelines provided by Scott (1990) and Platt (1981b) to ensure my collection of documents provided a reliable and valid result for this study: representativeness, credibility, authenticity and meaning.

Wadsworth (1997) defined 'representativeness' as "not so much a technique to get information, but more a way of ensuring that any technique that is used will get information from people in the total group or population" (p. 53). The ideal, therefore, was to ensure that the collection of publications covered a range of service types, key events in history and the key policy shifts. The best way to achieve a valid and reliable representation of documents was to use purposive convenience sampling techniques. Convenience sampling was simply gathering every single document that was legally obtainable. The staff of the Information on Disability Equipment and Aids (IDEAS), a government funded disability information service, assisted in locating some documents. The Australian Institute of Aboriginal and Torres Strait Islander Studies library archives, the NSW State Library and the Australian National University library and the University of Sydney Library were searched for documents. References from within all documents were searched to locate key people and agencies in order to obtain other documents. The workers of the governments and the two NGOs selected for this study were contacted to locate some documents that were mentioned in their agency's annual reports. This process was undertaken until the researcher was saturated with evidence and could not find any more historical documents that mentioned 'Aboriginal people with a disability' (Wadsworth, 1997; Walter, 2006).

A significant challenge was that in some cases documents could not be obtained or found. The Aboriginal NGO was a very small organisation with a limited amount of government funding in comparison to the Mainstream NGO. As such, the Aboriginal NGO did not have the resources to produce annual reports, large scale brochures or service profile reports and did not have a rigorous

archival system in comparison to the Mainstream NGO. As a result, the agency was only able to provide a small number of publically available documents for this study. Sadly, some time prior to accessing the field, a building of the Mainstream NGO suffered significant damage as a result of a natural disaster destroying a large amount of documents. Nevertheless, with the help of the Mainstream NGO managers, a good collection of documents were obtained from the various jurisdictions/branches of the organisation. Further, the archivist had extensive and highly credible historical knowledge of the agency covering decades, including knowledge of where some of the documents were located and who to contact.

It is important when considering 'credibility' to analyse the reliability of the document to ensure that the author was not deceptive. A document was considered reliable if the institution believes that the content reflects the actual opinion of the agency. To carry out this analysis, meetings were held with workers and Aboriginal people who were involved in either the writing of the documents that did not have a publication date or signature of a senior staff member (Platt, 1981a, 1981b; Scott, 1990).

The test for 'authenticity' involved an assessment of whether the document was what it purports to be (Madge, 1953). Two guidelines were established to test the authenticity of each document. Firstly, there must not be different versions of the same document as the different versions might contradict one another. Secondly, the document must display evidence that the agency was the author, such as logos or a signature from an agency senior manager.

Finally, an assessment of both the literal and interpretive 'meanings' of the document was made to ensure that there was proper and clear understanding of the language used within it (Madge, 1953). On occasion a document used traditional language of a particular Aboriginal community. The local Aboriginal Land Council and Aboriginal Home Care service were contacted to obtain an understanding of any traditional words.

The literal meaning, according to Scott (1990) and Platt (1981b) only provide a 'face value' meaning (Scott, 1990, pp. 30-31). The interpretive meaning of the document was the difficult process where "the researcher relates the literal meanings to the contexts" (Scott, 1990, pp. 30-31) wherein the document was produced. At its simplest, interpretation requires an understanding of the particular events, contentious issues, and location that may have affected the content of the

document. This process involved understanding where the document was produced and if there were any overtly contentious issues that may have influenced the production of the document (Platt, 1981a, 1981b; Scott, 1990). This was achieved by reading Indigenous and mainstream media articles about the political issues at the time of the publication of the document.

### **Analysing the data**

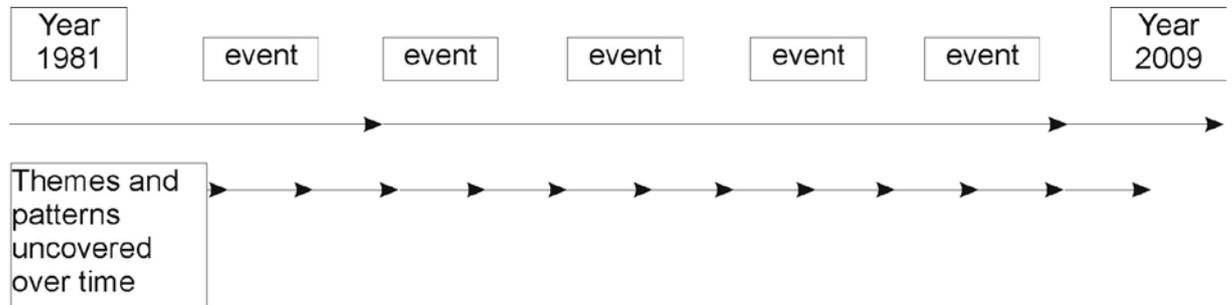
The main objective of this critical historical analysis was to uncover the tensions and contestation of the government and the non-government agencies in delivering services for Aboriginal people with a disability over a period of time. The first part of the process, once having developed the archive of documents, was sifting through the materials covering a range of policy discourses. I collected phrases and statements that were established and formulated within the given regulations, guidelines and culture within 'the disability services sector'.

Many scholars recommended Foucault for critical historical document analysis. Foucault (Bouchard, 1977; Couzens, 1986; Foucault, 1962, 1967; Lotringer, 1989; Smart, 1985) suggested that in searching for themes and patterns in critical historical document analysis, the author and events must be excluded. Foucault argued that by doing so, the researcher can uncover the sources of power in the multiple discourses that gave birth to institutions and people of 'authority' in mental health and disability affairs.

However, critics of Foucault (Couzens, 1986; Smart, 1985) expressed concern that excluding the authors of documents and the events in which the documents were developed consequently excludes the 'situation' and 'evolution' of the document. Such a position implies that people are not free thinking agents but rather agents or drones of social power. Furthermore, such a position does not adequately give a voice to people who rebel against social power structures.

As displayed in Figure 8, to ensure that the documents for this study were placed in context, the authors of the publications and the events that the documents were published in, were included in the analysis to place each statement in time and context at the intersections of each institution's histories. Munslow (2006) stated that acknowledging the authors of documents ensures that the relations between the institutions and the documents were captured within the historical moment, which in turn captures the events the documents were born in.

Therefore, the method captured the themes and patterns of how the government and the two NGOs as institutions of power within the disability services sector responded to the service participation of Aboriginal people.



*Figure 8* - Pictorial representation of the timeline method of analysis

With this process of enquiry, I unearthed how relations between non-Aboriginal people and Aboriginal people have produced a historical position for Aboriginal people at the intersection of different historical trajectories in the disability services sector. The method found that the Australian Government first mentioned the disability service participation of Aboriginal people at the start of the reforms to the disability services sector in the early 1980s. As such, the timeline started from 1981, which was the International Year of Disabled Persons (IYDP), to 2009.

The findings of each institution regarding the participation of Aboriginal people in disability services as a social problem were compared. Therefore, the problem was isolated in its evolutionary development: that is, in policy formation, practice, social relations, scientific discourses and institutions. In addition, not one 'author', cultural practice or event in any particular time was undermined. The method went to the core of the intersection of the multiplicity of discourses and actions to ascertain what it means in the publications to be labelled as an 'Aboriginal person with a disability', and how the NSW disability services sector influenced the participation of Aboriginal people in disability services. Rather than restricting the study to any particular 'Us versus Them' method of enquiry, this method focused on the plethora of intersections throughout history where the debates, contestations and conflicts interplay.

## **Conclusions**

This chapter has outlined the methodology for how the first objective of this study was achieved. Building a library of documents that were legally available was the best strategy to build a document library because there was no concise listing of documents on Aboriginal people with a disability produced by these three institutions. Documents developed between 1981 and 2009 were included. Only those documents that met the assessment criteria discussed in this chapter were used. The critical historical analysis of the documents focused on how the government and the two NGOs responded to the participation of Aboriginal people in disability services as a social problem. Furthermore, the analysis uncovered how the participation of Aboriginal people with a disability became identified as a social problem.

The findings of the critical historical document analysis are outlined in Chapters Four and Five. Chapter Four presents the findings of the analysis of the documents developed by the governments. Chapter five discusses the findings of the analysis of the documents developed by the two NGOs.

## **Chapter Four: The Government's Response to the Service Participation of Aboriginal People with Disabilities**

This chapter provides a historical literary analysis of how the governments responded to the low disability service participation of Aboriginal people as a specialised field that encompassed three parts: remoteness, disadvantage/vulnerability and cultural difference.

This chapter commences with the International Year of Disabled Persons (IYDP), which is regarded as one of the most significant events of the international Disability Rights Movement in the 1980s. This event was chosen as the starting point as Aboriginal people were not mentioned in any government publications uncovered for this study preceding IYDP. However, IYDP did lead to the biggest reform of the Australian disability services sector, which produced documents that mentioned Aboriginal people with a disability. This is then followed by a discussion on how the governments responded to the service participation of Aboriginal people as a specialised field from the introduction and implementation of the *Commonwealth Disability Services Act 1986 (DSA)* and the *NSW Disability Services Act 1993 (NSWDSA)* and then the Multilateral Agreement.

This chapter is written as a timeline of events that occurred in the disability services sector as experienced by the governments. This format makes it easier to read and follow. As discussed in Chapter Three, the critical literary review consisted of documents developed between 1981 and 2009.

### **International Year of Disabled Persons**

IYDP was a significant global event in the Disability Rights Movement held in 1981. Although IYDP was hallmarked as a significant event for people with a disability, it was not so for Aboriginal people with a disability. The achievements made during the Disability Rights Movement, such as normalisation and deinstitutionalisation, and those discussed in Chapter Two led to the IYDP. The theme of the IYDP was full participation and equality. The United Nations (UN) Advisory Committee for IYDP worked with all UN members on the development of a programme for the IYDP (Australian Government Department of Housing and

Construction (DHC), 1980; New South Wales Government Department of Youth and Community Services (YACS), 1981a, 1981b, 1981c). The agreed Objectives (DHC, 1980, p. 5) of IYDP were:

1. Helping people with a disability in their physical and psychological adjustment to society.
2. Promoting all national and international efforts to provide disabled persons with proper assistance, training, care and guidance, to make available to them opportunities for suitable work and to ensure their full integration in society.
3. Encouraging study and research projects designed to facilitate the practical participation of disabled persons in daily life.
4. Educating and informing the public of the rights of the disabled persons to participate in and contribute to various aspects of economic, social and political life.
5. Promoting effective measures for the prevention of disability and for the rehabilitation of disabled persons.

People with disabilities across Australia made it clear that they wanted to be heard both as individuals and through consumer organisations. They wanted to be viewed and treated as people first, as opposed to being defined by their *d*isabilities (DHC, 1980, p. 6).

Although there were many events and initiatives during IYDP, there were no dedicated events or initiatives for Aboriginal people with a disability. The Australian coordination of IYDP was undertaken by the National Advisory Council for the Handicapped (NACH) and the Standing Interdepartmental Committee on Rehabilitation (SIDCR). Many non-government organisations (NGO) received funding to undertake projects and research during IYDP, such as the Australian Council on Rehabilitation of Disabled (ACROD)<sup>1</sup>. In 1980, NACH released an IYDP information and activities programme which consisted of conferences, workshops, research and information/awareness initiatives. There were a large number of events and initiatives held for people from culturally diverse backgrounds, such as Chinese New Year and for people from Italian and Greek cultural backgrounds, which showed that cultural diversity was highly acknowledged during IYDP. However, there was no mention of any event or initiative that focused on Aboriginal people during IYDP (DHC, 1980).

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<sup>1</sup> The Australian Council of Rehabilitation of Disabled (ACROD) changed their name to National Disability Services in 2007.

Similar to the NACH and SIDCR, Aboriginal people with a disability were not mentioned by other New South Wales (NSW) Government advisory bodies during IYDP. The NSW Government Department of Youth and Community Services (YACS) set up the Advisory Panel for Physically Handicapped People and the NSW IYDP Observance Committee. These committees provided feedback to the Australian Government on IYDP and advised the NSW Government on policy and public sector recruitment. The Observance Committee published a monthly publication on IYDP called *Aware*, which detailed events leading up to and during IYDP and announced success stories on and for people with a disability (International Year of Disabled Persons NSW Steering Committee, 1980). There were no significant events, initiatives or programs for local Aboriginal communities. Even the YACS regional reports made no mention of Aboriginal people with a disability during IYDP.

IYDP brought to light a need to develop an information service for people with a disability to improve access to information and support on disability. YACS funded the development of the Disabled Persons Resource Centre to operate as an information and data hub for the NSW disability sector as an IYDP initiative. According to the YACS (1983) 1981-82 Annual Report, “four consumer groups, under the umbrella of the Handicapped Persons Alliance, merged to form the Centre and were funded by the Handicapped Persons Bureau” (p. 29). The subsequent two annual reports mentioned the work of the Centre but made no mention of Aboriginal people with a disability as a subject for the Centre (International Year of Disabled Persons NSW Steering Committee, 1980; YACS, 1983).

In response to the growing pressures from people with a disability regarding the overt level of *disablism* and disability discrimination, the Fraser Government added “physical impairment” to the NSW Anti-Discrimination Act 1977 (ADA) in 1980. This amendment was ground breaking for people with a disability, as New South Wales was the first government to have legislated protection against discrimination on the grounds of disability. On 25 November 1980, Premier Wran made the following statement in his Parliamentary second reading speech (NSW Parliament Legislative Assembly, 1980):

The report on discrimination and physical handicap forms the basis of the proposals contained in schedule 1 to the bill, which will introduce into the Act a

new part - discrimination on the ground of physical impairment. Honourable members will recall that, as the Act presently stands, there are three grounds - race, sex and marital status - upon which it is unlawful to discriminate. Now there will be four grounds - race, sex, marital status and physical impairment. For too long, physically handicapped people have got the raw end of the deal in virtually every aspect of community living. Now, so far as is possible, they will have to be treated like anyone else. This is so, generally speaking, in all areas of activity where discrimination is made unlawful on the ground of race, sex and marital status. Those areas, it will be recalled, may be summarized as work, provision of goods and services and accommodation.

This amendment required “all government departments and statutory authorities to prepare and implement equal opportunity management plans” that includes people with a disability (NSW Parliament Legislative Assembly, 1980). Although Aboriginal people were consulted during the formation of the amendment to the ADA, over time Aboriginal people with a disability largely became a focus of employment initiatives in the public sector under the terms ‘race’ and ‘physical impairment’.

IYDP did not bring to light a need to quantify the prevalence of disability in Aboriginal communities. The first Australian Bureau of Statistics (ABS) *National Disability Survey*, the Survey of Handicapped Persons conducted in 1981 to mark IYDP, did not include questions on Aboriginality (ABS, 1982). This survey complemented the national *Ageing Survey*, the *Family Survey* and the first *National Survey on People who are Ageing and are Living at Home*. Similar to the *ABS Disability Survey*, these surveys did not collect data on Aboriginality either.

Extensive reading of the literature did not uncover any initiatives, specialised services or programs dedicated for Aboriginal people under any government disability programs under the HPAA or the Homes Acts during IYDP. The government departments with responsibility for disability services identified programmes for Aboriginal people in homelessness, health and children’s services. However, Aboriginal people with a disability were not identified in any legislation up to 1986.

## Introduction of the Commonwealth Disability Services Act 1986

Although the IYDP documents analysed did not mention Aboriginal people, the events leading to, and during, IYDP did influence the governments to undertake its biggest reform of the disability services sector which first mentioned Aboriginal people with a disability. According to Senator Grimes (Australian Parliament Senate, 1986b, 1986c; DSA, 1986), 1985 marked the commencement of one of the biggest reforms in the disability services sector in Australia: the release of the handicapped programs review (1985) report *New Directions* and the development of the DSA of 1986. The Hawke Government reform of the disability services sector also marked the time when the participation of Aboriginal people in disability services became represented and treated as a social problem. The handicapped programs review marked the first time when the participation of Aboriginal people in disability services was discussed in government disability policy planning and development. Complementing previous reviews of the aged and disability services sector (New South Wales Government Department of Health (DOH), 1983), the review was the first broad and comprehensive review of the disability services sector to inform significant reforms.

*New Directions* represented Aboriginal people with a disability as a 'specialised field', which means that Aboriginal people were segregated as a population that required 'special consideration' and 'affirmative action' in the development of disability policy, services and programs. The treatment and representation of Aboriginal people as a specialised field encompassed three areas. Firstly, Aboriginal people were treated as a 'specialised field' in the context of 'cultural difference' with people from culturally diverse backgrounds (also described as 'ethnic' and 'migrants'). When the handicapped programs review commenced in 1983, the governments' publicised the consultations in "the ethnic press and Aboriginal publications" (Australian Government Department of Social Security (DOSS), 1984, p. 92) based on the assumption that it was 'culturally appropriate' for Aboriginal people (Handicapped Programs Review Australia, 1985). Although the review was publicised directly to Aboriginal communities there were only around 100 words committed to the topic under the chapter titled "Particular Groups", which merged Aboriginal people with people from minority cultural groups, women, older people and people living in remote regions (Handicapped Programs Review Australia, 1985, p. 93). *New Directions* reported that cultural

differences between Aboriginal and non-Aboriginal communities in defining 'disability' impacted on the participation of Aboriginal people in disability services as quoted below (DOSS, 1984; Handicapped Programs Review Australia, 1985).

Disability is a difficult concept to define as it relates to Aboriginal Australians. The definition of who is disabled depends not only on physical impairment but also on a combination of living conditions, societal role and community acceptance. For example, in one Northern Territory community of approximately 800 people, 102 were clinically assessed as disabled but only 8 described by community members as disabled (DSS internal report). Despite this definitional problem, it needs to be emphasised that Aboriginal people have a higher risk of incurring certain disabling conditions, such as trachoma, than the general Australian community. (Handicapped Programs Review Australia, 1985, p. 93-94)

Secondly, Aboriginal people with a disability were treated as a 'specialised field' in the context of 'remoteness' as quoted below. The Australian Government only recorded and documented the prevalence of disability in Aboriginal communities in the remote and rural regions of Australia. This was despite the fact that the ABS data showed that the largest number of Aboriginal people resided in the metro regions of NSW (DOSS, 1984; Handicapped Programs Review Australia, 1985).

Australian Aboriginal people live in settings which vary from isolated small communities to outstations, fringe camps and towns. Clearly this implies a range of different needs requiring different service models.

The Department of Aboriginal Affairs community profile statistics show a minimum of 1100 disabled Aboriginals in reserves, outstations and town camps – concentrated in Western Australia, the Northern Territory, Queensland and South Australia (in that order) with a significant proportion in the 60 years and over age group. These people share the difficulties of other people with disabilities living in remote and rural areas. (Handicapped Programs Review Australia, 1985, Ch 23)

Thirdly, Aboriginal people with a disability were treated as a specialised field due to 'disadvantage' and 'vulnerability'. The review reported funding disparities of "80% capital and 50% recurrent funding arrangement under HPAA. These funding

arrangements almost automatically excluded Aboriginal, ethnic, women's or rural organisations from being funded because of their limited ability to match these funds from a small fund raising base" (Handicapped Programs Review Australia, 1985, p. 95). *New Directions* is the first known government report that recommended that the population of Aboriginal people with a disability be managed by the government separately from the general population and disability services sector. These were the first government recommendations that emphasised a need to make disability services "more culturally appropriate" through creating specialised services, programs, research and data collections for Aboriginal people with a disability as a means to improve service participation (Handicapped Programs Review Australia, 1985, p. 97):

Existing and future programs take account of the specific needs of disabled Aboriginals, people of ethnic origin and women by providing for:

1. Recruitment of a proportion of staff providing services to ethnic and Aboriginal groups from those group;
2. Consumer data to monitor their access to generic services.
3. The most culturally appropriate services designed to provide ease of access
4. Flexible funding
5. The establishment of special services where appropriate
6. The use of advice from consumer organisations in planning and evaluating services
7. Research into disability and service needs in Aboriginal and ethnic communities.

The disability services sector and the governments accepted the findings and recommendations of the *New Directions* report, resulting in the treatment and representation of Aboriginal people as a 'specialised field' enshrined in disability legislation and policy. Senator Grimes reported in his parliamentary disability programmes introduction reading speech on 12 June 1986 that Aboriginal people with a disability form part of the 'disadvantage group', which also included people from culturally and linguistically diverse (CALD) communities and older people that face multiple challenges in accessing the Commonwealth Rehabilitation Program

(Australian Parliament Senate, 1986a). On 12 November 1986, the DSA was passed through Parliament. The DSA merged the HPAA and the Homes Acts covering the government administration and funding for supported/in-home accommodation, advocacy, vocational services, information services, recreation and respite care. The target group was defined as “persons with disability that is attributable to an intellectual, psychiatric, sensory or physical impairment or a combination of such impairments [that] is likely to be permanent” (DSA, 1986). Grimes noted that “the philosophical position of the government outlined in the draft Principles and Objectives (of the Act) attached to the statement of 12 June 1986 and refined in the consultation process since then in relation to people who experience double disadvantage because of sex, ethnic origin or Aboriginality” (Australian Parliament House of Representatives, 1986).

The government treated Aboriginal people with disabilities as a ‘special group’ with people from CALD backgrounds identified as ‘disadvantaged people’. The DSA was accompanied by a set of Principles and Objectives<sup>2</sup> to regulate the administration and operations of service delivery under the Act. Section 5 of the DSA Objectives states that “programs and services should reflect the needs of people with a disability who experience double disadvantage as a result of their sex, ethnic origin or Aboriginality” (Australian Government Department Community Services and Health (CSH), 1986; Australian Parliament Senate, 1986a; DSA, 1986).

### **Aboriginal people and national disability service reforms**

After the DSA was passed under the Hawke Government, the governments continued to respond to the service participation of Aboriginal people as a specialised field. The governments treated Aboriginal people with disabilities as a culturally different disadvantaged and vulnerable group who required additional support to engage with disability services. The governments developed and released information booklets, brochures and leaflets to guide organisations and the general community in addressing barriers to service participation for Aboriginal people with a disability as a ‘disadvantaged group’. For example, *Disability Society and Change* suggested that Aboriginal people be protected against discrimination

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<sup>2</sup> The Principles recognise that people with a disability have the same rights and obligations as other members of society and advocate the principles of individual independence and social inclusion. The Objectives relate more directly to the administration and minimum requirements and obligations of service delivery, such as person-centred planning, consumer rights and integration.

as a “double disadvantaged people” under Section 5 of the DSA (AOD, 1988; CSH, 1986, 1987a, 1987b; Graham & Browne, 1987). Protection against discrimination for disadvantaged groups was not raised in *New Directions* nor in the Australian Government’s public discussions during the formation of the DSA. However, similar to the publications that formed the DSA, the statement below shows that the government homogenised Aboriginal people with other cultural minority groups as a ‘special group’ that was ‘disadvantaged’ in the disability services sector (AOD, 1988, p. 34):

In Australia there is still a great deal of discrimination against people who are in the minority, and against women. Discrimination occurs for a number of reasons:

1. Because people are seen to be different.
2. Because some groups of people are small in numbers.
3. Because some groups have traditionally had lots of power and don’t want to lose it to others.

...Often people miss out on services which they could use because nobody provides the information in a way which makes sense to them, or because the information is only in English. More often than not, services are designed by white people, and make little or no sense to Aboriginal people. Again, there is a double disadvantage for a person with a disability who is also Aboriginal.

...This Objective is about services meeting the needs of people who experience double disadvantage, as a result of disability plus something else....If programs and services are to meet the needs of people with a disability, they must be provided in a way which ensures that needs which are a result of a person’s sex, of speaking a language other than English, of having a non-English speaking or Aboriginal background are also met.

Despite the Australian Government producing materials to support disability service providers to improve the participation rate of Aboriginal people in disability services, Aboriginal people were largely ignored in the major government reform initiatives of the disability service sector. The Disability Advisory Council of Australia (DACA) and the governments established numerous committees and working groups to formulate the DSA guidelines and assist with the disability

sector's transition to the DSA<sup>3</sup>. A search of the minutes of the working groups (such as the Disability Services Act Eligibility Working Group), the governments' annual reports and bulletins, parliamentary ministers' speeches and the DACA publications that were publically available, yielded no evidence of any discussions relating to Aboriginal people under Section 5 of the DSA Objectives. For example, the Disability Services Act Eligibility Working Group undertook a survey of disability service providers on the transition from Section 13 to Section 10 of the DSA. Although there was a focus on 'consumer outcomes', the survey did not explore how service providers were meeting Objective 5 of the DSA. The focus of the disability services sector's transition during this period was primarily on funding administration arrangements between the Australian Government and State/Territory governments and service eligibility (Australian Parliament Senate Estimates Committee, 1989a, 1989b; CSH, 1988, 1987a, 1987b; Disability Services Eligibility Working Group, 1988; Disability Services Seminar Coordinators, 1985).

Although Aboriginal people were recognised in the largest disability services demonstration project in Australia, they were later excluded from the final evaluation of the reforms. A component of the Hawke Government reform of disability services was the allocation of \$20 million for 117 two-year demonstration projects to allow the disability services sector to show the government innovative projects and service models that met the DSA Principles and Objectives. The projects emphasised on four core areas: devolution of large residential accommodation, development of vocational programs, individualised planning and information systems. Of the 117 projects, there was one project for Aboriginal people with a disability. According to the handbook on the demonstration projects, Awabakal Newcastle Aboriginal Corp received \$112,561 to develop and pilot culturally appropriate "Individual Personal Plans" and to improve awareness of disability services in Aboriginal communities in the Newcastle region (ACROD, 1989, pp. 1-3 and 34). The evaluation report on the demonstration projects did not mention Awabakal or how the other 116 projects met Section 5 of the DSA. The report also did not discuss how any of the 117 projects responded to the

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<sup>3</sup> Service providers funded under the previous HPAA and Homes Acts were given until June 1992 to transition and conform to the DSA Principles and Objectives. Service providers who fit outside of the target group or failed to commit to the DSA were grandfathered under the HPAA until alternative arrangements were made.

recommendations regarding Aboriginal communities raised in the handicapped programs review report (CSH, 1989).

Towards the end of the 1980s, it became apparent that disability service providers were struggling to meet the 1992 deadline to transition and conform to the DSA. In response to growing pressure from Australian Council on Rehabilitation of Disability (ACROD) and other disability service providers, the DSA was amended to postpone the deadline.

### **New South Wales Disability Services Act 1993**

Reflecting the theme of the DSA and the Multilateral Agreement, the service participation of Aboriginal people was further represented and treated as a specialised field under the NSWDSA. Parties to the Multilateral Agreement arranged that all state and territory governments were required to establish complementary legislation to the DSA under the Multilateral Agreement. In 1990, the Disability Council of NSW (DCNSW) released a consultation paper, *A Focus on Outcomes*, for public consultation to inform the development of the NSW disability legislation, with accompanying service principles and guidelines to compliment the DSA, and a NSW disability strategic plan. Interestingly, for the first time Aboriginal people were treated as a specialised field in relation to human rights together with cultural and gender diversity as quoted below (DCNSW and the New South Wales Government Department of Family and Community Services (FACS), 1990, p. 5):

All people have the same basic rights, responsibilities and expectations. All people are entitled to the services, support and assistance that they may require to meet their basic needs; ensure their rights and entitlements; and be able to fulfil their responsibilities and obligations as members of the community. All people are entitled to maximise opportunities for:

....individual identity, dignity and respect: recognition first and foremost as an individual and an equal, and not be defined or treated in terms of one's disability, ethnicity, Aboriginality, gender, religious beliefs or other lifestyle or social circumstances.

In February 1991, the DCNSW released a government response paper, *Suggestions for Change*, which did not mention Aboriginal people. The main focus of this discussion paper was the administration of funding and the delivery of services for people with a disability. Interestingly, the main criticism that came from the public consultations on the discussion paper “was that ‘*A Focus on Outcomes*’ concentrated on the services and functions of the Department of Family and Community Services” (DCNSW and FACS, 1991, p. 5) as opposed to the needs and rights of people with a disability and their families that underpinned the disability rights movement. This criticism may be the reason why Aboriginal people were not mentioned in the response paper.

In spite of not being mentioned in *Suggestions for Change*, Aboriginal people were categorised as a special field in the draft of the NSWDSA in the context of ‘multiple disadvantage’ as a culturally different population. The DOCS (1993) 1992-93 Annual Report stated that “the Disability Council of NSW developed a comprehensive community consultation programme in both metropolitan and rural areas” and held “discussions with members of the Aboriginal community” (p. 30-31). The strong emphasis in involving Aboriginal people in the drafting of the NSWDSA saw Aboriginal people being included in Section One of the Principles as meeting “the needs of persons with disabilities who experience an additional disadvantage as a result of their gender, ethnic origin or Aboriginality” (NSWDSA, 1993).

Despite the involvement of Aboriginal communities in the formation of the NSWDSA, Aboriginal people were not mentioned by government ministers in the NSWDSA NSW parliamentary introduction readings. The Fahey Government introduced the NSWDSA in March 1993. Minister Longley and Minister Chadwick noted the in-depth public consultations in their introductory reading speeches and the disadvantage and discrimination experienced by people with a disability. However, there was no mention of Aboriginal people with a disability. Nevertheless, during the upper house parliamentary motions, Senator Elisabeth Kirby applauded the government for including Aboriginal people in the NSWDSA Application of Principles under Clause 2 (NSW Parliament Legislative Assembly, 1993):

I am pleased also that in the “Application of Principles”, clause 2(e) states: “to meet the needs of persons with disabilities who experience an additional

disadvantage as a result of their gender, ethnic origin or Aboriginality". That is an important aspect and I am pleased that the Government has included it in the measure dealing with applications of principles.

Since the formation of the NSWDSA in the 1990s, disability service providers struggled to meet the Principles and Application of Principles, including Clause 2(e). In 1994, the NSW Government Department of Community Services (DoCS) provided all funded disability services a self assessment package to evaluate the performance of funded NGOs under the NSWDSA. The evaluation found that "a total of 326 disability services in NSW identified that they conformed to the Disability Standards and requested an independent assessment of their services" in 1994/95 (DOCS, 1995, p. 38). By 1996/97, this number decreased with "278 services found to conform with the NSWDSA while 813 services had some non-conforming practices and were required to prepare transition plans" (New South Wales Government Ageing and Disability Department (ADD), 1997b, p. 22-23). The main reasons given by disability services for the increasing number of non-conformities were a lack of financial support to transition to the DSA and the confusion surrounding 'good practice' in meeting the DSA standards (ADD, 1997b).

During the evaluation of disability services, the NSW Government re-released the *Disability Awareness Package* to increase awareness of disability types and the philosophies underpinning the NSWDSA. It was believed that the awareness package would help breakdown discrimination towards people with a disability and guide the public through the service system. Aboriginal people's service participation was represented as a 'specialised field'. Aboriginal people were discussed in the chapter titled "Service Issues for People with Double Disadvantage", which included people from culturally diverse backgrounds (Gething, 1994c, p. 29, 1994d). The chapter discussed how Eurocentric ideologies and institutional racism functioned as a participation barrier to disability services for Aboriginal people and provided strategies for disability services to prevent overt and covert discrimination (Gething, 1994c).

In 1996/97, the ADD established the Transition Planning and Funding Process to support funded service providers to meet the standards of the NSWDSA, which included good practice examples in meeting Clause 2(e). A total of \$39.4 million was allocated to 451 funded service providers to implement government approved

transition plans over a four year period. A component was the release of a good practice manual called *Standards in Action: Practice Requirements and Guidelines for Services funded Under the Disability Services Act* for stakeholders and government funded services. The Manual provided the following examples of good practice and poor practice for service providers in meeting Section 2(e) in areas of decision making/consultations, governance and cultural appropriateness quoted below (ADD, 1998, Sections 5.1.4, 5.2.2 and 8.3.1):

#### Good Practice Examples

- ✓ Members of the local Aboriginal and Torres Strait Islander community are invited to talk to an Agency governing body and senior staff about the type of respite they need.
- ✓ Services are developed that are culturally appropriate to its service users and meet the needs of those from non-English speaking backgrounds and Aboriginal and Torres Strait Islander decent.
- ✓ An agency has a communication plan to implement with service users and families, guardians or advocates of Aboriginal and Torres Strait Islander communities.
- ✓ An agency develops culturally appropriate information for consultation with local Aboriginal and Torres Strait Islander communities.
- ✓ An agency makes contact with Aboriginal and Torres Strait Islander groups and organisations to encourage advocacy for service users from those communities.

#### Poor Practice Examples

- ✗ An Aboriginal community is unable to participate in the planning and review process because the Agency does not include strategies that meet the community's cultural requirements.

The manual reinforced the position of Aboriginal people as a specialised field together with people from CALD backgrounds. The *Standards in Action* was the first government document identified that mentioned Aboriginal people's involvement in the decision making process of disability service providers. On the surface, this sounded like a partnership arrangement. However, the 'partnership' was predicated on the understanding that Aboriginal people with disabilities were a culturally different, remote and vulnerable social group in the disability services sector.

In 1998 the NSW Law Reform Commission (1999a, 1999b) reviewed the NSWDSA to determine whether the Objectives and Principles remained valid and,

if so, had the NSW Government achieved its aims. Aboriginal people were represented as a specialised field in terms of cultural difference. Aboriginal people were appointed as members of the Commission's Review Reference Group to "represent the views and interests of Aboriginal and Torres Strait Islander people" (NSW Law Reform Commission, 1999a, p. 5). The review team held group consultations specifically with Aboriginal people. Reflecting the theme of the policy document analysis, Aboriginal people were discussed under the NSWDSA review report's chapter titled "Subgroups" which included people from cultural diverse backgrounds (NSW Law Reform Commission, 1999a, p. 12). The review Issues Paper focused wholly on the cultural differences between Aboriginal and non-Aboriginal people under the following four sub-headings (NSW Law Reform Commission, 1999a, pp. 12-13):

1. Disability not the only disadvantage
2. Differing attitudes to disability
3. Discrimination
4. Aboriginal people and institutions

Similarly, the final report of the NSWDSA review discussed the findings on Aboriginal people in a 100 word paragraph under the chapter titled "Strengthening Support for Diversity", which included people from CALD backgrounds and sexual diversity. The NSWDSA review report focused on ways to make services more 'culturally appropriate' for Aboriginal people. For example, the report stated that Aboriginal people "preferred access to services with Aboriginal staff, or services which were at least known to be sensitive to Aboriginal culture, and which were already used by other Aboriginal people" (NSW Law Reform Commission, 1999a, p. 1-7 and p. 32-34). However, there were no other reported successful strategies that addressed the service participation of Aboriginal people.

### **The NSWDSA and disability action plans**

Aboriginal people were treated as a specialised field that was analysed and controlled by all government agencies (NSW Disability Services Act 1993). Section 9 of the NSWDSA required NSW public authorities<sup>4</sup> to produce Disability Action Plans (DAP) that detailed how they will improve access and support for people with a disability. All DAPs included strategies that addressed Clause 2(e).

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<sup>4</sup> A public authority is a government department or agency under the Public Sector Management Act 1988. For example, the NSW Opera House is a public authority.

Under the DAP, Aboriginal people were further treated as a specialised field in the context of 'disadvantage', remoteness and 'culture difference' along with people from cultural diverse backgrounds. *Disability Direction: Tomorrow's Blueprint: The New South Wales Disability Strategic Plan 1994* provided the framework upon which the governments structured and implemented the DAP. Cultural appropriateness was used as a concept to describe any practices that broke away from euro-centric ideals and philosophies. The framework only discussed Aboriginal people under the two sub-headings displayed below (New South Wales Office of Disability (NSWOD), 1994, pp. 22-31 and 61):

#### Multiple Disadvantage

People with a disability are not a homogenous group; some people experience additional disadvantage. For example, the national labour force participation rate for females with a disability (aged from 15-64 years) was 46.1%, compared with 62.6% for males with disabilities. Other groups may experience additional disadvantage: people in rural areas, Aboriginal people with a disability and people with a disability from non-English speaking backgrounds.

#### Principles for Disability Plans: Cultural Appropriateness

The ways in which public authorities deliver services is linked to perceptions and assumptions about how people live, their family backgrounds and their expectation of support and care.

It is important that Government support for disability services takes cultural and language differences into account.

The Government's NSW Charter of Principles for Culturally Diverse Society, February 1993 requires public authorities to diversify their policies and activities with the non-government sector to reflect the needs of and resources within the State's culturally diverse society.

Service provider issues which arise for people in this category include the need for support and information which address the cultural background of the family or extended family circle as well as language and communication difficulties. This is particularly important where the family uses a language other than English and the person with a disability uses English as his or her functional language.

In responding to these factors, the need for service provider cross-cultural training and the role of ethno-specific services should be considered.

If information or assistance with either the preparation or implementation of disability plans is required to ensure that they are responsive to the needs of people with a disability who are from a non-English speaking background, public authorities can consult the Ethnic Affairs Commission.

Similarly, public authorities should ensure that their disability plans take into account the concerns and needs of Aboriginal people with a disability, especially those living in rural and remote areas. Public authorities can consult the Office of Aboriginal Affairs for assistance.

In 1997, the NSW Government released a Discussion Paper (called the Green Paper) on the reforms to DAPs. Aboriginal people's service participation, as a specialised field, was objectified and treated as an object of scientific data collections, quantifiably measured and analysed together with CALD, women and rural communities. The Discussion Paper discussed the prevalence of disability and the diversity in conceptualising disability in Aboriginal communities (ADD, 1997c, p. 22-31 and p. 61):

NSW has one of the largest State populations of Aboriginal people. Aboriginal people live in rural, regional and urban areas and there is a diversity in individual, family and community aspirations.

Aboriginal and Torres Strait Islander people make up 1.3% of the NSW population, and, according to the 1994 National Aboriginal and Torres Strait Islander Survey, 0.9% of the people with a severe or profound participation restriction.

This rate increases sharply with age and the age at which this happens is significantly lower than in the non-Aboriginal population. The National Aboriginal and Torres Strait Islander Social Survey estimated that over the age of 45 years, 10.4% of Aboriginal and Torres Strait Islander have a severe or profound participation restriction. This compared to the 1993 ABS Survey of Disability, Ageing and Carers figure of 3.6% for the general population of this age.

This data must be seen in the context of having been gathered in two different surveys conducted in different calendar years, and using the answers that reflect cultural difference in people perceptions of need.

Further, there are no reliable data existing to allow conclusions about the percentage of the people in NSW with a disability who are of Aboriginal and Torres Strait Islander background. Effective planning needs at the very least this basic information.

Despite this lack of detailed data, it is known that the average life expectancy of Aboriginal and Torres Strait Islander people is significantly lower than that of non-Aboriginal people (62 years as against 81 years for females, and 57 years as against 75 years for males). The disabilities associated with ageing are experienced at much younger ages, and these disabilities can be exacerbated by the results of poor health and a deprived environment.

The Discussion Paper mentioned that the NSW Government has struggled to statistically quantify service demand for Aboriginal people with a disability for over a decade. The government decisions and discussions regarding Aboriginal people with a disability were based on limited statistical evidence. Given that the NSW Government can quantify the need for services for Aboriginal people as a specialised field, a benchmark for measuring performance was established. For the first time, ADD recommended in a discussion paper that all NSW Government authorities were to “address specific needs by developing performance measures for programs and services that will be appropriate to the needs of people with a disability who are female, of Aboriginal and Torres Strait Islander background, non English-speaking background and rural and remote areas” (NSWOD, 1994, p. 61).

In 1998, the NSW Government released a new updated Policy Framework to guide government authorities in developing and implementing DAPs. The Framework recommended that NSW Government agencies collect data on Aboriginal people with a disability as a strategy to identify the prevalence of need for disability services in Aboriginal communities. A comprehensive communication and consultation strategy was provided to the NSW Government authorities outlining ways to include Aboriginal communities in the decision making process. The communication and consultation strategy was summarised under the following dot-points (ADD, 1998, Chapters 4 and 5):

- Planning for an event/consultation with Aboriginal and Torres Strait Islander communities: Aboriginal people should be involved in the planning and the implementation of the DAP. Ensure that the correct protocols are followed, such as welcome to country.
- Venue: ensure that the venue is commonly used by Aboriginal people.
- Utilise Aboriginal community managed organisations, Elders and key Aboriginal people in the community.
- Utilise Aboriginal and Torres Strait Islander media
- Methods to produce and disseminate Aboriginal and Torres Strait Islander friendly information.

### **Aboriginal people under the multilateral agreement**

As discussed in Chapters One and Two, the Multilateral Agreement was the formal agreement between the Australian and the state and territory governments for the allocation of funding for disability services. Reflecting the DSA and the NSWDSA, the participation of Aboriginal people in disability services was treated as a social problem throughout the life of the Multilateral Agreement. In the early 1990s, reflecting the spirit of cooperation in streamlining the administration of government funded disability services, the Australian and state/territory governments established a working party for the planning, priority setting and program evaluation of the Multilateral Agreement. The idea was that a national planning approach would minimise the likelihood of any one area of service developing in isolation of the other. The Working Party formed a multilateral forum that focused on 'specialised issues' with priority given to the four areas quoted below (Australian Council of Social Welfare Ministers Working Party on Roles and Responsibilities for Disability Services, 1990, p. 17):

1. Assessment of needs in supply and demand
2. Consultation with consumers
3. Joint agreement on priorities
4. Addressing the needs of people with additional disadvantages eg, non-English speaking background, Aboriginals and women.

Reflecting the DSA and the NSWDSA, Aboriginal people as a specialised field were treated and objectified as an object of scientific data collections under the Multilateral Agreement data collection process, known as the Commonwealth State Disability Agreement Data Cubes (CSDA Data Cubes and later called the

Commonwealth State/Territory Disability Agreement Data Cubes). A key component of the Multilateral Agreement was the collection of data on access and outcome rates under a data collection system called the Minimum Data Set (MDS). The MDS was originally a national annual snap-shot survey of all clientele of Multilateral Agreement funded services throughout the 1990s. In the early 2000s the MDS changed to a national periodic reporting mechanism involving all clients (such as age, sex, disability type etc) and service outputs/outcomes (therapy delivered, days attending a day program etc) of all Multilateral Agreement funded services. All Multilateral Agreement clients were calculated under the following six categories (AIHW, 2010a; ADD, 1996):

1. Aboriginal
2. Australian but not Aboriginal
3. Australian but Aboriginality undetermined
4. Persons born in an English speaking country (other than Australia)
5. Persons born in a non-English speaking country
6. Language and cultural background not known.

The National Disability Administrators study on data collection concluded that the data collection methods on the participation rates of Aboriginal people were culturally inappropriate and did not actually reflect the service participation of Aboriginal people. In 1998, a conference was held in Canberra specifically to formulate a framework for the collection of data on Aboriginal people with a disability. New standards were then introduced in the ABS in relation to data collection in all areas of community services (ABS, 1998).

Aboriginal people with a disability continued to be treated as a culturally different vulnerable group towards the late 1990s. For example, the third Multilateral Agreement (known as the CSTDA) identified a need for affirmative action in addressing the “heightened vulnerability of people with high support needs, Indigenous Australians with disabilities and people from culturally and linguistically diverse backgrounds”. The CSTDA annual reports discussed how the parties to the Agreement addressed the needs of Aboriginal people through “collaborative projects” and compared outcomes of each project/initiative in all the states and territories (Australian Government Department of Families and Community Services (DFACS), 2004, 2005, 2006, 2007; AOD, 2002).

Although Aboriginal people were represented in the multilateral agreements over the two decades, the federal reviews of the multilateral agreements largely

ignored Aboriginal people in the metropolitan regions of NSW. The first review in 1996, called the CSDA review, identified many failures of the Multilateral Agreement in meeting the needs of Aboriginal people with a disability. The aim of the CSDA review was to evaluate the effectiveness and efficiency of the Multilateral Agreement for the provision of disability services. The terms of reference for the consultations included Aboriginal people as a specific target group. The CSDA Consultation Report had “ongoing contact with Aboriginal people who were accepted in their communities” (Ernst & Young, 1996, p. 10). Similar to the publications released from 1985, the evaluation largely focused on Aboriginal people in remote regions of the Northern Territory (NT) despite ABS data showing that the largest number of Aboriginal people resided in Sydney. Aboriginal people in NSW were only mentioned in the appended Demand Study in relation to qualitative research findings in rural and remote regions. The consultation report (Ernst & Young, 1996) and the final evaluation report (Yeatman, 1996) did not present the consultation findings regarding Aboriginal people with a disability in NSW. These reports presented the results of the consultations with the Ngaanyatjarra, Pitjantjatjara and Yankunytjatara Aboriginal Women’s Council (situated on the borders of the NT, SA and WA) as a small appendix of five pages (Ernst & Young, 1996; Yeatman, 1996, pp. 48-53).

### **NSWDSA strategic planning**

Under the NSWDSA, the NSW Government was required to establish time-frame strategic plans that detailed ways to improve the level of support and services for people with a disability. Reflecting the Multilateral Agreement and the NSWDSA, the service participation of Aboriginal people was treated as a specialised field under all the state-wide strategic plans for disability services.

The first NSW strategic plan, *Directions 1992/1995: Planning for Better Client Services*, merged Aboriginal people with CALD as a culturally different disadvantaged group that needed affirmative action strategies to address access and equity barriers to services. *Directions* outlined the main areas for reform and development in the human services sector. DoCS identified a need to increase access to services for Aboriginal people with a disability under “Sub-program Two: Community Support Services for Older People or Persons with a Disability and Disadvantaged Groups” (DOCS, 1992, p. 25). The NSW Government committed

to “increase accessibility for Aboriginal people and people of non-English speaking backgrounds” as a strategy to “improve community support services and direct resources to frail older people and person with a disability” (DOCS, 1992, p. 26).

Under this strategy, the NSW government commissioned a study that provided information on ways to improve the rates of access and outcomes for Aboriginal people in disability services. Unlike the other research and evaluation studies, the study reports did not compare, or homogenise, Aboriginal people with other ‘minority’ or ‘disadvantaged’ groups. The study, *Across the Divide: Distance, Diversity and Disability*, aimed to locate and identify the needs of people with a disability in rural and remote regions and provide solutions to address unmet need. Similar to the reviews of the NSWDSA and the Multilateral Agreement, group and individual consultations were held specifically with Aboriginal communities. A separate 75 page volume was released specifically presenting the findings of the study in relation to Aboriginal people (Gething, 1994a, 1994b).

In July 1997 ADD released the first strategic plan specifically for Aboriginal people with a disability, *Aboriginal and Torres Strait Islander Access and Equity Strategy*, in response to the “mounting evidence for a need to specifically focus on Aboriginal people” as a specialised field (ADD, 1997a, p. 10). It stated that “the strategy was prepared by an Ageing and Disability Department Aboriginal and Torres Strait Islander Liaison Officer in consultation with an appointed Aboriginal and Torres Strait Islander Access and Equity Advisory Reference group” (ADD, 1997a, p. 11). Its purpose was to “assist the Department to develop effective policies and programs to overcome immediate barriers in access and equity to specialist services for Aboriginal and Torres Strait Islander people with a disability, older people and their carers, as well as to plan for the future” (ADD, 1997a, p. 2). The *Strategy* also aimed to develop “culturally appropriate services and programs that were flexible and responsive” to achieve “equitable access to government and non-government community programs and services” for Aboriginal people (ADD, 1997a, pp. 8-9).

The *Strategy* defined cultural appropriateness in service delivery as service providers and government representatives having greater knowledge on the “cultural protocols” of Aboriginal communities to overcome the “historic of distrust” in Aboriginal communities of generic disability services (ADD, 1997a, pp. 14-16). Equitable access, on the other hand, was defined as strategies to increase the

rates of access and outcomes for Aboriginal people in government funded and managed services. The *Strategy* outlined six objectives to achieve this aim as summarised below (ADD, 1997a):

1. Access: to eliminate barriers of access to our programs and the services we fund.
2. Equity: to ensure that Aboriginal and Torres Strait Islander clients eligible for community programs and services receive a fair share of these resources
3. Communication: to provide information on eligibility, programs and services in a culturally appropriate manner.
4. Responsive Service Delivery: to ensure that our community programs and the services that we fund are flexible in service delivery and are culturally appropriate.
5. Participation: to foster participation by the Aboriginal and Torres Strait Islander community in all level of planning, policy development and evaluation of services.
6. Accountability: to be accountable for improved performance in Aboriginal and Torres Strait Islander equity.

Although there were numerous initiatives to achieve the aims of the Strategy, there was no specific funding committed for ACCOs. Rather, the strategy committed the NSW Government to “encourage and support the development of Aboriginal and Torres Strait Islander managed and controlled service organisations through the planning process” (ADD, 1997a, p22).

Reflecting the reviews of the NSWDSA and the CSDA, the Strategy stated that the barriers to services for Aboriginal people were similar to culturally diverse communities, women and people with intellectual and physical disabilities.

### **NSWDSA strategic planning and the compartmentalisation of Aboriginal people**

The year 2002/03 marked a change in how the NSW Government responded to the low participation rate of Aboriginal people in disability services as a specialised field. It is the year when Aboriginal people’s service participation was compartmentalised as a specialised field at a government level through the development of the NSW Department of Ageing, Disability and Home Care - Aboriginal Policy Unit (DADHC-APU), later called the Aboriginal Service Development and Delivery Directorate. Compartmentalisation is defined for the purposes of this study as a social or cultural group that is managed and controlled in isolation from the general community at a government department level.

The establishment of the DADHC-APU saw a stronger focus on Aboriginal people with a disability treated as 'participants' in NSW Government disability service and program policy planning and development, a change from being merely 'recipients' of government funded services. In saying this, Aboriginal people with a disability participated in state government policy accepting that the participation of Aboriginal people in disability services was to be treated as a specialised field.

The DADHC-APU was developed under the 2002 DADHC Statement to Aboriginal and Torres Strait Islander People. The Statement "highlights the department's commitment to working in partnership with Aboriginal people and their communities to develop and deliver services that reflect identified needs that empower people through ensuring greater autonomy" (DADHC, 2005b, p. 3).

Although there was a policy shift, participation of Aboriginal people in disability policy was predicated on the understanding and acceptance that Aboriginal people with disabilities needed to be treated as a specialised field under the NSWDSA. There were three main policies that clearly demonstrated this shift in the 2000s. In 2005, for example, DADHC released the *Aboriginal Policy Framework* (The Framework) accompanied by the *Aboriginal Consultation Strategy* to guide the Department in how it worked with Aboriginal communities. As quoted below in Table 6, the Framework's guiding principles, objectives and strategies for DADHC staff in addressing the needs of Aboriginal people with a disability, older people and their carers reflects this theme (DADHC, 2006a, 2006b):

Table 6

*DADHC Aboriginal Policy Framework Principles, Objectives and Strategies (DADHC, 2006a)*

Principles	Objectives	Strategies
<ul style="list-style-type: none"> <li>• Respect the values, culture and heritage of Aboriginal and Torres Strait Islander People.</li> <li>• Work together with Aboriginal and Torres Strait Islander communities to develop and deliver services and supports that reflect identified needs that empower people through ensuring greater autonomy.</li> <li>• Actively engage with Aboriginal and Torres Strait Islander communities in the development of policies, protocols, services and programs, and promote leadership within communities.</li> <li>• Build capacity of Aboriginal and Torres Strait Islander communities in delivering culturally appropriate services for our client group.</li> <li>• Influence policy and actions across the Government to support our client group to achieve a better quality of life.</li> <li>• Be accountable for ongoing monitoring and evaluation of the effectiveness and appropriateness of our services to Aboriginal communities.</li> <li>• Support and develop staff working with Aboriginal and Torres Strait Islander communities.</li> </ul>	<ul style="list-style-type: none"> <li>• Being flexible and focussed on meeting the identified needs of Aboriginal people.</li> <li>• Being accountable, and participate in ongoing monitoring and evaluation of the effectiveness and appropriateness for Aboriginal communities of all DADHC services.</li> <li>• Supporting and developing Aboriginal staff working within the Department.</li> <li>• Influencing policy and actions across the Government to support Aboriginal people to achieve a better quality of life.</li> <li>• Recognising that quality of life, health and wellbeing are essential to promoting community development and maximising the ability of people to function independently in society.</li> </ul>	<ul style="list-style-type: none"> <li>• The development of performance indicators that will accurately measure and report on participation by Aboriginal people in DADHC's funded services and programs.</li> <li>• The development of specific action plans to improve access by Aboriginal people to DADHC's programs and services.</li> <li>• The provision of specific training for DADHC staff working in and with Aboriginal communities.</li> <li>• The development and enhancement of the Aboriginal community's capacity to identify and address issues specific to Aboriginal people.</li> <li>• Improvements to the responsiveness of service delivery and the way our services are delivered for Aboriginal people.</li> <li>• Researching culturally appropriate models of service delivery to Aboriginal people.</li> <li>• Implementing an integrated planning approach by Aboriginal organisations, communities and Government agencies.</li> </ul>

Similar to *The Framework*, *The Consultation Strategy* standards quoted below, accompanied by a tool kit, guided DADHC staff in establishing 'partnerships' with Aboriginal communities to achieve the objectives of the Framework to improve the participation rate of Aboriginal people in disability services (DADHC, 2005a, p. 5):

1. DADHC will engage with Aboriginal people and their communities in NSW.
2. DADHC will consult Aboriginal people and their communities on a range of issues.
3. DADHC will use a variety of models to consult with Aboriginal people and their communities.

4. DADHC will regularly engage with Aboriginal people and their communities.

Similarly, in 2009 DADHC developed a three-year *Access and Equity Strategy 2009* (AES) to establish a service system that was responsive to the needs of older people, people with disabilities and carers in Aboriginal communities (DADHC, 2009a, 2009c). The AES (DADHC, 2009a) set out the Framework under three key areas:

1. Improving systems, capacity and evidence:
  - a. Policies are more culturally responsive
  - b. Resources and communication strategy for building cultural competence
  - c. Increased workforce capacity for culturally responsive services
  - d. Increase capacity in funded services
  - e. Planning for improved programs and services.
  - f. Better evidence to inform Aboriginal services
2. Strengthening our services
  - a. Improved partnerships
  - b. Greater awareness of services in Aboriginal communities
  - c. All services are more culturally responsive and more accessible
  - d. More Aboriginal-specific services
3. Better access
  - a. More Aboriginal people use DADHC services

Basically, the AES resembled ADD's 1997 Access and Equity Strategy. The AES aimed to establish a 'culturally responsive' disability service system as a means to address the disadvantage experienced by Aboriginal people with a disability, older people and their carers. Similar to *The Framework* and the *Consultation Strategy*, the focus was strongly on Aboriginal people participating in the government policy and planning process.

In 2006, DADHC released its ten-year plan, *Stronger Together: A New Direction for Disability Services*, to address the unmet need in the population of people with a disability, ageing and carers. Similar to previous plans, *Stronger Together* merged Aboriginal people with people from CALD. This is the first strategic plan that committed funding specifically for Aboriginal people with a disability. *Stronger Together* increased the level of service provider reporting on the access and

outcomes rates of Aboriginal people in all DADHC funded services (DADHC, 2006c).

*Stronger Together* is the first known plan that committed a specific amount of funding to Aboriginal community managed organisations. For example, the plan committed to funding “fifteen intensive family services to help up to 400 families at risk of breakdown, with three services specifically for Aboriginal and Torres Strait Islander communities” (DADHC, 2006d, p. 26). Furthermore, the plan stated that “funding of specialist service providers for Aboriginal and Torres Strait Islander people and people from other culturally and linguistically diverse communities in the Community Participation and Intensive Family Support programs” (DADHC, 2006d, p. 27). Although the ADD 1997 Access and Equity Strategy is the first known government document that specifically mentioned funding ACCOs for Aboriginal people, it did not commit the NSW Government to a specific amount of funding for disability services (ADD, 1997a).

Over subsequent years, DADHC regional offices established advisory groups of Aboriginal community members, DADHC Aboriginal staff and executives. DADHC Southern Region was the first regional office to establish an Aboriginal advisory group consisting of representatives of DADHC and external Aboriginal community members. Other regional offices opted to have Aboriginal advisory committees consisting of DADHC Aboriginal staff only. Members of Aboriginal advisory groups are also represented on other DADHC funded projects and initiatives, local Aboriginal service inter-agencies and inter-agencies established under the NDS Aboriginal Resources and Pathways project (DADHC, 2009c).

In 2008, DADHC established the Aboriginal Employment and Capabilities Framework (2008-2010) to increase the number and representation of Aboriginal people in the DADHC workforce. DADHC reported that a total of nine Aboriginal people graduated in the first year of the Aboriginal Trainee Program. Contrary to generic employment programs, trainees received free driving courses to obtain their provisional drivers license. Secondly, DADHC has increased the number of Aboriginal people working in residential services, policy and community care services (DADHC, 2009b, 2009c).

In the latter half of the 2000s, DADHC introduced measures that required funded service providers to develop action plans to respond to the needs of Aboriginal communities in their local area. These plans included strategies to

improve both service access and outcomes for local Aboriginal people and their families. DADHC's expectation that funded services meet the needs of Aboriginal people in a culturally competent manner continues to build momentum as the NSW Government moves to an individualised disability service purchasing framework, as discussed in Chapter Two. Government auditing and performance management of funded community services now includes the cultural competency of organisations to support Aboriginal people under service guidelines (DADHC, 2009c).

### **Conclusions**

The governments responded to the service participation of Aboriginal people as a specialised field that encompassed three areas: disadvantage/vulnerability, cultural difference and remoteness. The analysis of source documents shows that the government struggled to understand and respond to the low participation rates of Aboriginal people. Although the governments identified the low service participation rates as a social issue, their commitment to address the participation rate oscillated during the development of the DSA, NSWDSA and the Multilateral Agreement.

The governments did not identify the participation of Aboriginal people in disability services as a problem during the IYDP festivities. It was first raised as a social issue during the review and reforms of the disability services sector during the mid 1980s.

The governments did not see the low participation of Aboriginal people in disability services as a problem created by the disability services system. Rather the governments interpreted the low service participation rate as a result of Aboriginal people being a specialised field.

There was also no consistency in how the governments treated and represented Aboriginal people during the major disability legislative and policy reforms during the 1980s and 1990s. Since the late 1990s, the governments increased pressure on funded disability service providers to demonstrate how they addressed service participation barriers for Aboriginal people. The governments' policy documents situated Aboriginal people as the '*Other*' by treating Aboriginal people as a specialised field together with people from CALD backgrounds. Sometimes Aboriginal people in metropolitan regions of Australia were not

included in the major consultations on government policies. Worse still, Aboriginal people in metro regions were included in the consultations, but the findings were not reported in the major policy review reports.

There were times that the governments represented Aboriginal people as a specialised field in the context of human rights. However, this was not an ongoing theme in the documents analysed.

The governments tended to objectify and monitor Aboriginal people with a disability in statistical data collections. Aboriginal people with a disability were continually studied and analysed by both governments. The governments struggled to quantify the level of participation of Aboriginal people in disability services because the data collection methods were culturally inappropriate. In effect, the governments' response to this issue was based on inaccurate data.

From 2002, the DADHC developed a Unit specifically to address the participation rates of Aboriginal people in disability services in DADHC. Aboriginal people were not merged with people from culturally diverse backgrounds as 'culturally different'. Rather they were compartmentalised as a specialised field under the Multilateral Agreement and the NSWDSA. Interestingly, the DADHC-APU focused strongly on Aboriginal people as *participants* rather than merely *recipients* of DADHC funded services. However, this shift in thinking was predicated on the basis that the government and the community accepted that Aboriginal people's disability service participation is a *specialised field* that must be managed separately from non-Aboriginal people with a disability.

The Unit developed many policies specifically tailored to support Aboriginal people with a disability. The DADHC-APU saw the development of an Aboriginal workforce strategy, resulting with an increase in the number and representation of Aboriginal people in the disability services workforce. Although many policies were released, the impact of these was not reported. Furthermore, the access and equity policies replicated the phrases and objectives from previous policies, showing that there has not been much change in the approaches taken to address the low service participation rates of Aboriginal people with a disability since the development of the DADHC-APU.

The chapter that follows presents the findings of the historical analysis of the documents developed by the Aboriginal NGO and the Mainstream NGO.

## **Chapter Five: Non-Government Disability Service Providers Response to Aboriginal Disability Service Participation**

This chapter discusses the Mainstream NGO and the Aboriginal NGO responses to the low service participation of Aboriginal people as per the method discussed in Chapter Three. Similar to Chapter Four, this chapter is written as a timeline of significant events. As indicated in Chapter Three, the Aboriginal NGO could only produce a small number of documents for this study because it is a very small non-government organisation (NGO) in comparison to the Mainstream NGO.

The review found differences and similarities in how the Mainstream NGO and the Aboriginal NGO responded to the participation of Aboriginal people in disability services. The chapter commences with the ways the two NGOs responded to the service participation of Aboriginal people during the reforms to the disability services sector. This is then followed by the initiatives during the 1990s. Following there is a discussion on how the two NGOs involved Aboriginal people in disability programs, services and initiatives.

### **Aboriginal People During the Disability Reforms**

The document review found no evidence that the Mainstream NGO acknowledged the disability service participation of Aboriginal people as a social issue in the 1980s. At this time, the Mainstream NGO was concerned about the political paradigm shift in the government administration of disability services, particularly the development and implementation of the *Commonwealth Disability Services Act 1986* (DSA). It was a period of uncertainty for funded NGOs and people with a disability alike. In 1986, the Mainstream NGO undertook extensive service wide evaluations and reforms to improve the effectiveness and efficiency of its services in developing a wide range of services for clients (Andersons, 1986a, 1986b; Young, 1986a, 1986b, 1986c). There was no mention of Aboriginal communities in any of the reports and business plans. One report noted a high level of demand for the Mainstream NGO services in a metro region (Andersons, 1986b). However, Aboriginal communities were not discussed, despite the Australian Bureau of Statistics (ABS) data showing that the Mainstream NGO's

jurisdiction had the highest number of Aboriginal people in New South Wales (NSW) at that time.

The Mainstream NGO had been active in culturally diverse communities since the 1980s. The Mainstream NGO newsletters from 1982 noted that the regional/rural services found that the problems were many and varied and “relate to Ethnic families as well as the Australian born” (Support Services Coordinator, 1982, p. 3). In 1988, for example, the Mainstream NGO started to work with the Culturally and Linguistically Diverse (CALD) communities to raise funds for the Mainstream NGO services in the Inner Sydney region (Magazine Editor, 1988, p. 7). However, the Mainstream NGO was not actively involved in the local Aboriginal communities.

The year 1990 marks the period when the Mainstream NGO first identified the participation of Aboriginal people in disability services as a social issue. Reflecting the theme from the government literature analysis, the Mainstream NGO focused on Aboriginal communities in the non-metro regions during the 1980s and 1990s. The Mainstream NGO (2008b) reported in their history of rural services that:

The Mainstream NGO’s rural services have always been available to Aboriginal families. However, although a small number have travelled to [metro region] and used the Mainstream NGO accommodation, it was clear that our service model was not addressing their needs. In 1990, in an attempt to improve this, Aboriginal families from the North and North West of the state were offered services at the Mainstream NGO. This worked well from the outset with good outcomes for the children. (p. 11)

In November 1993, the Mainstream NGO recruited Aboriginal people to specifically work with Aboriginal families and to support the Mainstream NGO in becoming culturally responsive for Aboriginal communities. The first Aboriginal Liaison Officer was located in a non-metropolitan region in NSW. The Mainstream NGO Manager (1994) described the Liaison Officer as:

..a resource to the Mainstream NGO staff in all regions, and in particular, to staff who provide rural services. She is also a member of the Outreach Team to [a region]. The Aboriginal Liaison Officer acts as a support to Aboriginal families who are accessing the Mainstream NGO services from other Agencies. (p. 3)

The Aboriginal Liaison Officer made significant changes in the way the Mainstream NGO worked with Aboriginal communities. An Aboriginal specific Mainstream NGO promotional brochure and a poster were developed in 1995 to establish a shared understanding of the benefits available to Aboriginal people in accessing the Mainstream NGO services. This brochure had Aboriginal artwork and phrases from the local Aboriginal community language. Soon after the official launch, the Mainstream NGO (1995, p. 3) made the following report in their local newsletter:

Over 100 guests attended the Mainstream NGO on Friday 25 August, 1995 to celebrate the launch of a poster ....

Developed by ... Aboriginal Liaison Officer at the Mainstream NGO the poster enables Aboriginal families and local Aboriginal communities to be informed of the Mainstream NGO's services available in the [region].

The poster features a painting by local Aboriginal artist ... as well as photographs ... of some of the children from local Aboriginal communities who have recently used the Mainstream NGO's services.

The launch was an opportunity to express our gratitude to all those people and community services who helped to make it possible. In particular we wanted to thank the families who have used our services. They have helped us to understand the many ways in which we can work together to help each child's progress and learning.

Similarly, the Aboriginal NGO (2003) brochures and promotional materials had Aboriginal artworks and symbols. However, there were no phrases or words from the local Aboriginal community languages.

Similar to the governments, the Aboriginal NGO and the Mainstream NGO objectified Aboriginal people with a disability as an object of statistics. As part of their funding agreements with the NSW Government Department of Ageing, Disability and Home Care (DADHC), the Mainstream NGO and the Aboriginal NGO collected and analysed data on the population of Aboriginal people with a disability and the service rates to identify gaps in unmet and under-met need for services. For example, the Mainstream NGO developed an Aboriginal Community

Profile for each Mainstream NGO region consisting of the following information (Mainstream NGO, 1996, 2009a):

1. Population by Local Government Area
2. Age and sex
3. Family demographics
4. Representation of Aboriginal people in the Mainstream NGO services
5. Level of disadvantage
6. Aboriginal community managed organisations

The profile was used in a range of the Mainstream NGO documents, such as the 1997 NSWDSA Transition Planning and Funding Process Self Assessment, government funding applications and service description statements (Mainstream NGO, 1997b, 2001; Smith, 2010).

Although affirmative action was taken to tackle the low participation rate of Aboriginal communities in rural and remote regions of NSW during the 1990s, Aboriginal people were not included in the Mainstream NGO strategic plans, annual reports or service development plans until the late 2000s. During the formation of the Multilateral Agreement and the NSWDSA, the Mainstream NGO developed its 1992-1995 Strategic Plan and the 1995-1998 Strategic Plan. These strategic plans included proactive and innovative strategies to help the Mainstream NGO continue to grow and meet the needs of people with a disability during this transitional period. There was a strong emphasis on deinstitutionalisation and organisational growth to meet the increasing community demand and providing employment opportunities for people with a disability (Mainstream NGO, 1991, 1994, 1997a; Mainstream NGO Manager, 1994, 1995). The Mainstream NGO included CALD groups in strategic planning. For example, the 1998-2001 Strategic Plan incorporated strategies to disseminate information and resources that “reflect the cultural and linguistically diverse background of service users” (Mainstream NGO, 1997a, p. 14).

### **Government Pressure and Affirmative Action in the 1990s**

Increased government pressure on the Mainstream NGO to demonstrate how they were meeting the service needs of Aboriginal people resulted in ineffective policy responses. In response to the NSW Government’s NSWDSA Transition Planning and Funding Process Self Assessment in 1997, discussed in Chapter Four, the Mainstream NGO developed their first access and equity policy, *Access*

*and Equity for Indigenous Australians and those with Non-English Speaking Backgrounds* (AES). The Mainstream NGO's AES merged Aboriginal communities with CALD communities. Reflecting the NSWDSA, the Mainstream NGO defined the policy as recognising "that all people with a disability have a right to access and equity of services regardless of their race, religion, ethnicity and language and that as a service provider we will ensure the organisation responds appropriately and sensitively to the needs of the entire community including Indigenous and non-English speaking background (NESB) groups" (Mainstream NGO, 1997c, p. 1).

Similar to the governments, the Mainstream NGO treated the service participation of Aboriginal people with a disability as a specialised field due to cultural difference and disadvantage. The policy states that the objective and principles are needed because (Mainstream NGO, 1997c):

Indigenous people are the most disadvantaged people in Australia, having experienced discrimination and racism, limiting their access to all services. People from NESB and Indigenous background face barriers in accessing programs and services because of linguistic, cultural, socio-economic and other factors. Social policy recognises that both these groups are identified as having special needs. (p. 2)

Interestingly, the policy principles contradicted both the policy actions and priorities. Although the Mainstream NGO acknowledged that Aboriginal people were disadvantaged and culturally different, one of the policy statements claimed that "the needs of Indigenous and NESB people should not be viewed as different from the needs of other community members" (Mainstream NGO, 1997c, p. 3). This policy statement purports that no affirmative action was needed to address the service participation of Aboriginal people. However, under the policy procedures, regional managers were required to undertake the following (Mainstream NGO, 1997c):

1. Appropriate planning occurs in the development and review of services and support to ensure there is a clear understanding of the cultural and linguistic needs of a particular community.

2. There is an understanding that not all people from a certain background have the same beliefs and attitudes. Service delivery must therefore be based on individual needs (in line with the DSA and DSS).

Similarly, the five policy priority statements committed the Mainstream NGO to a range of affirmative action strategies. Action items included “cross-cultural training” for all staff, workers must engage with Aboriginal community controlled organisations (ACCO) and modify application forms to better reflect the needs of Aboriginal people (Mainstream NGO, 1997c). The final page of the policy displayed practical resources on access and equity for Aboriginal communities.

Thus, on the one hand Aboriginal people were seen as highly disadvantaged and regional managers were required to undertake planning to meet those needs. On the other hand, the needs of Aboriginal people should not be viewed as different from other community/cultural population groups. It would be difficult to undertake affirmative action targeting a specific cultural group to meet a policy principle that stated that everyone’s needs should not be viewed as different. This contradiction may be the reason why the review of annual reports and newsletters reported no activities or stories regarding Aboriginal people with a disability during the late 1990s and early 2000s.

The end of the 2000s saw the Mainstream NGO establish its first state-wide approach in supporting Aboriginal people with a disability under the banner of affirmative action. The 2007-2010 Strategic Plan committed the Mainstream NGO to “greater service participation by Aboriginal communities” under Strategic Plan Goal One, “services that are contemporary and creative” (Mainstream NGO, 2006, p. 7). The Mainstream NGO committed to achieve the following:

1. Establish data collection standards for monitoring demographics
2. Develop partnerships with Aboriginal service providers
3. Develop Aboriginal Action Plans for each region

The Mainstream NGO developed regional business plans that detailed strategies to meet the goals of the strategic plan in relation to Aboriginal communities. Each business plan consisted of ABS demographic data, trends in service participation by Aboriginal people, information on Aboriginal communities, language and key contacts in Aboriginal communities. Each business plan also included strategies to embed the Mainstream NGO in Aboriginal communities

through forged partnerships with local Aboriginal community managed service providers (Mainstream NGO Manager, 2008; Mainstream NGO, 2008b).

Under this strategy, The Mainstream NGO replaced their access and equity policy with the below “Diversity and Inclusion” policy to meet Goal One (Mainstream NGO, 2007, p. 1):

The Mainstream NGO believes in treating all people with respect and dignity and as such includes this as one of its core values. Valuing diversity and providing a culture that is inclusive and aware of the different contributions, skills, experiences and perspectives of others is important. By promoting a diverse and inclusive environment for clients, their families and its employees/volunteers, the Mainstream NGO will ensure a culturally competent and culturally appropriate organisation.

All managers/supervisors are to show leadership in this area and ensure every effort is made to adopt relevant work practices (as outlined in the procedures) that are inclusive and encourage diversity. The Mainstream NGO holds a zero tolerance towards inappropriate attitudes, behaviours and work practices that do not support diversity and inclusion.

In some instances, the Mainstream NGO’s policy and strategic planning was going in a different direction from DADHC. At this period DADHC compartmentalised Aboriginal people service participation as a specialised field. The Mainstream NGO, on the other hand, preferred to have Aboriginal people merged with CALD, under the same policy initiatives in the name of cultural diversity.

Unlike Government agencies, the Aboriginal NGO and the Mainstream NGO had a different approach in how they defined Aboriginality. The Mainstream NGO defined an Aboriginal person as “a person of Aboriginal or Torres Strait Islander descent, who identifies as an Aboriginal or Torres Strait Islander and is accepted within their community as such” (Mainstream NGO, 1997c, p. 2). The Aboriginal NGO did not define Aboriginality in their policies or service descriptions in relation to clientele. Similar to the Mainstream NGO and the government, all Aboriginal people were required to demonstrate their Aboriginality upon applying for Aboriginal identified positions (Aboriginal NGO, 2006, 2007).

Interestingly, the Aboriginal NGO had a broader definition of disability in comparison to the Mainstream NGO. The Aboriginal NGO did not define disability, or restrict the agency to the DSA, in their eligibility criteria. Rather, the Aboriginal NGO adopted the *Disability Discrimination Act 1992* (DDA) definition of disability

and how the person's 'disability' formed part of the "the problem the person is facing" (Aboriginal NGO, 2005, p. 2-4). This definition incorporated how general impairments, mental health and aged-related conditions impact on, or are impacted by, a person's social environment. In contrast, the Mainstream NGO defined as its target group those established by a particular government funded program, such as a DADHC funded community access program or an Australian Government funded employment service.

### **Aboriginal Community Involvement**

Similar to DADHC policy, the Mainstream NGO showed strong emphasis in involving Aboriginal people in the agency's decision making process. The Mainstream NGO held consultative meetings with local Aboriginal community members in a NSW metro region. Some agency Board members attended the meetings to ascertain how the Mainstream NGO executives and management could improve the rates of access and equity for Aboriginal families to disability services (Mainstream NGO Manager, 2009a, 2009b).

Under the 2007-2010 Strategic Plan, the Mainstream NGO developed a Working Party specifically to coordinate initiatives regarding Aboriginal service delivery under Goal One. The Working Party consisted of senior management and staff. The Working Party's objectives were (Mainstream NGO Greater Participation by Aboriginal Communities Working Party, 2007):

1. Drive the strategies
2. Identify opportunities for promotion of strategies with management and teams
3. Develop self-paced e-learning module and resources to assist The Mainstream NGO's teams with developing partnerships
4. Identify ways to enhance existing internal training modules to be complimentary to training provided by local Aboriginal community/services
5. Develop mechanisms for sharing research and resources.

Reflecting the theme of the government literature analysed, the Mainstream NGO Working Party reportedly made significant changes to meet their government funding agreements. Firstly, changes were made to data collection methodology and community profiling. The Mainstream NGO and a university forged a partnership to support 1<sup>st</sup> year medical students in gaining experience and skills in working with rural and remote communities. In 2009, the students

undertook an analysis on the number of Aboriginal people accessing the Mainstream NGO services and the prevalence of disability in a rural region of NSW (Mainstream NGO manager, 2008). Secondly, the Mainstream NGO undertook a consumer satisfaction survey of all its Aboriginal clientele. The purpose of the survey was to evaluate the quality of the services for all Mainstream NGO clients. The Chief Executive Officer reported in September 2008 that “although clients who are of Aboriginal or Torres Strait Islander background reported similar overall satisfaction to other clients, they demonstrated significantly lower satisfaction with aspects of services relating to frequency and usefulness of communication with staff, location of services and help with connecting to other families and carers” (Chief Executive Officer, 2008, p. 1).

The Working Party minutes, annual reports, media releases during this period conveyed that the Mainstream NGO has made ad hoc attempts to forge relationships with some local Aboriginal communities. In 2008 the Mainstream NGO and a local Aboriginal Medical Service signed an agreement engaging the Mainstream NGO to provide screening clinics for Aboriginal clients (Mainstream NGO, 2008b). In 2009, the Mainstream NGO teams around NSW organised, and participated in, events during National Aboriginal and Islander Day of Celebration (NAIDOC). Aboriginal communities were invited to official Mainstream NGO events, such as the opening of a new rural office in 2008. (Mainstream NGO Greater Participation By Aboriginal Communities Working Party, 2008a, 2008b, 2008c, 2008d, 2008e; Mainstream NGO, 2009b).

Comparatively, all Aboriginal NGO employees were required to be engaged in local Aboriginal community events and initiatives. For example, the Aboriginal NGO (2007) staff were required to “promote Aboriginal NGO in the Aboriginal community, the general community and to government departments”, such as joining Aboriginal community forums, committees, and other community groups, whether or not it was disability related. Furthermore, employees “may from time to time be required to undertake additional work on special community projects eg NAIDOC and Aboriginal NGO promotions” (Aboriginal NGO, 2006). There was no known evidence that the Mainstream NGO employees were required to engage with the local Aboriginal communities.

## Conclusions

Similar to the governments, the Mainstream NGO responded to the service participation of Aboriginal people as a specialised field under the banner of affirmative action. Aboriginal people with a disability were objectified and monitored as an object of statistics under government funding agreements. However, unlike the governments the Mainstream NGO did not compartmentalise Aboriginal people with a disability as a specialised field. Rather, Aboriginal people were merged with CALD under 'diversity' at a policy level.

In some cases, at an executive (macro) level, the Mainstream NGO was reactive to the government policies, political actions and accountability requirements. The Mainstream NGO demonstrated no affirmative action at a planning level in the 1980s and 1990s as government pressure was almost absent. The Mainstream NGO developed their first Aboriginal access and equity policy in response to the NSW Government's Transition Planning and Funding Process Self Assessment in 1997. Although this policy was developed, the Mainstream NGO did not effectively implement many initiatives to address the needs of Aboriginal people with a disability. Furthermore, the policies were not mentioned in any of the strategic plans or annual reports during the 1990s or early 2000s.

Although the Mainstream NGO had a committee dedicated to addressing the participation rate of Aboriginal people in services, the focus was primarily on meeting their commitments under government policies and funding agreements. In saying this, the Mainstream NGO demonstrated affirmative action at a regional (micro) level from 1990. In a non-metro region, the Mainstream NGO represented and treated the population of Aboriginal people with a disability as a specialised field. An Aboriginal person was recruited to specifically work with Aboriginal people with a disability and assist the Mainstream NGO to become culturally responsive for Aboriginal communities.

In terms of Aboriginal community involvement, all of the Aboriginal NGO employees were required to engage with the local Aboriginal communities as part of their employment roles and responsibilities. Aboriginal community engagement was not restricted to disability affairs. In contrast, no evidence suggests that the Mainstream NGO employees were required to engage in local Aboriginal communities. However, the Mainstream NGO demonstrated attempts in involving

Aboriginal people in the agency's decision making process in some metropolitan regions of NSW.

Despite the challenge in obtaining a large number of documents from the Aboriginal NGO, some comparisons between the Aboriginal NGO and the Mainstream NGO were made. The Aboriginal NGO had a much broader definition of disability than the Mainstream NGO. The Mainstream NGO's service eligibility was prescribed by funding bodies. The Aboriginal NGO adopted the DDA definition of disability in how it impacted on a person's problem areas. The Aboriginal NGO did not have a definition of Aboriginality in any documents that was read for this study. However, all employees were required to demonstrate documented evidence of their Aboriginality in job applications.

A different approach is needed for research regarding the participation of Aboriginal people in disability services. The first section of this thesis report has identified the evolution of many access and equity barriers for Aboriginal people to disability services. This study has also alluded to how some government funded research has contributed to these barriers. The governments and NGOs are struggling to address the needs of Aboriginal people with a disability in disability services because they have taken the same approach over the last few decades.

The next chapter proposes a Conceptual Framework that undertakes a different approach to the participation of Aboriginal people in disability services which may help empower Aboriginal people in disability studies and policy development.

## **Chapter Six: Conceptual Framework for Policy and Research Development with Indigenous People with a Disability**

*They came, They saw, They named, They claimed* (Tuhiwai-Smith, 1999, p. 1).

This chapter proposes a Conceptual Framework, informed from the data of Chapters Four and Five, to assist disability researchers and policy analysts working with Aboriginal people with a disability. Thus far, this study has found that there was no known culturally appropriate conceptual framework for research and policy development involving Aboriginal people with a disability. The previous chapters have shown that the governments and disability service providers have not successfully addressed the service participation needs of Aboriginal people by treating and responding to the issue as a *specialised field*. A Conceptual Framework is therefore needed for research regarding and involving Aboriginal people with a disability in NSW.

The proposed Conceptual Framework brings together the strengths of both the International Classification of Functioning, Disability and Health (ICF) and Indigenous Standpoint Theory (IST). This framework provides six criteria that bridge the cultural interface between Aboriginal and non-Aboriginal communities, whilst helping to emancipate Aboriginal people with a disability in the research and policy development process in Australian disability and Aboriginal affairs.

This chapter introduces the debates and challenges in defining disability. The “individual approach” and the “social approach” are the two most debated approaches in disability studies (Shakespeare, 2002). The challenges in obtaining an ‘Aboriginal’ definition of disability are discussed. This chapter then introduces the World Health Organisation’s (WHO) versions of an international classification system for defining disability. In 2001, WHO developed the ICF, which merged the individual approaches and social approaches to disability.

This chapter then shows how Western researchers appropriated and commodified and distributed knowledge about the ‘cultural Other’, thereby normalising and sustaining the Western colonial enterprise in disability studies and policy development (Denzin & Lincoln, 2008; Moreton-Robinson, 1998). IST is then introduced and discussed. Various versions of IST that aim to decolonise the

production of knowledge are then discussed. Indigenous scholars from around the world have proposed many variations of IST as decolonising frameworks for research involving Indigenous people. Many global Indigenous scholars have proposed a range of ISTs relating to the Australian Aboriginal experience (Nakata, 2004; Tuhwai-Smith, 1999; Moreton-Robinson, 2004). IST has only recently been explored in disability studies (Gilroy, 2009, 2010b). The chapter then proposes a Conceptual Framework that merges the strengths of IST and the ICF for the purposes of disability research and policy development.

### **Individual and Social Approaches to the Characterisation of Disability**

Two main interwoven approaches to the characterisation of disability have been debated in the international disability studies field: the “individual approach” and the “social approach” (Fitzsimons, 2009; Oliver, 1996; Shakespeare, 2006). When the locus of disability is identified as residing within an individual, the medical condition is the focus of intervention, either for prevention or to ameliorate functional incapacity. When disability is identified as being a consequence of environmental and social organisational factors, the disabling aspects of social structures, organisations, social policy and environments are the focus of scrutiny. Details and implications of each of these approaches to disability are discussed beginning with the more dominant and longstanding individual approach.

#### **Individual approach to the characterisation of disability**

The individual approach to the characterisation of disability encompasses three main approaches: medicalisation, charity/philanthropic and administration (Fitzsimons, 2009; Shakespeare, 2006). Disability is interpreted as a problem arising from poor health, sickness or mental/physical impairment of the individual. There is limited, if any, acknowledgement of the role that society plays in creating and maintaining ideological, systemic and physical barriers that cause or exacerbate disability. Oliver (1996) stated that individualised approaches to disability benefit professionals, policy makers and staff from organisations for disabled people because they have vested interests in maintaining the status quo underpinned by the individual model.

**The medicalisation of disability.** The medicalisation of disability, also known as the medical model of disability, perceives disability as a direct consequence of disease, personal/physical defect or a health condition (Fitzsimons, 2009; Shakespeare, 2006). The medical understanding of disability reduces interventions to focus on the ‘disease’ or ‘abnormalities’ of the body, as opposed to any social interventions. Imrie (2004) stated that this approach stems from the health profession and “reflects its interest in the impaired, or functionally limited, body as an object of scientific interest, classification and medical intervention” (p. 289).

The management of ‘disability’ in this light is aimed at ailing medical and health conditions and adjusting perceived ‘abnormal’ behaviours. Barnes (1998) stated that the conceptualisation of disability as non-normative was first identified by American sociologist Talcott Parsons in his works on sickness-related behaviour. Parsons (cited in Barnes, 1998) argued that the health system in a Western capitalist society has socially sanctioned a ‘normal’ state of being as ‘good health’. People with ‘bad health’ and ‘impairments’ (physical/intellectual/cognitive) or ‘disabilities’ deviate from this socially constructed ‘norm’ and are then deemed to be non-productive members of society.

Medical and psychological sciences (Colmar, Maxwell & Miller, 2006) focus on the experience of illnesses, whether chronic or acute, and the consequences associated with those illnesses to the economy. This approach encourages the study of how chronic and acute conditions affect bodily functions, and the implications perceived abnormalities may have on the person’s independence and engagement in the community. Deviance resides within the individual and can be identified and explained through analysis of psychological and/or physical characteristics of the person (Shakespeare, 2006).

**The philanthropic response to disability.** The philanthropic model, also known as the ‘charity model’, is promoted and promulgated by non-government charity organisations, such as those funded by the NSW Government under the Multilateral Agreement, treating and portraying people with a disability as vulnerable people in need of institutional ‘protection’ and

‘support’. Lyons (2001) noted that there has been a significant increase in the number of aged and disability organisations since World War Two, partly in response to an increase in government resourcing.

Shakespeare (2006) wrote that people with a disability are not opposed to non-government not-for-profit disability services; however, they are opposed to people with a disability being represented as hapless and helpless people. These institutions often portray negative images of people with a disability as a means to increase financial and human resources. People with a disability are depicted as passive recipients of charitable and tax-payer funded community services that cure or manage disability (French, 1994; Shakespeare, 2006). A good example is the “CareCareers campaign”, a NSW community care workforce campaign managed by National Disability Services (NDS) (2011a) between 2009 and ongoing through 2012. The name CareCareers was chosen to make the workforce more attractive for people who wish to undertake ‘care work’. NDS developed a website ([www.carecareers.com.au](http://www.carecareers.com.au)) and television advertisements that displayed images of happy support workers looking after dependent, needy and grateful elderly people and young people with a disability. There were also images of Aboriginal people with a disability and workers holding hands.

**Administrative response to disability.** The administrative approach to disability is interrelated with the previous two approaches. Titchkosky (2010) reminded us that the administration of the disability services system is “framed, occupied and controlled by Western bureaucratic practice and, as such, the inclusion and exclusion of disability is also framed, occupied and controlled by bureaucratic practice” (p. 1). Administrative models of disability are rigid processes embedded in government legislation, such as the *Commonwealth Disability Services Act 1986* (DSA), and policies and government funding agreements. Government processes usually relate specifically to assessment and eligibility criteria for individual ‘service systems’, such as Disability Day Programs or Supported Accommodation. These criteria are usually designed to ‘include’ and ‘exclude’ people based on medically diagnosed impairments, including intellectual disability even though 50% of individuals with this diagnosis are designated as such with no

medical diagnosis (Colmar *et al*, 2006), as opposed to the physical and social environments in which people live (French, 1994; Titchkosky, 2010).

People often perceive disability organisations as monolithic bureaucracies that envelop and isolate them into predefined categories of ‘disability’, ‘place’ and ‘time’. Some disability services funded under the Multilateral Agreement tend to restrict ‘service’ and ‘support’ to people with severe to profound disabilities. Eligibility for some services is determined on a clinical diagnosis of disability (Productivity Commission, 2011). For some disability types, the diagnostic process can take months or even years to be completed; for example, to have access to services designated for people with autism spectrum disorder or cognitive impairments. Medical specialists, other professionals and caregivers are required to focus on the person’s deficits, rather than the person’s strengths. It is common for parents to visit a number of specialists to get the diagnosis they need in order for their child to be able to access disability services and support. As such, administrative and bureaucratic processes are often disabling in themselves and people are labelled as ‘disabled’ at a young age in order to access intervention funding (Davis & Watson, 2006; Productivity Commission, 2011; Titchkosky, 2010).

### **Social approach to characterisation of disability**

The social approach to the characterisation of disability views society as disabling the individual. This approach is in contrast to the view that the cause of disability resides in the individual. The social approach accepts that disability is not an attribute of an individual but a complex interaction between environmental, social and hegemonic ideologies within society (Shakespeare, 2006). Of relevance here is the term ‘disabling society’ to describe environmental and ideological barriers within society that create, or exacerbate, barriers for people. In considering the effects of the disabling society, Reeve (2006) suggested that as society becomes more complex, as a result of increasing reliance on technology and growing urbanisation, the prevalence of disability will increase. Hence, the ‘management’ of disability requires collective social action to prevent and to overcome societal barriers.

Oliver (1996) stated that “from the 1950s onwards ... there was a growing realisation that if particular social problems were to be resolved or at least

ameliorated, then nothing more or less than a fundamental redefinition of the problem was necessary” (p. 3). Contrary to the characterisation of disability as residing within an individual, the social approach is focused on overcoming barriers to social inclusion and ensuring equal rights and full citizenship, rather than having a focus on curing the pathology or to medically ‘treat’ the disability. Early criticisms of the social model of disability identified that it neglects the embodiment of the experience of disability and the individual nature of that experience including the interactions between gender, class and culture in the experience of disability (Shakespeare, 2002, 2006).

The social approach underpinned the global disability rights movement during the last half of the 20<sup>th</sup> century (Shakespeare, 2006). From the 1980s, many disability rights organisations were established specifically to campaign for the rights of people with a disability to be socially included in all aspects of Australian culture. For example, in 2011 People with Disabilities Australia (2012) defined their vision on their website as “... a socially just, accessible and inclusive community, in which the human rights, citizenship, contribution, potential and diversity of all people with disability are respected and celebrated”.

People with a disability, their advocates and allies acknowledge that the population of people with a disability, just like the population of Aboriginal people, are a culturally diverse group with widely different beliefs and experiences associated with disability. A variety of grass roots initiatives have developed in order to identify and respond to the diversity of experience associated with disability. For example, in 1992 the Multicultural Disability Advocacy Association (2011) was formed to advocate specifically for people with disability from non-English speaking countries, their families and carers. In 2003 advocates for Aboriginal people with a disability (such as Uncle Lester Bostock, Ros Sackley, Damien Griffis and John Gilroy) worked to establish and promote the NSW ADN to bring together Indigenous people with a disability to create a voice for change (ADN, 2007, 2011, 2012).

### **Aboriginal Communities’ Approach to Disability**

Connell’s (2007) and Moreton-Robinson’s (2004) description of the Western sciences as the instrument of Western Imperialism helps explain why the disability studies field has struggled to establish a conceptual framework for disability

studies involving Aboriginal communities. Furthermore, this description helps explain why the government and the Mainstream NGO struggled to address the service participation rates of Aboriginal people discussed in Chapters Four and Five of this study. Connell (2007) and Moreton-Robinson (2004) suggested that Aboriginal people were continually viewed as the 'known' or the 'objects' of the Western sciences as opposed to the 'knowers' or 'actors' in the field. There are volumes of knowledge, a whole epistemological library in fact, on Indigenous people with a disability. This knowledge is not owned by Aboriginal people, rather this library operates as a resource for non- Aboriginal researchers and government decision makers to legitimate themselves as the controllers and bearers of the 'truth' on disability (Moreton-Robinson, 2004). Moreton-Robinson's (2004) theory of Whiteness demonstrated how non- Aboriginal researchers have racialised and subjugated global Indigenous knowledge production by describing themselves as the producers of knowledge (Moreton-Robinson, 2004):

...it is academics who represent themselves as 'knowers' whose work and training is to 'know'. They have produced knowledge about indigenous people but their way of knowing is never thought of by white people as being racialised despite whiteness being exercised epistemologically. Whiteness established the limits of what can be known about the other through itself, disappearing beyond or behind the limits of this knowledge it creates in the other others name. (p. 75)

Similarly, Connell's (2007) review of the evolution of the social sciences found that much of the written history on the social sciences was imagined. Much of the university sociology teaching textbooks posit the birth of the social sciences as commencing in the late 1800s, focusing on modernity and industrialisation. However, the majority of social science publications in the early history of the social sciences focused on ancient and medieval societies, colonial or remote communities, cultural sub-groups in Asia and Indigenous communities of colonised lands (including Australia). Similar to Whiteness theory, Connell (2007) found that the social science field was born from the desire to define the superiority of the West. Connell (2007) defines this spectrum of the social sciences as:

... the enormous spectrum of human history that the sociologists took as their domain was organised by a central idea: difference between the civilisation of the metropole and other cultures whose main feature was their primitiveness. I will call this the idea of global difference. Presented in many different forms, this contrast pervades the sociology of the late nineteenth and early twentieth centuries. (p. 15)

Analysis from the very genesis of social sciences was focused on the concept of *us* (Europe/Metropole/Healthy/Normative) *and them* (non-European/Indigenous/Sick/ Disabled/ Non-normative/Other). From the early 1900s, disability researchers defined and inscribed 'Indiginity' on what they perceived as 'real' Aboriginal culture. During the early 1900s, disability researchers focused on measuring the 'progress' of Aboriginal people's assimilation into European society. Researchers described and measured Indiginity on the basis of perceived 'traditional' and 'non-traditional' cultural beliefs and practices. For example, Bostock's (1924) and Cleland's (1928) studies on Aboriginal people's psychiatric hospital admissions in the 1920s focused on differences between 'traditional' and 'non-traditional' Aboriginal people. Aboriginal people who were admitted as a result of 'cursory' or 'witchery', such as being abducted by an evil spirit, 'sung to death' or had the 'bone pointed' at them, were labelled 'traditional'. Aboriginal people who were admitted as a result of acquiring psychosis from perceived 'non-traditional' cultural practices were labelled as 'non-traditional' people who were transitioning into European society.

The terms 'disability' and 'handicap' were imposed on Aboriginal communities by the various colonial spectrums of Western science. For over a century, medical and social scientists have attempted to develop or uncover an 'Aboriginal' definition of 'disability'. A historical review of anthropological and ethnographical material has shown that many Aboriginal communities had traditional words for some 'impairments', such as sensory and physical impairments. Gilroy (2010a) found that the earliest recording of the definition of 'impairments' in Aboriginal communities was in the last decade of the 1800s by Edward Curr during a study called the Great Australian Race. Curr collated literature on languages, including sign language (also known as gesture language), and cultural practices of Indigenous communities throughout Australia. A search of the final report found no compound noun that groups together multiple handicaps equivalent to the concept

of 'disability'. Rather there were multiple words and concepts for specific 'impairments'. For example, Curr found twelve different phrases relating to deafness, ten for blindness, four relating to insanity and three for being unable to speak using oral language. Aboriginal communities in close proximity to each other, such as Tasmania, had different dialects and terminologies relating to different and specific impairments (Gilroy, 2010a).

Aboriginal disability rights advocates and stakeholders point out that every Aboriginal community has a different understanding and interpretation of disability. As discussed in Chapter Two, Government and mainstream disability service agencies have reported that the concept of disability is relatively new to many Aboriginal communities and is conceptualised differently between and among Aboriginal and non-Aboriginal societies. Bostock (2004), president of the First Nation Peoples Disability Network, said that "there is no special category in Koori thinking for physical and intellectual disability" (p. 6). Gething (1994b) found that many Aboriginal communities in remote New South Wales do not differentiate between age related illnesses and disabilities. Reid (1985) examined the status of older people and Elders in Yirrkala and found that Aboriginal people did not classify older people who happen to have an impairment as having a 'disability'. Older people, and particularly Elders, were included in all aspects of community life. Reid (1985) reported that "difference between the fortunes of individual elders largely reflect their personalities and their differential location in the economic, political and social structures" (p. 92).

In more recent research, many Aboriginal people interpreted the consequences of European colonisation as disabling. Meekosha (2011) stated that "we cannot meaningfully separate the racialised subaltern from the disabled subaltern in the process of colonisation" (p. 673). Moreover, the consequences of the wars, dispossession, genocide and cultural destruction produce 'disabled' people. Many Aboriginal people see trauma and loss of their cultural lands and sacred sites as disabling. Disability is also seen to arise as a result of a lack of Western education, such as the inability to read or do arithmetic, and the difficulty in getting past the barriers of discrimination to access government and non-government managed services (Gilroy, 2009; Meekosha, 2011). An Aboriginal community health worker was reported stating that "just being black is a disability: no education, no jobs, kids don't think they can do anything" (Gething, 1994b, p. 81).

Labelling and categorising individuals by their perceived abilities within the disability studies field was considered offensive in many Aboriginal communities. As a consequence of past government policies, such as the Stolen Generation discussed in sections One and Two, many Aboriginal people perceived categorisation on the basis of perceived abilities as another attempt to erode their social solidarity. Ariotti's (1997) study of the Anangu perception of disability found that discussing a person's physical impairments brought shame and embarrassment to them and their family. Similarly, a Department of Health, Housing and Community Services study on the frail aged found that there was a social stigma associated with being labelled as 'handicapped'. The experience of age related physical impairments is commonly accepted as just part of life. Family roles often function as a barrier for the provision of disability services because offering help and assistance to Indigenous people with disabilities can be misinterpreted as an embarrassment and an insult to the competencies of their family (Gilroy, 2009).

Despite the efforts of numerous researchers (Bostock, 1924; Cleland, 1928; Gething, 1994a; Productivity Commission, 2011), an Aboriginal definition of disability that captures the diversity of cultures and experiences of colonisation amongst the Aboriginal population cannot be developed. As a result, Australian governments, disability service providers and Aboriginal communities continue to struggle to establish a shared understanding of disability (Gilroy, 2009, 2010a) and improve the service participation rate of Aboriginal people (NDS, 2010; Productivity Commission, 2011). In developing a Conceptual Framework for research and policy development regarding Aboriginal people with a disability, each Aboriginal community must be understood in the context of their experience of colonisation, disadvantage and cultural heritage.

### **World Health Organisation and the International Classification of Functioning, Disability and Health**

In 1980, in response to the growing global Disability Rights Movement, WHO developed its first conceptual framework on disability, the *International Classification of Impairments, Disabilities and Handicaps* (ICIDH). The ICIDH was originally intended to describe the effects of rehabilitation of chronic health conditions and physical impairments by merging the individual and social approaches to disability. WHO felt that the ICIDH provided an international

conceptual framework for the study and classification of disability. The ICDH was often described as taxonomy of handicap and impairment. Researchers adopted the ICDH to quantify the prevalence of disability in a given population. The ICDH described three dimensions – Impairment, Disability and Handicap (Senior, 2000; WHO, 2001):

1. **Impairment:** In the context of health experience, an impairment is any loss or abnormality of psychological, physiological or anatomical structure or function.
2. **Disability:** In the context of health experience a disability is any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being.
3. **Handicap:** In the context of health experience a handicap is a disadvantage for a given individual, resulting from an impairment or a disability, that limits or prevents the fulfilment of a role that is normal (depending on age, sex, and social and cultural factors) for that individual.

There was much criticism of the ICDH by people with a disability, advocates and disability studies scholars. Their concern was that the ICDH emphasised an individualised characterisation of disability (mostly influenced by medical and administrative responses to disability) and did not adequately capture the impact of structural factors, the social environment and the subjective cultural experiences of people with a disability themselves. The ICDH was seen as being primarily a tool for government and non-government bureaucracies to globally ‘manage’ the ‘disability problem’; therefore serving the vested interests of existing social structures, government funded service organisations and professionals and stakeholders (Hurst, 2000; Imrie, 2004; Pfeiffer, 2000; Shakespeare, 2006; Titchkosky, 2010). There was no acknowledgment that diversity – culture, Indigeneity, sexuality or gender –formed part of an individual’s experiences of disability. Hurst (2000) commented that the weakness of the ICDH in capturing the social factors of disability was a consequence of WHO not including members of the Disability Rights Movement in the planning and development of the ICDH.

During the 1990s, AIHW established one of a number of international collaborating centres to work with WHO to revise the ICDH, with specific focus on the participation and environmental impacts of disability. During the 1990s, two

revised drafts of the ICDH were released for testing and public comment. The second draft, named ICDH-2, had three dimensions (AIHW, 2002; Senior, 2000):

1. **Body functions and structure and Impairments:** body functions are the physiological or psychological functions of body systems. Body structures are anatomical parts of the body such as organs, limbs and their components. Impairments are problems in body function or structure as a significant deviation or loss.
2. **Activity:** is the performance of a task or action by an individual. Activity limitations are difficulties an individual may have in the performance of activities.
3. **Participation:** is an individual's involvement in life situations in relation to health conditions, body functions and structure, activities and contextual factors. Participation restrictions are problems an individual may have in the manner or extent of involvement in life situations.

In addition to these dimensions, the ICDH-2 included an annex on environmental factors and personal factors (known as contextual factors) that interact with the above three factors. AIHW (Madden & Hogan, 1997) described contextual factors as “the features, aspects and attributes of, or objects, structure, human-made organisations, service provision, and agencies in, the physical, social and attitudinal environment in which people live and conduct their lives” (p. 22). The most significant changes in the ICDH-2 was the renaming of ‘handicap’ to ‘participation’ as the third dimension and the term disability to activity, acknowledging that participation in activities of daily living was influenced by the range of individual choices and opportunities available within a social environment (Madden & Hogan, 1997).

In 1999, AIHW tested the applicability of the ICDH-2 in two Indigenous communities in the top end of the Northern Territory (NT). AIHW (2002) described the aim of the test:

This project will examine relevance of the concepts of disability to Indigenous people, using the ICDH-2 as the possible framework. The addition of the Contextual Factors annexe to the ICDH-2 may be particularly significant to understanding disability in these communities, given the importance of environmental and cultural factors among them. (p. 2)

AIHW found that the ICIDH-2 had benefits and limitations in these Aboriginal communities. The ICIDH-2 proved to be a practical tool to quantify the prevalence of functional limitations associated with health and disease in these communities. As such, AIHW reported that the ICIDH-2 would be useful for the planning and administration of health and disability services in Aboriginal communities (Senior, 2000).

The challenge, however, was that cultural differences between the Aboriginal communities and the non-Aboriginal researchers posed a significant problem in applying the contextual factors of the ICIDH-2. Although AIHW acknowledged a need to ensure the ICIDH-2 was applicable in Indigenous communities, cultural diversity in the Aboriginal population and colonisation was either not considered or acknowledged. Furthermore, AIHW did not acknowledge the impact of colonisation on the conceptualisation and experience of disability in Aboriginal communities. Reflecting the points made earlier in this chapter, some Aboriginal people who participated in the test perceived the term disability as a stigmatising label that was being imposed on them by outsiders. Some Aboriginal people reported that as long as family members provided support for them to participate in the community then they did not have a disability. The final report concluded that (Senior, 2000):

...one of the major problems with the use of the ICIDH to produce a meaningful classification, would be lack of knowledge about the community. .... One of the greatest hurdles that any classification has to face is the apparent apathy towards health and health-related activities that have been encountered in the two communities. This is due to different values that are placed on health and physical functioning. (p. 25)

As a consequence, the “application of the ICIDH-2, without a thorough knowledge of the community has the potential to produce misleading results” (Senior, 2000, p. 22). The values associated with disability in these two Aboriginal communities were different to those understood by the non-Aboriginal researcher. This demonstrates that the ICIDH-2 would only be a practical tool to understand Indigenous people’s experience of disability if it was used by Aboriginal people.

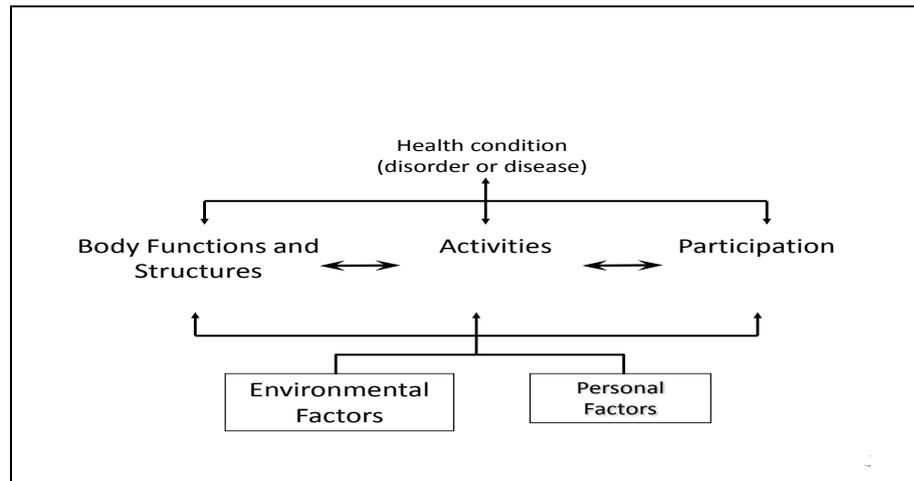
There were no known tests done in any Aboriginal community in any other states or territories. It can only be assumed that AIHW generalised the test findings for all Indigenous communities. The development of the ICF, similar to the

findings of Section Two of this study, categorised Aboriginal communities as the 'cultural Other'. AIHW's approach to Aboriginal communities reflects Hurst's (2000) description of the ICIDH-2 as "very white and industrialised-country centred" (p. 1086), because its development was primarily informed by non-Indigenous government representatives, the Western sciences and scholarship and Western disability rights advocates.

WHO (2001) endorsed the broad elements of the ICIDH-2 in 2001, renaming it as the *International Classification of Functioning, Disability and Health* (ICF). Similar to the ICIDH, the ICF is used to quantify the prevalence of disability. However, contrary to the ICIDH, the ICF is used as a tool to help capture the 'experience' of disability in a given population. As discussed in Chapter Two, the ICF recognises disability as a multi-dimensional experience by merging the social and individual approaches of disability relating to:

1. The body functions and structures
2. The activities people do and the life areas in which they participate
3. The factors in their environment which affect these experiences

Each of these components is defined in the context of a health condition. Unlike the ICIDH-2, the ICF does not describe a handicap. The ICF conceptualises functioning as the interactions between any or all of "an impairment of body, structure or function, a limitation in activities, or a restriction in participation" as graphically represented in Figure 9 (WHO, 2001).



*Figure 9* - Interactions between the factors that make the World Health Organisation International Classification of Functioning, Disability and Health (WHO, 2001)

A person's disability is conceived as an interaction between contextual factors (that is the *environmental* and *personal factors*) and health and functioning. *Environmental factors* refer to the physical, social and attitudinal environments where an individual lives and conducts their lives. Environmental factors have an external impact on the person's level of functioning. This includes discrimination, architectural design of the built environment and the community service system. *Personal factors*, on the other hand, refer to the actual lived experience of limitations. These factors include gender, sexuality, Indigeneity, fitness or lifestyle, and historical experiences. In addition, personal factors also include socioeconomic status and experiences relating to remoteness and high-risk behaviours, such as drug and alcohol abuse and domestic violence (AIHW, 2003b, 2004b; WHO, 2001).

Functioning has two parts: body function/structure and participation. *Activity* is measured on individual functional capacity whilst participation is measured in terms of performance in the individual's usual or current *environment*. A person's *health condition* can influence the quality of their *body functions* (such as mental health) and *structures* (organs and limbs) and how they *participate* in *activities* (the execution of a task) in their natural *environment*. An individual's personal factors can influence their level of performance in activities of daily living. The performance can thus be seen as a description of an outcome of disability (AIHW, 2003b, 2004b; WHO, 2001).

The ICF is often described as a “bio-psycho-social” approach to disability because “it takes its central tenet the individual’s experience with illness or disability” (Hubber, Sillick, & Skarakid-Doyal, 2010, p. 1955). A major advantage of the ICF is that it integrates information about an individual’s disability by both considering factors inside the person related to a health condition, and also social and environmental factors experienced by the individual in society. It is based on human functioning from the perspective of personal experience. It also acknowledges that although these interactions are specific, they are not always predictable on a one-to-one relationship (AIHW, 2003b, 2004b). For example a person may have:

1. Impairments without having capacity limitations (a disfigurement from a car accident may have no effect on a personal capacity).
2. Have performance problems and capacity limitations without impairments (diseases or health conditions associated with drugs and alcohol)
3. Have performance limitations without impairments or capacity limitations (discrimination based on disease, gender or race).

The label of disability therefore is a description of the individual’s outcome as an individual within their community and not merely a consequence of their perceived functional and health limitations. Bornman (2004) captured the benefits of the ICF:

The ICF is also etiologically neutral, emphasizes parity, is culturally appropriate and covers the whole lifespan. It can thus be used by any individual with a health condition in that it describes the consequences of any such condition, ranging from someone with a minor impairment such as hay fever, through to someone with severe impairments, activity limitations and participation restrictions, e.g.. an individual with a dual sensory impairment. The more severe end of the spectrum covers the category of individuals traditionally referred to as ‘disabled’. (p. 186)

After the endorsement of the ICF, a number of committees were developed to help ensure global consistency in the application of the ICF in data collection, research and policy development. AIHW involved Aboriginal people with a disability, such as sitting on committees, to ensure its cross-cultural applicability in Indigenous communities. A search of the publically available documents shows that to date there is limited involvement of Aboriginal people with a disability and their communities in the development and review of the ICF (AIHW, 2006a). The

ICF was focused on naming and claiming and is closely aligned with similar colonising enterprises based on the hegemony of Western science. The developers of the ICF assumed that the Aboriginal experience would fit in a preconceived purportedly 'universal' model. This was consistent with the conceptualisation of Aboriginal people as the 'cultural Other'. For example, the idea that participation and disability was culturally specific and community specific was not reflected in this model. This model also does not account for the disabling effects of colonisation.

### **Defining Indigenous Standpoint Theory**

Meekosha (2011) rightly claims that "disability studies differentiation between chronic illness, impairment and disability cannot usefully explain the contemporary lived experience of indigenous peoples" (p. 672). The disability and Aboriginal studies academics must challenge the imperial position of non-Indigenous researchers and research institutions. Meekosha (2011) suggested that Aboriginal peoples undertake a "process of intellectual decolonisation" (p. 672), which requires developing an Indigenous methodological framework.

IST offers an alternative to the practice of subjugating Indigenous people as the *cultural other* in studies regarding Indigenous people. Nakata (2007) described IST as a distinct form of analysis where the Aboriginal researcher's personal experiences elevates attention to aspects of the research enquiry that might not have been uncovered. IST is not about defining 'traditional' from 'non-traditional' knowledge and operations of knowledge production. "Knowledge to Indigenous people is not something primitive ... rather it is continuous, evolving and adapting to change" (Foley, 2006, p. 27). IST "is a process and ontology, an epistemological approach to learning within research applications that enables the Indigenous person to maintain/regain or learn their own epistemological standpoint that has been lost due to colonisation and the adoption of ethnocentric Western forms of approaches to knowledge" (Foley, 2006, p. 29).

IST has evolved into a global community of Indigenous scholars, who include Foley (2003), Huggins (1993), Langton (1993, 2001, 2003), Moreton-Robinson (1998, 2000, 2004, 2008), Brady (1992), Rigney (1999), West (1987) and Tuhiwai-Smith (1999). These Indigenous scholars saw it as their duty as Indigenous people to take control of a global cultural space relating to Indigenous politics. The

objective was to change the mindset of both non-Indigenous people and Indigenous people in defining Indigenous people as both the producers and participants in the production of knowledge. This entailed opening up dialogue between Indigenous and non-Indigenous researchers and stakeholders by exchanging skills and knowledge in conceptualising research epistemologies that were culturally appropriate for Indigenous people.

IST is not an Indigenous way of doing research. IST is a philosophical position situated in the Indigenous person's ancestry, "which informs the methodology in a science that is possibly tens of thousands of years old" (Foley, 2006, pp. 29-30). IST includes emancipatory principles developed by Aboriginal people in response to their involvement and experience in the struggle for Aboriginal self-determination and autonomy. For example, Moreton-Robinson (2000, p. xvi) suggested an IST for feminist studies as influenced by how an Indigenous woman experiences the following:

1. Sharing an inalienable land
2. Sharing a legacy of dispossession, racism and sexism
3. Resisting and replacing disparaging images of ourselves with self-defined images
4. Continuing our activism as mothers, sisters, aunts, daughters, grandmothers and community leaders
5. Negotiating sexual politics across and within cultures

Thus, in this case, an Aboriginal woman's standpoint is shaped by how and where they were socialised as an Indigenous woman. Similarly, Tuhiwai-Smith (1999, p. 185) defined Kaupapa Maori research as influenced by how Maori people have experienced colonisation and dispossession:

1. Is related to 'being Maori'
2. Is connected to Maori philosophy and principles
3. Takes for granted the validity and legitimacy of Maori, the importance of Maori language and culture
4. Is concerned with the struggle for autonomy over our own cultural well-being.

Nakata (1997, 2007) took a different approach to research based on his experiences as a Torres Strait Islander person. Nakata provided three principles for a standpoint theory. The first principle is "that Indigenous people are entangled in a very contested knowledge space at the cultural interface" (Nakata, 2007, p. 215). The cultural interface is the domain where the trajectories of two different histories, cultures, ideologies and practices intersect establishing conditions that

influence the ways Indigenous people, in both urban and rural regions, make sense of and participate within society. As Aboriginal and non-Aboriginal people are socialised within different cultural contexts, the cultural interface is a place of ideological contestation between Indigenous and non-Aboriginal societies. Non-Aboriginal researchers can have a level of understanding on 'Indigenous issues' and Indigenous cultures, but this understanding will always be limited and distorted as a result of the cultural interface. Non-Aboriginal people are not socialised into Indigenous culture and therefore can only understand it from an outsider's perspective (Nakata, 2004). "For in this space there are so many interwoven, competing and conflicting discourses that distinguishing traditional from non-traditional in the day-to-day is difficult to sustain even if one were in a state of permanent reflection" (Nakata, 2004, pp. 27-29).

The second principle is that the researcher acknowledges that Indigenous agency is framed within the cultural interface. Aboriginal people are expected to be both Aboriginal and non-Aboriginal at the same time. "This is experienced as a push-pull between Indigenous and non-Indigenous positions" (Nakata, 2007, p. 216). The third principle is to identify how the experiences of Aboriginal and non-Aboriginal people at the cultural interface has caused and maintains tensions between Indigenous and non-Indigenous people (Nakata, 2007, p. 216).

Indigenous academics Foley (2003) and Rigney (1999, 2007) have taken a political activist approach. Foley (2003) and Rigney (1999, 2007) suggested three fundamental principles for research regarding Aboriginal people. Firstly, the research must be counter-hegemonic to Western ideologies, strengthening and supporting the fight to alleviate the social conditions that debilitate the lives of Aboriginal people. As discussed above, Aboriginal people have been subjugated and oppressed by Western epistemology in Australia for nearly three centuries. Research on Aboriginal peoples must contribute to the fight for the Indigenous people's recognition and self-determination in the production of knowledge. Secondly, the research must privilege Aboriginal voices, which is fundamental to exposing the diverse experiences of Indigenous people with a disability as unique. This will ensure that the non-Indigenous population are aware of the concerns, arguments, aspirations and dreams of Aboriginal spokespeople (Foley, 2006; Rigney, 1999).

Finally, Foley (2003) and Rigney (1999) suggested that the research must be done by Indigenous researchers, which is fundamental to the fight against Western imperialism that is maintained by the Western sciences. IST has an emancipatory imperative in research regarding Aboriginal people.

Oates (2003) disagreed with Foley's (2003, 2006) and Rigney's (1999) suggestion that only Aboriginal people can do research on Indigenous affairs. Oates (2003) said that "the problem with this position is that insight and understanding are not dependent on the amount of melanin in the skin or whether the person can do a 'kangaroo dance' or 'Irish jig'" (p. 5). Oates (2003) has misinterpreted Foley in two ways. Firstly, Foley and Rigney did not define 'Indigeneity' on the basis of the darkness of a person's skin or cultural practices. Foley's and Rigney's principles did not forbid non-Aboriginal people from being involved in the research. Rather, their principles acknowledged that Aboriginal people have a level of experience and knowledge of colonisation and dispossession that a non-Indigenous person could not possibly acquire from birth. Similarly, Maori scholars encouraged non-Maori to be involved in Kaupapa Maori research. Tuhiwai-Smith (1999) stated the following in relation to Kaupapa Maori research':

One can ask, for example, 'can a Maori researcher who is anti-Maori carry out Kaupapa research?' The answer, based on current definitions, is 'definitely not'. Another question is less easy to answer: 'can a non-Indigenous researcher carry out Kaupapa Maori research'? The answer on current definitions is more complex. Perhaps it might read, 'a non-indigenous, non-Maori person can be involved in Kaupapa Maori research but not on their own, and if they were involved in such research, they would have ways of positioning themselves as a non-Indigenous person'. (p. 184)

Many Australian Aboriginal managed agencies, such as the National Health and Medical Research Council (NHMRC) (2003), suggested that excluding non-Indigenous people from working in Aboriginal affairs is counter-productive in achieving true practical reconciliation between Aboriginal and non-Aboriginal people. Non-Aboriginal researchers can adopt IST in their research regarding Aboriginal people only if Indigenous people were involved in the research process. Irwin (cited in Tuhiwai-Smith, 1999) and the NHMRC (2003) suggested that non-

Indigenous people can adopt a standpoint that empowers Aboriginal people if the researcher works with the local Elders, leaders and advocates whilst satisfying the rigor of research. For example, Nakata's theory of the cultural interface has been adopted by both Indigenous and non-Indigenous educators and government education facilities (Choy & Woodlock, 2007).

Although there are many models of IST in Indigenous scholarship, they all employed an emancipatory framework for research involving Indigenous people. The general objective that all these examples shared was that Indigenous researchers utilised their experiences and accounts as Indigenous people in the research process. As a result, IST breaks down the imperialist position of the Western sciences and contributes to the emancipation of Aboriginal people.

### **A Conceptual Framework for Research and Policy Development Regarding Aboriginal People with a Disability**

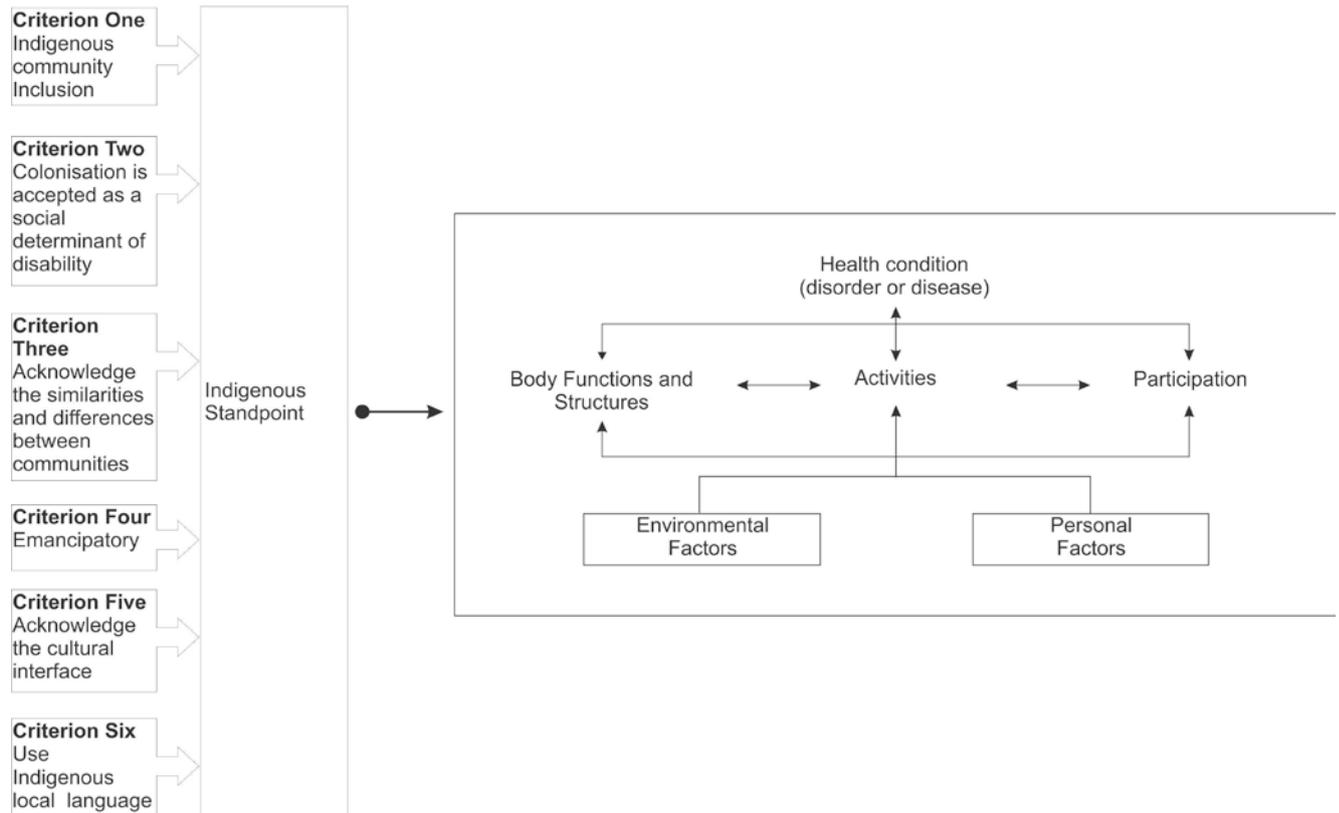
Supporting the political movement of Indigenous people with a disability requires a culturally responsible conceptual framework for research and policy development involving Indigenous people with a disability. The overall view from the literature is that the cultural diversity in the population of Aboriginal people means that there is diversity in the experiences of disability. There is also diversity in the experience of colonisation and the inequalities/equalities between Aboriginal communities and non-Indigenous communities at a local level. Therefore, a uniquely Aboriginal definition of disability cannot be reached.

The ICF is regarded as an accepted international conceptual framework that merged the individualised and social approaches to disability. The test of the ICF showed that a national model in conceptualising disability had its weaknesses and strengths in two Aboriginal communities. In order to address the identified flaws in the current widespread adoption and use of the ICF, there must be greater emphasis placed on the cultural and historical factors that contribute to the prevalence and experience of functioning and disability in Aboriginal communities.

As represented in Figure 10, it is proposed that an IST be established as a foundation for the examination of any of the ICF factors currently considered to influence human functioning. The six criteria displayed in the figure reflect the literature on the two approaches to disability and IST discussed earlier in this Chapter. The six criteria then create an IST for research and policy development

regarding Aboriginal people with a disability. The criteria are suggested as a starting point to help researchers and policy advisors develop a localised IST for working with Aboriginal communities that acknowledges the cultural diversity within the populations of Aboriginal people.

1. **Aboriginal community Inclusion:** The research team includes Aboriginal people with a disability and Aboriginal researchers/policy-advisors, bringing with them their own experiences as an Indigenous person. This ensures that the distribution of power and responsibility for the research are shared equally.
2. **Colonisation is accepted as a social determinant of disability:** The researchers must be well versed in how the factors of the ICF are influenced by European colonisation and the dispossession of Aboriginal communities' traditional lands and cultures. This knowledge is essential to comprehend the level of, and the impact of, colonisation and dispossession has on the prevalence and experience of disability for an Aboriginal person.
3. **Emancipatory:** The researchers are part of the struggle for Aboriginal communities' right to be self-determining.
4. **Acknowledge the cultural interface:** All participants involved in the project/research acknowledge that they operate in the cultural interface bringing with them their own knowledge and experience of disability and Aboriginality. The cultural interface is the realm where the trajectories of Aboriginal peoples' and non-Indigenous peoples' experiences of disability and Aboriginality intersect. These intersections are an essential element in understanding the complexity of factors prescribed in the ICF.
5. **Acknowledge the similarities and differences between communities:** The experience of functional limitation will be different for each Aboriginal community and between non-Aboriginal and Aboriginal communities in the same geographical region.
6. Wherever possible, use the **Aboriginal local language**.



*Figure 10 - Conceptual framework for research on disability with Indigenous communities merging Indigenous Standpoint Theory and the International Classification of Functioning, Disability and Health.*

Utilizing Indigenous standpoint with the ICF will ameliorate the current weaknesses of global contextual framework. An IST will increase the likelihood that the researchers or policy advisors (or team) will improve the quality of the outcomes in quantifying functional limitations in individuals with Aboriginal communities for Aboriginal communities. There is a more indepth discussion in Chapter Nine of this thesis.

## Conclusions

This chapter has proposed a Conceptual Framework that was developed from the literature reviewed in Section One and the data analysed in Section Two. There was no known available culturally appropriate framework for research and policy development regarding Aboriginal people with a disability. This section of the study has shown that non-Aboriginal researchers and policy advisers have continually disempowered Aboriginal people as the objects in knowledge

production in disability studies. Connell (2007) and Moreton-Robinson (2004) have shown how the social sciences has racialised, homogenized and subjugated Indigenous knowledge by instilling Western civilizations as the producers of knowledge. Researchers have attempted to define, prescribe and measure the prevalence and experience of 'handicap' and 'disability' in Indigenous communities within Eurocentric methodological frameworks. Similarly, Chapters Four and Five have shown that the governments and NGOs have treated Aboriginal people with a disability as objects in statistical data collections under the DSA and the Multilateral Agreement.

Section Two of this study has shown that researchers and policy developers have imposed the term 'disability' on Indigenous communities as part of Australia's colonization since the late 1800s. This finding helps explain why the government and the Mainstream NGO have struggled to address the low disability service participation rate of Aboriginal people.

Supporters of the ICF claim that WHO has improved on the ICIDH by more effectively merging the 'individual approach' and the 'social approach' to disability. Although the ICF acknowledges Indigeneity as part of the personal and environmental factors, in practice WHO and AIHW have homogenized Indigenous communities and subjugated Indigenous knowledge in formulating and testing the ICF. The ICF 'testing' in Indigenous communities was only done in two Indigenous communities in the Northern Territory. One objective of the development of the ICF in Australia was to fit the Indigenous experience within a predetermined purportedly global conceptual model for measuring individual functional limitation. The development of the ICF, together with other research on disability in Indigenous communities over the last century, categorized Indigenous people as the *cultural other*.

The Australian disability studies academy and Indigenous communities need to adopt an IST to break down the superiority of the disability studies academy in conceptualizing functional limitation in Indigenous communities. The above-mentioned criteria are suggested as a starting point to guide researchers and policy advisors to establish an IST in disability studies. Furthermore, an IST will help decolonise the disability studies and policy environment by equalising the power relationships between Aboriginal and non-Aboriginal people at a local level in the production of knowledge on Aboriginal people with a disability. With a

localised IST, research and policy advisors can then examine the interaction of factors identified in the ICF to more adequately reflect the prevalence and experience of disability. The Conceptual Framework was developed to help prevent disability researchers from contributing to the disempowerment of Aboriginal people with a disability.

The next section of this thesis aims to identify the factors that influence the service participation of Aboriginal people from the experiences of Aboriginal and non-Aboriginal disability services workers, consistent with the second objective of this study. Section Two has shown the evolution of the participation of Aboriginal people with a disability as a social problem for governments and NGOs, consistent with the first objective of this study. The following chapter outlines the methodology for data collection and analysis for the second objective of this study.

# Section Three: Learning from Disability Service's Workers

## **Chapter Seven: Learning From the Workers of Disability Service Providers**

Chapter Seven outlines the methodology which was employed to address the second objective of the study. This section of the research aimed to identify the factors that influence the service participation of Aboriginal people from the experiences of paid disability services workers in New South Wales (NSW). Underpinning this are questions which related to the individual experiences of non-Aboriginal and Aboriginal workers and managers of the Aboriginal NGO and the Mainstream NGO. What did disability service workers identify as the factors that influence the participation of Aboriginal people with a disability in disability services? What challenges and barriers did disability workers experience in working with families? Are there differences between Aboriginal workers and non-Aboriginal workers in the factors identified that influence the participation of Aboriginal people in disability services? This chapter outlines the methodology of the second section of this study.

The first objective of this study complements the second one. Chapters Four, Five and Six (Section Two) historically deconstructed how the government, the Mainstream NGO and the Aboriginal NGO identified and responded to the service participation of Aboriginal people in policy documents. The findings, reported in Chapters Four and Five, have shown how the service participation of Aboriginal people with a disability became identified and treated as a specialised field in the disability services system. In addition, the findings provided insight into how the disability services sector in NSW (both government and NGO agencies) has interacted with Aboriginal people with a disability. Chapter Six has proposed a Conceptual Framework regarding the participation of Aboriginal people in disability services informed by the data collected in Section Two.

This chapter explains the research design that was developed in order to achieve objective two of this enquiry. This is then followed by details of the data collection and analysis undertaken.

### **Research Design**

Nakata's (1997) theory of the cultural interface, as discussed in Chapter Six, is an Indigenous Standpoint Theory (IST) predicated on the notion that separating

traditional from non-traditional Aboriginal culture and practice is not possible. It is born from Australian Indigenous scholarship which defines the 'cultural space' where Aboriginal and non-Aboriginal people interact and engage on day-to-day basis. To understand how Aboriginal people interact in the '*real*' world, the researcher must focus on understanding the lived experiences and values of all non-Aboriginal and Aboriginal people who are involved in a particular environment (Denzin & Lincoln, 2008a, 2008b) as opposed to just critiquing the 'representation' and 'treatment' of Aboriginal people in Indigenous enquiries (Moreton-Robinson, 2004, 2000).

The cultural interface was adopted as a means to break away from the 'Us' versus 'Them' methods of enquiry by acknowledging that the interactions between Aboriginal and non-Aboriginal people are multifaceted and complex. The theory of the cultural interface has mostly been adopted in Aboriginal education (Jackson-Barret, 2011; Nakata, 2004, 2007; Yankaporta & Mcginty, 2009; Yankaporta, 2009) and Indigenous knowledge systems (Nakata, 1997).

Chapter Six has shown that there is a dominant pattern in previous research where the paradigmatic framework of the research, methodology and the research findings have 'culturally othered' Aboriginal people with a disability. The focus of this enquiry was on the cultural interface, a complex web of experiences of local Aboriginal and non-Aboriginal service workers and managers of generic and Aboriginal community managed disability service providers.

Therefore the paradigmatic framework selected for this phase of the research and most closely aligned with IST was a constructivist approach. In this section of the research the focus of the inquiry moved to an exploration of the day-to-day multiple realities and experiences of disability service staff regarding the participation of Aboriginal people in disability services. The disability services staff was of various backgrounds, disciplines and experience and worked in various organisations. Grounded theory methods were adopted and particularly the constructivist elements of grounded theory (Charmaz, 2005) as they have been applied to the substantive area of social justice. Major strengths of grounded theory methods relevant for this research are that they provide tools for analysing processes and potential for investigating social justice issues (Charmaz, 2005)

A constructivist framework takes into account the existence of multiple realities. Exploration of multiple and diverse individual experiences is necessary to

understand and explain phenomena. Its strength lies in identifying and exploring how reality is shaped and represented through each participant via their own words, culture and language.

It would be nonsensical to hypothesise what 'could', or even 'should' be influencing Aboriginal people's participation without firstly learning from the experiences of people who are involved at the coal face of the delivery of disability services. Therefore this section of the research is concerned with understanding people from the meanings and frames of reference that they attach to the reality of their lives and, therefore, concerned with issues of language, representation and social organisation (Way, 2004). Lincoln and Guba (1985, p. 269) pointed out that qualitative research is best adopted "when the interviewer does not know what he/she does not know" and supports the discovery of relationships between multiple variables previously unknown in the field.

The first and second sections of this study identified some of the diverse strategies adopted by the government, the Mainstream NGO and the Aboriginal NGO in their engagement with Aboriginal families. The third section of this study complements the previous two sections. This section provides a rigorous and detailed exploration of the factors influencing the participation of Aboriginal people in the disability services sector from the perspective of disability service workers at the front line of service delivery.

A number of organisations representing key stakeholder groups were consulted about the proposed methodology in order to ensure that the needs and interests of vulnerable stakeholder groups were addressed in the research questions and the conceptualisation, implementation and design of the research. Letters of support were obtained from three NSW Government Department of Ageing, Disability and Home Care (DADHC) funded, non-government organisations (NGO) (Carers NSW, Indigenous Disability Advocacy Service (IDAS) and the Aboriginal Disability Network of NSW (ADN)) and one DADHC funded NSW Government Aboriginal advisory group (NSW Aboriginal Community Care Gathering). These letters of support are attached at Appendix E. The status and progress of the study and proposed frameworks informed by the research findings were continually reported back to these agencies, scholars and Aboriginal people in the field. Ethical approval for the conduct of this study was obtained from the University of Sydney and is attached at Appendix D.

## **Recruitment of the participants**

Similar to the policy document analysis section of this study, the Mainstream NGO and the Aboriginal NGO were the organisations involved in the study. Although there were hundreds of disability service providers in NSW, these two agencies were selected based on age, service diversity and size.

The Mainstream NGO had a large number of service types which allowed the researcher to interview workers with a diverse range of experience and expertise in the field. In addition, the Mainstream NGO had services across New South Wales. Given that there is a high level of staff turnover in the disability services sector (National Disability Services (NDS), 2010), it is highly likely that a proportion of the Mainstream NGO's workforce has worked for other disability service providers in NSW.

The Aboriginal NGO was smaller than the Mainstream NGO, covering a small region of NSW for around ten years. The Aboriginal NGO had experience in working with other disability service providers and government workers.

The CEOs of both NGOs were briefed about the study and that participation for the organisation and staff was voluntary. Signed consent forms were obtained from the Chief Executive Officers (CEO). Permission was granted by the CEOs to recruit staff of the organisation to participate in this study, on a voluntary basis. The CEO of each organisation requested organisation managers to email the research Information Statement and Consent Forms to all staff informing them that they could voluntarily participate in the research. They also assisted with scheduling times and venues for focus group meetings. All staff completed consent forms prior to participating in the research.

The participants for this study were paid workers of the Mainstream NGO and the Aboriginal NGO. The participants included both Aboriginal and non-Aboriginal people who were employed in the Aboriginal NGO or the Mainstream NGO. Workers varied in their background, training, experience, expertise and engagement in Aboriginal communities. For example, an Aboriginal family's type and level of engagement with an information and referral worker was different to their engagement with a speech therapist. Similarly, the level of engagement for a line manager was different to a case manager. Tables 7 and 8 summarise some characteristics of the participants of this study in relation to their roles in management and non-management and by Aboriginality.

Table 7

*Number of Management Staff*

<b>Participant type</b>	<b>The Aboriginal NGO</b>	<b>The Mainstream NGO</b>
<b>Non- Aboriginal</b>	1	8
<b>Aboriginal</b>	1	0

Table 8

*Number of Worker Participants*

<b>Participant type</b>	<b>The Aboriginal NGO</b>	<b>The Mainstream NGO</b>
<b>Non- Aboriginal</b>	0	48
<b>Aboriginal</b>	2	4

A total of 60 participants from the Mainstream NGO and four participants from the Aboriginal NGO were involved in this study. A total of seven Aboriginal people and 57 non-Aboriginal people participated in this study. It was a significant challenge to obtain more Aboriginal participants from the Mainstream NGO. The management of the Mainstream NGO undertook a voluntary survey of the agency's workforce to ascertain the total number of Aboriginal workers. Disappointingly, this strategy concluded that the agency did not have many Aboriginal workers. As such, not many Aboriginal workers were able to be recruited in this study.

As discussed in the first two sections of this thesis, substantial research has already been undertaken regarding the views of Aboriginal people with a disability and their communities. The experience of disability service workers in supporting Aboriginal families is an area of research in need of further investigation. In addition it was important to include workers from an Aboriginal community controlled organisation (ACCO) as well as a generic NGO in the data collection. The potential influence of management and leadership at the front line of service delivery and over policy development could therefore also be explored across these diverse organisations.

## **Data Collection Methods**

A variety of data collection methods was employed to ensure that participants had every opportunity to contribute their perspectives.

### **Undertaking focus groups and interviews**

Data were collected through focus groups and individual interviews. A central proposition of the enquiry was that the staff of disability services can identify the main factors that influenced the participation of Aboriginal people in disability services, from their perspective. Twelve open-ended 'trigger' questions listed at Appendix F were developed, which were informed by the literature and the critical historical policy document analysis discussed in sections one and two. Trigger questions proved very useful to invigorate discussion on the topics relating to the participation of Aboriginal people in disability services. Structured clarifying questions, such as "Why is that the case" or "How often does that happen" or "Can you further explain that for me, please?", were posed during the discussions. As the participants talked about their experiences in working with Aboriginal clients and their families, a mental picture about the factors was built. Many attempts to confirm these factors were made through probing questions:

1. So would you say that is very common with Aboriginal clients?
2. It sounds as though this is common. Would everyone in this room agree?

Each focus group consisted of a small number of volunteer participants. The benefit of the focus groups was that all the participants got involved in the discussions and bounced ideas off each other (Stewart, Shamdasani & Rook, 2009). Focus groups worked well for people who felt more comfortable talking in groups. For example, Madriz (2009) noted that many women were more comfortable talking in groups than in individual interviews. More importantly, focus groups provided a "safe environment where they can share ideas, beliefs, and attitudes in the company of people from the same socioeconomic, ethnic, and gender backgrounds" (Madriz, 2009, p. 835). In my personal and work experience, the same is true in Aboriginal communities where focus groups are called "yarn ups". Many Aboriginal people feel more comfortable yarning amongst their relatives and peers as opposed to individual interviews.

At the very start of a focus group each participant judges the focus group leader/ researcher, which means that the researcher only has a few minutes to

build trust and rapport with each member. The objective at the start of the focus groups and interviews in this study was to help calm everyone's nerves and encourage people to speak (Stewart et al., 2009). This challenge was addressed in the following ways:

1. Created an informal friendly atmosphere: I set the tables into a horseshoe shape where I stood and walked around in the middle. This fostered engagement between me and the participants. I introduced myself both as a worker in the field and as a researcher. Whilst I was introducing myself I made a few funny jokes. I then explained my strong belief in maintaining confidentiality when I explained the consent forms.
2. Personal presentation: I dressed in very informal casual clothes to prevent the visual look of 'the expert'.
3. Non-verbal communication: I practiced 'minimal encouragers' as practiced in counselling (Geldard & Geldard, 2001, pp. 38-39). This involved demonstrating I was listening and interested in what each person had to say through non-verbal behaviour – such as nodding my head and smiling – and voice-expressions such as saying "ok" or "ah-ha" or "awesome".
4. Explaining the purpose of this research and about my involvement in the disability services sector as a Koori from the Yuin Nation. Although a description of the research was given to the participants in the Information Statements, it was always important to provide more background to the objectives of the research at the beginning of the discussions.
5. Prompting and involving: there were times when a couple of people were whispering amongst themselves when someone else was talking. At such times, I encouraged them to speak after the first person finished. This allowed them to be involved during the discussion on a particular topic and helped reduce the number of private conversations during the discussions.

All the participants were given the opportunity to participate in this research in an individual interview. This was particularly important to allow participants the opportunity to express their experiences privately. Interestingly, only Aboriginal workers took this opportunity to talk about some really personal issues. This strategy provided valuable data for this research in relation topics on discrimination, stolen generation and "Aboriginal family politics".

Following Lincoln and Guba's suggestion (1985), all focus groups and interviews were undertaken at the participants' place of work, as this was the participants natural setting. The management focus groups from both organisations consisted of the CEO, finance managers, service and regional managers and program/organisation development staff. The Aboriginal NGO management focus group consisted of the CEO and one Board member. The worker focus groups consisted of people who worked as caseworkers, client

program coordinators, disability and family support workers, advocates, therapists and client service/program assessors. Unpaid volunteer workers were not permitted to participate in this study. A general census of the focus groups found that the majority of participants had previously worked for other disability service providers. The focus groups often ran for two hours with one small break. The two individual interviews went for about one hour. Table 9 below provides a breakdown of the number of focus groups and interviews. Data were collected from seven focus groups and two interviews.

Table 9

*Number of Interviews and Focus Groups*

Type	The Mainstream NGO	The Aboriginal NGO	Total
<b>Worker Focus group</b>	3	1	4
<b>Manager Focus Group</b>	2	1	3
<b>Individual interview</b>	1	1	2

The focus groups and interviews were completed in the second half of 2010. The member checking<sup>5</sup> occurred in the first half of 2012. The transcripts and field notes were analysed throughout the data collection process and the questions were refocused for subsequent data collections. Later stages of data analysis continued through 2011 and 2012. All participants were informed of the voluntary nature of the study when they were given the Consent Forms and Information Statements. Permission was also confirmed again before the audio recording commenced. All participants agreed to be audio-recorded. All recordings were transcribed and filed on a password protected computer.

### **Data Analysis**

A number of analytic tools derived from grounded theory were employed, acknowledging that Strauss (Strauss & Corbin, 1990, 2008) is recognized for the depth of his contribution to the conceptualization of social organization (Charmaz, 2005). The widespread usefulness of grounded theory and the range of clearly

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<sup>5</sup> Member checking is the process undertaken when the researcher revisits the participants to double check findings and discuss theories and conclusions from the data gathered.

explained and identified analytic techniques that have been developed and applied in a wide variety of research was also considered in the adoption of this approach.

Grounded theory is often described as a constant comparative method of analysis as it is a process by which data are broken down, conceptualised, and pieced back together again in new ways (Strauss & Corbin, 2008). Situational analysis expands and develops the constructivist dimensions of grounded theory. This includes addressing the concepts of perspective, reflexivity, difference and the universality of theory in the analytic frame. The data analysis in this enquiry focused on the exploration of emergent phenomena using situational analysis and therefore focused on grounded theorizing through the development of sensitizing concepts rather than grounded theory (Clarke, 2005).

Clarke (2005, p. 29) defined situational analysis as an analytical method used “to analyse a particular situation of interest through the specification, re-representation, and subsequent examination of the most salient elements in that situation and their relations”. Situational analysis was identified as the data analytic framework which was most closely aligned with the paradigmatic framework of the research and the primary research questions (Clarke, 2005). Congruent with the purpose this research, ‘conditional elements of the situation are specified in the analysis as they are ‘constitutive of it’, not merely surrounding it or framing it or contributing to it (Clarke, 2005, p. 30). This includes consideration of the structural relationships and power elements in the themes and patterns which emerged over the course of the data collection.

Various techniques used in the analysis of the data and contributing to the situational analysis are described in turn below.

### **Open coding**

Respondents’ accounts in the interview audio transcripts and field notes were categorised into ‘main themes’. This process was conducted after each interview and focus group. As Table 10 shows, each new idea was categorised using a consistent ‘term/phrase’ that best described key aspects of that segment of the speakers’ response. The text in Table 10 was taken from the focus group transcript at Appendix G. This was an intense and time-consuming ‘line by line analysis’ of each respondent’s statement in order to ‘open or fracture the data’. This allowed the researcher to take a step back and open up

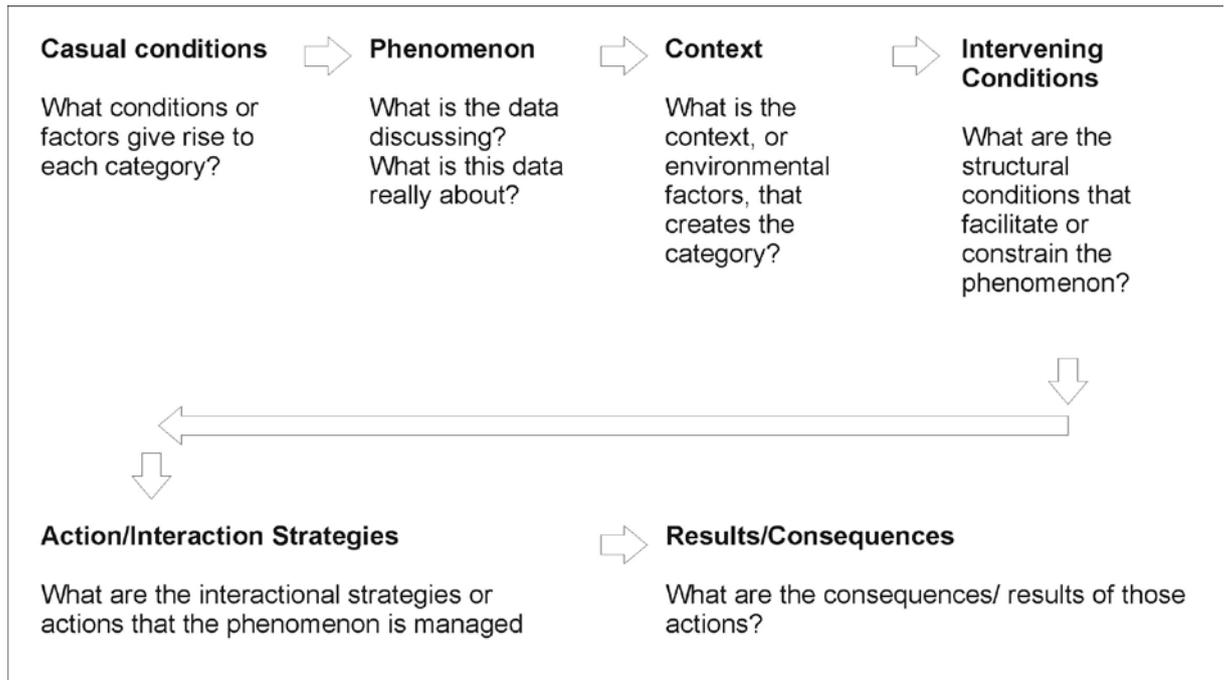
all possible avenues in theory development and bring to light further questions during the data collection. Key concepts emerged from the data.

Table 10 - The Data Analysis Categories used for the First Part of the Data Analysis

Discussion	Initial (open) Codes	Categories	Field notes
<p>1. <b>Participant#</b> I think probably previously we had a worker who just left, not very long ago, who had had a parent had a background in working with an Aboriginal service and</p> <p>2. she automatically had that connection with them and</p> <p>3. so she wasn't Aboriginal herself.</p> <p>4. But she actually had all the key names</p>	<p>Mainstream NGO non-Aboriginal workers connections with Aboriginal communities.</p> <p>Knowing the key names are essential when working with Aboriginal clients</p>	Aboriginal community connections	Must explore further the importance of connections and relationships between disability service workers and Aboriginal communities.

### Axial coding

This involved specifying and describing relationships between the 'main themes'. Each transcript was basically 'pulled apart' and 'pieced back together' again under the main themes. Key concepts were examined in detail including the "casual conditions, phenomenon, context, intervening conditions, action/interactional strategies and consequences" (Strauss & Corbin, 1990, pp. 99-107). The themes and issues in text were highlighted as depicted in Appendix G. Figure 11 below illustrates the types of dimensions that were explored in relation to key concepts:



*Figure 11 – Axial coding part two of the data analysis (adapted Strauss & Corbin, 1990)*

### Selective coding

Selective coding was the third stage where the core abstract and theoretical concepts emerged and were defined. This stage is also known as ‘theoretical sampling’ where the researcher moves back and forward between theory or the explanatory framework and the data. The theory was dictated by the emerging data. It was the “process of selecting the core category, systematically relating it to other categories, validating those relationships, and filling in categories that needed further refinement and development” (Strauss & Corbin, 1990, p. 116).

In open coding the core categories were developed and ratified, then placed into relationships using axial coding. Selective coding was when the story unfolded of how the experiences described by participants could be understood and operated within an explanatory theoretical framework.

The texts of each of the transcripts were printed, cut out and pasted onto large sheets of paper under the categories that best reflected the content of the texts. This provided a good visual of the ‘context’ and ‘explanatory relevance’ of each of the categories.

## **Situational analysis**

The analytic tools described above contributed to the development of a situational analysis. Situational analysis goes further than the previous three analytic tools into exploring and describing the most important human and non-human elements in the situation of concern and mapping out what these situations meant for Aboriginal people. The experiences of the participants were analysed through the specification, re-representation and subsequent examination of the most salient elements of their relations (Clarke, 2005). This included consideration of:

- Who was in this situation?
- What is this situation about?
- What elements made a difference for Aboriginal people with a disability in this situation?
- What hinders and fosters Aboriginal people's participation in services in this situation?

The objective was to highlight the symbolic meanings and discursive elements that constructed the situations and events involving the participation of Aboriginal people in disability services as explored and described by the previous data analysis. The situational analysis map is displayed in the photograph below in Figures 12, 13 and 14. Adopting Clarke's (2005, p. 87) recommendation, the analysis included "all the analytically pertinent human and non-human, material and symbolic/discursive elements of a particular situation as framed by those in it and by the analyst" which had been identified using the analytic techniques described above. The human actors and elements were generally easy to specify, such as individuals, workers, agencies, clients and cultures. The non-human actors and elements were those that "structurally condition interactions within the situation through their specific agencies, properties and requirements" (Clarke, 2005, p. 87). For example, technological aids and equipment for people with a disability, the geographical location of events (events include meetings and service delivery locations and methods), access to utilities and transport are categorised as non-human elements (Clarke, 2005). The mapping of the data analysis is depicted in the figures below.



Figure 12 - Photo one of the data analysis mapping



Figure 13 - Photo two of the data analysis mapping



Figure 14 - Photo three of the data analysis mapping

Consistent with the analytic tools described above, the next step was to identify the relationships among the various key elements and actors. As shown in the photographs above, the segments of text were grouped together and

stuck up on large sheets of paper on the wall, the researcher used coloured highlighters and coloured string to present a 3D visual picture. The relationships between the elements and actors within each situation under each data code were then identified. For example, whenever Aboriginal workers were used to help Aboriginal clients achieve a 'service outcome' the text was coloured orange. In this example, Aboriginal workers discussed different situations, such as children undertaking therapy, or experiencing disadvantage, various incidents in the child's lives or events such as miss scheduled appointments or other characteristics of the situation such as client's living a long distance from services. Each colour and linkage then highlighted the main factors, or elements of the situation that influenced the participation of Aboriginal people in disability services as understood by the participants. These factors, relationships between factors and their articulation in an explanatory framework are presented with illustrative transcript excerpts in the report of the findings in the next chapter.

### **Maintaining trustworthiness in qualitative research**

Creswell (2007) stated that qualitative researchers have received much criticism for not adhering to the traditional principles of 'reliability' and 'validity'. Such criticisms include the inability to 'generalise' findings from social inquiries to the documentation of results from ethnographic studies. Many scholars argue that it is pointless to compare the procedures for maintaining/assessing validity and reliability of research between the qualitative and quantitative methods because the principles and purposes of these methods are completely different (Creswell, 2007; Guba et al, 1981; Silverman, 2004). Whilst quantitative researchers depend on predetermined instruments to establish direction and objectivity in their enquiry, qualitative researchers rely heavily on 'the-human-as-instrument' during the collection and analysis of data. Guba et al (1981) stated that, unlike quantitative research, the operational paradigm of qualitative researchers as 'human instruments' requires completely different procedures for maintaining validity and reliability during the data collection process and analysis. Qualitative researchers are not independent of their subject matter and are therefore conceptualised as the very instrument by which qualitative research is conducted. Creswell (2007) and Silverman (2004) noted that writers who continue to use quantitative

techniques for measuring validity and reliability in qualitative research continue to subordinate qualitative method as inferior to positivist methods.

Qualitative researchers generally agree that not all accounts of individual's situation, phenomenon, activity, documents or text are equally useful, rigorous or credible and this has contributed to our understanding of the hallmarks of credibility and rigour in qualitative research (Denzin & Lincoln, 2005; Maxwell, 1992, 2009). For example, the ways in which researchers critically assess the *data* does not pertain entirely to the *account* itself but rather to the relationship between the account and something external to it: that is the phenomena that the account is about. Validity, in a nutshell, pertains to this relationship between the account and something outside of that account.

Denzin and Lincoln (2005) and Maxwell (2009), consistent with the work of Guba and Lincoln (1981, 1985), suggested the use of the term *trustworthiness* to adhere to the principles and objectives of validity and reliability. Denzin and Lincoln (2005), Guba and Lincoln (1985), Maxwell (1992, 2009) and Creswell (2007) suggest strategies for maintaining a trustworthy research process can be grouped into three core categories: credibility, confirmability and transferability.

- 'Credibility' is characterised by various activities in the field that make it more likely that credible findings and interpretations were produced. The following three techniques were applied in this inquiry that supports the credibility of this research.

I. Intensive long-term involvement in the field to gather data: Before commencing this research I had worked in the disability services sector and with Aboriginal communities for around ten years. Aboriginal community managed disability services, carers support services and respected peak bodies assisted in the planning and implementation phases of my research. Given that researchers are highly distrusted in many Aboriginal communities, a long history of working in the sector has also allowed me to build trust and rapport in both Aboriginal communities and the disability services sector. It was due to my reputation in the field that participants were open and candid in their responses, resulting in a rich dataset.

The researcher's long-term involvement and recognition in the disability services sector was evidenced in a focus group. In response to my question "how do you know if you are speaking to the correct Elders" one of the

participants responded “we just ask you, John” which resulted in laughter among other participants who agreed with this remark.

Intensive long-term involvement in the field provided data that were detailed enough to develop a full complex and revealing picture. In particular, spreading the data collection over a period of time allowed the researcher to revisit the data. Data were collected and analysed over two years (June 2010 to June 2012).

II. Discrepant data: Discrepant data were accounts that could not be interpreted or explained either on their own or together with the other data. Maxwell (2009) stated that identifying and analysing discrepant data was an important validity test for qualitative research. Maxwell (2009) explained that the basic principle in maintaining credibility was that both the supporting and discrepant data must be examined to determine the possibility of retaining or remodifying any theories or claims made. Maxwell (2009, p. 245) suggested that in “difficult cases, the best that you may be able to do is to report the discrepant evidence and allow readers to evaluate this and draw their own conclusions”. This issue was not experienced in this study as the data were inclusive of all accounts.

III. Respondent validation: Respondent validation, also known as member checks (Lincoln & Guba, 1985), involved systematically reporting back the preliminary findings to the participants in the study. This was the best strategy to prevent misinterpretation of the information collected over the course of the research.

Meetings were held with the managers and Boards of the two NGOs to discuss the results during the research. Follow up meetings were held with some of the participants. In these meetings participants were asked whether the emerging findings adequately summarised, represented and encapsulated their experiences. In addition, the preliminary findings of the research were presented at disability conferences in Australia and New Zealand to obtain feedback on the research process and results.

- ‘Confirmability’ involves the transparency of the research process and is demonstrated by establishing an audit trail. An audit trail involves the record of materials and documentation that demonstrates the process the researcher undertook in planning and implementing the research. The possibility of being

audited requires a researcher/project-manager to have an established file recording system. Similarly, McVilly (2005, pp. 22-23) encouraged researchers to develop “audit trails that enable others to scrutinise the research process”. Each dated draft of the transcript coding, data analysis, photos of situational analysis and the emergent findings was retained by the researcher and text copies held by supervisor.

Another aspect of confirmability involved the *dependability* of the data analysis process. During the research, the de-identified transcripts were provided to the supervisory team (consisting of three academics) and meetings were held with independent Aboriginal and non-Aboriginal researchers and lecturers in the same field at the university to discuss emerging codes. This strategy supported the confirmability of the claims made based on the data.

Prolonged engagement and the multiple perspectives obtained through interviews and ongoing member checks provided a comprehensive and well-articulated view of the experiences of workers over the period of the study. The researcher discussed and confirmed with members of each NGO (including participants) whether they considered that the findings adequately reflected their experience. In addition participants indicated that they were satisfied that their confidentiality had been adequately safeguarded in the findings (Guba & Lincoln, 2005).

- ‘Transferability’ in qualitative research is the applicability of the findings listed to future research investigating similar phenomena. The comprehensive description of the methodology including the data analysis approach and the rich descriptions provided in the findings would support future research in this area.

### **Reflexivity and researcher effects**

Whatever the results and challenges that occur during the data analysis phase, Silverman (2004) stated that it is the task of the researcher to provide as much detail as possible regarding the challenges involved in data collection and analysis. There were a number of challenges during this phase of this study.

To begin with, a failing audio recorder was a significant challenge during one of the Mainstream NGO management focus groups. Thankfully, only the first ten

minutes of the recording was lost and the note-taker who was also recording all of the information took highly detailed notes. Member checking confirmed that the issues raised had been captured and were interpreted correctly.

Separating the managers and the frontline workers was an effective way for all participants to be open and candid in their responses during the focus groups as it eliminated the fear of being reprimanded or judged by their managers. Some frontline workers expressed their appreciation that there were no managers present in the focus groups or individual interviews. An unforeseen consequence in separating managers from frontline workers was that in one focus group a small number of frontline workers openly voiced their distaste and criticism for the research because it was focused specifically on a cultural group. This negative response could have resulted in other people reconsidering their participation, despite the voluntary nature of participation having been made clear previously. In response to these comments, the strictly voluntary nature of participation was re-emphasised and that they did not have to participate or attend the focus group unless they wished to. These negative comments did not appear to influence any other workers who re-affirmed their interest in participating. The workers concerned asked if they could stay but not participate in the research. This was permitted.

At the time, this opposition made me feel personally attacked for being a Koori person who was doing research on Koori people. However, reflecting back there could be many reasons for this event occurring. Firstly, these workers may have misunderstood the voluntary nature of the participation and been oppositional to a perceived demand to participate made by management. Secondly, it could be that the workers did not like their work or aspects of their work. Thirdly, this could have been further evidence of views expressed by other participants that the identification and focus of services on target groups such as Aboriginal people was a form of discrimination against the non Aboriginal population or cultural separatism. Finally, they could just want to get back to the office. Further details regarding the reflexive nature of the researcher's role in this inquiry will be discussed in the final chapter.

## **Conclusions**

The second objective of this study was to identify the factors that influence the participation of Aboriginal people in disability services as understood by paid workers of the Aboriginal NGO and the Mainstream NGO. Consistent with the constructivist paradigmatic framework of this inquiry and the grounded theory methodology and data analysis framework, interviews and focus groups were chosen as the most appropriate data collection tools. Data were collected from seven focus groups and two interviews. A total of 64 participants (60 from the Mainstream NGO and four from the Aboriginal NGO) were involved in this study. The focus groups and interviews were completed over 2010 - 2011. Member checking was carried out in the first half of 2012.

The transcripts and field notes were analysed throughout the data collection process and the questions were focused and deepened for subsequent data collection. Measures were put in place to maintain the trustworthiness of the data collection process. The data were coded using grounded theory techniques to complete a thorough situational analysis that comprehensively addressed the research questions.

The findings of Section Two are presented in Chapter Eight. Each of the major factors influencing the participation of Aboriginal people in disability services will be described and explained in accordance with the experience of the disability service workers who participated in this study.

## Chapter Eight: Section Three Findings

This chapter presents the findings that address the second objective of the study, which was to identify the factors that influence the participation of Aboriginal people in disability services according to the experiences of people who work for disability service providers. The data were collected as described in the methodology presented in Chapter Seven. As discussed in Chapter Seven, participants were asked questions about their experiences in working with Aboriginal families and their views of the factors that influence Aboriginal people's participation in disability services.

The second section of this thesis explained the manner in which governments, the Mainstream NGO and the Aboriginal NGO identified, treated and represented the participation of Aboriginal people in disability services as a specialised field. There were similarities and differences between the Mainstream NGO and the Aboriginal NGO in their strategies to address the service participation rate of Aboriginal people.

Twelve major factors influencing the participation of Aboriginal people in disability services have emerged from the analysis of interviews and focus groups. All of the factors were inter-related and inter-dependent. The relationships between the factors are explained throughout this chapter. The major factors identified are listed below:

1. **Conceptualising disability:** Conflict in the conceptualization of disability between Aboriginal communities and disability services
2. **Family and Kin:** Reliance on family and kinship systems as the support mechanism
3. **Colonisation and Trauma:** Understanding of colonization and intergenerational trauma as social determinants of health and disability among disability workers.
4. **Racism:** Experiences of racial discrimination in the disability services sector.
5. **Choice of Workers:** Choice of workers in disability services
6. **Choice of Organisations:** Choice of Aboriginal community managed services or generic services.
7. **Community Connections:** Connection between Aboriginal communities and disability service providers
8. **Trustworthiness of mainstream services**
9. **Multiple Agency Intervention:** Number of agencies involved in intervention
10. **Trusting Workers:** Trust between caseworkers and Aboriginal clients
11. **Mobility:** Remoteness and travel mobility

## 12. **Affirmative Action Policy:** Understanding and response to affirmative action policies

This chapter is written in two parts. Firstly, the findings are discussed under the heading of each factor listed above. Each factor is presented with a short summary to help the reader follow the presentation of each of the findings in turn. The second segment of this chapter presents the conclusions drawn from the findings.

The data have identified differences in the findings between the Mainstream NGO focus groups in the city and the outer-city regions. This chapter uses the phrases “the Mainstream NGO city focus group” and “the Mainstream NGO outer-city focus group” to indicate the differences between the metro and non-metro regions.

Throughout the report, particular characteristics of the participant's' quotes have been mentioned if it was important to the interpretation of the comments. Consideration was given to the protection of the identity of the contributors. Given the diversity and nature in the occupation roles and responsibilities of the participants in both NGOs, comparisons were made between workers and managers of the participating NGOs. The participants were also categorized by their Aboriginality to contrast the experiences of the Aboriginal and non-Aboriginal staff. The disability case workers who did not identify as Aboriginal people from the Mainstream NGO are identified as ‘Mainstream NGO non-Aboriginal worker’ and the managers are identified as ‘Mainstream NGO non-Aboriginal manager’. The participants who identified as Aboriginal people from the Mainstream NGO are labelled as ‘Mainstream NGO Aboriginal worker’. The participants who identified as Aboriginal people from the Aboriginal NGO are labelled as ‘Aboriginal NGO worker’ and ‘Aboriginal NGO manager’. There was only one non-Aboriginal participant from the Aboriginal NGO that participated in this study. This participant was identified as ‘Aboriginal NGO non-Aboriginal manager’.

### **Identified Factors**

This chapter is written in order of the factors listed above. The factors are discussed and presented with direct quotes from the focus group and interview audio transcripts. For the purposes of clarity and ease of reading, all participant quotes are given in italics.

### **Conceptualising disability: conflict in the conceptualization of disability between Aboriginal communities and disability services**

At the start of the discussions with the focus groups and the individual interviews, I presented on the Australian government data on the prevalence of disability in the Aboriginal population. The participants pointed out that there was a diversity of conceptualizations of disability in Aboriginal communities. The conceptualizations of disability were often different from the disability organisations, which may create discrepancies in the government's data. An Aboriginal NGO worker stated that:

*A lot of times [Aboriginal] people don't even know [or] don't relate to that [word disability]. So the statistics [on disability prevalence] are probably higher because they [Aboriginal people] don't identify as such.*

There were differences between the Aboriginal NGO and Mainstream NGO non-Aboriginal participants in discussions about the conceptualisation of disability. The Aboriginal participants often used the term “*normal*” to describe how Aboriginal communities conceptualised disability as “*part of living*”. Some participants stated that many Aboriginal families modified and adapted their families to be inclusive of people with a disability. For example, an Aboriginal NGO manager said:

*Well I think the word ‘disability’ in a lot of [Aboriginal] people’s minds says ‘you’re in a wheelchair’ or you’re in a comatose state or you’ve been hit by a car and you’re totally disabled. ... So in Aboriginal communities you’ve got Nan who’s got dementia - “oh that’s just Nan, she goes walkabout. We have to go and follow her, bring her back home”. So they’re not labelling it as a disability. ... So what happens in the Aboriginal communities is that people just live their life. They accept these conditions and they just treat it as a normal part of living.*

An Aboriginal NGO worker provided another example:

*... Aboriginal communities actually adapt to a normal surrounding with people that have recognised disabilities ... So if Johnny’s born with ... a disability, they actually believe that it’s quite normal and they just change their family function or the way they exist in order to make allowances for those different*

*characteristics and they think it's really just quite normal that that's part of their lifestyle or their family existence.*

The Aboriginal NGO participants accommodated the diverse understanding of disability in Aboriginal communities by having a broad definition of 'family', 'disability' and 'carers' in the organisation's policies. The Aboriginal NGO participants found that this policy position provided flexibility in access pathways for Aboriginal people. An Aboriginal NGO manager explained below:

*The development of how [The Aboriginal NGO] functions and the policies came about through [Aboriginal community managed organisations] staff working with representatives ... [from Aboriginal organisations, and Mainstream organisations and government representatives] on our steering committee ... So we had a lot of advocacy experience in the room and government experience in the room sort of helping us write the policies. ... our view was that any Aboriginal person was entitled to receive service from us. Any Aboriginal disabled person or their families or their carers. And we didn't define family, disability or carers very tightly...*

The non-Aboriginal participants from the Mainstream NGO did not discuss the diverse conceptualisations of disability amongst the population of Aboriginal people. Rather, these participants talked about the "lack of awareness" of their organisation's definition of disability in the population of Aboriginal people. The Mainstream NGO participants spoke about increasing the level of awareness of disability in Aboriginal communities through education and dissemination of information on services. Improving awareness of disability was discussed simultaneously with improving awareness of disability services. The lack of awareness was often discussed as one of the causes of the low participation rate of Aboriginal people in services. For example, a Mainstream NGO non-Aboriginal manager said:

*Some of the barriers are around ... awareness of disability and services that are available ... there are families out there that could be accessing services and aren't accessing it. So it's just that lack of knowledge and information ... [about] what disability might mean....*

In order to participate in services, Aboriginal people must accept 'disability' as defined by the disability service provider. A Mainstream NGO non-Aboriginal worker told about an Aboriginal client:

**Mainstream NGO non-Aboriginal worker:**

*... He initially came in on the physio referral. ... A few other issues came up that needed OT. The interesting thing was that we really did get mum on board at quite a certain point. But the young man was 16 years of age and I think we lost him. He really had to make the changes.*

**Interviewer:**

*What do you mean you lost him?*

**Mainstream NGO non-Aboriginal worker:**

*He wasn't interested. ... I don't know whether he felt helpless or he didn't want to acknowledge his disability. ... so they eventually exited themselves.*

This client's case exemplifies that if an Aboriginal person (or any person) does not accept a service provider's definition of disability, then that person may not participate in disability support or services. Therefore, 'acknowledgement of disability' influences participation in disability services.

Similarly, an Aboriginal NGO non-Aboriginal manager said that Aboriginal people had to accept the Western conceptualization of disability to accept services. However, he used the phrases "educating" and "stigmatizing" to describe how Aboriginal people had to change their mindset to receive services:

*... there's that sort of traditional non-recognition of disability .... Traditionally ... there was no major culture recognition of disabilities. That's my understanding. ... I don't think there's a long history ... of Aboriginal [people] talking about being disabled. Again, I think it's a concept from outside the culture that's taking some familiarity and getting used to what it means ... So it's that education process that you're stigmatising yourself, you're actually making yourself ... receive some help.*

The participants from the Mainstream NGO expressed their concern of how their organisation's conceptualisation of disability is considered to be offensive by some Aboriginal people. For example, a Mainstream NGO non-Aboriginal worker commented:

*Well I think it's often used in the school yards as a derogatory term like 'you're a Spastic' ... so if a parent has a child with cerebral palsy at the [the Mainstream NGO] ... they worry about that terminology. What does that say about their child? It's not as valued ... So I think ... they're dealing with a diagnosis [of disability]... [and] a lot of grief around that diagnosis. So it's not just the name but I think it's ... they don't know who we are and what we do, it's very scary...*

Some of the Mainstream NGO non-Aboriginal participants spoke about how their strategies to increase the level of awareness of disability services in Aboriginal communities have not been successful in attracting Aboriginal families. The participants from the Mainstream NGO city focus group reported that “*even in the past though, when we represented a house service at [an] Expo for School there's never been a high attendance of Aboriginal families with children with disability looking for services*”. Promoting disability services and increasing awareness of disability was spoken about simultaneously. A Mainstream NGO non-Aboriginal worker described the Mainstream NGO's promotion material as not “*presented as Aboriginal friendly*” in comparison to other disability service providers:

*I don't think our information is presented as Aboriginal friendly. So I know at another service that I was associated with they'd have one program that they have one set of information that was Aboriginal identified and another that wasn't. And I don't think we promote ourselves that way. ... The Aboriginal documentation was a lot less formal and it showed Aboriginal symbols. I don't think we do that well. The documentation that I see doesn't do that.*

There were some cases where ACCOs made referrals to the Mainstream NGO, not knowing what the Mainstream NGO provided. For example, a Mainstream NGO non-Aboriginal worker stated that:

*[Aboriginal] medical service is a fairly big organisation in [non-metro region that has] ... a number of different arms and so they have a disability specific section within their service. So we've had referrals for families from them. ... The family has to consent to the referral but I think a lot of the times they don't*

*really know what they're consenting to [as the programs are] so hard to explain and lots of people kind of get it a bit wrong.*

Participants talked about how Aboriginal people with a disability are missing out opportunities provided by the disability service sector, because of the lack of awareness of disability as understood by the disability service system in Aboriginal communities. An Aboriginal NGO worker said that Aboriginal people with a disability are missing out on services and supports that may improve their health and wellbeing:

*They're missing out on support from other services because they don't realise that this is classified as a disability ... And possibly disability pensions. Transport concessions. Like a whole range of services for disabled people that they may not be getting if they're not acknowledging themselves and being acknowledged as disabled.*

**Factor one summary.** There was a conflict at the cultural interface in defining and conceptualising disability between local Aboriginal and non-Aboriginal communities. Many Aboriginal people perceived the Western scientific pathological model of disability as offensive. The Mainstream NGO considered this as a lack of awareness of disability and disability services. The Aboriginal NGO had a much broader definition of disability and service eligibility criteria than the Mainstream NGO. Aboriginal people had to accept the Mainstream NGO's definition of disability and service criteria in order to receive services and supports.

### **Family and kin: reliance on family and kinship systems as the support mechanism**

Participants discussed that Aboriginal families relied on existing resources of their family and kinship networks to support people with a disability. The participants from both agencies discussed that many Aboriginal families did not expect disability services to exist. This expectation was a result of the differing and contradicting understandings and beliefs regarding 'disability' between the disability service sector and Aboriginal families that was discussed in the factor above. A Mainstream NGO non-Aboriginal worker said that "...*there is that natural*

*leadership group with eldership and aunties and extended families ... that [Aboriginal people] use to gain support and advice”.*

The participants stated that Aboriginal people utilized family and kinship networks for support. For example, a Mainstream NGO Aboriginal worker said that “...they [Aboriginal people] probably think they don’t need a service, they can manage on their own”. Similarly, a Mainstream NGO Aboriginal worker said that “...they [Aboriginal people] do keep within the community to do these things”. The Aboriginal NGO focus group reported that many of their clients have never accessed a disability service before they accessed the Aboriginal NGO. An Aboriginal NGO worker stated that “...they were disabled but they’d never received any assistance from anyone”. Similarly, an Aboriginal NGO worker said that some of their clients “...have not talked to anyone from a government department or a community based organization...” about disability services.

“Pride” and “family responsibility” were some of the reasons raised by many of the study participants to explain why some Aboriginal families preferred to not access disability services. The Mainstream NGO Aboriginal workers said that many Aboriginal families did not want to access disability services because they were too “proud” to accept support. A Mainstream NGO Aboriginal worker stated that “Aboriginal people do tend to stick together ... [and] a lot of them are proud and don’t want to access the service”. Similarly, a Mainstream NGO Aboriginal worker said that some Aboriginal families “think they don’t need a service, they can manage ... [and] just do it on their own”. Some of the participants stated that there was a relationship between the ‘awareness’ and ‘conceptualisation’ of disability services and the expectation that family and kinship networks would fulfil the caring role of people with a disability in Aboriginal communities. For example, a Mainstream NGO Aboriginal worker said:

*I think it’s just very much education and the awareness of [disability services] ... it just wasn’t ever really communicated. I guess at the same time, it was just they [Aboriginal people] never bothered to look because they just sort of see it as their own problem or burden. It’s their child. It’s their responsibility.*

The link between *family* and *kinship* and *culture* was raised in many client case-studies discussed by the participants. The word *culture* was associated with connections with family heritage. The Mainstream NGO non-Aboriginal

participants were the only participants that raised 'family' and 'culture' as inhibitors of service participation. For example, a Mainstream NGO non-Aboriginal manager discussed a client's case where the Mainstream NGO non-Aboriginal workers did not know how the Aboriginal cultural factors of "country" and "family" interacted with an individual's 'disability':

*... it's about affirming who people are and their experiences and sometimes people say things ... [of] cultural significance or importance but it's not affirmed. ... so someone might just say something about their country or family connections in a broader context that we maybe don't talk about generally, that isn't part of normal, typical conversations but it is really quite significant and we could have maybe asked more questions and been more interested in that. .... People sort of would say afterwards 'oh it took them awhile to work out that it was likely that this mum would probably go back to South Australia at some time in the future because that's her home country and she was wanting to go there' but people didn't think of that to start with. And we maybe could have done more to help with that process because that's what she wanted to do but we sort of took awhile to become aware ...*

A Mainstream NGO non-Aboriginal worker described Aboriginal people's connection to family/kin as a "philosophy". A Mainstream NGO non-Aboriginal worker discussed her experience in working with a client:

*...So I'm working more with [a] family ... that sort of changes ... from week to week. And I think that's kind of been the way it sort of always is and it kind of looks like the way it will be. ... people move in and out of the house or something happens with another family member so this parent has to, you know, to go to help out. But it's very much that kind of philosophy that when something happens to one, it happens to all. And I see that as being a little bit different to some of the other families that we work with. So for instance, in this Christmas holidays, there was an issue with her sister in Sydney so the child with cerebral palsy was in respite and so the mum went to Sydney to support her sister.*

Learning about the cultural heritage and connections of Aboriginal clients was expressed as an element in maintaining participation of Aboriginal people in

services. For example, a Mainstream NGO non-Aboriginal worker said that he learnt about one client's family/kin and culture by learning about the meaning behind their traditional artworks:

*I suppose my time with the family, getting to, I suppose, hear their story took quite a bit of time. ... Mum's a very talented indigenous artist and at different times she's, I suppose, produced different pictures which she will use to initially talk about painting but it's usually connected with some aspect of her life. So quite a bit of my knowledge about her family and her background has actually come through her talking about her paintings which has been fascinating, it's been lovely and it sort of helped my learning as well. Mum's connection with her indigenous culture is very, very strong. And the art is just part of that. Her children also have a really strong connection with their culture and in different ways through education and also through mum's efforts, you know, they've come to have a very strong sense of identity in relation to their Aboriginality. It's something that they're very proud of and also happy to talk about with people. And hearing their stories about their Aboriginality has really helped me understand, I suppose, some of the different experiences that they've had with services over time. Good and bad.*

Some of the participants in the Mainstream NGO talked about how some of the Aboriginal clients' family responsibilities were given greater priority than attending meetings with disability case workers. A Mainstream NGO non-Aboriginal worker spoke about a client's case:

*... [the Mainstream NGO] had sporadic contact with them [Aboriginal family] ... because ... [h]er [Aboriginal mother] partner who ... had a job up in Mackay, so she went up there a couple of times to visit and she also had family troubles in Armidale where they were from. And so she sort of had to go and attend to that basically and that became her priority for awhile.*

The participants reported many Aboriginal client cases where the client prioritized addressing family problems above issues relating to a 'disability', which often created difficulties for many disability caseworkers to address the needs of people with a disability. For example, a Mainstream NGO non-Aboriginal worker explained that sometimes case workers have difficulty in accommodating the

Aboriginal family/kin cultural practices into service planning and delivery for an Aboriginal client:

*... sometimes when I'm talking with her, we're talking about something that's happening with her family and then it goes off on a tangent to whoever, other family members or people who aren't living in the house – and I just feel like that I need to keep pulling or drawing her back to what's most important .... Your house. Your family. Your responsibility. ... She doesn't seem to be able to allow them to accept responsibilities without being involved. ... It's just that I find that hard because you're just working with the mum around what she's wanting to do for her household – so talking about her family within that household. But then other factors come in from the other outside family members, whether it's her two daughters, whether it's sort of the care of the granddaughter, whether it's her sister or whatever, and there seems there's a lot of other families ... that things are happening with. So she goes off on a tangent for them rather than staying focused on her own house.*

**Factor two summary.** Aboriginal families relied strongly on family and kinship networks to provide support for people with a disability. The word 'culture' was associated with connections to 'land' and family heritage. Similar to the definition of disability (factor one) discussed above, supporting and strengthening the capabilities of family and kin in caring for people with a disability was described as a philosophy. As such, supporting family and kin was often prioritised above the requests and demands made by the disability services sector.

The study participants reported that many Aboriginal families did not expect disability services to exist. This expectation was a result of the differences in the definitions of disability between Aboriginal communities and disability service providers.

### **Colonisation and trauma: understanding of colonisation and intergenerational trauma as social determinants of health and disability in Aboriginal communities amongst disability workers**

Many of the participants related the history of colonisation and trans-generational trauma as social determinants of health and disability in Aboriginal communities. An Aboriginal NGO manager said:

*... [disability] goes back to the beginning of colonisation ... from the cycle of poverty, then you've got bad housing, lack of education, lack of nourishment ... people living in poverty suffer ill health probably more so than other people. So you've also got the disabilities ... Also with the alcoholic syndrome, babies are born with problems. Heroine intake – babies are born addicted. So the cycle of poverty sets up a lot of substance abuse.*

A Mainstream NGO non-Aboriginal worker stated that the prevalence of disability in Aboriginal communities has “...a little bit to do with historic positioning... [of Aboriginal people]” and another Mainstream NGO non-Aboriginal worker commented that “...Aboriginal people die earlier and certain illnesses are more prevalent in Aboriginal communities”. Similarly, a Mainstream NGO non-Aboriginal worker said that “health amongst Aboriginals ... at some places, have a third world rating and if you actually look at people's health ... they might be far more susceptible for illnesses to take place that could cause birth defects. Also the social issues ... and health issues being quite prevalent ...”. An Aboriginal NGO worker linked the high prevalence of disability to the past inaction of government and non-government organizations to address the health inequities and inequalities between Aboriginal and non-Aboriginal populations:

*...it's because of health related issues that happen in [the] Aboriginal community. [Over] many years, a lot of those health related [barriers] ... have never been addressed, hence why people live with disabilities and with no access [to services].... If you're not going to deal with one little issue then that grows then those health outcomes become greater and impact stronger on the families.*

Aboriginal participants discussed trans-generational trauma as a mental health issue that functions as a service access barrier for Aboriginal people. The Mainstream NGO participants did not discuss trans-generational trauma. An

Aboriginal NGO manager stated that “*trans-generational trauma has left a blot on the psyche of every Aboriginal Australian person*”. An Aboriginal NGO manager later explained:

*So you're suffering from this generational trauma which means people then turn to drugs and alcohol because they're suffering and that's their escape. You start taking drugs and alcohol, your health falls down. Your children's health falls down. You have babies with disabilities.*

Trans-generational trauma has been linked to racism and discrimination. As such, Aboriginal people felt that they did not have the same opportunities as non-Aboriginal people. The Aboriginal NGO manager provided a good explanation:

*... I think ... the effect of post colonial racism ... [has] told Aboriginal people they're ... not the first class citizens ... [in effect] creates self-esteem issues which lead to a variety of abuses. But also, having the bulk of the population treat you as maybe not the first class citizens, denies opportunity which feeds back into the loop of health, not so good health and poorer living conditions ... it just seems to make the whole population generally more disposed to disability.*

**Factor three summary.** The disability service workers described European colonization and intergenerational trauma as strongly influencing the social determinants of health in Aboriginal communities. Participants reported that colonisation and intergenerational trauma were access barriers to disability services. Furthermore, colonisation was interpreted as disabling in Aboriginal communities.

### **Racism: experiences of racial discrimination in the disability services sector**

Only Aboriginal participants commented that racial discrimination was prevalent in the disability services sector. Non-Aboriginal participants did not discuss racial discrimination.

The Aboriginal participants indicated that some non-Aboriginal disability workers were judgemental towards Aboriginal people. Some Aboriginal participants had their Aboriginality questioned by some non-Aboriginal workers. An Aboriginal participant discussed her experience of non-Aboriginal disability workers being racially discriminatory towards her as an Aboriginal staff member:

*...found it a lot just telling somebody that I'm Aboriginal. People just seem to look at you and go 'oh ok'. To look at me, you probably wouldn't think I'm Aboriginal ... I do feel like some kind of people do judge me on that."*

Another example from an Aboriginal participant:

*I've had clients go to Centrelink and Housing and it's like they don't look Aboriginal and then the client services officer will be saying, you know, questioning the fact 'are they Aboriginal?' 'are you sure they're Aboriginal?' And I'm saying 'well they've come to our service. They acknowledge they're Aboriginal. You know, I said 'I don't feel the fact that they have to basically prove themselves as Aboriginal under a Court order' – and they go 'oh because they don't look like a typical Aboriginal'. And that, to me, is you know, its racism. And then the client feels victimised then. And then therefore they storm out of Centrelink, you know, and they like no-one's willing to help. They can't help that they're white [in appearance]. You know, and on the other hand, it can happen to someone who is dark skinned as well. As soon as they go into Centrelink or Housing, it's like 'oh what are you here for now', you know. That they're looked down at.*

An Aboriginal worker told of her experience of how a disability case worker expressed racial judgements of an Aboriginal client based on Aboriginal stereotypes:

*... you know, just labelled as being poor and don't they work – you know, [not] worth sort of worrying about ... by some staff. ... I guess just ignorance really [of] ... the non-Aboriginal staff members at times.*

A further example from an Aboriginal participant:

*... putting them into one box. Or 'you know what they're like' or like automatically assuming that a lot of our clients lie. And that frustrates me. But it frustrates me with a lot of mainstream organisations too. Like the disability organisations that I'm working with now, and they automatically put Aboriginal people – well you know 'they lie', or 'you know they're only using the money to buy alcohol' and 'you know they're only using the money to buy drugs'. And that frustrates me so I get really – and sometimes it makes it really difficult when*

*you're trying to advocate for someone and you know that you don't – you can't communicate well with someone because you know they're automatically going to assume that they're – the clients are lying.*

An Aboriginal worker also gave an example of how a disability caseworker voiced discriminatory judgments of an Aboriginal client in relation to the purchasing of disability aids and equipment:

*... I've been in a situation where a non-Aboriginal staff member has tried to tell me that I can claim benefits even though I work in a full time job. I still get more than what she makes every week and all the rest of it. And I pretty much told her to go out and get an education and learn to know what she's talking about because I work as hard as what she does – yeah just small minded sort of thinking ... [non-Aboriginal worker asked] "why can't [Aboriginal client] afford it? They [Aboriginal client] get enough from the government" ... To just stay professional in my role ... I can't be ... taking things too personally and stuff ... but I voiced my opinion and things. But I just sort of left it at that. I didn't see the point in getting into a full blown argument about it, about our difference in opinions or this, that or the other. I just moved on. But in saying that, I would support him [Aboriginal client] in speaking up and saying that this actually isn't the case. Yeah. Maybe you [non-Aboriginal worker] should get to know this family ... a bit more and understand the reasons why behind it or go and speak to our team leader or coordinator or whatever about it if you have any further concerns. So that's pretty much how I deal with it.*

The Aboriginal worker believed that ignoring the racist viewpoints of colleagues and not reporting racial discrimination to the manager was a way of "staying professional". This indicates that "taking things personally" was her way of overcoming racism in the disability services workforce. Interestingly, two Aboriginal participants made a formal complaint about non-Aboriginal workers making racist judgements about an Aboriginal client:

*... it frustrates me but I can actually say that one worker that I've worked with, I went to ADHOC and complained – I said "I'm not working with her anymore, in regards to my client, because every time I speak to her she just automatically assumes that my client's lying or that my client's using money wisely. I said "If*

*it's his money, he can use it however he wants". Like it's not for her to judge. That's not the position that she's in. She's in there to support him with accommodation, not to support – you know, automatically assuming all the time that he's lying.*

And another example:

*Well to be honest, I would pull them up and say 'hey, stop there' ... how can you basically ... make a comment on someone's cultural background from the way they look?' ... And I said "well, the thing is do I look Aboriginal?" I said "because I get asked if I'm Lebanese or Italian" because my mum is Dutch and German. And I said "I've basically got more of mum's genes that have come out in me where my other brothers and sisters, they're more like my dad". And I said "you can't criticise someone for the colour of their skin or because of their features". And when it comes to the fact that they are dark skin and they do look Aboriginal, it's – I basically say to them 'you can't just run them down or make a criticism or remark about how they are' – like with their money and stuff like that, they're not going there because they want extra money or whatever, they've got problems. They've got disabilities. They've got medical conditions.*

Aboriginal participants felt that the racism in the disability service sector is historically entrenched in the general Australian community. Racism was often described as like a battle between Aboriginal and non-Aboriginal people. For example, a Mainstream NGO Aboriginal worker described how her community attempts to eradicate racism by educating school children about Aboriginal culture:

*... we can teach the kids ... a different perspective but if we can't change their parents' mind ... 'we're never going to win'*

Similarly, an Aboriginal NGO manager stated that:

*... there still is racism. If you go out and ask somebody 'would you rent your house to an Aboriginal family?' I bet the answer is no. [then ask] 'Would you rent it to the immigrants?'... [answer would be] 'yeah'. So the racism is there. Sorry, that's how I view it.*

Two Aboriginal workers said that some affirmative action strategies adopted by the disability service sector to address disadvantage can fail to achieve their objectives and reinforce current racist perceptions of Aboriginal people. One example that was discussed at length was an Aboriginal workforce strategy adopted by DADHC. The participants felt that the program had failed to address Aboriginal disadvantage and had consequently reinforced racist perceptions amongst the non-Aboriginal disability service workforce. A Mainstream NGO Aboriginal worker said that the Aboriginal disability workers were “*thrown in there ... [and] haven't really ... had the training yet*”. A Mainstream NGO Aboriginal worker said that some of the DADHC's non-Aboriginal disability workers reported that “*... the clients and the other staff ... have to ... carry them [Aboriginal workers] through [the working day]*”. As a result, the non-Aboriginal disability workforce felt that the Aboriginal workers have “*been employed because they're Aboriginal ... [and that] the government loves to know that there's so many Aboriginals that are employed in different services*”. What this shows is that because some of the Aboriginal workers were not properly equipped or trained to perform their workplace duties, current racist perceptions of Aboriginal people in the non-Aboriginal community have been escalated or reinforced.

The Aboriginal participants spoke about how Aboriginal people were viewed as another ‘cultural group’ together with migrants and people who have English as a second language. The Aboriginal participants found this to be discriminatory towards Aboriginal people. An Aboriginal NGO worker said that Aboriginal people were not like people from culturally and linguistically diverse (CALD) backgrounds: “*... CALD are coming here for a different lifestyle choice which they made. We're coming from a history of where we've been denied access [to services] and put in a position for our whole life. So automatically that's a barrier.*”

When asked what strategies could help overcome racism in the disability services sector, the Aboriginal participants recommended that non-Aboriginal workers need to be educated on Aboriginal affairs through formal staff training, often called Aboriginal cultural awareness training or Indigenous cultural awareness training. The training aims to change the inter-generational cycle of racism within the disability services sector. The below is an excerpt from a focus group with Aboriginal participants who suggested Aboriginal cultural awareness

training as a method to overcome racism as a barrier to Aboriginal participation in disability services:

***Aboriginal participant1:***

*I think the workers have to be a little bit more sort of like – educated. Aboriginal cultural awareness training. It does happen but a lot of them haven't got it.*

***Aboriginal participant2:***

*Well it takes a long time to change an ingrown pattern.*

***Aboriginal participant1:***

*That's it. That's right.*

***Aboriginal participant2:***

*They can go through all the training but unless it's actually [clicking her fingers] changed within, it'll still repeat itself over*

**Factor four summary.** Aboriginal workers and Aboriginal clients of disability service providers reported racial discrimination experiences in the disability services sector. Only Aboriginal participants discussed racism as a barrier to service participation for Aboriginal people with a disability. Racism influenced the culture of supporting and caring for people with a disability inside the family in Aboriginal communities.

**Choice of workers: choice of workers in disability services**

The participants spoke highly of the benefits of Aboriginal workers in influencing the participation rate of Aboriginal people in disability services. Aboriginal workers were often described as a factor in forging relationships between Aboriginal clients and disability support staff.

The Mainstream NGO Aboriginal workers stated that since they have commenced their roles in the disability service sector that they have helped improve awareness on disability services in their families and local Aboriginal communities. Some of the Aboriginal participants reported that their families were not aware of disability services until they commenced working in the disability services sector. A Mainstream NGO Aboriginal worker said she helped her brother support her nephew to access disability services by “...more or less [giving] them

*the information and they passed it on...*". Similarly, a Mainstream NGO Aboriginal worker said that she helped her parents in rural NSW to access disability services.

The Aboriginal participants reported that the level of awareness of disability in their communities improved since they commenced working in the disability services sector. When asked about their perception of disability and disability services since commencing working for the Mainstream NGO, a Mainstream NGO Aboriginal worker responded "*gosh, look what's available. Like I didn't know any of it existed*".

Participants often used the phrase "*trust*" to explain why some Aboriginal people prefer to work with Aboriginal workers than non-Aboriginal workers. An Aboriginal NGO manager said that Aboriginal clients confided openly to her "*because [she is] an Aboriginal person*". Similarly, an Aboriginal NGO worker stated that "*I would say 95% of my clients would much prefer to work with an Aboriginal worker... [and] 25% are quite happy to go either way ... But I would say a great amount of them would say 'oh no, I don't want to go there because it's not culturally appropriate*". An Aboriginal NGO manager further elaborated:

*So much research has been done on Aboriginal people having to work with their own and it's true because we think differently, we talk differently and we act differently to non-Indigenous people. ... You've got to let them [Aboriginal people] open up as they wish. Some people will just start talking and talking, it'll go round and round in circles and as I said, I can sit there for 3 hours before I pinpoint what the problem is. Because they don't – we don't talk like white people so we don't come out and say 'this is our problem, dah dah dah. This is it.' We go around in circles and then eventually it comes through. There is an instant rapport. And a lot of that rapport happens on an unconscious level because we're sympatico. So the trust is there.*

Aboriginal workers were a factor in developing culturally appropriate services. The participants discussed at length how Aboriginal workers were essential for developing culturally appropriate services for Aboriginal clients. A Mainstream NGO non-Aboriginal worker provided a good example of how Aboriginal workers have helped create a culturally appropriate respite service for an Aboriginal family. The worker stated that an ageing mother needed a break from caring for her daughter. The daughter "*resented*" going into centre-based respite care as "*... her earlier experiences of respite had basically been ... stuck in front of a television at*

*a respite centre and ... she ... [felt] it was pretty boring, it was meaningless, no-one really engaged with her and it felt sort of like a punishment for her that she was sent away".* The worker stated that the mum felt "judged as a blackfellow" and that "they've been looked down upon" by other service providers. The Aboriginal workers helped the Aboriginal clients maintain pride in their identity and Aboriginal culture. The Mainstream NGO non-Aboriginal worker found that once he put Aboriginal workers in place, the daughter enjoyed attending respite care. The Aboriginal workers helped build trust between the Aboriginal family and the disability service system. The Mainstream NGO non-Aboriginal worker described the major changes below:

*... This time away we went about ... talking to different services and centres, making sure they were aware of, you know, the girl being Aboriginal and long story short, we got her onto a service who did have some Aboriginal people on staff and where possible made sure that they were rostered on when the girl would be attending their centre ... [and] scheduling in some quite fun activities for her when she is there. But she has an interest in Aboriginal art herself, so although physically she's unable to do any art work ... actively herself, it is something that she's interested in because of her mum's abilities and interest in it. So the staff members at the respite centre will often just sort of sit, they might do their own work but they will take the time to engage the girl in it by telling her what it's about and describing the processes to her. Again, that's been a really nice experience for her, developing those connections with other people from the Aboriginal community who aren't her own family members. ... So for someone to actually sit and take the time to talk through with her how the painting was being put together, what the different symbols really meant, what was the story that was being produced on the canvas was quite a nice thing for her. ... It was important because I suppose that the strong sense of identity that this girl has with her Aboriginality. Because of, I think, the family dynamics, some of the family issues, as well as how this girl can sometimes present, they've been unfairly judged or assumptions have been made about the family previously through different services – and not necessarily just respite. But it was something where – and this is more from what mum has talked about, rather than daughter, but it's where the mum has very much felt judged as "a black fellow" and that they've been looked down on. That the*

*experiences of support services haven't always been, I suppose, affirming in terms of their Aboriginality. She felt that it was something that they were being looked down on in relation to*

Aboriginal workers have helped address access barriers by assisting Aboriginal clients in outer-metro regions to attend scheduled appointments in metro-regions from as far back as the 1990s. For example, a Mainstream NGO non-Aboriginal manager discussed how Aboriginal workers assisted a mother to obtain funding and support for an electric wheelchair for her son in the early 1990s. The participant stated that in this period, the disability service operated within a “*medical model*”:

*There was a family that we worked with, again it was a little boy from the south coast [who] had significant physical disability but I would say probably a mild intellectual disability ... [who] just started school. ... [H]e came up with his mum and with the [Aboriginal worker] from down there who ... was employed by Health. [Aboriginal worker] ... helped with, you know, with getting on the train, getting up to Sydney and then she was instrumental in ensuring that what we worked on, in terms of our recommendations in Sydney, they would be followed up once the family went back home again. ... So over a number of visits, we explored using a powered wheelchair. Now we probably would not have even gone down that path to be honest if we hadn't have the support from the worker who came up. ... And these are back in the days where ... It wasn't probably so much a family centred practice type approach. It was probably a more medical model because there was a doctor who worked with us then. ... As I said, probably wouldn't have gone down the path if we didn't know there was support there. ... After those number of visits, we ... got the funding. And the case worker actually did a great job of getting it up and running, you know, getting him in it, getting him using it...*

Many participants used the words “*connections*” and “*engagement*” and “*time*” to describe how Aboriginal workers have helped Aboriginal people participate in disability services. The participants reported that Aboriginal workers that had established networks with the local ACCOs have helped disability service staff support Aboriginal families in meeting agreed service outcomes. The Mainstream NGO participants often stated that building “*connections*” and “*networks*” with

Aboriginal community members took a long “*time*”. A Mainstream NGO non-Aboriginal worker explained how Aboriginal workers participated in disability caseworker teams:

*... we had a worker who ... [knew] all the key names. ... [the Aboriginal worker and] I went to a meeting with the family ... [when the worker mentioned the] the key things [and] names within those Aboriginal services ... the family actually engaged with her much easier than ... when we just actually talked about the services. And ... that was actually a really good thing for us, like as a team, because we could use her to be able to ... actually enhanced some of those connections [in Aboriginal communities].*

And another example by a Mainstream NGO non-Aboriginal worker:

*...[building] connections and networks [with] those key people [in the Aboriginal community] ... takes awhile .... And there's some very important people within the community that might not be linked to organisations necessarily but are a wealth of information and knowledge and I think formally able to facilitate ... connecting people to services...*

Aboriginal workers in the government sector have influenced the participation of Aboriginal people. The participants often worked with Aboriginal workers from a range of government agencies. A Mainstream NGO non-Aboriginal manager listed the following government agencies that had Aboriginal workers that helped them:

*... sometimes it's Community Health ... DADHC ... Dept of Education. It can be any one ... often it's one of the community services. ... Schools are fantastic.*

The Mainstream NGO participants raised concerns that there were not enough Aboriginal workers in the government sector to provide sufficient support for Aboriginal clients of disability services. For example, a Mainstream NGO non-Aboriginal worker said that an Aboriginal client “*did actually say to me that she wishes when ... the DoCS workers come, that they'd send an Aboriginal person so I was able to feed that back to DoCS ... 'when allocating your case workers do you think you could actually allocate an Aboriginal worker to an Aboriginal family'.*” Similarly, a Mainstream NGO non-Aboriginal worker stated that an Aboriginal

worker from the Department of Education and Training *“[helped] very much...but then his funding ended ... so that was disappointing”*.

The Aboriginal NGO worker focus group expressed strong support for government and non-government agencies having Aboriginal workers as a means to address access and equity barriers for Aboriginal people. The Aboriginal NGO worker focus group discussed the challenges they faced in accessing Aboriginal workers in government agencies for their clientele. The Aboriginal workers felt that there were not enough Aboriginal workers in some government agencies. Aboriginal participants stated that Aboriginal people need to have a choice in utilising Aboriginal workers. An Aboriginal NGO worker said that *“... Centrelink is just a nightmare now. ... even though I lived here in [suburb] personally, if I had to access Centrelink I’d always go to [another suburb] because there was always an Aboriginal person there that I could access”*. An Aboriginal NGO worker stated that there were a few Aboriginal workers at the Department of Housing *“in all different offices ... [but in] DoCS you can’t get access to Aboriginal workers”*. In regards to DADHC, an Aboriginal NGO worker stated that *“... DADHC’s good. I don’t have any issues with DADHC [Aboriginal workers]”*. Another Aboriginal worker said in response to DADHC that *“You can ring up, you can go there [or] just door knock and ask to see someone ... if someone’s available”*.

The Aboriginal NGO worker focus group discussed that people from culturally and linguistically diverse backgrounds have a greater degree of access to interpreters and support workers than Aboriginal people. An Aboriginal NGO worker discussed how the lack of Aboriginal workers is a form of discrimination against Aboriginal people:

*... people who have got English as a second language have the opportunities to ask for an interpreter. So they have the opportunities, they have that feeling of empathy from frontline services ... but for an Aboriginal person, they never give them the same opportunities [in Government services in the metro region]...*

The Mainstream NGO Aboriginal workers said that they felt that their service was isolated from other services in the Mainstream NGO. Some of the Mainstream NGO Aboriginal workers said that they did not know if there were other Aboriginal workers in the organisation. A Mainstream NGO Aboriginal worker stated that *“I*

*don't know whether they have Aboriginal workers [in the organisation] ...". A Mainstream NGO Aboriginal worker said that:*

*... we've got services all over the place, you know, I don't know ... whether there's any Aboriginal people that do work for the [the Mainstream NGO]. I don't know. I've got no idea. As I said, [region is] sort of alienated a bit.*

Similarly, many of the non-Aboriginal workers reported that they did not know of many Aboriginal workers in their organisation. For example, a Mainstream NGO non-Aboriginal worker used the phrase "*white organisation*" to describe the low number of Aboriginal workers in the organisation:

*If I was Aboriginal coming into the [The Mainstream NGO], I would see it as a very white organisation. ... I don't know what our levels of employment of Aboriginal staff are across the organisation, but they don't strike me as much at all.*

The participants talked about how Aboriginal staff can also inhibit Aboriginal people's service participation. The barrier stems from factional "*politics*" between Aboriginal families within Aboriginal communities. The participants discussed that the politics in local Aboriginal communities can discourage Aboriginal clients from engaging with disability services that have Aboriginal staff. Some participants stated that some Aboriginal people were concerned that Aboriginal workers would breach client "*confidentiality*". A Mainstream NGO non-Aboriginal worker said that a client said that "*I don't like that particular person because they know this person and [personal information will] get back to everyone' and so [I] go [to] that [person]*". A Mainstream NGO non-Aboriginal worker explained that some Aboriginal families had travelled long distances to access services because they did not trust local Aboriginal workers:

*... sometimes the family doesn't necessarily want to engage with an Aboriginal worker because they think that [the] Aboriginal worker is linked into the community ... Because of confidentiality issues ... they would actually be quite refreshed to know that they could work with someone outside of their community ... that we would actually travel and go somewhere else so that they could go and get support around the goals that they were working on*

*outside of their community because they just didn't want it to be everybody else's business. So that was something to be mindful of, I think, when you're working in the Aboriginal community – that sometimes it can be quite incestuous in answer to that whole sharing of information and everyone knows everyone's business and it's very ... [Aboriginal families] think 'well if I go there, then they're going to know that and they're going to share it with Auntie and blah, blah, blah and then mum will find out and I'll be up the creek' and all that sort of thing. So, you know, they were actually quite refreshed that they could come to someone that could help them and not have everyone else that lived in their street know about their business.*

Similar to the discussion with the Mainstream NGO focus group, the Aboriginal NGO worker focus group discussed how political associations between Aboriginal families in local communities posed challenges in addressing access barriers to disability services for some Aboriginal people. An Aboriginal NGO worker described it as “*the political thing where, you know, when you say [The Aboriginal NGO] and they said 'oh does that person work there?' And then you say 'yes' and they tend to not communicate with you as much*”. One Aboriginal participant reported one example where an Aboriginal client opted out of the service due to one Aboriginal person working there:

*I was working with someone and they disengaged our services because they discovered that one of their family members worked here. So they were here one day and we were chatting and all this. And another worker came in and when that other worker come in, and when I rang them – we were supposed to meet the following week and I rang them and they've gone 'oh I don't want anything to do with you because she works there'. Well at that particular point in time, I have to disengage because she said no, I don't want to work with you because of that person. I can't change that, the fact that person works here. So that was really quite confronting to me, you know, the politics. So again, just disengaged with that person because if they want our service they'll ring back.*

The Mainstream NGO outer-city focus group provided a few suggestions on ways to overcome Aboriginal workers being a barrier for Aboriginal people's service participation. A Mainstream NGO non-Aboriginal worker said that they

offered Aboriginal clients “the *choice, around who they work with*”. A second Mainstream NGO non-Aboriginal worker said that they asked the Aboriginal family “*[if working with a local Aboriginal worker] is an important thing for them, in terms of ... accessing the [The Mainstream NGO]*”. A Mainstream NGO non-Aboriginal worker said that she did not work with the Aboriginal workers of the education system when she was supporting one Aboriginal client because the referral came through a local school.

A Mainstream NGO non-Aboriginal manager gave an account of how a client utilised the organisation’s Aboriginal worker to return to South Australia. Interestingly, the client was at first reluctant to contact the local Aboriginal worker because she was from a different Aboriginal community. The non-Aboriginal workers were sensitive to the Aboriginal client and allowed the client to make their own decision to contact the worker:

*... This family was ... going through a bad phase ... [so] the therapist sort of said to mum ‘would you like to access our Aboriginal liaison officer?’ and the mum said ... ‘No, she’s not my mob’. And everyone assumed from that, that there was no contact anywhere. As soon as the therapist had left, mum got on the phone to the Aboriginal liaison officer and has set up an appointment with her and then they went from there and there was a strong support that happened after that. ... So us offering it wasn’t the right [way or we] didn’t offer it in the right way and we didn’t give the right space around it ...[or we were too] directive ....*

**Factor five summary.** Providing Aboriginal people with a disability the choice of the Aboriginality of disability service workers was a factor in maintaining the participation of Aboriginal clients. Trust was a significant factor for many Aboriginal people preferring to have an Aboriginal worker over a non-Aboriginal worker. Many Aboriginal workers were known or connected in the local Aboriginal communities, which is why Aboriginal workers were described as family by the Aboriginal participants.

Aboriginal workers have a high level of knowledge on the history, culture and politics of local Aboriginal communities and networks with ACCOs and Aboriginal workers and service providers in the region. Aboriginal workers also

knew how disability was understood and defined in the Aboriginal communities. Non-Aboriginal workers have utilised Aboriginal workers to help achieve service outcomes for Aboriginal people. Aboriginal workers also foster cross cultural pollination amongst the disability services workforce on Aboriginal culture and issues.

Interestingly, Aboriginal NGO workers were required to be engaged in community events, committee meetings and advisory bodies. However, Mainstream NGO Aboriginal workers were not expected to be engaged in local Aboriginal communities as part of their workplace duties.

Aboriginal workers can also function as a service access barrier for Aboriginal people with a disability. This was well known and accepted amongst the Aboriginal participants in this study. Aboriginal community and family politics can result in Aboriginal opting to not access disability service providers who have Aboriginal workers.

### **Choice of Organisations: choice of Aboriginal community managed services or generic services**

There was a divide amongst the research participants on the benefits of having government funded Aboriginal community managed organisations. All of the Aboriginal participants supported the existence of Aboriginal community managed organisations and services. The Aboriginal participants used the phrases “*trust*” and “*comfortable*” to help describe why Aboriginal services were an important factor in influencing the participation of Aboriginal people in disability services. An Aboriginal NGO worker said that Aboriginal clients were “...*comfortable dealing with us because we’re an Aboriginal corporation*”. Similarly, an Aboriginal NGO worker provided the below extract to explain why many Aboriginal people “*trust*” Aboriginal organisations:

*...when they do know where there are services they [Aboriginal people] like to deal with their own kind. ... like us, being an Indigenous agency – when they know that we’re around, they know what we can do for them, they’ll rely on us and they can trust us.*

An Aboriginal NGO worker told a story of how she accidentally met up with an Aboriginal person who she knew from the Aboriginal community on a bus. The

person knew of the Aboriginal NGO through the Aboriginal community and became a client:

*... one particular client I met I just happened to be sitting on a bus. ... A client who I know from [the] Aboriginal community got on the same bus as me ... was really quite agitated and unwell. And I ... helped him become calm ... So once he said that to me 'Can you help me because I'm not well' then I went through the process of introducing him to the service and doing all the right processes. And then I began to advocate with him and I actually introduced him to the Housing First Program ... He's doing quite well now. He's gone back, he's doing casual work and so it was that process of first just meeting a fellow on a bus. So you know, and through that client he introduced me to three other clients ... in similar circumstances ....*

The Aboriginal NGO non-Aboriginal manager said that there exists a high level of “*mistrust*” of generic services in the population of Aboriginal people. This trust barrier impacts on the diagnosis of disability and access to services and supports:

*I think there's a large ... element of ... mistrust of mainstream systems ... which prevents diagnosis ... [and] the discovery 'I might be disabled'. So those are specific barriers for Aboriginal people. There's then, if you sort of take on that maybe they don't trust mainstream providers as much as Aboriginal providers and you say that we're the only Aboriginal provider in [the region of this service type] ... that's an access issue and that's a barrier.*

The Aboriginal NGO participants said that they always worked with the local ACCOs before they work with generic services because Aboriginal people “*trust*” Aboriginal community managed services. An Aboriginal NGO worker said that:

*... I always go ... to Aboriginal services first. I love networking with Aboriginal services. And not only that, you find that they're some [clients who say] 'alright I'll go there' because they know it's an Aboriginal service.*

Similarly, some of the Mainstream NGO participants stated that sometimes they have arranged client meetings at ACCOs or venues because it was “*accessible*” for the Aboriginal clients. The participants’ conceptualized “*accessibility*” in this sense to identify that the Aboriginal community managed organizations were

culturally sensitive for the Aboriginal clients. A Mainstream NGO non-Aboriginal manager said that they have organized meetings at ACCOs because “*the family know the [Aboriginal organisation] ... [and] the family are happy with that arrangement*”. Another Mainstream NGO non-Aboriginal manager concurred that ACCOs were “*accessible ... and the family ... usually feel ok about going ...*”.

Similar to the participant discussions regarding Aboriginal workers, the participants provided examples of some Aboriginal clients not wanting to access Aboriginal services due to family factional politics in the Aboriginal community. On the one hand ACCOs improved the participation of Aboriginal people and on the other hand they have inhibited participation of Aboriginal people in disability services. A Mainstream NGO non-Aboriginal worker explained this point using a client’s experience:

*... So she’d actually had a falling out with a service, with an Aboriginal homecare service. ... Her perspective on that was that because she’s not a local Aboriginal woman, she’s originally from Queensland. She felt that the service that she had contact with was against her for not being a local woman and being from Queensland.*

Similarly, an Aboriginal NGO worker said that some Aboriginal families did not engage with ACCOs or the generic organisations that have Aboriginal staff due to family factional politics in the local Aboriginal communities:

*... politically ... we’re always going to find it no matter what. You know, like I meet a client. And you say to them “I’ll advocate for you to get access from this service” and they don’t want to go to that service because such and such’s brother works there and they don’t like such and such and, you know, just other Aboriginal families. I would say that I met someone who doesn’t want to access this service because there’s someone that works here that they won’t politically associate with. ... I would say it’s a bit of bummer with some clients because I meet a client and I think ‘oh this service would be absolutely perfect. Just advocate for you to link into that service and you’re going to solve three of your issues with one service’ and they just say ‘no I won’t go there. I won’t go to that service.’ I had another client ‘Nup. I won’t go to the AMS. I don’t want to go to the AMS’. AMS has got funding...*

There was a divide amongst the Mainstream NGO participants on the benefits of government funded ACCOs. On the one hand, some of the Mainstream NGO participants supported the existence of ACCOs, suggesting that it helped address access and equity barriers to services for local Aboriginal communities. On the other hand some the Mainstream NGO participants felt that funding Aboriginal specific services was “*divisive*” and exacerbated “*cultural separatism*” between Aboriginal and non-Aboriginal communities. A Mainstream NGO non-Aboriginal worker said that “*I think it is necessary because there’s such a big gap between Aboriginals and non-Aboriginals [and] to assist to bridge that gap*” between Aboriginal and non-Aboriginal health outcomes. A Mainstream NGO non-Aboriginal worker used the phrase normal to describe generic services. A Mainstream NGO non-Aboriginal worker provided the following statement explaining why the government should not fund ACCOs:

*... across the board it’s very divisive ... to funding to normal Australians if you like. If that’s not the case, then it certainly separatist. If ...DADHC funded streams to all Australians, then there are certain ethnic groups who are separated out, then that’s divisive in itself. ... what I believe is to [be] the fundamental issue is suspicion of mainstream [services, which creates]... a cultural non-acceptance [in Aboriginal communities] of what disability services provide.*

Another Mainstream NGO non-Aboriginal worker felt that the funding of Aboriginal specific services separates Aboriginal people from the ‘general’ community. However, this worker felt that the funding of Aboriginal specific services is essential to help address service gaps in Aboriginal communities:

*... I think already Aboriginal people, whether they have disabilities or not, [are] already segregated .... I do think that if you separate everybody in their ethnic groups that it becomes a problem .... they’re already segregated so ... not having funding for Aboriginal families with children, or even young adults with disabilities, it separates them further than they already are. So then they just have no access, less access to services so if you have funding for them specifically, then it gives them a bit more of an opportunity. Whereas if you did a whole group of funding they’d probably get lost along the way somewhere ...*

Similarly, an Aboriginal NGO manager stated:

*Well to me, if we're advocates for Aboriginal people, we're dealing with a lot of mainstream organisations which to me is proof in itself that we're bridging that gap. Because the people can't really talk to themselves. So we're acting as the go-between ... the client and the mainstream. So that in itself is saying that yes, we're bridging that gap so we're fostering unity not separatism.*

There was also a debate in the Mainstream NGO management focus group along the same lines as the Mainstream NGO workers focus groups. A Mainstream NGO non-Aboriginal manager said that "...the whole concept of Aboriginal specific programs actually marginalise people more from the mainstream because it's set up all around them and it becomes a service that's set up specifically for a small type of group and then it becomes very difficult sometimes for them, or those services to connect with others". The second participant referenced the United Nations concept of "twin tracks" to describe the need for "specialised" services to address disadvantage:

*... [the] concept of twin trackers always nice isn't it? That you have this specialised service and then you have your generic services. And it's like DNA, you've got to have the double band to hold things together. And so people need to be able to have their choices around what they're accessing, and the two can be complementary and supportive of each other. So if there are working partnerships between specialised services and say the [the Mainstream NGO], so specialised Aboriginal services from the [the Mainstream NGO], that's really a positive. And families have got choice within there about what they do and who they choose and support that can happen there, that can be great.*

Some of the participants said that the funding of Aboriginal specific services and programs reconciles community service providers and Aboriginal communities. An Aboriginal NGO non-Aboriginal manager stated that the Aboriginal NGO is "helping ... clients get into the mainstream structures which they may not have been dealing with themselves ... [therefore] we actually play a linking role even though we're an indigenous specific service". The Aboriginal NGO worker focus group gave an account of how many different government agencies funded an

Aboriginal event during International Day of People with a Disability that empowered Aboriginal people with a disability and united Aboriginal and non-Aboriginal communities:

*... when we had our [International] Day of Disability last year in December, I sent an invitation to DADHC to attend our day which [the Australian Government Department of Families and Community Services and Indigenous Affairs] FACSIA just rang us out of the blue and said 'we've got this money for International Day of People with Disability – here's [amount], host a morning tea'. So we said 'alright, we'll host a morning tea'. And at the same time we'll go one step further and access services and say thank you to some of the services that works with us in partnerships. So we hosted at [an Aboriginal NGO] and they said 'yeah, come along, use our services, you don't have to give us any money'. So we went over there. [Region] City Council said 'yeah, alright, we'll give you some money'. And they hired ... the bus to make sure that we could get clients and transport them there. So I sent an invitation to DADHC to come and they done even one better, they messaged me back and said 'yeah, yeah, we'll come and we'll give you money'. So they said like we'll give you [amount]. ... the best thing about it is some of the money we got from them we actually empowered some of our clients. And our clients come in and cooked the bbq. And so then we were able to give them \$50 and say thank you for a job well done. Some other clients come in and helped cut up the salads and things like. So we gave them a gift saying thank you – that's we done with most of the money that they gave us. So at the same time we empowered some of our client groups ...*

**Factor six summary.** Similar to the Choice of Workers factor, giving Aboriginal people with a disability a choice of ACCOs or generic disability services helped address access and equity barriers for Aboriginal people. Many Aboriginal people preferred to access ACCOs because they did not trust disability service providers or non-Aboriginal workers. This trust barrier is historically and culturally entrenched in local Aboriginal communities. ACCOs have helped empower Aboriginal people with a disability by fostering reconciliation between disability services and local Aboriginal communities. Disability service providers

utilised ACCOs to help support Aboriginal clients, such as facilitating meetings and client service planning.

Similar to Aboriginal workers, many Aboriginal people did not utilise ACCOs due to Aboriginal community and family politics. There was a divide amongst the non-Aboriginal participants on the funding of ACCOs. Some of the non-Aboriginal workers from the Mainstream NGO felt that funding ACCOs and Aboriginal specific services foster cultural separatism.

### **Community connections: connection between Aboriginal communities and disability service providers**

The participants spoke at length on the importance of established “relationships” and “connections” between Aboriginal community-managed stakeholders and generic disability services as a factor in influencing the participation of Aboriginal people in disability services. The issues raised during these discussions differed between Aboriginal participants, Mainstream NGO non-Aboriginal workers and managers.

Participants from both NGOs reported that their networks and relationships in the local Aboriginal communities have influenced the types and numbers of client referrals. The Aboriginal NGO participants received many referrals from ACCOs and Aboriginal workers at Aboriginal community meetings. The Aboriginal NGO workers gave examples of clients being referred from Aboriginal workers at the Koori Inter-agencies and Aboriginal staff from community services and ACCOs. The Aboriginal NGO participants reported that Aboriginal client referrals were mostly self-referral because the organisation is imbedded in the local Aboriginal community. An Aboriginal NGO worker said that “*as a whole ... I’ve met 80% of my client group*” through self referral.

The mainstream NGO City focus group did not know of any Aboriginal clients who were referred from ACCOs or Aboriginal community workers. The Mainstream NGO outer-city focus group received referrals from an ACCO and a small number of referrals from Aboriginal community workers. Most of the Mainstream NGO’s Aboriginal client referrals were through the formal referral pathways.

The Aboriginal NGO participants reported that all their client referrals were the result of established relationships in local Aboriginal communities. The Aboriginal NGO participants spoke at length of the importance of being engaged in Aboriginal

community events, community projects and interagency committees. The Aboriginal participants said that relationships with Aboriginal community stakeholders were essential to open client pathways to their disability services. The Aboriginal NGO participants stated that informal networks were just as important as formal networks to open access pathways for Aboriginal people to services. An Aboriginal NGO worker used the phrase “*governing points*” to describe the process of being involved in local Aboriginal communities to open client access referral pathways:

*... That's how I meet them, you know, sitting on a bus or another client I met just went to a program at the local church and seen a client ... as soon as they seen the Aboriginal flag on my case they just started talking to me .... So it's just a process of being out there. And you find that a lot of our clients don't have access to a home phone. So they tend to travel to different areas. ... So overall, you need to be there. You need to have those governing points where you can be at places where people can access you but also need to be able to speak because if you don't speak to them, then no-one will get services.*

The Aboriginal NGO participants stated that the Aboriginal NGO policies and procedures require all Aboriginal workers to be involved in Aboriginal community events, committees and programs. An Aboriginal NGO worker commented that:

*...our policies and procedures enable us to work, you know, from an interagency or across communication pathway, so it's also something that's promoted within our policies and procedures in order to make sure that we have good access with the communities. ... You know, interagencies being part of the whole process of the community as a whole. The disability interagencies, carer interagency and all that sort of thing. So we wouldn't survive if we were doing it on our own. We'd have to make sure that we're out there and we're doing things and our policies reflect that. Of course, we're allowed to do those sort of processes to work efficiently in what we do.*

The below extract exemplifies how the Aboriginal NGO workers reported their experiences of “*networking*” and building relationships with both generic organisations and ACCOs through interagency committees. The Aboriginal NGO workers used the analogy “*family*” to describe the intimacy of the relationships

between Aboriginal community service workers and Aboriginal community members:

*...what I've observed since I've been here, different Aboriginal organisations in the communities are willing to basically have us networking with them. Everyone likes to network with each other. For instance, I had a good visit this morning ... from a lady and she said "Look there's a Koori inter-agency meeting on Thursday. I'd like you to come along". ... I'll be going there. Attending at Campbelltown and then from there Bankstown. So you're getting to meet all different organisations and getting to know what they do.... we get brochures ... [and] invitations to go here and go there. ... it's like everyone's like family. They basically say 'ok well do you know about this place? Go there for help.' So everyone's sort of educating each other.*

Contrary to the Aboriginal NGO workers, Mainstream NGO Aboriginal workers were not engaged in their local communities as representatives of the Mainstream NGO, because they did not have any Aboriginal clients. A Mainstream NGO Aboriginal worker stated that the Aboriginal staff she worked with did not network with the ACCOs on behalf of the organisation because they "*had no Aboriginal families come through ... since [they] worked [there]*". Another Mainstream NGO Aboriginal worker felt that her networks in the Aboriginal community had not helped her organisation "*... because [they] don't have any Aboriginal clients. So it's hasn't really been able to apply anything*".

A Mainstream NGO Aboriginal worker stated that she did not work with any ACCOs because she had no Aboriginal clients. This worker also felt that she was the only Aboriginal worker in the Mainstream NGO:

*... I can only speak for the clients that I know and work with. They're the only ones that I do know through the [The Mainstream NGO] because I don't really travel or able ... [to] ... really catch up with any other services around and I think I'm the only [Aboriginal person] working [in the Mainstream NGO] that they do have.*

The Mainstream NGO non-Aboriginal workers reported that they could only engage in Aboriginal communities if it was an expected part of their employment roles and responsibilities. The majority of the Mainstream NGO city focus group

participants had no connections and relationships with Aboriginal community stakeholders. A Mainstream NGO non-Aboriginal worker responded to the question “do you receive referrals through Aboriginal community meetings” in this way:

*It goes to [another branch] which is ... another Department within the [the Mainstream NGO]. So we don't actually...*

Some participants from the Mainstream NGO have established relationships with Aboriginal community managed stakeholders specifically to support their Aboriginal clients to achieve ‘client outcomes’. Not only did the Mainstream NGO participants use the phrase “connections” they also used the phrase “engagement” to describe these types of relationships. A Mainstream NGO non-Aboriginal manager stated that:

*Well our teams ... work really hard to find out ... who the key ... [Aboriginal] organization[s] might be in the area ... [and] make direct contact with that organisation. Find out, explain a little bit about what we do. Find out what their engagement is. What they're able to provide. ... [relationships have] been in place long enough now to know who the local organisations are for their [the Mainstream NGO's] outreaches. Our team in [town] would know who would be on the far north coast, all the way down to [town] ... the tricky thing ... for our teams [is] to keep a handle on who the different agencies [are] ... [and] what they have the brief to do ... and how engaged they are with that family as well.*

The non-Aboriginal participants from the Mainstream NGO used the phrases “sharing stories” and “sharing information” to explain the need to improve the level of knowledge of Aboriginal communities and Aboriginal affairs in disability services. A Mainstream NGO non-Aboriginal manager told of how attending a local Aboriginal community event helped build “connections” between the Mainstream NGO support teams and local Aboriginal disability workers of an Aboriginal NGO:

*I went to a consultation group up in [region] ... it was good in itself and it was great to hear stories and to share stories ... I also then heard of something ... for intensive family support workers for the Aboriginal intensive support*

*workers ... so I sort of said 'hey would you mind if... we could go along to that' and so then all the connections happened there and so then there was an avenue to make a new connection with the [service]. ...sometimes it's surprising ... what the future connections will [be]come but there's often new pathways that you weren't expecting. That's always a real positive in terms of ... another doorway opens and there is another avenue to explore. That makes it really worthwhile doing.*

The Mainstream NGO focus groups discussed some challenges they faced in establishing relationships between their organisation and Aboriginal communities. Similar to the comments of Aboriginal workers and ACCOs, the Mainstream NGO participants used the phrase “connections” to describe the development of relationships between generic services and Aboriginal communities. The Mainstream NGO management focus group participants raised two challenges in forging relationships with Aboriginal stakeholders: “knowledge” and “awareness” of who to contact and receiving “invitations” to attend Aboriginal community meetings. The Mainstream NGO management participants indicated that “demonstrating” their “willingness” to work with local Aboriginal community stakeholders was challenged by not knowing who to contact or how to be invited to participate in meetings. The below extract of a discussion with the Mainstream NGO management focus group on the development of an Aboriginal community event in a metro region of NSW exemplifies this finding:

***Mainstream NGO non-Aboriginal manager 1:***

*...when we first started it was actually a knowledge [gap] of what services ... [and] Aboriginal service networks were out there. ... there was no [Aboriginal service] directory. ... I think that, for us, to get started you need some place to go and say 'well in this area there are 6 services' or 'there are 2 services only' etc. And that was a barrier for us to some degree because we didn't know where to go and who to make contact with. ... I think that's the other thing is that people must start making connections ... [and pass] that [knowledge] on to other staff so it remains quite alive in the organisation. So it's not, you know, person dependent. So I think that is often the issue. And then getting an invitation. But often, I think if you demonstrate a willingness to go to things, turn up and contribute, then more often you get the invitation back. ...*

**Interviewer:**

*Is that the experience for all of you?*

**Mainstream NGO non-Aboriginal manager 3:**

*I think so. I think the hardest step is always the first step in making the connections. But people are pretty forgiving in the community so if it's not the right time then something else will come up and [community] invitations are often extended. [Someone agreeing] I think once you've voiced an interest or demonstrated that this is the way you want to work, even if you're not exactly spot on in perhaps the right way of approaching that, that doesn't matter – there's still an opportunity to keep trying and working*

**Mainstream NGO non-Aboriginal manager 2:**

*I think the [the Mainstream NGO] Board forum was a good example that we started [someone saying yes] ... And as a consequence of the connections made there ... [knowledge of who to] connect with etc [improved]. So I think the biggest barrier sometimes to know where to start, who to start with. And sometimes it's a bit of a hit and miss game. [several agreeing]*

Some of the Mainstream NGO participants used the words “*fear*” and “*anxiety*” to describe their concern about offending Aboriginal people by breaching cultural protocols in forging “*connections*” in Aboriginal communities. The Mainstream NGO management focus group were concerned that if their organisation breached Aboriginal cultural protocol it could create “*barriers to access*” for Aboriginal people. The Mainstream NGO management gave an account of an organisation event in an Aboriginal community in a non-metro region of NSW where the organisation breached Aboriginal cultural protocols. The Mainstream NGO management also reported that the Aboriginal communities were forgiving:

**Mainstream NGO non-Aboriginal manager 2:**

*And we're working out of our recent opening in [a non-metro region] and we thought we were talking to the right person and then [were] very clearly told that we weren't. And the right person was somebody else. ...*

**Mainstream NGO non-Aboriginal manager 1:**

*I think that's hard to know those connections. [several agreeing]*

**Interviewer:**

*So what's the consequence of getting that wrong?*

**Mainstream NGO non-Aboriginal manager 2:**

*... I think part of the problem is that we don't understand what the consequence is. We're anxious ... in causing offence [as] it may create further barriers to access [for Aboriginal people]*

**Mainstream NGO non-Aboriginal manager 4:**

*Yeah, we're on a blacklist for a couple of months until we get it right ...*

The Mainstream NGO management focus group was also concerned that any breaches in the local Aboriginal cultural protocols could impact on the reputation of the organisation in the local Aboriginal communities. For example, the Mainstream NGO non-Aboriginal manager said that:

**Mainstream NGO non-Aboriginal manager 3:**

*... you do notice the gaps in the participations in [the] service and it doesn't change and you don't know actually what's been said. But we hear that the grapevine is quite healthy and strong.*

**Mainstream NGO non-Aboriginal manager 2:**

*So [recent events]... had some impact on our reputation as a provider. ... you're not quite sure what's been said but you've heard something has been said and you're going to have to wait [to know the reasons for Aboriginal people not participating in the services].*

The Mainstream NGO managers were concerned about how their engagement and actions in the local Aboriginal communities will impact on the reputation of the organisation. The reputation of a disability service was described as both a “*facilitator and a barrier*” to forging relationships between generic services and

Aboriginal communities. The below extract was from a mainstream NGO non-Aboriginal manager:

*Often word of mouth ... can both be a facilitator and a barrier. If something does go wrong, that message certainly gets out there in the [Aboriginal] communities and so you've got to be aware that what you do do, you do it quite carefully. But if things do go wrong, you need to be aware that maybe they need to go back in and build bridges. And often ... things are misinterpreted so it's ... our awareness of what is actually happening ... in delivery of the service. So I think there's definitely a lot of barriers ... in communication ... [and] the images that we give out about our services. This is something about our welcome, our communication, that makes it easier for Aboriginal people, Aboriginal communities to say 'yes, we could access that service'.*

**Factor seven summary.** The participants spoke at length on the importance of relationships and connections between Aboriginal communities and disability service providers. Interagency relationships helped break down the historically entrenched trust barriers between Aboriginal communities and disability service providers.

Relationships fostered client referrals and built mechanisms of support for Aboriginal clients. The Mainstream NGO city focus group did not know of any Aboriginal people who were referred by an ACCO or an Aboriginal service. The Mainstream NGO outer-city focus groups knew of Aboriginal people who were referred by ACCOs and Aboriginal services.

Aboriginal NGO participants reported that most of their referrals were self-referral because the organisation was imbedded in the local Aboriginal communities. However, most of the Aboriginal client referrals to the Mainstream NGO were through formal referral pathways. The participants from the Mainstream NGO reported that all referrals went through the agency's bureaucratic process.

## Trustworthiness of generic services

The participants identified a “culture of *mistrust*” of generic disability services in Aboriginal communities as a factor that inhibited Aboriginal people’s participation in disability services. There were three main reasons for this culture of mistrust.

Firstly, some of the participants spoke about how some of their clients’ wariness of services was a result of being disempowered in the generic community service system. The participants reported that many Aboriginal families did not seek assistance from the human services sector as they did not trust generic services. Some participants reported that some Aboriginal people did not trust government agencies or officials. As such, some Aboriginal people identified disability services as just another government agency. A Mainstream NGO manager discussed their concern:

*...if they [Aboriginal people] don't know who we [disability service providers] are and what we [disability service providers] do, it's very scary because I think, like the Health system, is much more vigilant than us [disability service providers] and they [Aboriginal people] perhaps don't have good experiences with the Health system and they think this [disability service provider] is just another branch of that [health system] .... I don't think people know enough about us [disability service provider] in perhaps the Aboriginal community.*

Secondly, some participants reported that some Aboriginal clients distrusted disability services due to some past failed government interventions. Some Aboriginal families felt disempowered by previous interventions and were therefore suspicious that the Mainstream NGO caseworkers would treat them the same way. A Mainstream NGO non-Aboriginal worker gave an example of one of their clients who was “*weary*” and “*distrustful*” of services due to previous government community services being “*quite directive*”:

*... I guess when I started working with them I found granddad to be quite weary of working with services. His past experiences with the services have been quite directive, so they've come in and told him what they wanted him to do, what his needs were, what the child's needs were ... I guess I spent a lot of time with him discussing his relationship with the services and his past experiences. ... he was carrying with him his experiences ... and then the*

*experiences he's had with his grandchildren. Both of his grandchildren were in foster care. One resident with him and one with ... [a] foster care family. I guess, he was really dissatisfied ... with the service he had been provided up until then. And was quite distrustful of people coming in and getting involved .... He didn't really have any expectations that people would listen to what he had to say. I guess he was really used to that very directive type service. And really part of that distrust was ... that [previous] services hadn't really understood the importance of his contact and the grandchildren's contact with the wider family. In particular, the little girl, the granddaughter who was recently with another foster family, didn't really have a lot of contact with great aunts and uncles and cousins and those sorts of things.*

Thirdly, some Aboriginal clients have experienced discrimination. Some of the participants reported that they have witnessed many referring agencies making discriminatory remarks towards some of their Aboriginal clients. The Mainstream NGO non-Aboriginal workers realized first-hand that the Aboriginal families were not going to trust them. A Mainstream NGO non-Aboriginal worker used the referral of a client's family as an example:

*...school was making lots of noises about non-participation and non-follow through with medical things. Had a couple of discussions with ... the school counsellor who made some fairly derogatory comments about the family, about rolling up at the door and being given ... a pizza box to write a phone number on and there [were] holes in the wall and she was going to put in DoCS reports and all this sort of stuff. .... So I guess from our point of view, for them to come in through our service for some extra support just around reengaging the therapy needs ...[and] getting them to trust us given that the other people hadn't been particularly trustworthy.*

**Factor eight summary.** The participants identified a culture of mistrust of non-Aboriginal generic agencies in Aboriginal communities. The culture of mistrust is historically and institutionally entrenched in the disability services sector and Aboriginal communities. There were three reasons for the mistrust. Firstly, Aboriginal people had a history of being disempowered in the service system since colonisation. Secondly, past failed government interventions since colonisation have created suspicion amongst many Aboriginal families of the

intentions of Mainstream NGO non-Aboriginal workers. Thirdly, some Aboriginal clients have experienced racism and discrimination in the disability services sector.

### **Multiple agency intervention: number of agencies involved in carrying about intervention**

The participants discussed how most of their clients experienced interventions from numerous government and non-government service providers. Most of the clients used as examples by the participants in this study had many agency interventions before becoming a client of the disability organisations that participated in this study. Some of these interventions were not related to 'disability'. The participants discussed the negative impact that multiple agency interventions had on Aboriginal families. Many Aboriginal clients that the participants used as examples for the purposes of the study were fully dependent on government financial support to cover their living expenses. Some of the participants' clients were required to meet the competing demands and requests of many caseworkers from a range of health and community services.

There were five major consequences that multiple agency interventions had on Aboriginal clients. Firstly, some of the participants reported that the multiple service interventions reduced the client's disposable income and increased personal stressors, often resulting in clients missing scheduled appointments and/or exiting the service system. A Mainstream NGO non-Aboriginal manager explained that some agencies get upset when "*... people miss appointments because there's an allocation of resources to that appointment, it's always frustrating for the service, whether it's the local GP or the paediatrician or our service...*". A Mainstream NGO non-Aboriginal worker said that "*issues of attendance could usually [be] traced back to all the issues with transport ... getting caught out ... and the whole issue of disability...*". A Mainstream NGO non-Aboriginal manager suggested that caseworkers who "*... want to build ... positive relationships between the client and the services ... [then workers should] actually not judge people when they don't turn up to appointments but try to understand what are the factors behind not accessing those appointments*". A Mainstream NGO non-Aboriginal worker said that many agencies that referred Aboriginal clients described Aboriginal people who did not attend scheduled appointments as "*difficult to engage*":

*... the sporadic attendance to appointments actually gives families a reputation. So when referrers refer them, they will say to you ... 'they're not regular coming to appointments. I don't know whether they can be bothered. They're difficult to engage.' So they will tell you 'these are really difficult people to engage'. Actually I think it's the structure of the programs ... [not] allowing ... flexibility and the timeframes which make it difficult for those families to engage.*

Secondly, the participants indicated that it was difficult to isolate some of their clients' service needs due to the large number of agencies involved in the client's lives. The participants provided examples of clients who experienced additional problems and crises as a result of multiple agency interventions. A Mainstream NGO non-Aboriginal worker said that he had difficulty isolating the main problems experienced by one of his Aboriginal clients because *"it was a very complex family who'd had lots of involvement with lots of agencies ... [resulting] with a fair amount of distrust [of The Mainstream NGO]"*. A Mainstream NGO non-Aboriginal worker said in relation to one client:

*... I think it's really hard to be able to isolate what the real needs and issues of the family are at the present time because there are a lot of people involved. And also, because Mum can only cope with so much at a time – she's got a huge amount on her plate. And she's doing really well to cope with what she's got.*

An Aboriginal NGO worker gave an account of a client who left the disability services system due to stress caused by having multiple organisations:

*I had some issues with a client that ... was a referral from another community based organisation. So when I got in contact with the community based organisation, she said "I also referred her over to this place" and so then I went looking for her. So I went to that place. And they said 'oh no, she didn't want to come here because when she said that she was [The Aboriginal NGO] client, I said can I ring [the worker] and chat to her". So for her, I don't know whether it was multiple organisations or whether it was still a personal thing about the communication between her and another person and she didn't want anything to happen. But she disengaged with all three organisations. The*

*referrer, the one where she was referred to and, of course, [The Aboriginal NGO] services.*

Thirdly, the participants reported that they had to be flexible around scheduled appointments to prevent over burdening the Aboriginal clients who had multiple agency interventions. This was particularly important for clients who resided in rural/regional areas of NSW. For example, a Mainstream NGO non-Aboriginal worker said that:

*...one day I had a lot to do with ... [a family who] would just ring up and say 'I'm coming down today' ... because they had petrol or they could do it ... we would have to kind of rearrange our appointments to fit them in because it's important to fit them in. But we might already have a lot people booked in that day. So sometimes we couldn't do it but yeah, but we tried to where we could. And that's been a sort of pattern and sometimes, you know, we make appointments and we'll try our doctor and sometimes they don't and but we just make another appointment ... That's been important to have that flexibility.*

Another example was provided by a Mainstream NGO non-Aboriginal manager of how the Mainstream NGO staff had to support Aboriginal clients to get to appointments scheduled by other agencies:

*The family ... will be told the appointment by the doctor or the assessment service and they come to us and say something like 'you wouldn't believe it, they've made the appointment for 9 o'clock. We can't possibly get there for 9 o'clock from where we live with the kids'. So then it will be 'what can we do'. We would sometimes talk to the agency and see if they could make it later, that would be one thing. Or alternatively, you organise someone to be there at a time to pick them up ... carers groups [or] some Aboriginal services [or] the Aboriginal liaison officer ... to get to an appointment.*

A Mainstream NGO non-Aboriginal worker used the analogy of a “treadmill” to describe the stress that Aboriginal clients experience in meeting the competing expectations of multiple agencies:

*... this family was actually referred to us by three different agencies ... at the same time. ... [there were] DoCS ... Special Ed Unit ... and [the] Aboriginal*

*Medical Service.... So I worked with all of them. And I guess, for me, it was more around educating them around the care that they would take when thinking about this family. This is not just a family on a treadmill that you just tick the boxes. Don't just go ticking boxes with this family. 'oh they didn't show up today', tick the box. That kind of thing. Let's look into this and see what's going wrong. And Mum had low literacy levels. They would send her a letter with an appointment time on it, that's really not going to work. You're going to have ring, make contact, set that up – how are you going to get here? Do you need a hand with transport? Can I send you a taxi voucher? Something like that. But I guess the thing with most services is that they say 'oh we don't have the time to do that sort of stuff'.*

Fourthly, many of the participants reported that some health and community service providers were 'process focused' and had little regard for their clientele. A Mainstream NGO non-Aboriginal worker described this focus as the "*treat them and street them kind of attitude where it's like get them in, tick the boxes, get them out*". A Mainstream NGO non-Aboriginal worker gave another account of how some agencies were process focused:

*... the hospital was concerned, all her other children had intellectual disabilities so, you know, there's a history there for this family. And they wanted to keep a check on him so – but they'd do things like set him up with an appointment at 2.30 in the afternoon. So then, you know, she'd need to be at school to pick up one kid from school, be back at home to meet the bus for the other kid coming back from special ed and get this one to the appointment. Now how do you [do] that when you're walking everywhere. And the little girl that was going to special ed, DoCS had made a place for her to go to preschool 2 days a week. So mum had a 20 minute to half an hour walk to walk this little 3 year old to preschool with the new premmy baby in a pram. So half an hour there, half an hour home. And any day that she didn't turn up the preschool would report to DoCS to say that she hadn't turned up today. Like you know, did they look out the window and see if it's pelting with rain and are you going to take a new born premmy baby out in the pelting rain to walk with a pram 20 minutes, half an hour to get the other one to preschool. By the time you get there, everyone's saturated. She's already dealing with ... all the sort*

*of known difficulties that young Aboriginal children are facing. Just like all these really unrealistic [service provider] expectations.*

The participants gave many examples of how organisations were so processed-focused that multiple agency interventions resulted in duplication of resources within the disability services sector. The Aboriginal NGO Manager provided an example:

*The client needed a particular bed for the child. And everyone involved ... was basically after the same bed and people saying 'no, no, no there are no beds'. So again, that's when you've got multiple agencies who aren't communicating with each other about the client. So everyone's trying to get the same bed. Do you know what I mean? That communication thing because nobody's actually sat down and gone 'well, yes she needs this bed and so and so is accessing that or we're going to apply for that' but nobody knew of all the other different agencies that were involved. And, you know, I, myself, if I had all these agencies coming in, I'd be going 'get the fuck out of my way. Give me some peace'.*

The fifth impact that the participants reported was that that some Aboriginal families struggled to understand some of the processes and requests made by some of the agencies. This lack of understanding and clarity adds to the emotional and financial stress placed on families. A Mainstream NGO non-Aboriginal worker gave an example of one Aboriginal family:

*... I was able to explain to her [Aboriginal mum] what it was that these other services were looking for and that's why they keep doing these things ... because no-one had actually taken the time to explain to her why they kept wanting him [the young boy] to come to appointments and why she kept having to see the paediatrician and why she had to see the family health nurse every week. ... no-one had ever taken the time up until this point to even explain to her about meeting milestones and indicators of child development. Maybe some other kinds of disasters for her other kids could have been circumvented [if] she'd had an understanding of why it was that they wanted her to do some cross body stuff with their little fella to get the brain activity going. Things like that. They assume a lot, I think, the services.*

A number of the Mainstream NGO participants reported that some Aboriginal clients have resisted engaging with caseworkers as a direct result of the stress caused by multiple agency interventions. A Mainstream NGO non-Aboriginal worker gave an account of an ageing Aboriginal client who adopted a “passive resistance” strategy against the disability service providers who were involved in his life:

*... he really took the road of sort of passive resistance. He listened to what people told him, and then he didn't follow through with anything. So there was a lot of frustration on the part of services, and I guess when I got involved with them, the conversation I had with Community Services was 'we need to get the Grandad on board, this is what the child needs, can you go and get him to agree to do these things'. ... And [he] was quite distrustful of people coming in and getting involved and I guess again, his response was really sort of a passive resistance thing.*

Two Mainstream NGO non-Aboriginal workers reported that they had Aboriginal clients change their contact details in response to numerous disability caseworkers and other agencies phone calls:

*...her history with all other service providers is to not answer the phone ... if they ring too much [or] to buy a new sim card and change the number ... so they couldn't contact her. ... maybe day 2 of my visit ... she said 'oh, you know, they just ring me too much I just go and buy a new sim card and change my number'. And I said to her 'If I tick you off that much, I really want you to tell me. I won't be offended. Just tell me if I tick you off, don't change your number on me. Promise me that you'll do that'. And she said 'ok I promise'.*

And the second example:

*I would keep phoning and maybe it was like [mainstream non-Aboriginal worker] said, she changed her sim card but I don't think so. One time the phone actually got handed to another family member for about a month and I didn't know all that. But I'd just keep getting the answer phone. And she didn't have another contact.*

Some Aboriginal clients resisted by not following through with any of the recommendations and requests made by community service caseworkers. A Mainstream NGO non-Aboriginal worker said that they received a call from a school teacher making complaints about “...*non-participation and non-follow through with medical needs*”. A Mainstream NGO non-Aboriginal worker told about a DoCS caseworker who referred a client to them requesting assistance to make the Aboriginal family to do what was requested of them by DoCS.

Although multiple agency interventions were causing problems for some Aboriginal clients, the participants also reported examples of clients who were “*connected*” or “*linked*” to other services or were “*re-connected*” or “*re-engaged*” with the existing services that were involved. For example, a Mainstream NGO non-Aboriginal worker said that with a client he decided that “*rather than working directly with children’s behaviour [problems], it was really looking at helping the Grandparents re-engage and feel confident that ... people were listening and enabling what they wanted [from these services]*”.

A number of participants reported that they worked with their clients to address problems caused by multiple agency interventions. For example, a Mainstream NGO non-Aboriginal worker stated the main outcome for one Aboriginal client was providing some therapy for her child just to confirm “*what mum was doing was really good ... [as] she didn’t have any confidence ... [because] she got quite a bit of criticism from other service providers that she should have been doing more*”. Another Mainstream NGO non-Aboriginal worker said that with one of her clients, it was very common for her “*to have contact with different agencies and services that were already involved with the family ... some of those were Aboriginal specific [and] some of them weren’t*”.

**Factor nine summary.** The participants discussed how many Aboriginal people with a disability experienced interventions from multiple government and non-government agencies. There were five major consequences of multiple agency interventions:

1. Multiple service interventions reduced the level of disposable income of Aboriginal families, often resulting in clients missing scheduled appointments and/or exiting the system.

2. Disability service workers indicated that it was difficult to isolate the clients service needs due to the large number of agencies involved in the client's family. The participants provided examples of how other agencies created new problems or exacerbated existing problems in the families.
3. Disability workers had to be flexible and patient with appointments to prevent over burdening the families that had multiple agency interventions.
4. Some community service providers were focused on bureaucratic process and had little regard for their clientele.
5. Many Aboriginal families struggled to understand some of the processes and requests made by the agencies who were involved in their lives.

### **Trusting workers: trust between caseworkers and Aboriginal clients**

Eight strategies to establish trusting relationships between non-Aboriginal disability workers and Aboriginal clients were identified. The development and maintenance of relationships between Aboriginal clients and disability caseworkers was discussed by the participants. Similar to previous factors, the terms “*trust*” and “*judgement*” were used to describe the development of trusting relationships between caseworkers and Aboriginal clients.

As raised earlier in this chapter, the Aboriginal NGO workers stated that overcoming trust barriers was not a challenge for them in building relationships with their clientele. Reasons being were that many Aboriginal people trust Aboriginal workers and Aboriginal community managed services.

Firstly, the Mainstream NGO non-Aboriginal participants expressed that it generally takes more “*time*” to develop “*trust*” and “*rapport*” with Aboriginal clients than non-Aboriginal clients due to the culture of “*mistrust*” of generic disability services in Aboriginal communities. A Mainstream NGO non-Aboriginal worker described effectiveness in service planning and delivery as “*engaging on a positive level and establishing a good working relationship*”. A Mainstream NGO non-Aboriginal worker provided an example of building a relationship with an Aboriginal client:

*... I think back to what was originally ... identified or presented to me by Mum as being the challenges or the difficulties but then as our relationship has got closer and the trust has increased and the stories have unfolded, it's not that*

*those things have changed but I suppose the complexities have sort of gone a bit deeper and maybe what Mum was identifying as a problem was just that the tip of the iceberg ... not that the problem was necessarily greater but that there were more underlying things, you know ... it was to do with history. Until we had those pieces of the picture put on the table ... we were just ... trying to deal with what we were seeing but there was a lot more to it.*

Many of the participants reported that they could not determine how long it may take to develop a trusting-relationship with Aboriginal clients. A Mainstream NGO non-Aboriginal manager said that “*often our service is very much time managed and we have to ... do things within time but we build flexibility.*” Some of the Mainstream NGO caseworkers reported that they had to postpone service deadlines to meet Aboriginal family’s needs. A Mainstream NGO non-Aboriginal manager said that the Mainstream NGO caseworkers had to extend the service timeline for one Aboriginal family to meet the family’s service needs:

*It took a long time. ... We hav[e] a driver to meet our commitments ... with DADHC around providing the service ... for this family. We’re prepared to make it ... go for as long as [it] needs to go to get the best outcome.*

Secondly, service planning did not commence at the start of the relationship between the caseworker and the client. A Mainstream NGO non-Aboriginal worker said that “*the worker ... actually [goes in] with a clean slate and not say what they would do ... [Aboriginal people] don’t want you just to [commence] planning or anything like that for quite some time*”. A Mainstream NGO non-Aboriginal manager reported that often Aboriginal families did not feel comfortable talking with the caseworker about their personal problems and needs in formal meetings. The non-Aboriginal participants reported that clients often raised their issues in informal settings once a trusting relationship was established between the client and the disability service provider. A Mainstream NGO non-Aboriginal worker stated that it took years to build a relationship with one client because the client feared that they were being judged by the non-Aboriginal workers:

*... I think you’ve got to build trust. ... people don’t share their stories with you because I guess they think you might judge them.... I really don’t know why but it just seems to take years to start to piece together fully the story that*

*belongs to the family and their circumstance and you hear it little bit by little bit. ... Often it's when kids are getting plasters done and everyone's standing around the table and things are happening – and stories, you start to share what's actually happening in life. The little things really ... start to build a picture and then you ask a question and because you're interested ... you get told a bit more. And then when the people feel safe ... That takes time.*

Thirdly, the management focus group reported that an individual's disability was not the underlying factor for some clients. A Mainstream NGO non-Aboriginal manager stated that “... *it isn't necessary ... the case ... [that] we're going to address issues about disability ... even though there is disability in the family ... [it] may not be the dominant thing that makes a difference to people getting on better.*” For example, a Mainstream NGO manager gave an account of a worker who established a trusting relationship with one Aboriginal family by driving them to visit their deceased relatives and rectifying problems unrelated to the individual with a disability:

*With the worker going up regularly, and being there for longer days, it took probably a couple of weeks [to build trust]. But this is an intensive service. ... it starts off with that, you know, doing some nice things together that aren't focused on anything in particular .... So it was going for this drive and visiting the nearby town and they popped into the graveyard on the way back and visited the relatives that were buried there. And that really made a big difference [as]... they hadn't been able to do that for ages. So it was starting to do those sorts of things [that] seemed to be a good stepping stone into then talking about what they would do around looking at the Centrelink payments, looking at getting some therapy, looking at the way the house was set up and making those sorts of, in theory, practical things that we might think are important. They came over time. They don't have to start right up front.*

Fourthly, some of the Mainstream NGO non-Aboriginal participants reported that it was important to take time in order to learn how Aboriginality was a factor in understanding the clients' service needs. A Mainstream NGO non-Aboriginal worker said that when they were working with a client “... *I was always quite conscious of the fact that I was a white female ... working with an older Aboriginal man and so I'd chat with him a lot about [the] cultural understanding that I didn't*

*have and asking him how his background and his Aboriginality, you know, laid over the issues that we were talking about*". The Mainstream NGO non-Aboriginal workers reported that they built a trusting relationship with Aboriginal clients by taking time to learn about how their client's Aboriginality and history impacted on their engagement with past community service organisations. For example, a Mainstream NGO non-Aboriginal worker gave an example of his work with an Aboriginal mother:

*... just being mindful and I suppose respectful of the family's Aboriginality as being a factor, in my work with them. And then as the working relationship developed and got stronger, I suppose taking opportunities directly and indirectly to learn a little bit more ... specifically about their sense of identity as Aboriginal people and their history, their story. And sometimes ... in my work with this Mum, she doesn't always want to talk about all the challenges that are currently there for her and her family, and she'll just tell me that 'I don't want to talk about this today'. And sometimes I just ask her a little bit more about, you know, tell me about your times in Queensland or tell me about your time doing A, B or C. I think showing her that I was genuinely interested in that part of her personal history, and how that ties with in [with] broader Aboriginal culture, was for want of a better word a good sort of bonding thing in terms of our working relationship. You know, demonstrating respect and interest. So no it ... [was] looking for opportunities to expand my understanding.*

A Mainstream NGO non-Aboriginal manager also provided an example of the importance of learning about the client's Aboriginal culture in relation to planning and implementing the client's service needs. The manager said that Aboriginal clients prioritise meeting cultural responsibilities above the Mainstream NGO's requests:

*... someone had died in the [Aboriginal] community and so basically everything shuts down for a week, I think. ... Nothing was going to happen. So ... our team is very much ... scared to ring ... [to plan] to go for a [client] visit.... It's going to be another 2 weeks before we can maybe get there – which is probably more their issue than [the] family's issue. Well, the family weren't really worried .... The interpretation of the team was 'the family weren't*

*concerned that we didn't come [or] when we came next'. But we were concerned that we wanted to get that particular issue addressed.*

Other participants from the Mainstream NGO had a different philosophy on situating 'Aboriginality' in building trusting relationships with Aboriginal clients. Most Mainstream NGO non-Aboriginal workers reported that formal training on Aboriginal culture and history (also known as cultural awareness training) did not teach them how to forge relationships with Aboriginal clients. Many Mainstream NGO non-Aboriginal participants stated that disability workers needed to learn how to respect "*cultural diversity*" as opposed to focusing on, or learning about, Aboriginality. A Mainstream NGO non-Aboriginal worker said that "*we are ... working in disabilities ... [which includes] all cultures, all colours, all creeds or what religion – if you have a certain disability we're specialists*". Similarly, a Mainstream NGO non-Aboriginal worker said that "*we are taught to be knowledgeable first in that we accept all different cultures ... [and] not use your views and your values against someone else who might have the complete opposite*". A Mainstream NGO non-Aboriginal worker described respecting cultural diversity as "*normal*" in the disability services sector:

*... we are willing to communicate and learn as many things about new cultures. I mean, we work with culturally diversity people every day. Our teammates, we're all, you know, it's just learning and respect and understanding for somebody else. And their culture does not become – it just becomes normal'.*

Fifthly, Mainstream NGO non-Aboriginal participants stated that the location of the client meetings was essential in building trusting relationships with Aboriginal clients. The Mainstream NGO non-Aboriginal managers said that clients' requests not to have meetings at the client's home were more common with Aboriginal clients than non-Aboriginal clients. A Mainstream NGO non-Aboriginal manager stated that "*... there are some communities where we just know that ... it's not easy to sort of rock up [to the person's home]*". A Mainstream NGO non-Aboriginal worker gave an example of an Aboriginal family who preferred to meet with the Mainstream NGO staff and services at the centre:

*... [The family] definitely didn't want us ... to go to the home at all. ... it was giving them time really. I think bottom line was giving them time. And acknowledging that Mum didn't want us working at home. She wanted to come to the centre. What we did we did ... through the school ... meetings – they were all set up around mum, when she could make it, how she wanted it structured. A few other issues came up that needed OT. The interesting thing was that we really did get Mum on board at ... a certain point.*

The sixth strategy identified was that the participants often had to demonstrate to some Aboriginal families that they were not like other government officials whom people may have experience in the past. This often took multiple visits over a long time. There were two good examples of how the two NGOs overcame this trust barrier. A Mainstream NGO non-Aboriginal worker gave an account of a mother of four children who had their first two children in DoCS ordered foster care. A Mainstream NGO worker scheduled the therapy services for the client's children who were in foster care at the same time as the children in her care. The mother saw her children that were in foster care whilst her older two children received therapy treatment. The Mainstream NGO worker said that the client became more trusting "*... of services because she ... had a good experience with these two girls receiving services from the Mainstream NGO via the foster mum... [and] ... was able to get good reports from the foster mum that things were going OK*". The second example was how an Aboriginal NGO worker lobbied DoCS on behalf of a client whose child was removed and placed into temporary care:

*... she was having a meeting with DoCS about the child being returned to home. ... So I rang DoCS and DoCS just said "Oh no, no, we haven't put [that] in the agenda" and I said "I'm coming. I'm advocating on behalf the boy and of the Mum ... 'they're my clients. I'm going to be there". And so they agreed and they said 'Oh you can come but you can't come for the first part of the meeting. ... And so Mum and her partner went in at 9.30. I was called in at 10.30. And Mum and the partner were just sitting there with their heads down and you could really see it was them telling them. And so I asked. I said 'What happened in the first part of the meeting? Were there any outcomes reached?' And they've gone 'Yes, we're not returning the child to Mum.' And I said 'No. I've got a different story' and I laid down my care plan that I'd drawn*

*up for the child and mum to make sure that the process of the boy being returned was going to be in the boy's best interest. And they're looking at it and I had documentation from doctors and financial people that were going to support the boy. And I said "I've already done all this on behalf of Mum and the boy." And I said 'I've already sent this through to the barrister and the magistrate as well to say that when we go to Court ... this is what [is being proposed]'... they [DoCS] wanted to have shared parental rights but mum and partner wanted full parental rights. They didn't want to share with DoCS.' And so I said bluffed them with bullshit and I said 'Well if you want to share you can pay for this and you can pay for that and you can pay for this'. And they've gone 'We're not going to do that'. And I said 'well then Mum is going to do it so give mum full parental rights back'. When they [went] to Court on the Friday the Magistrate agreed with the care plan and the process and they verified that everything was done right and ordered DoCS to return the child back to [their] home.*

The seventh strategy was empowering Aboriginal people. The research participants described client empowerment as a philosophy of the disability services sector. The participants of both agencies shared a similar definition of empowerment. Participants used phrases, such as “*families in the driver's seat*” and families having control over the “*decision making*” process. A Mainstream NGO non-Aboriginal worker described individual empowerment as “...[families] *driving everything because they're the one living with it every day and so we can talk about our expertise and our knowledge around stuff that we know about the particular disability or accessing particular services ... but we're not ... about to tell them what decision they need to make or what direction they need to go in ... I think [that is] the basis of everything that we do*”. An Aboriginal NGO worker said that “[people with a disability] *do need to be empowered ... [and] have self independence and we try and encourage that*”.

Some of the Mainstream NGO participants said that empowering client's required caseworkers to have an “*open minded*” and “*non-judgmental*” attitude. A Mainstream NGO non-Aboriginal worker said that the Mainstream NGO's practice was “... *just go in with an open mind ... get a description from the referrer about*

*what the family is like ... [and] set it to one side and go in with a clean slate".* A Mainstream NGO non-Aboriginal worker said that:

*... Whether it's an Aboriginal family or not, I just find that ... although you've already got the background information, just to go in thinking 'ok, let's see for ourselves what's happening with this family'. What is it that they really want? ... because quite often we've been sent a whole bunch of other things from referrers and it's not what the family wants at all.*

Another example from an Aboriginal NGO worker:

*...some clients you think they're capable, financially they're capable. But they just [like] to be babysitted, you know – pick them up, drop them off. But one or two clients, I've actually had to say 'well if you can't do it, I can't do it for you'. Because otherwise I'm disempowering them. You know, like babysitting them.*

Although the participants held strong values of “*empowerment*”, many participants raised numerous examples of how Aboriginal people felt disempowered in the disability services sector. The participants described disempowerment in many ways. For example, an Aboriginal NGO manager used the phrase “*feel worthless*” to describe how clients do not understand the disability services system:

*... a lot of my clients have actually said to me, and I'm quoting here “I feel I need a university degree, the way these people speak to me because I don't know what they're saying and I feel they speak down to me. So some of the barriers are that they're made to feel worthless because they're not educated and they don't have that university degree because they don't understand what the worker is saying to them.*

Similarly, an Aboriginal NGO worker said that the feeling and acceptance of disempowerment of Aboriginal people is a “*learned trait*” in Aboriginal communities. As such, Aboriginal people do not speak openly during service planning and development, which impacts negatively on the client's service outcomes:

*So because Aboriginal people are disempowered, it's just a learned trait which is really quite sad. So you sit there and it's [organisations saying] 'I'm telling you what's right', 'I'm telling you what you're going to do', 'I'm telling you'. So because they automatically felt disempowered, they don't go in thinking positively about the outcomes*

An Aboriginal NGO worker gave a good client example of when she advocated on behalf of a mother whose child was in DoCS custody. The client felt disempowered during her meetings with DoCS as she did not know her rights in relation to caring for her son with a disability:

*... after we walked out of the meeting, Mum's gone [to me] 'They've never spoken like that at the table the way they were speaking with you. They always say to us "you're doing this, you're doing that, you're doing that otherwise we're going to keep your child ... that's how they speak to me. That's why I never speak back because I just want to do everything right so I can get my boy home." And I thought that was really, really wrong how they [DoCS] disempowered that mother and they took that boy away from the mother for 10 months and his lifespan's 20 [years] [estimated related to disability]. You know, so – but mum said "Oh [Aboriginal NGO worker], I can't believe it. When they started asking you what else would you like...? What else would you like?" ... But mum was just so impressed and she's gone "They've never spoken to me like they did at the end of the meeting".*

The eighth strategy was postponing formal paperwork to improve retention rates of Aboriginal clients. The Mainstream NGO non-Aboriginal participants stated that some Aboriginal families opted out of the service enrolment process due to caseworkers requesting forms to be completed. A Mainstream NGO non-Aboriginal worker described the paperwork process as “... a very western concept”.

The participants gave many reasons for Aboriginal people not wanting to complete formal paperwork. A Mainstream NGO non-Aboriginal worker said that reasons “...can be literacy... and some of the wording used on [the forms]...”. A Mainstream NGO non-Aboriginal worker stated that “there was something to do with their traumatic past ... [or] there was quite a degree of suspicion [in Aboriginal communities] around signing documents”. Some of the participants reported that

many Aboriginal families feared that their personal information would be provided to government agencies, such as DoCS or Centrelink. For example, a Mainstream NGO non-Aboriginal worker said that he “... *had to be ... very careful about where information went to ... [and] had to really make sure [the Mainstream NGO] had permission from the Mum to speak to teachers*”.

A Mainstream NGO non-Aboriginal manager said that the organisation’s “*diversity policy*” enabled caseworkers to postpone the formal paperwork if it addressed access barriers:

*... [the policy] enabled staff to be able to say [that] if the family ... didn't fill in the paperwork like they were meant to, that didn't matter. Now it gave legitimacy to the staff to be able to ... provide ... flexibility and the adaptations that were needed to [un]block access to services... What we could [do] was [to] do [the paperwork] in a reverse order. And that's the sort of thing that having a policy like that just actually gives the staff the permission to check it with their manager and then do that to make those adaptations.*

The Aboriginal NGO participants have the paperwork completed on the first client visit. The Aboriginal NGO manager said that they commenced paperwork immediately to ensure that it gets completed:

*I always found that you'd go in and you just start talking and talking and talking by the time you left, there was no paperwork, which we have to get. So I had to retrain myself to say to the client 'look, let's get this out of the way because I'll totally forget it. I just need your signatures, and then we can talk'. And that's the only way it worked for me because I'd walk away without getting confirmation, authority, anything. So I had to retrain myself. And once we got that out of the way, then we could sit down and yarn. Otherwise I'd forget. And they were perfectly ok with that. And because I put it that way to them, you know ... we all hate it, I hate it, so just let's get it all done and then we can talk.*

The Aboriginal NGO participants said that their paperwork process is less formal than many generic disability organisations. The Aboriginal NGO worker said that the generic agencies need to make the referral and assessment process less formalised to increase the participation rate of Aboriginal people:

*... So I've been there at a joint thing when someone's done an assessment. And I started to fall asleep through their process. You know, their paperwork is 'Oh do you ever do this?' and I'm thinking 'Oh my gosh, didn't they just tell you 10 minutes ago ... So I think they're just so formalised. Formalised in their approach that they tend to stick to the paperwork. ... I said 'that's why you frustrated them when you asked them again'. I said 'sometimes you have to try and keep mental notes, you know, because then they'll think did you hear me?' You know, like they're not listening because I've already said that and you ask them the question again. And so [at] that particular point in time, I know it's a bit tedious, sometimes they just need to ask the question [again] and I said so that they can get that answer from you because it's you talking, you know.*

The Aboriginal NGO manager stated many Aboriginal people trust Aboriginal workers. Thus trust helps speed up the process in achieving client outcomes:

*I think it's because ... there's an Aboriginal person here. The link is there. And we might react differently with different clients, but that rapport is sort of instantaneous so we don't have to come in a bureaucratic way and start doing question after question after question. Again, it's goes back there's an inbuilt fear about questions. Do you know there's all these things – everything keeps impacting. So it's that – it's the unspoken level of communication between Aboriginal people. That's very important*

The participants gave four indicators that trusting relationships between case workers and Aboriginal clients have been successfully established. The first indicator of an established trusting relationship is that the caseworkers and Aboriginal clients had open and honest discussions. For example, a Mainstream NGO non-Aboriginal worker knew an Aboriginal client trusted her when she was able to have honest discussions about a contentious issue regarding child caring:

*... I guess what I noticed was that everyone [other service/community workers] was noticing the stuff but no-one was talking to Mum about it. No-one was sort of saying – because she would sort of say this to me 'oh you know, the school's reporting me again'. And so we kind of build a relationship where we could have some fairly honest conversations. And I'd be able to say things to*

*her 'well, you know, when they [the children] do turn up in a really stained dress and nits in their hair, that does cause concern for people and so they will make reports. That's their job. So, you know, if you don't want people to report your children, then we need to put into place some things that are going to help you present them to the community in a way where they're thinking those kids are getting good care at home. So as much as you don't care what people think, really it does matter because these reports just keep getting made if you don't pay attention to that sort of stuff'. And she was able to take that on board which was really good. And she was able to, I guess, really lift up her game in that sense, the fact that she was paying a bit more attention to that.*

The second indicator of trustworthiness was that Aboriginal clients contacted organizations requesting support for a problem. A Mainstream NGO non-Aboriginal worker said that "...they come and visit us when they need us. So it's that ability to be able to tap into using us when it makes sense to them". A Mainstream NGO non-Aboriginal worker said that one of their clients "...liked the chance to be able to talk about what she was going to do ... but didn't need us to do it for her but give [her] ... the confidence to go on and keep doing it".

On a related note, the third indicator of trustworthiness was that the clients did not resist disability service workers and responded 'positively' to the advice and recommendations provided by the disability workers. The participants stated that if clients continued to engage with respite or attending scheduled appointments for therapy or assessment that indicated that they trusted the organisation. A Mainstream NGO non-Aboriginal manager said that she felt confident that families trusted them if the "*family actually feels they can re-contact us ... [and] they actually are making use of the knowledge or the information or the equipment*" provided to them.

The fourth indicator of established trusting relationships was that existing or past clients referred new people to the organization. The Aboriginal NGO participants said that many of their clients were referred by current and past clients. The Mainstream NGO participants could only recall one Aboriginal client that was referred by an Aboriginal family.

**Factor ten summary.** Trust was identified as a major access barrier to disability service providers for Aboriginal people. Trust was identified as a consequence of the long history of colonisation and racism discussed earlier in this chapter. The study has identified eight strategies that were employed to build a trusting relationship between non-Aboriginal disability workers and Aboriginal clients:

1. It generally takes more time to build trust and rapport with Aboriginal clients than non-Aboriginal clients due to the culture of mistrust of generic service providers in Aboriginal communities.
2. Permitting service planning not to commence at the start of the relationship. Aboriginal families often did not feel comfortable talking to disability service workers about personal issues until trust was established.
3. Recognising that disability was often not the underlying factor for many Aboriginal families.
4. Taking time to learn about how the family's Aboriginality was a factor in understanding the client's service needs.
5. Choosing a location for client meetings in a family friendly setting, such as at a cafe or an ACCO.
6. Differentiating disability service workers from other government officials.
7. Aboriginal families had to be empowered in the intervention. Client empowerment was described as a philosophy.
8. Postponing formal paperwork.

Four indicators that a trusting relationship was achieved were identified:

1. The caseworkers and Aboriginal clients had an established and open dialogue.
2. Aboriginal clients contacted the disability service workers requesting support, information and advice.
3. The Aboriginal clients did not rebel or resist engagement with disability workers.
4. The Aboriginal clients refer Aboriginal people to the service.

### **Mobility: remoteness and travel mobility**

Remoteness and travel mobility was identified as an access barrier by the participants. Lack of affordable public transport was raised as a major hurdle for clients who depended on government financial support, such as the pension. Access to affordable public transport was a bigger problem for people who lived in outer-city regions and experienced multiple agency interventions.

The participants provided examples of how some clients had to relocate to metropolitan regions to obtain better access to affordable public transport and disability services and supports. The Mainstream NGO outer-city focus group provided an example of a young family that relocated a distance of 400 kilometres from their home town to access affordable public transport and disability services.

The Aboriginal NGO worker focus group provided an example of how clients relocating to improved service access can result in families being further disadvantaged within a complex bureaucratic disability service system. An Aboriginal NGO worker discussed how a young family relocated three times to obtain an affordable rental home, public transport and improved access to disability services. Consequently, the family relocated to a new DADHC jurisdiction, resulting in having to resubmit assessment forms for services. As a result, the child was removed from the family:

*Because they were transient families and they were always moving, they were always ... re-applying to different areas so they just give up ... So they had a 14 year old son who was in need of serious ... support for A, B and C but he'd gone through many years where he just didn't get it because of their transient family lifestyle. ... he needed occupational therapy that was recommended ... when he was 8. But because they're a transient family ... there's always a waiting list .... So this was impacting on him socially as well as his health outcomes because he needed speech pathology for the muscles in his throat ... Because of the cystic fibrosis he was having swallowing problems and of course that impacted on his eating and his diet and his weight gain ... So, you know, all these problems would have been eliminated if it would have started when he was 8 rather than wait until he's 14. In that process, DoCS became involved and DoCS actually removed him from the family unit when he was 13. No fault of Mum. You know, Mum was an incredible woman but just because*

*they were a transient family moving from one area to another, these things impacted on this particular family.*

**Factor eleven summary.** Remoteness and travel mobility was an access barrier. Lack of affordable transport was a significant challenge for people who depended on government income support. The Mainstream NGO outer-city focus groups provided examples of Aboriginal clients who travelled vast distances to access services. Many Aboriginal families had to relocate to metropolitan regions to access disability services. This was further compounded by complex bureaucratic process affecting access to services such as intake arrangements and waiting lists in different areas.

### **Affirmative action policy: understanding and response to affirmative action policies**

The participants discussed the development of their organisation's affirmative action policies. It was mostly the Mainstream NGO managers who discussed policies in great depth. The Mainstream NGO managers reported that the development of their cultural diversity policy, *Service Access: Access and Equity for Indigenous Australians and Those with Non-English Speaking Backgrounds (NESB) 1997*, was driven by internal and external forces:

*... just socially what was happening in terms of recognition of ... Aboriginal communities ... has a much greater profile generally. People were talking about it. People were saying 'Well what are you doing about it?' So it was pressure from outside to say 'Where's your policy'? But it was also, I think, from our point of view, a recognition that [there] needed to be more focus on a particular group of individuals that we hadn't [had] before. So it was external and internal ... pressures to say [and] to do something ... and there were other funders saying 'Well what are you doing?' There were donors saying 'Well what do you do for Aboriginal families?' And money was actually in the communities saying 'if you're interested in doing this, money [is] around in terms of implementing strategies'.*

Although the policy was developed, the Mainstream NGO management focus group stated that there was limited focus on implementing the policy. The first

affirmative action policy was originally developed to meet the requirements of government and philanthropic agencies:

*... it got pulled out every so often as a presentation "Here's our policies. What are we doing?" It was almost the piece of paper that said "We've got a policy. Show us how you're demonstrating it". We went through cycles where it wasn't ... regarded as token but there wasn't a lot of energy and effort being done about it.*

The Mainstream NGO management focus group said that their affirmative action policy reform in 2007 "was very much a political agenda" to reflect "the language change that was happening just in the general community about perceiving diversity in general rather than actually honing in on just Aboriginal and CALD communities because although those two communities are quite marginalised, there are other communities that are diverse that are also marginalised and the organisation decided rather than just hone in on 2, it actually needed to have a much broader perspective on diversity in general ... without losing too much about some of the specific strategies we wanted to do for Aboriginal and CALD communities".

The Mainstream NGO did not have in place an Aboriginal workforce strategy. Rather, a Mainstream NGO non-Aboriginal manager stated that the management's focus was on quantifying the number of Aboriginal workers to understand the organisation's "... workforce better in terms of 'do [they] recruit people with an Aboriginal background' and "... [they] changed [their] recruitment strategies so all of [the] adds actually had that [they] were ... welcoming people from an Aboriginal community to apply for [job] applications ... [and included the] standard [information] ... to encourage people from Aboriginal backgrounds to apply for positions".

The Mainstream NGO management focus group said that a previous Aboriginal disability worker helped develop the first affirmative action strategy to address access and equity barriers for Aboriginal people. The Mainstream NGO management focus group said that their Aboriginal and Torres Strait Islander Committee "... was developed in response to the strategic plan". However, discussions with the Mainstream NGO Aboriginal workers found that none of the

Mainstream NGO Aboriginal participants was aware of the suite of Aboriginal affirmative action policies and initiatives.

No participants from the Mainstream NGO City and Outer-city focus groups were aware of any of the affirmative action policies regarding Aboriginal affairs. The Mainstream NGO City focus group laughed when the interviewer asked questions on the organizations policies, with one participant responding “*don’t get us to rattle it off*”. Similarly a Mainstream NGO Aboriginal worker said that “*well to be honest I didn’t realize that they had even some sort of Aboriginal policy in place. ... I’m only a support worker so I’m not really up to date with all their policies ... even though I should know them because I’ve just been on a whole series of training*”. In comparison, the Aboriginal NGO workers were well rehearsed in their organisation’s Aboriginal affirmative action policies.

**Factor twelve summary.** The Mainstream NGO developed their Aboriginal policies in response to pressure from government and philanthropic agencies. The Mainstream NGO was not actively implementing initiatives or actions under their Aboriginal affirmative action policies. There was a lack of knowledge about the Mainstream NGO’s Aboriginal affirmative action policies in the agency’s workforce.

## **Conclusions**

This chapter has presented the research findings consistent with the second objective of the study following the methodology discussed in Chapter Seven. This chapter has identified twelve factors that influence the participation of Aboriginal people in disability services. These factors were:

1. Conceptualising disability: conflict in the conceptualisation of disability between Aboriginal communities and disability services.
2. Family and kin: reliance on family and kinship systems as the support mechanism.
3. Colonisation and trauma: understanding of colonisation and intergenerational trauma as social determinants of health and disability among disability workers.
4. Racism: experiences of racial discrimination in the disability services sector.

5. Choice of workers: choice of workers in disability services.
6. Choice of organisations: choice of Aboriginal community managed services or generic services.
7. Community connections: connection between Aboriginal communities and disability service providers.
8. Trustworthiness of generic services
9. Multiple agency intervention: number of Agencies involved in intervention.
10. Trusting workers: trust between caseworkers and Aboriginal clients.
11. Mobility: remoteness and travel mobility.
12. Affirmative action policy: understanding and response to affirmative action policies.

There were differences in the findings between the Mainstream NGO city focus groups and the Mainstream NGO outer-city focus groups. Contrary to the Mainstream NGO outer-city focus group, none of the participants from the Mainstream NGO city focus group had connections with ACCOs or any Aboriginal stakeholders. The Mainstream NGO city focus group participants reported that they promote their services at community disability expos and schools as a means to increase awareness on services for people with a disability. They stated that these promotion strategies did not work to influence the participation rate of Aboriginal people. In contrast, many participants from the Mainstream NGO outer-city focus groups gave examples of how they have participated in Aboriginal network groups and training days as a means to engage with the local Aboriginal people. This type of engagement influenced the participation of Aboriginal people in services.

There were also differences between the factors between the Mainstream NGO management and non-management focus groups. The Mainstream NGO managers' focus groups provided a lot of emphasis on policies. However, the Mainstream NGO worker focus groups did not place much emphasis on policies. One Mainstream NGO workers focus group laughed when the researcher asked them if they knew about the Mainstream NGO'S Aboriginal policies.

There were some major differences in the factors between the Aboriginal workers in the Aboriginal NGO and the Mainstream NGO. In particular, the Aboriginal participants discussed in great detail about the influence racism and

discrimination has on the service participation of Aboriginal people. The non-Aboriginal participants did not discuss this issue.

Another example is the role and influence DADHC funded ACCOs and Aboriginal services play in Aboriginal service participation. The Aboriginal workers strongly support funding ACCOs and Aboriginal services. However, the Mainstream NGO non-Aboriginal participants were split on this issue. This was also identified in the Mainstream NGO management focus group, where managers debated the benefits and challenges in DADHC funding ACCOs and Aboriginal services. Many Mainstream NGO non-Aboriginal participants did not support DADHC funding ACCOs or Aboriginal services.

The findings have uncovered that the Aboriginal workers are working in a contentious environment. For example, Aboriginal workers have to ensure that the Aboriginal clients have the right Aboriginal worker or even want an Aboriginal worker. Furthermore, many Aboriginal clients do not want ACCOs. An Aboriginal NGO worker described this issue as “*a bit of a bummer really*”. For example, a Mainstream NGO non-Aboriginal worker reported that some Aboriginal families travel vast distances to access their services because there were no Aboriginal workers.

All of the identified factors were inter-related historically, social and institutionally. The inter-relatedness demonstrated that the disability service workers have faced significant challenges in supporting Aboriginal people with a disability and their families. Furthermore, the factors were historically, institutionally and culturally entrenched in the disability services sector and each local Aboriginal community. For example, the recruitment of Aboriginal workers was connected with racism and discrimination experienced by both Aboriginal workers and Aboriginal clients when community conflicts did not compromise confidence. Aboriginal families prefer Aboriginal workers because they felt safer and more fully understood than with non-Aboriginal workers. In addition, a lack of trust was a barrier to accessing services that was inter-related with the legacies and experience of colonisation and racial discrimination.

Similarly, the conceptualisation of disability in disability services and the historic of distrust of government agencies have influenced Aboriginal families' suspicion of disability services. Multiple agency intervention has contributed to further disadvantage which is exacerbated by transport issues. Flexibility in the

interpretation of policy has permitted some workers to establish more trusting relationships.

The following Section will discuss the importance of the findings of this study in conjunction with the literature and theory presented in this thesis. Consistent with the third objective of this study, Chapter Nine will propose an Explanatory Framework to represent the relationships between the identified factors.

# Section Four: Factor Relationships, Conclusion and Future Implications

## **Chapter Nine: Discussion on the Research Findings and the Emergence of an Explanatory Framework**

This chapter contains a discussion of the findings of this study in the context of the literature. The overall research objectives outlined in Chapter One were to:

1. Identify how and when the participation of Aboriginal people in disability services was identified in documented policy.
2. Identify and describe the factors that influence the participation of Aboriginal people in disability services as perceived by Aboriginal and non-Aboriginal employees in two NSW Government Department of Ageing, Disability and Home Care (DADHC) funded disability services.
3. Develop an Explanatory Framework that adequately encapsulates and represents the factors identified in this study as influencing the participation of Aboriginal people in disability services.

There are three sections to this chapter. The first section will focus on the proposed merging of the Indigenous Standpoint Theory (IST) and the International Classification of Functioning (ICF) as a single Conceptual Framework. In particular, the utility of the Conceptual Framework as an alternative approach to typical Eurocentric colonising methodological frameworks typically employed previously in disability studies research and policy development will be discussed.

The second section of this chapter will focus on a discussion of findings concerning the factors that influence the participation of Aboriginal people in disability services as perceived by Aboriginal and non-Aboriginal workers. This section will also compare the differences and similarities in the factors identified by Aboriginal and non-Aboriginal workers consistent with the second primary objective of this research. Concluding statements summarise each of the major sections of this discussion.

Consistent with the third objective of this study, the third section of this chapter will propose an Explanatory Framework, the *Aboriginal Service Participation Universe*, and the extent to which this framework adequately represents and encapsulates the relationships between the factors that influence the participation

of Aboriginal people in disability services as perceived by Aboriginal and non-Aboriginal workers.

### **Adopting Indigenous Standpoint Theory in Disability Studies Research and Policy Development**

This study proposed a new culturally appropriate Conceptual Framework, developed from the data collected in relation to the first objective of this study, noting the absence of an existing available framework (Meekosha, 2008; Rigney, 2007). Much of the research on disability in Aboriginal communities was identified to employ a Eurocentric colonising methodological framework that locates Aboriginal people as 'objects' of science. Existing global conceptual frameworks did not adequately capture the unique diversity of cultures and experiences of Aboriginal people with a disability in a colonised country like Australia.

The "Individual" approach and the "Social" approach were the two most debated approaches used to characterise the experience of disability in disability studies. Despite the efforts of numerous researchers, an Aboriginal definition of disability that has captured the diversity of cultures, languages and experiences of colonisation in Aboriginal communities has not yet been developed. It was identified that the concept of disability was relatively new in many Aboriginal communities and that many Aboriginal communities object to labelling people by perceived disabilities (Aboriginal Disability Network (ADN), 2012; Bostock, 2004).

Since the 1980s, WHO has attempted to develop a global conceptual framework for defining and categorising salient features of the experience of disability. The World Health Organisation (WHO) and the Australian Institute of Health and Welfare (AIHW) did not adequately include Aboriginal people in the planning and development of the ICF. Documents reviewed and analysed in this study indicated that Aboriginal people were not involved or mentioned in the development of the International Classification of Impairment, Disability and Health (ICIDH) during the International Year of Disabled Persons (IYDP). AIHW only involved two Aboriginal communities in the Northern Territory in the review and beta-testing of the ICIDH-2. The testing concluded that "one of the major problems with the use of the ICIDH to produce a meaningful classification would be lack of knowledge about the community" (Senior, 2000, p. 25). Consequently, the cultural diversity and the impact of colonisation on the population of Aboriginal people

were not considered by AIHW. The ICF did not capture the diverse cultures and experiences of colonisation in local Aboriginal communities. The population of Aboriginal people was treated as one homogenous group of people.

The development of the ICF validated Moreton-Robinson's (2004) and Connell's (2007) claims that the social sciences academy has racialised, homogenised and subjugated Aboriginal knowledge by enforcing and normalising Western sciences as the producers and controllers of knowledge. Non-Aboriginal disability researchers were engaged in the process of 'naming and claiming' the issues of concern regarding Aboriginal people with a disability and did so without reference to Aboriginal people. Similarly, disability studies scholar Meekosha (2011) claimed that disability studies have not included Aboriginal people in the development and discussion of major policies and philosophies. Since the 1800s, researchers have defined, prescribed and measured the prevalence and experience of handicap and disability in Aboriginal communities within a Eurocentric methodological framework. Thus, Aboriginal people have never owned or controlled the Aboriginal research process in the disability studies field.

This highlights the need to develop research approaches that are informed by the perspectives and experiences of Aboriginal people. As discussed in Chapter Six, Indigenous scholars proposed that researchers develop an IST to help decolonise western sciences in relation to Indigenous studies. IST is not an Aboriginal way of doing research. Rather, IST is a philosophical position situated in the Aboriginal person's ancestry that informs the methodology in a science.

The Contextual Framework for this study proposed IST as a culturally appropriate framework for disability research and policy development with Aboriginal people. The principles of IST address the failings of Eurocentric colonising research and policy frameworks that have dominated previous studies of Aboriginal people. Utilising IST with the ICF provides a pathway for the amelioration of the weaknesses of the global contextual framework of the ICF for the purposes of researching disability with Aboriginal communities. The Contextual Framework allows for the adoption and exploration of the interaction of the individual and social approaches as understood by the Aboriginal people.

**Conclusion:**

This study developed a Conceptual Framework for research and policy development involving Aboriginal people with a disability. The Conceptual Framework was based on the ICF and the use of the IST as a point of reflection. The Conceptual Framework has the potential to assist Aboriginal people with a disability to break down the Eurocentric colonising methodological frameworks typically adopted by non-Aboriginal disability researchers and decision makers. Merging the ICF with IST acknowledges the Individual approach and the Social approach to disability while taking into account the diverse perspectives of Aboriginal communities and individuals in the post colonial era. Furthermore, this study has helped empower Aboriginal people by having a standpoint theory that honours Aboriginal knowledge and perspectives.

**Discussion of Findings Concerning the Factors that Influence the Participation of Aboriginal People in Disability Services.**

Identified in this segment of the chapter are the findings concerning the factors that influenced the participation of Aboriginal people in disability services under the first two objectives of the study. This section will also compare the differences and similarities in the factors that were discussed by Aboriginal and non Aboriginal employees.

**The power of definition**

A major finding of this study was that Aboriginal people were required to accept disability service providers' definition of disability to obtain support and services when family/kin resources and networks were unavailable. This finding mirrors the research findings of Aboriginal communities discussed in Chapter Two (ADN, 2010, 2012; Aboriginal Community Care Gathering, 2007; Bostock, 1991, 2004; Gething, 1995; Human Rights and Equal Opportunity Commission (HREOC), 1993, Smeaton, 1998). For example, an Aboriginal NGO non-Aboriginal manager described Aboriginal people's experience in accessing generic disability services as "stigmatising". This finding was consistent with the results achieved under objective one, discussed in Section Two, of this study and the development of the Conceptual Framework which identified that Aboriginal communities considered categorising people by 'abilities' and 'disabilities' as culturally unacceptable.

Furthermore the conceptualisation of disability in the 'metropole' or centres of Western (and typically northern hemisphere) power (Connell, 2007) was unrecognised in Aboriginal communities. For example there was no known Aboriginal language with a word equivalent to the concept of 'disability' (Gilroy, 2010b, 2009). The terms 'disability' and 'handicap' have been imposed on Aboriginal communities by non-Aboriginal scientists and specialists since the commencement of colonization. Therefore, Aboriginal people are expected to accept disability service providers' conceptualisation of disability in order to obtain services consistent with the experience of colonization and the hegemony of the Western academy through the power of definition. Similarly, as reported in the findings of the data collected under objective two, presented in Section Three, of this study Aboriginal families experienced the labelling of disability in the disability services sector to be isolating and culturally offensive. In this context, not accepting services could be characterized as a form of resistance to the hegemony of non-Aboriginal cultures and the government funded disability services sector.

The finding that Aboriginal families considered supporting people with a disability as 'family business', meant that Aboriginal families often preferred supporting people with a disability themselves over participating in disability services. Yet many policies identified in the historical analysis of the policy documents and literature have had a devastating negative effect on family and social structures in Aboriginal communities. While there was some acknowledgement of these influences among the factors identified by disability workers, the impact of these factors on intake, access and eligibility for services has not been considered and acknowledged.

The problems with the conceptualisation of 'disability' and well-being have a profound impact on every aspect of service development and research. For example, government policy documents analysed under objective one of this study found that both the disability services sector and the local Aboriginal communities have struggled to bridge the cultural interface in supporting Aboriginal people with a disability. Over the last three decades, governments have not been able to adequately quantify the prevalence of disability in Aboriginal communities. One reason given by the review report of the Multilateral Agreement was that governments were using a culturally inappropriate data collection methodological

framework. Similarly, many of the participants reported that diversity in the conceptualisation of disability in the population of Aboriginal people may have also distorted the government's data collection on the prevalence of disability.

The documents analysed in relation to objective one of this study, identified that major policies governing the provision of disability services, such as the New South Wales Disability Services Act 1993 (NSWDSA) and the Multilateral Agreement, did not define disability as a multidimensional experience as conceptualised in the ICF. Rather, the DSA and the Multilateral Agreement adopted a pathologically focused definition of disability. As such, the social factors of disability as identified under the ICF were largely ignored in Australian Government disability legislation.

Access to government funded disability services required a 'diagnosis' and/or 'assessment' of disability and service needs/requirements consistent with the dominant western scientific medical discourse. Section Two of this research shows that although the Mainstream NGO and the Aboriginal NGO were government funded disability service providers, they both had different definitions of 'disability' and 'service eligibility'. The services provided by the Mainstream NGO required the individual to have received, or have been in the process of obtaining, a formal medical diagnosis of disability from a medical specialist, such as a psychologist or a medical practitioner. The Mainstream NGO excluded a range of social or structural factors, such as the environment and the intergenerational effects of colonisation and racism, from consideration regarding service eligibility criteria. This practice consequently excluded the key factors that may be relevant to Aboriginal community members in need of support. Similarly there was no reference to Aboriginal people's understanding of wellbeing, discussed in Chapter Two, or other relevant cultural aspects in relation to gaining access the formal service system. Furthermore, there was no consideration of the conceptualisation of how culturally relevant services and supports may be configured for Aboriginal people.

Therefore, participation in the Mainstream NGO's service required the individual to *accept* that they have a disability within a Western medical discourse. In comparison, the Aboriginal NGO defined disability in the context of how body functions limit or restrict activities of daily living as defined in the *Disability Discrimination Act 1992* (DDA). The Aboriginal NGO adopted a definition of

disability for service eligibility that was flexible in accommodating the cultural diversity within the Aboriginal population. Interestingly, the Western definition of disability was still foreign in many Aboriginal communities despite the growth of the disability services sector.

**Conclusions.** The results of this study indicated that:

- a) The disparities in the way Aboriginal families conceptualise, experience and respond to 'disability' can at times undermine the participation of Aboriginal people with disabilities in disability services. This has implications for the way government funded 'disability' services are conceptualised and framed, including the way disability services and supports are interpreted and accessed.
- b) The dominance of the medical/pathological model of disability in current policy documents ignores the important structural factors that may influence the access of Aboriginal people to appropriately responsive supports and opportunities for promoting well being.

### **The hegemony of cultural othering and whiteness**

A major finding was that the disability services sector has 'culturally Othered' Aboriginal people as a 'specialised field' in comparison to non-Aboriginal people. The treatment of Aboriginal people with a disability as a specialised field encompassed three parts: remoteness, cultural difference and disadvantage/vulnerability. The "Othering" of Aboriginal people effectively normalised the hegemony of "Whiteness" in disability services sector policy and practice, as defined by Aboriginal scholar Moreton-Robinson (2004). The governments and the Mainstream NGO have 'subconsciously' defined, inscribed and reinforced a normal person with a disability ('white' skinned and non-Indigenous) by inscribing what was not a normal person with a disability ('black' skinned and Indigenous). As a consequence of being caught up in the ongoing comparative analysis and review of cultural difference, the disability services sector has not been able to adequately address the low participation rates of Aboriginal people in disability services.

Non-Aboriginal disability researchers and disability service workers often blamed cultural differences between Aboriginal and non-Aboriginal communities for the low disability service participation rate of Aboriginal people. Governments'

policy documents analysed in order to address objective one have shown that governments and the Mainstream NGO merged Aboriginal people with culturally and linguistically diverse communities. The governments have been focused on learning and analysing the cultural differences between Aboriginal and non-Aboriginal people since the disability service reforms in the mid 1980s. Similarly, the disability studies academy has been focused on cultural differences since colonisation.

The disadvantage experienced by Aboriginal people was often compared and contrasted with people from culturally diverse backgrounds. The Aboriginal affirmative action policies produced by the Mainstream NGO merged Aboriginal people with 'cultural diversity', because they were viewed as culturally different. The Mainstream NGO non-Aboriginal participants often spoke about Aboriginal people as a culturally different group. For example, one Mainstream NGO non-Aboriginal worker stated that disability workers "work with culturally diverse people everyday".

Comparatively, the Aboriginal participants did not feel that they were like people who migrated to Australia. The Aboriginal participants viewed such comparisons as discriminatory. The Aboriginal NGO participants felt that merging or comparing Aboriginal people to culturally diverse groups dismissed consideration of Aboriginal people as the First Nation people of Australia. Furthermore, the Aboriginal participants felt that merging Aboriginal people with people who migrated to Australia (often identified as culturally and linguistically diverse communities) ignored the influences and roles of European colonisation on the participation of Aboriginal people in services. For example, one Aboriginal NGO worker reported that "CALD are coming here for a different lifestyle choice which they made. We're coming from a history of where we've been denied access and put in a position for our whole life".

**Conclusions.** The results of this study have indicated that:

- a) The government and the Mainstream NGO have been focused on analysing and reviewing the cultural differences between Aboriginal and non-Aboriginal people with a disability. Consequently, the disability services sector has normalised Whiteness by defining and inscribing a 'normal' person with a disability.

- b) Many disability services initiatives and strategies to address the low participation rate of Aboriginal people in services have not fully addressed the continuing impact of colonisation.

### **The social determinants of health need to be the focus for intervention**

The study has highlighted that the factors that influence the participation of Aboriginal people in disability services were underpinned by social determinants of health. As discussed in Chapter Two, WHO (2008) defined the social determinants of health as:

... the conditions in which people are born, grow, live, work and age, including the health system. These circumstances are shaped by the distribution of money, power and resources at global, national and local levels, which are themselves influenced by policy choices. The social determinants of health are mostly responsible for health inequities - the unfair and avoidable differences in health status seen within and between countries. (p. 31)

A major finding of this study was that the disability services sector must pay greater attention to the social determinants of health to help improve the service participation rate of Aboriginal people. The prevalence of disability in Aboriginal communities was attributable to the poor status of health and ongoing disadvantage. AIHW (2010a) noted that ill health and disability rates in Aboriginal communities were interrelated with low social status and inequality. Many Aboriginal communities have reported that disability is a low priority in their communities in comparison to other health and social issues (ADN, 2012; Maher, 1999; National Disability Administrators, 2004; Productivity Commission, 2004; Smeaton, 1998; Sackley, 2003; Thompson & Snow, 1994).

The policy documents analysed in Section Two found numerous accounts of how the governments, the Mainstream NGO and the Aboriginal NGO represented Aboriginal people with a disability as a 'disadvantaged' or a 'vulnerable' population due to their social and health status. All the governments' legislation, policies, programs, policy reports and annual reports labelled Aboriginal people with a disability as 'disadvantaged'. Over the past few decades, the Aboriginal NGO and the Mainstream NGO described the purpose of their policies as aiming to overcome the high rates of disadvantage in the population of Aboriginal people as barriers to service participation.

The Mainstream NGO and the Aboriginal NGO acknowledged that the rates of disability were related to ill health. However, in practice Aboriginal people's participation in disability services has exacerbated the consequences of ill health and disability for some Aboriginal people. Many study participants reported that they have referred clients to more community services because disability services were unable to address aspects of client needs. The study participants provided examples of how many of their clients, who lived in poverty, struggled to meet the competing demands, requests and monitoring made by multiple disability service workers and government officials within their existing stretched resources. Consequently, these interventions have placed additional burden on Aboriginal families, resulting in an ongoing vicious cycle of agency interventions and surveillance.

The study participants described the participation of Aboriginal people with a disability in services as being "historically positioned" from colonisation, racism and past government social segregation and assimilation policies. This reflected the findings of the WHO (2008) report on the social determinants of health, that racism and colonisation were contributing to the low participation rate of Aboriginal people in disability services.

Racism and colonisation were factors that influenced the participation of Aboriginal people in disability services. The experiences of racism and discrimination also existed outside of the formally funded disability services sector. The study participants have provided examples of how their clientele have faced racism from government workers, such as Centrelink and the NSW Government Department of Housing, and disability workers. For example, an Aboriginal NGO worker gave an account of a government worker who questioned the Aboriginality of a client based on physiognomy stereotypes. Some Aboriginal disability workers have faced and witnessed racial discrimination in their workplace. The study participants reported that Aboriginal families who received multiple agency interventions were at greater risk of being exposed to racism and discrimination.

The history of racism and discrimination in the social services and disability sector has contributed to the high level of distrust and resistance of generic disability services in Aboriginal communities. The distrust and resistance of generic disability services was intergenerational and not limited by age or sex.

Aboriginal people who were members of the Stolen Generation experienced symptoms of post-traumatic stress when they engaged in the disability services sector. Members of the Stolen Generation educated younger generations about their lifetime experiences of racism. The actions of disability workers reinforced Aboriginal people's perceptions of disability service providers as institutions of racism. Many Aboriginal families who struggled to support people with a disability feared that if they did not meet the demands of service providers, child protection services would intervene and place the person with a disability in residential care away from the family. For example, one of the participants told about a grandfather who was removed from his parents as a child and who informed the Mainstream NGO that he did not need disability services. In every interaction with the Mainstream NGO he identified that his first priority was for his grandchildren to be returned from child protection services custody with the NSW Government Department of Community Services (DOCS). Similarly, an Aboriginal NGO worker told of a mother of four children who herself was removed from her parents. This mother was so scared that her children would be removed that she walked kilometres to take her children to childcare everyday to appease DoCS orders.

As a consequence, non-Aboriginal disability workers had to take a longer amount of time to build a trusting relationship with Aboriginal clients than with non-Aboriginal clients. Many Aboriginal people had negative experiences with generic disability services and may feel reluctant to access another disability organisation. As such, many Aboriginal people felt disempowered when utilising generic disability services. Non-Aboriginal disability workers took extra effort to build trust with Aboriginal clients than was the case for many non-Aboriginal clients. In comparison, Aboriginal workers did not have to take extra time to build trust with Aboriginal clients as the trust was already established.

The influence of racism and colonisation on the participation of Aboriginal people in disability services resembles Eckerman's (2010) conceptualisation of the impact of the social determinants of health discussed in Chapter Two. Figure 15 illustrates this with excerpts of the transcriptions from the interviews and focus groups in this study. The figure demonstrates how racism and colonisation impact on the social determinants of health in the population of Aboriginal people with a disability, hence influencing the participation of Aboriginal people in disability services.

Aboriginal people have experienced the physical and mental health effects of racism since colonisation. The irrevocable loss of land and fragmentation of traditional cultures resulted in a high prevalence of social and personal stresses and risk-taking behaviours (such as alcohol abuse and domestic violence) in Aboriginal communities. Because Aboriginal people were seen as a cultural minority, their service needs were undermined by the needs of other non-Aboriginal cultures under the banner of cultural diversity (Reconciliation Australia, 2010). They became an inferior social class disempowered in the human and disability services sectors.



Figure 15 - The spiral of colonisation and alienation in Aboriginal Australia with quotations (adapted Eckerman, 2010)

The results also support previous studies (Reconciliation Australia, 2010) on racism which indicate that more Aboriginal people report racial discrimination than non-Aboriginal people. Racism was discussed in this study by more Aboriginal participants than non-Aboriginal participants. Non-Aboriginal participants only discussed racism when it was brought to their attention during the Member Checking phase of the data collection.

**Conclusions.** The results of this study have indicated that:

- a) Although disability service providers acknowledged the low social and health status of Aboriginal people, the disability services sector needs to more comprehensively address the social determinants of health in supporting the participation of Aboriginal people and to reduce over-burdening of Aboriginal families.
- b) Racism and discrimination underpins the social determinants of health and disability in Aboriginal communities. This study supports the findings of previous studies on how racism and discrimination influence the health and social outcomes of Aboriginal people. The cycle of poverty, unemployment and poor housing environment and low educational outcomes further impacts on the participation rate of Aboriginal people in disability services. Therefore, the disability services sector must focus its efforts to address the social determinants of health to improve service participation.
- c) The experience of racism and colonisation has created a high level of distrust of generic community service institutions in local Aboriginal communities. As a consequence of intergenerational experiences of racism and discrimination amongst Aboriginal families, non-Aboriginal disability workers have spend time in building a trusting relationship with Aboriginal clients.
- d) Racism was a barrier to disability service participation for Aboriginal people in both government and non-government agencies. Barriers caused by racism also occurred outside of the formally funded disability services sector.

## **Challenges in implementing person-centred planning for Aboriginal families**

The conceptualisation of disability by Aboriginal communities, identified by the study participants, was more clearly aligned with principles underpinning person-centred planning and the social model of disability than the policies and procedures of disability service providers and government agencies. For example, the Aboriginal participants from both NGOs reported that Aboriginal people conceptualised disability as “normal” and “part of living” and that families were inclusive of people with a disability. The link between ‘family’ and ‘kinship’ and ‘culture’ with regards to supporting people with a disability was described by the Aboriginal participants as a “philosophy” in the Aboriginal population.

Non-Aboriginal participants described this as “a lack of awareness” and sought to promote awareness through community education programs to gain acceptance of their organisation’s definition of disability. Many non-Aboriginal participants felt that there exists a connection between “lack of awareness” and conceptualisation of “disability”. Awareness strategies adopted by disability service providers had a limited impact on the participation rates of Aboriginal people. For example, promoting disability services at school events for children with a disability in ‘special education classes’, as adopted by the Mainstream NGO, resulted in no Aboriginal families enquiring about services. The Aboriginal NGO, on the other hand, was engaged in the local Aboriginal community events, committees and working groups, some not directly related to ‘disability affairs’, as a means to promote its services. In this regard, non-Aboriginal disability service staff could learn about the processes, values and attitudes supporting the social inclusion of people with a disability from Aboriginal people.

While disability organisations often espoused person-centred policies and practices, this study has highlighted that some fundamental aspects of person-centred planning were not common practice. Aboriginal community member’s use of family and kinship networks to obtain support and advice was consistent with the principles of natural supports and networks which underpinned person-centred planning discussed in Chapter Two. As per the eight strategies in building trusting client/worker relationships discussed in Chapter Eight, learning about the cultural heritage and connections of Aboriginal families was consistent with person-centred planning principles used to understand ‘who is the person’ – their hopes, dreams, choices and priorities.

The findings of this study have highlighted the importance of client/work relationships and connections influencing the participation of Aboriginal people with disabilities in community services. The impact of the high staff turnover (National Disability Services (NDS), 2011a, 2011b) on the relationships between disability workers and Aboriginal families was not discussed by the participants. This issue may be largely unrecognised by the participants due to its prevalence. It would be important to explore more fully the utility of these relationship building factors and the reduction of staff turnover rates in improving service outcomes for all people with a disability.

While some of the uniquely tailored responses to people's needs were reported, so too were examples of bureaucratic barriers and a failure to recognise the whole person in context, leading to the fragmentation of services and the dangers of Aboriginal people exiting the service system. This study also foreshadows some of the difficulties for services that may emerge for a generic organisation if person-centred planning was taken up beyond a tokenistic level.

This study has identified that non-Aboriginal disability service workers and Aboriginal people struggled to bridge the cultural interface in service planning. Some Aboriginal people missed out on quality services due to subtle cultural and language differences between the disability service system and Aboriginal communities. For example, a Mainstream non-Aboriginal manager gave an account of an Aboriginal mother who informed the workers that she wanted to move back to "country". Almost twelve months later the organisation's Aboriginal worker realised that the mother had informed the organisation that she wanted to move back to her family in South Australia, but the organisation had not acknowledged or acted on this plan in any engagement of service planning or delivery.

The disability services sector needs to bridge the cultural interface as it edges closer to implementing 'self managed' packages and individual client focused funding arrangements discussed in Chapter Two. One of the principles underpinning self-managed services was that the family can purchase services and supports from outside of the disability services sector to empower the person with a disability (NSW Government Department of Family and Community Service Ageing, Disability and Home Care, 2012b). Furthermore, Aboriginal people could

purchase services from culturally appropriate service providers inside and outside of the disability services sector (ADN, 2012).

**Conclusions.** The results of this study have indicated that:

- a) The Aboriginal communities' complex family and kinship system and the diversity in cultures and languages pose challenges for disability service workers as the disability services sector gradually moves towards adopting a person-centred practice. Aboriginal families often prioritised family responsibilities above fulfilling the requests and requirements of the human service systems. Disability service providers had difficulty in accommodating Aboriginal client's family priorities.
- b) Non-Aboriginal disability service workers need to better align with the local Aboriginal community and family definitions of disability and family/kin supports within a person-centred planning framework.

### **Embedding the principles of cultural competence in the disability services sector**

The study has identified areas where improvements were needed in cultural competence. The Australian Indigenous Doctors Association (2004) defined cultural competence as:

... the relationship between the helper and the person being helped, in a cross-cultural context. While cultural safety centres on the experiences of the patient, cultural competence focuses on the capacity of the health worker to improve health status by integrating culture into the clinical context. This last point is important, and demonstrates the importance of moving beyond cultural awareness. Recognition of culture is not by itself sufficient rationale for requiring cultural competence; instead the point of the exercise is to maximise gains from a health intervention where the parties are from different cultures.  
(p. 1)

Section Two of this thesis has shown that government policy in the disability services sector has not been effective in addressing the low participation rates of Aboriginal people in disability services. The governments often treated and

represented Aboriginal people as a rural and remote population; thus Aboriginal people in metropolitan regions were sidelined. There were examples where Aboriginal people were consulted by government authorities during the major disability services reforms but the results of those consultations were not publically reported. There were numerous accounts where Aboriginal people were totally ignored in major government policy developments and reviews. For example, Aboriginal people were ignored in the evaluation report on the government demonstration projects during the implementation of the DSA in the late 1980s.

Similarly, the study has shown that the policies and practices of the Mainstream NGO would not be described as culturally competent. This study has found that the Mainstream NGO did not implement any initiatives under their old Aboriginal affirmative action policy between 1997 and 2007. This policy was developed in response to the government's evaluation of disability services. A Mainstream NGO non-Aboriginal manager described the policy as "just a piece of paper".

Following the reform of the Mainstream NGO's affirmative action policies discussed in Chapter Five, the Mainstream NGO developed strategies to quantify the participation rate of Aboriginal people in services and implemented cultural awareness training for non-Aboriginal staff. However, these strategies did not reflect many of the principles of cultural competency. It appeared that the agency was focused on meeting government funding requirements in order to seek funding, rather than improve the skills and abilities of disability workers and participation rates of Aboriginal people. Furthermore, there was no plan set with timeframes and benchmarks to achieve the objectives discussed in their Diversity Policy.

Contrary to the Mainstream NGO, the Aboriginal NGO had embedded principles of community empowerment in their policies. For example, all the Aboriginal NGO participants were expected to participate in Aboriginal community inter-agencies and committees as a means to promote services and foster referrals. The Aboriginal NGO participants reported that their services formed part of the overall Aboriginal human services system. In comparison, the Mainstream NGO Aboriginal workers did not work with other Aboriginal workers because it was not part of their workplace duties. Some of the Mainstream NGO non-Aboriginal workers only networked with Aboriginal workers when they had Aboriginal clients. Interestingly, engaging Aboriginal disability workers with the general Aboriginal

community services sector reflected the principles of community involvement and empowerment discussed in Chapter Two.

The study participants suggested staff cultural awareness training as an effective strategy to eliminate racism and discrimination in the disability services sector. Cultural awareness training was adopted by government agencies and the Mainstream NGO to help address service access barriers to participation for Aboriginal people, discussed in sections One and Two of this thesis. Section One has shown that many Aboriginal people with a disability recommended that non-Aboriginal disability workers should undertake cultural awareness training. In addition, the Aboriginal participants in this study suggested community education as a broader strategy to overcome racial discrimination as a barrier to disability service participation.

However, the cultural competence literature discussed in Chapter Two suggested that cultural awareness training is “the beginning step towards understanding that there is difference” (Eckermann, 2010, p. 186). The findings from objective one of the study have identified that the history of the disability services sector was built on identifying ‘differences’ between Aboriginal and non-Aboriginal people with a disability.

Concurring with the cultural competence literature, this study has found that increasing the level of ‘awareness’ of cultural differences between Aboriginal and non-Aboriginal people in the disability services sector has not influenced service participation. Reflecting the literature on cultural competence, some of the non-Aboriginal participants felt that cultural awareness training did not assist them to improve the participation of Aboriginal people. This study has found that cultural awareness training has exacerbated the fears and anxieties of disability workers in working with Aboriginal people. Some of the participants reported that cultural awareness training amplified their insecurities and placed them in a state of constant self-reflection when they worked with Aboriginal families. The non-Aboriginal disability workers have become more self-conscious of their actions when they engage with Aboriginal people.

The evidence from the study suggests that the types and strengths of the relationships between disability stakeholders and Aboriginal communities have influenced the quantity and type of service referrals. As discussed in Chapter Eight, established relationships between local Aboriginal communities and

disability service workers were a key factor in breaking down the culture of mistrust of community and health agencies in Aboriginal communities. Established connections and relationships between disability organisations and local Aboriginal communities were an important element of cultural competency.

Some of the Mainstream NGO participants who were interviewed gave examples of how they have involved Aboriginal communities in the organisation's decision making process. Established working relationships between generic health and human agencies at a governance level were at the heart of culturally competent organisations (Centre for Cultural Competence Australia, 2012; NSW Government Department of Family and Community Services (FACS), 2011). However, this initiative only occurred in a small region of NSW. The Mainstream NGO did not widely practice involving Aboriginal people from any other region of New South Wales (NSW) in the decision making processes of the agency.

The Aboriginal NGO was heavily involved in events, initiatives and committees in the local Aboriginal communities. The Aboriginal NGO participants reported that most of their referrals occurred through the relationships they have built with Aboriginal community members. Contrary to the Mainstream NGO, the Aboriginal NGO received the majority of their referrals through 'self-referral'. The Mainstream NGO received most of their referrals through formal referral pathways.

Interestingly, some of the Mainstream NGO participants reported that they have not actively engaged with Aboriginal communities, because they feared that if they culturally offended Aboriginal people that it may damage the reputation of their organisation. The Mainstream NGO participants were self-conscious that they did not have sufficient knowledge on how to network and build relationships with Aboriginal people and ACCOs.

**Conclusions.** The results of this study have indicated that:

- a) The Mainstream NGO was not effective in achieving the objectives set out in their Aboriginal affirmative action policies. The Mainstream NGO would adopt the principles of cultural competence in organisation policy and practice to improve the rates of Aboriginal people's service participation.
- b) Cultural awareness training has reinforced the fears and anxieties of some of the non-Aboriginal disability workers in supporting Aboriginal families.

As a consequence, disability workers were less inclined to work actively with Aboriginal families.

- c) Established networks and relationships between disability service providers and Aboriginal communities influenced the type and quantity of referrals of Aboriginal people. The Aboriginal NGO mostly had self referrals because they were constantly engaged in the Aboriginal communities. In contrast, the Mainstream NGO was not constantly engaged in the local Aboriginal communities, resulting in most referrals of Aboriginal clients coming through the agency's formal process.
- d) Some of the non-Aboriginal workers who participated in this study did not engage with the local Aboriginal communities because they were afraid of offending Aboriginal people and damaging the reputation of their organisation.

### **Develop a competent Aboriginal disability services workforce**

The development of an Aboriginal services workforce was identified as a strategy to help build a culturally competent disability service system. This study identified many benefits in having Aboriginal workers in the community services sector. DADHC developed an Aboriginal workforce strategy to increase the number and representation of Aboriginal people in the government disability services sector. In comparison, the Mainstream NGO encouraged Aboriginal people to apply for vacant positions, but stopped short of developing an Aboriginal workforce strategy.

The study has identified that Aboriginal workers enjoyed working and networking with other Aboriginal workers. One Aboriginal participant described the Aboriginal workforce as "like a family". The Aboriginal NGO workers reported that they preferred to utilise Aboriginal workers and Aboriginal community controlled organisations (ACCO) before they utilised non-Aboriginal workers and generic organisations. In contrast, some of the Mainstream NGO Aboriginal participants expressed their concerns that they were unaware of other Aboriginal workers in the organisation. The Mainstream NGO Aboriginal workers felt isolated in their workplace. The Mainstream NGO participants interviewed in this study reported that they utilised Aboriginal workers to help improve the participation rate of

Aboriginal people in disability services, such as respite, therapies and outreach services.

The study found that an Aboriginal workforce has its benefits and consequences in influencing the service participation of Aboriginal people. The study participants reported that Aboriginal workers helped foster “connections” and “engagement” between some Aboriginal clients and government and non-government disability and community service providers. The Aboriginal community, health and disability services workforce helped breakdown the culture of mistrust between mainstream government and non-government agencies and local Aboriginal communities.

The data collected under objectives one and two has shown that Aboriginal workers in a mainstream disability service provider helped build relationships between non-Aboriginal disability workers and local community service Aboriginal workers and ACCO. These relationships helped maintain the participation of Aboriginal people in disability services by fostering connections and referrals of Aboriginal people between ACCOs and disability service providers. Furthermore, Aboriginal disability service workers had knowledge of the cultures, issues and community politics that many non-Aboriginal workers did not obtain. For example, a Mainstream NGO Aboriginal worker participated in Aboriginal client visits to help build trust between the non-Aboriginal workers and the Aboriginal families.

Chapter Eight has shown that an inadequately trained Aboriginal disability services workforce has detrimental consequences for Aboriginal people. The Aboriginal participants gave one example of how a government Aboriginal workforce strategy has exacerbated and reinforced existing racial stereotypes of Aboriginal people, such as ‘bludgers’ and ‘don’t like to work’, amongst their non-Aboriginal peers. One Aboriginal participant stated that in this program Aboriginal people were “...employed because they’re Aboriginal ... [and that] the government loves to know that there’s so many Aboriginals that are employed in different services”.

The Aboriginal participants suggested that stakeholders need to recruit Aboriginal people and ensure that they have the opportunities to build occupational skills and competencies based on their roles and responsibilities. A person’s Aboriginality should not be given a higher priority in job application assessments than individual occupational competencies.

A major finding was that the Mainstream NGO non-Aboriginal workers gave Aboriginal people a 'choice' regarding the Aboriginality of their case-workers within a person-centred planning framework. Consequently, local Aboriginal community and family politics had a negative impact on the participation of Aboriginal people in disability services. Many participants reported that some Aboriginal people did not want an Aboriginal worker for fear that Aboriginal workers breached client confidentiality. This was not raised in the cultural competency and Aboriginal health workforce literature.

Simply prescribing an Aboriginal client an Aboriginal worker will not ensure that the Aboriginal family will continue to engage with the disability service provider. The participants in this study reported numerous accounts indicating that Aboriginal clients had requested not to be referred to an Aboriginal worker. The Mainstream NGO non-Aboriginal workers overcame this barrier by offering Aboriginal clients a choice of an Aboriginal worker, rather than assuming that an Aboriginal person required an Aboriginal worker. Interestingly, none of the Aboriginal NGO participants provided recommendations on how to overcome Aboriginal family politics as a barrier. An Aboriginal NGO participant described this as a "bit of a bummer really".

The study participants reported that there were many Aboriginal families not accessing disability services because they did not trust Aboriginal workers. The Mainstream NGO participants provided examples of some Aboriginal families who travelled out of their local community to access services that had no Aboriginal workers. This practice of avoiding local Aboriginal community workers was a costly and stressful exercise for Aboriginal families that had a low level of disposable income.

**Conclusions.** The results of this study have indicated that:

- a) The Aboriginal NGO workforce was networked with other Aboriginal workers in the social and community services sector. However, the Mainstream NGO Aboriginal workers were not networked with other Aboriginal workers in the agency. The Mainstream NGO workers felt isolated from other local Aboriginal community workers.
- b) An Aboriginal workforce helped address the cultural needs of Aboriginal people with a disability, their families and communities.

- c) Aboriginal workers in the disability and community services sectors influenced social connections and engagement between Aboriginal clients and government and non-government disability and human service providers.
- d) Aboriginal people should not be recruited in the disability services sector based on their Aboriginality alone. Rather, Aboriginal disability workers need to be adequately skilled and trained in their field of occupation, just the same as non-Aboriginal workers.
- e) Aboriginal people with a disability should be given a choice regarding the Aboriginality of their support worker. Some Aboriginal people do not want an Aboriginal worker due to Aboriginal community family factional politics. Furthermore, some Aboriginal people fear that Aboriginal workers do not maintain confidentiality.
- f) Some Aboriginal families travelled out of their local community to access services that had no Aboriginal workers.

### **Supporting Aboriginal community autonomy: Aboriginal community controlled organisations and services**

The data collected under objective two of this study have identified a number of benefits and challenges in funding ACCOs and services to foster Aboriginal participation. The National Aboriginal Community Controlled Health Organisation (NACCHO) (1995) defined an ACCO as:

... a process which allows the local Aboriginal community to be involved in its affairs in accordance with whatever protocols or procedures are determined by the Community. The term Aboriginal Community Control has its genesis in Aboriginal peoples' right to self-determination. (p. 1)

The study has found that the needs of Aboriginal people with a disability cannot be generalised across the whole Aboriginal population in relation to funding ACCOs. The study has identified how funding ACCOs influenced Aboriginal people's service participation through fostering reconciliation between Aboriginal communities and generic government agencies and NGOs. The Aboriginal NGO gave an account of a celebration event for International Day of People With Disability (IDPWD) that received funding from a range of government sources. The

event brought together ACCOs, disability organisations and Aboriginal community members in the planning and facilitation of the event.

Funding ACCOs empowered some Aboriginal people with a disability and their communities by providing choice in disability services. The study participants provided accounts of how many Aboriginal families had a higher level of trust of ACCOs than generic organisations. An Aboriginal NGO worker stated that Aboriginal people “know where there are services they like to deal with their own [Aboriginal communities] ... they’ll rely on us and they can trust us”. Similarly, the Mainstream NGO non-Aboriginal participants reported that many mainstream disability service providers utilised ACCOs to attract and support Aboriginal clients. Thus, ACCOs were a ‘hub’ for non-Aboriginal workers and mainstream organisations in working with Aboriginal people with a disability.

However, government funding of ACCOs also had the potential to create an elitist culture within local Aboriginal communities which inhibited the participation of some Aboriginal people in disability services (Pearson, 2000; Peters-Little, 2000). The participants reported that many Aboriginal people did not utilise ACCOs due to Aboriginal community factional politics. The Aboriginal NGO provided examples of Aboriginal clients who opted out of the agency, because certain Aboriginal people were employed there.

Furthermore, some Aboriginal families who were not local to their town experienced racial discrimination by ACCOs. For example, a Mainstream NGO non-Aboriginal worker told of how an Aboriginal client experienced racial discrimination from an ACCO because she was from Queensland. Some of the Mainstream NGO participants reported that some Aboriginal families travelled outside of their local community to access disability services due to conflict with, or conflict between, local ACCOs. In saying this, all Aboriginal participants supported the funding of ACCOs and services for Aboriginal people with a disability.

The study identified a divide amongst the non-Aboriginal participants regarding the practice of the government funding ACCOs and Aboriginal specific services. Some Mainstream non-Aboriginal participants did not support the government in funding ACCOs and services, describing it as “culturally divisive”. However, none of the participants could provide any examples of how or where this has occurred in the disability services sector. It seems this may be a philosophical opposition to funding ACCOs.

**Conclusions.** The results of this study have indicated that:

- a) ACCOs in the disability services sector foster Aboriginal community empowerment and reconciliation between Aboriginal communities and non-Aboriginal communities. Many Aboriginal people trust ACCOs more than mainstream service agencies. Many disability service providers utilised ACCOs as support hubs for Aboriginal clients.
- b) Aboriginal community family factions may influence the participation of Aboriginal people in government funded ACCOs. This has disadvantaged Aboriginal people with a disability, resulting in many Aboriginal people with a disability travelling out of their local communities and townships to participate in services.
- c) Many of the Mainstream NGO non-Aboriginal participants were in principle opposed to the government funding ACCOs, claiming it was culturally separatist and divisive.

### **Bureaucratisation of disability and disadvantage**

Surely there can be no doubt that if 'love thy neighbour' were a federal regulation, it would become meaningless and useless. ... A more serious part of our common problem is that too much of humanism has gone scientific. And too much of our science makes it easier to banish our brothers from our lives. (Blatt, 1981, p. 346)

The impartial application of abstract rules in the lives of families caring for a person with a disability has undermined relationships of trust and connections between Aboriginal communities and generic disability service providers. The trajectories of Aboriginal peoples' and disability service workers' journeys through the disability services sector was highly influenced by the bureaucratisation of the disability services sector. The lives of Aboriginal people with a disability have been framed and occupied by government bureaucracy. This was particularly illustrated when multiple agencies and disability service providers were focused on meeting government funding requirements.

Consistent with Weber's views, bureaucratisation of this nature has undermined the freedom of people with a disability by ensnaring them in the logic of an opaque, wilful, impersonal even tyrannical system. As Blatt (1981) and Parmenter

(1991) stated, the problem with rules and regulations lies not in any perceived 'evil' or 'ablest' intentions of those who work in bureaucracies, but rather in the so-called democratic process of the regulations themselves. Some of the non-Aboriginal participants described themselves as "specialists in 'disability'" and were expected to primarily support issues that related to a person's disability within the service or program guidelines. The study participants have provided many examples of how government and non-government human service agencies were bureaucratically "processed focused" and had little regard for the impact of bureaucratic procedures on clientele. A Mainstream NGO non-Aboriginal worker used the phrase "meet them and street them" to describe the impersonal nature of the human and disability services sector bureaucracy. The lives of many Aboriginal families were highly stressed due to multiple agency interventions at the point of engagement in the disability services sector. As a result, many Aboriginal families rebelled against the disability services sector and opted out of the system altogether.

A major finding was that the study participants were oblivious to the fact that they contributed to the overburdening of their Aboriginal clientele by referring them to more agencies and services. The disability organisations that participated in this study attempted to ameliorate the issues faced by Aboriginal clients within their limited scope. Disability service providers were required to refer families to more agencies, because services and programs were not effectively developed to cater to the diverse and complex challenges faced by people with a disability.

A significant finding was that some of the study participants were required to help some Aboriginal clients cope with the additional burden of the disability and community services bureaucracy. This shows that the already stretched Multilateral Agreement funding was being used to support Aboriginal people and their families to navigate or circumnavigate the often complex disability services system. Thus, not only was participating in the disability services sector an emotionally and financially taxing and burdensome experience for the Aboriginal families, it was also a taxing and burdensome experience for the disability service workers and organisations.

Some of the study participants had to reconfigure or breach the bureaucratic process and guidelines of their own organisation to improve the participation of many Aboriginal families. For example, participants delayed completing the formal

paperwork until trust was established with the Aboriginal family. This practice was identified by the participants as a direct consequence of previous agencies mistreating and disempowering Aboriginal people.

The policy document analysis has shown that since the formation of the DSA, the governments have treated Aboriginal people as a specialised field in order to address the low participation of Aboriginal people in disability services. The governments objectified Aboriginal people in Australian data collections, constantly analysing, reviewing and quantifying Aboriginal people with a disability and their service participation. When DADHC found that the problem was too 'complicated' to address, Aboriginal people with a disability were compartmentalised with the development of the NSW Department of Disability, Ageing and Home Care - Aboriginal Policy Unit (DADHC-APU). The DADHC-APU developed a number of policies covering Aboriginal workforce, access and equity and increased funding for ACCOs and specific services for Aboriginal people with a disability and their communities.

The DADHC-APU also increased pressure on funded agencies to address access and equity barriers for Aboriginal people and improve data collection on the participation rate of Aboriginal people in services. Although the governments increased pressure on disability service providers to address the participation rate, it did little to boost the level of commitment and effectiveness of disability service providers to address access and equity barriers for Aboriginal people. Rather, the governments just increased the bureaucratic burden on the Mainstream NGO staff. This was well demonstrated by the Mainstream NGO's development and implementation of their Aboriginal affirmative action policies from the 1990s. The Mainstream NGO management focus group participants admitted that their agency developed those policies to meet the expectations of government and philanthropic agencies during the NSW Government's review of Multilateral Agreement funded organisations. A Mainstream NGO non-Aboriginal manager reported that some of the agency's staff participated in cultural awareness training. However, this training was not undertaken as an initiative under the Aboriginal policy so much as it was undertaken to meet government expectations. Furthermore, the reforms to the Mainstream NGO's Aboriginal policy in 2007 were also driven by government regulations, such as statistical reporting and recruitment practices. This shows that the Mainstream NGO was not focused on

identifying the factors that influence the participation of Aboriginal people in government funded services and therefore was unlikely to be effective in addressing those factors. Similarly, government policies were not effective in initiating change in disability services to improve the participation rate of Aboriginal people in funded services.

The impersonal bureaucratic nature of the disability services sector has resulted in resistance amongst some Aboriginal people with a disability and their families. Some Aboriginal clients were refusing to comply with disability agencies and disability service staff and exiting the service system. For example, a Mainstream NGO non-Aboriginal worker reported that one of their clients changed their phone number so that they could not be contacted by community and disability service providers. Another Mainstream NGO non-Aboriginal worker reported that a client gave their phone away so they could not be contacted by government and non-government agencies.

**Conclusions.** The results of this study have indicated that:

- a) The population of Aboriginal people with a disability were enshrined in a complex bureaucratic system that had little flexibility. The disability service system's rigid service guidelines and processes have contributed to the multiple agency interventions, which has contributed to clients' personal stress. Disability service providers struggled to address the multiple issues of Aboriginal clients resulting with clients being referred to more disability service providers.
- b) The disability service workers were oblivious to the stresses caused by multiple agency intervention as a result of referring Aboriginal people to more services. Disability service workers were required to support Aboriginal families to manage the disability and community services bureaucracy. Some of the disability workers had to reconfigure or breach bureaucratic guidelines to maintain the participation of Aboriginal people.
- c) The governments have constantly objectified Aboriginal people in the collection of data and statistics. Government policy was not effective in leading significant change in the disability services sector as the emphasis was constantly on cultural differences between Aboriginal and non-Aboriginal people with a disability.

- d) Increased government pressure on mainstream disability service providers to address the low participation rate of Aboriginal people in disability services has not resulted in an effective response. Rather, disability service providers reconfigured their policies and procedures to address government funding requirements and mandatory procedures.
- e) The complex bureaucracy of disability services has contributed to many Aboriginal people refusing to comply with the requests and suggestions made by disability services workers. As a result, there exists a culture of resistance against the disability services system amongst many Aboriginal people and their families.

### **The Relationships Between the Factors**

Consistent with the third objective of this study, an Explanatory Framework to describe the relationships between the 12 identified factors is proposed. The Explanatory Framework, called the *Aboriginal Service Participation Universe* (the Universe) and displayed in Figure 16 below, was informed by the research findings discussed in Chapter Eight.

The Universe is illustrated with excerpts of the transcriptions from the interviews and focus groups. The relationships between all the factors were multifaceted inter-related and inter-dependent institutionally, historically and culturally. O'Brien's (1980) concept of the Vicious Circle, represented in Figure 5, guided the development of The Universe. The Vicious Circle acknowledged that the values, beliefs and expectations of society and social groups regarding people with a disability influenced the expectations and opportunities available to people with a disability. The vicious circle starts off when specialists in the medical profession, diagnose and assess 'disability' based on a medicalised norm, defining and determining what is known as 'disability'. Society perceives and treats people with a disability as unproductive and dependent members of society. Consequently, the devaluation of people becomes a self fulfilling prophecy, as the subsequent reduction in expectations and limitations of opportunities guarantees that performance will be diminished (O'Brien, 1980, 1989, 2003). As a consequence, the potential growth of people with a disability is limited and the "person's label becomes a life sentence" in a rigid bureaucratic system called the disability services sector (O'Brien, 1980, p. 6).

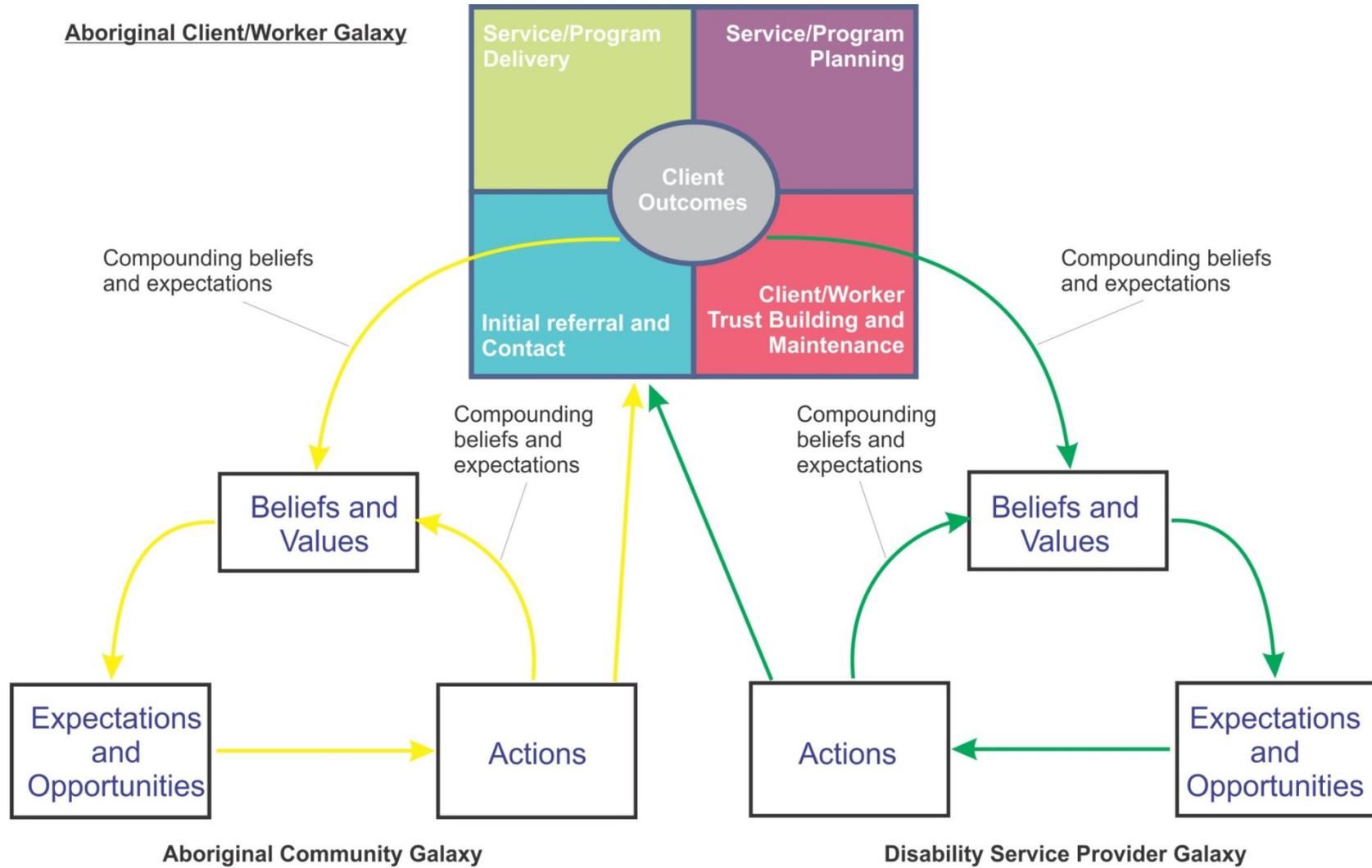


Figure 16 – Aboriginal service participation universe

O'Brien (1980, 2003) suggested that the vicious circle should be the focus of attention to generate positive change for people with a disability. The Universe includes two '*vicious circles*' defined in this Explanatory Framework as galaxies. The first galaxy displayed in Figure 17, *Aboriginal Client Galaxy*, shows some examples of how the beliefs and values influenced the "expectations and opportunities" and "actions" taken by the Aboriginal community for the care and support of people with a disability. Aboriginal communities had their own beliefs and values, such as the definition of disability and family expectations of personalised care and support, which influenced the informal care and support arrangements for people with a disability within the family and kinship circles.

No word that collectively defined handicaps and impairments equivalent to the Western concept 'disability' existed in the traditional languages of Aboriginal people. In addition, there exists a high level of mistrust of generic disability services in Aboriginal communities due to a history of negative experiences with government and non-government social service agencies. The participants reported that Aboriginal people were often suspicious of generic non-Aboriginal disability workers and perceived generic disability services as institutions of racism and discrimination. These beliefs influenced Aboriginal people's expectations of the services available to people with a disability within the disability services sector. As such, many Aboriginal people did not actively seek formal disability services and supports until the resources within their family and kin networks were depleted. Aboriginal people's individual actions reinforced the beliefs and values within their communities. Therefore, Aboriginal people with a disability live out their lives in a vicious circle.

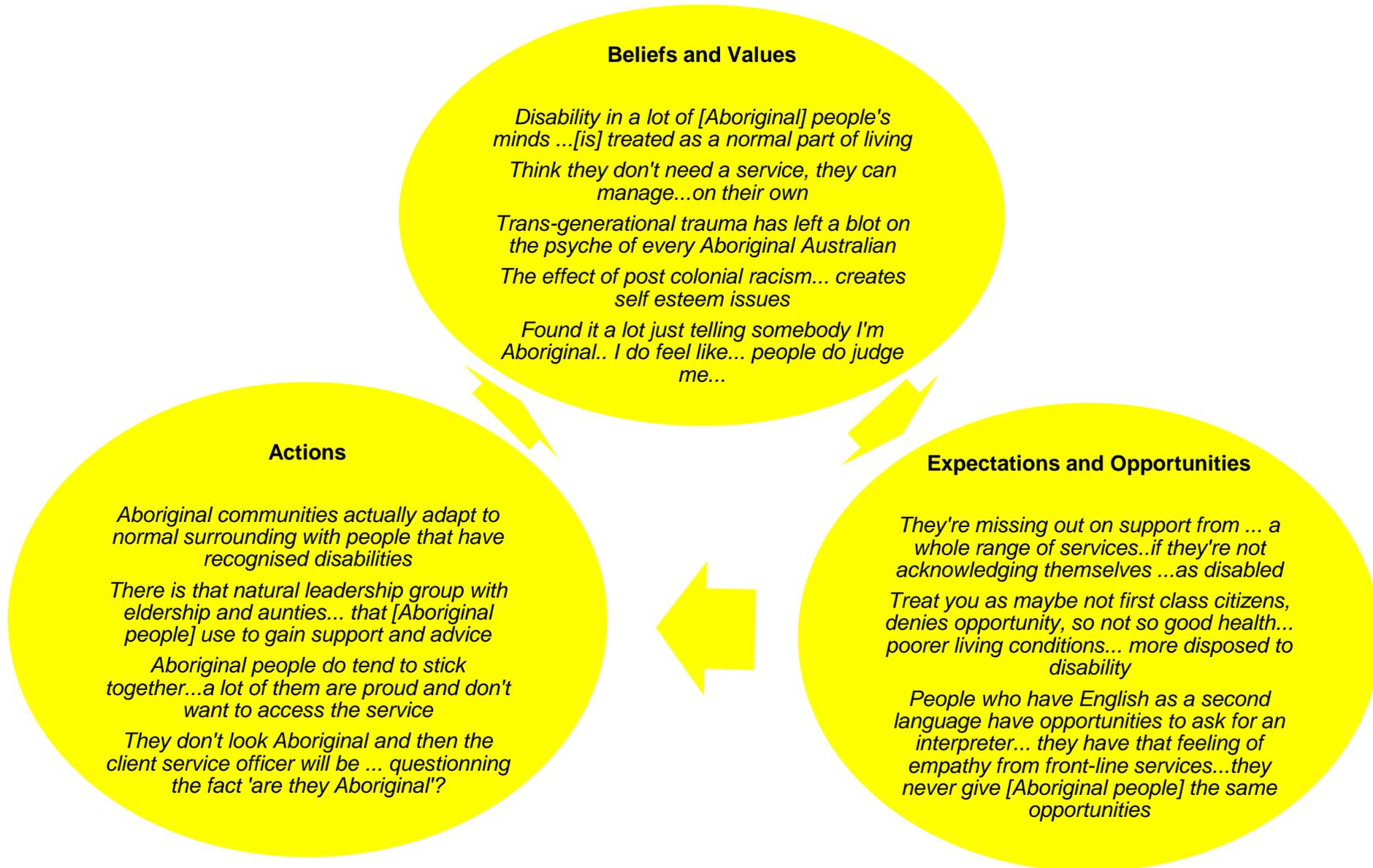


Figure 17 - The Aboriginal client galaxy, part one of the Aboriginal service participation universe

Similarly, the government funded disability service providers functioned and operated within their own galaxy called the *Disability Service Provider Galaxy*, displayed in Figure 18. Some of the extracts from the interview and focus group transcripts are used as examples to show how the Aboriginal NGO and the Mainstream NGO traversed their own galaxy similar to the Aboriginal communities. There were many similarities between the Aboriginal NGO and the Mainstream NGO in their beliefs and values and expectations. For example, both agencies believed that people with a disability need to be empowered in the disability services system. Furthermore, both agencies often stated that people with a disability “need to be in the driver’s seat” in service planning and development. Also, both agencies believed that non-Aboriginal workers needed to participate in Aboriginal cultural awareness training as a means to develop a culturally responsive disability services sector. Both agencies believed that Aboriginal clients prefer to work with Aboriginal workers.

There were many differences between the Aboriginal NGO and the Mainstream NGO in their beliefs and values and expectations. The Aboriginal NGO workers were required to be involved and participate in Aboriginal community events, committees and initiatives. However, the Mainstream NGO workers were not expected to be involved in the local Aboriginal communities as part of their occupational role. As such, most of the Aboriginal NGO’s clients were self-referred and the majority of the Mainstream NGO’s clients came through the formal agency referral pathways. Mainstream NGO participants believed that cultural diversity and individual client empowerment were the primary philosophies of disability services. In contrast, the Aboriginal NGO believed that cultural diversity in the Aboriginal communities and client empowerment were the main philosophies when supporting Aboriginal people.

The Disability Service Provider Galaxy also clearly shows the contestation surrounding the funding of ACCOs between the Mainstream NGO participants and the Aboriginal NGO participants. Some of the Mainstream NGO participants were against the funding of ACCOs. However, the galaxy shows that ACCOs fostered reconciliation between the Mainstream NGO and the local Aboriginal communities. Many of the Mainstream NGO participants often networked with ACCOs and Aboriginal workers. Connections between the disability service providers and local Aboriginal communities assisted with the level and types of referrals.

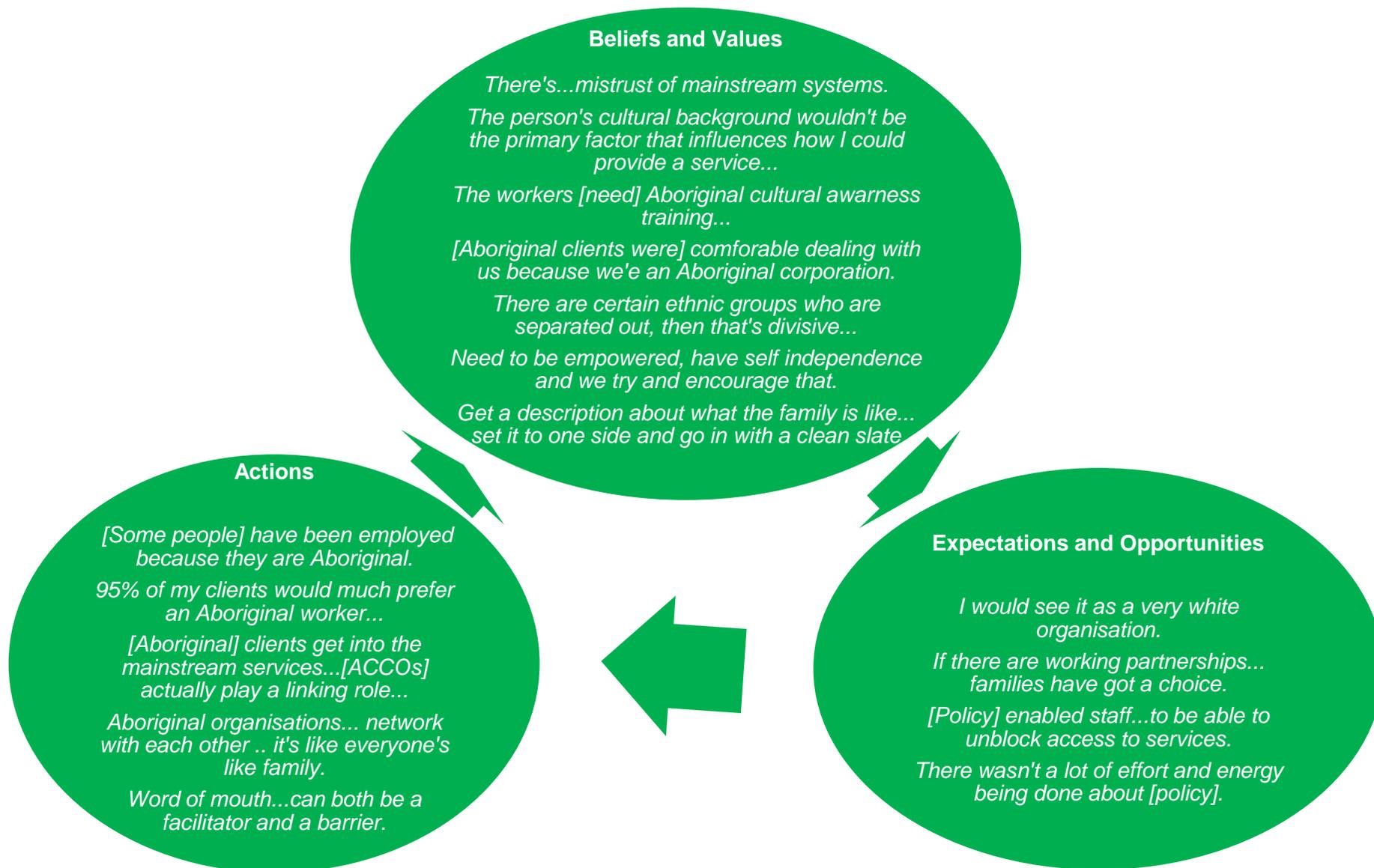


Figure 18 - The disability service provider galaxy, part two of the Aboriginal service participation universe

The beliefs of each of the two agencies influenced the expectations and actions of disability workers. The Aboriginal NGO participants believed that being part of the overall Aboriginal community services sector was the role of a community service provider. However, the Mainstream NGO believed that engaging in Aboriginal communities was not the primary role of disability workers unless there were Aboriginal clients. Furthermore, the Mainstream NGO participants felt that Aboriginal people prefer to “keep to themselves” and were “not aware of disability services”. As such, the Aboriginal NGO was more engaged in the local Aboriginal communities than the Mainstream NGO, such as participating on committees, initiatives and events. As a result, the Mainstream NGO non-Aboriginal workers continued to believe that Aboriginal people were not participating in disability services because “they like to keep to themselves” and Aboriginal people “were not aware of disability services”.

Both agencies believed that the governments had power and control of funded services. The policy documents analysed in this study under objective one has shown that the Mainstream NGO adopted the DSA’s and the Multilateral Agreement’s definition of disability for service access and eligibility. In contrast, the Aboriginal NGO adopted the *Disability Discrimination Act 1992 (DDA)* definition of disability and how it impacts on an individual’s activities of daily living. As such, both agencies fulfilled the government’s requests and expectations, such as collecting client data, developing policies and reporting to DADHC on a regular basis. Similar to Aboriginal people with a disability, disability service providers operated within a vicious circle.

The previous two galaxies then created the third galaxy in the Universe *the Aboriginal Client/Worker Galaxy*, displayed in Figure 19. Using some excerpt examples from the interview and focus group transcripts, the *Aboriginal Client/Worker Galaxy* shows how the factors influenced the service participation of Aboriginal people at the moment Aboriginal people with a disability engaged and connected with the disability services sector. Each phase was blended in with the next phase. The experiences of Aboriginal people and disability service workers at the time of the initial referral and contact influenced and determined the outcomes of the client and worker trust building and maintenance phases. For example, the Mainstream NGO non-Aboriginal workers had to spend more time into building trusting relationships with Aboriginal clients than the Aboriginal NGO workers. The length of time depended on a range of things, such as the experiences of the

clients with other generic agencies or a history with government agencies. Furthermore, those Aboriginal clients who had a history of negative experiences often took longer to build a trusting relationship with the Mainstream NGO non-Aboriginal workers. If the Mainstream NGO non-Aboriginal workers did not take time to build a healthy relationship with their Aboriginal clients then the clients would rebel against the service provider or, worse, opt out of the service system.

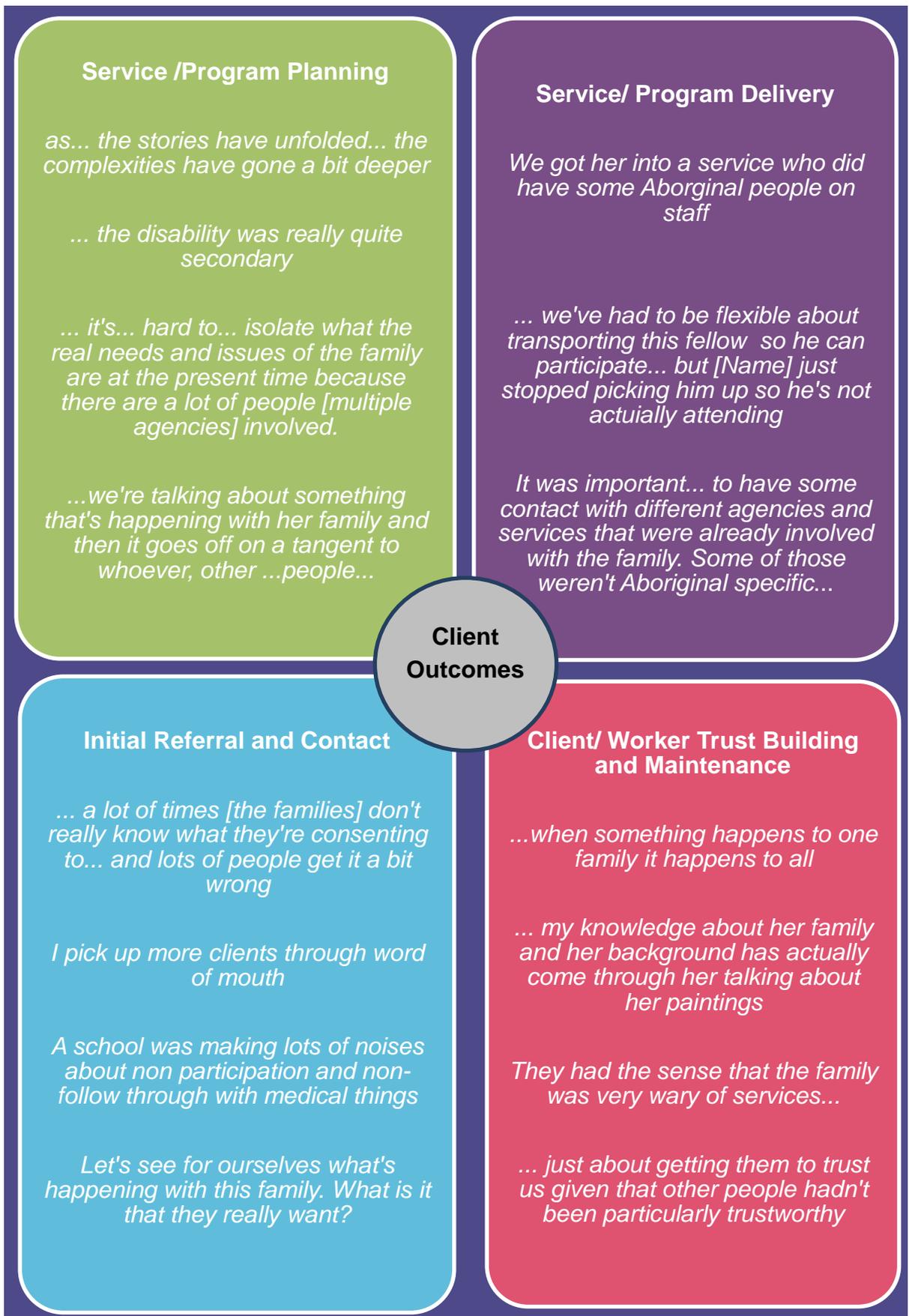


Figure 19 - The Aboriginal client/worker galaxy, part three of the Aboriginal service participation universe

The *client/worker trust building and maintenance* phase blurred into the *service/program planning* phase and the *service/program delivery* phase of the *Aboriginal Client/Worker Galaxy*. The two latter phases were heavily dependent on the outcomes of the first two phases. Often the Mainstream NGO and the Aboriginal NGO participants delayed some of the bureaucratic processes, such as paperwork, until trust was established between the Aboriginal clients and the Mainstream NGO workers. There were times where the participants did not discuss the service planning phase or issues relating to 'disability' during initial client visits. For example, one Mainstream NGO non-Aboriginal worker took an Aboriginal family for a drive to the cemetery as a means to learn about the family and build a trusting relationship. There was no discussion on any issue regarding disability or disability services during this outing. However, after subsequent outings the family and the Mainstream NGO worker discussed services and supports.

The factors that influenced the participation of Aboriginal people in disability services functioned within this Universe. The clients' outcomes, from the moment they engaged in the *Aboriginal Client/Worker Galaxy*, influenced the beliefs and values of the *Aboriginal Client Galaxy*. Similarly, the experiences of the disability workers at the moment they met the Aboriginal clients influenced the beliefs and values of the *Disability Service Provider Galaxy*. The multiple beliefs, expectations and actions within the first two galaxies determined the participation of Aboriginal people in disability services before the Aboriginal clients interacted with the disability service workers and managers who participated in this study. Thus, negative client/worker outcomes and experiences either reinforced or generated negative beliefs and values in the *Aboriginal Client Galaxy* and the *Disability Service Provider Galaxy*. For example, experiences of racism in the disability services sector have reinforced the current perception of disability service providers as institutions of racism and discrimination. As a consequence, Aboriginal people opt out of the disability services sector, reinforcing the non-Aboriginal disability service worker's perception that Aboriginal people prefer to engage with ACCOs or Aboriginal people prefer to keep to themselves. Both positive and negative beliefs were then rumoured within the *Aboriginal Client Galaxy* and the *Disability Service Provider Galaxy*, reinforcing or changing the expectations and actions of Aboriginal people with a disability and disability services workers.

Similarly, positive client/worker outcomes and experiences either reinforced or generated new positive beliefs and values. For example, Aboriginal clients being allocated Aboriginal workers has helped breakdown the culture of mistrust of generic disability services providers in Aboriginal communities. Furthermore, Aboriginal disability workers have improved the level of awareness of Aboriginal affairs amongst the non-Aboriginal disability services workforce. These positive experiences then change the beliefs and expectations within the *Aboriginal Client Galaxy* and the *Disability Service Provider Galaxy*.

## Conclusions

This chapter has brought together the findings of the study in the context of the three research objectives together with the literature reviewed.

The Conceptual Framework discussed in Section Two has the potential to help empower Aboriginal people in the research and policy process. Merging the IST with the ICF ameliorated the weaknesses of the ICF as a Eurocentric global framework for research with Aboriginal people with a disability.

The disparity in the way disability is conceived and defined between Aboriginal communities and disability service providers has undermined the participation of Aboriginal people in disability services. The Western scientific pathological conceptualisation of disability was imposed on the Aboriginal population since colonisation. Non-Aboriginal disability researchers have measured, prescribed and defined the prevalence of handicap and disability in Aboriginal communities within Eurocentric methodologically colonising frameworks.

Non-Aboriginal disability service workers need to better align the local Aboriginal community's definition of disability, family and kin within a person-centred framework to improve the participation of Aboriginal people. The conceptualisation of disability and family/kin supports and responsibilities within local Aboriginal communities was more clearly aligned with person-centred practice than the actions and beliefs of the Mainstream NGO non-Aboriginal participants of this study.

The governments and the Mainstream NGO have been so caught up in understanding the cultural and language differences between Aboriginal and non-Aboriginal communities that they have ineffectively addressed the participation rate of Aboriginal people in disability services. The analysis of policy documents in

this study identified that the disability services sector has 'culturally Othered' Aboriginal people with a disability as a specialised field in relation to their participation in disability services. Consequently, the disability services sector has normalised Whiteness by defining and inscribing a 'normal' person with a disability and marginalising Aboriginal people with a disability as the cultural Other.

The disability services sector acknowledged that the high prevalence of disability was strongly linked to poor health and greater disadvantage. Therefore, disability services guidelines need to be widened to enable service providers to address the social determinants of health. The service participation of Aboriginal people was identified, represented and treated as a specialised field by the disability services sector.

The governments and the disability services sector are yet to fully adopt the principles of cultural competence to promote the participation of Aboriginal people in disability services. The governments and the Mainstream NGO have demonstrated some success in developing cultural competence, such as involving local Aboriginal communities in agency planning and recruiting Aboriginal people. However, since the formation of the DSA the level of emphasis placed on the service participation of Aboriginal people with a disability has oscillated. The Mainstream NGO developed Aboriginal affirmative action policies but did not report any actions under those policies. Established networks and relationships between disability service providers and local Aboriginal communities influenced the types and quantity of referrals of Aboriginal people.

The impersonal nature of the bureaucratic system has resulted in ineffective attempts to address the low participation of Aboriginal people in disability services. Since the formation of the DSA, the service participation of Aboriginal people with a disability was framed and occupied in government bureaucracy. The bureaucratisation of disability has created difficulties for disability service workers in supporting Aboriginal clients according to a person-centred approach consistent with current and emerging service and program guidelines. Multiple agency intervention was often a consequence of a complicated disability services bureaucracy, exacerbating the poor social and health status of Aboriginal people with a disability. The impersonal bureaucratic nature of the disability services sector has resulted in some Aboriginal clients withdrawing from disability agencies and exiting the service system.

Racism and discrimination were service participation barriers for Aboriginal people. Racism and discrimination have functioned like a negative spiral, influencing the social determinants of health in Aboriginal communities. Furthermore, racism and discrimination have created and reinforced a culture of mistrust of disability services in Aboriginal communities. Cultural awareness training has had a limited impact on the participation rate of Aboriginal people in disability services.

The government funding of ACCOs has helped influence the participation of Aboriginal people in disability services by empowering Aboriginal communities to be autonomous and self-determining. Disability service workers found that ACCOs have helped build trusting relationships between Aboriginal clients and disability service providers. Funding ACCOs has had a negative impact on the participation of Aboriginal people in disability services and created and fostered the growth of elite factions in Aboriginal communities.

Similar to the government funding of ACCOs, adequately trained Aboriginal workers have benefits in influencing the participation of Aboriginal people in disability services. Like ACCOs, many Aboriginal people preferred to work with Aboriginal workers because they did not trust non-Aboriginal workers due to bad experiences with previous community and disability service providers. Aboriginal workers have helped bridge connections and engagement between Aboriginal clients, government and non-government disability service agencies.

The study has proposed an Explanatory Framework, called the *Aboriginal Service Participation Universe*, to help explain the complex and multifaceted relationships between the factors that influenced the participation of Aboriginal people in disability. O'Brien's concept of the Vicious Circle influenced the development of the Universe. The Universe includes three galaxies to demonstrate how some factors have influenced the participation of Aboriginal people before they have actually engaged in disability services. Furthermore, the Universe shows how the factors that influenced the participation of Aboriginal people were historically socially, culturally and institutionally imbedded.

The following chapter will demonstrate the significance of this research for the disability sector and the disability rights movement in the context of Aboriginal communities. The final chapter will canvas the limitations of the study and suggest future research directions.

## Chapter Ten: Conclusions and Recommendations

The purpose of this final chapter is to consider the study as a whole in order to determine what has been learned and what significance the findings have for the disability services sector and Aboriginal communities.

The chapter will provide an overview of the purposes, methodology and outcomes of the research. This will be followed by a discussion of the research limitations and significance. The study has generated some hypotheses and implications for future research. The study has also generated a number of practical recommendations to improve the participation of Aboriginal people in disability services.

### Overview of the Study

This study was initiated by a personal and professional interest in identifying the factors that influence the participation of Aboriginal people in disability services. The disability services sector is in the middle of massive reforms initiated through the Council of Australian Governments (COAG). A concern regarding the higher prevalence of disability and the low disability services participation rate in the Aboriginal population compared to the non-Aboriginal population was instrumental in determining the focus of the study. Although there is a plethora of literature on Aboriginal people with a disability, very little is known about the experiences of disability service providers in working with Aboriginal people with a disability. As a result, disability service providers are ill-informed about the factors that influence the participation of Aboriginal people with a disability in the New South Wales (NSW) Government funded disability service sector. In light of these considerations, the overall research purposes were to:

1. Identify how and when the participation of Aboriginal people in disability services was identified in documented policy.
2. Identify and describe the factors that influence the participation of Aboriginal people in disability services as perceived by Aboriginal and non-Aboriginal employees in two NSW Government Department of Ageing, Disability and Home Care funded disability services.

3. Develop an Explanatory Framework that adequately encapsulates and represents the factors identified in this study as influencing the participation of Aboriginal people in disability services.

Research objective one and two were addressed by means of an overview of literature and a qualitative study. The literature focused on international and Australian policy and the political arena of the disability rights movement. The literature review also demonstrated that the population of Aboriginal people with a disability were one of the unhealthiest and disadvantaged sub-groups in Australia.

The qualitative study was undertaken in two phases to meet the three objectives of this study. Consistent with the first objective, a critical historical literary analysis of policy documents produced by the governments, the Mainstream NGO and the Aboriginal NGO was undertaken. The analysis aimed to identify how they responded to the participation of Aboriginal people in DADHC funded disability services was undertaken. This included a rigorous search of publications in private and public archives, libraries, databases and meetings with key people and authors of the publications. The analysis found that the disability services sector treated, represented and labelled Aboriginal people with a disability as a specialised field that consisted of themes, such as 'cultural difference', 'remoteness' and 'disadvantage/vulnerability'. The level of government and generic NGO emphasis on addressing the low participation rate has oscillated since the formation of the *Commonwealth Disability Services Act 1986* (DSA) and the *New South Wales Disability Services Act 1993* (NSWDSA). The data showed that the government and the Mainstream NGO were so focused on analysing differences between Aboriginal and non-Aboriginal people that they have not effectively addressed the low participation rate of Aboriginal people with a disability in disability services. The Aboriginal NGO and the Mainstream NGO adopted different definitions of disability for service eligibility. Interestingly, both non-government organisations (NGO) were responsive to the governments' requests under their funding agreements. The Conceptual Framework was proposed as a strategy to overcome the challenges faced by governments and disability service providers.

Consistent with the second objective of the study, data were then obtained from interviews and focus groups with paid employees of the Aboriginal NGO and the Mainstream NGO. The data identified twelve factors that influenced the

participation of Aboriginal people in disability services. These factors were multifaceted and historically interrelated and interdependent institutionally, culturally and historically.

The third objective of the study was achieved with the development of an Explanatory Framework, called the *Aboriginal Service Participation Universe*, informed from the data collected from interviews and focus groups discussed in the third section of this thesis. Guided by O'Brien's (1981) concept of the Vicious Circle, the Universe consists of three interdependent galaxies. The first galaxy, the *Aboriginal Community Galaxy*, shows how the factors that influence the disability service participation of Aboriginal people function before Aboriginal people made contact with a disability service provider. Similarly, the second galaxy, the *Disability Service Provider Galaxy*, demonstrates how disability service workers influence the participation of Aboriginal people before they meet an Aboriginal client. The third and final galaxy of the Universe, the *Aboriginal Client/Worker Galaxy*, shows how the factors influenced the participation of Aboriginal people in disability services occur at the moment the clients make contact with the disability service workers. The results and experiences of both the clients and the workers influenced the beliefs and values of the Aboriginal communities and the disability service providers in the first mentioned galaxies.

### **Limitations of the Study**

Limitations of the study relate to the characteristics of the participants, the two disability service providers purposively chosen for this research and the data analysis techniques. There were attempts made to limit or compensate for the effects of the study limitations.

#### **With the characteristics of the participants**

The Aboriginal NGO and the Mainstream NGO were chosen to best reflect the disability services funded by DADHC under the DSA and the Multilateral Agreement. Consequently, there are not many DADHC funded Aboriginal community controlled organisations (ACCO) in NSW. Furthermore, DADHC funded ACCOs are small organisations. Comparatively, there are many large DADHC funded generic disability service providers in NSW that have been in operation for many decades. To compensate for the limitations of the DADHC

funded ACCOs, the Aboriginal NGO was chosen as it provided DADHC funded service types in a small region of NSW and does the occasional outreach visit. The Mainstream NGO was chosen as it has existed as a state-wide service provider for many decades and provides a full range of DADHC funded services. Furthermore, the Mainstream NGO had Aboriginal workers.

The differences between the two disability service providers impacted on the quantity and types of publications analysed under objective one. The Aboriginal NGO did not publish annual reports, nor had a large, populated website in comparison to the Mainstream NGO. This is not unusual in a small community organisation. As such, caution must be made in comparing how these agencies represented and responded to the participation of Aboriginal people in disability services.

The participants in the interviews and focus groups were mostly non-Aboriginal workers. There were only seven Aboriginal workers who participated in this study. This was due to the Aboriginal NGO being a small service provider and the Mainstream NGO not having many Aboriginal workers. Furthermore, the Mainstream NGO did not know exactly how many Aboriginal people were employed in its agency.

### **In the data gathered**

Because the study aimed to learn about the experiences of paid workers of the disability services sector and their perspective of the factors that influence the participation of Aboriginal people in disability services, the data are limited by the method of data gathering. Research can only gather and make inferences about the nature and experiences of the factors as defined from the external data collected. However, efforts were made to verify the claims and findings made in this study through the member checking stage.

It is likely that the participants' views of the factors that influence the participation of Aboriginal people in disability services may change overtime and with changes in policy. The study could only make inferences and conclusions from the data gathered within the specified timeframe.

## **In the data analysis technique**

As stated in the methods chapters, it is recognised that in all qualitative research the researcher's biases may affect the data collection and interpretation. Other researchers may have interpreted the data in different ways. However, a number of the de-identified transcripts and policy documents were provided to other researchers for review and comment. Furthermore, the data analysis methods were explained to the study participants and all findings subjected to extensive member checks.

## **Significance of the Study**

In fulfilling the research purposes, this study has made a contribution to disability studies theory, Indigenous Standpoint Theory (IST) and has implications for the disability services sector in supporting Aboriginal people with a disability and their families. The findings will also be used to contribute to the current national reforms to the disability services sector and the Disability Rights Movement.

## **Theoretical contributions**

A unique Conceptual Framework was developed during the study because there was no known culturally appropriate framework available for research and policy development. By merging the International Classification of Functioning, Disability and Health (ICF) together with the IST, the study was able to benefit from the strengths of the application of the Individual and Social approaches to disability among the populations of Aboriginal people. The Conceptual Framework was also demonstrated to have the potential to help emancipate Aboriginal people with a disability from the Eurocentric methodologically colonising framework typically adopted by non-Aboriginal disability study researchers.

## **Methodological contributions**

This study has collected the data in a two-phased process. This study not only provided a traditional review of literature on Aboriginal people with a disability and disability services, it also undertook a rigorous critical historical analysis of the policy documents published by the governments, the Aboriginal NGO and the Mainstream NGO. A thorough search and collection of publications provided a

large library of documents spanning over three decades of the Disability Rights Movement. This method uncovered just how the disability service participation of Aboriginal people was represented and treated since it was first mentioned in history.

The policy document analysis informed the method in undertaking the interviews and focus groups with paid workers of disability service providers, particularly the types of questions posed to the study participants. The policy document analysis was revisited during the analysis of the interviews and focus groups.

The structure of the interviews and focus groups allowed Aboriginal participants to participate without fear of intimidation from their non-Aboriginal peers. This ensured that the Aboriginal participants were given a voice in this study. Member checking was an important element of this study, as it demonstrated to the participants that they were involved in the whole study and that their views were interpreted correctly.

### **Empirical contributions**

As described in Chapter One, this study was focused on learning about the experiences of the disability services sector and its paid workforce in NSW in supporting Aboriginal families. The study developed an Explanatory Framework, called the *Aboriginal Service Participation Universe*, to help describe the relationships and operations of the factors that influence the participation of Aboriginal people in disability services. The Universe demonstrated how the factors were inter-related and inter-dependent historically, culturally and institutionally. Furthermore, the Universe showed how the factors all influenced each other before, during and after the Aboriginal client engaged with the disability services sector.

### **Practical contributions for the disability services sector**

The findings of this study extended our knowledge about the engagement and participation of Aboriginal people in government funded disability services in NSW. The findings have practical contributions for the current national reforms to the disability services sector and the disability rights movement.

The findings of this study have provided evidence and information to empower Aboriginal people in the disability rights movement. The current position of Aboriginal people with a disability has been historically constructed since colonisation. As discussed in Section Two, the representation and treatment of Aboriginal people as a specialised field has ineffectively addressed the service participation rate of Aboriginal people.

The study findings can assist the disability services sector in their efforts to ensure that COAG reforms effectively address barriers to service participation for Aboriginal people. The COAG reforms provide an opportunity for the disability services sector to reduce multiple agency interventions in the lives of Aboriginal people with a disability. The factors identified by the study participants provide vital information on areas that can be targeted under a new national disability service system. A new national disability service system must breakdown service participation barriers caused by the bureaucratisation of disability at both government and non-government levels. Disability service providers need to better equip disability workers with knowledge and tools to enable them to empower Aboriginal families under a person-centred planning framework. Aboriginal communities often care and support people with a disability within the family. The participants of this study identified challenges in strengthening and supporting this cultural practice. This poses risks for Aboriginal families as the government further implements individualised person-centred funded programs.

The findings highlighted the culture of mistrust of the disability services sector in Aboriginal communities and suggested strategies to overcome this culture. The culture of mistrust negatively influenced the level and type of engagement of Aboriginal people with a disability in the disability services sector. Disability service providers and local Aboriginal communities need to address the contestation at the cultural interface to overcome barriers to service participation for Aboriginal people with a disability.

The results provide a practical insight into the experiences of paid disability service workers in working with Aboriginal people with a disability and their communities. The participants had no difficulty in explaining how they effectively worked to build a trusting relationship with individual Aboriginal clients. This information is beneficial to disability service providers to help train current and future disability workers in how to effectively work with Aboriginal families in partnership with Aboriginal communities.

This study has shown that increasing government pressure on disability service providers to address barriers to service participation for Aboriginal people is not effective. Funded disability service providers respond only by meeting the requirements of their funding agreements.

### **Recommendations for Future Research and Practice**

This study has implications for future research which could clarify and elaborate on the factors that influence the participation of Aboriginal people in government funded disability services in NSW. These areas include theoretical development, methodology and disability services policy.

#### **Theoretical recommendations**

The disability services sector could benefit from further testing of the proposed Conceptual Framework developed during this study. IST has not been adopted in disability research before this study. The Conceptual Framework has demonstrated its potential to help emancipate Aboriginal people from the Eurocentric methodologically colonising frameworks typically adopted by non-Aboriginal researchers and policy developers.

The application of the Conceptual Framework can be further tested in the disability services sector to improve the cultural appropriateness of service delivery. In particular, the Conceptual Framework could inform the development of a cultural competence model specifically for the disability services sector in NSW.

#### **Methodological recommendations**

The findings and Explanatory Framework developed requires validation by studies involving more Aboriginal workers in the disability services sector across Australia using the same methodology. The Explanatory Framework has the ability to assist the disability services sector to improve the disability services participation rates of Aboriginal people.

It is possible that one or more of the galaxies could be tested and applied at any one time. The findings of which could contribute to the disability services sector's understanding of service delivery in Aboriginal communities at a local level.

## **Disability services sector policy**

Further investigation of the Universe with regards to cultural competence and person-centred planning in the disability services sector is needed. The disability services sector is further implementing person-centred practice and individualised services and programs. The data indicated that disability service workers experienced challenges in meeting the cultural needs of Aboriginal people within a person-centred framework.

The principles of cultural competence have not been fully adopted in government or non-government disability services policies and practice. The Conceptual Framework and the Universe can assist the disability services sector to implement cultural competence and person-centred practice in disability services policy and protocols.

Further research on the causes and implications of multiple agency intervention in the lives of Aboriginal people with a disability is also needed. This study has uncovered some of the challenges Aboriginal people and disability services workers face when multiple service agencies intervene. However, there is a need to investigate further the policy implications of multiple agency intervention.

## **Conclusions**

This study has focused upon the factors that influenced the participation of Aboriginal people in disability services in NSW as understood by the NSW DADHC funded disability services sector. As such, it has complemented previous work that has focused more on the perspectives and experiences of people with a disability. The two-phase qualitative method used in this study has also brought to light the historical development of the conceptualisation of the service participation of Aboriginal people as a social problem.

This study has provided insight into the relationships between the factors that influence the participation of Aboriginal people in disability services through the development of an Explanatory Framework, called the *Aboriginal Service Participation Universe*. The factors were inter-related and inter-dependent historically, culturally and institutionally. The framework demonstrates that the factors that influence Aboriginal people's service participation existed before Aboriginal people engaged with the disability service system.

The Conceptual Framework developed from the data gathered in second section has demonstrated the potential to help emancipate Aboriginal people from the Eurocentric methodologically colonising frameworks typically adopted by the disability studies academy. The Conceptual Framework combined the strengths of the ICF and IST and provides a theoretical foundation for future research in this area.

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## Appendices

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**Appendix A -  
Maps of each Department of Ageing, Disability and Home Care Region in  
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## Appendix B - Population Data on the Population of People with a Disability by Aboriginality

Table B1 - The population of Aboriginal people and people with a disability in the NSW Government Department of Ageing, Disability and Home Care Northern Region in 2006 by New South Wales Local Government Area (Australian Bureau of Statistic, 2006).

DADHC Northern Region LGAs	Aboriginal Population	Total Population	Representation of Aboriginal people	Aboriginal Population under the age of 65 years	Total Population under the age of 65 years	Representation of Aboriginal people under the age of 65 years	Total Aboriginal people with disabilities	Total people with disabilities	Representation of Aboriginal people in the population of people with disabilities	Total Aboriginal people with disabilities under 65 years	Total people with disabilities under the age of 65 years	Representation of Aboriginal people in the population of people with disabilities under 65
<b>Moree Plains</b>	2,704	13,975	19.35%	2,595	12,522	20.72%	107	456	23.46%	73	243	30.04%
<b>Narrabri</b>	1,201	13,118	9.16%	1,161	11,251	10.32%	55	568	9.68%	47	270	17.41%
<b>Gwydir</b>	133	5,310	2.50%	130	4,278	3.04%	17	303	5.61%	17	139	12.23%
<b>Gunnedah</b>	1,169	11,524	10.14%	1,119	9,579	11.68%	43	538	7.99%	34	242	14.05%
<b>Liverpool Plains</b>	716	7,540	9.50%	663	6,153	10.78%	50	424	11.79%	32	208	15.38%
<b>Inverell</b>	824	15,509	5.31%	799	12,745	6.27%	35	852	4.11%	28	404	6.93%
<b>Uralla</b>	332	5,735	5.79%	318	4,950	6.42%	20	242	8.26%	15	138	10.87%
<b>Tamworth</b>	3,705	53,589	6.91%	3,605	45,242	7.97%	146	2,539	5.75%	125	1,124	11.12%
<b>Tenterfield</b>	457	6,534	6.99%	443	5,319	8.33%	25	391	6.39%	19	196	9.69%
<b>Glen Innes Severn</b>	467	8,780	5.32%	453	7,052	6.42%	25	575	4.35%	19	250	7.60%
<b>Guyra</b>	432	4,231	10.21%	417	3,552	11.74%	18	201	8.96%	15	90	16.67%
<b>Armidale Dumaresq</b>	1,273	23,369	5.45%	1,234	20,383	6.05%	53	950	5.58%	46	439	10.48%
<b>Walcha</b>	184	3,188	5.77%	178	2,648	6.72%	13	154	8.44%	13	66	19.70%
<b>Kyogle</b>	540	9,256	5.83%	516	7,844	6.58%	24	516	4.65%	17	303	5.61%
<b>Tweed</b>	2,332	79,319	2.94%	2,230	61,714	3.61%	106	4,685	2.26%	82	1,847	4.44%
<b>Byron</b>	446	28,766	1.55%	431	25,283	1.70%	19	1,174	1.62%	14	598	2.34%
<b>Lismore</b>	1,579	42,211	3.74%	1,546	36,464	4.24%	88	2,146	4.10%	78	1,066	7.32%
<b>Ballina</b>	1,050	38,462	2.73%	1,017	30,933	3.29%	49	2,036	2.41%	38	813	4.67%
<b>Richmond Valley</b>	1,234	21,313	5.79%	1,203	17,503	6.87%	54	1,348	4.01%	48	665	7.22%
<b>Clarence Valley</b>	2,306	48,146	4.79%	2,220	38,844	5.72%	122	3,113	3.92%	100	1,466	6.82%
<b>Coffs Harbour</b>	2,310	64,911	3.56%	2,247	54,113	4.15%	126	3,584	3.52%	113	1,666	6.78%
<b>Bellingen</b>	320	12,416	2.58%	307	10,144	3.03%	11	597	1.84%	7	266	2.63%
<b>Nambucca</b>	1,025	17,897	5.73%	995	13,850	7.18%	45	1,265	3.56%	36	558	6.45%
<b>Kempsey</b>	2,540	27,387	9.27%	2,447	22,563	10.85%	142	1,740	8.16%	113	894	12.64%

<b>Hastings</b>	1,766	68,430	2.58%	1,703	52,779	3.23%	101	3,927	2.57%	92	1,656	5.56%
<b>Greater Taree</b>	1,928	45,145	4.27%	1,858	36,430	5.10%	122	2,834	4.30%	98	1,405	6.98%
<b>Gloucester</b>	171	4,798	3.56%	162	3,729	4.34%	12	274	4.38%	8	108	7.41%
<b>Great Lakes</b>	1,003	32,765	3.06%	951	23,671	4.02%	68	2,190	3.11%	56	879	6.37%
<b>TOTAL REGION</b>	<b>34,147</b>	<b>713,624</b>	<b>4.79%</b>	<b>32,948</b>	<b>581,538</b>	<b>5.67%</b>	<b>1,696</b>	<b>39,622</b>	<b>4.28%</b>	<b>1,383</b>	<b>17,999</b>	<b>7.68%</b>

**Table B2 - The population of Aboriginal people and people with a disability in the NSW Government Department of Ageing, Disability and Home Care Western Region in 2006 by New South Wales Local Government Area (Australian Bureau of Statistic, 2006).**

DADHC Western Region LGAs	Aboriginal Population	Total Population	Representation of Aboriginal people	Aboriginal Population under the age of 65 years	Total Population under the age of 65 years	Representation of Aboriginal people under the age of 65 years	Total Aboriginal people with disabilities	Total people with disabilities	Representation of Aboriginal people in the population of people with disabilities	Total Aboriginal people with disabilities under 65 years	Total people with disabilities under the age of 65 years	Representation of Aboriginal people in the population of people with disabilities under 65
<b>Unincorporated</b>	31	1,122	2.76%	26	992	2.62%	0	27	0.00%	0	13	0.00%
<b>Broken Hill</b>	1,205	19,361	6.22%	1,173	15,687	7.48%	64	1,352	4.73%	51	603	8.46%
<b>Wentworth</b>	613	6,781	9.04%	590	5,824	10.13%	27	283	9.54%	13	128	10.16%
<b>Central Darling</b>	700	1,933	36.21%	664	1,720	38.60%	25	71	35.21%	16	40	40.00%
<b>Balranald</b>	163	2,438	6.69%	154	2,101	7.33%	9	91	9.89%	6	37	16.22%
<b>Murrumbidgee</b>	226	2,503	9.03%	214	2,180	9.82%	13	105	12.38%	10	52	19.23%
<b>Deniliquin</b>	210	7,431	2.83%	196	5,993	3.27%	8	383	2.09%	8	147	5.44%
<b>Bourke</b>	910	3,096	29.39%	881	2,789	31.59%	36	102	35.29%	25	46	54.35%
<b>Cobar</b>	518	4,919	10.53%	500	4,381	11.41%	15	146	10.27%	12	65	18.46%
<b>Carrathool</b>	167	2,819	5.92%	162	2,394	6.77%	4	83	4.82%	4	29	13.79%
<b>Hay</b>	142	3,383	4.20%	135	2,874	4.70%	9	151	5.96%	9	73	12.33%
<b>Wakool</b>	96	4,361	2.20%	93	3,540	2.63%	0	157	0.00%	0	66	0.00%
<b>Murray</b>	182	6,417	2.84%	169	5,103	3.31%	12	302	3.97%	9	111	8.11%
<b>Brewarrina</b>	1,157	1,944	59.52%	1,108	1,768	62.67%	31	64	48.44%	17	34	50.00%
<b>Bogan</b>	336	2,882	11.66%	326	2,437	13.38%	3	111	2.70%	3	50	6.00%
<b>Lachlan</b>	993	6,668	14.89%	937	5,470	17.13%	47	304	15.46%	29	114	25.44%
<b>Griffith</b>	893	23,801	3.75%	873	20,602	4.24%	45	1,000	4.50%	38	427	8.90%
<b>Leeton</b>	494	11,111	4.45%	474	9,569	4.95%	30	480	6.25%	27	230	11.74%
<b>Conargo</b>	21	1,673	1.26%	21	1,496	1.40%	0	25	0.00%	0	14	0.00%
<b>Jerilderie</b>	30	1,642	1.83%	30	1,371	2.19%	6	69	8.70%	6	30	20.00%
<b>Berrigan</b>	106	7,993	1.33%	101	6,250	1.62%	6	405	1.48%	6	138	4.35%
<b>Corowa</b>	121	10,976	1.10%	110	8,571	1.28%	3	525	0.57%	3	190	1.58%
<b>Walgett</b>	1,957	6,944	28.18%	1,860	6,035	30.82%	91	379	24.01%	68	223	30.49%
<b>Coonamble</b>	1,069	4,209	25.40%	1,024	3,558	28.78%	66	219	30.14%	52	117	44.44%
<b>Warren</b>	333	2,750	12.11%	315	2,327	13.54%	15	107	14.02%	9	41	21.95%
<b>Gilgandra</b>	568	4,522	12.56%	547	3,711	14.74%	23	253	9.09%	15	114	13.16%
<b>Warrumbungle</b>	747	9,809	7.62%	704	7,949	8.86%	43	555	7.75%	30	259	11.58%
<b>Mid-Western Regional</b>	573	21,087	2.72%	552	17,618	3.13%	28	1,116	2.51%	23	512	4.49%
<b>Narromine</b>	1,030	6,507	15.83%	997	5,526	18.04%	43	243	17.70%	36	120	30.00%
<b>Dubbo</b>	3,911	37,844	10.33%	3,799	33,002	11.51%	173	1,614	10.72%	139	798	17.42%
<b>Wellington</b>	1,237	8,121	15.23%	1,196	6,589	18.15%	68	470	14.47%	55	232	23.71%
<b>Parkes</b>	1,026	14,281	7.18%	992	11,885	8.35%	54	711	7.59%	46	326	14.11%
<b>Cabonne</b>	284	12,397	2.29%	265	10,375	2.55%	18	544	3.31%	12	218	5.50%
<b>Orange</b>	1,544	35,338	4.37%	1,517	30,278	5.01%	84	1,757	4.78%	76	870	8.74%
<b>Forbes</b>	630	9,361	6.73%	604	7,742	7.80%	32	508	6.30%	24	217	11.06%

<b>Bland</b>	162	6,101	2.66%	159	5,029	3.16%	10	257	3.89%	6	119	5.04%
<b>Weddin</b>	58	3,643	1.59%	53	2,903	1.83%	9	213	4.23%	9	109	8.26%
<b>Temora</b>	83	5,859	1.42%	76	4,710	1.61%	10	316	3.16%	10	145	6.90%
<b>Coolamon</b>	51	4,030	1.27%	42	3,323	1.26%	0	185	0.00%	0	84	0.00%
<b>Narrandera</b>	563	6,013	9.36%	538	4,877	11.03%	26	377	6.90%	16	130	12.31%
<b>Urana</b>	43	1,258	3.42%	40	1,040	3.85%	3	70	4.29%	3	34	8.82%
<b>Wagga</b>	2,337	57,016	4.10%	2,285	49,973	4.57%	105	2,129	4.93%	90	1,059	8.50%
<b>Gundagai</b>	66	3,693	1.79%	61	3,077	1.98%	3	173	1.73%	0	61	0.00%
<b>Lockhart</b>	42	3,181	1.32%	42	2,644	1.59%	3	147	2.04%	3	61	4.92%
<b>Greater Hume</b>	160	9,732	1.64%	154	8,214	1.87%	3	411	0.73%	3	175	1.71%
<b>Tumut</b>	353	10,801	3.27%	333	8,989	3.70%	13	470	2.77%	13	211	6.16%
<b>Cowra</b>	752	12,476	6.03%	727	10,138	7.17%	39	618	6.31%	39	280	13.93%
<b>Cootamundra</b>	261	7,315	3.57%	247	5,807	4.25%	18	428	4.21%	15	209	7.18%
<b>Junee</b>	311	5,778	5.38%	304	5,049	6.02%	9	246	3.66%	9	122	7.38%
<b>Tumbarumba</b>	82	3,533	2.32%	75	2,922	2.57%	0	134	0.00%	0	48	0.00%
<b>Blayney</b>	156	6,593	2.37%	149	5,578	2.67%	15	345	4.35%	12	174	6.90%
<b>Albury</b>	974	46,282	2.10%	944	39,946	2.36%	41	1,880	2.18%	41	860	4.77%
<b>Lithgow</b>	605	19,757	3.06%	574	16,720	3.43%	40	1,078	3.71%	30	544	5.51%
<b>Bathurst</b>	1,235	35,844	3.45%	1,210	31,404	3.85%	52	1,399	3.72%	45	676	6.66%
<b>Oberon</b>	106	5,030	2.11%	106	4,386	2.42%	9	160	5.63%	9	76	11.84%
<b>TOTAL REGION</b>	<b>32,623</b>	<b>562,359</b>	<b>5.80%</b>	<b>31,428</b>	<b>476,436</b>	<b>6.60%</b>	<b>1,539</b>	<b>25,748</b>	<b>5.98%</b>	<b>1,230</b>	<b>11,861</b>	<b>10.37%</b>

**Table B3 - The population of Aboriginal people and people with a disability in the NSW Government Department of Ageing, Disability and Home Care Hunter Region in 2006 by New South Wales Local Government Area (Australian Bureau of Statistic, 2006).**

DADHC Hunter Region LGAs	Aboriginal Population	Total Population	Representation of Aboriginal people	Aboriginal Population under the age of 65 years	Total Population under the age of 65 years	Representation of Aboriginal people under the age of 65 years	Total Aboriginal people with disabilities	Total people with disabilities	Representation of Aboriginal people in the population of people with disabilities	Total Aboriginal people with disabilities under 65 years	Total people with disabilities under the age of 65 years	Representation of Aboriginal people in the population of people with disabilities under 65
<b>Upper Hunter</b>	401	12,975	3.09%	382	10,964	3.48%	19	530	3.58%	14	222	6.31%
<b>Muswellbrook</b>	725	15,236	4.76%	712	13,689	5.20%	25	522	4.79%	25	286	8.74%
<b>Singleton</b>	581	21,937	2.65%	566	19,859	2.85%	29	714	4.06%	29	371	7.82%
<b>Dungog</b>	173	8,062	2.15%	165	6,806	2.42%	11	413	2.66%	11	203	5.42%
<b>Maitland</b>	1,622	61,879	2.62%	1,567	54,645	2.87%	120	2,752	4.36%	107	1,512	7.08%
<b>Cessnock</b>	1,602	46,206	3.47%	1,553	39,930	3.89%	88	2,770	3.18%	78	1,409	5.54%
<b>Port Stephens</b>	1,742	60,484	2.88%	1,674	50,256	3.33%	91	3,017	3.02%	76	1,462	5.20%
<b>Newcastle</b>	3,021	141,754	2.13%	2,909	119,347	2.44%	175	8,055	2.17%	151	3,597	4.20%
<b>Lake Macquarie</b>	4,297	183,138	2.35%	4,146	152,385	2.72%	256	9,874	2.59%	223	4,477	4.98%
<b>Wyong</b>	3,806	139,802	2.72%	3,666	114,216	3.21%	224	7,713	2.90%	190	3,379	5.62%
<b>Gosford</b>	2,653	158,158	1.68%	2,555	129,429	1.97%	127	7,056	1.80%	103	2,846	3.62%
<b>TOTAL REGION</b>	<b>20,623</b>	<b>849,631</b>	<b>2.43%</b>	<b>19,895</b>	<b>711,526</b>	<b>2.80%</b>	<b>1,165</b>	<b>43,416</b>	<b>2.68%</b>	<b>1,007</b>	<b>19,764</b>	<b>5.10%</b>

**Table B4 - The population of Aboriginal people and people with a disability in the NSW Government Department of Ageing, Disability and Home Care Metro North Region in 2006 by New South Wales Local Government Area (Australian Bureau of Statistic, 2006).**

DADHC Metro North LGAs	Aboriginal Population	Total Population	Representation of Aboriginal people in the general population	Aboriginal Population under the age of 65 years	Total Population under the age of 65 years	Representation of Aboriginal people in the general population under the age of 65 years	Total Aboriginal people with disabilities	Total people with disabilities	Representation of Aboriginal people in the population of people with disabilities	Total Aboriginal people with disabilities under 65 years	Total people with disabilities under the age of 65 years	Representation of Aboriginal people in the population of people with disabilities under 65
<b>Hawkesbury</b>	1,163	60,561	1.92%	1133	54690	2.07%	63	2,025	3.11%	57	1,024	5.57%
<b>Blacktown</b>	7,054	271,709	2.60%	6889	249473	2.76%	339	10,203	3.32%	302	5,514	5.48%
<b>Penrith</b>	4,048	172,140	2.35%	3966	158097	2.51%	176	5,995	2.94%	160	3,386	4.73%
<b>Blue Mountains</b>	944	74,067	1.27%	911	64170	1.42%	61	2,996	2.04%	48	1,402	3.42%
<b>Holroyd</b>	738	89,765	0.82%	689	78845	0.87%	49	4,039	1.21%	38	1,730	2.20%
<b>Parramatta</b>	1,202	148,323	0.81%	1147	130048	0.88%	68	6,755	1.01%	57	3,045	1.87%
<b>Hornsby</b>	447	151,326	0.30%	421	131088	0.32%	29	5,179	0.56%	26	1,640	1.59%
<b>Manly</b>	93	37,110	0.25%	93	31826	0.29%	3	896	0.33%	3	255	1.18%
<b>Baulkham Hills</b>	431	159,392	0.27%	421	144918	0.29%	23	3,635	0.63%	18	1,714	1.05%
<b>Ryde</b>	267	96,948	0.28%	255	82848	0.31%	15	3,934	0.38%	15	1,467	1.02%
<b>Auburn</b>	442	64,959	0.68%	428	59122	0.72%	12	2,513	0.48%	12	1,188	1.01%
<b>Warringah</b>	444	133,836	0.33%	417	113558	0.37%	13	4,275	0.30%	13	1,380	0.94%
<b>Ku-ring-gai</b>	109	101,083	0.11%	104	84127	0.12%	3	2,776	0.11%	3	698	0.43%
<b>Hunter's Hill</b>	71	13,241	0.54%	71	10745	0.66%	0	761	0.00%	0	111	0.00%
<b>Lane Cove</b>	63	30,428	0.21%	59	26419	0.22%	0	891	0.00%	0	220	0.00%
<b>Willoughby</b>	76	63,606	0.12%	65	55777	0.12%	0	1,669	0.00%	0	504	0.00%
<b>North Sydney</b>	110	58,257	0.19%	105	51303	0.20%	0	1,102	0.00%	0	331	0.00%
<b>Mosman</b>	25	26,235	0.10%	19	22242	0.09%	0	754	0.00%	0	138	0.00%
<b>Pittwater</b>	168	54,156	0.31%	156	46067	0.34%	0	1,518	0.00%	0	415	0.00%
<b>TOTAL REGION</b>	<b>17,895</b>	<b>1,807,142</b>	<b>0.99%</b>	<b>17349</b>	<b>1595363</b>	<b>1.09%</b>	<b>854</b>	<b>61,916</b>	<b>1.38%</b>	<b>854</b>	<b>26,162</b>	<b>3.26%</b>

**Table B5 - The population of Aboriginal people and people with a disability in the NSW Government Department of Ageing, Disability and Home Care Metro South Region in 2006 by New South Wales Local Government Area (Australian Bureau of Statistic, 2006).**

DADHC Metro South LGAs	Aboriginal Population	Total Population	Representation of Aboriginal people in LGA	Aboriginal Population under the age of 65 years	Total Population under the age of 65 years	Representation of Aboriginal people in the general population under the age of 65 years	Total Aboriginal people with disabilities	Total people with disabilities	Representation of Aboriginal people in the population of people with disabilities	Total people with disabilities under the age of 65 years	Representation of Aboriginal people in the population of people with disabilities under 65	
Wingecarribee	256	42,273	0.61%	526	34,682	1.52%	26	1,766	1.47%	23	748	3.07%
Wollondilly	763	40,344	1.89%	763	36,759	2.08%	22	1,216	1.81%	16	657	2.44%
Liverpool	2,195	164,602	1.33%	2,107	151,046	1.39%	117	6,603	1.77%	94	3,457	2.72%
Camden	651	49,649	1.31%	631	45,424	1.39%	29	1,577	1.84%	29	764	3.80%
Campbelltown	3,831	143,077	2.68%	3,769	132,467	2.85%	215	5,768	3.73%	198	3,497	5.66%
Fairfield	1,113	179,891	0.62%	1,065	159,809	0.67%	65	9,383	0.69%	45	4,021	1.12%
Bankstown	1,123	170,489	0.66%	1,046	146,688	0.71%	66	8,423	0.78%	49	3,578	1.37%
Canterbury	747	129,962	0.57%	716	112,433	0.64%	31	6,136	0.51%	31	2,547	1.22%
Hurstville	362	73,724	0.49%	340	62,275	0.55%	20	2,980	0.67%	17	952	1.79%
Kogarah	181	52,535	0.34%	170	44,810	0.38%	15	1,976	0.76%	15	660	2.27%
Rockdale	453	92,126	0.49%	438	77,722	0.56%	15	4,310	0.35%	12	1,349	0.89%
Botany Bay	633	35,993	1.76%	599	30,867	1.94%	21	1,711	1.23%	21	666	3.15%
Randwick	1,474	119,884	1.23%	1,388	104,013	1.33%	60	3,982	1.51%	45	1,334	3.37%
Marrickville	1,080	71,812	1.50%	1,050	64,300	1.63%	55	2,898	1.90%	55	1,175	4.68%
Waverley	196	60,714	0.32%	189	52,792	0.36%	7	1,764	0.40%	3	434	0.69%
Woollahra	99	50,160	0.20%	92	42,214	0.22%	8	1,214	0.66%	8	278	2.88%
Leichhardt	408	48,777	0.84%	394	44,114	0.89%	24	1,542	1.56%	24	635	3.78%
Sydney	1,981	156,572	1.27%	1,899	143,753	1.32%	122	3,807	3.20%	103	1,741	5.92%
Ashfield	197	39,667	0.50%	179	33,903	0.53%	14	2,185	0.64%	6	570	1.05%
Canada Bay	216	65,743	0.33%	202	56,463	0.36%	9	2,280	0.39%	4	656	0.61%
Burwood	119	30,928	0.38%	115	26,283	0.44%	9	1,490	0.60%	6	412	1.46%
Strathfield	93	31,982	0.29%	86	27,978	0.31%	0	1,186	0.00%	0	356	0.00%
Sutherland	1,255	205,449	0.61%	1,182	178,095	0.66%	45	5,885	0.76%	34	2,274	1.50%
<b>TOTAL REGION</b>	<b>19,426</b>	<b>2,056,353</b>	<b>0.94%</b>	<b>18,946</b>	<b>1,808,890</b>	<b>1.05%</b>	<b>995</b>	<b>80,082</b>	<b>1.24%</b>	<b>838</b>	<b>32761</b>	<b>2.56%</b>

**Table B6 - The population of Aboriginal people and people with a disability in the NSW Government Department of Ageing, Disability and Home Care Southern Region in 2006 by New South Wales Local Government Area (Australian Bureau of Statistic, 2006).**

DADHC Southern Region LGAs	Aboriginal Population	Total Population	Representation of Aboriginal people	Aboriginal Population under the age of 65 years	Total Population under the age of 65 years	Representation of Aboriginal people under the age of 65 years	Total Aboriginal people with disabilities	Total people with disabilities	Representation of Aboriginal people in the population of people with disabilities	Total Aboriginal people with disabilities under 65 years	Total people with disabilities under the age of 65 years	Representation of Aboriginal people in the population of people with disabilities under 65
<b>Young</b>	305	11,985	2.54%	291	10,005	2.91%	20	604	3.31%	20	272	7.35%
<b>Harden</b>	120	3,580	3.35%	105	2,868	3.66%	13	212	6.13%	9	93	9.68%
<b>Boorowa</b>	40	2,294	1.74%	32	1,890	1.69%	4	122	3.28%	0	57	0.00%
<b>Upper Lachlan</b>	100	7,054	1.42%	100	5,789	1.73%	0	324	0.00%	0	136	0.00%
<b>Yass Valley</b>	235	13,134	1.79%	235	11,501	2.04%	3	470	0.64%	3	206	1.46%
<b>Goulburn Mulwaree</b>	572	26,086	2.19%	557	22,087	2.52%	31	1,363	2.27%	31	660	4.70%
<b>Palerang</b>	105	12,319	0.85%	102	11,133	0.92%	0	321	0.00%	0	191	0.00%
<b>Queanbeyan</b>	936	35,973	2.60%	922	32,686	2.82%	33	1,099	3.00%	29	587	4.94%
<b>Cooma-Monaro</b>	165	9,726	1.70%	165	8,131	2.03%	9	443	2.03%	9	189	4.76%
<b>Snowy River</b>	63	7,187	0.88%	60	6,463	0.93%	0	136	0.00%	0	68	0.00%
<b>Bombala</b>	37	2,546	1.45%	37	2,081	1.78%	3	124	2.42%	3	57	5.26%
<b>Wollongong</b>	3,122	184,214	1.69%	3,005	155,468	1.93%	183	9,195	1.99%	151	3,887	3.88%
<b>Shellharbour</b>	1,401	60,337	2.32%	1,368	52,849	2.59%	76	2,908	2.61%	68	1,531	4.44%
<b>Kiama</b>	222	18,986	1.17%	222	15,415	1.44%	6	849	0.71%	6	253	2.37%
<b>Shoalhaven</b>	3,313	88,404	3.75%	3,171	69,699	4.55%	161	5,211	3.09%	119	2,354	5.06%
<b>Eurobodalla</b>	1,557	35,009	4.45%	1,494	26,977	5.54%	92	2,106	4.37%	82	882	9.30%
<b>Bega Valley</b>	816	31,061	2.63%	786	25,271	3.11%	38	1,512	2.51%	33	692	4.77%
<b>TOTAL REGION</b>	<b>13,109</b>	<b>549,895</b>	<b>2.38%</b>	<b>12,652</b>	<b>460,313</b>	<b>2.75%</b>	<b>672</b>	<b>26,999</b>	<b>2.49%</b>	<b>563</b>	<b>12,115</b>	<b>4.65%</b>

Appendix C - Users of Multilateral Agreement Funded Support Services, by Indigenous Status per 1000 Indigenous Population and Potential Population Aged between 2003 to 2010

Year	Accommodation Support Services		Community Support Services		Community Access Services		Community Respite Services		
	NSW (h)	Aust	NSW (h)	Aust	NSW (h)	Aust	NSW (h)	Aust	
<b>Indigenous people using support services per 1,000 Indigenous potential population aged under 65 years</b>									
2003-04	1.20	2.20	na	na	1.40	2.60	1.58	2.21	
2004-05	1.10	2.10	5.60	7.60	1.50	2.30	1.40	1.95	
2005-06	1.30	2.40	6.60	8.00	1.70	2.50	1.60	2.86	
2006-07	1.30	2.80	8.10	9.90	2.20	3.00	2.30	3.25	
2007-08	1.40	2.80	8.90	11.20	2.40	3.10	2.60	3.30	
2008-09	1.80	2.80	11.60	13.10	2.70	3.40	3.20	3.70	
2009-10	2.20	2.80	15.60	14.40	3.50	3.60	3.80	3.90	
<b>Indigenous people using support services per 1,000 Indigenous potential population</b>									
2006-07	14.60	39.10	91.20	138.70	25.20	42.10	na	na	
2007-08	15.80	39.70	104.00	160.00	28.30	44.80			
2008-09	23.40	44.30	149.90	208.00	35.30	54.90			
2009-10	28.40	45.10	102.60	128.90	44.70	57.40			
<b>Non-Indigenous people using support services per 1000 non-Indigenous population aged under 65 years</b>									
2003-04	1.10	1.50	na	na	1.10	2.00	na	na	
2004-05	1.00	1.50	3.10	3.60	1.10	1.80	0.70	1.00	
2005-06	1.20	1.60	3.40	4.50	1.30	2.00	0.80	1.30	
2006-07	1.20	1.60	3.30	5.00	1.80	2.30	0.90	1.40	
2007-08	2.20	1.60	3.40	5.20	1.90	2.30	1.00	1.50	
2008-09	1.40	1.60	4.10	5.70	2.00	2.30	1.20	1.60	
2009-10	1.40	1.60	4.70	6.10	2.30	2.40	1.40	1.60	
<b>Non-Indigenous people using support services per 1000 non-Indigenous potential population</b>									
2006-07	31.70	42.40	86.10	128.60	46.40	58.60	na	na	
2007-08	30.5	40.50	87.60	131.10	49.30	57.40			
2008-09	40.20	45.80	116.20	162.40	58.20	65.30			
2009-10	41.30	46.30	135.00	171.60	64.20	66.60			
<b>All people using services per 1000 total population aged under 65 years</b>									
2003-04	1.10	1.60	na	na	1.10	2.00	na	na	
2004-05	1.00	1.50	3.20	3.70	1.10	1.80	0.70	1.00	
2005-06	1.20	1.60	3.50	4.60	1.30	2.10	0.80	1.30	
2006-07	1.20	1.70	3.50	5.20	1.80	2.30	1.90	1.40	
2007-08	1.20	1.60	3.50	5.30	1.90	2.30	1.10	1.50	
2008-09	1.40	1.70	4.30	5.90	2.10	2.30	1.30	1.60	
2009-10	1.50	1.70	5.00	6.30	2.30	2.40	1.40	1.70	

## Appendix D - Ethics Approval Letter



**The University of Sydney**

**Human Research Ethics Committee**

ABN 15 211 513 464

**Gail Briody**

*Manager*

*Office of Ethics Administration*

**Marietta Coutinho**

*Deputy Manager*

*Human Research Ethics Administration*

Telephone: +61 2 8627 8175

Facsimile: +61 2 8627 8180

Email: [gbriody@usyd.edu.au](mailto:gbriody@usyd.edu.au)

Telephone: +61 2 8627 8176

Facsimile: +61 2 8627 8177

Email: [mcoutinho@usyd.edu.au](mailto:mcoutinho@usyd.edu.au)

**Mailing Address:**

Level 6

Jane Foss Russell Building – G02

The University of Sydney

NSW 2006 AUSTRALIA

Ref: DC/JH

23 July 2009

Prof. Trevor Parmenter  
Centre for Disability Studies  
Royal Rehabilitation Centre  
PO Box 6  
Ryde NSW 1680  
Email: [trevorp@med.usyd.edu.au](mailto:trevorp@med.usyd.edu.au)

Dear Prof. Parmenter,

Thank you for your correspondence dated [date] addressing comments made to you by the Human Research Ethics Committee (HREC). After considering the additional information, the Executive Committee at its meeting on **21 July 2009** approved your protocol entitled **“Factors that influence the participation of Aboriginal people in mainstream disability services in the Sydney Metropolitan Region”**.

Details of the approval are as follows:

**Ref No.:** 07-2009/11792

**Approval Period:** 21 July 2009 to 21 July 2010

Authorised Personnel: Prof. Trevor Parmenter  
**Mr. John Gilroy**  
**Dr. Michelle Donelly**

The HREC is a fully constituted Ethics Committee in accordance with the *National Statement on Ethical Conduct in Research Involving Humans-March 2007* under Section 5.1.29

The approval of this project is **conditional** upon your continuing compliance with the *National Statement on Ethical Conduct in Research Involving Humans*. We draw to your attention the requirement that a report on this research must be submitted every 12 months from the date of the approval or on completion of the project, whichever occurs first. Failure to submit reports will result in withdrawal of consent for the project to proceed.

**Chief Investigator / Supervisor's responsibilities to ensure that:**

- (1) All serious and unexpected adverse events should be reported to the HREC as soon as possible.
- (2) All unforeseen events that might affect continued ethical acceptability of the project should be reported to the HREC as soon as possible.
- (3) The HREC must be notified as soon as possible of any changes to the protocol. All changes must be approved by the HREC before continuation of the research project. These include:-
  - If any of the investigators change or leave the University.
  - Any changes to the Participant Information Statement and/or Consent Form.
- (4) All research participants are to be provided with a Participant Information Statement and Consent Form, unless otherwise agreed by the Committee. The Participant Information Statement and Consent Form are to be on University of Sydney letterhead and include the full title of the research project and telephone contacts for the researchers, unless otherwise agreed by the Committee and the following statement must appear on the bottom of the Participant Information Statement. *Any person with concerns or complaints about the conduct of a research study can contact the Manager, Ethics Administration, University of Sydney, on (02) 8627 8175 (Telephone); (02) 8627 8180 (Facsimile) or [gbriody@usyd.edu.au](mailto:gbriody@usyd.edu.au) (Email).*
- (5) Copies of all signed Consent Forms must be retained and made available to the HREC on request.
- (6) It is your responsibility to provide a copy of this letter to any internal/external granting agencies if requested.
- (7) The HREC approval is valid for four (4) years from the Approval Period stated in this letter. Investigators are requested to submit a progress report annually.

- (8) A report and a copy of any published material should be provided at the completion of the Project.

Yours sincerely

A handwritten signature in black ink, appearing to read 'D I Cook', written in a cursive style.

**Professor D I Cook**  
**Chairman**

**Human Research Ethics Committee**

CC: Mr. John Gilroy, Email: [jgil4499@mail.usyd.edu.au](mailto:jgil4499@mail.usyd.edu.au)

Encl. Approved Participant Consent Form

Approved Letter of Invitation to Organisations

Approved Participant Information Statement (Service Executives and Managers)

Approved Participant Information Statement (Service Staff)

Subject:20121109 11792 Parmenter Modification Approved

Date:Fri, 9 Nov 2012 02:51:24 +0000

From:Human Ethics <[ro.humanethics@sydney.edu.au](mailto:ro.humanethics@sydney.edu.au)>

To:Trevor Reginald Parmenter <[trevor.parmenter@sydney.edu.au](mailto:trevor.parmenter@sydney.edu.au)>

CC:[jgil4499@uni.sydney.edu.au](mailto:jgil4499@uni.sydney.edu.au) <[jgil4499@uni.sydney.edu.au](mailto:jgil4499@uni.sydney.edu.au)>

Dear Professor Parmenter,

Title: **Factors that influence the participation of Aboriginal people in mainstream disability services in the Sydney Metropolitan Region**

Protocol No: **11792**

Addition of Authorised Personnel:

**Dr Susan Colmar**

Your request to modify the above application was considered by the Executive Committee of the Human Research Ethics Committee (HREC) at its meeting on **9 November 2012**. The modification has been approved as attached.

The Committee had no ethical objections to the modification/s and has approved the protocol to proceed.

Please do not hesitate to contact Research Integrity (Human Ethics) should you require further information or clarification.

Yours Sincerely

Human Research Ethics Committee

The University of Sydney

## Appendix E - Letters of Support from the four DADHC funded non-government agencies

Aboriginal Disability Network New South Wales



Human Research Ethics Board  
Ethics Administration  
University of Sydney

**Re: letter of support for John Gilroy, PhD Student, to achieve the objectives of his Doctoral studies**

I write to inform the University of Sydney Human Research Ethics Board that the Aboriginal Disability Network (ADN) will provide John Gilroy the upmost support to achieve the aims and objectives of his PhD studies.

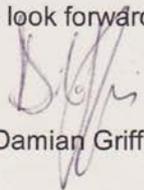
ADN is funded to provide systemic advocacy for Aboriginal people with disabilities, their families and communities.

ADN has worked with Mr Gilroy in his former roles for the Department of Ageing, Disability and Home Care and the National Disability Services for over five years. Over this period, Mr Gilroy has demonstrated the upmost respect and commitment in working with disability services and Aboriginal communities on projects involving Aboriginal people with disabilities.

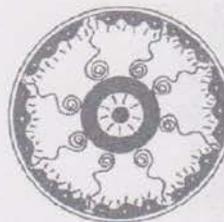
ADN is committed to supporting Mr Gilroy in his studies on Aboriginal people with disabilities as part of our long established relationship and commitment to improve the rates of access and outcomes for Aboriginal people with disabilities in disability services.

If you would like discuss this letter of support, please contact Damian Griffis, Executive Officer, ADN on 02 9370 3100 or email [damiang@pwd.org.au](mailto:damiang@pwd.org.au).

I look forward to your response.

  
Damian Griffis

## NSW Aboriginal Community Care Gathering Committee



Human Research Ethics Board  
Ethics Administration  
University of Sydney

**Re: letter of support for John Gilroy, PhD Student, to achieve the objectives of his Doctoral studies**

I write to inform the University of Sydney Human Research Ethics Board that Aboriginal HACC Gathering (Gathering) will provide John Gilroy the utmost support to achieve the aims and objectives of his PhD studies.

The Gathering provides independent advice to government and non government Providers in improving the quality and quantity of support and services for Aboriginal people in NSW. The Gathering develop policies about improving systems to provide HACC Funded service provision.

The Gathering has worked with Mr Gilroy in his role for National Disability Services over a two year period, of which Mr Gilroy has been a member for a year. Over this period, Mr Gilroy has demonstrated the utmost respect and commitment in working with disability services and Aboriginal communities on projects involving Aboriginal people with disabilities.

The Gathering is committed to supporting Mr Gilroy in his studies on Aboriginal people with disabilities as part of our long established relationship and commitment to improve the rates of access and outcomes for Aboriginal people with disabilities in disability services.

If you would like discuss this letter of support, please contact Sheree Freeburn, Chair Person of the Gathering, Carers NSW on (02) 9280 4744 or email [shereef@carersnsw.asn.au](mailto:shereef@carersnsw.asn.au).

I look forward to your response.

Sheree Freeburn



## *Indigenous Disability Advocacy Service*

Human Research Ethics Board  
Ethics Administration  
University of Sydney

**Re: letter of support for John Gilroy, PhD Student, to achieve the objectives of his Doctoral studies**

I write to inform the University of Sydney Human Research Ethics Board that the Indigenous Disability Advocacy Service (IDAS) will provide John Gilroy the utmost support to achieve the aims and objectives of his PhD studies.

IDAS is funded to service Indigenous persons with a disability in the Western Sydney and Regional centers in areas of high need in NSW, in consultation with the Department of Families, Housing and Community Services and Indigenous Affairs and the Department of Ageing, Disability and Home Care (DADHC).

IDAS has worked with Mr Gilroy in his former roles in DADHC and the National Disability Services for over five years. Over this period, Mr Gilroy has demonstrated the highest level of respect and commitment in working with disability services and Aboriginal communities on projects involving Aboriginal people with disabilities.

IDAS is committed to supporting Mr Gilroy in his studies on Aboriginal people with disabilities as part of our long established relationship and commitment to improve the rates of access and outcomes for Aboriginal people with disabilities in disability services.

If you would like to discuss this letter of support, please contact Betty Salvatori, CEO, IDAS on 02 9687 7688 or email [betty.salvatori@idas.org.au](mailto:betty.salvatori@idas.org.au).

I look forward to your response.

Sincerely

Betty Salvatori  
CEO  
Indigenous Disability Advocacy Service

Human Research Ethics Board  
Ethics Administration  
University of Sydney



**Re: Letter of support for John Gilroy, PhD Student**

I write to inform the University of Sydney Human Research Ethics Board that Carers NSW supports the work being undertaken by John Gilroy to achieve the aims and objectives of his PhD studies.

Carers NSW is the peak organisation representing carers in NSW and is committed to working with all carers, governments, business and the community to support and enable recognition of carers in NSW. Carers NSW currently carries out a range of activities to support carers across NSW.

These can be grouped as:

**Carer Services:**

- Information and Referral
- Carer Support Kit
- Counselling Support Program
- Specific Carer Projects – Aboriginal Carers, Young Carers, CALD Carers, Older Parent Carers, Family and Carer Mental Health Program

**Education and Training:**

- To carers
- To service providers

Carers NSW has worked with Mr Gilroy in his former roles for the Department of Ageing, Disability and Home Care and the National Disability Services for over five years. Over this period, Mr Gilroy has demonstrated knowledge, respect and commitment in working with disability services, carers and Aboriginal communities on projects involving Aboriginal people with disabilities and their carers.

If you would like discuss this letter of support, please contact Elena Katrakis CEO Carers NSW on 9280 4744 or email [elenak@carersnsw.asn.au](mailto:elenak@carersnsw.asn.au)

I look forward to the project work being undertaken.

Elena Katrakis  
CEO

9 February 2009

Carers NSW Inc. ABN 45 461 578 851

Roden Cutler House, Level 18, 24 Campbell Street, Sydney NSW 2000 • PO Box 20156, World Square NSW 2002

P 02 9280 4744 F 02 9280 4755 E [contact@carersnsw.asn.au](mailto:contact@carersnsw.asn.au) [www.carersnsw.asn.au](http://www.carersnsw.asn.au)

Carers line: 1800 242 636 (free call)

Carers NSW is funded by State and Australian Governments

Donations over \$2 are tax deductible

## Appendix F - The Trigger Questions.

1. According to the ABS, the incidence of disability is higher in local Aboriginal communities than in the general population? Why do think this is so?
2. According to DADHC, the participation rate of Aboriginal people in mainstream disability services is under-represented. Why do you think this is the case? Is this the case for your organisation?
3. If you can, without naming or identifying anyone, give me an example of an Aboriginal person who has accessed the services and supports provided by your organisation? Without naming or identifying that person-
4. Are there any barriers for Aboriginal people to access your organisation's supports and services? If so, could you explain them to me? If there are no barriers what do you do to ensure there are no barriers?
5. Are there any barriers for your organisation in engaging with Aboriginal communities or Aboriginal community managed organisations?
6. If there are barriers for your organisation in engaging with Aboriginal communities, are they different in working with 'culturally diverse' communities? If so how/why?
7. In your experience, what factors are essential to establish clear pathways to your organisation for Aboriginal families and individuals to access your services/programs?
8. Over the last ten years your organisation has had an access and equity policy relating specifically to Aboriginal people. How has this policy, and its accompanied strategies, assisted your organisation to address the access and equity barriers for Aboriginal people?
9. DADHC and philanthropic agencies offer funding for services specifically for Aboriginal people with disabilities. Has your organisation ever applied, or partnered with other NGOs, for funding specifically for local Aboriginal communities? If so why? If not why not?
10. What formal professional training and organisational development would/ has assist/ed you, or your staff, to be able to respond to the needs of Aboriginal people under this policy?
11. Any other comments you wish to make?
12. Would you mind if I get back in touch with you if there is anything further I need to clarify arising from our discussion today?

## Appendix G – Example of Colour Coding Raw Data from Focus Groups and Interviews

### KEY

Blue: Mobility/Remoteness/Disadvantages/History

Yellow: Multiple intervention

Green: Trust/Suspicion

Grey: connections with Aboriginal workers/communities

Red: Client Rebels

Pink: Service culture/judgements/ideologies

Brown: Perceived barriers/Resistance

Aqua: client background and referral

????: Issues/inaudible-comments for Member Checking

**Interviewer:** That's ok. Is it possible that – I could hear from each of those service types, could provide me with a typical example of an Aboriginal family that they have supported through that service? Is that possible or?

**Participant4:** I mean, I don't know if this is typical but both of the Aboriginal families that I supported were grandparent lead families, so they were grandparents raising grandchildren.

**Interviewer:** Yeah, that's fine. That's fine. So do you want to start off?

**Participant4:** so this is [service type].

**Interviewer:** Oh so this is [service type]?

**Participant4:** That's right. So grandparents are in their 60s. Raising 2 grandsons both with autism. 7 and 5 year olds. Have been removed from their parents because of drug and alcohol issues around domestic violence. What other information do you need?

**Interviewer:** Well basically how did they become part of the service? How they did they find out about you? How did you support them?

**Participant4:** They were referred to us through DoCS. And actually one of the barriers I think, and it goes to what we were saying over here, the sporadic attendance to appointments actually gives families a reputation. So when referrers refer them, they will say to you, you know, 'they're not regular coming to appointments. I don't know whether they can be bothered. They're difficult to engage.' So they will tell you 'these are really difficult people to engage'. Actually I think it's the structure of the programs and the allowing to flexibility and the timeframes which make it difficult for those families to engage.

**Interviewer:** Of their previous service or with [service type]?

**Participant4:** Well it's only a very short term program as well. So 12 weeks isn't very long. [service type], for example, is [time limited]. But when you don't have the flexibility to be able to extend ourselves for the Aboriginal families

**Interviewer:** So how do you work around the challenges of flexibility with a time limited timeframe with family?

**Participant4:** Well I think it's actually understanding that flexibility is necessary and not making a judgement about that kind of sporadic attendance or what it looks like to be a resisting service because it really isn't, in my opinion, a resisting service – it's a long process to gain trust.

**Interviewer:** What's a resisting service?

**Participant4:** Well because they don't attend appointments or they'll cancel or you'll turn up and they'll say 'oh I forgot you were coming, can you do it another day?' Other services will tell you that they've been resisted or that 'we told them to do all these things and they won't do it. You need to go and tell them to do it'. That's also seen as resistance. And I think it's about re-interpreting that integration and say 'actually that's not resistance but is' – then beats people asking for autonomy and it's respectful.

**Interviewer:** Ok. So what's a – how did you support that family during that 12 weeks? So what did it actually provide? What kind of work did you do with the [service type] program?

**Participant4:** Primarily it was a therapeutic intervention with the grandparents. So looking at the grief around the [someone coughing so can't hear what was said]? with their child who is the father of their grandchildren. And how can you feel confident to re-engage with the services that they already had around them. So rather than working directly with the child's behaviour, it was really looking at helping

the grandparents re-engage and feel confident that they were getting – that people were listening and enabling what they wanted for the service for it to work they were provided.

**Interviewer:** So were they referred – so are the immediate intervention – the 12 week intervention, were they be referred to other services and linked in with other services?

**Participant4:** Actually I would say that they were just looking to more effectively back into the services that they already had. So when I met them, they were quite disengaged – you know, they were unconfident that the services that were around and were listening to exactly what they wanted. It was more that the services were telling them what to do and they didn't like that, as most people don't like that. So they felt quite victimised. I think by the end of the intervention that had changed and they felt more empowered.

**Interviewer:** That's incredible. So then you're from [service type]? Can I have an example from the therapy team?

**Participant 5:** The family that I know but generally we had in the past. And they've been with us since he was about 12 months of age and they're shared out of Taree. Being supported at Taree Hospital and there were ??? at his birth. That's why I had some rapport with him. It's been uncomplicated.

**Interviewer:** Do you think in terms of his birth, what does that mean?

**Participant 5:** He wasn't – his mother was ignored when she raised issues – this is what was told me.

**Interviewer:** Oh so the hospital was negligent?

**Participant 5:** Yes. The hospital was negligent. And yeah, so they're being compensated and it's been like proven that's what happened, which was already bad. But they've been coming to us since he was about 12 months. And as I said, they used to come down whenever they could, when they had petrol. Something like that. They then moved to [NSW region]. So they could get better services. And it very dedicated family. Mum was about 16 when she had [child]. And [child] was about 19. And they had really good family back-up back in [NSW Region] and that's been really important. They've been really consistent in coming and keeping contact. And I think having trust with those has been really important. I've learnt a lot from them as well. I think one of the things that they needed was time and if there was a problem they needed to go back home and we'd talk about it with their family. And later, a couple of weeks to come up with an answer.

**Interviewer:** Problem like? What do you mean by problem?

**Participant 5:** There was a problem with him starting school and school was really quite discriminatory initially. And I was getting like angry at them, jumping up and down, and they just went back up home and talked about it with their extended family. And then didn't say anything. They just came back and just enrolled him at the school, even though the school were saying 'well they couldn't have him' and all this sort of thing. And so they just went along and carried on as normal. And then the practice and they were supposed to do initially. And they appreciated that I advocated for them. But I do it in a white person's way which I jump up and down and get nowhere. And they actually they liked I advocated but they actually do it their way and it seems to work better.

**Interviewer:** So could you explain to me what is a white way – jumping up and down? And their Aboriginal way – what is the differences between the two?

**Participant 5:** I think that [can't hear]. You know, they took a couple of weeks to tell me that they enrolled him, that the school didn't want to have him and they were trying to force him onto other places because it's a little school and they wanting him to go to the fed school. And so by the time they told me it was actually school holidays. And so I couldn't contact anybody – the Department of Education – I'd ring up people and say 'Take this client and jump up and down'. And then, you know, I eventually get onto someone about it late in January – to sort of talk about the problem. In the meantime they just decided, and they talked about it, and they just rolled up on the first day and enrolled him. And then in the end, the Principal got moved and Department of Education had to quickly to put everything in place - the teacher's aide and all those sorts of things. And then we had a growth in the first year. After that they had subsequent problems at that school for a couple of years and now everything is really good. And they just, you know, persisted there. And despite sometimes we needed to comment so – that's been fantastic.

**Interviewer:** So as part of your involvement as a therapist with the [Mainstream NGO], is advocacy a part of component of it?

**Participant 5:** Yeah. Definitely. Yep. Advocacy but not trying to take charge of that. I think, you know, we ?? get on with the negotiations but we're just being saying 'this is your rights. You should be able to do this. And you know, he has to go to a mainstream school. Yes, we can do this. What do you think about this? You know, like if we get this equipment – showing them different bits of equipment that they need. They've always felt so over a few years ago. So and then later they can make a decision around it.

**Interviewer:** So very quickly, what's the difference between a main stream school and an orthopaedic school?

**Participant 5:** Oh sorry. Mainstream school is just a regular school where, and sometimes children with a disability might go to *[somebody coughing so can't hear]* purposes. And so this might be because they need a lot more care, physical care or cognitively they seem to not be able to cope in a mainstream school. Every child has a right no matter what disability to go to a mainstream school. But it's a lot tougher for parents to try and maintain that sometimes. Even though they might not *[difficult to hear]* difficulties. And in this bloke's case, he's got a severe physical disability, he's non-verbal. And so he has high support needs. And cognitively, you know, probably not taught but probably ok. And so for him – he could have gone to an orthopaedic school but it wouldn't have been a stimulating environment for him. It's much better that he goes to his mainstream school. He's got a teacher's aide full time. And his brother goes to that school now. And his little sister will be. So he's much more within his community. So much more better off on lots of levels, but it is really hard for the parents to try and keep their child at that mainstream school. They have to do a lot of advocacy for their child.

**Interviewer:** So we've heard from {service type}, heard from {service type}. The next one is [service type] – is that right? Do I have a volunteer from [service type]?

**Participant 6:** I actually think the person who would have done that isn't here. Anyway - now brought up, if you want?

**Interviewer:** That'd be great. I want to hear it. That'd be excellent.

**Participant 6:]** I'm involved from an intake point of view, a few years ago, and we did get one of our other family support workers who's no longer with us to come in – hard that to then raise that particular the situation. One on the [NSW region] where the school was making lots of noises about non-participation and non-follow through with medical things. Had a couple of discussions with – I can't remember if it was the support teacher or the – I think it was the school counsellor – who made some fairly derogatory comments about the family, about rolling up at the door and been given, you know, a pizza box to write a phone number on and there holes in the wall and she was going to put in DoCSs reports and all this sort of stuff. So for us it was more around, obviously their story or background from the school's perspective. So I guess from our point of view, for them to come in through our service for some extra support just around reengaging the therapy needs – was really just about getting them to trust us given that the other people hadn't been particularly trustworthy.

**Participant 7:** It was a very complex family who'd had lots of involvement with lots of agencies. So I think there was a fair amount of distrust in terms of 'what are you going to do and what are you going to say'. We had to be very careful – I was part of the therapy, a team that had been very careful about where information went to and who you spoke to. We had to really make sure we had permission from the mum to speak to teachers. And part of the problem with this boy starting with us, it was a kind of an unusual diagnosis. For all intents and purposes he looked like a boy without a disability but it had the effect that he had very – with the team, very very quickly and had – some days he was quite ?? – so there were lots of elements involved in it. But it was almost sometimes the mum felt like nobody believed her and she said the boy had this disability. I think she had a tough time with the medical profession to even getting the diagnosis. And as I said, lots of background family issues. But we weren't involved in that but did make that engagement quite difficult.

**Interviewer:** So how did you go about identifying their needs and supporting the family to address those – address the particular issue – particularly the trust. How did you go about building rapport and trust with the parent?

**Participant 7:** He initially came in on the physio referral. And it really was – they definitely didn't want us to – and they clearly they didn't want us to go to the home at all. It was quite – it was giving them time really. I think bottom line was giving them time. And acknowledging that mum didn't want us working at home. She wanted to come to the centre. What we did we did it through the school. And eventually through attending meetings and really it was – they were all set up around mum, when she could make it, how she wanted it structured. A few other issues came up that needed OT. The interesting thing was that we really did get mum on board at quite a certain point. But the young man was 16 years of age and I think we lost him. He really had to make the changes.

**Interviewer:** What do you mean you lost him?

**Participant 7:** He wasn't interested. He didn't – I don't know whether he felt helpless or he didn't want to acknowledge his disability. Now I don't really know. But they stopped making contact and wouldn't – we'd ring and there'd be no answer. So they eventually exited themselves.

**Participant 6:** Just to go back a step. At the beginning, in terms of actually setting up some of those initial meetings, we did that in a mutual place. So it wasn't at home and it wasn't at school. It was at a community office where we did have a [Mainstream NGO] office.

**Participant 7:** We had an Aboriginal liaison officer.

**Participant 6:** Eventually we did. Not at the beginning. I think that came in a little bit later – we only had community transport to bring the mother in. I got commissioned to, from memory this is how it worked – to slightly vary the system that we had in terms of our paperwork being taken because normally we'd set up those – some of the things that we did until we had a signed contract with the parent – that was something that really freaked mum out because she thought that, you know, it was DoCS – as soon as she'd signed anything, she'd sign over all these rights and things. So I was actually to connect the service with her and then went back and did that paperwork when she got a bit of a trust with us. So that was a really flexibility around our organisation in that particular case. I think we also aiming to feedback to the school about that timeframe and they were thinking that things weren't happening, because they weren't happening as fast as they wanted, just to feedback. Another very interesting conversation that was had with that school counsellor to actually try to say 'well actually we see this as progress because we've actually met with mum a couple of times' – so I think just having a bit of a chance to change their perspective of what was all successful was interesting as well. We did then get a local Aboriginal support worker involved.

**Interviewer:** Did that person help a lot?

**Participant 6:** Very much. But then his funding ended. His CSA had funding for a certain amount of time for an Aboriginal support worker so that was disappointing when that finished.

**Interviewer:** Was that an Aboriginal NGO.

**Participant 6:** No. It was an Aboriginal – he was employed to be an Aboriginal liaison officer or something like that?

**Participant 7:** Wasn't he from DEET?

**Participant 6:** No. There was one at the school but also ?? but this was through the local Family Support Service – that it was under time limited contract – working on a project thing – something like that.

**Participant 7:** We managed to keep them engaged for about 3 years but it was quite difficult. A lot of work in adjusting and being flexible about ?? and I think it might actually – we gained her trust and she made some moves forward but then this 16 year old boy, it was a bit tougher.

**Interviewer:** So are there any barriers for Aboriginal people in accessing the [Mainstream NGO] services? And if there are, what they are? And if there are no barriers that you guys can identify, how do you guys assure that there are no barriers for Aboriginal people?

**Participant 1 or 2:** I would have said paperwork but someone backs me up

**Interviewer:** Why is paperwork a barrier for Aboriginal families? Across the board in your experience.

**Participant 2:** It's just things – it can be literacy, it can be just a whole – it's a very western thing and they have to waivers and liability things and contracts and some of the wording used on – I think is a very western concept.

**Interviewer:** So how do you overcome that as a barrier?

**Participant 2:** Get permission not do it for awhile until they trust you.

**Interviewer:** Is that across the board? From your experience?

**Participant 2:** Yeah. [several agreeing]

**Interviewer:** So what other barriers are there?

**Participant 4:** I don't think our information is presented as Aboriginal friendly. So I know at another service that I was associated with they'd have one program that they have one set of information that was Aboriginal identified and another that wasn't. And I don't think we promote ourselves that way.

**Interviewer:** What's the difference between Aboriginal way of promoting services and a non-Aboriginal way of presenting services? Like the example you just gave.

**Participant 4:** Yeah, well with the organisation that I was with before, the Aboriginal documentation was a lot less formal and it showed Aboriginal symbols. I don't think we do that well. The documentation that I see doesn't do that.

**Interviewer:** So we've got forms, we've spoken about information, what other barriers

**Participant 3:** I think there's ideas about health and things like pain – like for kids with cerebral palsy, some of them have, you know, like different problems – like muscular skeletal problem with ?? pain and I think with one of our other clients, it wasn't the mum's ability or her inability to deal with her daughter's pain level and for some procedures that might have had to happen like surgery or something like that – and what that crying meant to them, and if someone else could actually take the mum's place rather than the mum having to deal with that, that might work better. But I think just that we didn't know enough about that – what the culture and that passion for it and the mum dealing with their child's pain and perhaps we need to look at that stuff as an issue at some point.

**Interviewer:** Are there any other examples that you guys can think of? *[no response]* What about some examples of your or the [Mainstream NGO] or the team that you work in this region – in working with Aboriginal communities generally? Are there any barriers or that you guys face in working with Aboriginal communities? So we've spoken about how Aboriginal families access the [Mainstream NGO]. So I want to talk about how the [Mainstream NGO] meets with communities and works with Aboriginal communities or Aboriginal workers such as their schools – you spoke about how you worked with schools and how you worked with Health professionals – what about your experience within that?

**Participant 6:** I think from a therapy point of view, one of the nice things about working for the [Mainstream NGO] is we can meet you anywhere really. And I think that helps with the ?? within the [Mainstream NGO]. From my personal experience generally families don't want us in their home. And I'm not sure why that is. You may have a different experience.

**Participant 5:** Yeah, I think that some families yeah, they don't want– and I think because there are other things happening at home – the number of people that might living in public housing it may not be quite correct according to the quote or whatever, and I suppose that that's why going to do them in – some of those things what's said to them or something like that. So that might be why they sometimes they're letting you in, I don't know. But I think trust, their trust is important. Like having you build up that relationship so we give them a bit of time to do that and then I think we need to liaise with other agencies but once you've got the trust with your family and that means that you'll be talking about the same things because I think sometimes initially they might – they might say 'I'll agree to different things' even though perhaps they don't because they need more time to actually think about that – but once they get to know you and trust you then they can say they don't want to do something or they do want to I think, and we can represent them more.

**Participant 8:** I think probably previously we had a worker who just left, not very long ago, who had had a parent had a background in working with an Aboriginal service and she automatically had that connection with them and so she wasn't Aboriginal herself. But she actually had all the key names so I went to a meeting with the family and, you know, we could talk about different things and soon as she said the key things names within those Aboriginal services, you know, you could see that the family actually engaged with her much easier than, you know, when we just actually talked about the services. And I would talk to the liaison officer or blah blah blah – but she could actually, you know, rattle off the names and go 'oh yeah' you know, about the different people and it was automatically 'yeah, they'll go talk to them' and I don't want you to talk to that one, can you talk to that one? 'Yeah no problem'. So that was actually a really good thing for us, like as a team, because we could use her to be able to go 'who should we really talk to about these things?' "Who's the best person to talk to at a particular service'. So that's probably a bit of a loss at the present time for us around that so – because I think that actually enhanced some of those connections.